Family Presence during Resuscitation

A constructivist grounded theory

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Declaration

I certify that this thesis does not incorporate without acknowledgement any material previously submitted for a degree or diploma in any university: and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

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Tracey M Giles   September 2015

Thesis Summary

Each year, thousands of people suffer cardiac arrest in hospitals around the world. Despite ongoing advances in resuscitation technology, around 90% of these people die – often surrounded by clinical experts, but separated from their loved ones. Family presence during resuscitation was introduced in the early 1980s so that family could be with their loved ones during life-threatening events. Since that time, this phenomenon has been discussed extensively in the international literature and there is growing support from health professionals and the public. The current body of evidence supports important benefits for family members, including helping with closure and grieving, and reducing incidences of post-traumatic stress. Yet, despite this evidence and endorsement from professional groups in Australia and overseas, family presence during resuscitation is not practiced widely or consistently in Australia and rationales for poor uptake are unclear.

Existing Australian research into the phenomenon is limited and significantly skewed toward quantitative aims. A constructivist grounded theory approach was therefore used to examine factors and perceptions impacting family presence during resuscitation practices in Australian hospitals. In-depth interviews were conducted with registered nurses, doctors, paramedics, family members and a resuscitation patient to interpret and explain their meanings and subsequent actions when deciding whether to practice or participate in family presence during resuscitation. The systematic application of core grounded theory methods facilitated the generation and integration of a conceptual theory that explains the phenomenon from the perspective and in the context of the people who experienced it.

The substantive grounded theory developed during this study was *the social construction of conditional permission*. This theory comprised a series of value-laden judgements as part of the decision-making process to practice or participate in family presence during resuscitation. The substantive theory offers an explanation for the wide variations and inconsistencies that are evident in current practice. In the absence of any formal policies, decision-making around family presence during resuscitation was influenced primarily by

people's values, preferences, and pre-existing expectations around societal roles and status. As a result, current practices were highly subjective and variable.

Although some findings in this study were shown to link to existing constructs, this theory is unique in how it has used a new approach to interpret and explain rather than merely describe attitudes and practices around family presence during resuscitation. This theory contributes to an enhanced understanding of related practices in Australian hospitals and has important implications for future practice, education, research and policy around. The introduction of clinical protocols and associated education is recommended as an important starting point to ensure future practice is guided by evidence and standards for health consumer safety and welfare, rather than by the personal values and preferences of the individuals 'in charge' of permissions.

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List of Abbreviations

ACEM	Australian College of Emergency Medicine
ACHS	Australian Council on Healthcare Standards
ACoSaQiHC	Australian Commission on Safety and Quality in Healthcare
AHA	American Heart Association
ARC	Australian Resuscitation Council
AVCC	Australian Vice Chancellors Committee
CCU	Coronary care unit
CENA	College of Emergency Nurses Australia
CPR	Cardiopulmonary resuscitation
ED	Emergency department
FCC	Family-centred care
FM	Family member
FPDIP	Family presence during invasive procedures
FPDR	Family presence during resuscitation
Defib	Defibrillator / defibrillation
GP	General practitioner doctor
GTM	Grounded theory method
HP	Health professional
HP-FM	Health professional who is also a family member
ICU	Intensive care unit
MET	Medical emergency team
NE	Nurse educator
NHFoA	National Heart Foundation of Australia
NHMRC	National Health and Medical Research Council
NP	Nurse practitioner
Resus	Cardiopulmonary resuscitation
RN	Registered nurse
SA Health	South Australian Health; a large portfolio of health networks and services
SBREC	Social and Behavioural Research Ethics Committee

Works Arising from this Thesis

Peer Reviewed Publications

Giles, T, de Lacey, S & Muir-Cochrane, E 2016, 'Coding, constant comparisons and core categories: a worked example for novice constructivist grounded theorists', *Advances in Nursing Science,* (Accepted for publication 20 August 2015, in press).

Giles, T, King, L & De Lacey, S 2013, 'The timing of the literature review in grounded theory research: An open mind versus an empty head', *Advances in Nursing Science,* vol. 36, no. 2, pp. E29-E40.

Internal Publications

Giles, T (2013) Family Presence during Resuscitation (CPR): who decides? *Research Pulse,* Faculty of Medicine, Nursing and Health Sciences, Flinders University, Adelaide, Dec 2013.

Conferences

Giles, T, de Lacey, S & Muir-Cochrane, E 2015, 'Family presence during resuscitation; who decides and how?' Nurses and Midwives Research Symposium, South Australian Department of Health, Adelaide, South Australia, May 2015.

Media

Giles, T 2013, Family presence during resuscitation, Radio Interview, 101.5 Radio Adelaide, 7th November 2013.

Giles, T 2013, Family presence during resuscitation, Radio Interview, 720 ABC Radio Perth, 16th October 2013.

Giles, T 2013, Family presence during resuscitation, Radio Interview, 891 ABC Radio Adelaide, 10th October 2013.

Publication Awards

Giles, T 2015, Research Higher Degree Student Publication Award, Flinders University Faculty of Medicine, Nursing and Health Sciences, Adelaide, South Australia.

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Giles, T 2012, Research Higher Degree Student Publishing Incentive Award, Flinders University School of Nursing and Midwifery, Adelaide, South Australia.

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It was a fun and challenging four years. It's great to be finished!

Prologue

My interest in this topic can be traced to my early career as a registered nurse (RN). I completed my hospital training in 1990 and worked for around 15 years in a variety of clinical specialities - including cardiac, emergency and trauma. My first experience with family presence during resuscitation (FPDR) took place several years post registration while working in a regional hospital. Fairly new to the profession, I had not heard of FPDR as a phenomenon and I was unaware of the early research from the United States and the United Kingdom. However, during one particular late shift I was introduced to the possibility of having family members present in the resuscitation room as I tried to balance the needs of a patient and his family, while also maintaining professional boundaries.

Midway through the shift, Bruce[1] arrived at the emergency department (ED) with crushing, central chest pain. His wife, Yvonne, had driven him 20 minutes from the nearest town. One of the challenges for regional health professionals is the likelihood of knowing people in your care and, as they walked into the ED, I recognised them as close acquaintances. I knew immediately that Bruce was critically ill. His face and body was grey and waxy, slick with perspiration. He was leaning on Yvonne for support. We helped him onto a trolley and he sat there with his legs dangling over the side as I slipped an oxygen mask over his face and implemented the chest pain treatment protocol. I was focused on stabilising Bruce along with the duty general practitioner (GP) and did not notice Yvonne disappear from the room – most likely guided out by the other RN on duty. Several minutes into his treatment plan, Bruce looked up at me, grabbed my hands and said 'Trace, you have to help me.'

'We're going to do everything we can,' I replied. Seconds later, he slumped sideways and lost consciousness. Bruce had suffered a major heart attack and was in cardiac arrest. We started CPR. Several minutes into the resuscitation, the other RN on duty relieved me from compressions and I started documenting the arrest. The GP expressed his doubts that the arrest was reversible and I told him Yvonne was waiting outside the room, hovering in the corridor. He sent me out to convey our standard information for difficult resuscitations;

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[1] The names in this experience have been changed to maintain confidentiality.

'We're doing everything we can - but it's not looking good.' This was common practice to 'prepare' the family member for impending death while continuing to resuscitate the patient. But this time, a preparatory message didn't seem enough. I wanted to bring Yvonne to the bedside so she could be with Bruce and say goodbye; but this suggestion was met with a firm 'no' from the GP. I was a junior staff member, and fearful of breaching professional boundaries, so I did not argue with the decision. Instead, I was sent out to advise Yvonne yet again that the prognosis was grim. We did everything we could - but we couldn't revive Bruce. I consoled Yvonne as best I could, then prepared her for what she would see when I took her into the resuscitation room - to be with her husband and to say goodbye.

I participated in many resuscitation events during my clinical career. Occasionally, family were present for a short time if the resuscitation was unexpected. However, they soon left the room - usually directed or escorted out by a nurse. I never worked in a clinical setting that practiced or invited FPDR as standard. Reflecting on these experiences I realise that, despite being a strong advocate for family-centred care, I was not a strong advocate for family members to be present during the resuscitation of their loved ones.

Throughout my academic career my interest in family-centred care grew, with a particular focus on the role of family and their support needs when loved ones are hospitalised with a critical illness. When I commenced my doctoral research, I wanted to explore an issue within this broad interest area. During a general literature search, I discovered some research on FPDR and was immediately reminded of Bruce and Yvonne and other resuscitations I had been involved in. My preliminary reading alerted me to the fact that in certain healthcare settings in some countries, FPDR had been practiced successfully for many years; yet there appeared to be contentious debate around FPDR practices between various professional groups.

I wanted to learn more about this phenomenon, particularly in an Australian context. This thesis is the culmination of four years of intensive research into family presence during resuscitation that aimed to examine current practices and identify areas for improvement.

Chapter One: Introduction

CHAPTER OVERVIEW

Chapter one provides an overview of the thesis. Specifically, this chapter helps contextualise the study by providing background information about sudden cardiac arrest, cardiopulmonary resuscitation and family presence during resuscitation. This background discussion leads into the problem statement, the study purpose and the aim of the research. The significance of the study is then explicated (including the premise for the study design), key terms are defined and an overview of the thesis is presented in relation to chapter progression. Chapter one concludes with an explanation of my use of the first person throughout this thesis.

BACKGROUND

Each year, millions of people around the world die from cardiac arrest (Sayre *et al.* 2010). These arrests occur suddenly and often without warning. As a result the heart cannot adequately pump blood to vital organs, the person loses consciousness within seconds and death occurs within minutes if treatment is not initiated (AHA 2015a).

Cardiopulmonary resuscitation (CPR) was developed in the 1960s as a life-saving intervention to reverse sudden death from cardiac arrest (Abella *et al.* 2005). CPR is defined as the preservation or restoration of life by the establishment and/or maintenance of airway, breathing and circulation in conjunction with related emergency care (ARC 2006). More specifically, CPR is the technique of chest compressions combined with rescue breathing with the aim of temporarily maintaining a circulation sufficient to preserve brain and other organ function until specialised treatment[2] is initiated (ARC 2012a).

Resuscitation of the dead and dying has a long history that can be traced back for centuries. Early resuscitation attempts involved the use of flogging, inversion, bouncing on a trotting horse, rolling the patient over a barrel and insufflating the rectum with smoke. Modern techniques began to be implemented from 1740 when the *Paris Academy*

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[2] For example defibrillation, advanced airway management, medications, and correction of underlying causes.

of Sciences officially recommended mouth-to-mouth resuscitation for drowning victims. Several decades later, the Dutch *Society for the Recovery of Drowned Persons* became the first organised effort to deal with sudden and unexpected death (Timmermans 1999a; AHA 2015b). Ongoing resuscitation developments included the first successful use of external chest compressions in human resuscitation in 1903, and the invention of mouth-to-mouth resuscitation in 1956. In 1957, the United States military adopted mouth-to-mouth resuscitation to revive unresponsive victims (AHA 2015b), and CPR was developed in 1960. The same year, the American Heart Association implemented a program to acquaint physicians with closed-chest cardiac resuscitation and became the forerunner of universal CPR training for the general public (AHA 2015b).

In developed countries, between one and five of every 1000 hospital in-patients suffer cardiac arrest (Goldberger *et al.* 2012). In Australia, cardiac arrest is a leading cause of death, with an estimated 30,000 people affected each year (St John Ambulance Australia, ARC & NHFoA 2012). Since its introduction in the 1960s, CPR quickly became the standard response to sudden cardiac arrest in the hospital and community setting (Tercier 2008; Levinson & Mills 2014). Founding proponents claimed that anyone, anywhere could implement universal CPR (Timmermans 1999a), and this message is still promoted today. For example, the Australian Resuscitation Council's home webpage greets public and professional readers with the message that *Any Attempt at Resuscitation is Better Than No Attempt* (see <http://resus.org.au/>).

Yet despite significant investment into resuscitation research (Sasson *et al.* 2010), ongoing advances in resuscitation technology, intensive staff training, and widespread adoption of CPR by the public (Nichol *et al.* 2008), survival rates have remained consistently low for more than 30 years (Abella *et al.* 2005; Sasson *et al.* 2010). These static survival rates could be due to increasing levels of patient acuity and critical illness that are less responsive to even the most advanced resuscitation and life support measures (Ehlenbach *et al.* 2009; Boyde *et al.* 2013). Or it could be that there is a maximum attainable survival rate following sudden cardiac arrest.

Precise survival rates are difficult to determine and vary considerably between sources. Two recent systematic reviews provide what is probably the most reliable indicator of

survival rates from sudden cardiac arrest. American researchers performed a meta-analysis on data from 79 studies reporting out-of-hospital cardiac arrest in 142,740 adults. The pooled survival rate to hospital discharge was 7.6%, with an aggregate survival rate of between 6.7% and 8.4% (Sasson *et al.* 2010). A similarly low survival rate to discharge was reported by researchers from the Netherlands, who examined data from 67 prospective studies of adult and paediatric out-of-hospital cardiac arrest (Berdowski *et al.* 2010). They reported an overall global survival to discharge rate of 7%, and an Australian survival rate of between 6% and 13%.

There is no doubt that CPR saves many lives, and it is certainly not the intention of this thesis to discourage CPR in response to sudden cardiac arrest and sudden death. However, if the most common outcome of CPR is death – then perhaps it is time to re-contextualise CPR from its current 'high tech' status to a more holistic approach that combines advanced technologies with patient/family-centred care (Timmermans 1999a). Tercier (2008, p. 169) argues that a focus on implementing the advanced technical demands of CPR can often overshadow the psychological and spiritual needs of the dying patient and their family. Likewise, Timmermans (1999a, 2005) proposes that if health professionals can surrender the idea that CPR is *just* about saving lives, they would be able to find a way to improve the resuscitation ritual by not only discussing the possibility of sudden death with loved ones but by providing a 'good death' for the dying patient and their family members.

According to Timmermans (1998), a good and dignified sudden death requires family to understand that death is imminent, requires the dying person's wishes to be respected and includes family involvement in the last minutes of life. Prior to the nineteenth century dying was a community event, with family and friends gathering to pay their last respects and to conduct various end-of-life rituals. But according to Timmermans (1996) and Tercier (2008), the introduction of life saving medical interventions saw care of the dying moved to hospitals and the exclusion of family and friends from critically ill and dying patients. Indeed, the literature has many examples of family members being separated from their dying loved ones during resuscitation events (Ersoy & Yanturali 2006; Badir &

Sepit 2007; Demir 2008; Gunes & Zaybak 2009; Taraghi *et al.* 2014; Soleimanpour *et al.* 2015).

However, this view is beginning to change as health professionals and health consumers place increasing importance on a more family-centred and holistic approach to emergency resuscitative care. A holistic approach focuses on the delivery of care that addresses the physical and psychological needs of the patient, as well as the emotional welfare of family members. This family-centred approach to emergency resuscitative care saw the emergence of family presence during resuscitation; the practice where family members[3] are in a location where they can see and sometimes touch the patient during active cardiopulmonary resuscitation (Chapman *et al.* 2014; Lederman, Garasic & Piperberg 2014; Tudor *et al.* 2014).

The origins of family presence during resuscitation (FPDR) can be traced to the Foote Hospital in Michigan in the United States (Doyle *et al.* 1987; Post 1989; Hanson & Strawser 1992). In 1982, health professionals (HP) were forced to question their long standing policy of automatically excluding all family members from the resuscitation room after several people demanded to be present. A man who accompanied his wife in the ambulance while she was being resuscitated refused to leave her side when they arrived at the ED. On another occasion, the wife of a police officer who had been shot begged to enter the resuscitation room to be with her husband. In both cases, an exception to the exclusion policy was made and a chaplain accompanied the respective family members into the resuscitation room to observe the event.

Despite some initial reservations from staff about having family members in the resuscitation room (Post 1989), the overall feedback from staff and family members was positive. This prompted the ED staff to survey 18 family members of recently deceased patients to determine whether they would have liked to be present during the resuscitation. Seventy-two percent (72%) responded in the affirmative (Doyle *et al.* 1987) and a new protocol was developed to invite select family members to participate in

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[3] Family members in this context refer to people 'who are closest to the patient in knowledge, care and affection. This may include the biological family, the family of acquisition (related by marriage or contract), and the family and friends of choice' (ACoSaQiHC 2015, p. 33).

supported FPDR. Nine years later, researchers from the Foote hospital reported no problems and widespread acceptance of FPDR among health professionals and the community (Hanson & Strawser 1992).

Since that time, FPDR has become a contentious area of practice that has attracted widespread international debate (McMahon-Parkes *et al.* 2009). The current body of evidence supports important benefits for family members, including helping with closure and grieving, and reducing incidences of post-traumatic stress (Jabre *et al.* 2014).[4] FPDR has been endorsed by many international and local professional bodies over the past decade. The Australian Resuscitation Council (ARC 2012b), the European Resuscitation Council (Baskett, Steen & Bossaert 2005), and the American Heart Association (Morrison *et al.* 2010) all support FPDR and there is increasing support from the public (Morrison *et al.* 2010; Mortelmans *et al.* 2010; Leung & Chow 2012; Bashayreh & Saifan 2015; Dwyer 2015). Yet, views among health professionals remain divided - with support for the practice ranging from 3% to 98% in attitudinal surveys.[5] Australian research into FPDR is limited and significantly skewed toward quantitative aims, limiting our understanding of current practices. Further, FPDR does not appear to be practiced widely or consistently in Australia and rationales for poor uptake are unclear (as detailed in the preliminary literature review).

PROBLEM STATEMENT

The possibility that individual staff preferences and practices may have a considerable impact on FPDR practices warrants further investigation in order to examine how decisions are influenced in relation to FPDR, and the rationales behind these decisions.

STUDY AIM

The purpose of this study is to generate a grounded theory about family presence during resuscitation practices. More specifically, the aim of this research is to explore factors and perceptions that impact decision-making about family presence during resuscitation in Australian hospitals from the multiple perspectives of health professionals, family members and patients.

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[4] Also refer to table 5 on page 35 of the preliminary literature review for further benefits.
[5] Statistics regarding HP support for FPDR are detailed in chapter two.

SIGNIFICANCE OF THE RESEARCH

This research is significant because it contributes an enhanced understanding and valuable insights into a longstanding problem – the modest and inconsistent adoption of FPDR practices in Australia and internationally. This insight is derived through an inductive approach to research which allows for deeper understanding and the development of foundational concepts. The current body of evidence dates back to the 1980s. However, it is significantly skewed toward descriptive research examining the attitudes and beliefs of health professionals using closed-response surveys. Understanding rationales for practice is an important first step when practice changes are needed. This thesis goes beyond describing current attitudes and practices to explore and explain people's meanings and actions as they make decisions around whether to practice or participate in FPDR. Included in this study are the often forgotten voices of vulnerable family members and surviving resuscitation patients alongside health professionals to form a multifaceted perspective of decision-making around FPDR. As a result, insights from this study help to inform the ongoing and often contentious debate around family presence during resuscitation, assist in the resolution of such conflicts and contribute to the formation of evidence-based policies and guidelines.

The grounded theory developed during this study will also help inform education and practice as well as make important recommendations for future research, both in Australia and internationally. Findings from this research have potential relevance for health professionals and educators, policy makers, health consumers and the general public.

DEFINITION OF KEY TERMS

Throughout this thesis, the following definitions are used to describe key people and meanings in relation to family presence during resuscitation.

- *Family Member* - family member, loved one or significant other who was present in the resuscitation room (or wanted to be) in an acute healthcare setting during active cardiopulmonary resuscitation (CPR).

- *Resuscitation Patient* - a person who underwent CPR in an acute healthcare setting who had a family member present in the room during that resuscitation, or would have liked a family member to be present.

- *Health Professional* – a registered nurse, medical doctor or paramedic who performed CPR on a patient while on duty in an acute healthcare setting where a family member was present in the resuscitation room, or wanted to be present.

- *Resuscitation* - cardiopulmonary resuscitation (CPR) and associated specialised interventions (such as defibrillation, insertion of intravenous lines and advanced airways, administration of medications etc.) initiated in response to cardiac arrest with the aim of preserving or restoring life.

- *Family Presence during Resuscitation* – a situation where a family member is present in the resuscitation room at one point or continuously during a CPR attempt.

THESIS OVERVIEW

This thesis began with a short prologue to situate myself as the researcher, to increase transparency, and to declare my previous knowledge and experience in relation to family presence during resuscitation.

Chapter one began with an overview of sudden cardiac arrest and cardiopulmonary resuscitation, before introducing the concept of family presence during resuscitation. This was followed by a problem statement and introduction of the study aim. The significance of the research was then discussed, followed by the definition of key terms used within the thesis. Chapter one concludes with an overview of the thesis.

Chapter two presents a preliminary review of relevant Australian and international research. The chapter explains and justifies the use of literature in this grounded theory method study, presents a summary of reviewed literature, and identifies methodological limitations and the most suitable methodology for the current study. Gaps and limitations in previous participant groups, resuscitation settings and contexts are acknowledged. The chapter concludes with a discussion of recommendations drawn from the reviewed literature and details how the aim of this study was developed to address previous knowledge gaps and methodological limitations.

Chapter three presents the research methodology and theoretical framework used to meet the study aim, and details the way in which symbolic interactionism, social constructionism and constructivism underpinned the chosen methodology. The chapter concludes with a discussion of Charmaz's constructivist approach to grounded theory method and how it was applied in this thesis.

Chapter four provides a detailed discussion of the specific methods employed to conduct the study, including the use of sensitising concepts to develop the aim, ethical considerations, participant recruitment and the processes used to generate and analyse data. The role of core grounded theory methods such as theoretical sampling, reflexivity and the constant comparative analysis method are then detailed. The chapter concludes with a discussion around establishing study rigour.

Chapter five is the first of six chapters presenting the study findings. This chapter introduces the study participants, and provides an overview of the substantive grounded theory and theoretical conceptual model that was developed to explicate the theory.

Chapters six, seven and eight present three major processes of the substantive grounded theory; claiming ownership, opportunistic presence and valuing family presence. While these processes are discussed separately in discrete chapters, the relationship between them is also explicated in each of these chapters to demonstrate how *together* they impacted the core category and to highlight their role in the substantive theory.

Chapter nine presents an in-depth discussion of a series of value-laden judgements that were enacted during *the social construction of conditional permission* – which is the central theory in this study. These judgements are discussed within four sub-categories (prioritising preferences and rights, assessing suitability, setting boundaries, and protecting others and self), and the relationship between these sub-categories and the central theory is explicated.

Chapter ten offers a theoretical discussion of the substantive grounded theory and discusses how the theory is situated in and builds upon existing knowledge. This theory captures the patterns of meanings and actions of participant experiences and explains the

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major social process at work when people were faced with a decision to practice or participate in FPDR.

Throughout chapters six to ten, significant findings are discussed in relation to existing literature in order to support the emerging theory (Glaser & Strauss 1967; Strauss & Corbin 1998; Charmaz 2014), to situate the current research within the body of related literature, and to demonstrate how the current study built upon this body of evidence (Charmaz 1990; Stern 2007; Charmaz 2014).

Chapter eleven provides a discussion of the overall study contribution before detailing the strengths and limitations of the research. The implications of the study are then presented in relation to future research, practice, education and policy development. This chapter ends with concluding remarks and a thesis epilogue.

Throughout this thesis, I have intentionally written in the first person in order to write myself 'into' the research in line with recommendations from Charmaz and Mitchell (2011), Mills, Bonner and Francis (2006a) and Webb (1992). Using my own voice rather than the more traditional third person to report this qualitative research acknowledged my role as the researcher during what Charmaz (2006, 2014) refers to as a co-construction of knowledge.

Chapter Two: Preliminary Literature Review

CHAPTER OVERVIEW

Chapter one introduced the study, identified the research problem and highlighted the rationale for exploring FPDR practices in an Australian context. This chapter presents a review of Australian and international research that has examined FPDR in the acute care (hospital) setting.[6] Chapter two begins by explaining and justifying the use of literature in this grounded theory method (GTM) study, before presenting a summary of the reviewed literature. A critique is then provided, which identifies methodological gaps and limitations and enabled identification of the most suitable research design for the current study. Past and present FPDR experiences, attitudes, beliefs, practices and policies are then scrutinised in order to identify gaps and limitations in previous participant groups, resuscitation settings and contexts. The chapter concludes with a synthesis and discussion of recommendations drawn from the reviewed literature.

JUSTIFICATION FOR THE REVIEW

The timing of the literature review in GTM research is an issue of ongoing debate and confusion (McCallin 2003a, 2003b; Charmaz 2006; Bryant 2009; Skeat 2010). Two broad perspectives are apparent in the literature; 1) to delay the review until after data collection and analysis begins, and in some cases until codes and categories begin to emerge, or 2) to undertake a preliminary review prior to the study which is then expanded during data collection and/or analysis.

In order to determine the most appropriate timing of the review for this study, I undertook an examination of the ongoing debate. The resultant published article (included as appendix 2 on page 241) presents an in-depth exploration, analysis and critique on the timing of the literature review in GTM research (Giles, King & de Lacey 2013). The article argues that a preliminary review does not jeopardise the rigour of GTM research as previously thought and may in fact enhance creativity, theoretical sensitivity and rigour. More specifically, a preliminary review allows the researcher to:

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[6] The comprehensive search strategy for this preliminary review is detailed in appendix 1 on page 239.

- Become familiar with the literature and identify gaps (Annells 2006; Dey 2007; Lempert 2007; McGhee, Marland & Atkinson 2007; Wiener 2007).

- Gain a critical knowledge of key concepts (McCann & Clark 2003a; Lempert 2007; McGhee, Marland & Atkinson 2007).

- Avoid conceptual and methodological pitfalls of previous studies (McCann & Clark 2003a; Lempert 2007; McGhee, Marland & Atkinson 2007).

- Provide justification, background and framework for the study (Bryant & Charmaz 2007a; Lempert 2007; McGhee, Marland & Atkinson 2007; Skeat 2010).

- Direct theoretical sampling (Strauss & Corbin 1998; McGhee, Marland & Atkinson 2007).

- Enhance theoretical sensitivity (Strauss & Corbin 1998; Dey 2007; Gibson 2007; Bryant 2009).

This preliminary review of the literature heeds Lempert's (2007) and Bryant and Charmaz's (2007b) warning for researchers to avoid conveying 'new' ideas that have already been reported in related literature. I agree with Lempert's assertion that:

> *In order to participate in the current theoretical conversation, I need to understand it. I must recognise that what may seem like a totally new idea to me (an innovative breakthrough in my research) may simply be a reflection of my ignorance of the present conversation. A literature review provides me with the current parameters of the conversation I hope to enter. Utilizing comparisons from the literature alerts me to gaps in theorizing, as well as ways that my data tells a different, or more nuanced story. It does not, however, define my research (Lempert 2007, p. 254).*

For the reasons outlined above, and elaborated upon in my peer-reviewed article (Giles, King & de Lacey 2013), I undertook a preliminary review of the literature. A secondary, ongoing review was completed during the analysis and writing phase in order to link previous research and theory with the concepts and properties of the current research study and to support the emerging theory (Glaser & Strauss 1967; Strauss & Corbin 1998; McCann & Clark 2003b; Urquhart 2007; Charmaz 2014). Relevant literature is therefore woven into the findings chapters in order to situate the current research within the body

of related literature and to demonstrate how I built upon this body of evidence (Charmaz 1990; Stern 2007; Charmaz 2014).

SUMMARY OF THE LITERATURE

Location and timelines of included studies

The first published FPDR study took place in the United States of America (US) in the 1980s (Doyle *et al.* 1987). Since that time, interest in FPDR has grown steadily throughout the world. The figures presented in appendix 3 (see page 253) depict the number of FPDR studies published each year since 1987 and the country of origin.

Study participants

The majority of available studies have explored FPDR from a health professional perspective, with a much smaller number focusing on the perspective of family members. Very few studies have explored FPDR solely from the patient perspective (Eichorn *et al.* 2001; O'Brien & Fothergill-Bourbonnais 2004; Mcmahon-Parkes *et al.* 2008; Albarran *et al.*2009), and only one from a family *and* patient view (Mortelmans *et al.* 2009). The deficit of research into these latter perspectives demonstrates a large gap in the available body of evidence that was addressed in the current study.

Resuscitation patients and study settings

Many FPDR studies did not identify the age of resuscitated patients, or included both paediatric/adolescent and adult patients. This review began with a focus on FPDR in the emergency department (ED). However, many studies included dual settings (for example EDs and intensive care units (ICU), and it became apparent that similar barriers and constraints to FPDR had been reported from a variety of acute healthcare settings. All acute care settings were therefore included to allow a comparison of attitudes and practices within different contexts.

METHODOLOGICAL REVIEW

The body of FPDR evidence has developed over almost three decades using a variety of methodologies to explore attitudes, beliefs, experiences and efficacies from quantitative and qualitative paradigms. The logical progression of evidence usually expected and

desired, starting from the weakest and building up to the strongest level of rigour (Polit &
Beck 2010), is not apparent in FPDR research. Instead, there has been an ongoing reliance
on descriptive studies when making recommendations for future research and practice.
Table 1 presents a summary of the various study designs used to examine FPDR since the
first study in 1987.

Table 1: A summary of reviewed study methodologies (n = 122 studies)

Methodology	Design	Sub-design	No.
Quantitative	Descriptive	Simple descriptive	44
		Comparative descriptive	27
	Correlational	Descriptive correlational	15
		Pre-test post-test correlational	1
(n = 98)	Pre-experimental	One group pre-test post test	3
	Quasi-experimental	Post-test with non-equivalent control group	4
		Pre-test post-test with non-equivalent control group	2
		Randomised comparison study	1
	Experimental	Randomised controlled trial	1
Qualitative	Descriptive	Content analysis (no specific style mentioned)	3
		Constant comparison analysis	3
		Thematic analysis	3
		Content analysis using Berg, Cavanagh & Burnard	2
(n = 22)		Conceptual Analysis (Palmquist)	1
		Miles & Huberman analysis	1
		Grounded theory methods analysis	1
		Descriptive study using van Manen's thematic analysis	1
	Phenomenology	van Manen's thematic analysis	2
		Hermeneutic, interpretive	1
		Husserl's analysis/framework	1
		Interpretative using Colaizi	1
		Interpretive, thematic analysis	1
	Grounded Theory	Used grounded theory coding, not a GTM study	1
Mixed Method	Quantitative and Qualitative	Quant = Simple Descriptive. Qual = Descriptive	1
(n = 2)	components used	Quant = Correlational Descriptive. Qual = Descriptive	1

Quantitative studies

Most studies used a quantitative approach (n=98), where the variables of interest were
measured and results quantified and coded as numerical data (Polit & Beck 2010). In
those studies, FPDR was depicted as objective (Polit & Beck 2010), with a primary aim to
uncover facts about people rather than to understand the complex picture of people's
experiences (Nagy *et al.* 2010). There is an expectation that the knowledge and truth
obtained from quantitative research can withstand scrutiny and be upheld in different
environments and population groups (Jirojwong, Hohnson & Welch 2011). However,
many of the quantitative studies were not able to generalise their findings due to

limitations related to sample size, sampling and recruitment strategy, ethical limitations, instrument rigour and study design.

Quantitative studies were critically appraised using the NHMRC levels of evidence (NHMRC 2009) and the 'Body of Evidence Assessment Matrix' from Schneider, Whitehead and Elliot (2007, p. 56). Overall, they were deemed to have a satisfactory level of evidence in relation to volume of evidence, consistency, clinical impact and generalisability and a good level of evidence in relation to applicability. However, there has been an over-reliance on descriptive survey designs. In addition, data from quantitative studies were predominantly retrospective and largely confined to self-reporting from convenience samples, which can lead to selection bias (Taylor, Kermode & Roberts 2011).

Factors influencing external validity such as small sample size, low response rates and the use of only one or two clinical settings limit generalisability of results to the sample populations (Schneider & Whitehead 2013). In addition, reliability and validity of data collection tools was not tested in many studies, which further reduces rigour (Taylor, Kermode & Roberts 2011).

In some studies, participants were asked about hypothetical events or asked to respond to written scenarios which were free from the emotion of reality and could elicit significantly different responses to participants reflecting on actual events. In most cases, the aim of the quantitative studies was to examine the experiences, attitudes and beliefs of participants. However, the use of closed-response surveys and pre-determined multiple-choice questions or Likert scales did not allow an in-depth exploration of participant experiences (Taylor, Kermode & Roberts 2011).

The evidence gained from related quantitative research is useful to inform research consumers about baseline attitudes, belief and practices of FPDR, and whether educational interventions and programs are effective. However, quantitative research cannot seek to understand personal experiences, interpretations and constructs from the participant perspective in the same way as qualitative research (Schneider & Whitehead 2013).

Qualitative studies

Qualitative studies included in this review were critically appraised using guiding questions from the Critical Appraisal Skills Programme '10 questions to help you make sense of qualitative research' (CASP 2013) and the Guidelines for Critical Review Form: Qualitative Studies by Letts *et al.* (2007). Qualitative studies are useful to answer questions about human responses in a particular situation and context, and the meaning humans bring to those situations (Melnyk & Fineout-Overholt 2011). They can be useful when very little is known about a phenomenon, or when much is known (as is the case with FPDR) but what *is* known in certain areas is deficient in quality, depth or detail (Melnyk & Fineout-Overholt 2011). A qualitative approach was used by 22 studies in this review to explore the attitudes, beliefs and experiences of FPDR from the perspective of health professionals, family members and patients.

Ethical permissions were gained for all of the included qualitative studies and recruitment strategies were well described. In most cases a qualitative approach was well suited to the study aims. However, most studies did not discuss the theoretical or philosophical underpinnings of their chosen methodology and the majority identified themselves simply as a 'descriptive qualitative' study. Several studies that were identified as qualitative also presented quantitative results (Eichhorn *et al.* 2001; Weslien *et al.* 2005), bringing into question the rigour of the chosen methodology. In some studies, health professionals were asked to identify benefits and harms of FPDR on behalf of family members rather than asking family members directly, thus introducing speculation. In other studies, the exclusion of family members whose loved ones had died limited the richness of the findings.

METHODOLOGICAL SUMMARY

The existing body of FPDR evidence has grown steadily since the seminal US study, and there are currently well over one hundred published studies on the phenomenon. However, the body of evidence is significantly skewed towards quantitative research, in particular simple descriptive research, which limits rigour and does not allow an in-depth exploration of FPDR. Qualitative research can be particularly useful to raise awareness for the need for changes to FPDR practices and policies (Schneider & Whitehead 2013), and

this significant gap in the literature provides justification for the methodology chosen for this study. Further justification for this study is evident because the majority of FPDR research has occurred outside Australia in different health care systems and cultures. It is therefore important that the body of FPDR evidence is developed further in an Australian context.

CONTENT REVIEW

This content review presents a synthesis of findings from included studies, identifies gaps and inconsistencies and offers recommendations for future research which have informed this thesis. More specifically, the review examined broad finding categories around FPDR experiences, attitudes, beliefs, practices and policies from varying perspectives including health professionals, family members and patients. During this review, study findings were analysed and synthesised into several themes and sub-themes using recommendations by Cooper (1998) and Elliott (2007). In keeping with the aims of a preliminary literature review outlined earlier in this chapter, broad results are presented rather than specific study outcomes. Detailed findings relevant to the substantive grounded theory are discussed within the findings chapters in line with recommendations by Charmaz (2014) and Glaser and Strauss (1967). However, several themes presented within this chapter also contain detailed study findings in order to highlight gaps and inconsistencies in the literature which were addressed in this current study.

Attitudes and beliefs

Double standards

A double standard was evident among some health professionals who were reluctant to practice FPDR for fear of traumatising family members, yet would expect to be present if their own loved one required resuscitation (Beckman *et al.* 2002; Ellison 2003; Yanturali *et al.* 2005; Basol *et al.* 2009; Mortelmans *et al.* 2009; Sheng, Lim & Rashidi 2010; Wacht *et al.* 2010; Kosowan & Jensen 2011; Soleimanpour *et al.* 2015). However, this double standard was not universal, with several studies reporting similar levels of support for general public family members and health professional family members to be present

during resuscitation (Booth, Woolrich & Kinsella 2004; Demir 2008; Perry 2009; Davidson *et al.* 2011).

Nurses and doctors

When their attitudes and beliefs were directly compared, nurses were often more supportive of FPDR than doctors (Mitchell & Lynch 1997; Jarvis 1998; Helmer *et al.* 2000; Meyers *et al.* 2000; Beckman *et al.* 2002; McClenathan, Torrington & Uyehara 2002; Grice, Picton & Deakin 2003; Mangurten *et al.* 2006; Duran *et al.* 2007; Kuzin *et al.* 2007; Mian *et al.* 2007; Zakaria & Siddique 2008; Baumhover & Hughes 2009; Wacht *et al.* 2010; Leung & Chow 2012; Taraghi *et al.* 2014; Zavotsky *et al.* 2014; Porter, Cooper & Taylor 2015). A link between holistic care practices and increased support for FPDR has been posed to explain higher levels of support from nurses. For example, Baumhover and Hughes (2009) reported a relationship between a holistic perspective and support for FPDR and argued that differing educational approaches could explain the higher levels of support overall from nurses over doctors.

The few studies that reported doctors as marginally more supportive of FPDR than nurses (Weslien & Nilstun 2003; Mortelmans *et al.* 2009), or found no significant difference between the two groups (Fein, Ganesh & Alpern 2004; Ong *et al.* 2004; Egemen *et al.* 2006; Lam *et al.* 2007; Holzhauser & Finucane 2008; Kianmehr *et al.* 2010; Mahabir & Sammy 2012) often reported similar *low* levels of support. This overall low level of support could be linked to cultural beliefs and practices; particularly in Turkey (Weslien & Nilstun 2003; Egemen *et al.* 2006), Iran (Kianmehr *et al.* 2010), Asia (Ong *et al.* 2004) and the West Indies (Mahabir & Sammy 2012) where the study authors identified that family-centred care is not always prioritised in the same way as in Western countries. For example, parental presence during resuscitation was introduced into Turkey less than a decade ago and was not accepted by many local health professionals (Egemen *et al.* 2006).

Previous experience with FPDR was not a reliable indicator of health professionals' support for the practice (Jarvis 1998; Grice, Picton & Deakin 2003; Leung & Chow 2012). There was some evidence that a negative experience with FPDR reduced subsequent levels of support, while education programs appeared to positively impact attitudes and

behaviours. However, this impact was inconsistent and education alone did not necessarily encourage support for FPDR (Mian *et al.* 2007). Given the paucity of related literature, further examination of the impact of exposure and education on FPDR practices is warranted.

Health professionals and patients/family members/the public

When they were directly compared, family members and the public often reported higher levels of support for FPDR than health professionals (Meyers *et al.* 2000; Mangurten *et al.* 2006; Ong, Chung & Mei 2007; Zakaria & Siddique 2008; Itzhaki, Bar-Tal & Barnoy 2011; Leung & Chow 2012). In studies where health professionals were largely unsupportive, the difference between the groups (family members/the public and health professionals) was stark. For example 73.1 % vs 10.6% (Ong, Chung & Mei 2007), 80% vs 12.9% (Leung & Chow 2012) and 94% vs 0% (Zakaria & Siddique 2008). In this latter study, the difference could be explained by the fact that family members were asked if they would like to enter the room just before the patients' death - which does not meet the definition of FPDR used in most studies.

Very few studies directly compared attitudes and beliefs of family members and patients (Grice, Picton & Deakin 2003; Duran *et al.* 2007; Mortelmans *et al.* 2010), and only one study (Mortelmans *et al.* 2010) recruited participants who had all actually experienced FPDR. The latter study reported similar numbers of patients (72%) and family members (75%) who wanted FPDR in a German ED. However, due to low survival rates, responses from patients who had been resuscitated comprised only 2.7% of responses, and no significant comparisons could be made between the two groups. While this study provided a valuable insight into the attitudes and FPDR preferences of patients who survived resuscitation, the structured questionnaire did not allow an in-depth exploration of the study aims.

Duran and colleagues (2007) also reported positive views towards FPDR from family members and patients, and several studies that examined hypothetical views of the general public also reported large numbers of participants who would want FPDR both as a potential patient and family member (Mazer, Cox & Capon 2006; Chew & Ghani 2014; Bashayreh & Saifan 2015; Dwyer 2015). It is important to note, however, that few

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participants in the above mentioned studies had previously experienced FPDR and were therefore often providing opinions on a hypothetical situation.

Despite some limitations, the current literature suggests family members and patients are more supportive of FPDR than health professionals and that many family members want to be offered FPDR. In addition, it has been reported that surviving resuscitation patients are more likely to want to witness a family member's resuscitation, more likely to want a family member at their own resuscitation and more likely to cite benefits from FPDR (Albarran *et al.* 2009). Further, 91% of resuscitated patients and 75% of non-resuscitated patients were not concerned about confidentiality issues, which is a barrier commonly cited by health professionals (barriers are detailed later in this chapter). This disparity between views warrants further exploration from multiple perspectives in order to provide a more balanced view.

Different departments and health care settings

The impact of working in different speciality departments on FPDR practices and attitudes is largely unknown (Bassler 1999; Gold *et al.* 2006; Duran *et al.* 2007; Zavotsky *et al.* 2014). It has been suggested that ED nurses are more supportive than coronary care unit nurses (Bassler 1999), that ICU nurses are more supportive than ED nurses (Omran, Al Ali & Alshahrani 2015) and that nurses and doctors are more supportive than pharmacists and security officers (Zavotsky *et al.* 2014). However, these findings should be interpreted with caution due to limitations associated with small sample size, use of convenience samples, low response rates and missing details about study design.

Future research that explores different attitudes and practices of health professionals in different specialty settings could be useful for the development and implementation of FPDR policies and procedures. A recent study compared opinions of physicians in Iran and Austria in order to examine cultural variances in FPDR practices (Soleimanpour *et al.* 2015). These authors reported an overall low level of support for FPDR, but found much higher levels of support for FPDR from physicians in Iran than Austria (40% versus 3.1%). These large differences were explained by a higher proportion of physicians from Vienna than Iran in the study. However, there is a clear disparity in overall levels of support for FPDR in Western and non-Western countries that warrants further exploration.

Decision to practice family presence during resuscitation

Staff decision

The most popular decision-maker from a public perspective was the doctor in charge of patient care. For example, a general public survey in the US found 43% of respondents agreed the doctor should decide, 40% said the decision should be made by the patient and 17% said family and friends should decide (Mazer, Cox & Capon 2006). Of note, this structured survey did not include nurses as potential decision-makers so it was not possible to determine the level of support this choice would have received from the public.

Most doctors believed they should be the primary decision-maker around FPDR (Beckman *et al.* 2002; Ong *et al.* 2004; Gold *et al.* 2006; Sheng, Lim & Rashidi 2010; Vavarouta *et al.* 2011). Nursing support for doctors as the decision-maker varied considerably; some nurses were more supportive of doctors than nurses as decision-makers (Gunes & Zaybak 2009; Taraghi *et al.* 2014; Tudor *et al.* 2014), while other studies reported similar levels of support for nurses as decision-makers (Fulbrook *et al.* 2007; Axelsson *et al.* 2010).

Studies that examined FPDR from both a nursing and medical perspective all reported higher levels of support for nurses as decision-makers from other nurses than from doctors, but a higher level of support overall for doctors (Beckman *et al.* 2002; Ong *et al.* 2004; Sheng, Lim & Rashidi 2010; Taraghi *et al.* 2014). The lowest overall approval for nurses as decision-makers (0.7%) was from a Malaysian study of ED staff, despite one third of participants being nurses (Sheng, Lim & Rashidi 2010). Similar low levels of support were found in a US ED where 11.3% of nurses and only 0.3% of doctors thought nurses should decide whether to practice FPDR (Beckman *et al.* 2002). These findings suggest many health professionals and researchers do not value the nursing role in FPDR decision-making. Several studies did not include nurses on their structured questionnaire as a potential decision-maker (Gold *et al.* 2006; Mazer, Cox & Capon 2006), while others did not report findings relating to nurses as sole decision-makers (Redley & Hood 1996; Demir 2008; Vavarouta *et al.* 2011; Chapman *et al.* 2012). It was therefore not possible to determine the level of support this choice may have received if that option was offered.

Team consensus was shown to impact the decision to practice FPDR (Madden & Condon 2007; Tomlinson *et al.* 2010; Jones *et al.* 2011), and nurses ranked 'team decision' considerably higher than 'nurse decision' or 'physician decision' (Beckman *et al.* 2002; Ong *et al.* 2004; Fulbrook, Albarran & Latour 2005; Badir & Sepit 2007; Fulbrook *et al.* 2007; Demir 2008; Gunes & Zaybak 2009; Axelsson *et al.* 2010; Koberich *et al.* 2010; Vavarouta *et al.* 2011). In contrast, doctors ranked 'physician decision' higher than 'team decision' or 'nurse decision' (Beckman *et al.* 2002; Ong *et al.* 2004; Sheng, Lim & Rashidi 2010; Vavarouta *et al.* 2011; Taraghi *et al.* 2014). In all of the studies mentioned above, nurses rated 'team decision' more highly than did doctors across different countries (Europe, Turkey, Germany, Asia, Greece, USA) and across multiple settings (critical care, ED, ICU). This finding could reflect the professional ethos of nurses, who are encouraged to work and make decisions as part of a multidisciplinary team. It could also reflect the nurses' wish to be included in decision-making.

It is clear that - overall - nurses are more supportive of FPDR than doctors, while doctors consistently receive a higher level of support as decision-makers than nurses. It is likely then that doctors are driving much of the decision-making around FPDR, but may be influenced by the attitudes and beliefs of nurses. However, it is not clear how and why decisions to practice FPDR are made, and further research is needed to provide an in-depth exploration into the power relationships between staff who support FPDR practices and those who are seen to be in charge of FPDR practices.

Family member / patient decision

Most studies that surveyed decision-making around FPDR from a health professional perspective did not include family members or patients as potential decision-makers (Ong *et al.* 2004; Badir & Sepit 2007; Fulbrook *et al.* 2007; Gunes & Zaybak 2009; Axelsson *et al.* 2010; Sheng, Lim & Rashidi 2010; Vavarouta *et al.* 2011). It was therefore not possible to accurately determine the level of support this group may have received. However, results from seven studies that did mention the family member/patient decision-making role indicated that some members of the healthcare team were supportive of involving family members/patients in decision-making to varying degrees (Beckman *et al.* 2002; Fulbrook, Albarran & Latour 2005; Demir 2008; Chapman *et al.* 2012; Hayajneh 2013; Taraghi *et al.*

2014; Tudor *et al.* 2014) . In most cases, the level of support for family members/patients as decision-makers was lower than for nurses, doctors and the resuscitation team as decision-makers. However, several studies (Chapman *et al.* 2012; Hayajneh 2013; Tudor *et al.* 2014) reported higher levels of support for family members and patients than for nurses and doctors.

In contrast to studies reporting findings from a health professional perspective, a much higher percentage of the general public thought patients and their families should be involved in the decision to be present during resuscitation. A phone survey of the general public in the US found 17% of participants thought family/friends should make the decision, while 40% said the patient should decide whether they wanted family presence during resuscitation (Mazer, Cox & Capon 2006). However, the study did not elaborate on how patient consent would be gained if they were being resuscitated (and thus unconscious). Similarly Boie *et al.* (1999) found a large number of parents (83.4%) would want to stay with their child during major resuscitation, and 65.5% would choose to be present for all five of the hypothetical invasive procedures and resuscitation scenarios presented to them in this study. In contrast only 6.5% of the parents wanted the doctor to determine parental presence in all five scenarios (Boie *et al.* 1999).

There appears to be a large disparity between the decision-making preferences of health professionals and health consumers that warrants further exploration. While we know these divergences exist, we do not know why and therefore cannot begin to address these inconsistencies because no studies to date have explored rationales for decision-making in relation to FPDR.

Policy driven decision

Only one study reported formal policies being involved in the decision to practice FPDR. It is likely that the policy option was reported in this study because of the way the questionnaire was structured (Sheng, Lim & Rashidi 2010). The researchers provided a list of potential decision-makers for health professionals to choose from, which included senior doctors (43.7%), department policy (31.5%), team decision (23%), nursing officer (0.7%), and don't know (1.1%). The only other study that examined the role of formal guidelines reported that nurses were more likely than doctors to support the role of

advanced care directives in FPDR decision-making (Chapman *et al.* 2012). None of the other studies discussed within this theme provided a structured choice of 'department policy' as the decision-maker. The role of policy will therefore be discussed in a different context in the following section.

Policy relating to family presence during resuscitation

Many healthcare settings did not appear to have a policy around FPDR; 24 studies reported that no policy existed at the time of the study and a further 64 studies did not mention a FPDR policy at all. Appendix 4 (page 255) provides a tabulated overview of the presence or absence of FPDR policies in each of the reviewed studies. Very few studies reported the percentage of staff who claimed to work in a unit with a written policy, along with their current practices. When this *was* reported, the percentage of staff working with a current FPDR policy ranged from 2% to 11% (see appendix 4, page 255). In almost all of these studies, more participants reported having invited or having previously experienced FPDR than those who reported working in a unit with a formal FPDR policy. In other words, health professionals were inviting FPDR in the absence of any guiding policies.

In some cases, health professionals reported working in a unit that *informally* practiced FPDR in the absence of policy (MacLean *et al.* 2003; Oman & Duran 2010). Often, a higher number of family members requested to be present than there were units supported by a formal policy (refer to appendix 4, page 255) (MacLean *et al.* 2003; Fulbrook, Albarran & Latour 2005; Fallis, McClement & Pereira 2008; Mortelmans *et al.* 2009; Axelsson *et al.* 2010; Koberich *et al.* 2010; Hayajneh 2013). This suggests adequate policies were not in place to support the needs and preferences of family members.

Poor knowledge of or disregard for existing policies was evident in several studies. For example Fallis *et al.* (2008) found 23.6% of the critical care nurses in their study did not know if there was a policy in their unit, yet 65% had taken family to the bedside or would do so if opportunity arose. At other times, nurses did not offer FPDR despite the existence of a policy supporting the practice. For example, Maxton (2008) found that while a formal FPDR policy existed in an Australia paediatric ICU, this choice was not always offered by staff. Thus, the presence of a FPDR policy did not always ensure consistent practice, and

in some cases there were large differences in where the family was located in the room during the resuscitation, while others were not invited into the room at all (Tinsley *et al.* 2008).

Several studies included a brief evaluation following implementation of a FPDR policy, with mixed results. The only negative evaluation was reported by Davidson *et al.* (2011) who explored inhibitors and facilitators to FPDR in an attempt to discover why no perceivable change in practice had been noted since the introduction of a policy. The authors attributed the poor uptake on the lack of a designated support person (Davidson *et al.* 2011). In contrast, all other studies that included an evaluation reported positive responses to FPDR practices from staff (Boyd & White 2000; Meyers *et al.* 2000; Mangurten *et al.* 2006; Basol *et al.* 2009; Feagan & Fisher 2011; Curley *et al.* 2012; Lowry 2012) and from family members (Pasquale *et al.* 2011).

The most positive evaluation was presented by Lowry (2012) who explored the attitudes of US emergency nurses. A written policy had existed in this setting since 1992 and, according to Lowry (2012), nurses in this study described a degree of comfort with FPDR that had not previously been reported in the literature. It was concluded that the policy on FPDR seemed to be learned and accepted more by modelling than by nurses' familiarity with the protocol, and current practices suggested that acceptance of FPDR by nurses was positively affected by long-term participation (Lowry 2012).

Practices around FPDR within units that did not have a formal policy varied widely and there were often conflicting views between staff within the same healthcare setting. Knowledge deficits about current policies and practices were also evident. Some healthcare settings without a policy reported that their standard practice was not to practice FPDR (Bassler 1999; Kotkis & Tabak 2008; Itzhaki, Bar-Tal & Barnoy 2011; Al-Mutair, Plummer & Copnell 2012). However, actual practice did not always comply with this unofficial policy. For example, Al-Mutair, Plummer & Copnell (2012) reported that usual practice was not to implement FPDR and yet 55.3% of the nurses in this Saudi Arabian study claimed past experience with FPDR. Similarly, usual practice in a US ED was not to implement FPDR and yet seven of the ten parents interviewed for this study had been present at their child's resuscitation (McGahey-Oakland *et al.* 2007). These findings

indicate that wide variations in practice can occur in the absence of clear policies and guidelines.

At times, staff claimed to be working under policies that did not exist (Demir 2008; Mortelmans *et al.* 2009; Tomlinson *et al.* 2010), while others reported practicing FPDR in the known absence of policies or guidelines (Hallgrimsdottir 2000; Badir & Sepit 2007; Madden & Condon 2007; Twibell *et al.* 2008; Kianmehr *et al.* 2010; Tomlinson *et al.* 2010; Nykiel *et al.* 2011). One ED department went further to implement standardised FPDR practices despite the absence of a formal policy, providing a support person for family members who wished to remain present and offering the services of a social worker and chaplain if desired (Weslien *et al.* 2006).

More than half of the primary studies included in this preliminary review did not mention whether the study setting had a formal policy (refer to appendix 4, page 255), yet most participants reported previous experience with FPDR. Instead of a policy, several studies mentioned current standard practices that included the following; FPDR not being offered in an Australian ED (Holzhauser & Finucane 2008); FPDR being occasionally practiced in a Turkish ED (Yanturali *et al.* 2005); nurses deciding who should or should not be present in a multiple specialty setting in the US (Knott & Kee 2005); asking relatives to sit in the 'relative waiting room' in an Australia ED (Holzhauser, Finucane & De Vries 2005), excluding FPDR in a Saudi Arabian hospital (de Beer & Moleki 2012), and highlighting that the concept of FPDR was novel in eight West Indian EDs (Mahabir & Sammy 2012).

It appears that many health professionals are practicing FPDR in the absence of formal policies - or with limited knowledge of relevant policies and procedures when they do exist. Given that the existence of formal written policies has been recommended as an important facilitator for the implementation and consistent practice of FPDR (Jarvis 1998; Meyers *et al.* 2000; MacLean *et al.* 2003; Fein, Ganesh & Alpern 2004; Knott & Kee 2005; Lam *et al.* 2007; Madden & Condon 2007; Fallis, McClement & Pereira 2008; Zakaria & Siddique 2008; Bassler 2009; Fernandez *et al.* 2009; Hallgrimsdottir 2000; McClement Fallis & Pereira 2009; Tomlinson *et al.* 2010), the scant attention paid to policy existence, development, implementation and evaluation in the literature needs to be redressed.

In addition, we have a limited understanding of resuscitation outcomes between health care settings with or without supporting FPDR policies. A recent US study (Goldberger *et al.* 2015) reported no statistically significant differences in resuscitation outcomes and processes of care in hospitals with and without policies. However, the authors concluded that further research is needed to measure the direct impact of FPDR on processes and outcomes, and on patients and their families.

Pre-requisites for family presence during resuscitation

The decision to practice FPDR was often based on a series of pre-requisites. The following six requirements (separately or in various combinations) were integral to the decision-making process for many health professionals; irrespective of country, profession or healthcare setting.

1) Support person
2) Case-by-case approach
3) Special allowances for a child
4) Level of invasiveness
5) Family request to be present
6) Personal beliefs and preferences

Support person

The most common pre-requisite was availability of a family support person to provide comfort, support and information about ongoing interventions and patient progress (Back & Rooke 1994; Chalk 1995; Jarvis 1998; Hallgrimsdottir 2000; Grice, Picton & Deakin 2003; MacLean *et al.* 2003; Booth, Woolrich & Kinsella 2004; Fein, Ganesh & Alpern 2004; Gold *et al.* 2006; Badir & Sepit 2007; Fulbrook *et al.* 2007; Perry 2009; Koberich *et al.* 2010; Oman & Duran 2010; Gordon *et al.* 2011; Kosowan & Jensen 2011; Al-Mutair, Plummer & Copnell 2012; Leung & Chow 2012; Lowry 2012; Hayajneh 2013; Chapman *et al.* 2014; Chew & Ghani 2014; Taraghi *et al.* 2014; Zavotsky *et al.* 2014). Similarly, some studies reported a very strong hypothetical level of support for FPDR if a support person was available (Back & Rooke 1994; Chalk 1995; Grice, Picton & Deakin 2003; Fein, Ganesh & Alpern 2004; Kosowan & Jensen 2011; Al-Mutair, Plummer & Copnell 2012; Porter,

Cooper & Taylor 2015), with several studies concluding that for FPDR to be successful, a support person *must* be available (Knott & Kee 2005; Davidson *et al.* 2011).

Further highlighting the importance placed on the availability of a support person, the absence of a support person was commonly cited as a reason not to practice FPDR (Back & Rooke 1994; Booth, Woolrich & Kinsella 2004; Fulbrook *et al.* 2007; Fernandez *et al.* 2009; Lowry 2012; Chapman *et al.* 2014). In addition, an awareness of the support role has been shown to increase support for FPDR (Fernandez *et al.* 2009), even when the majority of staff are not supportive of FPDR (Leung & Chow 2012), once again stressing how vital this role is for future planning and implementation of FPDR policies and practices.

Case-by-case approach

An individualised, case-by-case approach was seen as vital by some staff, with FPDR practices depending on the family and the circumstances (Back & Rooke 1994; Timmermans 1997; Meyers *et al.* 2000; MacLean *et al.* 2003; Fein, Ganesh & Alpern 2004; Gold *et al.* 2006; Duran *et al.* 2007). Specific considerations included; the ability of family members to decline presence, being able to remove family members from the room if necessary, having only a pre-determined number of family in the room, ensuring staff were adequately trained and that a pre-defined definition of 'family member' is set (Back & Rooke 1994; Fein, Ganesh & Alpern 2004). Some health professionals highlighted the importance of a 'controlled environment' in order to practice FPDR (Redley & Hood 1996; Lam *et al.* 2007), where staff perceived they were in control of the situation.

A study involving ED nursing and medical staff in the US and Germany reported that if staff made the decision to practice FPDR, the family member needed to be 'fully present' and not 'peeking around the door' (Timmermans 1997). Timmermans (1997) further argued that if health professionals take a holistic view of resuscitation, family members can potentially become active participants where they care about the patient *with* the staff instead of being cared for *by* the staff. A holistic view of resuscitation would allow recognition that death is a likely but not necessarily 'bad' outcome. In other words, the resuscitation can be viewed as a 'success' even if the patient dies – as long as staff also cared for the family. However this cannot occur without policies and guidelines

supporting a consistent approach to FPDR across health care settings, and across professional disciplines.

Special allowances for a child

There was commonly a higher level of support for FPDR if the patient was a child (Back & Rooke 1994; Booth, Woolrich & Kinsella 2004; Knott & Kee 2005; Mortelmans *et al.* 2009; Chapman *et al.* 2014; Porter, Cooper & Taylor 2015). Reasons for this included parents already being in the room and thus invited to stay (Knott & Kee 2005), or because staff made special allowances, believing parents have a right to stay with their children (Knott & Kee 2005; Chapman *et al.* 2014). However, some health professionals argued that parental presence should be used as an example to encourage FPDR for *all* age groups rather than singling out a particular cohort (Chapman *et al.* 2014).

In contrast, several studies found no difference in levels of support for FPDR between adults and children (Baumhover & Hughes 2009), or found health professionals were less likely to practice FPDR if the patient was a child (McClenathan, Torrington & Uyehara 2002; Kianmehr *et al.* 2010). Researchers from the latter study explained this finding as a lack of experience with children among participants. However, low support rates overall in this study indicated that this population was not comfortable with FPDR for patients of any age (Kianmehr *et al.* 2010).

Perceived level of invasiveness

The perceived level of invasiveness was a consideration for some staff when deciding whether to practice FPDR. Support was found to decrease as the level of invasiveness increased (Beckman *et al.* 2002; Fein, Ganesh & Alpern 2004; Bradford *et al.* 2005; Egemen *et al.* 2006; Ong, Chung & Mei 2007; Curley *et al.* 2012; Lowry 2012). In contrast, one study that compared attitudes and beliefs of health professionals in an Asian ED with those of the general public found conflicting views (Ong, Chung & Mei 2007). While 93.9% of health professionals thought FPDR should only be implemented once all invasive procedures were completed but before the resuscitation stops, 59.3% of the general public thought FPDR should be practiced as soon as the patient enters the resuscitation room and 35.2% thought FPDR should occur once all invasive procedures have finished but before resuscitation stops (Ong, Chung & Mei 2007). This represents a significant

divergence between staff views and those of (potential) family members that would be useful to explore further.

Family request to be present

Family member requests for FPDR were shown to impact staff practice to varying degrees. Some health professionals were more likely to practice FPDR if a family member asked to be present (Jarvis 1998; Hallgrimsdottir 2000; Grice, Picton & Deakin 2003; Chapman *et al.* 2014), while for others, family requests did not significantly impact clinical practice (Egemen *et al.* 2006). In one study, 'family request' was listed as a reason to practice FPDR, with the majority of nurses (64%) believing family were best placed to decide whether or not they wished to be present (Chapman *et al.* 2012).

For some health professionals, their decision to agree to requests for FPDR was linked to their existing support for the practice (Chapman *et al.* 2014). In some cases, they were influenced by family requests to remain in the resuscitation room but also highlighted that different family preferences must be respected (Chapman *et al.* 2014).

Personal beliefs and preferences

The influence of personal values and preferences was found to potentially impact decision-making around FPDR in several studies, from a variety of healthcare settings and professions. Some ED staff agreed that differences in attitudes, personality and personal preferences had the potential to cause conflict between resuscitation team members and in turn affect implementation of FPDR practices and policies (Helmer *et al.* 2000; Yanturali *et al.* 2005; Gordon *et al.* 2011). While staff with a personal preference for having their own family present if they needed resuscitation were more likely to perceive greater benefits and fewer risks associated with FPDR (Chapman *et al.* 2012)

At times, the same concept was seen as positive by some staff and as negative by others. For example, some health professionals thought that 'humanising' the situation by practicing FPDR was helpful and rewarding, while others believed it was harder because they preferred to place 'a little distance' between themselves and the patient to facilitate 'going through the motions' (Davidson *et al.* 2011). These findings suggest that individual

value systems may have an important impact on FPDR practices which warrants further examination.

Measured effects of family presence during resuscitation

There have been a multitude of descriptive studies examining the perceived effects of FPDR on the performance and wellbeing of health professionals and on the wellbeing of family members. Yet, very few studies have attempted to *measure* the effects of FPDR on these key groups in an acute healthcare setting. A recent randomised controlled trial in France evaluated the psychological consequences for family members who were offered FPDR in the *pre-hospital* setting (Jabre *et al.* 2014). Those who were not offered FPDR developed post-traumatic stress disorder-related symptoms more frequently than those who were. In addition, major depressive episodes were significantly higher among family members who were not offered FPDR than those who were. Jabre *et al.* (2014) concluded that at one year after the resuscitation event, psychological benefits had persisted for family members who were present during resuscitation.

In an acute care context, only three studies included in this review measured and compared the psychological impact of FPDR on family members who were or were not present at their loved one's resuscitation (Robinson *et al.* 1998; Compton *et al.* 2011; Pasquale *et al.* 2011), with varying results. Robinson and colleagues (1998) found that family members who were present reported no adverse psychological effects. None had been scared or had to leave the resuscitation room, and seven of the eight family members said their grief had been eased by sharing those last moments with their relatives. Overall at 3 and 9 months the median scores for anxiety, depression, intrusive imagery, post-traumatic avoidance behaviour and grief were *lower* in the group who were present than in the absent group (Robinson *et al.* 1998). In contrast, Compton *et al.* (2011) and Pasquale *et al.* (2011) more recently reported that anxiety, satisfaction and well-being were not statistically different between family members who were or were not present. However, like Robinson and colleagues, they did not report any adverse effects in the groups that experienced FPDR.

Each of the acute care setting studies outlined above used different tools to measure and evaluate the psychological effects of FPDR, making it difficult to compare results. In

addition, all three studies had limitations, such as small sample sizes and incorrect randomisation procedures because some staff were so convinced of the benefits, they invited family members to be present even when randomised into the absent groups. In some cases, successful resuscitations were excluded from the study due to the questionnaire being deemed inappropriate. The views of this group were therefore not known and would have been a valuable comparison (Robinson *et al.* 1998). In another study, most resuscitation patients died and the overall effect of FPDR may have been different had more patients survived (Pasquale *et al.* 2011). Despite their limitations, these studies offered a direct comparison of the psychological effects of actual, rather than hypothetical, experiences. The studies found no significant differences between family members who were present and those who were absent. One study went further to state median scores for anxiety, depression, intrusive imagery, post-traumatic avoidance behaviour and grief were *lower* for family members who were present than those who were absent (Robinson *et al.* 1998).

Findings reported from studies *measuring* the effects of FPDR are in direct contrast with common *perceptions* about FPDR. For example, many health professionals have reported concerns that family members will suffer negative psychological effects, and they often cite these perceptions as a reason to justify not practicing FPDR. Further research is needed to measure the effects of FPDR on everyone involved so that researchers and policy makers have a better understanding of the benefits and risks of this practice for family members and health professionals.

While little attention has been paid to measuring the effects of FPDR on health professionals, their perceptions have been measured using several tools developed primarily for that purpose; the *Family Presence Risk-Benefit Scale* and the *Family Presence Self-Confidence Scale* (Twibell *et al.* 2008; Chapman *et al.* 2012). There was a significant positive correlation between the perception of more benefits and fewer risks, and more self confidence in the ability to manage FPDR. In addition, participants who reported a higher education level, a certified clinical specialty and greater experience in inviting FPDR were significantly more likely to perceive more benefits and fewer risks and more self-confidence.

The few studies that have measured the effects on health professionals reported similar findings that indicate FPDR does not significantly increase stress levels or negatively impact performance. Researchers in the UK who examined perceived symptoms of stress among ED staff did not find large differences between those who did and those who did not have family present during resuscitation (Boyd & White 2000). However, these researchers used a stress management scale alone and did not ask staff if they felt stressed in order to triangulate findings. Nor did they state how long after the arrest the questionnaire was completed, and the stress response could have been from the physical exertion of the resuscitation rather than just from the emotional aspects of the resuscitation. Further studies measuring the psychological impact of FPDR are needed, using mixed methods in order to triangulate findings.

Interrupted care (i.e. care being interrupted by a disruptive family member) is a commonly cited barrier and is used as a rationale to not practice FPDR. However, the limited research on interrupted care indicates that, contrary to common fears, FPDR can be practiced successfully with no interruptions and without negatively affecting patient care if protocols exist to support and guide practice (Mangurten *et al.* 2006). In addition, simulated trials have shown that even when a family member is present and displaying overt grief reactions, staff performance is not negatively impacted (Fernandez *et al.* 2009). While the simulated nature of the latter scenario reduces the emotional impact of FPDR, it could be a useful way to provide realistic education and preparation of health professionals for the introduction of a standardised protocol.

Barriers to family presence during resuscitation

Multiple barriers have been identified over the past few decades, including fear of litigation and concerns that family members could become disruptive and interrupt care. However, there are no documented cases of related litigation and few cases where care has been interrupted. Many of the reported barriers outlined in Table 2 (page 33) are perceived rather than drawn from observation of actual events, and further research is needed to investigate the source of these perceptions. In addition, many of these barriers were reported by health professionals who have *not* experienced FPDR, leading to the identification of hypothetical barriers. Further, the quantitative design of most FPDR

studies provided varying pre-determined barriers for participants to agree/disagree with, which does not allow for an in-depth exploration of how and why these barriers are experienced, or their subsequent impact on clinical practice.

Table 2: Perceived barriers to FPDR affecting health professionals

Barriers relating to staff	Studies
Fear of litigation	49
Family member could interfere, argue, be disruptive, interrupt care	43
Increased stress and emotional trauma for staff	40
Team/staff performance could be negatively affected	37
Resuscitation may be prolonged, difficulty stopping resuscitation	25
No support person available, not enough staff	22
Performance anxiety, difficult to concentrate or make decisions	20
Space limitations	20
Staff reluctance to practice FPDR	11
Staff worried they may say something inappropriate	10
Staff worried about being seen as inexperienced, doing something wrong	8
May inhibit communication between team members	7
May affect staff training opportunities	7
Staff focus distracted from patient to the family member	6

Bibliographic details for all studies in this table can be found in Appendix 5 (see page 257)

The most commonly reported barriers potentially affecting both patients and family members (which were mostly identified by health professionals) were that FPDR would be too distressing or traumatic, and concerns about patient confidentiality (refer to Table 3 on page 34). However, it is important to note that many of these potential barriers were challenged by the studies discussed in the previous section that measured the effects of FPDR.

Table 3: Perceived barriers to FPDR affecting patients / family members

Barriers affecting patients	Studies
Concerns about confidentiality	14
Concern for patient privacy, dignity	10
Staff believe FPDR not beneficial to patient	7
No consent from patient	3
Barriers affecting family members	
Too distressing, traumatic for family members	47
Staff worried family member may not understand CPR, consider it offensive or chaotic	20
Potential long term psychological effects	15
Unpleasant or traumatic memories, bad last impression of the patient	11
Family member may panic	3
Family member does not ask to be present	1
Family do not arrive in time to be present	1

Bibliographic details for all studies in this table can be found in appendix 5 (see page 257)

Facilitators and benefits of family presence during resuscitation

The most significant facilitators to the implementation and consistent application of FPDR practices were the availability of a family facilitator or support person, existing policies, and staff education and support (refer to Table 4).

Table 4: Perceived facilitators of FPDR

Facilitators to FPDR	Studies
Family facilitator / support person	22
Existing policies, guidelines and conditions	14
Staff education and support	11
Previous experience with FPDR	4
Consensus among staff	2

Bibliographic details for all studies in this table can be found in appendix 6 (see page 260)

Alongside the barriers previously outlined, FPDR was also viewed as beneficial for family members, patients and health professionals. The most commonly reported benefit was allowing family members to see everything possible was done for the patient and facilitating the grieving process. FPDR was also seen to benefit the patient by allowing

family members to provide support and advocacy for their loved one, and by humanising the patient. An increased bond between staff and family was also seen as an important benefit, alongside an enhanced level of communication. A summary of the perceived benefits of FPDR is presented in Table 5.

Table 5: Perceived benefits of FPDR

Benefits for Patients	Studies
Family member can provide support to patient	8
Personalises, humanises the patient	6
FPDR is beneficial for the patient	4
Family member can advocate for the patient	2
Provides holistic care	1
Benefits for Family Members	
Help family member with the grieving process	34
Help family member know/see everything was done	32
Family member can share last moments with loved one	14
Closure for family member, ability to say goodbye, helps them accept the death	13
Prevents a distorted image of CPR, allows a more realistic view	11
Staff can provide support to family member	6
Family member can be informed of patient progress	5
Can decrease family member anxiety	4
Helps family member to adjust to the illness	3
Enables family member to give last religious rites	2
Decreases fear of the unknown	2
Family member will suffer fewer psychological complications	1
Benefits for health professionals	
Family member more likely to accept treatment withdrawal	9
Team performance positively affected, improves professional behaviour	9
Family member more satisfied with care, appreciate staff efforts	6
Reduces litigation	5
Easier to tell outcome in the resuscitation room	2
Benefits for staff and family members	
Creates a stronger bond between family member and staff	12
Family member can provide information, help make decisions	8
Family member included as part of the team	5
Can enhance communication between staff and family member	3

Bibliographic details for all studies in this table can be found in Appendix 7 (see page 261)

DISCUSSION

Many contradictions exist in the FPDR literature. There are varying levels of support for FPDR between different health professionals, and between health professionals and family members. In addition, many barriers and facilitators are based on perception rather than actual events. The influence of personal values and preferences on the decision to practice FPDR from a variety of healthcare settings and professions also appears to be an important consideration. Because individual value systems and staff consensus may have a considerable impact on implementation and adherence to FPDR, this finding warrants further investigation in order to examine rationales for practice. An enhanced understanding of rationales and motivators will help identify sound recommendations for future practice and policy development. Decision-making is therefore examined in detail from multiple perspectives in this thesis to determine the factors and perceptions that impact the decision to practice or participate in FPDR.

The existing body of evidence has not adequately documented the level of FPDR policy implementation around the world. This needs to be addressed given that a significant facilitator to the implementation and consistent application of FPDR practices are organisational and structural factors such as the availability of a family support person, existing policies, and staff education and support. Future research needs to focus on evaluating and comparing current attitudes and practices in settings that do and do not have current policies in place.

The majority of published studies have explored FPDR from a health professional perspective, with a much smaller number focusing on family members and patients. The most obvious gap is the patient's voice, which is a particular challenge because of low survival rates from resuscitation events. Qualitative interviews with surviving patients would address this knowledge gap and help determine whether they would have wanted their family members present and why. Given the important role family members play in their loved ones' lives, it is also important to consider their current and preferred role in decision-making around FPDR. Asking family members and patients about their preferences could also prompt families to discuss FPDR in much the same way they discuss other end-of-life decisions such as organ donation or advanced directives.

Finally, it is evident that nurses are more supportive of FPDR than doctors, and that family members are more supportive of FPDR than health professionals. However, it is unclear why and to what extent these varying levels of support affect clinical practice. Further research is needed into rationales for health professionals' attitudes, preferences and beliefs, including how they impact decision-making and subsequent FPDR practices.

CHAPTER SUMMARY

This chapter explained and justified the use of literature in this GTM study, provided an in-depth examination and critique of the published body of evidence and scrutinised past and present FPDR experiences, attitudes, beliefs, practices and policies in order to identify gaps and limitations. The aim of this doctoral study was developed in order to address some of these knowledge gaps and the identification of methodological limitations enabled selection of the most suitable research design for the current study.

The aim of the study presented in this thesis was to examine factors and perceptions that impact family presence during resuscitation practices in acute healthcare settings from the perspectives of health professionals, family members and patients. The following chapter presents the methodology used to address this aim.

Chapter Three: Methodology

CHAPTER OVERVIEW

The purpose of this study was to examine decision-making around family presence during resuscitation. More specifically, the aim of this study was to examine the factors and perceptions that impact FPDR practices from the perspectives of health professionals, family members and patients. Chapter two examined the related literature and identified many contradictions regarding barriers, facilitators, attitudes and practices. This chapter details the methodology used for the study. Chapter three begins with a brief overview and evolution of grounded theory method (GTM) before discussing symbolic interactionism, social constructionism and constructivism and how they underpin the chosen methodology. The chapter concludes with a discussion of Charmaz's constructivist approach to GTM and how it was applied in this thesis.

The term grounded theory is ambiguous, and is often used interchangeably to signify the methodology, the method and/or the resulting theory. This thesis therefore uses Bryant and Charmaz's (2007a) recommended terms as follows; *grounded theory method* (GTM) is used to describe the methodology and research process, while *grounded theory* is used to refer to the result of the research process.

GROUNDED THEORY METHOD: ORIGINS AND EVOLUTION

GTM is a research methodology used to create conceptual frameworks or theories through inductive and abductive data analysis, rather than via hypothetical deductions or prior assumptions (Glaser & Strauss 1967; Charmaz 2014). In more simple terms, GTM consists of a set of systematic guidelines for collecting and analysing (primarily) qualitative data in order to construct theories that are grounded in the data (Glaser & Strauss 1967).

A key feature of GTM is the concurrent generation and analysis of data, with each informing and focusing the other; this allows analysis to become progressively more theoretical as the research progresses (Glaser & Strauss 1967; Glaser 1978; Strauss 1987; Strauss & Corbin 1990, 1998). Other core tenets of GTM include theoretical sampling,

constant comparison of data to theoretical categories, writing theoretical memos and a focus on the development of theory through the theoretical saturation of categories rather than through substantive verification (Hood 2007). The fundamental processes of GTM are discussed in detail in chapter four.

At its core, GTM aims to understand behaviour and meanings participants give to their experiences in a particular setting (Glaser 1978). GTM can provide a behavioural perspective, enable explanation (and sometimes prediction) of behaviour, and facilitate the development of conceptual understandings that can be applied in practical situations (Glaser & Strauss 1967). The use of GTM allows the researcher to move beyond exploration and description of a phenomenon to the generation of a conceptual theory that explains the phenomenon from the perspective and in the context of those who experienced it (Birks & Mills 2011).

GTM was originally described by sociologists Glaser and Strauss (1967) following their collaborative research with Nurse Jeanne Quint (now Benoliel) examining the experience of patients dying in hospital (Benoliel 1996). Benoliel's collaboration with Glaser and Strauss demonstrated the usefulness of conceptualising issues in clinical practice settings and explicating their significance (Quint 1967). Glaser and Strauss's (1967) seminal text *The Discovery of Grounded Theory* described a set of procedures they used to generate theory from empirical data. Their three other texts, *Awareness of Dying* (Glaser & Strauss 1965), *Time for Dying* (Glaser & Strauss 1968) and *Status Passage* (Glaser & Strauss 1971) completed their 'complex methodological mix' of grounded theory methods which were viewed by many as a way to formalise qualitative research methods (Bryant & Charmaz 2007b, p. 31).

Glaser and Strauss's early works challenged many widely held beliefs of the time including views that qualitative research was merely a forerunner to more 'rigorous' quantitative methods, and that qualitative methods were unsystematic and impressionistic (Birks & Mills 2011). Glaser and Strauss also contested assumptions that qualitative research was unable to contribute to theory development and offered systematic strategies for qualitative research practices (Birks & Mills 2011).

In their original collaboration, Glaser and Strauss (1967) introduced a general comparative method that continuously and systematically compared data with emerging concepts using simultaneous data collection and analysis. The most basic processes that established the foundation for category building were coding and the constant comparison of data, codes and emerging categories. Two basic rules of category building were outlined in Glaser and Strauss's seminal text that according to Kelle (2007, p. 193), remain integral to category building in GTM research; 1) categories should emerge from the data during analysis rather than being forced onto the data from pre-existing sources, and 2) the researcher must employ theoretical sensitivity (theoretical sensitivity is detailed in chapter four).

Soon after the publication of their final collaborative text, Glaser and Strauss adopted diverging approaches that reflected their respective theoretical and epistemological beliefs. In keeping with his rigorous quantitative training at Columbia University, Glaser's objectivist approach (Glaser 1978, 1998, 2001) emphasised positivism and researcher neutrality while aiming for abstract generalisations irrespective of time, place or individual experiences. In other words, Glaser's objectivist GTM assumed that a neutral observer can discover data in an external world that can be kept completely separate from the researcher's values, past experiences, tacit assumptions, status or the setting. In contrast, Strauss's Chicago school heritage and roots in pragmatism and symbolic interactionism led to the development of an approach that considered human agency, social and subjective meanings and the study of action (Strauss & Corbin 1990, 1998).

The most noted difference between Glaser and Strauss's diverging approaches was their method of coding and theory construction. Glaser placed greater focus on emergence and theoretical sensitivity. He presented the ideas of theoretical coding and coding families, where researchers have a variety of theoretical concepts at their disposal that allow them to structure the developing categories and the emerging theory (Glaser 1978). Strauss instead recommended that the most important categories should be developed and related to each other using a paradigm model of human action and interaction (Strauss 1987). Later, Strauss and Corbin (Strauss & Corbin 1990, 1998) developed a prescriptive

coding paradigm that included axial coding and the coding matrix, which they believed helped structure the data and clarify relationships between categories.

In their original text, Glaser and Strauss (1967) invited researchers to use GTM strategies flexibly and develop their own versions of the methodology. Consequently, other researchers have modified GTM in order to use it from a variety of epistemological positions and perspectives (Charmaz 2006; Mills, Bonner & Francis 2006b; Bryant & Charmaz 2007b). One of the leading experts who developed a constructivist approach to GTM is Kathy Charmaz.

The following section discusses the theoretical and epistemological perspectives that underpin a constructivist approach to GTM, which includes symbolic interactionism and social constructionism. The chapter then introduces Charmaz's constructivist GTM, and describes the relationship between constructivist GTM, symbolic interactionism and social constructionism. This chapter concludes with a critique and defence of Charmaz's constructivist GTM and discussion of how the method was applied in this thesis.

THEORETICAL PERSPECTIVES

The theoretical perspective of a study is the philosophical stance that informs the methodology and in turn provides a context for the research process, including its logic and criteria (Crotty 1998, p. 3). Symbolic interactionism is a theoretical perspective that informs a range of methodologies, including GTM (Annells 1996; Crotty 1998; Clark 2005; Charmaz 2006; Bryant & Charmaz 2007b; Holton 2007; Aldiabat & Le Navenec 2011; Charmaz 2014).

Symbolic interactionism is an approach to understanding and explaining human society, while constructionism and constructivism are epistemologies that embody many theoretical perspectives, including symbolic interactionism (Crotty 1998). Epistemology is the theory of knowledge embedded in the theoretical perspective and therefore in the methodology (Crotty 1998), and is a way of explaining and understanding how we know what we know and the nature of the relationship between the knower and would-be-knower (Denzin & Lincoln 2008).

The theoretical perspective then is a way of looking at the world and making sense of it, and involves knowledge and an understanding of what is entailed in knowing – in other words, *'how we know what we know'* (Crotty 1998, p. 8). The connection between the research methodology, epistemology and the underlying philosophy is the balance between what a researcher wants to understand, what exists, and what can be known (Higgs, Horsfall & Grace 2009).

It is inevitable that researchers will bring personal assumptions to their chosen research methodology, and it is important for the integrity of the research to explain and justify these assumptions. Crotty (1998) contends that by elaborating our theoretical perspectives we can clarify assumptions embedded in our view of the human world, the social life within that world, and how we generate meaning from them. Symbolic interactionism deals directly with these issues and according to Crotty (1998) is a theoretical perspective that can explicitly ground our assumptions about the human world and social life within that world.

The following section presents a discussion on symbolic interactionism; including a brief history, core premises, the nature of human society and social interaction, human and collective action, and pragmatism. This is followed by a critique and defence of symbolic interactionism.

SYMBOLIC INTERACTIONISM

History of symbolic interactionism

Symbolic interactionism is both a theory of human behaviour and an approach to inquiring about human conduct and group behaviour (Annells 1996). Symbolic interactionism suggests that the mind and self are social products and that people structure their extended world through their perceptions and interpretations of what they believe the world to be as they interact with others around them (Meltzer, Petras & Reynolds 1975; Bulmer 1979). Central to symbolic interactionism is the view that we construct our own and other's identities through our everyday encounters with each other in social interaction (Burr 2003, p. 13).

Many prominent scholars including Cooley, James, Dewey and Darwin contributed to the intellectual foundations of symbolic interactionism. However, what we know today as symbolic interactionism is said to originate from the thoughts of social psychologist George Herbert Mead, who was influenced by pragmatist philosophers of the time - in particular John Dewey (Blumer 1969; Crotty 1998; Barkway 2001; Jeon 2004). Mead's (1962) basic tenet was that we define our *self* through social roles, expectations and perspectives imposed on that self by society and the people within society.

Symbolic interactionism was named and further advanced by social constructionist Herbert Blumer in 1937. According to Blumer (1969), Mead's contribution to symbolic interactionism was primarily philosophical and lacked an explicit theoretical framework of human society. Blumer claimed to be more concerned with developing symbolic interactionism as a sociological theory and research approach and built on Mead's work by explicating some of his central ideas. More specifically, Blumer (1969, p. 6) posited that symbolic interactionism was grounded on 'root images' that depict the nature of human groups and societies, social interaction, objects, the human being as an actor, human action and the interconnection between the lines of action. Together these root images represent the way symbolic interactionism views human conduct and society (Blumer 1969). These issues will be discussed in more detail; but first it is necessary to consider the core premises of symbolic interactionism before they can be applied to understanding social reality.

Core premises of symbolic interactionism

While refining and extending the theory of symbolic interactionism, Blumer (1969) contended that the central issues of symbolic interactionism were 'rooted' in Mead's basic tenets of 'I', 'Me', and 'Self', and the inner conversations that occur between them during social interaction. Blumer (1969, p. 2) therefore centralised the concept of *self* within his vision of symbolic interactionism and proposed three fundamental premises to explain social reality:

1) People will act toward things (people, objects, situations, institutions) depending on the meaning those things have for them.
2) The meanings of things arise from social interactions between people.

3) These meanings change through interaction with self and others, which in turn influences further interactions. People use an interpretive process to direct and modify the meanings as they interact with the objects they encounter.

Blumer (1969) acknowledged that the first premise is not exclusive to symbolic interactionism, but believed the second premise concerning the source of meaning is unique to the theory. Symbolic interactionism differs from other ways of accounting for meaning such as intrinsic meaning; i.e. the objective/realistic perspective that a chair is a chair and that people merely need to recognise the meaning that is inherent in the 'thing' (Blumer 1969). In contrast, symbolic interactionism sees meaning as originating from the process of interaction between people. Interactionists believe the meaning of things is a social construct and grows from the ways in which other people act toward the person with regard to the thing (Blumer 1969).

The third premise further differentiates symbolic interactionism - where the use of meaning by a person in action involves an interpretive process, and that meanings change through interaction. During this interpretive process;

> The actor selects, checks, suspends, regroups, and transforms the meaning in the light of the situation in which he is placed and the direction of his action. Accordingly, interpretation should not be regarded as a mere automatic application of established meanings but as a formative process in which meanings are used and revised as instruments for the guidance and formation of action. It is necessary to see that meaning play their part in action through a process of self-interaction (Blumer 1969, p. 5).

Put more simply, Blumer argued that the meanings *things* (people, objects, situations, institutions) have for individuals are central to our understanding of social reality, including the nature of human society, social interaction, and human and collective action.

The nature of human society and social interaction

A symbolic interactionist society exists in the minds of individual people who belong to that society (Meltzer, Petras & Reynolds 1975). From Blumer's (1969, p. 4) symbolic interactionist perspective, meaning does not emanate from the things people come into

contact with, but rather is brought to the thing by the person for whom the thing has meaning.

According to Blumer (1969) human society consists of people interacting with each other; of people engaged in action either singly or collectively, and sometimes acting on behalf of groups or organisations. Both society and individuals are said to arise from interaction between people through the use of symbols that have meaning for people (Burr 2003). People must interpret these symbols, including what others are doing or planning to do, and modify their own actions in order to fit their activity in some way with others (Blumer 1969).

The symbols, objects and meanings at the core of each society are continuously being reproduced by its members and reflected in that society's ways of thinking, talking and acting (Shalin 1991). Society is therefore seen as the emergent expression of both the individual and society in a constant state of instability and change (Shalin 1991), and influenced by the contextual meanings and perceptions of the people in that society (Byrne & Heyman 1997). Further, the individual and society are inextricably linked and can only be expressed in relation to each other (Shalin 1991). In other words, the individual is both the cause and the effect of society as a whole and both are continuously emerging.

It is important for interactionist researchers to understand that the indeterminacy of social reality is not merely a sign of confusion in individuals' minds, but that significance and meaning are inherently uncertain features in human interactions (Shalin 1991). In essence, people within society are continuously engaged in a process of fitting their actions into what they and their particular society deem appropriate in a particular situation, setting, time or context. Shalin (1991) considers ambiguity, uncertainty and indeterminacy valuable for encouraging people to face ever changing demands without losing their sense of human autonomy. He believes this root image of semi-ordered chaos can draw a researcher's attention to hidden agendas that people rely on to sustain the appearance of order and structure. As a result, researchers using an interactionist approach can analyse not only 'rule bound' behaviour but also the ongoing process of negotiations and conflict related to organisational practices and policies. Blumer (1969)

also gave consideration to societal rules when he emphasised that people interact in diverse and varying forms including with cooperation, conflict, tolerance, indifference, and by either upholding or breaking societal rules. The activity of others can therefore become either a positive or negative influence that compels people to review, intensify or discontinue their own actions as a result.

A crucial tenet of symbolic interactionism then is that human groups exist in action, and that they must be seen in terms of their action. In order to analyse and change social action it is therefore necessary to observe the process by which it was constructed (Blumer 1969). Researchers seeking to examine social structures such as roles and status must examine these in terms of how people act toward each other, both as individuals and as groups.

The nature of human action and collective action

Individual human action consists of a person identifying and interpreting the things around them and acting based on their interpretations. As a result, individuals live in a world that they must interpret in order to act upon rather than merely respond instinctively to (McCall & Simmons 1966; Blumer 1969; Meltzer, Petras & Reynolds 1975). According to Mead (1962) people are acting beings by virtue of possessing a *self* - able to be an object of their own action by seeing themselves from the outside. This is only possible by placing themselves in the position of others and viewing or acting toward their own self from that position (Blumer 1969). While the self emerges in the context of social interaction, society emerges through joint action. Blumer (1969) contended that examination of joint action allows the symbolic interactionist to examine the interaction that comprises and maintains social arrangements.

Blumer (1969) defined collective action as the behaviours of groups, institutions and organisations where the individuals within those groups fit their actions to one another. Collective action occurs through an interlinkage of the separate acts of individuals and must undergo a constant process of formation even if the action appears well established. For example, a health care protocol that seems fixed and stable only appears that way because the everyday actions of health professionals are defined, interpreted and consciously acted upon within the group in order to construct the observed stability.

However, if that protocol was re-interpreted (for example if someone questions a particular way of doing something) this opens up the possibility of examining ways in which the group can change their ideas and in turn their actions.

Because symbolic interaction stresses the ongoing influence of socialisation, it was important for this thesis to consider how interactions with other group members can contribute to an individual's beliefs, attitudes and behaviours (Byrne & Heyman 1997). Health professionals are often influenced by information obtained through professional training and socialisation that occurs in the workplace setting. They can therefore both create and be influenced by a culture that defines their practice.

Pragmatism and symbolic interactionism

During the formulation of the core premises of symbolic interactionism, both Mead and Blumer were said to be strongly influenced by pragmatist philosophy (Blumer 1969; Crotty 1998; Grbich 2010). The underpinning philosophies of pragmatism are similar to those of symbolic interactionism. A general pragmatic notion shared by symbolic interactionists is that knowledge resides in human action (Barbalet 2009). At its core, pragmatists believe the truth or meaning of 'something' lies more in its observable practical consequences than its theoretical or abstract meaning.

According to Charmaz (2014) pragmatism is a philosophical tradition that views reality as indeterminate, fluid and open to multiple interpretations by people who are active and creative. In pragmatism, meanings emerge through practical actions performed to solve problems and it is through these actions that people come to know the world. Pragmatism is compatible with relativity, provisional truths and multiple realities (Charmaz 2014). These multiple realities must then be interpreted by a 'thinking agent' (person) who has the power to convert an unspecified reality into a determinate one – something that person is only able to do because they are an active being (Shalin 1986). In other words, pragmatist philosophy deems that individuals continuously adapt to their environment, change their actions to meet the demands of the situation and transform the situation to satisfy their practical needs.

Pragmatic and symbolic interactionist philosophies were important considerations during the exploration of decision-making in family presence during resuscitation. The examination of multiple meanings and perspectives within a dynamic health care environment, as well as issues regarding subjective experiences, agency and institutional culture fit within a philosophical framework that acknowledges a symbiotic relationship between knowledge and action.

Critique and defence of symbolic interactionism

Symbolic interactionism, particularly in its classic form, has attracted criticism by some scholars for ignoring influences such as institutions, class, power and culture (Biddle 1986; Stryker 1987; Fine 1993; Annells 1996; Snow 2001; Salvini 2010). Critics have warned that such omissions can produce a distorted view of social reality (Annells 1996) and significant bias (Stryker 1987). Snow (2001) believes it was Blumer's primary focus on meaning and interpretation that deflected attention from the issues outlined above. However, Fine (1993) argues that criticisms of symbolic interactionism as a micro-sociological perspective - with no interest in structure or belief in power of organisations and institutions - is misleading. Fine (1993) contends that Blumer's (1969) inclusion of 'acting units' in addition to 'actors' in his writings demonstrated a balance between the structure and agency underpinning Blumer's interactionist approach to social order.

Fields, Copp and Kleinman (2006) also highlighted criticisms relating to what some have called a 'micro' focus in symbolic interactionism. Fields and colleagues were referring to what they saw as Blumer's resistance to using social institutions as units of analysis in favour of exploring the collective action of people who reproduce these institutions. Blumer (1969) did this in order to increase understanding of the conditions that support the continuation of these institutions and the everyday lives of people associated with them. However Fields, Copp and Kleinman (2006, p. 159) claim that other interactionists have been able to successfully apply the principles of symbolic interactionism to explore both the 'upward' impact of individuals on social structures and the 'downward' influence of culture, structure, and social institutions. Symbolic interactionism is therefore able to highlight individual accountancy and agency while also addressing structural, cultural and

material conditions as people experience and reproduce them in their every-day lives (Fields, Copp & Kleinman 2006); all important considerations for this thesis.

The following section provides an in-depth discussion of the epistemological considerations for this study including realism and relativism, constructionism and constructivism, and the nature and construction of knowledge and meaning.

EPISTEMOLOGY

Realism and Relativism

The status of reality and truth are often discussed in a 'realism versus relativism' debate (Crotty 1998; Burr 2003). Realism posits the existence of an external world independent of human interpretation (Burr 2003), while relativism maintains that because there are multiple realities, there are multiple interpretations of those realities that can be judged only in relation to each other and not by comparison with some ultimate truth (Burr 2003; Andrews 2012). Burr (2003) describes realists as having a 'top down' view in which reality produces our knowledge and descriptions of the world, and relativists as having a 'bottom up' approach where language is seen to generate reality as we know it.

Realism and relativism represent two polarised perspectives (Andrews 2012) and both approaches can be problematic for qualitative research. Researchers who adopt a realist position often disregard the role of the researcher during interpretation of the findings. Realists assume that reported findings are a true and correct interpretation of a knowable and independent reality. In contrast, relativism can lead to the conclusion that nothing can ever be known for sure because there are multiple realities, none of which have precedence over another regarding truth and reality (Burr 2003; Denzin & Lincoln 2005; Andrews 2012).

Comparisons of knowledge, truth and reality over time and across cultures make it quite clear that there have been and continue to be very different interpretations of the same phenomena (Crotty 1998). Relativism then is necessary to account for the fact that different people inhabit different worlds with diverse ways of knowing. This means that narration and description, for example of in-depth interviews, can no longer be seen as a

straightforward representation of reality. When researchers describe something, they are reporting on (and therefore interpreting) how something is seen and reacted to and therefore meaningfully constructed within a particular community or society (Crotty 1998).

One solution to the realist - relativist dilemma is to adopt a position of what Hammersly (1992) calls subtle realism which is midway between the two. Subtle realism acknowledges the existence of an independent reality but denies there can be direct access to that reality without *interpretation* of it.

Social constructionism and constructivism

Social constructionism and constructivism are epistemologies that embody many theoretical perspectives, including symbolic interactionism (Crotty 1998). Varying definitions exist for both approaches and the terms constructivism and constructionism are often used interchangeably in the literature (Crotty 1998; Burr 2003; Weinberg 2009; Andrews 2012). For example Guba and Lincoln (2005, p. 197) refer to themselves as *'social constructivists/constructionists'* when they propose that criteria for judging reality should come from community consensus regarding what is 'real', what is useful, and what has meaning.

Social constructionism has been defined as the view that all knowledge, and therefore all meaningful reality, depends on human society being constructed (rather than discovered) during the process of interaction between individuals and groups and their world (Crotty 1998). Crotty's definition awards greater importance to collective rather than individual interactions, as cultures and societies impart their understandings of the world to the future generations. Guba and Lincoln (2005) offer a similar definition for their constructionist / constructivist approach, asserting that social phenomenon consists primarily of the meaning-making activities of groups and individuals. Guba and Lincoln (2005) stress that meaning-making activities are of central interest to social constructionists/constructivists because they largely shape action or inaction.

According to Burr (2003) the main difference between constructionism and constructivism is the extent to which the individual is seen as being in control of the

construction process, and the degree to which their constructions are the product of structural or interactional social forces. Similarly, Andrews (2012) and Crotty (1998) view the difference in terms of individual versus collective generations of meaning. According to Andrews (2012), constructivism proposes that each individual person mentally constructs their world of experience through cognitive processes, while social constructionism focuses more on social rather than individual interactions. Likewise, Crotty (1998) encourages the term constructivism to describe the meaning-making activity of individuals and the term constructionism when focusing on the collective generation and transmission of meaning. In other words, Crotty believes constructivism should describe the individual person interacting with and making sense of objects in their world and constructionism should describe group meaning where individuals are introduced directly into a whole world of truth and meaning.

The nature and construction of knowledge and meaning

Social constructionists view knowledge as historically and culturally specific and as such theories and explanations cannot be taken as ultimate descriptions of human nature (Burr 2003). People are said to create meaning and shape society on an ongoing basis through their interactions with each another and the world around them. It is important to consider however, that people are also born into a world of meaning - where the concepts and categories used by individuals and groups in a particular culture already exist (Crotty 1998; Burr 2003). In other words, the interpreted world is already there but it is also ready for further and ongoing interpretation.

Societies inherit what Crotty (1998, p. 54) refers to as a *'system of significant symbols'* which shape the way people see and experience things. Many things that are taken for granted as fixed and absolute are in fact socially derived and maintained. These meanings are acquired by each person as they develop the use of language, and are then reproduced every day by people who share a language and culture (Burr 2003).

As a result, society is said to exist as both a subjective and objective reality; subjective through interactions between people and the world and objective because the social world in turn influences people and forms habits and routines (Berger & Luckman 1991). According to Andrews (2012), frequently repeated actions can soon become patterns that

can be reproduced with minimal effort. These actions become embedded as routines that form the current state of knowledge in a society. These actions are then institutionalised by society to the extent that future generations experience that particular knowledge as objective. This knowledge is then continuously reaffirmed during ongoing interaction between individuals and groups (Andrews 2012).

Social constructionists are sometimes accused of being anti-realist by denying that knowledge is a direct perception of reality (Andrews 2012), and by not recognising an objective reality (Burr 2003). However as Burr (2003) maintains, taking a relativist stance does not mean denial of existence of a reality beyond discourse but rather that language can be used to refer to reality for practical purposes. The argument then is not about whether or not something actually exists – but that it does so as a socially constructed reality (Edley 2001). To say that reality is socially constructed does not mean it is not real. This reality refers to the subjective experience of everyday life and how the world is understood rather than to the objective reality of the natural world (Berger & Luckman 1991). Social constructionism therefore is both realist and relativist (Crotty 1998; Burr 2003).

The following section provides an in-depth discussion of Charmaz's constructivist GTM; in particular the relationship between constructivist GTM, symbolic interactionism, social constructionism and how the methodology was applied in this study.

CHARMAZ'S CONSTRUCTIVIST GROUNDED THEORY METHOD

Charmaz is considered the leading expert of a constructivist approach to GTM research (Mills, Bonner & Francis 2006b) and has extensive experience in the application of the methodology. Charmaz learned GTM directly from Glaser and Strauss, and was supervised by Strauss during her PhD candidature; as such, both GTM founders had a significant influence on Charmaz as she developed her constructivist approach (Charmaz 2006). Also influential were her strong roots in symbolic interactionism, social constructionism and pragmatism (Charmaz 1980, 1990, 2005, 2011, 2014).

According to Charmaz (2014, p. 12) her constructivist GTM *'adopts the comparative, emergent, and open-ended approach of Glaser and Strauss's (1967) original statement'*

and re-examines these statements through a contemporary methodological lens (Charmaz (2006, p. xi). Charmaz's constructivist approach adopts the methodological strategies developed by an objectivist Glaser, while also building on the social constructionism that underpinned Strauss's symbolic interactionist perspective (Charmaz 2006; 2007). Charmaz's approach also incorporates Strauss's emphasis on meaning and action inherent to pragmatist traditions (Charmaz 2014).

Charmaz (2006, 2014) believes that researchers construct grounded theories through their past and present interactions with people, their personal perspectives and their research practices. A constructivist approach therefore allows a representation of experience rather than an exact replication of it (Charmaz 2006, 2014) and sees the researcher as an interpreter rather than the ultimate authority in defining the data (Bryant & Charmaz 2007b, p. 52).

A constructivist approach to GTM starts with the lived experience, then asks how participants constructed that experience (Charmaz 1990, 2006). The researcher can explore how and why participants constructed meanings and actions in certain situations, while keeping in mind that the resultant theory is itself an interpretation that is dependent on the researcher's perspective (Charmaz 1990, 1997, 2004, 2006; Crotty 1998). What researchers see and hear will depend on their past experiences and interests, their prior interpretation of the phenomenon, the research context, the researcher-participant relationship, and the modes of generating and recording the data (Charmaz 2005, 2006, 2011). As such, the researcher should treat the research process itself as a social construction, and scrutinise all research decisions and directions (Charmaz 2007).

Constructivist GTM has moved the methodology beyond the positivist stance that researchers should come to the data with no preconceptions (Kennedy & Lingard 2006; Bryant & Charmaz 2007b). However, Charmaz (2004) reminds us that in order to learn the meaning other people attribute to certain objects, researchers must be reflexive about their own meanings for those same objects to minimise bias and avoid imposing preconceived ideas on the data. In order to account for preconceived knowledge and ideas during the research and in particular during data collection and analysis, the

researcher must openly acknowledge the influence of previous work on their perspective of what is emerging from the data (Charmaz 2006). In other words the researcher's past experiences, knowledge and values must be acknowledged by themselves and by their research consumers as an inevitable part of the outcome (Guba & Lincoln 1989).

Charmaz (2006) believes the logical extension of a constructivist approach to GTM means learning how, when and to what extent the studied experience is embedded in larger and often hidden situations, relationships and networks. Constructivist GTM can therefore highlight hierarchies of power in particular contexts. It can also identify differences and distinctions between people and situations, and situations/interactions that maintain or overcome those differences (Charmaz 2006).

The influence of symbolic interactionism

According to Charmaz (1980), the emphasis that symbolic interaction places on interpretative processes between individuals makes it a particularly suitable framework for learning about the effects of experiences on meanings - or alternatively the effects of meanings on experiences. This perspective also emphasises how individuals make sense of problematic situations in their everyday lives, and places greater emphasis on some ideological beliefs while ignoring others.

Charmaz believes a symbolic interactionist framework can allow researchers to explore the conditions contributing to the stability or alteration of subjective meaning by examining the individual's interpretation of their experiences. For example, people may have a similar social experience (such as being involved in a resuscitation attempt) but may not share the same social world (the resuscitation occurred in a different specialty setting). Building on Blumer's (1969) original statements to 1) gain intimate familiarity with the phenomenon of study; 2) respect the research participants and 3) bring sensitivity concepts to research to open inquiry, Charmaz developed the following methodological principles for qualitative research.

Charmaz's methodological principles for qualitative research

Intimate familiarity forms the foundation of qualitative inquiry

Intimate familiarity facilitates an interpretive understanding of social life and can be achieved through sustained interaction with participants and written data (Charmaz 2004, 2008). Without this familiarity, researchers' understanding of the social world can be significantly reduced, leading to weak description and the imposition of existing theories on the data. Intimate familiarity can be achieved during in-depth interviews by looking beyond what participants are saying to examine their tacit meanings, their use of silence, and their actions and inactions (Charmaz 2002, 2008).

Respect for participants supersedes research objectives

Researchers can demonstrate respect for participants by acknowledging them as thinking, feeling, and acting individuals rather than as objects to study, and by prioritising their safety and wellbeing over research objectives (Charmaz 2004, 2008). Charmaz (2008) believes that treating participants with respect and gaining intimate familiarity is reciprocal. Treating people with respect allows the researcher to learn about participants' beliefs, experiences and actions; and in turn the commitment to gain intimate familiarity demonstrates respect. It important to remember that demonstrating respect extends to providing a fair and faithful representation of participants' individual and collective stories rather than attending to personal research agendas (Charmaz 2004, 2008).

Existing theoretical perspectives provide starting not ending points

Charmaz (2008) believes it is possible to avoid imposing personal experiences and perspectives on the study by attending to Blumer's (1969) methodological statement regarding sensitising concepts. Consistent with Blumer's sensitising concepts, Charmaz recommends that researchers begin a study with a particular research interest and a set of general concepts. These concepts provide ideas to pursue, and sensitise the researcher to ask particular questions about the phenomenon under study. If these concepts are used as a *'point of departure'* they can help researchers to develop rather than limit ideas (Charmaz 2006, p. 17). It is important to note that these concepts should be viewed as tentative and conditional in order to facilitate effective analysis. The *abductive* nature of

GTM (Charmaz 2006, 2014; Bryant & Charmaz 2007b) encourages researchers to consider all of the possible theoretical interpretations of an unexpected finding before checking these interpretations with further data collection – thus taking the analysis beyond pure induction (Charmaz 2008). Abduction refers to a type of reasoning where the researcher scrutinises the data, thinks of all the possible explanations for the data, then develops hypotheses to confirm or refute these explanations until the most plausible interpretation is reached; as such abduction is both inductive and deductive (Charmaz 2006).

Constructionist renderings complement being faithful to the studied phenomenon

Charmaz (2004) argues that her social constructionist perspective does not preclude her from being faithful to the phenomenon. While the notion of being faithful to the studied phenomenon assumes the objective presence of the phenomenon, Charmaz believes constructionists can still account for this by examining how participants *construct* the phenomenon and explaining the conditions under which they do this. In other words, it is possible to be faithful to something that is believed to be real while also acknowledging the views of a multiple reality. Charmaz's version of truth – or way of knowing the world – is therefore provisional, subject to revision and is based on shared assumptions (Charmaz 2004).

From her constructionist / constructivist stance Charmaz (2004, pp. 980-983) believes that while researchers can know about the social world by describing it from the outside, they cannot understand what living in that world actually means unless they learn about it from the inside. She therefore offers the following premises for the construction of meaning and knowledge that can be applied during in-depth interviews:

- *Researchers must enter the studied world in order to understand it deeply* – being fully present during interviews allows researchers to sense what having the experience was like for participant. Researchers must not assume they already know what is significant - they must discover what is significant from the viewpoints and actions of the individual who experienced the phenomenon.
- *Meanings matter* – to understand what is happening in a particular social setting, researchers must determine what things mean to participants. By understanding

participant meanings, researchers are more likely to understand participant actions and vice versa.

- *Significant meanings are often liminal, unstated, unacknowledged, or silent –* people may not disclose the things that concern them most in their social setting.

- *Actions make taken-for-granted meanings visible –* what happens in a particular social setting might be quite different from what people are willing to say about it.

- *Relationships between meanings and actions are dynamic and reciprocal –* people's meanings shape their actions and their actions convey meaning. It is therefore important to examine how people interpret and act upon the larger social meanings available to them in their social setting.

- *The questions we ask shape the answers we receive –* the way a research problem is framed can affect what the researcher looks for and what they see. The researcher's interviewing style and how interview questions are worded can affect what participants will say.

- *Truths are relative, multiple and subject to redefinition –* the researcher's attitudes and beliefs will affect what they see and what they view as the truth. A truth from one participant's perspective may differ significantly from another.

According to the last premise, Charmaz (2004) believes gaining multiple views of the studied phenomenon can strengthen the power of the researcher's claim to understand it. Charmaz stresses that she does not discount accuracy, but instead advocates a situated version of truth that is relative, multiple and subject to redefinition. A constructivist approach therefore does not perceive reality as a 'real world' waiting to be discovered and categorised, but rather aims to find out what participants define as real through their words and actions.

The role of theory in constructivist grounded theory

According to Glaser and Strauss (1967, p. 31), a grounded theory can be presented as either a well-codified set of propositions or in a running theoretical discussion using conceptual categories and their properties. They preferred to present their grounded theory as a theoretical discussion because their strategy of comparative analysis for generating theory placed emphasis on theory as a process. As such, Glaser and Strauss

viewed theory as constantly evolving rather than as a final product. They stressed a distinction between their substantive theories which were closely linked to the context in which the theory was grounded and formal theories that gain this status only after they have been tested, adopted and used in other contexts (Glaser & Strauss 1967, 1971; Strauss 1987).

While a central role of GTM is to construct theory, it is important to understand that grounded theories are not meant to be seen as universal explanations (Bryant 2009). Charmaz (2014) posits a definition of theory which emphasises theoretical understanding that is abstract and interpretivist. In other words the understanding from the theory relies on the theorist's interpretation of the studied phenomenon. In line with the definitions outlined above, this thesis used Charmaz's interpretive approach to theorising in order to allow for indeterminacy, which is compatible with both constructivism and symbolic interactionism. The substantive grounded theory is presented in chapters five to ten as a running theoretical discussion using conceptual categories and their properties in line with Glaser and Strauss's (1967) recommendations.

Critique and defence of Charmaz's constructivist grounded theory method

Charmaz's interchangeable use of the terms constructionism (Charmaz 1990, 1997, 2004, 2005, 2007, 2011), and constructivism (Charmaz 2000, 2003, 2005, 2006, 2011) to explicate her GTM method makes it difficult to accurately determine the philosophical assumptions underpinning her approach. Charmaz most consistently refers to her version as *constructivist grounded theory*, while at the same time highlighting that her approach is underpinned by social constructionism (Charmaz 2006, 2011).

According to Charmaz (2014, p. 342) *constructivism* is a social scientific perspective that addresses how realities are made and acknowledges that people construct the realities in which they participate. Within her definition, Charmaz emphasises the role of the researcher in the co-construction of reality and stresses that their interpretation of the studied phenomenon is in itself a construction. Charmaz (2014, p. 344) describes her view of *social constructionism* as a theoretical perspective where people create their social realities through individual and collective actions. Instead of assuming realities in an

external world, Charmaz believes social constructionists study what people see as real and how they construct their views and actions in varying contexts.

In response to critical feedback about her interchangeable use of terminology, Charmaz (2014, p. 14) recently explained her choice of the term *constructivist* grounded theory as the result of her dissatisfaction with social constructionist approaches to research in the late 1980s and early 1990s. She believes many researchers of the time were incorrectly treating their analyses as accurate renderings of the studied world rather than as constructions of them. Charmaz also believes researchers were not adequately acknowledging their integral role in what Charmaz (2014) refers to as the *co-construction* of knowledge.

In an attempt to acknowledge the subjectivity each researcher brings to their research and to distance herself from what she saw as conventional social constructionism, Charmaz adopted the term constructivist grounded theory to describe her research method. She aligned her position with fellow social constructivists Lev Vygotsky and Yvonna Lincoln, who emphasised social contexts and interpretative understandings along with the belief that knowing and learning are embedded in social life. However, Charmaz (2014) believes social constructionism has evolved over time into a form that is now consistent with constructivism and with her constructivist approach to grounded theory.

Charmaz's constructivist approach has been criticised by some scholars for its underlying epistemological assumptions, particularly regarding the researcher's active role in co-constructing the data (Glaser 2002; Greckhamer & Koro-Ljungberg 2005; Hernandez & Andrews 2012). Unlike Glaser and Strauss's (1967) original text, Charmaz (2006) believes that neither data nor theories are external objects waiting to be discovered. Instead, Charmaz acknowledges the researcher as an integral part of the world they study and the generated data. In keeping with this core assumption, Charmaz (2011) believes researchers and participants *co-construct* data during and through their interactions.

A potential limitation of a *co-construction* of data is the risk of placing the researcher in control of 'meaning-making' and knowledge production, something that has been raised previously by Greckhamer and Koro-Ljungberg (2005). Researchers must also consider

how relative contributions to the analysis can be acknowledged when data has been co-constructed. Hernandez and Andrews (2012) go further to question whether it is possible to determine the relative contributions of the researcher and participant to the analysis, and claim that Charmaz sees the researcher's view as the most important. However, I disagree with this assertion. Unlike Glaser (2004), who claims that participants' voices are 'moot' in GTM research, and Breckenridge and colleagues (2012) who believe GTM is not about people but rather patterns of behaviour - Charmaz stresses the importance of maintaining the voices of participants as a crucial part of her constructivist approach.

Charmaz ensures participants' voices are maintained by using reflection in her research and by including participants' voices throughout the analysis (Charmaz 2006). She recommends memoing in particular (detailed later in this chapter) to encourage researchers to reflect, remember, question, analyse and make meaning about time spent with participants and the data that was co-constructed (Charmaz 2006). In addition, Charmaz recommends making emerging categories consistent with studied life to help keep that life in the foreground, and using active codes and categories to preserve images about the experience. Charmaz (2003) also believes the initial line by line coding inherent to GTM keeps the researcher studying the data - not only to start to build ideas inductively but also to deter the researcher from imposing existing theories or their own beliefs on the data. This form of coding therefore helps the researcher consider participants' views of their own realities rather than assume the researcher and participants share the same views and worlds.

Another criticism of constructivist GTM relates to preconceptions and bias. Glaser (2002) for example believes the researcher's active involvement in constructivist GTM research introduces bias, and claims the approach does not address how to account for, prevent or overcome this bias. However Glaser (2002, p. 1) also asserts there is *'no such thing for GT [grounded theory method] as bias data or subjective data or objective data or misinterpreted data or vague data. It is what the researcher is receiving, as a pattern, and as a human being (which is inescapable). It just depends on the research.'*

Glaser (2002, p. 2) further contradicts himself by first claiming that passive, non-structured interviews can hold constructivism to a minimum, but then acknowledges that

as human beings researchers will to some degree allow their personal bias and interpretations to affect the collection and analysis of data and *'ergo this is called constructivist data'*. Glaser (2002, p. 2) further argues that this data is then *'rendered objective to a high degree by most research methods and GT(M) in particular by looking at many cases of the same phenomenon.'* As a result Glaser believes personal input from the researcher becomes irrelevant and the data become objectivist rather than constructivist.

My constructivist stance in this thesis disagrees with Glaser's assumptions. Instead, I subscribe to the notion that the positivist stance of a neutral observer gathering data about the world, from which theories somehow emerge, has been widely discredited (Bryant 2003; Bryant & Charmaz 2007b). This thesis agrees with Bryant and Charmaz's view that it is not possible for a researcher to be able to approach a topic without preconceptions or having rid themselves of all prejudices and biases. Bryant (2009) argues that a concept cannot simply emerge from the data – there must be recognition of the active role of the researcher. Charmaz (2005) agrees that no research can be neutral and believes researchers who do not make their assumptions and interpretations explicit risk elevating their own assumption to an objective status. According to Charmaz (2003), it is the researcher's *interpretation* of the data that shapes the emergent codes in GTM, and it is now widely recognised that people's prejudices can actually encourage innovative insights and alternative accounts from research (Bryant 2009).

Glaser (2002) and Hernandez and Andrews (2012) have both charged Charmaz's constructivist GTM with an inability to go beyond accurate description to conceptual theory generation. However, the logic of Charmaz's constructivist GTM closely reflects Glaser's classical version. They both involve fragmenting empirical data through coding the data, constructing abstract categories that fit these data and offering a conceptual analysis of them (Glaser & Strauss 1967; Glaser 1978, 1998; Charmaz 2011, 2012).

Charmaz (2003, 2006) believes GTM offers a set of flexible strategies rather than rigid prescriptions. She claims that her constructivist version of Glaser and Strauss's (1967) classic statement adopts their original methodological strategies but integrates relativity and reflexivity throughout the research process (Charmaz 2011). The adaptation of

flexible strategies risks misinterpretation of methods and processes by individual researchers. It is therefore necessary to ensure that each interpretation can be defended and justified by individual researchers, something that was prioritised during this study. This thesis observes Charmaz's (2000, 2003) belief that a focus on meaning while using GTM enhances rather than limits interpretive understanding, and that it is possible to successfully adopt GTM strategies without embracing its earlier positivist leanings.

APPLYING THEORY TO METHOD

Existing literature has explored general attitudes and beliefs about FPDR, but has not been able to adequately explain how and why decisions are made to adopt or reject this practice. A qualitative approach was deemed most suitable to meet the aims of this study for its ability to provide rich insight into human behaviour, and multiple ways of understanding the complexity and variability of behaviour and experience in varying contexts (Higgs, Horsfall & Grace 2009). Conceptualising behaviour within a particular FPDR context allowed examination of this behaviour in relation to the social circumstances, conditions and rules that governed people's shared meanings, and how they affected the behaviour of individuals and groups involved in FPDR (Charmaz 2006).

There are multiple understandings of and attitudes towards FPDR, and the resistance to widespread implementation of this practice that is evident in the literature has occurred at both an individual and institutional level. The meanings that people assign to physical, social and abstract objects are the most important predictors for why those people act in certain ways toward those things (Blumer 1969). The concepts and assumptions inherent in symbolic interactionism, constructivism and social constructionism were therefore particularly important considerations for this study to examine shared meanings of FPDR and how they impacted on decision-making and practice.

There are strong compatibilities between the interpretive tradition of symbolic interactionism and GTM (Clark 2005; Charmaz 2006; Bryant & Charmaz 2007b; Holton 2007; Aldiabat & Le Navenec 2011). The primary goal of both is to provide a theory that explains human behaviour (Aldiabat & Le Navenec 2011). Both symbolic interactionism and GTM posit that people are self-organising, proactive and self-regulating beings who do not merely react to environmental forces or inner impulses (Bryant & Charmaz 2007b).

The emphasis on meaning and action in symbolic interactionism is congruent with the question grounded theorists ask in the empirical world; what is happening? (Glaser 1978).

According to Charmaz (2003, p. 525) *'constructing constructivism'* means seeking meanings from the perspectives of the participants and the researcher. In order to elicit meanings that participants attach to objects it is necessary to go beyond superficial or presumed meanings. Researchers must seek participants' views and values as well as their actions, and look for beliefs and ideologies as well as situations and structural processes. By studying these tacit meanings, Charmaz (2003) believes it is possible to clarify participants' views about their reality.

Constructivist GTM was chosen for this study for its ability to provide a behavioural perspective, enable explanation of behaviour and facilitate the advancement of a conceptual theory that could be applied in practical situations (Glaser & Strauss 1967; Charmaz 2006). Constructivist GTM was particularly suited to this research because it endeavoured to understand the processes people use to construct meaning out of their inter-subjective experiences (Charmaz 2004; Suddaby 2006). This approach allowed me to move beyond description and enabled conceptual theorisation that explained decision-making around FPDR practices from the perspective and in the context of people who had experienced this phenomenon (Charmaz 2006; Birks & Mills 2011).

CHAPTER SUMMARY

This chapter provided an overview of the theoretical, epistemological and methodological considerations for this research, and how they were applied. The following chapter provides a detailed discussion of the specific methods employed to conduct the study, including the use of sensitising concepts to develop the aim, and the ethical considerations for the study. Participant sampling and recruitment are described, and the processes used to generate and analyse data are then outlined, including the role of theoretical sampling, reflexivity and the constant comparative analysis method. The chapter concludes with a discussion around rigour, including the criteria used to evaluate this GTM research.

Chapter Four: Methods

CHAPTER OVERVIEW

The aim of this study was to examine the factors and perceptions that influenced decision-making around FPDR practices in acute care settings. Chapter three detailed and justified the methodology used for the study. This chapter presents the grounded theory methods and processes used to generate and analyse the data, and demonstrates how the flexible guidelines, principles and practices outlined by Charmaz (2006, 2012, 2014) were used to generate a substantive grounded theory. As discussed in chapter three, the constructivist GTM approach used for this study was informed by a symbolic interactionist and social constructionist perspective. The ways in which these perspectives were used to generate and analyse the data will be highlighted throughout this chapter.

The GTM process is not linear; so while the methods are presented in a linear fashion within this chapter, they were actually applied in a cyclical process in keeping with GTM tenets. Figure 1 (see page 63) presents a diagrammatic representation of the processes and methods used and the relationship between various stages of the research, all of which are discussed in detail throughout this chapter.

As outlined in the introductory chapter, I have intentionally written in the first person throughout this thesis (and particularly within this chapter) in order to write myself 'into' the research in line with recommendations from Charmaz and Mitchell (2011), Mills, Bonner & Francis (2006a) and Webb (1992). Using my own voice rather than the more traditional third person when reporting this qualitative research acknowledged my role as the researcher during what Charmaz (2006, 2014) refers to as a co-construction of knowledge.

USING SENSITISING CONCEPTS TO DEVELOP THE RESEARCH AIM

The term 'sensitising concepts' was first described by Blumer (1954, p. 7) as that which *'gives the user a general sense of reference and guidance in approaching empirical instances … whereas definitive concepts provide prescriptions of what to see, sensitising concepts merely suggest directions along which to look.'* Building on Blumer's definition,

Charmaz (2003) refers to sensitising concepts as background ideas that inform the overall research problem and offer different ways of seeing, organising, and understanding experiences.
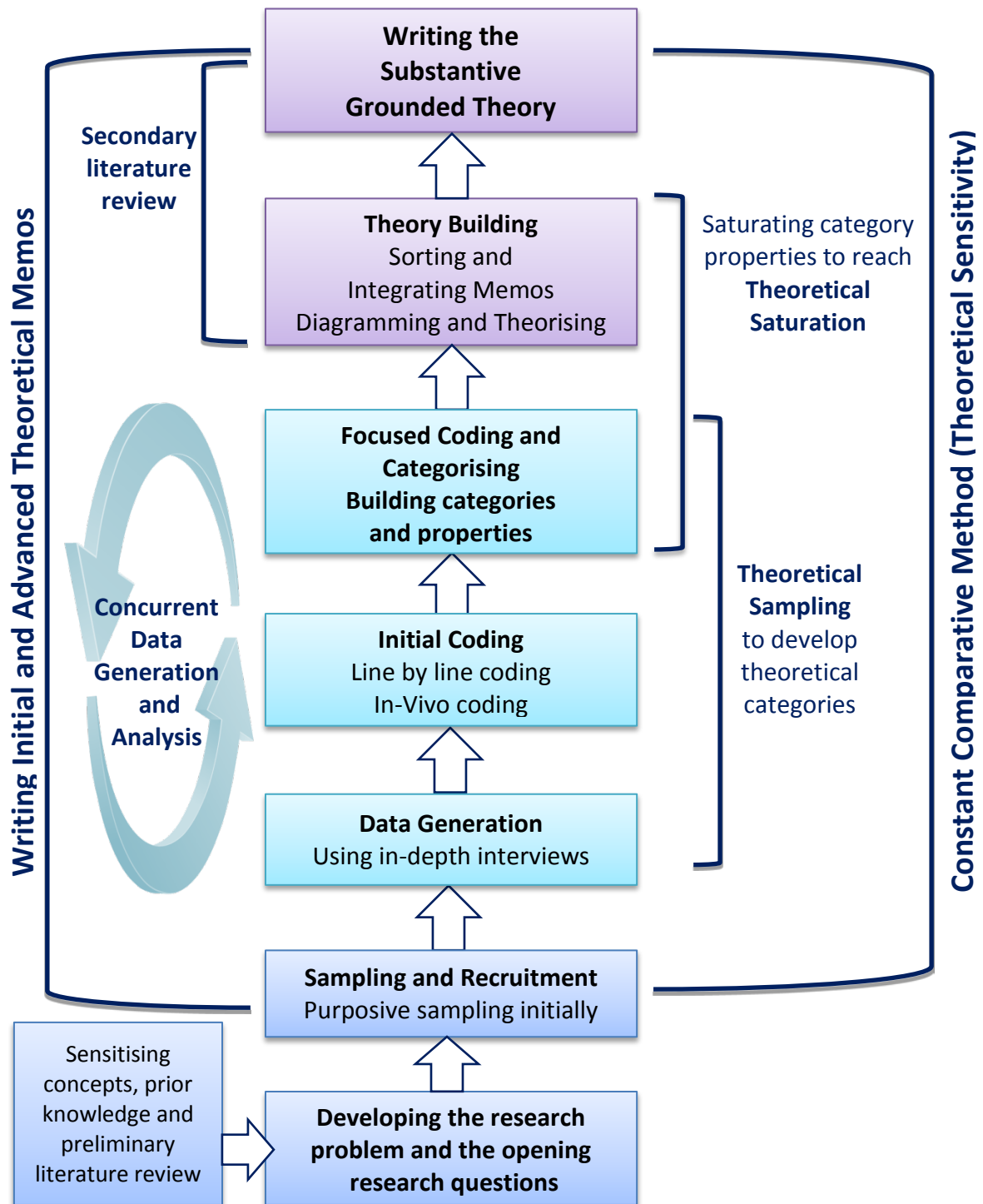
Figure 1: Grounded theory processes and methods used to guide the current study

I began this study with a particular research interest and a set of general concepts about FPDR in acute healthcare settings, as outlined in the introductory chapter. These concepts provided me with ideas to explore the phenomenon, and sensitised me to ask particular beginning questions (Charmaz 2006). I then undertook a preliminary review of the literature in order to develop the specific study aim for this research, which was to examine factors and perceptions that impact decision-making around family presence during resuscitation in acute healthcare settings. Sensitising concepts were also used as point of departure to formulate interview questions (Charmaz 2006), to suggest possible directions to pursue during data collection and analysis (Kelle 2007), to examine the data, to listen to participants and to think analytically about the data (Charmaz 2006).

PARTICIPANT PROFILE

Three types of participant were initially invited to take part in this study:

1. Health professionals (registered nurses and doctors) with two or more years of clinical experience who had performed CPR in an acute healthcare setting in the presence of a family member, or had a family member ask to be present.
2. Family members/significant others who had been present in the room during CPR of a loved one in an acute care setting or wanted to be present.
3. Resuscitation patients who underwent CPR in an acute healthcare setting with a family member present in the resuscitation room, or who wanted to be present.

In keeping with GTM tenets, the people invited to take part in this study had all experienced the phenomenon of FPDR and as such, shared a basic problem or central issue of concern (Glaser 1992 p. 4). They were therefore able to share first-hand experiences specifically related to the study aims. Because the goal of this research was to develop a substantive grounded theory, the same substantive class of groups was sought (i.e. people who had experienced FPDR in an acute healthcare setting), regardless of the specialty area (i.e. ED, ICU) in order to explore a diverse set of experiences and contexts related to the central phenomenon (Glaser & Strauss 1967).

ETHICAL CONSIDERATIONS

Ethical considerations play a vital role in qualitative research because of the close interaction between participants and the researcher and due to its unstructured and at times unpredictable nature (Kvale & Brinkman 2009; Liamputtong 2009; King & Horrocks 2010). Ensuring this study was undertaken in an ethical manner and promoting the ongoing wellbeing of participants were primary concerns throughout the study. This study was conducted in accordance with the ethical principles recommended in the *National Statement on Ethical Conduct in Human Research* (NHMRC, ARC & AVCC 2007).

Merit and integrity of the research

Adherence to a code of ethics promotes the integrity of research and demonstrates a commitment to the development of knowledge that can benefit individuals and groups within society (SBREC 2007; Kvale & Brinkman 2009). This research was conducted to generate knowledge that could be used to support and guide clinical practice and potentially enhance the wellbeing of healthcare consumers (Hammersley & Traianou 2012). Ethical approval for this study was gained from Flinders University Social & Behavioural Research Ethics Committee (refer to appendix 8, page 264 for the human research ethics committee final approval notice). Their role was to ensure the study was conducted in accordance with the *Australian Code for the Responsible Conduct of Research*, and ethically reviewed and monitored in accordance with the *National Statement on Ethical Conduct in Research* (NHMRC, ARC & AVCC 2007).

Respect, beneficence and informed consent

I demonstrated respect for the people participating in the study by honouring their opinions and experiences and treating them with dignity throughout the research process (Denzin & Lincoln 2005). I was careful to respect their privacy, confidentiality, cultural sensitivities, and to consider their welfare, beliefs and perceptions (NHMRC, ARC & AVCC 2007).

I took care to ensure participants were fully informed about the research processes so they were able to make an informed decision about taking part (King & Horrocks 2010). Every participant was sent an information package via email which included a letter of

introduction, an information sheet and consent form. These documents (which are included as appendix 9, 10 and 11 respectively on pages 266-271) clearly outlined the study purpose and detailed what participants would be asked to do if they took part. Participants were made aware that by signing the consent form, they had agreed to participate in the study but that this participation was entirely voluntary and they could withdraw from the study at any time during the interview and until data analysis commenced.

Beneficence was demonstrated by taking into account potential risks and benefits of the research to participants and to the wider community; and by being sensitive to the welfare and interests of the people involved in the study (NHMRC, ARC & AVCC 2007). There is always some risk of harm in qualitative research (Hammersley & Traianou 2012). It was therefore imperative to implement strategies to minimise harm and to support participants should harm occur. Due to the sensitive nature of this research, it was necessary to consider that participants may experience emotional reactions at the time of the interview or at a later date (Liamputtong 2010). I observed participants closely for signs of distress and the need to pause or cease the interview. Participants who became distressed were comforted and referred to Lifeline (a free crisis support service) for emotional support - as detailed later in this chapter in the section entitled 'promoting participant wellbeing'. The contact details of the Lifeline counselling service were also included in the information letter for participants to refer to at any time in the future.

Confidentiality

To maintain confidentiality, data were stored with identifying information removed and known only to me as the principal researcher (King & Horrocks 2010). Digital data were stored on my computer, which was password protected and kept in my locked office. Data that were generated into hard copy format were stored in a locked filing cabinet in my office in accordance with the Flinders University Social and Behavioural Research Ethics Committee guidelines. All data will be stored for a minimum of five years.

Pseudonyms were allocated to promote confidentiality during generation of demographic data and the recorded interviews, and within the interview transcripts, the written thesis and subsequent publications. When participants described events and experiences that

could potentially identify them, this information was de-identified. For example, workplaces were allocated generic names and the Australian state in which participants lived was not disclosed to avoid the possibility of being able to identify health professional participants based on their job title and specialty.

Data were transcribed by me as the principal researcher and on one occasion by a professional transcription service that was bound by a confidentiality agreement (Interview 5). Due to the cost and length of time taken to return the completed transcript, I transcribed all other interviews. This enhanced what Charmaz (2014) refers to as intimate familiarity with the data and enriched data analysis.

Relationship between participants and the researcher

A constructivist approach requires acknowledgement of the subjective inter-relationship between participants and the researcher (Charmaz 2006; Mills, Bonner & Francis 2006a). I was therefore committed to building a relationship of reciprocity with participants to facilitate the co-construction of knowledge and meaning, and ultimately a theory grounded in both the participants' and my experiences (Mills, Bonner & Francis 2006a). This approach also required me to consider power imbalances within these relationships. I attempted to redress these imbalances through full disclosure of research processes so that participants could take part knowing all that the study involved (Mills, Bonner & Francis 2006a, Liamputtong 2010). I provided participants with a detailed information package about the study, encouraged them to clarify any ambiguous issues before, during and after the interview, and allowed participants to choose the time and location of their interview. I also actively and reflexively planned my time with participants in order to become aware of potential power differentials and to avoid adopting a judgemental stance toward their attitudes, belief and experiences (Mills, Bonner & Francis 2006a). Uniquely, I interviewed a married couple during this study, which required additional consideration of reciprocity between the participants and me, and between the participants themselves. At the beginning of the interview, I established the importance of hearing about their individual and combined experiences. During the interview, I allowed additional time for both participants to share their own experience and, with their permission, invited them to reflect on each other's experiences.

Promoting participant wellbeing

I applied Charmaz's methodological principles for qualitative research during the in-depth interviews in order to promote participant wellbeing. These principles were detailed in chapter three, and included showing respect for participants by acknowledging them as thinking, feeling and acting individuals rather than as objects to study. Subsequently, I placed a higher level of importance on participant well-being than on the data, and continually monitored participants for any signs of distress. I also advised participants that the interview could be stopped at any time if they became upset or distressed. Three participants became visibly upset during the interview as they recounted their experiences. When this occurred, I allowed them to pause with a view to stopping the interview, however all participants were eager to share their stories and continued talking with few pauses - even when visibly upset.

Non-invasive or 'easy' questions were asked toward the beginning of the interview in order to allow participants to 'ease into' the interview. Once rapport was established, more invasive or complex questions were asked. For example, toward the beginning of the interview I asked participants to share their general FPDR experiences. After some time, I asked questions about what they would do in hypothetical situations where they or a loved one might need resuscitation. These sensitive questions were prefaced with a warning or lead up statement; for example, *'I am going to ask you about a sensitive hypothetical situation now.'*

At the end of the interview, I reminded participants about free counselling services available should they need assistance dealing with any distressing memories. I also took care to ensure interviews were closed in an appropriate manner by focusing dialogue toward a conversational tone, thanking the participant for their contribution and allowing them to ask questions and offer any final contributions (Minichiello, Aroni & Hays 2008). This allowed participants to finish the interview on a positive note.

I placed a high priority on ensuring participants remained emotionally safe throughout the interview and the study. The openness and intimacy of an in-depth interview coupled with the researcher's ability to listen attentively can lead to a quasi-therapeutic relationship and the potential for participants to disclose information they may later

regret sharing (Kvale & Brinkman 2009). In order to minimise this risk, I advised participants that their interviews would be audio-recorded and transcribed in full and invited them to review their transcripts prior to analysis. I reminded participants of their right to change or withdraw particular excerpts or the entire transcript up until analysis of their interview began (King & Horrocks 2010). Three participants chose to review their transcripts and none made any changes beyond agreeing with omissions that I had suggested to avoid breaching a third party's confidentiality. Participants were informed that, due to the nature of GTM's simultaneous data generation and analysis, once analysis began they would not be able to withdraw their transcripts. They were asked again if they were happy to continue their participation, and all were happy to do so.

SAMPLING AND RECRUITMENT

Purposive sampling was initially used as a point of departure to locate people and situations relevant to the study aims (Charmaz 2006). I recruited potential participants by advertising in *The Advertiser* (a South Australian newspaper), by participating in three radio interviews (720 ABC Radio Perth, 891 ABC Radio Adelaide, 101.5 Radio Adelaide) and through snow-ball sampling. After receiving site specific ethical approval from each organisation, I posted recruitment flyers in seven Australian hospital emergency departments. I also posted flyers at a South Australian University campus. Health professionals were additionally recruited through professional contacts and via advertising in Australian professional organisation publications; the Australian Nursing and Midwifery Federation Journal and medicSA (an Australian Medical Association publication). Additional ethical approval was gained from the Australasian College for Emergency Medicine and the College for Emergency Nurses Australia, and both organisations emailed the recruitment flyer to all members.

In keeping with the logic and inherent requirements of GTM research, theoretical sampling was later employed to recruit further participants or to re-interview existing participants in order to saturate category properties. During analysis, it became apparent that paramedics who had experienced FPDR in the pre-hospital as well as the acute healthcare setting would be able to provide valuable insights to further develop and

refine category properties. These additional participants were recruited through professionals contacts, with relevant modifications made to the information pack.

DATA GENERATION AND MANAGEMENT

Rationale for using in-depth interviews

Using a social constructionist and symbolic interactionist perspective (as detailed in chapter three), in-depth interviews were used as the primary method of data generation to facilitate the telling of individual stories (Warren & Xavier Karner 2010). Rather than viewing interviews as a neutral exchange of asking questions and receiving answers, I attempted to facilitate all conversations in such a way that respected a co-construction of knowledge and experience with participants (Fontana & Frey 2005; Charmaz 2014). Semi-structured interviews allowed a richer expression of variations in people's experiences than could be gained through the use of forced-choice surveys or structured interviews (Taylor, Kermode & Roberts 2011) and provided a deep insight into the decision-making processes around FPDR.

A pilot interview was undertaken to evaluate my interview technique and questions (Birks & Mills 2011). I critically reviewed the interview transcript with the thesis supervisors, and suggestions for improvement were applied to subsequent interviews. I continued to reflect upon each interview and adjusted my technique as necessary to ensure continual improvements. For example, in early interviews I asked several closed follow-up questions, but adjusted my technique in future interviews to ensure follow-up questions began with open phrases such as 'can you tell me about …' rather than with 'do you …?'

Data generation

Participants took part in one-on-one, in-depth, semi-structured interviews lasting between 25 - 65 minutes. In order to increase their feelings of comfort and safety, I prioritised the development of rapport and trust. This began by inviting participants to elect their preferred interview location in order to maximise their convenience and comfort. Participants chose a variety of settings including their own home or office, my office and a cafe.

Face-to-face interviews were chosen as a first option to further build trust and rapport through the use of appropriate kinesics and proxemics. However, because some participants lived interstate this was not always possible and thus a mixture of face-to-face and phone interviews were conducted. Following the second phone interview, I reflected upon the differences between face-to-face and phone interviews in a general memo and was able to improve my interview technique in subsequent phone interviews.

> **Memo excerpt following phone interview 2**
>
> I need to improve my phone interview technique. Because I am not able to rely on body language to demonstrate active listening, I tend to use verbal acknowledgements. In addition, the participant spoke about experiences that were not related to the research topic. Next time I plan to introduce the interview more thoroughly. I will inform participants that I may remain silent while they are talking to make sure I do not interrupt them ... I will remind them that the purpose of the interview is to talk about their experiences with FPDR, and that I may at times steer them back onto topic if they stray too far. However, I need to continue to be aware that sharing their experiences is very personal and often cathartic, and when people are reminiscing about particularly stressful or traumatic memories, I will listen without interruption or redirection to allow them time to debrief and work through their memories, and then gently redirect them back to the topic when able without being disrespectful.

Rapport and trust were further developed by being punctual, adhering to the ethical guidelines and principles outlined in this chapter, and by actively listening and allowing participants to tell their stories without imposing my own agenda, as demonstrated in the above excerpt.

Interviewing, symbolic interactionism and social constructionism

Conducting in-depth interviews allowed me to enter participants' symbolic world, to examine their actions based on the meanings they attributed to FPDR, and to explore how their interpretations affected their decision-making around the phenomenon (Charmaz 2006). My constructivist approach to interviewing focused on eliciting the participants' definition of terms, situations and events and tried to interpret their assumptions and implicit meanings (Charmaz 2006). I achieved this by asking for more

detail when participants used ambiguous or specialist words or phrases, as evidenced in the following excerpt.[7]

Participant: … ideally you can see the MRX and here's the red kit to draw up your drugs, make sure that everyone can see the MRX, and here's the oxygen; your airway kit needs to be behind the head – well do you think that actually works when you're [in the field]? You put it where you can fit it!

Interviewer: Yep, so it's a completely different environment. Can you just clarify for me what an MRX is?

Participant: Oh – the heart start. Heart stopper really.

Interviewer: Ok so it's the defib.

Participant: The defib yes, yes.

To further reduce ambiguity, I explained any potentially confusing terms at the beginning of each interview to ensure all participants shared a baseline understanding of the research terminology. For example, the terms 'resuscitation' and 'family presence during resuscitation' were defined in the participant information sheet and verbally prior to the interview.

All interviews were audio recorded, which allowed me to offer my full attention to each participant in order to build rapport and trust and also to note how they were acting in relation to what they were saying (Charmaz 2006). Audio recording allowed transcription of the entire interview which facilitated comprehensive analysis and access to verbatim quotes that were used to substantiate coding and to illustrate the final substantive grounded theory (Birks & Mills 2011). Notes were also taken during interviews to record key points, as a reminder to return to earlier points and explore them in more detail, and also to help frame follow-up questions (Charmaz 2006).

The interview questions

The interview questions reflected my symbolic interactionist emphasis on learning about participant's attitudes, beliefs, experiences and actions (Charmaz 2006). For health professional participants, interview questions focused on both organisational and social practices. Questions were therefore posed about collective FPDR practices as well as

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[7] Please note that because I have not yet introduced the study participants, I have referred to them throughout this methods chapter as 'participant.'

individual participation in these practices, and their personal views of both. For family members and former patients, questions were related to individual and social practices, how they were constructed and beliefs about these practices (Charmaz 2014).

Each interview began with participants answering a short demographic questionnaire (see Appendix 12, page 272) in order to *'break the ice'* (Minichiello, Aroni & Hays 2008, p. 155), to provide background to each person's social reality and to acknowledge that each narrative was embedded in an individual's geographical, political, social and cultural context. A flexible interview guide was then used to explore rather than cross-examine participants about their experiences (Charmaz 2006, 2014).

As data generation and analysis progressed, the range of interview questions became progressively more focused in order to gather specific data to develop the emerging theory and as part of the theoretical sampling process (Charmaz 2006). Several prompting questions that were originally included in the interview guide were later omitted in order to focus on the emerging codes and categories. For example, prompts relating to the relationship of the family member to the patient, the age of the patient, and how long the resuscitation lasted were replaced with more specific questions to progress the emerging theory. Questions added to the interview guide included asking who FPDR is for, what would need to happen for FPDR to occur as standard practice and what influences different decision-making and practices between clinical settings that do and do not practice FPDR. Appendix 13 (see page 273) depicts the interview guide used for interview 1 while Appendix 14 (see page 274) depicts a modified interview guide used for interview 23.

As recommended by Charmaz (2014), questions were not asked in a linear fashion and in many cases not all questions within the guide were posed. Similarly, the prompts within the guide were used only when necessary to further compare, explore and refine an emerging concept or property. Questions were used to guide each interview according to the way individual participants shared their experiences. For example, following the first open-ended question many participants spoke for long periods of time with little more than an occasional 'mmm hmm' to prompt them and demonstrate active listening.

I was aware of the extent to which interview questions and style could shape the context, framework and content of the study and potentially force interview data into pre-conceived categories (Charmaz 2006). I minimised this by allowing participants to share their experiences unimpeded, and by taking care to ensure the open-ended questions were compatible with the research aims but also with participant's experiences. In other words, the questions were general enough to cover a wide range of experiences yet narrow enough to elicit and elaborate on the participant's specific FPDR experience (Charmaz 2006).

In order to clarify what Charmaz (2006, p. 35) referred to as *'taken-for-granted meanings'*, I paid close attention to participants' language and strove to learn about their meanings rather than making my own assumptions. For example, when I asked one participant who he thought FPDR benefitted most he replied, '*I think it benefits the patient the most, if they live, and the family the most if they die.'* This answer made sense to me based on my specialised knowledge and experience, but I was careful not to rely on my own taken-for-granted meanings and instead sought to learn more about his meaning, as evidenced in the following excerpt.

Interviewer:	*Right; can you expand on that?*
Participant:	*Sure. I think that the patient is at the worst possible time of their life. If they have any insight into their family being present, then I think they find that very reassuring.*
Interviewer:	*Mmm.*
Participant:	*Um, if the resuscitation has not gone well and the person has died, then the grieving process is aided I believe by understanding that everything was done and that death became inevitable.*

By remaining active and alert during the interviews, I was able to become immediately aware of interesting leads to explore in more depth and to shape subsequent questions that would elicit rich data. This allowed me to respond to each participant's individual story (Warren & Xavier Karner 2010; Birks & Mills 2011). For example, one health professional participant referred to staff being focused on a major trauma with little time to attend to family members who were present. In order to determine this participant's

views on supporting family members during FPDR, I asked several follow-up questions to once again clarify any taken-for-granted meanings.

Interviewer: *You mentioned just then that nursing staff are sometimes consumed with a major trauma; do you still have family members stay in the room even if they're there on their own?*

Participant: *No, I think that we always allocate someone to them … I've turned around a few times to find someone standing in the corner of the room, nobody really explaining what's happening. We need to tidy that up … we don't know what they're seeing, and what they're seeing may or may not be a reality. It's clearly their reality. But how they decipher that is – unknown.*

Interviewer: *Mmm, so would it be fair to say that you think it's vital that family members have explanations along the way in order to be able to stay?*

Participant: *Absolutely, yeah. They need to understand what is happening. Otherwise it just becomes - just an overload of information and situations which they may not be able to decipher, and will put on only the worst interpretation.*

DATA ANALYSIS

Data analysis began after the first interview in order to facilitate simultaneous generation, coding and analysis of the data, and to provide the focus for subsequent data collection as per GTM requirements (Glaser & Strauss 1967; Charmaz 2014). Coding was undertaken manually to avoid several limitations that have been associated with computer assisted analysis programs. These limitations include one-dimensional or superficial analysis (Charmaz 2003), the simplistic act of applying labels in the absence of analysis (Charmaz 2011), impaired creativity, an inability to conceptualise hidden patterns of social behaviour (Holton 2007) and a poor quality theory as a result of rushed and incomplete analysis (Hesse-Biber 2007).

Coding

GTM coding provides a tool to sift through, sort and synthesise data, and assists the researcher to begin to unify ideas analytically by keeping in mind what the possible theoretical meanings of the data might be (Charmaz 2014). Coding was therefore the first step to move beyond concrete statements in the data to making analytic interpretations (Charmaz 2006). In other words, coding allowed me to define what was happening in the data and begin to understand its meaning (Charmaz 2006). Close attention to coding in

this way ensured implementation of a core GTM mandate - to study the emerging data (Glaser 1978).

Complete interview transcripts were coded in order to provide a deep understanding of the phenomenon and to generate ideas that might otherwise have been missed (Charmaz 2006). The two main coding processes outlined by Charmaz (2014) were employed:

1. Initial coding; where fragments of data (lines, segments, incidents) were closely studied for their analytic import, and at times inVivo codes were adopted directly from participants.
2. Focused coding; where the most useful initial codes were identified and then tested against extensive data.

Initial coding

Initial coding began by allocating a short label (code) to each line or segment (i.e. sentence) of the interview transcripts that both summarised and accounted for each fragment. This allowed me to closely attend to what the participants said, to remain open and recognise subtle nuances in the data (Charmaz 2006, 2014), and to actively engage with and begin to conceptualise the data (Charmaz 2012).

Due to its corrective nature, line by line coding in this initial phase reduced the likelihood of imposing my preconceived ideas on the data (Charmaz 2006). However, it was also important at this stage to acknowledge my previous specialised knowledge and experience while remaining open to what could be seen in the data. Applying initial codes allowed me to ask questions about and look at the data critically and analytically. Coding in this way also allowed me to identify and define significant processes,[8] as well as the role participants played within these processes and their beliefs concerning them (Charmaz 2006, 2014).

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[8] In this context, a process consists of unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in-between. Single events become linked as part of a large whole (Charmaz 2014, p. 17).

These initial codes were treated as provisional and comparative in order to remain open to other analytic possibilities and create codes that best fit[9] the data (Glaser 1978; Charmaz 2014). Codes that were deemed to most closely fit the data were compared with further data to explore and develop these codes (Charmaz 2014). Some codes were later re-named to improve their fit with the data (Charmaz 2006). For example, during the first interview it became apparent that the participant's views on FPDR did not match her clinical practice when she *spoke* about being supportive of FPDR, yet in *practice* preferred to exclude family members from the room during resuscitation events. I initially coded this disparity as *'theoretical opinion differing from usual practice'*. As the study progressed, I saw this disparity demonstrated by other health professionals and renamed the initial code *'conflicting beliefs & practices'* in order to more closely fit the relevant data.

To develop fresh ideas about the data, initial coding was done quickly and spontaneously as recommended by Charmaz (2006, 2014). In order to facilitate effective coding and to ensure that the codes fit the data rather than forcing the data, I kept initial codes simple, short and precise, used gerunds to preserve actions and continually compared data with data (Charmaz 2006, p. 49). Initial coding also provided an insight into the kind of data that needed to be collected next early on in the research, and continued until codes emerged that required further exploration. These codes were then compared with subsequent data to see whether they were also able to account for that additional data (Charmaz 2012). Figure 2 (page 80) provides an example of initial coding using the recommendations outlined above.

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[9] In GTM research, 'fit' refers to the degree to which codes capture and condense participants' meanings and actions. Codes that most closely fit the data were those that explicated how people enacted or responded to FPDR, what meanings they held toward those events and the way in which those actions and meanings evolved (Charmaz 2014).

INITIAL CODES	INTERVIEW EXCERPT
Acknowledging FMs right to be present Acknowledging FMs right to see what's happening Being concerned that FPDR would cause problems Being concerned that FPDR would increase staff anxiety Weighing up benefits and disadvantages of FPDR Expecting FMs to stay quiet if present Valuing staff preferences above FM's rights and wishes	I feel like, you know, they should have the right in a way to be able to say I wanna see what's going on, what's happening with my mum or with my dad. But, but then - in a way if they come in they're like all anxious and frightened and causing more problems and making us more anxious rather than helping - I'd probably say no, I would say no - If umm - but then, if the family if they are quiet and think, I know my mum she would have wanted me to be there she would have wanted me to be present, then yes but [at the] end of the day their judgement doesn't really count , it always comes down to what we [staff] want, that's what I think, it always comes down to what we think.

Figure 2: An example of Initial Coding of an interview excerpt (interview 1).

In vivo codes

In vivo codes are special terms or codes that are initially spoken by the participants. These terms were used as an analytic point of departure during data analysis in order to preserve participants' meanings of their views and actions in the coding (Charmaz 2006). In vivo codes were subject to the same comparative and analytic treatment as all other codes and were not automatically integrated into the emerging theory. Several in vivo codes were particularly useful in this study; for example many participants described situations where family members either chose or were directed by health professionals to observe the resuscitation from a distance. This incident was initially coded in various ways including *'staying out of the way'* and *'stepping back.'* During Interview 10, the participant used the phrase *'watching from a distance'* to describe a similar incident. I adopted *'watching from a distance'* as an in vivo code which I used to code subsequent interviews and also to recode earlier interviews. This code was eventually renamed *'watching from a safe distance'* and became a property of one of the major categories.

Focused coding

The codes developed during focused coding were more directed, selective and conceptual than the initial coding outlined previously. Focused coding was used to synthesise and explain larger segments of the data (Charmaz 2006, 2014) by using the most significant

and or frequent initial codes to sift through large amounts of data and determine the adequacy of earlier codes.

Moving from initial to focused coding was not a linear process; I moved back and forth between initial coding and focused coding when new threads for analysis became apparent (Charmaz 2006, 2014). Focused codes were initially developed by comparing data with data. Further data were then compared to these focused codes in order to refine them. Focused coding was used to compare people's experiences, actions and interpretations. Figure 3 provides an example of focused coding using the recommendations outlined above.

FOCUSED CODES	INTERVIEW EXCERPT
Valuing FPDR	I feel like, you know, they should have the right in a way to be able to say I wanna see what's going on, what's happening with my mum or with my dad. But, but then - in a way if they come in they're like all anxious and frightened and causing more problems and making us more anxious rather than helping - I'd probably say no, I would say no - If umm - but then, if the family if they are quiet and think, I know my mum she would have wanted me to be there she would have wanted me to be present, then yes but [at the] end of the day their judgement doesn't really count , it always comes down to what we [staff] want, that's what I think, it always comes down to what we think.
Holding /relinquishing decisional power	
Assessing suitability	
Setting boundaries	
Protecting others and self	
Valuing FPDR	

Figure 3: An example of Focused Coding of an interview excerpt (interview 1).

CONSTANT COMPARATIVE ANALYSIS METHOD

One of the core tenets of GTM research is the constant comparative method which was first described by Glaser and Strauss (1967). The constant comparative method is used to establish analytic distinctions, and therefore to make comparisons, at each level of analytic work. Charmaz (2006, p. 187) defines the constant comparative method as;

> … a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with category, category with category and category with concept. Comparisons then constitute each stage of analytical development.

Throughout the analytic process, I used constant comparative analyses to; 1) compare different people's beliefs, actions and experiences, 2) compare data from the same individuals at different points in time, 3) compare incident with incident, 4) compare codes with categories, 5) compare categories with other categories and 6) to compare categories with theoretical memos (Charmaz 2000, p. 515). The constant comparative method was used throughout all stages of analysis to recognise similarities and differences in the data, to refine emerging concepts (Wiener 2007), to progress the emergence of conceptual data (Charmaz 2000) and to compare the final analyses with relevant theoretical and research literature (Charmaz 2012).

Constant comparisons were reflected upon and analysed during memo writing. This allowed me to develop analytical interpretations of the data in order to focus further data collection, which in turn was used to inform and refine the developing theoretical analysis (Charmaz 2000, p. 509).

MEMOING

Memo writing is a core tenet of GTM research that facilitates analytical momentum (Glaser & Strauss 1967; Strauss & Corbin 1998; Charmaz 2014). Memoing helped me think analytically about the data, treat codes as categories to analyse, demonstrate connections between codes and categories, discover gaps in data collection and create ideas to check with subsequent data (Charmaz 2006, 2012). GTM research is particularly focused on studying processes (Charmaz 2006). Memoing allowed me to begin to specify the conditions under which a process arose, persisted or changed (Charmaz 2012). Asking these analytic questions during memoing allowed me to move from description to conceptualisation of the data.

Initial memos were written to record what was happening in the data, to explore and develop resultant codes, and to direct and focus further data collection (Charmaz 2006). Appendix 15 (see page 275) depicts an initial memo written after Interview 2 that demonstrates a beginning level of descriptive analysis and interaction with the data. Appendix 16 (see page 278) depicts a later initial memo written after Interview 8 that demonstrates a higher level of analysis - with direct comparisons between other interviews and emerging codes and tentative categories.

Advanced memos were written during subsequent focused coding in order to refine conceptual categories. Advanced memos were used specifically to trace and categorise relevant data, describe how each category emerged and changed, identify the beliefs and assumptions that supported it and place the topic within an argument (Charmaz 2006, p. 81). Appendix 17 (see page 280) provides an example of a more advanced theoretical memo, written while attending a three day GTM Master Class facilitated by Professor Kathy Charmaz.[10] This memo portrays an attempt to refine several conceptual categories and determine the relationship between them.

THEORETICAL SAMPLING

Theoretical sampling differs from conventional sampling because it is responsive to the data rather than establishing the entire sample before the study begins (Corbin & Strauss 2008; Charmaz 2014). Theoretical sampling was used in this study to develop and refine the properties of developing categories and the emerging substantive grounded theory (Charmaz 2014). As such, theoretical sampling was not employed until several tentative theoretical categories had emerged from the data in order to direct further sampling (Charmaz 2006, 2012, 2014). Theoretical sampling strengthened this study by allowing me to specify the relevant properties of each category, which in turn increased category precision and moved coding beyond description to abstract analysis (Charmaz 2006).

Theoretical sampling was undertaken in several ways. Data were simultaneously generated, coded and analysed in order to decide what data to collect next and where to find them in order to keep developing the theory as it emerged (Glaser & Strauss 1967, p. 45). As the research progressed, I asked increasingly focused questions that were specific to emerging categories. I also recruited people with certain experiences that illuminated and defined the boundaries and relevance of the developing codes and categories and contributed to the development of the emerging grounded theory (Charmaz 2006).

In the early stages of the research, several preliminary categories were checked and elaborated upon using theoretical sampling, which in turn allowed me to explicate the relationships among categories. Early theoretical sampling also allowed me to identify

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[10] GTM Master Class Research Series, LaTrobe University, Melbourne, Australia, March 17-19, 2014.

and define gaps among categories. It was noted early on in the research that some tentative categories did not account for the full range of relevant experiences. For example, an early tentative category '*holding decisional power*' did not encompass the experiences of people who gave up their decisional power (or voice) in the decision-making process. Subsequent participants were therefore asked about this process and how they managed it, and existing data (interview transcripts) were re-coded in order to compare this process among participants. This tentative category was subsequently renamed '*claiming or relinquishing decisional power*' in order to account for the experiences of all participants, and the properties of this category were explored as the research progressed.

A further example of theoretical sampling involved the type of participants recruited into the study. Initially I sought to speak with three participant groups; 1) health professionals (specifically registered nurses and doctors), 2) family members and 3) resuscitation patients. After the first 12 interviews it became apparent that I needed to speak with paramedic staff in order to fully explore several important and recurring processes. The following memo excerpts detail the thinking behind this theoretical sampling process, and also the impetus for further theoretical sampling around the tentative category '*ownership of the space*'*.*

Excerpt from Initial Memo written after Interview 3
Why did the paramedics ask this person to stay for the resus? Do they have different expectations about who can be present during a resus? Do they feel less out of control during a resus than the RNs [from interviews 1 & 2]? Are they more used to members of the public watching them work in a crisis situation? It might be useful to speak with paramedics about their decision-making. Another consideration after interview 1 was ownership of the space. It is possible that FMs are more likely to stay during an out-of-hospital resus because they themselves might own the space; for example - their home. Other participants spoke about lack of space in a rural ED, however this participant described the resus of his wife in a very crowded bedroom, and yet he was not asked to leave. Ownership of the space needs further exploration.

Excerpt from Initial Memo written after Interview 12
This interview once again raises the need for me to speak with paramedics (theoretical sampling) about their experiences with FPDR both pre-hospital and

also once they bring the patient into the ED setting. However, I think I need to wait until I have some fully developed tentative categories because I will need to submit an ethics variation.

In the later stages of the research, theoretical sampling was used to demonstrate links between categories. With participants for whom particular concepts appeared significant, I asked them to add their experiences to the existing data set about a particular concept or category. These participants were asked to supplement information about linkages between categories, thus contributing to the emerging theory (Morse 2007). For example during Interview 12 *'valuing FPDR'* emerged as an important tentative category that required further exploration to explore, define and refine subsequent properties.

THEORETICAL SENSITIVITY

Theoretical sensitivity relates to the researcher's ability to have insight, to understand and give meaning to the data and to separate the relevant from the irrelevant (Strauss & Corbin 1990, 1998; McCann & Clark 2003a). According to Glaser (1998, p. 44) theoretical sensitivity is achieved when the researcher is able to *'self-consciously conceptualize and formulate a theory as it emerged from the data.'*

Developing theoretical sensitivity allowed me to apply what Charmaz (2014, p. 160) refers to as *'analytic precision'* during data analysis and substantive theory generation, as I sought to understand and define phenomena in abstract terms and demonstrate abstract relationships between studied phenomena. Developing theoretical sensitivity allowed me to see relevant data, to reflect on that data and to maximise the emergence of the substantive grounded theory (Glaser 1978). I used my professional knowledge and experience as sources of theoretical sensitivity, while at the same time using reflexivity to avoid being blocked by these previous experiences (Strauss & Corbin 1998). The preliminary literature review presented in chapter two was also used to gain and apply theoretical insight to the exploration of FPDR in this thesis.

REFLEXIVITY

Reflexivity is an active process that explicitly and critically examines the research process (including the researcher's decisions and interpretations) in order to assess how and to what extent their interests, positions and assumptions may have influenced the inquiry

(Charmaz 2006; Liamputtong 2010). Reflexivity recognises that all knowledge is affected by the social conditions under which it was constructed and is grounded in the history and social location of the participants and the researcher (Hesse-Biber 2007). Reflexivity thus acknowledges that the researcher plays a significant role in how data are analysed and shaped, and explicitly identifies the researcher's contribution to the interpretative process (Liamputtong 2009).

Throughout the study I was constantly aware that what I saw and heard during data generation and analysis was dependent upon my knowledge, past experiences, interests and prior interpretation of the phenomenon (Charmaz 2005, 2006, 2011). In order to learn the meaning that participant's attributed to their beliefs, actions and experiences I was actively reflexive about my own meaning for those same beliefs, actions and experiences in order to minimise bias and to avoid imposing preconceived ideas on the data.

I practiced reflexivity consistently and systematically throughout the research process, particularly during the development of theoretical sensitivity, and during data generation and analysis. Self-awareness through analytical memo writing was integral to the process of reflexivity, making personal assumptions explicit and enabling a *turning back* on my initial reflections on the data (Birks & Mills 2011). These analytic theoretical memos were discussed regularly with the thesis supervisors in order to seek critical feedback and external acknowledgement of reflexivity. In the following memo excerpt written after the fifth interview, practicing reflexivity made me wary of forcing data into pre-existing codes.

> **Memo Excerpt following Interview 5**
> This participant is also an RN and some of the themes that emerged from her contribution during the interview resonated with me in relation to my Nurse-Family Member research. Although I was not asking questions related to the Nurse-FM experience, she spoke about experiences that related to several key themes from my previous research. I need to be aware of pre-existing themes and avoid forcing the data into pre-existing categories.

Actively and critically reflecting during the research process allowed my personal assumptions to become explicit and I was able to articulate how prior knowledge and experience had influenced data analysis. I also published an article during this research

study that included a discussion about the role of reflexivity during grounded theory research (Giles, King & de Lacey 2013).

THEORETICAL SATURATION AND SAMPLE SIZE

Theoretical saturation in GTM occurs when data generation is yielding little or no new information such that further generation would not add anything useful to the study (Glaser & Strauss 1967; Charmaz 2006). More specifically, data collection needs to occur until no new properties of the core theoretical categories emerge or until the properties of the data are saturated - rather than the data itself.

Several recommendations exist regarding sample size in GTM research. According to Glaser and Strauss (1967, p. 225), *'the researcher can always try to mine his data further, but little value is learned when core categories are already saturated.'* Similarly, Glaser (1992, 1998, 2001) believes sampling should continue until the properties of the core categories are saturated, rather than until a predetermined number of participants have been recruited; even if this means the sample size is quite small. Stern (2007) goes further to provide an example of an acceptable sample size, adding that in her experience 20 to 30 interviews is usually adequate to reach theoretical saturation in GTM research. Charmaz (2014) further advises that rather than just focusing on a specific number of participants, researchers should also consider how sample size might affect the credibility of a study when making claims about the studied phenomenon. This current study used Charmaz's (2014) recommendations that 25 interviews are sufficient for small studies making modest claims.

After analysing interview transcripts from 18 participants, some codes and themes were noted to be emerging over and over again. But more importantly, very few new properties were emerging for each tentative category. However, the properties were not yet considered fully saturated. I continued to code new interviews and re-code earlier interviews, employing the constant comparative method to help raise my analysis to a more conceptual and abstract level. I attended a three day Master Class facilitated by Professor Kathy Charmaz, during which I further developed my coding, analysis and memoing techniques. I also enhanced my clustering (mind mapping) and diagramming at

this Master Class, and employed both techniques while continuing to develop the substantive grounded theory.

After interviewing 25 participants, several core processes (detailed later in this chapter) emerged that were subsequently developed into the final core category. I re-interviewed three key participants (one registered nurse, one doctor and one family member) in order to saturate the properties of each major category and sub-category (refer to appendix 18 on page 282 for a list of follow-up questions). I also presented several key findings to those three participants in person and to all participants via email in order to evaluate the theory. These findings are included in the matrix on page 134 and the table in appendix 19 (see page 283).

THEORETICAL SORTING AND INTEGRATION

Theoretical sorting and integration allowed me to construct a substantive grounded theory that captured the essence of participant experiences (Birks & Mills 2011). The analytic diagrams and memos written during each stage of analysis helped me develop categories that became progressively more theoretical as analysis progressed (Charmaz 2006). Once analysis was complete, these memos were manually sorted in order to integrate the emerging theory (Charmaz 2006; Stern 2007; Birks & Mills 2011). According to Charmaz (2006, p. 115) sorting in GTM research *'gives you a logic for organizing your analysis and a way of creating and refining theoretical links that prompt you to make comparisons between categories.'* In other words, sorting allowed me to compare categories at an abstract level, and helped me generate the emergent theoretical conceptual framework, which in turn facilitated the full articulation of a grounded theory through an integrated set of hypotheses (Holton 2007).

Sorting was done by hand in order to harness the creativity needed to recognise a theoretical code in the memos while they were being compared and placed into their final order (Stern, 2007). Memos were printed and sorted on a large table where they could all be seen and moved around as necessary (Charmaz 2006). During the sorting process, I continued to compare categories in order to refine these comparisons further and see relationships between categories more clearly (Charmaz 2006). During this

sorting process, I also integrated relevant literature into the emerging theory, which was subsequently sorted along with the memos (Charmaz 2014).

Theoretical sorting and theory integration sometimes incorporates theoretical codes, many of which were developed by Glaser (Holton 2007). However, grounded theory experts have highlighted several limitations to the use of these codes in GTM research. For example, Kelle (2007) stresses that Glaser did not clearly explain the use of his theoretical codes, and claims the codes mixed logical and substantive issues. Kelle (2007, p. 200) further asserts that using Glaser's *'unsorted list of terms'* is unreliable if the researcher does not possess a broad background in the different theoretical perspectives on the list. In addition, Bryant and Charmaz (2007a) claim that in recent years, Glaser has distanced himself from the theoretical codes he developed in his earlier works. For these reasons, theoretical codes were not used in this thesis. However, by identifying similarities, connections, and underlying uniformities in the memos and relevant literature, I was able to make a series of theoretical decisions about the precise location and order of each memo and concept (Charmaz 2014).

EMERGENCE OF THE SUBSTANTIVE GROUNDED THEORY

According to Charmaz (2014, p. 344) a substantive grounded theory is a *'theoretical interpretation or explanation of a delimited problem in a particular area.'* Charmaz's definition of theory emphasises a theoretical understanding that is abstract and interpretivist, where the understanding from the theory relies on the theorist's interpretation of the studied phenomenon. As previously outlined in chapter three, this thesis used Charmaz's (2006, 2014) interpretive approach to theorising in order to allow for indeterminacy, which is compatible with both constructivism and symbolic interactionism.

The systematic application of the grounded theory methods and process detailed throughout this chapter facilitated the emergence of several core processes or concepts that were eventually developed into the final substantive grounded theory. These theoretical concepts emerged during the iterative process of going back and forth between progressively more focused data and successively more abstract conceptualisations of those data (Bryant & Charmaz 2007b). The methodological diary

included as appendix 20 (see page 284) tracks the development and emergence of the codes, categories and properties into the final substantive grounded theory using constant comparative analysis of data generated throughout the study. This emergence is further detailed in a peer-reviewed coding article I wrote, which was accepted for publication during construction of this thesis (Giles, de Lacey & Muir-Cochrane 2016). This article is included as appendix 21 on page 289.

As the substantive grounded theory was emerging, a secondary review of relevant literature was undertaken in order to support and strengthen the emerging theory and to situate the current research within the existing literature (Charmaz 2014). This secondary review has been woven into subsequent chapters that present the substantive grounded theory.

RIGOUR - EVALUATING THE GROUNDED THEORY RESEARCH

Glaser and Strauss (1967) originally recommended that appraisal of GTM research must take place in the context of practical applicability of the theory. They believed a grounded theory should demonstrate an appropriate fit with the relevant field, the theory should be understandable by the people who work in the field, it should be general enough to make it flexible when applied and the user should have control over its use. Glaser (1978) later modified these criteria to recommend that the theory must fit the data, must work by being able to explain and predict behaviour, which in turn will make the theory relevant to experts in the field. He also believed the theory must be modifiable in order to accommodate later variations and to ensure ongoing relevance of the theory.

Charmaz (2014) recommends building on Glaser's criteria in order to evaluate how the constructed theory represents the data. She stresses that a strong combination of originality and credibility increases a study's resonance, usefulness and subsequent value of contribution to clinical and professional healthcare practice. Charmaz's criteria for establishing rigour in GTM research (Charmaz 2014, pp. 337 - 338) were applied during this study to construct and evaluate the substantive grounded theory. Appendix 22 (see page 314) presents these criteria and details how they were met in this study.

Glaser and Strauss's (1967) criteria of credibility was also met through the detailed presentation in this thesis of the coding and analysis trail, evidence of multiple and constant comparisons and the explicit emergence of the categories and substantive grounded theory from the data. In relation to Charmaz's (2014) criteria of usefulness and value of contribution, several participants spoke positively about their interview and thanked me for the experience. For example, one participant (who was interviewed together with her husband) revealed that during the interview she became privy to information and experiences that her husband had not previously shared with her.

Participant (wife):	*This should have happened, regardless of you doing a thesis, but some sort of counselling should have happened 12 months after. That's what I think. The things I've heard today, I haven't heard before. But this is like debriefing - that's what I'm saying. If we'd had this and probably didn't even think about it but I'm just thinking of what it's doing to us. If we'd had this, 12 months after.*
Participant (husband):	*Six to 12 months, while it's still fresh in your mind.*
(Wife):	*Yeah. I think that would have been very beneficial.*
(Husband):	*I'd agree with that totally.*
(Wife):	*Well I think it's been beneficial for us because, we have talked about it a bit before, but not in depth.*

Another participant took the time to phone me several days after her interview to thank me for the experience and to advise me that to her, the interview had been a valuable debrief. Several other participants advised me that they found the interview beneficial and spoke positively about the research topic at the end of their interview. For example;

Thank you for doing the research. It would be good to put it [FPDR] on the radar for people out there to actually start thinking about it.

Thanks for doing the study because it's something that really needs to be looked into ... it [FPDR] definitely needs to be brought to the front for sure. Like I say, we deal a lot with writing up people's 'do not resuscitate', but we don't bother with people that want to be resuscitated and whether or not they want family present ... it's like they're [FMs] out there somewhere but we don't wanna know 'em.

In relation to Charmaz's (2014) criteria of resonance and value of contribution, several participants used the interview to reflect on their practice. For example;

Thank you. I have actually reflected upon it and you know, talking about what the patient would want and things like that, I've never really, it doesn't occur to me during that situation – so thank you.

… since you brought this back up, we've been looking at a whole lot of issues about how we enmesh families in the care of babies and things … It's an interesting topic. When I first [heard about the topic], I thought hmm? But it's actually quite a fascinating topic and in fact it's such a sharp edge thing that it actually focuses all the other principles you have throughout the processes so if you can get it right there, all the rest will be fine.

CHAPTER SUMMARY

This chapter detailed the constructivist grounded theory methods used to explore decision-making around FPDR, and how those processes were used to generate a substantive grounded theory. Particular attention was paid to ethical considerations, the relationship between the methods and processes used at various stages throughout the research, and establishing and evaluating study rigour. The following chapters present the substantive grounded theory constructed during this study.

Chapter Five: The Grounded Theory

CHAPTER OVERVIEW

This constructivist GTM study was designed to develop an abstract theoretical understanding and explanation of FPDR practices in Australian acute healthcare settings. Chapter five is the first of six chapters presenting findings from in-depth interviews with 25 participants who had first-hand experience of the phenomenon. This chapter begins by introducing the study participants in order to contextualise their experiences. Chapter five then introduces the substantive grounded theory that was constructed as a result of this study and the conceptual model that symbolises the social processes that occurred as part of this theory. Chapter five concludes with a description of the way in which different aspects of the substantive grounded theory are presented in discrete chapters in order to explicate each of its major processes.

This thesis employs what Charmaz (2014, p. 317) refers to as a *'linear logic'* to organise the analysis and findings into an understandable format for the reader. However, the experience of FPDR was not conveniently delineated within clear boundaries. Thus, while findings are presented in sequential chapters, the processes and actions were experienced in a more cyclic and interconnected nature. Each findings chapter was designed to progressively build an understanding of a substantive grounded theory that aimed to interpret and explain behaviour and meanings around FPDR from the perspective and in the context of the people who experienced it (Charmaz 2014).

PARTICIPANT PROFILE

Extensive in-depth data were co-constructed with 25 participants over the course of 27 interviews; 24 initial interviews with 25 participants (husband and wife participants were interviewed together), and three follow-up interviews with three participants. Demographic data is presented in table 6 (page 94) in order to contextualise participant experiences and the emergent theory.

Table 6: Participant demographics

	Pseudonym	Gender	Age	Occupation and work setting	Time since latest resus experience
1	Jackie	F	25	Registered Nurse – Emergency Department Major Metropolitan Hospital	1 month
2	Elizabeth	F	58	Registered Nurse - Rural Hospital	unknown
3	Trevor	M	69	Family Member (Husband)	5 weeks
4	Dana	F	63	Registered Nurse /Registered Midwife - Major Tertiary Hospital	< 1 week
5	Mary *	F	64	Family Member (Wife)	6 years
6	Frank#	M	62	Resuscitation Patient	6 years
7	Sally**	F	59	Family Member (Sister) & Registered Nurse Major Rural Hospital	< 1 year
8	Rosy	F	57	Family Member (Daughter)	40 years
9	Mandy	F	45	Registered Nurse - Rural Hospital	3 years
10	Dooley	M	61	Family Member (Father)	21 years
11	Anthony	M	61	Doctor – Intensive Care Unit Major Metropolitan Hospital	ongoing
12	Lauren	F	41	Doctor - Emergency Department Major Metropolitan Hospital	2 weeks
13	Darren	M	55	Nurse Practitioner/RN – Emergency Department Major Metro Hospital	Ongoing
14	June	F	56	Registered Nurse - Major Metropolitan Hospital	20 years
15	Gemma	F	48	Registered Nurse/Registered Midwife/Nurse Educator – Regional Hospital	6 years
16	Grace	F	32	Registered Nurse – Emergency Department Major Metropolitan Hospital	< 1 year
17	Michael	M	47	Registered Nurse – Emergency Department Major Metropolitan Hospital	< 1 year
18	Bella	F	31	Registered Nurse/Registered Midwife – Regional / Rural Hospital	< 1 year
19	Jane	F	31	Registered Nurse – Emergency Department Suburban Metropolitan Hospital	2 months
20	Katherine	F	32	Registered Nurse – Emergency Department Major Metropolitan Hospital	< 1 year
21	Neil	M	50	Nurse Practitioner/RN – Emergency Department Major Metro Hospital	< 1 year
22	Helen	F	60	Paramedic - Major Regional Area	< 1 year
23	Sarah	F	30	Paramedic - Major Metropolitan Area	< 1 year
24	Carol***	F	49	Family Member (Mother) & Registered Nurse Major Metro Hospital	5 years
25	Matt	M	35	Paramedic - Major Metropolitan Area	< 1 year

TABLE KEY: *Mary is a registered nurse but recounted an experience of being a family member only; **Sally recounted her experiences as a family member and as a Registered Nurse; ***Carol recounted her experiences as a family member and as a registered nurse; # Frank and Mary are a married couple who were interviewed together.

Demographic data has been de-identified and summarised to protect participant privacy and to comply with the ethical principles detailed in chapter four. Sub-specialties, job titles, workplaces and the Australian state in which participants lived were all excluded from this thesis to prevent inadvertent identification. Pseudonyms were allocated to further protect confidentiality.

Sixteen women and nine men (refer to table 6, page 94) shared personal experiences that took place between one week and 40 years previously, with most experiences occurring within the last six years. Family members Rosy and Dooley shared experiences from 40 and 21 years ago respectively, from a time period when FPDR was not well known or established. Despite this, Dooley remained with his son for the entire resuscitation. However Rosy, who was 17 years old at the time, was not permitted in the room when her mother required emergency care. From a health professional perspective, the only participant who recounted an experience from more than six years ago was June, who shared a 20 year old experience of FPDR in a setting where it was not usually practiced or recognised as a legitimate intervention. June's nursing career has spanned many decades, and her current practice does not include FPDR as standard.

Despite the length of time that had elapsed in some cases, almost all participants[11] were able to recall their experiences in great detail; including their thoughts, feelings and actions, and the actions of others. It is important to remember that these experiences were a reproduction of occurrences, with participants reporting (and in some cases justifying) past events from the vantage point of the present (Mead 1962; Charmaz 2014). During their interviews, participants were able to reflect on past and current practices and beliefs and clarify their meanings and actions (Charmaz 2014). As such, regardless of the time perspective from which these experiences were shared, they represented participants' current attitudes, beliefs and preferences toward family presence during resuscitation.

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[11] Rosy was unable to recall some details of her mother's illness. However, she was able to articulate how she felt during and after her mother's hospital admission in relation to family presence. She was also able to clearly convey her current beliefs about FPDR.

Participant quotes have been used throughout the findings chapters to help ground the abstract analysis and to support the claims being made about them (Charmaz 2014). As such, excerpts from participant interviews provide empirical evidence for the theoretical presentation of the data (Charmaz 2014). All participants' voices are represented at some point within the findings chapters. However, it is not necessary in a GTM study to provide equal weighting to each participant. Rather, development of a grounded theory requires a focus on theoretical concepts and their relationships rather than on individual participants (Corbin & Strauss 2008; Charmaz 2014). Therefore, examples and excerpts that were most representative of emerging concepts are presented in this thesis.

AN INTRODUCTION TO THE GROUNDED THEORY CONCEPTUAL MODEL

The substantive grounded theory *The Social Construction of Conditional Permission* was constructed using conceptual abstraction (detailed in chapter four) beginning with and always grounded in the participants' perspectives of their own reality of FPDR (Charmaz 2014). This theory explained the major social process at work when health professionals and family members were faced with a decision to practice or participate in FPDR. The grounded theory presented in this thesis contributes to an understanding of decision-making around FPDR in Australian acute healthcare settings. However, it is important to remember that this theory provides an interpretation and conceptual understanding (Charmaz 2014) within the contexts outlined previously in this thesis and therefore may not be applicable to experiences in different circumstances.

The conceptual model depicted in Figure 4 (see page 97) was constructed to symbolise and explicate the theory. The model depicts the cyclic and inter-related nature of the processes enacted from the moment a patient required resuscitation in the direct or indirect presence of a family member. The first three processes enacted were; 1) claiming ownership, 2) opportunistic presence and 3) valuing family presence. These three processes were interconnected and impacted not only each other, but all other processes depicted in the conceptual model.

The model also illustrates the four interconnected properties of the core category that manifested as value-laden judgements to guide decision-making and place particular conditions on FPDR. These judgements included; 1) prioritising preferences and rights,

2) assessing suitability, 3) setting boundaries and 4) protecting others and self. These judgements directly impacted the core category while also being influenced by the three initial processes of claiming ownership, opportunistic presence and valuing family presence.
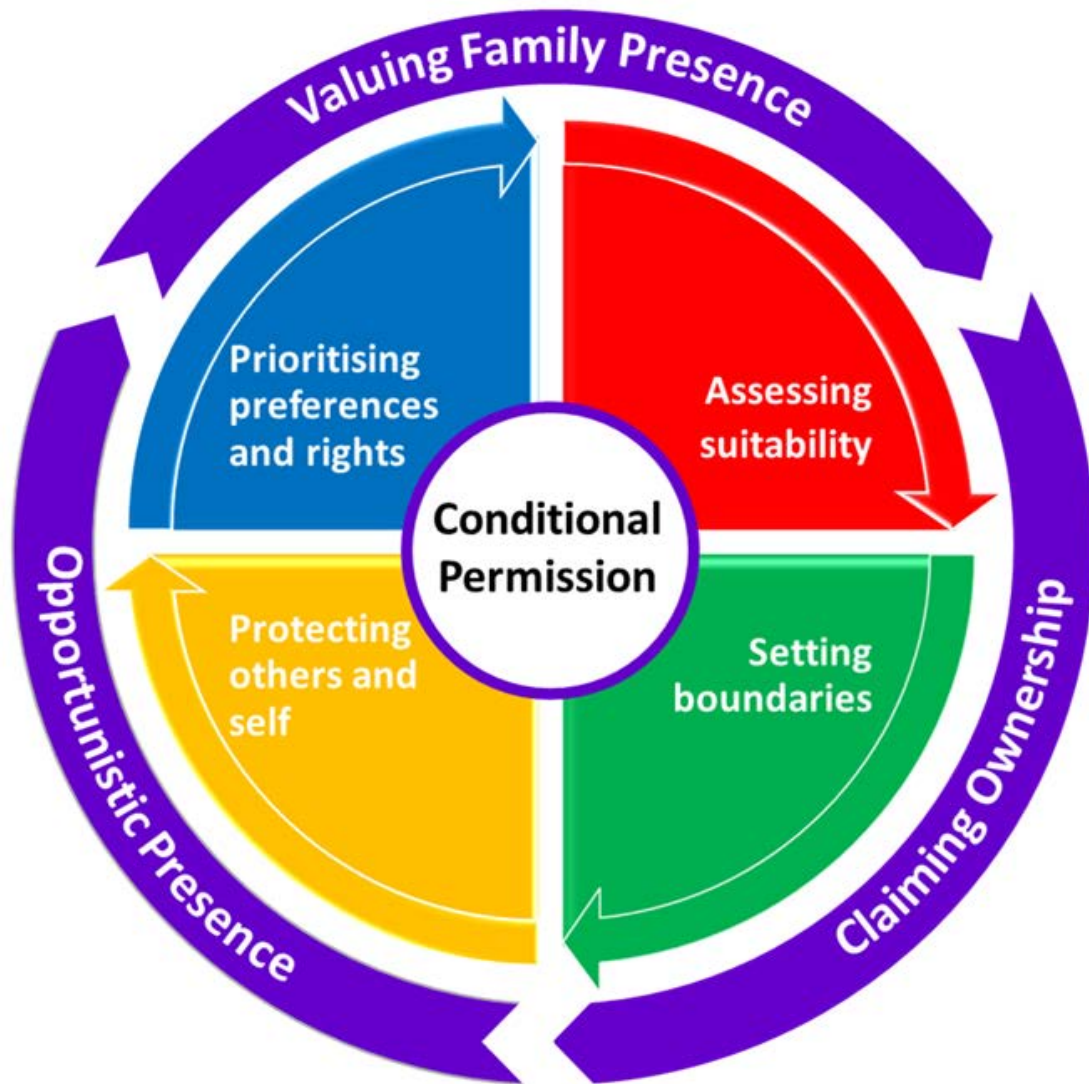
Figure 4: Conceptual model
The Social Construction of Conditional Permission
A grounded theory of Family Presence during Resuscitation

Permission for FPDR was always conditional, continually reassessed throughout the resuscitation event and subject to retraction if the boundaries of conditional permission were breached. Staff and family members who valued FPDR placed fewer conditions on presence, and were more likely to ensure those conditions could be met in order to

ensure presence could occur. Conversely, health professionals and family members who did not value FPDR placed multiple conditions on the practice - sometimes to the extent where meeting these conditions became almost impossible. Further, those conditions were often used to justify denying FPDR. *The social construction of conditional permission* was therefore impacted most by the extent to which FPDR was valued by the individuals and groups who were (perceived to be) in control of permissions.

OVERVIEW OF THE FINDINGS CHAPTERS

This chapter (chapter 5) introduced the study participants, and provided an overview of the substantive grounded theory and theoretical conceptual model that was developed to explicate the theory. Chapter six presents the first major process of the theory - *claiming ownership* of the patient, the space and the resuscitation act. Chapter seven examines the second major process, *opportunistic presence*, while chapter eight discusses the third major process, *valuing family presence.* While these three processes are discussed separately in discrete chapters, the relationship between them is also clarified to demonstrate how *together* they impacted the core category and to highlight their role in the substantive theory.

Chapter nine presents an in-depth discussion of the value-laden judgements made by health professionals and family members during *the social construction of conditional permission* for FPDR. These judgements are discussed within four sub-categories; 1) prioritising preferences and rights, 2) assessing suitability, 3) setting boundaries and 4) protecting self and others, and once again the relationship between these sub-categories and the central theory is explicated.

Chapter ten presents a theoretical discussion of the substantive grounded theory – *The Social Construction of Conditional Permission* - that interpreted and explained decision-making around FPDR in Australian acute healthcare settings. Conditional permission was shown to be a social construction made possible by the ongoing interactions and interpretations of people playing a particular role in a particular setting or context.

Throughout chapters six to ten, significant findings are discussed in relation to existing literature in order to support the theory (Glaser & Strauss 1967; Strauss & Corbin 1998;

Charmaz 2014), to situate the current research within the body of related literature and to demonstrate how the current study built upon this body of evidence (Charmaz 1990; Stern 2007; Charmaz 2014).

CHAPTER SUMMARY

This chapter introduced the research participants in order to contextualise the emergent theory, and presented the conceptual grounded theory model that was developed to explicate the central theory in this study. Chapter progression for the remaining study findings was then detailed to inform the reader of the way in which each chapter was designed to progressively build an understanding of the substantive grounded theory. The following chapter presents the first major processes of the grounded theory - *claiming ownership* of the patient, the space and the resuscitation act.

Chapter Six: Claiming Ownership

CHAPTER OVERVIEW

The previous chapter introduced the study participants and presented an overview of the substantive grounded theory and conceptual model. This chapter presents the first of three major processes (claiming ownership, opportunistic presence and valuing family presence) enacted during a resuscitation event when a family member was in the room or nearby, and examines the relationship between the major processes depicted in figure 5, and their role in the grounded theory.
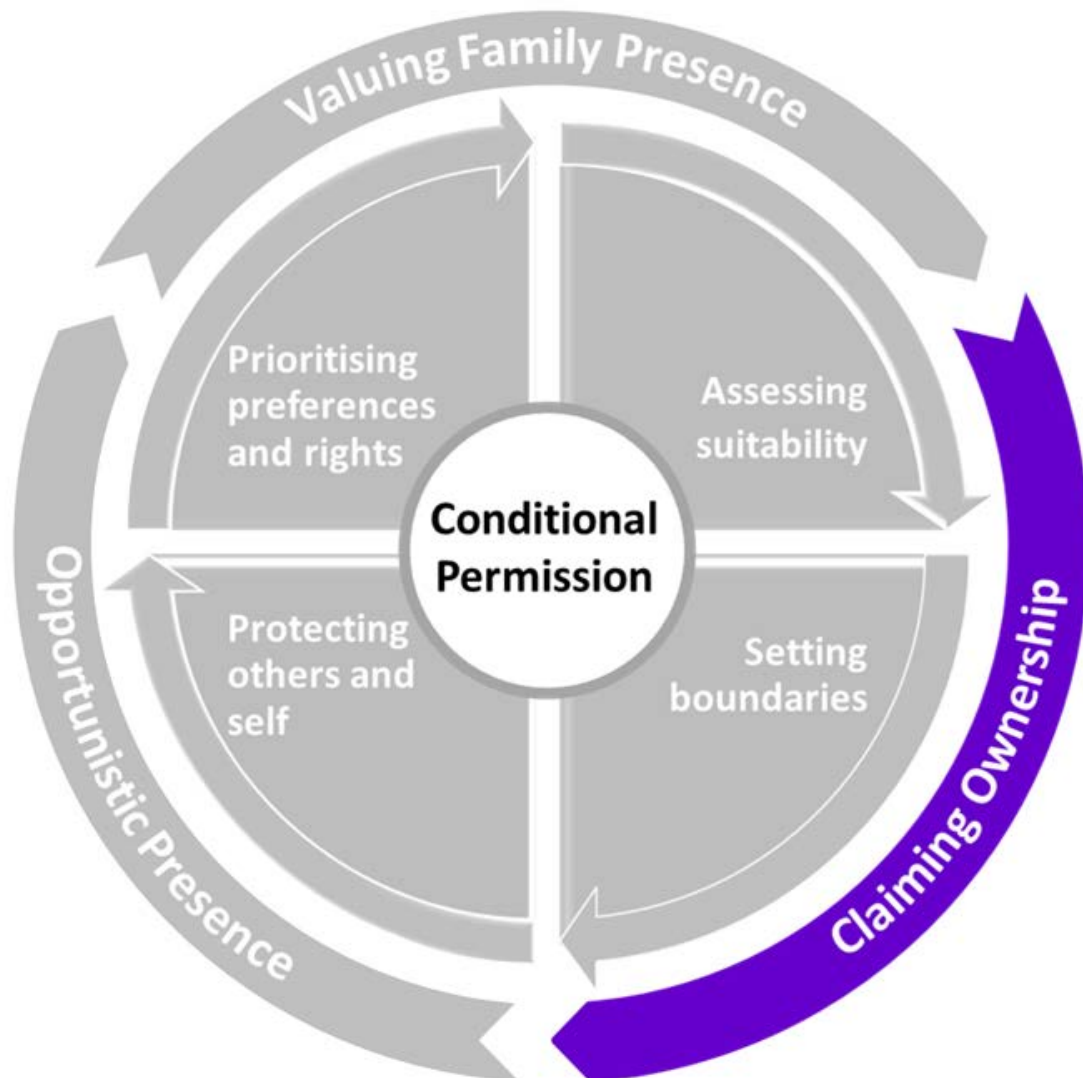
Figure 5: Claiming ownership – the initial social processes enacted during a resuscitation event when a family member was in the room or nearby.

Claiming ownership was a process whereby a person or group of people laid claim to one or more of three things: 1) ownership of the patient, 2) ownership of the space, and 3) ownership of the resuscitation act. Individuals and groups claiming ownership included registered nurses, doctors and paramedic staff (who together comprised a health professional group) and family members.

OWNERSHIP OF THE PATIENT DEFINED

A general definition of the term ownership is *'the act, state, or right of possessing something'* (Oxford Dictionaries 2015). To own a person is of course an infringement on their right to exercise autonomy and self-determination, and the very term is fraught with controversy (Shields *et al.* 2003). However, the *concept* of patient ownership can influence relationships between health professionals, patients and family members. Much like Shield and colleagues' (2003) discussion of who owns the hospitalised child, no other word was deemed able to sufficiently and succinctly encapsulate this major process that emerged from the data in the current research. Therefore, the term *ownership* has been used in this thesis with careful consideration of the following definitions.

Patient ownership has been defined previously as health professionals knowing all relevant information about a patient and doing everything necessary for them (Van Eaton, Horvath & Pellegrini 2005). The resultant sense of responsibility often included the instinct that patients *belong* to the health professionals responsible for their care (Yedidia *et al.* 1993). According to McLaren *et al.* (2013), ownership of patient care by health professionals encompasses seven core elements; advocacy, autonomy, commitment, communication, follow-through, knowledge and teamwork. As such, ownership of patient care by health professionals encompasses professionalism, competent care and patient safety (McLaren *et al.* 2013). For the purpose of this study, claiming ownership of the patient refers to a person or group believing they have the most significant connection to or right to be with the patient and to make decisions on their behalf at a particular point in time.

CLAIMING OWNERSHIP OF THE PATIENT

When a patient first entered the hospital environment, competing ownership claims began almost immediately between health professionals and family members. Health

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professionals often asked family members to leave the room if they were already present, or excluded them from the room until the patient was stabilised or recovered - or in some cases until the patient died.

While some health professionals were happy to share ownership of the patient by inviting family members to be present; many were not - claiming sole ownership and expecting family members to temporarily relinquish their claim on the patient until the crisis was over. In other words, when the patient was in a critical condition that health professionals believed was reversible, family members were kept away and only allowed into the room once the patient recovered. However, when health professionals believed the patient was going to die (or had died) family members were let in – to be present in death and reclaim ownership of their loved one. For example, Elizabeth said that;

> *I think, depending on how the resuscitation is going and if we know that there's no hope of success, I think the family member should be allowed into the room. (Elizabeth: RN)*

This separation of family members from their dying loved ones has been referred to previously as the isolation and professionalism of contemporary dying (Timmermans 1998, 2005). By this, Timmermans was referring to the contemporary practice of health professionals claiming control of the dying process, including who can and cannot be present – something that was evident in this current study.

Ownership claims to the patient were made through language and through actions. Health professionals used actions by excluding family members from the room and their ownership claims were more likely to be effective than those of family members.

> *… it still comes back down to the doctors, to the nurses … even if the family says I wanna be there, and from our assessment we think no, you shouldn't be here, there's no way we will allow them to come in … their [FM] judgement doesn't really count; it always comes down to what we [HP] want … it always comes down to what we think. (Jackie: RN)*

When health professionals used language to claim ownership of the patient, they did so in a symbolic way to claim overarching and theoretical ownership of all patients by all health professionals rather than claiming ownership of an individual person.

> *… at the end of the day, you're doing what's in the best interest of your patients*
> *and their loved ones, and I think that's what we all strive to achieve in our job*
> *every single day. (Bella: RN/RM)*

The generic nature of these claims to ownership were indicative of the professional distance that exists between health professionals and patients (Timmermans 1999a, 1999b; Rousseau 2004; Corbett & Williams 2014) as part of their therapeutic relationship (May 1992; Sharp 2007). These claims also reflected the traditional sense of ownership that health professionals instinctively feel toward their patients as mentioned previously (Yedidia *et al.* 1993; Shields *et al.* 2003; Van Eaton, Horvath & Pellegrini 2005). However, the language used by health professionals when claiming ownership of their *own* loved one as a potential patient was less professional and more personalised, and often included evocative language and detailed rationales to support their claims. For example;

> *If it was one of my family members, I would not be leaving. There's no way you'd*
> *get me out … Wild horses wouldn't get me away … If it was my child I wouldn't be*
> *leaving, they'd need to taser me to leave … (Matt: Paramedic)*

> *… try keeping me out of the room … it's my mum, or my dad, or my sibling. They're*
> *the most important people in my life. I want to be there … you know, they're*
> *people I care about and I want to be there for them… (Bella: RN/RM)*

Many health professionals also used language that acknowledged the close existing relationship between patients and family members, which in turn indicated their acknowledgement of a family member's right to claim (at least partial) ownership of the patient. However, this acknowledgment was often theoretical and did not always extend to practice.

> *I think sometimes it's family-centred care so in a way … they [FM] should be given*
> *the opportunity because it's their close [family] member … husband or wife or a*
> *child, maybe sometimes they want to be present in the room. (Elizabeth: RN)*

According to Charmaz (2004), actions can make taken-for-granted meanings visible and what actually happens in a social setting is often quite different from what people are willing to express verbally. In Elizabeth's case, her actions portrayed her meanings in a way her language was not able to fully illustrate. Elizabeth mentioned that family members are entitled to claim ownership of the patient by nature of their existing

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relationship. However, by using the phrase *'in a way'*, Elizabeth's language suggested ambivalence about whether family members should actually be afforded this right. Elizabeth's actions reinforce this conjecture because she does not support FPDR in her everyday practice. In contrast, some health professionals, like Darren, used language to acknowledge family member ownership of the patient while at the same time supporting their words with actions by providing examples of advocating for and allowing FPDR in their everyday practice.

> *… to me, really we are just passing briefly through these people's lives, and it's the person that's been with them all their life … often for many, many years, who has far more rights … (Darren: RN/NP)*

Health professionals who were supportive of FPDR stressed that unlike staff, who possess only a superficial knowledge of the patient, family members have known and loved the patient all their life. As such, they are usually the most important person in the patient's life and should have their claims to the patient acknowledged. Advocates for family presence during critical events (Timmermans 1998, 1999a, 2005; Berwick 2009; Davidson *et al.* 2014) agree that family members' rights should be acknowledged and respected. Davidson *et al.* (2014) warn of the emotional and psychological distress that can occur as a result of forced separation of family members from their loved ones, while Berwick (2009) argues that forced separation of this kind is a form of violence. While Berwick acknowledges his is an extremist view, it is likely he used such evocative language to stress the importance of a family-centred approach to care that promotes patient/family rights as vital for the provision of quality health care.

Some health professionals not only acknowledged family members' rights to claim ownership of the patient; they modified their practices and the environment to ensure family could (safely) remain present, such as the example provided by Sarah.

> *I did one arrest where the family member wanted to keep holding on to the person and so I got him to sit, at her foot end, and just have him hold on to her foot because that was far away from where we could do [our job]; so he still felt connected to her, but was not in our way. (Sarah: Paramedic)*

While health professionals used both actions and language to claim ownership of the patient, family members were more likely to use language alone; using terms such as *'my wife'* or *'my family member'* or *'my child'* as primary reasons for wanting to be present during resuscitation. For example, Trevor spoke passionately about wanting to remain with his wife when she arrived at hospital – but he was excluded from the room by staff. When asked how that made him feel he replied;

> *… it was my wife, I wanted to be with her … it's just my family and I wanted to be there. (Trevor: FM, Husband)*

While some family members verbally expressed their desire and resolve to be with their loved ones during resuscitation, in reality most (like Trevor) allowed themselves to be physically excluded from the room by health professionals. Others who *were* present indicated they would have allowed their ownership claims to be overridden if the situation arose. For example, Carol disclosed that if she had been asked to leave her critically injured son, she would have done so – despite being in her own workplace where she had already experienced elevated levels of inclusion and access to her son compared to general-public family members.

> *I'm his mum, he needs me … I don't think I would have made a fuss if they'd said go … but, no-one said anything so I stayed. (Carol: FM, Mother & RN)*

In some case, family members were already present when the resuscitation began. This *opportunistic presence* (detailed in chapter seven) strengthened family members' claim to patient ownership and had a significant impact on whether FPDR was practiced. It appeared to be much more difficult to remove a family member who was determined to stay than to prevent someone from entering the room to begin with – particularly within the hospital environment where health professionals traditionally own the space (ownership of the space is discussed later in this chapter).

It's different for a child

The age of the patient significantly impacted patient ownership claims. When the patient was an adult, many health professionals claimed sole ownership and excluded family members from the room; while a smaller number were willing to share or concede

ownership, allowing family members to stay. However when the patient was a child, there was widespread agreement and support for parental ownership of the patient - or at the very least, shared ownership between parents and health professionals. Parental presence during resuscitation was seen as a 'given' and accepted as a 'standard practice' that was expected and encouraged in a way that FPDR for an adult patient was not, as demonstrated in the following excerpt.

> *If we have a child come in, in cardiac arrest particularly, the family aren't ever not in the room … I think obviously the parents are in very much a nurturing relationship with their child already and I don't think we should take them away from that. (Lauren: Doctor)*

Parental claims to the patient were accepted, and at times expected, by health professionals to such an extent that parents who did not exert this claim had their motives questioned.

> *The parents in that particular case, believe it or not they weren't there because they wandered off… they didn't recognise how sick their child was … they'd just wandered off … [in exasperated tone] 'Your child's floppy, where are you?' (Katherine: RN)*

There was a pervasive theoretical acceptance of parental ownership of the child patient in the current study. This acceptance could be explained by the widespread adoption of family-centred care practices over the past three decades in response to the realisation that excluding parents during hospitalisation of a child is detrimental to the child's mental health (Shields 2010). As a result, parents are being increasingly encouraged to stay with their hospitalised child and participate as desired in their care (Power & Franck 2008; Smith *et al.* 2009; Franck, Oulton & Bruce 2012; Macdonald *et al.* 2012). However, as mentioned previously, there was a disparity in the current study between *theoretical support* for FPDR and *actual practice* that needs to be taken into account.

In contrast with the current study, varying levels of theoretical support for FPDR for a child patient have been reported in the literature. Some studies have reported higher levels of support for FPDR for a child than an adult patient (Back & Rooke 1994; Booth, Woolrich & Kinsella 2004; Knott & Kee 2005; Mortelmans *et al.* 2009; Chapman *et al.*

2014). Rationales included the fact that parents were often already in the room and were therefore invited to stay or that staff made special allowances, believing parents have a right to stay with their children (Knott & Kee 2005; Chapman *et al.* 2014). In contrast, several studies found no difference in levels of support for FPDR between adults and children (Baumhover & Hughes 2009), or found that health professionals were less likely to allow FPDR if the patient was a child (McClenathan, Torrington & Uyehara 2002; Kianmehr *et al.* 2010). However, researchers from the latter study cited low comfort levels with FPDR at any age in conjunction with participants' limited experience caring for children to explain this outcome.

The patient's perspective on patient ownership

Thus far I have examined patient ownership claims from a health professional and family member perspective. However, it is important to also consider the patient perspective – something that has not been widely explored due to low resuscitation survival rates and difficulties accessing patients in this unique position.[12] Some health professional participants, like Mandy, spoke about successful resuscitations where the revived patient immediately asked for their loved one.

> We had a gentleman who arrested; he was defibrillated, came round, very positive. But the first thing he wanted was his wife. And that's all he was asking for … [and] she was there! There were lots of tears and lots of hugs and he just wanted to hold her hand and that's all he wanted. It didn't matter what we did to him after that, we could do whatever we wanted, as long as she was there. (Mandy: RN)

While it was important to hear about patient reactions and preferences, learning these from a third party can be unreliable. Ideally, patient experiences should be heard from the patients themselves whenever possible. The following account from Frank provides a unique and often unheard patient perspective in relation to FPDR. Frank suffered four cardiac arrests over several days. His wife Mary (also a participant in this study) was present during one arrest, but excluded from the room during the other three events. While recounting his experience, Frank described lapsing in and out of consciousness

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[12] The low representation from surviving patients in FPDR research was discussed in the preliminary literature review presented in chapter two.

during his resuscitation events. Whenever he was conscious, Frank wanted Mary there with him. Frank was comforted when Mary *was* there (as depicted in the first excerpt below) and distressed when she was excluded from the room (as depicted in the second excerpt on the following page).

> *I was really glad Mary was there. That was very, very important to me. I just thought to myself, I would hate to be doing this by myself … and I can't say that floating in the corner of the room and hearing Mary's voice is what gave me the will to fight … but hearing the voice was reassuring. Do you know what I mean? Because Mary calling out, 'stay with us Frank', I recognised the voice. (Frank: Patient)*

> *I was conscious for a lot of mine [the resuscitation] … and Mary wasn't allowed to be with me… I thought, hell, you're in big trouble here. Then Mary's not there … I thought, if I'm going to go, I'd rather have Mary there holding my hand. Everyone would like to hold the hand of someone dear as they go. But when you're conscious and you haven't got your best mate … that was upsetting. But, I had to accept it. There's nothing I could do about it. I asked for Mary and they said no. (Frank: Patient)*

It is important to acknowledge that one surviving patient's experience cannot and does not represent the views of all resuscitation patients. It was evident from other participants in this study that people have varied preferences and beliefs about whether (hypothetically, as the patient) they would want a family member present during resuscitation. This variation was also seen in the existing literature, as discussed in the preliminary review in chapter two.

However, Frank's experience was similar to reports from the few studies that could be located that explored surviving resuscitation patient experiences and preferences rather than hypothetical scenarios. For example, Mortelmans *et al.* (2010) reported high levels of support for FPDR among patients (72%) and family members (75%) - although, low survival rates meant only 2.7% of these responses were from surviving patients. Similarly, Albarren *et al.* (2009) reported that patients who had been resuscitated were more likely to want to witness a family member's resuscitation, more likely to want a family member at their own resuscitation and more likely to believe family members would benefit from FPDR.

It is important to acknowledge the often absent patient voice in the FPDR debate and explore how their preferences and rights can be considered during decision-making around FPDR. Participants in this study stressed the importance of respecting not only family member wishes but those of the patient. However, gaining patient preferences just prior to or during a resuscitation event is rarely possible because of the unpredictable nature of cardiac arrest and the unconscious state of the patient.

One possible solution could be the inclusion of FPDR preferences in advanced care directive templates in order for people to clearly communicate their family presence wishes during a future resuscitation event. Advanced care directives are life management documents that allow people to plan ahead for situations in which their decision-making is impaired and/or absent, to allow them to live and die with dignity and according to their personal values (National Advanced Care Directives Working Group 2011). The process of completing an advanced care directive involves family discussions which are vital to ensure patient and family preferences are shared and understood. However, a recent systematic review cautioned that there are currently 14 advanced care directive templates available in Australia and many do not comply with the Australian standards (Luckett *et al.* 2015). The inclusion of FPDR preferences into advanced care documents would therefore require careful consideration to ensure that patient preferences would be accurately reflected in all available versions of the document.

CLAIMING OWNERSHIP OF THE SPACE

Space limitations have been regularly cited by health professionals as a barrier to practicing FPDR (see table 2, page 33). However, ownership of the space has not been previously discussed in the FPDR literature. Ownership of the space in the current study referred to individuals or groups claiming ownership of (or authority over) who could and could not enter/remain in the resuscitation space. Resuscitation efforts took place in multiple locations including the home, public spaces, in the back of an ambulance and within the hospital setting. Practices around FPDR differed depending on the space in which the resuscitation occurred and who was thought to own that particular space at that particular point in time.

Registered nurses and doctors were much more likely to successfully claim ownership of the resuscitation space in the acute healthcare (hospital) setting than family members and paramedics. Consequently, they were in a position to authoritatively 'allow' or 'deny' FPDR. These ownership claims began as soon as the patient arrived at the hospital, with many family members directed immediately into a nearby waiting room by hospital staff and paramedics. The language in the following excerpt demonstrates the value some health professionals placed on what they saw as their own space, into which only certain people are permitted.

> *… most of our patients would arrive by ambulance and they've [FMs] all been there already. Paramedic crew don't exclude them from the garage or from the lounge room or wherever this has happened. They've seen it. So I think it's rather precious of nursing staff to say that they need their own, sacrosanct area. (Darren: RN/NP)*

The phrase *'sacrosanct area'* in this excerpt alludes to the 'mystery' of resuscitation that is often perpetuated by health professionals who are protective of their professional space. Similarly, the term *'golden resus doors'* in the following excerpt further exemplifies a sequestered space that staff claim for themselves and exclude 'outsiders' from.

> *If there's family members [who] get through those golden resus doors with the paramedics, someone will just automatically be like, 'oh you can't be here' and turf them out and show them where to go. (Bella: RN/RM)*

The 'outsiders' alluded to previously were family members who did not belong to the health professional group and were therefore not granted automatic access to the resuscitation space. However, not all health professionals made such claims to space ownership. For example, Darren stressed the importance of acknowledging and respecting consumer rights to access space in the hospital setting.

> *Yes I am [aware of being observed] and that is their absolute right … I don't come from a perspective that we have any special rights in a hospital. We are there to serve the community and the community should be able to see what we're doing. (Darren: RN/NP)*

Ownership of the space changed significantly between the pre-hospital and hospital setting. Paramedics, who in the pre-hospital setting practiced FPDR, subsequently excluded family members from the hospital resuscitation room - citing hospital staff expectations and preferences. Paramedics often sought direction from hospital staff and followed their preferences without question, thus conceding ownership of the space to hospital staff in the hospital setting.

> *… we will move the patient over, the nurse will start CPR, ambos out, doctors and nurses in; we have absolutely nothing to do with them after that … [we] let them make that decision, because it's their area. And I guess I would hope they would have the same respect for me, in my area. (Sarah: Paramedic)*

Paramedics respected the professional boundaries between hospital and pre-hospital staff and their language and actions designated hospital staff as the 'legitimate' owners of the space. Paramedics appeared to have a limited role in the hospital setting and withdrew from the resuscitation space once they handed over the patient. Sarah spoke about the potential for paramedics to advocate for FPDR; yet in practice she did not do this, most likely to avoid breaching professional boundaries and ownership claims. Exclusion of family members from the resuscitation space was therefore facilitated by paramedics transporting the patient to hospital, acting on hospital staffs' stated (or unstated) directions.

> *… you just basically get them [the patient] to the resus doors, and then they're [FMs] usually ushered by someone, one of the hospital staff or sometimes a paramedic will take that role and usher them to the waiting room. (Matt: Paramedic)*

> *… that is what the hospital wants us to do and so that's what we do … I will generally ask the nurse 'what would you like me to do with the family member?' and do it that way. (Sarah: Paramedic)*

There were times however, when professional boundaries became blurred in terms of ownership of the space (and also with ownership of the resuscitation act, which is discussed later in this chapter). For example, there were times when the most experienced health professionals (i.e. specialist retrieval team) took charge of the space

in the hospital setting, most likely in an attempt to achieve the best outcome for the patient.

> *… when a MET [medical emergency retrieval] team comes in, we immediately step back. There's a pecking order. We greens [paramedics] would step back from the reds [retrieval team]. We are there to assist them if they require it … but they direct the scene, they took over, in the hospital setting in this instance. And that is because they are emergency specialists. (Helen: Paramedic)*

The previous examples all suggest that ownership of the space is impacted significantly by professional boundaries, role expectations, and levels of legitimate power and authority between different specialties, and between senior and junior staff. These issues are therefore examined and discussed in detail toward the end of this chapter.

Contextual ownership of the space

Ownership of the space varied contextually for some individuals, particularly those who were both health professionals *and* family members. For example, in her clinical leadership role, Carol did not practice FPDR under any circumstances. Yet when her son was critically injured in a road accident and admitted to her workplace, she requested and was permitted access to staff-only areas during invasive interventions. Similar to many others, Carol's perception of ownership of the space changed when the situation became personal to her. Being a nurse *and* a family member, Carol's experience was *different* to general public family members because she felt comfortable in the health professionals' space in a way that general public family members most likely do not.

> *Because I've worked in that area, I knew I could sort of be on this side because I knew they were working over there on the pneumothoracies and putting in chest drains and – they actually had me hold his arm up while they were doing the chest drain. (Carol: FM, Mother & RN)*

Further contextual differences in ownership claims were evident between those made by health professionals in the pre-hospital setting (by paramedics) and those made by health professionals in the hospital setting (by nurses and doctors). Paramedics recognised and respected family members' intrinsic claim to space ownership in their own homes, particularly when that family member had commenced the resuscitation.

> *… when I get there and someone's already doing CPR – how can I say 'please leave, we'll take over now?' Normally, if the person has commenced CPR in the home, they are involved. They're not likely to want to leave. (Helen: Paramedic)*

However, some paramedics claimed ownership of the space even in the family member's own home and even when they had commenced CPR.

> *… often a family member is performing CPR prior to our arrival, so they're actively involved in the resuscitation … if there's someone who's actually doing an OK job we may keep them on the chest until our second crew arrives … once we've got enough hands there, we would then try and actually put one of our people with the family and take them out into another room. (Matt: Paramedic)*

Despite the fact that family members had often been involved in the resuscitation initially, some health professionals excluded them to allow the 'professionals' to take over. In doing so, they claimed ownership of both the resuscitation act and of the space in a setting that is usually owned by family members. This ownership claim was justified by health professionals by focusing on their aim to promote the best possible outcome for the patient, even if that impinged on the family member's preference or right to be present.

In contrast some health professionals, like Sarah, attempted to *control* the space rather than claiming outright ownership. They recognised family members' preferences and rights for FPDR and accommodated them when possible.

> *… if we do it in an outdoor area, then we'll have people hold up blankets and that kind of stuff … if it's someone you don't know then I feel you're invading that person's privacy if you're standing and staring at us trying to save that person's life. But if we're in someone's home, then that's a personal connection to them, and they have every right to be there if they want to be there. (Sarah: Paramedic)*

A double standard often occurred during ownership claims, where family members were permitted into the resuscitation space during a pre-hospital arrest but were then excluded once the patient entered the hospital setting. In the following excerpt, Bella reflected on how this exclusion could significantly devalue the family member's relationship with their loved one and confuse them with contradictory claims from health professionals regarding ownership of the space and the patient.

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Nine times out of ten, these family members are the ones that are there when their loved one collapses, or they find their child drowned in a bath tub or they're the one that starts resuscitating at home … and then all of a sudden they get to hospital and get told, 'no you can't come in.' I think that's really rude and shows a lack of understanding on our behalf … I think at the end of the day it needs to be the family members who are given that option to be able to be there because they've been there the whole way through. (Bella: RN/RM)

Sharing or conceding ownership of the space

Some health professionals were willing to share ownership of the space with family members in the hospital setting, acknowledging that over time there has been an increasing acceptance of family presence during clinical interventions.

But I think more and more we're doing it, more people are open to it now … and I think the families are staying for more and more different procedures. They used to be sort of whisked in, have a look, out you go now; whereas now they're sort of there for a lot of it. (Gemma: RN/RM)

However, even in their own home, family members often conceded ownership of the space to health professionals during a resuscitation event, as shown in the following excerpt.

… you might have this rush of relatives come running into the room real quick and have a look and then rush right back out, and then they all go and huddle together. I think there's this understanding of - well we don't want to interrupt them while they're doing their thing. (Sarah: Paramedic)

The most likely reason for family members conceding ownership of the space is learned deference to health professionals with their associated knowledge and experience (Joseph-Williams, Elwyn & Edwards 2014). Family members thus conceded ownership to avoid being in the way, to achieve the best possible outcome for the patient, to avoid entering a 'sacrosanct' space, and to allow health professionals to work unimpeded.

CLAIMING OWNERSHIP OF THE RESUSCITATION ACT

Claiming ownership of the resuscitation act is closely linked with ownership of the space. Health professionals claimed ownership of the act for varying reasons; some did not want family members to see the complete and inner workings of the resuscitation act but

rather the outer and more presentable 'facade'. In other words, some health professionals preferred to present a sanitised version of resuscitation events to family members rather than the whole (at times what they saw as unpalatable) 'truth'.

> *It's about the person's comfort, the practicing medical person's or nursing person's comfort more than the family member's comfort ... the medical staff, some of them [say] 'not just yet, we've got to do this first and then they can come in'... particularly if things are difficult, you're trying to do a procedure and things are not going straightforward (sic). It's all very well if something's gone 'bang, done', but you don't want a family member to see the person trying to have two or three goes at doing something before it's in ... It's about their [staff] comfort I think. (June: RN)*

Some health professionals did not want to admit family members into their 'sacrosanct' area, preferring to perform resuscitation acts in private. Keeping their work what Anthony referred to as a 'mystery' may serve to maintain an aura of professionalism that some health professionals wish to preserve in order to elicit unreserved trust and be perceived as 'infallible' professionals. This view of health professionals as 'infallible' is supported by Turner (1987), who believes the hospital represents the institutionalisation of specialised knowledge, and as such is a symbol of the social power of the medical profession. However, there are other reasons that health professionals claimed sole ownership of the resuscitation act (and by extension the space). Family members were excluded to protect them, but also to protect health professionals from scrutiny and from family members seeing the 'whole truth' of what they do. These reasons are detailed in chapter nine, under the sub-category 'protecting others and self'.

Health professionals often claimed ownership of the act automatically, without conscious thought of their rationales. When attempting to explain the reasons behind their actions, some health professionals (like Jane) were unable to articulate them clearly.

> *Ah, I'm not sure, I suppose because it's um - ah - I suppose um - they might see it as a - um uncomfortable thing, or um - you know even though - ah - the patient you know would be feeling it, um - I'm not sure exactly but that seems to be common practice that we do, that we do ask people to pop out while we're putting in lines, um and I suppose sometimes it can take a little while, to get all of the appropriate lines in and, and um - you know sometimes it's a little bit of - um*

> *poking and prodding around that, that, you know - that don't, that the family*
> *member, you know, doesn't possibly need to see. (Jane: RN)*

While this account is halting, it is evident that Jane excludes family members from the resuscitation act for two reasons; to protect them from 'graphic' scenes and to maintain the 'facade' that health professionals present by offering a sanitised and controlled version of what they do. Similarly, Neil spoke about how some health professionals try to maintain a 'facade' of care; they perpetuate the mystery that surrounds resuscitation and protect family members from resuscitation scenes - whether they want this protection or not.

> *I think that the traditional mindset that – we do our job and you get the finished*
> *product – or we come out and say, 'really sorry, we've done everything we can, did*
> *you wanna come and see the body?' And I think that maybe there's also an*
> *element where people think that we shouldn't allow the general public to be*
> *confronted [by resus scenes]. (Neil: RN/NP)*

Although the exclusion of family members from the resuscitation act/space was a common occurrence in some contexts, many health professionals challenged the traditional mindset that they should have sole ownership of the resuscitation act. They emphasised that resuscitation has been taught to members of the general public for many years and that increasing numbers of people are being resuscitated by bystanders in the pre-hospital setting.

> *We teach people resuscitation don't we, around swimming pools and for kids …*
> *and I think kids in year 12 get taught how to resus people, so there's a lot more of*
> *it going on in the community. There's been quite a few people resuscitated outside*
> *the hospital by lay people … there's a lot more people doing it, not just nurses and*
> *doctors any more, and ambulance [staff] … (Sally: RN & FM, Sister)*

The resuscitation act is thus no longer seen as the sole domain of professionals within a specific healthcare environment, something that was highlighted by Timmermans more than a decade ago in his writings about the development of universal CPR (Timmermans 1999a). The argument that denying FPDR protects family members from potentially upsetting resuscitation scenes is flawed because many family members had already seen and had sometimes been involved in resuscitation attempts. Some health professionals

maintained that it was neither necessary nor even possible to protect the public from the entire reality of resuscitation. They supported the notion that reducing the mystery of resuscitation can benefit family members by allowing them to see everything possible was done for their loved one, and that staff tried their best for the patient.

> *You always have cases where you'd rather go back and do something else - but I think that's reality. I don't think we should buffer the rest of the world from the reality of what we do - that is the reality of it. If the father wants to be present then I think they should be present to see the process. Otherwise it's a mystery isn't it? You have [an] unknown black box you never get to look inside. There's that comfort in knowing people tried their very best, and that despite that, [the] babe couldn't be resuscitated. (Anthony: Doctor)*

Sharing ownership of the resuscitation act

Many health professionals engaged in a theoretical discussion about the benefits of sharing the resuscitation act with family members; however this did not always translate into practice. Health professionals in the pre-hospital setting were more likely to share ownership of the resuscitation act with family members than those in the hospital setting; not just allowing family to be present, but involving them in the resuscitation, acknowledging their contribution and keeping them fully informed about what was happening.

> *… if they've [FM] been happy enough to do CPR, we'll let them continue until we get another pair of hands … the times I've done it [I've told the FM] 'you're doing a really good job, please continue.' And most of the time they're pretty happy to continue if you've given them that encouragement. I think it's a big thing to be able to say to them afterwards that, because of what you did, you've given the [patient the] best chance to survive, so that's a good thing for them, being part of it. (Sarah: Paramedic)*

Some health professionals in the hospital setting were more likely to share the resuscitation act when family members had already been involved in the resuscitation in the pre-hospital setting. For example, Mandy shared the act with an elderly gentleman who had resuscitated his wife when she collapsed only days into their holiday around Australia.

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He just sort of kept out of the way, watched us do what we had to do. He did ask
some questions afterwards. Because he'd actually been there he could say, oh why
did you do that? He just wanted clarification, because he'd started CPR on his
wife, prior to hospital, so I think he needed to know that he had done the right
thing … he'd done a first aid course prior to his trip, so he'd just learned to do CPR
and then ended up having to use it on his wife. (Mandy: RN)

Mandy supported this man's presence during resuscitation because he had already been involved in the pre-hospital setting; as such he already co-owned the act. For Mandy, excluding him in the hospital setting would have perpetuated the double standard that other health professionals referred to previously, where family members involved in pre-hospital resuscitations were excluded once they arrived at the hospital.

Family members shared ownership of the resuscitation act in various ways. Some did so simply by being there and observing that everything possible was done, while others stressed the benefits of not only being there, but feeling useful.

…and he [the paramedic] said 'you happy to participate, rather than me kicking
you out the room?' So that's when they gave me the drip bag to hold. I thought I
was, you know, 'helping,' in inverted commas, even though it was all too late, I
felt happy to be involved. (Trevor: FM, Husband)

Some family members felt compelled to step in and become involved in the resuscitation act when their loved one was in crisis. For example Mary (a registered nurse) was present when her husband arrested, and helped staff commence CPR.

And then he crashed … I went into nurse mode. Initially I was sitting next to him
but when he started to go off [arrest], I was on my knees on the bed and there
was a nurse on the other side and we elevated the bed - and then because he was
gurgling, I thought, 'oh suck him out.' Then the others came in, masked him. But
anyway, yeah, that's the only time I really went into nurse mode. Then when they
came in, I sort of stood back. (Mary: FM, Wife)

Mary's experience was much more hands on than other family members because she possessed the necessary knowledge and skills to legitimately claim co-ownership of the act and contribute effectively to the intervention. When additional staff arrived, Mary stepped back to allow them to do their job but remained in the room and as such continued to share the act (and the space and the patient) by being present.

THE IMPACT OF POWER, AUTHORITY AND PROFESSIONAL BOUNDARIES ON OWNERSHIP

Ownership of the patient, the space and the resuscitation act was consistently and successfully claimed by health professionals in the current study, which enabled them to make authoritative decisions to 'allow' or 'deny' FPDR. These ownership claims were further legitimised by their expert power and authority. The following discussion examines the relationship between ownership claims, power and authority, and professional boundaries.

Weber (1962, p. 117) provided a general definition of power as *'the opportunity existing within a social relationship which permits one to carry out one's own will even against resistance and regardless of the basis which this opportunity rests.'* Similarly, Waters and Crook's (1989) defined power as an asymmetric social relationship where one person has control and where the subordinate person is dependent on the other person for something they need. Both notions of power were evident in this study, with many health professionals making decisions to claim ownership of the patient/space/act without consultation or input (and sometimes despite competing preferences) from colleagues or family members. In health care, there is traditionally an unequal relationship between health professionals and patients/family members (Kettunen, Poskiparta & Gerlander 2002; Joseph-Williams, Elwyn & Edwards 2014). This is due to a myriad of factors including professional knowledge and expertise and patient/family member reliance on health professionals for a particular service.

Evidence suggests a very close relationship between knowledge and power. Access to a 'scientific' body of knowledge allows health professionals, and particularly doctors, to exert a significant influence on the general public (Freidson 1970b; Turner 1987; Elston 2002). The asymmetrical relationship between health professionals and the public is affected by what Waters and Crook (1989) refer to as 'positional power', whereby individuals have different levels of power according to the roles they occupy. French and Raven (1959) proposed five bases of power; coercive, legitimate, reward, referent and expert. Of these, legitimate and expert power are said to be sources of authority (Lunenburg 2012). Authority in turn is the sanctioned or legitimate power that has been

delegated to an individual within an organisation, and allows them to make decisions and perform role-related functions (Bacharach & Lawler 1980; Mintzberg 1983). In the current study, health professionals used their authority as a source of legitimate power to support their ownership claims.

Professional boundaries also impacted ownership claims; particularly between pre-hospital and hospital staff, between senior and junior staff, and between different professions. Professionalisation is a process undertaken by groups to secure exclusive ownership of specific areas of knowledge and expertise. When health professionals breach professional boundaries (i.e. they are seen to be infringing on another's area of expertise), tensions can arise (Freidson 1970b; Nancarrow & Borthwick 2005).

Some health professionals in the current study relinquished their ownership claims for fear of breaching professional boundaries. For example, Helen worried she was potentially overstepping her boundaries as a paramedic by interacting with family members in the hospital setting, which is traditionally the domain of nurses and doctors. However, hospital staff did not always automatically claim ownership of the resuscitation act. Sometimes the most senior staff member from the pre-hospital setting became the team leader (i.e. a retrieval team). This finding suggests some health professionals claim ownership of the resuscitation act itself, regardless of who 'owns' the space. As such, it appears that owning the resuscitation act in the hospital setting indicates a higher level of authority than owning the resuscitation space.

CHAPTER SUMMARY

Claiming ownership was one of the first processes enacted when a patient required resuscitation and involved claiming ownership or 'being in charge' of the patient, the space and the resuscitation act. Due to their pre-existing, legitimate power and authority, health professionals were able to successfully claim overall ownership with little or no resistance from family members - who commonly deferred to professional authority. Ownership was sometimes shared by health professionals and family members; but only when health professionals invited shared ownership or, uncommonly, when family members claimed ownership by refusing to leave the resuscitation room. Power differentials and professional boundaries impacted ownership claims between different

health profession groups, with doctors and medical emergency teams most commonly claiming ownership of the patient, space and act.

Ownership claims were contextual and enacted when health professionals believed the resuscitation may be effective. In other words, health professionals claimed ownership when they believed the patient could be 'saved'. However, once the patient was deemed un-revivable, the resuscitation act transformed from a life-saving event into a preparation for sudden death, and ownership of the patient was relinquished to family members who were invited to claim their loved one in death.

The subjective nature of ownership claims was evident in the varying attitudes toward FPDR depending on the age of the patient, the status of the family member and past experiences. The outcome of these ownerships claims had a significant impact on the core process of *constructing conditional permission*. Two other major processes impacted these ownership claims and directly influenced whether a family member was present during resuscitation. These processes, *opportunistic presence* and *valuing family presence* are discussed in the following chapters.

Chapter Seven: Opportunistic Presence

CHAPTER OVERVIEW

The previous chapter detailed the first of three processes that initially occurred in relation to FPDR. When a patient first suffered cardiac arrest, the people involved in the resuscitation event went through a process of *claiming ownership* of the patient, the space and the resuscitation act. These ownership claims were influenced by the second process, *opportunistic presence,* which is discussed in this chapter. Figure 6 depicts how the first three major processes are inextricably linked and demonstrates the position of *opportunistic presence* in the substantive grounded theory.
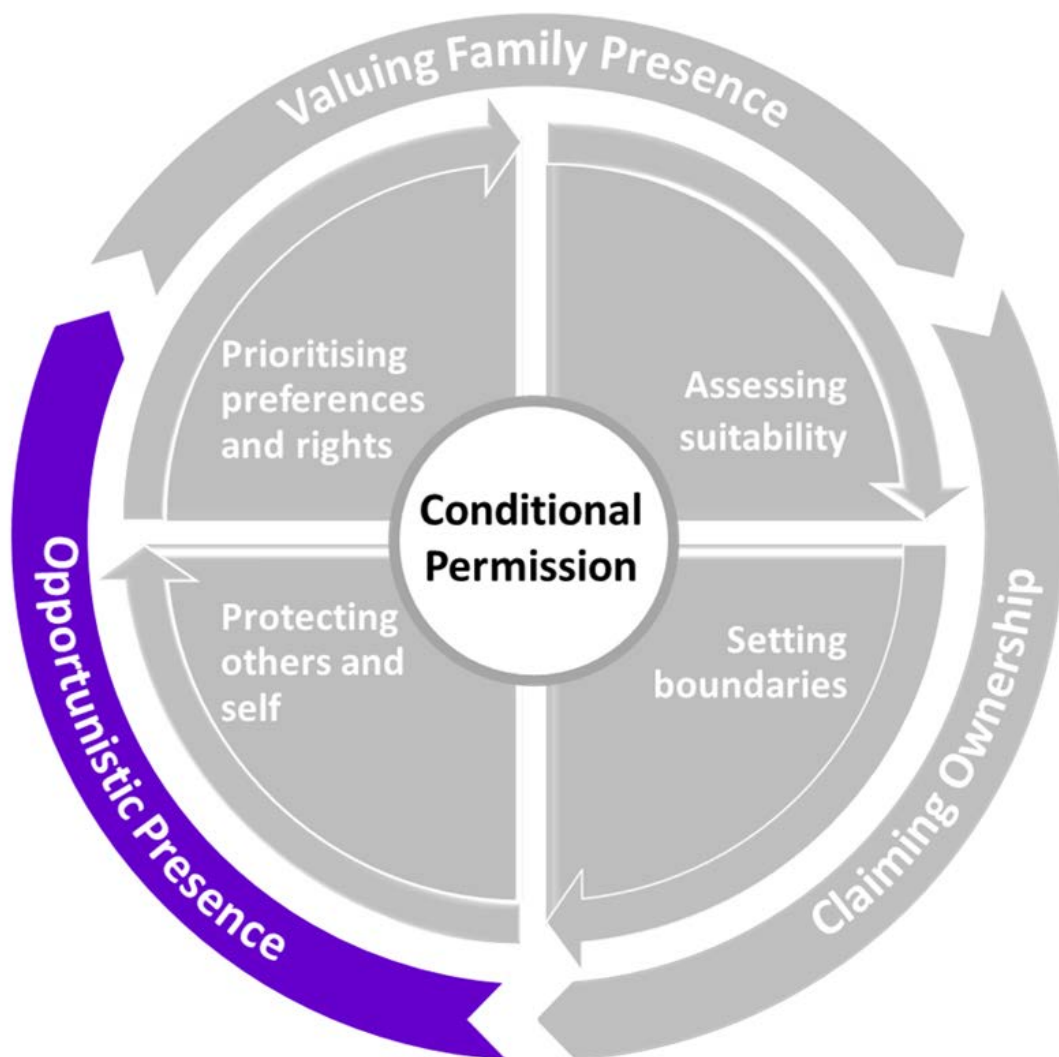
**Figure 6: Opportunistic presence - Initial processes enacted during
a resuscitation event when a family member was in the room or nearby.**

OPPORTUNISTIC PRESENCE

The term opportunistic has been defined as *'making use of immediate opportunities, regardless of planning'* (Oxford Dictionaries 2015). Opportunistic presence in this thesis refers to the process whereby family members were present at some point during resuscitation of a loved one without prior planning, consultation or invitation. Opportunistic presence during resuscitation has not been discussed previously in the literature, and has the potential to help explain inconsistencies between FPDR practices in the absence of formal guidelines. Opportunistic presence also offers an explanation for how seemingly entrenched attitudes toward FPDR can suddenly change.

Opportunistic presence began in two ways; family members were already present when the patient suffered cardiac arrest and required resuscitation, or family members entered the resuscitation room uninvited - either alone or by following staff. For example, family members often accompanied patients when they were transported via ambulance to hospital. When they arrived at the hospital, some family members were directed by staff into a waiting room while others managed to get through what Bella referred to as the *'golden resus doors'* into the resuscitation room. At times, this occurred without staff knowing and they were often surprised to suddenly realise a family member was in the room.

> *… the ambulance crews would bring the patient in who is being actively resuscitated. Some will hold the family and bring the patient in [to the resuscitation room], and some will bring the patient and family in together … I've turned around a few times to find someone standing in the corner of the room. (Darren: RN/NP)*

> *… the family come [in] with the child who's injured or unwell, and somehow they make it into the resuscitation room with you … (Michael: RN)*

Some family members made a deliberate decision to enter the resuscitation room uninvited, hoping they would be permitted to stay. For example, Carol and her husband entered and stayed in the room with their critically ill son through a combination of opportunistic presence and by claiming ownership of the patient.

> *And we just sort of barged in [slight laugh].We just, we were going through, and*
> *when I said something to my husband about that he said, 'well, it's my boy, and*
> *no-one's keeping me out.' (Carol: FM, Mother & RN)*

Family members who were already present in the room when the resuscitation began
were more likely to stay, something that has been mentioned previously in the literature
(Knott & Kee 2005). However, health professional and family member responses to
opportunistic presence varied considerably, and continued family presence during the
resuscitation event was dependant on those responses. The following section details the
circumstances under which opportunistic presence occurred, and how health
professionals and family members experienced this phenomenon.

Rescinding opportunistic presence

Some opportunistically present family members were asked to leave by health
professionals for various reasons (these reasons are detailed in chapter nine). In some
cases, health professionals were following the unofficial but standard practices of their
workplace.

> *… they brought the patient from the acute ward to the ED room. The family*
> *member did follow in, but we very politely, kindly had a support staff member*
> *with that family member [who] took them into a private area and then kept them*
> *updated of what was going on. (Elizabeth: RN)*

When asked to leave, some family members complied without question - conceding
ownership of the patient/space/act to staff as discussed in the previous chapter.
However, along with this acquiescence came a sense of fear and confusion if staff did not
adequately support the family member or explain what was happening with the patient.

> *I walked in through the door, and it was all happening and I was asked to leave. It*
> *was pretty heavy … I think it was a nurse or someone [said] 'you can't be in here'*
> *or something like that … when I was told to I did, yeah, I left the room. And I don't*
> *remember if I hovered in the corridor or what I did after that actually … I think it*
> *would have been good if someone said something to me. I don't believe anyone*
> *did talk to me, so I think I was left in a strange space. Do I stay? Do I go? What do I*
> *do? (Rosy: FM, Daughter)*

While most family members, like Rosy, readily left the resuscitation room when asked, some refused; thus asserting their ownership claims on the patient/space. In some situations where family members refused to leave, staff were too intimidated or lacked sufficient time to assert their requests further, and instead continued working with an uninvited (and sometimes unwanted) observer.

> *… we've had bikies bring in one of their mates, which was always going to be of interest to the police … they wouldn't move, wouldn't leave … there was no-one ever going to change that - short of getting the police up - but we were too busy. (Neil: RN/NP)*

However, it was rare that family members refused to leave the resuscitation room when asked. Instead, most family members followed staff direction without question, often regardless of their personal preference to stay.

Implied permission

Two forms of implied permission were evident during opportunistic presence – deliberate and inadvertent. When implied permission was inadvertent, family members were not asked to leave because health professionals were too busy focusing on the needs of the patient, and in some cases forgot about or did not realise family were present. In most cases health professionals did not regret this inadvertent permission, provided family members did not impede the resuscitation. However, some health professionals stressed that FPDR was not their usual practice and indicated a preference to exclude family members if possible.

> *… if they're already there, that's fine; like I would turn around and say that's fine that you stay, but you do need to keep out of the way. (Mandy: RN)*

> *… because they were there all along and we were trying to fix the problem quickly, we kind of forgot about them and they were there for most of the resus … even after they [the patient] come back they [FM] they were still there … (Jackie: RN)*

In contrast, some health professionals enacted an implied permission that was more deliberate. While they did not overtly invite FPDR, when opportunistic presence occurred these health professionals were aware that family members were present and were happy for them to stay. In other words, some health professionals *allowed* but did not

invite FPDR. Deliberate, implied permission occurred in all settings, but most commonly in neonatal and paediatric settings where parents were often already present.

> *Neonatal resuscitations frequently take place in the delivery room, or operating theatre where [parents] are present … I don't think we ever ask that people be ushered away, so it's not uncommon for the father to be hovering around the edges … it's a consequence of the process rather than a structured thing … It's not actually intended, although obviously in many of the situations we acknowledge there's some urgency and the possibility that the baby will need resuscitation, intubation and perhaps cardiac massage. But having said that … I'm not sure we actually think through that and say 'now what are we going to do with dad when this happens?' It's sort of, just all part of the hubbub I guess, the process. (Anthony: Doctor)*

Overt permission

In contrast with the previous examples, some health professionals actively invited family to stay if they were already present. It was more common for family members to already be present for the resuscitation of a child than for an adult, due to the nature of their nurturing relationship and the fact that most parents accompanied their children to hospital. In addition, parents were commonly (overtly) invited to stay with their child in the resuscitation room.

> *Most of the paediatric resusses I've been involved in … there's usually a parent in the ambulance with them …The parents come [into the resuscitation room] with the child and that's always, it's just how it seems to have happened … whereas with adults and a relative comes in, the relative is usually stopped at the resus door and directed to the waiting room. (Bella: RN/RM)*

While there was widespread support for parents to remain with their children, some health professionals questioned the rationale behind placing a higher level of import on FPDR for children than for adult patients.

> *… you know if we can allow the parents of a three year old child to be here why can't we allow the parents of a 30 year old child to be here. (Bella: RN/RM)*

As discussed previously in chapter two, most of the existing studies that have explored attitudes and beliefs related to patient age reported a higher level of support for FPDR if the patient was a child (Back & Rooke 1994; Booth, Woolrich & Kinsella 2004; Knott & Kee

2005; Mortelmans *et al.* 2009; Chapman *et al.* 2014). However, like Bella, some health professionals in the study by Chapman and colleagues (2014) stressed that parental presence should be used as an example to encourage FPDR for *all* age groups rather than singling out a particular cohort.

OPPORTUNISTIC PRESENCE FOSTERING FAMILY PRESENCE

Health professionals who did not usually practice or support FPDR often allowed family members to remain in the resuscitation room when they were already present. Family members who were already present were also more likely to be actively invited to stay. It may be that health professionals did not feel comfortable asking a family member who was already present to leave, or that the very act of seeing them in the room helped to humanise the patient (humanising the patient is discussed further in chapter eight) and reminded health professionals that family members are an integral part of the patient's life.

> *He [the doctor] hadn't been in our hospital that long, so I'm not sure whether that had been his way before, or whether he felt, because the father was there, that he should ask him [to stay] … he was already there you see, the husband was already in the room so I think he [the doctor] was sort of caught off guard. I mean if he had been saying, um – 'well you can leave now' – it might not have been the right thing to say, at that time. (Sally: RN & FM, Sister)*

> *… we commenced resuscitation while the wife was still there in the cubicle. Quite often in my experience family members are asked to step out to make room for staff members, but in this case … one of our senior nurses approached the wife and asked her if she wanted to leave, and at the same time the doctor who was team leader said, it's ok if she stays … we all seemed to respect the doctor's call that it was ok for her to stay, and also respect the wife's wish to stay. (Jane: RN)*

In the latter example, power differentials between different health profession groups (as discussed in chapter six) impacted the overt permission given to the patient's wife to stay. The senior nurse in this scenario was in the process of asking the family member to leave when the doctor, who was labelled resuscitation team leader by Jane, overrode this decision and invited the wife to stay. This act is closely linked to the ownership claims discussed in chapter six, and suggests that during a resuscitation event, the senior doctor

is often awarded the most legitimate power and authority by other individuals and groups to make decisions around FPDR.

CHAPTER SUMMARY

Opportunistic presence was a process whereby family members were present at some point during cardiopulmonary resuscitation of a loved one without prior planning, consultation or invitation. Opportunistic presence was shown to have a significant impact on family presence during resuscitation and was therefore an important facilitator that has not previously been explored in depth.

Opportunistic presence was shown to impact the ownership claims discussed previously in chapter six, and family members who were already present were much more likely to remain in the room during resuscitation of their loved one. Family members who entered the room uninvited were in effect claiming ownership of the patient; while health professionals who allowed them to stay demonstrated a willingness to share this ownership – even when they would not usually invite FPDR. Health professionals' subjective responses to opportunistic presence varied widely, and it is likely that this variation contributed to large inconsistencies between FPDR practices in the absence of formal or standard guidelines. In particular, the value placed on FPDR appeared to significantly impact staff responses to opportunistic presence. The following chapter thus presents the third process enacted when a patient suffered cardiac arrest in the direct or indirect presence of a family member - *valuing family presence* - and examines the relationship between this and other major processes in the substantive grounded theory*.*

Chapter Eight: Valuing Family Presence

CHAPTER OVERVIEW

Chapters six and seven detailed the first two processes enacted by health professionals and family members in relation to FPDR. When a patient first suffered cardiac arrest, the people involved in the resuscitation went through a process of *claiming ownership* of the patient, the space and the resuscitation act. These ownership claims were influenced by the second process of *opportunistic presence,* whereby family members who were already present or who entered the room uninvited were more likely to be present during resuscitation than those who were not in the room when the resuscitation began. This chapter presents the third process, *valuing family presence,* and discusses the impact of this process on determining whether family members were present during resuscitation. Figure 7 depicts the relationship between the major processes of the substantive grounded theory and highlights the position of *valuing family presence* in the grounded theory.
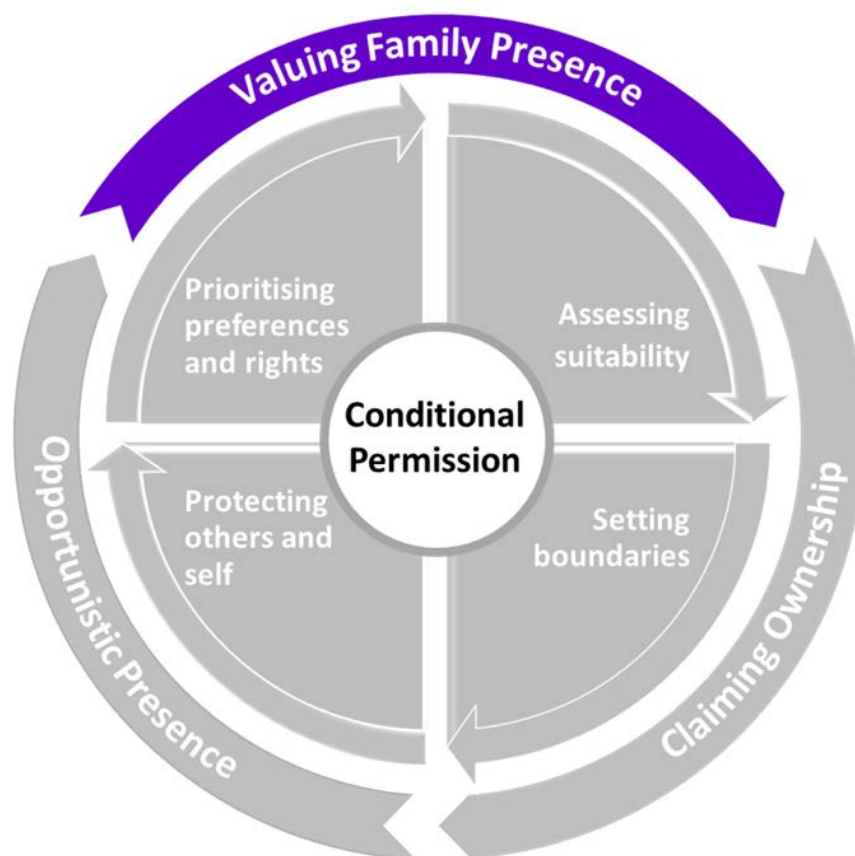
Figure 7 Valuing family presence - initial social processes enacted during a resuscitation event when a family member was in the room or nearby.

VALUING DEFINED

The term value is used in everyday language; yet what it actually means to value something is not often considered explicitly. Put simply, the value of something is its relative worth, merit, or importance. *Valuing* something, then, is to consider something to be important, useful or worthwhile (Oxford Dictionaries 2015). Seidman (2009) proposes that valuing something simply means caring about it; while Watson (2004) claims that a person's *actions* are reflective of what they most value. This latter view fits within a pragmatic view of society (as discussed in chapter three) in which the truth or meaning of something can be determined more by its observable practical consequences than its theoretical meaning (Barbalet 2009). Watson's view also supports the symbolic interactionist and social constructionist perspectives of this thesis, which considers that 'meaning making' largely shapes action or inaction (Blumer 1969; Guba & Lincoln 2005). This chapter describes and interprets participants' meanings and actions in relation to the value they place on FPDR.

VALUING FAMILY PRESENCE DURING RESUSCITATION

The extent to which people valued FPDR was interpreted through both their language and their actions. Most participants spoke about the benefits of FPDR, and stressed family members' inherent right to be with their loved one. In most cases, the value a person placed on FPDR verbally was also reflected in their actions. For example, participants who claimed to value/care about FPDR were much more likely to advocate for and strive to ensure family members were present during resuscitation of their loved ones, and vice versa. To illustrate this point, consider the following experiences from Darren and Jackie.

Darren is a nurse practitioner who works in the ED of a major metropolitan hospital. While this ED did not have a formal policy,[13] their standard practice was to allow and invite FPDR. Darren shared both positive and negative experiences, but maintained that the overall benefits of FPDR far outweighed any potential risks or barriers. When asked why he thought some health professionals worked to overcome barriers while other appeared to use those same barriers as a reason to deny FPDR, Darren replied;

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[13] None of the healthcare settings included in this study had a formal FPDR policy or guidelines.

> *I guess it depends on how much you value the presence of the family member.*
> *How important is it? To me, really we are just passing briefly through these*
> *people's lives, and it's the person that's been with them all their life, often for*
> *many years, who has far more rights. We're really just a team, trying to stave off*
> *death. Sometimes we win, sometimes we don't. But we don't want to leave any*
> *more debris than we have to … I think our role is not only to resuscitate the person*
> *but to help the family through that. (Darren: RN/NP)*

Darren's account is symbolic of the high value he placed on FPDR and on the inherent right of family members to be with their loved ones. By providing multiple examples of inviting FPDR in practice, Darren actions further supported the spoken account of his views. A symbolic interactionist/social constructionist perspective of Darren's meaning making suggests he valued FPDR highly, which in turn influenced his everyday practice.

In contrast, several participants appeared to place a low value on FPDR. For example, Jackie is a registered nurse who, like Darren, works in the ED of a metropolitan hospital. Jackie's ED does not have a formal policy, but their standard practice is to deny FPDR. Despite this, Jackie had experienced several instances of FPDR – both as a result of opportunistic presence (a detailed account of opportunistic presence was presented in chapter seven). Jackie's language indicated a fluctuating value placed on FPDR depending on the context. For example, Jackie cited multiple risks and barriers as a reason to deny FPDR. However, when asked if *she* would want to be present during the resuscitation of one of her loved ones, Jackie stressed that she would and listed several benefits to justify why she should be given special permission based on her nursing status.

> *Yeah, I would want to be present … I can't imagine not being there … If I was*
> *asked to leave I would tell them, I'm a nurse. There's nothing you're doing I*
> *haven't seen before. I'd probably be of help to you … I know my dad pretty well; he*
> *would be happy for me to be here. You know, I could be helpful in some way,*
> *some questions that you might need to ask … I would be saying all of these things*
> *to make sure I could stay. (Jackie: RN)*

Apart from wanting FPDR for herself, Jackie's language mostly indicated a low value placed not only on FPDR, but on family members' rights to presence in general. In the following excerpt, Jackie equated *'a very good day'* with excluding family members from the resuscitation room. The low value verbally expressed by Jackie was further reinforced

by her actions, because in her workplace all family requests for presence were denied. The only exception to this was when family members were already in the room and staff had forgotten about them (opportunistic presence).

> *That was why I think they had a chance of being there coz (sic) on a very good day*
> *no way. We never have family members present for resus … (Jackie: RN)*

Darren and Jackie's accounts represent widely opposing views in terms of the value placed on FPDR. However, they both exemplify the strong link between *valuing* FPDR and *practicing* FPDR evident among all participants. A similar link was reported by Fischer *et al.* (2008), who found that nurses who believed family presence was important were more likely to include them in daily care in a general hospital setting. Fischer and colleagues went further to suggest that family-centred care could be enhanced by providing appropriate education to staff around the value of family presence, something that was also raised by several participants in the current study.

The link between *valuing* and *practicing* family presence however was not always straight forward, and several participants who claimed to value FPDR did not practice it regularly. For example, Carol did not practice FPDR despite her verbal support for the practice, and despite valuing being present as a family member during her son's resuscitation.

> *I think they [FMs] should be given a choice … [but] it's not something I've thought*
> *about. As the manager of the [specialty setting], I do feel for the families that are*
> *following the patient to that cut off zone and then they're just sort of in the*
> *corridor … and they're just sort of left there. (Carol: FM, Mother & RN)*

Despite finding the exclusion of family members 'sad' and despite her senior position as a clinical manager, Carol made no attempt to advocate for FPDR in her workplace. It was evident that some participants who claimed to value FPDR in theory were restricted from practicing it due to external influences such as organisational norms or being overridden by more powerful individuals or groups. The relationship between valuing FPDR and power was therefore an important factor to consider, and is discussed later in this chapter.

Many participants demonstrated the high value they placed on FPDR by citing multiple benefits, which have been summarised in table 7. These benefits have been reported previously in numerous national and international studies (see table 5, page 35), suggesting that the multiple benefits reported in this study reflect a widespread, multinational societal view.

Table 7: Perceived benefits of FPDR reported in the current study

Benefits	Details
Demystifying resuscitation for family members	Seeing/knowing what is happening Seeing/knowing that everything possible was done for the patient
Preparing family members for death	Knowing the prognosis Helping family members accept the death of their loved one
Facilitating grieving and closure	Providing a chance to say goodbye Allowing family members to 'be there' at the end
Enhanced communication between staff and family members	Staff being able to explain what's happening Family members being able to ask questions Family members providing information/history about the patient Promoting open disclosure
Involving family members in the resuscitation	Feeling useful/helpful Knowing and imparting the patient's wishes Being involved in the decision to stop resuscitation Feeling comforted by being there Providing comfort and support to the patient
Family members protecting / advocating for the patient	Wanting to be there for the patient Not wanting the patient to be on their own with strangers Ensuring a good death Patient wanting someone they know in the room Patient being comforted by their family member's presence
Enhancing staff – family relationships	Family members thanking staff for their efforts Allowing family members to see that staff care and are human Staff being able to support family members
Enhancing the overall resuscitation experience	Personalising / humanising the patient Promoting staff professionalism

In this study, the higher the value participants placed on FPDR, the more benefits they listed in relation to perceived risks or barriers (which are discussed later in chapter nine)

and the more likely they were to practice FPDR. The most commonly cited benefits were that family members could see what was happening and know that everything possible was done for the patient. FPDR was also said to help prepare the family member for impending death and facilitate grieving and closure. The most poignant accounts were those describing the very personal impact of family presence;

> *… she was sitting by her husband's side and holding his hand. That just really struck a chord with me … it didn't matter how many times we tried to defibrillate him or give him different kinds of drugs or how much medical support we were giving him. That was lovely to see; his wife sitting and holding his hand, squeezing his hand, and talking to him throughout [the resuscitation]. (Jane: RN)*

All participants provided first-hand accounts of how valuable it was for family members to be with their loved one in order to say goodbye and gain closure. Frank provided a unique patient perspective when he spoke about how comforting (valuable) it was for him to have his wife Mary in the room during his resuscitation.

> *I could hear Mary saying, stay with us Frank. I can't say that floating in the corner of the room and hearing Mary's voice is what gave me the will to fight … but hearing the voice was reassuring. Do you know what I mean? If I'd kept going it would have been the last words I heard coming from my wife. (Frank: Patient)*

Some health professionals spoke passionately about the value of FPDR in terms of personalising and humanising the patient, while at the same time enhancing staff professionalism. These factors have been cited previously in the literature (see table 5, page 35) and are hailed as a significant benefit of FPDR (Timmermans 1997, 1999a, 2005; Ellison 2003).

> *I feel the team works better when family are there. When family aren't there sometimes they [staff] become a bit unprofessional. You know, you talk about other things, and you might have a laugh or a joke. But [when FMs are present] everyone's a bit more respectful to each other … there's not as much shouting or yelling … everyone actually performs better because you're reminded that it's a real person. (Grace: RN)*

Other health professionals spoke about the value of FPDR in terms of being able to improve end-of-life care for patients and their families. Similarly, sociologist Stefan

Timmermans refers to the 'sudden death' of failed resuscitation as an opportunity to promote quality end-of-life care for family members who were usually denied access to their dying loved ones (Timmermans 1996, 1997, 1999a, 2005). Timmermans (1999a) further argues that the very low resuscitation survival rates evident worldwide should form the impetus to refocus many resuscitation attempts into an opportunity to support and prepare family members for impending death rather than as a medical failure to save an un-saveable patient. Smith (2000) agrees with this view, adding that if death is seen as a failure rather than an integral part of life then we cannot adequately prepare for it and health professionals cannot give the attention they should to helping people die a 'good death.'

As mentioned in the preliminary literature review, multiple benefits of FPDR have been published over several decades and many people have expressed a desire for FPDR. In addition, the practice is supported and recommended by many national and international resuscitation bodies including the Australian Resuscitation Council (ARC 2012b), European Resuscitation Council (Baskett, Steen & Bossaert 2005) and the American Heart Association (Morrison *et al.* 2010). Further, many experts agree that FPDR is vital to ensure the provision of quality end-of-life care (Timmermans 1999a; Casey *et al.* 2011; Williams *et al.* 2012).

Yet in the current study, FPDR appeared to be significantly impacted by the subjective value placed on the practice by individuals rather than being guided by evidence, or by standardised protocols and guidelines. As a result, FPDR was not practiced consistently and many family members missed potential benefits based on personal preferences and setting norms. The dangers of health professionals imposing their personal values on what they believe constitutes a 'good' death have been raised previously (Borbasi *et al.* 2005). It is important then to consider not only what these values are, but how they change over time in order to make recommendations about the most effective way to influence current and future clinical practice.

CHANGING VALUES OVER TIME

Simply being exposed to FPDR was an important way for health professionals to begin changing their attitudes and values. Some health professionals also valued FPDR more

highly after accessing evidence supporting the practice - a finding that is supported by previous literature (as detailed in chapter two) that links education and experience to higher levels of FPDR implementation. However, as Bella highlighted, despite evidence supporting the benefits of FPDR, it is still not commonly practiced in many Australian healthcare settings.

> *… we live in this day and age of evidence-based practice, and all the evidence out there about family presence during resuscitation is positive. But it's still something that doesn't happen … at the end of the day, you're doing what's in the best interest of your patients and their loved ones … why, in that most critical tipping point in someone's life, where they're on the edge of life and death, would you all of a sudden not do what's in the best interest of the patient or relative? (Bella: RN/RM)*

The value attributed to FPDR was therefore based on *more* than evidence and past experiences. Personal experience combined with increased *confidence* could also improve the likelihood of FPDR. In addition, a philosophical approach to death and dying - where participants believed that death was part of life - also appeared to impact FPDR practices. Some attitudes had changed over time to the extent where FPDR was practiced consistently in certain healthcare settings and seen as a 'normal part' of the resuscitation process.

> *I think that family presence is part of the resuscitative process; it's just a bit different than it was before we had family presence. (Darren: RN/NP)*

> *People are quite comfortable with it now and it's sort of more the norm to have family members present; particularly for children but also for adults. (Michael: RN).*

In these examples, family presence appeared to be a 'given' or 'the right thing to do' for those involved, once again highlighting the link between valuing FPDR and practicing it. However, what was not as clear is why some people place more value on FPDR than others to the extent where they practice it as part of their usual routine.

This divergence in values (and subsequent practices) could be due in part to existing procedural 'norms' in individual healthcare setting – where new and existing staff members interpret the actions they see around them and then act based on their

interpretations of those actions (McCall & Simmons 1966; Blumer 1969; Meltzer, Petras & Reynolds 1975). In other words, health professionals interpret setting norms and accepted practices through their interaction with others. If FPDR is accepted as standard or usual practice, new staff members are likely to 'join in' to be accepted into the group, and vice versa.

However, while some people will uphold institutional rules and become enculturated into setting norms, others will oppose these rules and norms. The activities of others can therefore become a positive or negative influence that compels people to review and then either intensify or discontinue their own actions as a result (Blumer 1969). For example, June's workplace does not have a formal protocol and has always denied FPDR as standard practice. Existing and new staff tend to continue this practice because *'that is the way it's always been done'* (June: RN). Despite valuing FPDR, June felt powerless to change what she viewed as an embedded workplace culture because she believed her view was in the minority.

> *… you have to have a large number of people with the same ideal, the same value of it. Because if you've got a large group of people and only a tiny minority value it [FPDR] you have a huge group of people who are absolutely adamant about it, that's it's never gonna happen – you're not gonna change that attitude … they're never gonna change – and you've gotta accept that. (June: RN)*

However, it is important to understand that a setting norm that seems fixed or stable only appears that way because the everyday actions of health professionals are defined, interpreted and consciously acted upon within the group in order to construct that observed stability (McCall & Simmons 1966; Blumer 1969; Meltzer, Petras & Reynolds 1975). If the setting norm were to become re-interpreted (for example, questioned by a health professional who practiced FPDR in a previous workplace, or who undertook research or education into FPDR) then this opens up the possibility of individuals and groups changing their ideas - and in turn their actions. The key to challenging long held beliefs and practices around FPDR is therefore to provide information, education and positive role modelling around the multiple benefits (the value) of FPDR for family members, patients and health professionals (Byrne & Heyman 1997).

OVERCOMING BARRIERS

In addition to the benefits discussed previously, multiple barriers and risks to FPDR have been cited over the past few decades. While some barriers/risks are based on actual experiences, most centre on personal perceptions and fears of what *might* happen rather than what has actually occurred. The barriers/risks reported in this current study echoed those in the existing literature (see tables 2 and 3, page 33-34). However, this study also builds on that evidence to suggest that people who *valued* FPDR were much more likely to generate ways of overcoming any barriers/risks, while those who did not value FPDR used those same barriers/risks as reasons to deny FPDR.

For example, a common barrier reported by health professionals was a fear of being judged by family members observing the resuscitation. However in practice, most health professionals were too focused on the patient to be concerned with who was watching them. Often the fear of being judged was related to low confidence or competence levels, or fear of making a mistake in front of family members. Participants who did not believe it was valuable subsequently denied FPDR; while those who valued the practice offered suggestions to minimise barriers, such as ensuring resuscitation staff were adequately trained and competent.

RELATIONSHIP BETWEEN VALUING FAMILY PRESENCE AND POWER

As mentioned previously, there was a strong link between *valuing* and *practicing* FPDR. However, simply valuing the practice was not always enough to ensure it was implemented. People's actual or perceived power was also a major influence on FPDR practices. The impact of power and authority on ownership claims was discussed previously in chapter six. In essence, due to their professional status, health professionals were much more likely to successfully claim ownership of the patient and the resuscitation space than family members. They were subsequently in a position to authoritatively 'allow' or 'deny' FPDR. However, what also needs to be considered is the relationship between the real or perceived power a person has and the extent to which they value FPDR - and how that relationship impacted clinical practice.

The analytic matrix presented in figure 8 (see page 139) depicts the relationship between actual/perceived power and the value placed on FPDR during decision-making. Each

quadrant represents a different power/value ratio for both health professionals and family members which are discussed in the following sections.

High value high power

A high value - high power ratio provided the greatest likelihood of FPDR occurring in clinical practice. When most or all health professionals in a particular setting valued FPDR, their legitimate power and authority supported that view and allowed them to implement FPDR with minimal or no resistance. For example, Darren worked in a setting where senior staff members were all supportive of FPDR. The high value Darren placed on FPDR was therefore supported by the legitimate authority (as discussed in chapter six) of senior nursing and medical staff in his work setting.

> *Nearly all the staff are supportive of the practice, I don't know that anybody has been overtly opposed to it. We have a defined team leader who's usually an emergency physician, and the decision is ultimately made by them. All the emergency physicians are supportive of it here, so they would be the ultimate arbitrator I guess. (Darren: RN/NP)*

		Level of actual/perceived power	
		HIGH POWER	**LOW POWER**
Value placed on FPDR	**HIGH VALUE**	Staff more likely to advocate for FPDR and more likely to override opposing views from other staff Family members more likely to *want* to stay/more likely to insist on staying even if denied initially by staff	Staff more likely to advocate for FPDR but less likely to override staff who did not support/want FPDR Family members more likely to *want* to stay but less likely to insist on staying if initially denied by staff
	LOW VALUE	Staff less likely to advocate for FPDR and more likely to gain the outcome they desired – i.e denying FPDR because they did not value it Family members less likely to *want* to stay, less likely *to* stay even if initially invited by staff or expected to stay	Staff less likely to advocate for FPDR but also less likely to override opposing views from other staff who supported FPDR and wanted family to stay Family members less likely to *want* to stay, *more* likely *to* stay if asked to because they felt powerless to refuse

Figure 8: Analytic matrix: the relationship between actual/perceived power and the value placed on FPDR during decision-making.

High value low power

When people placed a high value on FPDR, yet had low actual/perceived levels of power to support their values and preferences, the likelihood of FPDR occurring was lower than in the previous scenario. In particular, junior health professionals who valued FPDR were quickly overruled by more senior staff who exerted their legitimate authority to gain their preferred outcome of denying presence.

> *… some of the junior staff who've got very little perceived power and very little ability sometimes to have a voice, but really do value it and see that it's been used in other places and it's worked in other places, and [they] have suggested 'why don't we do that?' And it's, yeah, it doesn't happen … for some staff, it's all about power, full stop. I'm in control, I'm going to say what happens, and I'm going to disregard everybody else's beliefs or values. (June: RN)*

June's example illustrates what many other health professional participants shared about the difficulties of changing clinical practice in the face of competing preferences and values from more senior staff. June was a very senior registered nurse in a major metropolitan ED, and valued FPDR highly. Yet, the only time she practised it was when opportunistic presence was supported by more senior staff. In other words, people with the most legitimate power were (almost) always more likely to gain their desired outcomes than those with less power, even if they valued FPDR highly. The only exception to this was when a family member valued FPDR highly, and stayed with the patient despite being asked to leave by staff, as recounted by Mandy.

> *… one of the other staff did turn round and say to her, 'I'm sorry but if you're not going to settle down you're gonna to have to leave' … and she basically turned around and told us that she would have to be removed by the police because she wasn't leaving her daughter. (Mandy: RN)*

In this situation, the family member refused to leave the room and as such, claimed ownership of the patient and setting. However, very few family members actually disregarded health professionals' direct requests to leave the room. In fact, most family members in this situation allowed staff to override their strong desire to stay and left the room when asked, or did not try to enter the room to be with their loved one. However, when asked if they would want to be present for the hypothetical resuscitation of a loved

one, most participants stressed that they would want to and detailed how they would 'fight' to remain in the room to be there for the patient - highlighting once again the difference between peoples' ideologies and their actions, the latter of which are impacted by social conventions and power relationships (Charmaz 2014).

The only surviving resuscitation patient in the study spoke about how upsetting it was to ask for his family member to be present, only to have his wishes disregarded.

> *And I'm thinking, I'm in real strife here. But I thought, if I'm going to go, I'd rather have Mary there holding my hand. Everyone would like to hold the hand of someone dear as they go. But when you're conscious and you haven't got your best mate … that was upsetting. But, I had to accept it. There's nothing I could do about it. I asked for Mary and they said no.' (Frank: Patient)*

In this situation, Frank felt powerless to insist his wife be there with him, despite the high value he placed on her presence.

Low value high power

As mentioned previously, health professionals who did not value FPDR were much less likely to practice it. Within this category of low value high power, health professionals with more legitimate power were able to override other staff preferences.

> *… one staff member was absolutely adamant against it, and that overrode the team's wishes … [They] just did not believe in it … they were the more senior person so the team went along with their wishes. (June: RN)*

> *Usually the outcomes are regarding who the most assertive is at the time, and if they're really, you know 'they need to go out' - you think, oh this isn't the time to argue with this … We've had discussions at the desk after to say … why did they have to leave … if they're not in the way, if they're not obstructing any of the management we're trying to instigate – um yeah but usually it's whoever screams the loudest will usually get it [their way]. (Gemma: RN/RM)*

Hypothetically, family members in this category did not value FPDR and were less likely to want to remain in / enter the room and less likely *to* stay even if initially invited by staff or expected to stay. However, there were no actual examples of family members within this category in this study.

Low value low power

Health professionals in this category attributed a low value to FPDR, but due to their low actual or perceived power/authority they were unlikely to override the directives of more senior staff members who implemented FPDR. Family members in this category were less likely to *want* to stay but were *more* likely *to* stay if asked to by staff because they felt powerless to refuse. This latter finding highlighted the importance of offering options and supporting choices regarding FPDR. Not all family members wanted to be present for a variety of reasons (refer to the sub-category 'prioritising preferences and rights' in chapter nine), as demonstrated by the following account from Elizabeth – who felt pressured to be present with her husband in her own workplace, against her personal preferences.

> *… he had a heart problem and he came into the hospital and because of conflict of interest, I left … I didn't want to go into the room. But, his pain came back and he was really in a lot of pain. So he requested that I go into the room and I did. I felt a little bit uncomfortable … because I am a senior person, I work in the hospital. But, the staff member called me and said they wanted me to be at his bedside and I did go and stand there and hold his hand and stayed there … I didn't want to interfere in anything, I didn't want to put any IV up or anything because that's their call … there's a nurse and there's a doctor and I would just be a family member.*
> *(Elizabeth: RN)*

While Elizabeth's account was in the minority (most participants wanted to be present for the actual or hypothetical resuscitation of a loved one) it is important to acknowledge different preferences and support individual choices. From her account, it initially appeared Elizabeth was worried she would be asked to perform nursing interventions on her husband, something that has been reported previously by family members who are also nurses (Salmond 2011; Giles & Hall 2014; Giles & Willamson 2015). As such, a discussion with staff may have reassured Elizabeth that she could be present *just* as a family member. However, as the interview continued it became apparent that Elizabeth was more concerned about her own reaction to the resuscitation and the potential long term emotional effects of being present, despite acknowledging that her presence would have comforted her husband.

> *I think it was more as a support, knowing that I was present. I think he felt more secure because he probably thought something was going to happen to him … but I, really speaking, if he was really going to go to CPR, I wouldn't have stayed in that room … I think it would have affected me emotionally. I would have witnessed this whole thing and it would've been traumatic for me … later on in days or weeks or months, it'd always be on my mind. (Elizabeth: RN)*

Elizabeth's account indicates a low value placed on FPDR in combination with a low perceived level of power. As such, Elizabeth allowed herself to be directed into the room against her wishes. Elizabeth's example is a reminder for health professionals to ensure the preferences and rights of all people involved in a resuscitation event are considered to ensure the delivery of safe and effective family-centred care.

CHAPTER SUMMARY

This chapter interpreted participants' meanings and actions in relation to the value they placed on FPDR. In addition, the relationship between three major processes, 1) claiming ownership, 2) opportunistic presence and 3) valuing family presence was examined; both in relation to each other and to the core substantive theory.

The value placed on FPDR was one of the most important factors influencing its practical implementation. This value sometimes changed over time in response to past experiences, education, confidence, role modelling and organisational norms. People who valued FPDR were more likely to cite multiple benefits and fewer risks, and more likely to overcome any barriers to ensure family members could be with their loved one during a resuscitation event. Conversely, people who did not value FPDR were more likely to focus on perceived risks and barriers, and use them as rationales to exclude family members from the resuscitation room.

However, the link between valuing FPDR and practicing FPDR was not straightforward and the interplay between valuing FPDR and actual/perceived power to enforce one's values was an important consideration. Due to their professional status and subsequent expert authority, health professionals were in a position to authoritatively 'allow' or 'deny' FPDR. Furthermore, health professionals in the most senior positions were seen to be in charge of permissions. As a result, the value placed on FPDR by the most senior members of the

healthcare team were those most likely to impact clinical practices in a particular setting. In other words, senior health professionals who valued and wanted to practice FPDR were able to defend their personal, subjective preferences with their legitimate power and authority. In the same vein, senior health professionals who did not value FPDR were able to exclude family members without resistance from more junior members of the healthcare team.

The impact of subjective, value-laden preferences became evident when discussing the relationship between valuing FPDR and practicing FPDR. While health professionals had the legitimate power and authority to take control of 'permissions' around FPDR, family members also played an important role in *the social construction of conditional permission*. The following chapter provides an in-depth discussion of the value-laden judgements made by health professionals and family members in relation to FPDR. These judgements were; 1) prioritising preferences and rights, 2) assessing suitability, 3) setting boundaries, and 4) protecting self and others.

Chapter Nine: Making Value-Laden Judgements

CHAPTER OVERVIEW

The previous three chapters detailed the way in which decision-making around FPDR was initially influenced by three interrelated processes; *claiming ownership*, *opportunistic presence* and *valuing family presence*. While these processes were being enacted, the people involved in the resuscitation event also made a series of value-laden judgements during *the social construction of conditional permission*. Chapter nine details these value-laden judgements in relation to four interconnected properties of the substantive theory; 1) prioritising preferences and rights, 2) assessing suitability, 3) setting boundaries, and 4) protecting self and others. Figure 9 depicts the interconnected nature of these value-laden judgements and their position in the grounded theory.
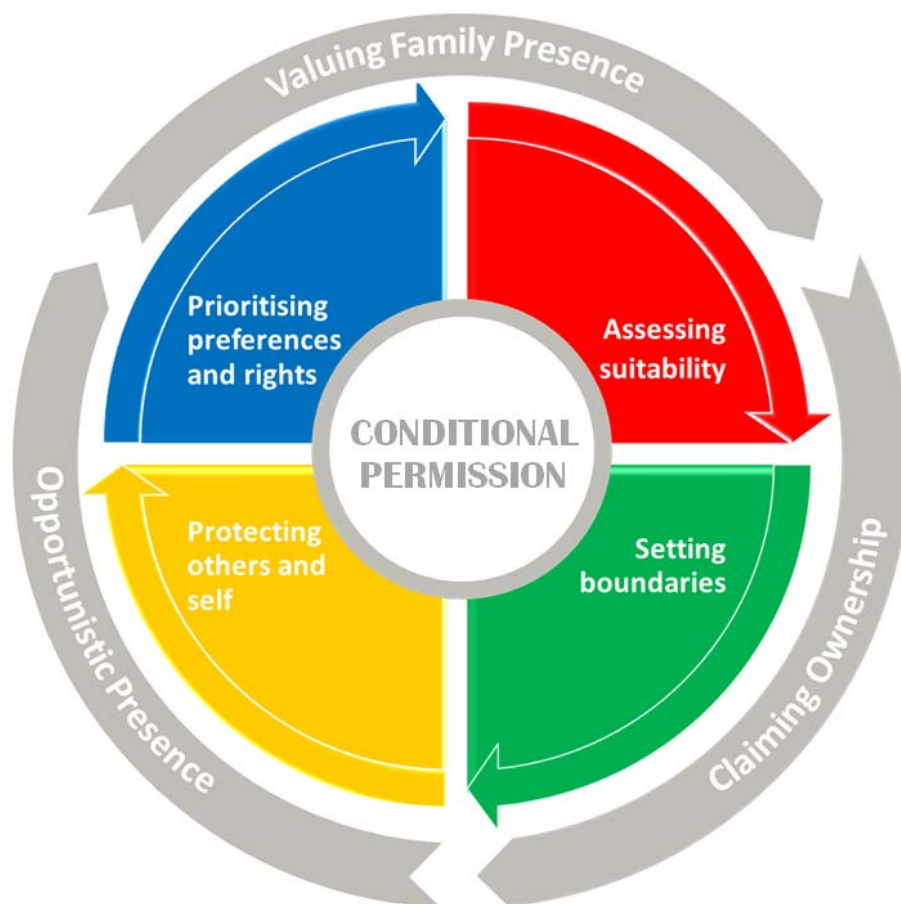
Figure 9: The value-laden judgements enacted as part of the process of constructing conditional permission for FPDR

MAKING VALUE-LADEN JUDGEMENTS

The value-laden nature of clinical decision-making has been discussed extensively in the literature (Clemens & Hayes 1997; Guyatt *et al.* 2000; Nelson 2004; Aulisio & Arnold 2008; Hearns *et al.* 2010; Klein, Trousdale & Ulrich 2010; Kon 2010; Johnson *et al.* 2011; Goldenberg 2013), with particular emphasis on the subjective nature of these decisions. Decisions about end-of-life care are commonly reported to be intrinsically value-laden, and questions have been raised previously about whose values should have most impact on decisions taken (Oberle & Hughes 2001). However, value-laden decision-making has not been previously discussed in relation to FPDR and the term 'value-laden' has not been adequately or consistently defined, with many authors using the term without clarification.

Several existing definitions were considered when delineating the value-laden decisions discussed within this thesis. I subscribed to Beresford and Sloper's (2008) claim that people who are impacted by a particular decision-making problem will frame that problem differently from others depending on their personal values and beliefs. In addition, I noted Frick's (2009, p. 51) definition of values as *'motivated preferences [or] conceptions of what is desirable, in personal or collective terms, that influences the selection of available modes, means and ends of action.'* For the purpose of this study, value-laden judgements were considered to be decisions that were influenced by a person's inherent beliefs and preferences and the extent to which they valued FPDR.

The value-laden nature of the judgements made when constructing conditional permission for FPDR was evident throughout all stages of the decision-making process – including the three interrelated processes discussed in chapters six, seven and eight. The value-laden nature of decision-making in relation to FPDR is now presented in detail in relation to four interconnected properties of *conditional permission;* 1) prioritising preferences and rights, 2) assessing suitability, 3) setting boundaries and 4) protecting self and others.

PRIORITISING PREFERENCES AND RIGHTS

Following the processes of *claiming ownership*, *opportunistic presence* and *valuing family presence,* individuals and groups enacted a process of prioritising the preferences and

rights of people involved in a resuscitation event. Because the patient was unconscious, these judgements were made by family members and health professionals – but mostly the latter due to their previously successful ownership claims (as discussed in chapter six).

At the core of this prioritisation process were judgements about whose preferences and rights should take priority – patients', health professionals' or family members'. The subjective nature of these judgements caused a wide variation in practices and rationales for prioritisation in the absence of any formal guidelines. Several examples of prioritising preferences and rights are presented in table 8.

Table 8: Examples of the prioritisation undertaken by and about health professionals, family members and patients when constructing conditional permission for FPDR

Participant	Example of prioritisations
Health professionals	- Staff preference often prioritised over family members' due to professional judgement and authority - Projecting own preferences onto the family member / patient - Considering the benefits and risks of FPDR - Considering who FPDR is for
Family members	- Inherent right to be with their loved one - Allowing staff to work unimpeded - Recognising individual preferences regarding FPDR
Patients	- Focusing on saving the patient's life - Protecting patient privacy / confidentiality - Asking patient preferences prior to/ after resuscitation - Only wanting certain family members present - Staff and family members believing they know what's best for the patient

The most common prioritisations were focusing on saving the patient and wanting staff to be able to work unimpeded. However, the outcome of this prioritisation differed according to the value placed on FPDR. For example, health professionals who valued FPDR spoke about the inherent right of family members to be with their loved ones during resuscitation. These health professionals were able to create a balance between prioritising patient care and supporting family members who were present to ensure the resuscitation was unimpeded. However, some health professionals seemed to prioritise their own needs above family members and excluded them from the room based on a

personal preference to not be observed. Further, family members allowed this prioritisation to occur, most likely due to their high regard for professional status.

> *I think still there is a sort of deity thing with doctors, and their rights, and what they're doing is more important that what anybody else is doing … I think it's Australian society, that doctors are here [holding hand high in the air], and he is god like and he will be able to fix this. That's why they accept the fact that, well he's doing something wonderful so I'll just leave, and let him do his work.*
> *(Helen: Paramedic)*

Personal preferences have been previously shown to influence health professionals' clinical practice, particularly in the absence of formal guidelines.[14] For example, Needle *et al.* (2012) reported that doctors were more likely to offer and recommend treatments similar to their own end-of-life preferences; while Vermeulen and colleagues (2007) found that health professionals' wound dressing choices were based on their personal preferences.

In the current study, personal preferences impacted individual FPDR practices. Furthermore, these personal preferences impacted the way in which individuals perceived the preferences and rights of *others*, as discussed in the following section.

Projecting personal preferences and values

Experts have written about the concept of projection in several guises. For example, 'attributive projection' where people see others as they see themselves – i.e. a helpful person will see others as more helpful (Sherman, Presson & Chassin 1984); 'functional projection' where people with particular goals or emotions then *over perceive* those same goals or emotions in the people around them (Maner *et al.* 2005); and 'social projection' where a person who believes or does something also deems that others would believe or act in the same way (Gilovich 1990).

Health professionals in the current study exhibited both functional and social projection when constructing conditional permission. In many cases, projection of personal preferences was a major influence on decisions around FPDR, as evidenced by the following excerpts;

---

[14] None of the health professional participants worked in a setting with formal FPDR policies or protocols

> *One doctor has said to me that he's based the decision on the fact that if it was his family member, he wouldn't want to watch. So he, on principle, doesn't allow anybody in. (Mandy: RN)*
>
> *It probably depends on your own belief set and your own professional clinical experience. If it's your belief that if you were the patient you'd want someone there, or if you were the family member you'd wanna be there for your family member, then I think that you would obviously try to overcome the barriers to implement [FPDR] for someone else. (Jane: RN)*
>
> *If it were me, I would probably want to be in there and see it … I would like to know that everything's been done that could be done. And based on that, I feel it's their right, if they wanna come in and see it then they should be able to. (Sarah: Paramedic)*

Health professionals' personal attitudes, beliefs and values about FPDR appeared to influence their perceptions of how widely those attitudes, beliefs and values were shared with others. This phenomenon has been previously labelled as the 'false consensus effect', whereby people overestimate the degree to which others share the same characteristics, behaviours, attitudes, values and beliefs as they do (Ross, Greene & House 1977; Sherman, Presson & Chassin 1984; Gilovich 1990; Burns & Knussen 2005). In order for this to occur, an individual must first interpret what the phenomenon means to them before then projecting it onto others.

When deciding whether to practice FPDR, health professionals in this study first determined exactly *what* the practice meant to them. How they constructed this phenomenon subsequently impacted not only their own preferences, but their estimates of the preferences of others (Gilovich 1990). To illustrate this point, when a health professional viewed FPDR primarily in terms of potential risks and barriers, they projected this negative view onto family members and presumed they would not want to be present. Conversely, health professionals who viewed FPDR in terms of its multiple benefits projected a similar view onto family members and believed they would want to be present in order to experience those benefits.

The danger of the false consensus effect in relation to FPDR is that health professionals may fail to recognise that people can attribute different interpretations or meanings to

the same phenomenon. Indeed, many health professionals in this study failed to make adequate allowances for those different interpretations when making consensus estimates. A possible explanation for this failure could be that the process of *interpreting* the meaning of FPDR is so reflexive and immediate that it is often overlooked. In other words, health professionals assumed that their interpretation was an objective reality of FPDR and shared by everyone involved.

Some health professionals (particularly those who denied FPDR in their everyday practice) rationalised their projection of personal values and beliefs onto others as 'knowing what's best' for patients and family members. These health professionals spoke about wanting to protect family members and patients from perceived hazards and risks (the process of 'protecting others and self' is detailed later in this chapter). However, some health professionals went further to question the nature of value-laden judgements made by staff under the guise of protecting others.

> *I wonder whether we as staff are actually impeaching (sic) that onto the patient when we don't even know what they want. So we say we're protecting their privacy, but what do you mean you're protecting their privacy? You don't know. You haven't asked the family. Coz you might find the family know what the patient's wishes are. Or they've got power of attorney... (June: RN)*

Here June is questioning rationales for denying FPDR, suggesting that health professionals' motivations do not always withstand deeper questioning and critique. In other words, health professionals do not always know what is in the best interests of the patient or family member - and those who believe they do without direct input from those parties are making value-laden judgements about the preferences and rights of others.

The accuracy of value-laden judgements has been questioned previously by health professionals. They were concerned that, when the patient was unconscious, end-of-life decisions were biased by personal values rather than those of the patient and their family (Oberle & Hughes 2001). The literature on decision-making on behalf of adult others focuses on 'proxy' or 'surrogate' decision-makers whose role it is to make a decision on behalf of another person unable to make those decisions for themselves (Beresford &

Sloper 2008; Kelly, Rid & Wendler 2012; Lederman, Garasic & Piperberg 2014). These studies suggest that, in contrast with health professionals' assumptions in this current study that they know what is best for the patient, family surrogate decision-makers were able to predict patient preferences more accurately than doctors (Shalowitz, Garrett-Mayer & Wendler 2006). However, the latter study focused on surrogates predicting what the patient would want to receive in terms of treatment; whereas decisions about FPDR impact both the patient *and* the family member – which raises the question of who FPDR is for, which is discussed later in this chapter.

Rather than projecting their own preferences and values onto family members, health professionals need to understand that each resuscitation event is unique and that each family member and patient is different. A flexible approach to decision-making around FPDR that considers individual preferences and rights is therefore needed, as evidenced by the following excerpt from Darren who, like other health professionals in this study, was passionate about offering flexible options and supporting informed choices.

> *We give them the choice. If they're not in the room then we give them a choice whether they wish to be present or not. On one occasion I've had a family member who wanted to remain in the corridor just outside the resuscitation room, with the curtains closed … not seeing the person being resuscitated and so it depends … some people just don't want to be present, but by far the majority of people have wanted to be there. (Darren: RN/NP)*

Yet even when offering flexible choices, the language used by health professionals to describe their approach to FPDR (bolded in the following excerpts for emphasis) once again often reflected the subjective and value-laden nature of their decision-making around FPDR.

> ***My personal thing is*** *I think it's really, really important that family be given at least a choice. If they don't wanna be [present], that's fine. But they should at least be given the choice to come in, at any part of the resus. If they don't want to come in straight away, that's fair enough. If they wanna come in half way through, so be it. But I think they should at least be given the opportunity to do that. (Sally: RN & FM, Sister)*

> ***When I'm in charge**, I'll always go look for a family member and bring them in.*
> ***Personally what I do is** I call the family in … we would have already had a*
> *discussion of who's who and introduced ourselves and I speak to whoever's the*
> *head of the family or who appears to be in authority and they sort of decide who's*
> *coming in. (Grace: RN)*

The introduction of formal yet flexible guidelines was often suggested as a way to reduce the current reliance on value-laden preferences. Yet, despite most health professionals stressing the importance of structured protocols to guide consistent FPDR practices, none of them worked in a setting with formal policies or guidelines, further perpetuating the implementation of subjective practices based on personal preferences and past experiences.

The facade of team consensus

While individual preferences played a large part in the decision to practice FPDR, some health professionals also considered team consensus an important determinant of conditional permission.

> *I think it has to be a team decision, I don't think there can be any leader …*
> *everybody has to be comfortable with it. If you've got one person that's not*
> *comfortable with it, it just changes the dynamics completely coz there's the*
> *potential that they won't want to do their work [if] they're not comfortable with*
> *it. (June: RN)*

However this reliance on a team consensus was often a facade, with individual team leaders (most often the senior doctor on duty) being able to override the competing preferences of other team members.

> *It's the senior person involved in the resuscitation, and that's usually the doctor …*
> *I think the person who has the responsibility of coordinating the resuscitation*
> *should have the right to make that decision. If there was a member who felt*
> *uncomfortable, I'm not sure if I would agree [that] you have to have a straw poll*
> *and everyone has to agree … I think it has to be more divulge [acquiesce] to the*
> *boss, who's running the resuscitation. (Anthony: Doctor)*

> *The ultimate decision would be the team leader of the resuscitation. So if it's*
> *gonna compromise the treatment of the patient - that should be the paramount*
> *consideration. I think that if you've got a couple of team members who are not*

> *comfortable, then they need to come to terms [with the decision]. (Darren: RN/NP)*

> *It really should be the team's decision - but in the end, it often is the team leader, which by default is usually the emergency consultant or registrar. (Katherine: RN)*

In situations where competing preferences for FPDR became an issue of debate, several solutions were offered - such as team debriefs and simulation training. Some health professionals described heated debates around FPDR that ended with the most assertive person dictating the level of presence at the time of the resuscitation – followed by a discussion of the process after the event.

> *We've had MET [medical emergency team] calls before where someone will want the partner out of the room and others will say they can come in … that's usually a heated discussion … We've had discussions at the desk after to say, why did they have to leave? If they're not in the way, if they're not obstructing any of the management we're trying to instigate - but usually it's whoever screams the loudest will usually get [their way]. (Gemma: RN)*

Unresolved competing preferences often led to family member preferences being overridden by health professionals, and staff conflicts between those who did and did not support FPDR. Staff-to-staff conflicts were deemed most detrimental due to the potential to compromise patient care – and as such, junior health professionals would often acquiesce to senior staff in order to maintain a facade of team harmony.

Thus far, personal preferences have been shown to significantly impact the decision to practice FPDR and lead to potential conflicts. These preferences were driven by personal values and beliefs and, importantly, beliefs about *who* FPDR is for, which is discussed in the following section.

Determining who family presence is for

When making decisions to practice or participate in FPDR, individuals were making value-laden judgements about who they believed family presence was for. In other words - who would benefit from FPDR if and when it was practiced? Some participants stressed the importance in terms of benefits for the patient; for example to comfort the patient and to ensure they were not alone when they died.

When I talked to my son, he said he could hear our voices and he found that quite comforting. (Carol: FM, Mother & RN)

I believe that the patient, no matter how unwell, can still have some awareness of what's happening and can maybe hear their family member speaking to them, or feel them holding their hand. (Jane: RN)

Others spoke about the benefits for both the patient and their families. However, overall, participants believed FPDR was *most* beneficial for family members. They emphasised that the majority of resuscitation events they had been involved with were unsuccessful and that FPDR should therefore focus on supporting the people who are left behind.

I think [FPDR] benefits the patient the most if they live, and the family the most if they die … The patient is at the worst possible time of their life. If they have any insight into their family being present, then I think they find that very reassuring. If the resuscitation has not gone well and the person has died, then the grieving process is aided by understanding that everything was done, and that death became inevitable. (Darren: RN/NP)

I think particularly in poorer outcomes - and usually, you know, a lot of our resuscitation efforts are unsuccessful once you get to CPR - I think you're doing it for the family; you're not doing it for the person on the table anymore. (Lauren: Doctor)

When sharing preferences for their *own* resuscitation (whether they would want their family member present) most participants offered a philosophical argument that, as the dying patient, their preferences and rights were less important than their family members' and that support should be directed toward the living.

In a way I'm the least important in that decision process. Coz I think this issue is actually for the observer... (Anthony: Doctor)

… if I'm dead I'm dead, you know, it's not going to affect me. It'll be about the people that are left behind. So if they felt they needed to see that, then I have no problem with that. And so for me, it's for the people who are living. (Katherine: RN)

Questions were also raised about why FPDR practices should be any different for a resuscitation event than for patients in an intensive care unit (ICU); where a family-

centred approach to care supports consistent family presence, even when the patient is unresponsive.

> *… you've got someone three days into a coma who's got no brain activity whatsoever, but you still encourage those family members to be there and hold their hand and you can see that they respond to those things … That's something we actively encourage in an ICU situation with a very unconscious patient. How can you not extrapolate that into a resus situation where you've got someone with fluctuating levels of consciousness? How would that not be a supportive and calming presence for someone? (Bella: RN/RM)*

Prioritising preferences and rights of the people involved in FPDR was the first value-laden judgement made when constructing *conditional permission*. On most occasions, health professionals took control of the prioritisation process, and often elevated their own preferences and rights over those of family members and patients. Following on from this, health professionals began *assessing suitability* of the people, the space and the resuscitation context before *setting boundaries* around conditional presence.

ASSESSING SUITABILITY

The process of assessing suitability was undertaken on an initial and ongoing basis by health professionals and to a much lesser extent by family members to determine the level of FPDR implemented. More specifically, participants performed a series of assessments in order to identify any potential risks in relation to; 1) the people involved, 2) the resuscitation space and 3) the resuscitation context. Assessing suitability in this way was a form of risk assessment, which is a key quality improvement strategy for Australian health care (ACHS 2013). The Australian Council on Health Care Standards (ACHS 2013, p. 5) define risk as;

> *…the effect of uncertainty on objectives. In the context of risk, uncertainty is defined as 'the state, even partial, of deficiency of information related to understanding or knowledge of an event, its consequence, or likelihood'. Any deviation from the expected can result in a positive and/or negative effect. Therefore, any type of risk, whatever its nature, may have either (or both) positive or negative consequences.*

This definition was certainly appropriate to describe how potential risks of FPDR were identified and responded to. However, risk assessments in the current study did not appear to be based on any existing models of risk management.[15] Instead, they were based on personal judgements and preferences about FPDR. The subjective, value-laden nature of risk assessment has been discussed previously in the literature (Clemens & Hayes 1997; Slovic & Gregory 1999; Slovic 2001), highlighting the significant impact that values, emotions and preferences can have on clinical decision-making.

In the rush of what was usually an unexpected resuscitation, there was little time for informed, conscious decision-making in the current study about whether it was suitable or desirable for family members to be present. When making decisions in a time pressured situation such as a resuscitation event, emotions will often drive those judgements because emotional processes are faster than cognitive processes (Svenson 2003; Beresford & Sloper 2008). As such, these assessments were often made unconsciously, based on setting norms, or on previous experiences, preferences and attitudes about FPDR, as discussed previously.

Some people made a decision about the level of FPDR they found desirable, and then justified that choice with reasons or 'evidence' in what has been referred to previously as blurring the 'fact-value distinction' (Nielsen 2012). In other words, some health professionals spoke about multiple barriers to FPDR as if referring to scientific fact, and used those 'facts' as reasons to deny family presence. Conversely, some health professionals highlighted multiple benefits of FPDR in the same way. I support Nielsen's (2012) argument that using 'science' to substantiate an individual's value-laden judgements and preferences in this way is misleading, and I propose that a lack of consistent FPDR policies and protocols in Australia is contributing to this. The current dependence on personal judgements in the absence of formal policies and guidelines that was evident in the current study increases the subjectivity of FPDR assessments and decision-making (Clemens & Hayes 1997; Slovic 2001). Further, it contravenes core evidence-based practice goals, which include '*…the conscientious, explicit and judicious*

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[15] Risk management involves the systematic application of management policies, procedures and practices to the activities of communicating, consulting, establishing the context, and identifying, analysing, evaluating, treating, monitoring and reviewing risk (ACHS 2013, p. 5).

use of current best evidence in making decisions about the care of individual patients' (Sackett *et al.* 1996, p. 71) in conjunction with individual clinical expertise, while also considering client preferences and values (Sackett *et al.* 2000; Melnyk *et al.* 2014).

The following sections provide an in-depth discussion of the value-laden judgements made by participants when assessing suitability of the people, the space and the resuscitation context.

Assessing the people

Assessing suitability of the people involved in the resuscitation was undertaken by health professional and family members in various contexts. This assessment was performed on an ongoing, case-by-case basis, with the major intention of keeping people safe and ensuring health professionals and family members were able to cope with all that FPDR entailed.

Keeping people safe

For the most part, family members were calm and unobtrusive when present during a resuscitation event. However, there were several occasions where they became particularly distressed and even verbally disruptive and subsequently needed to be removed from the room. The removal of distressed family members was viewed not only as a way of keeping *them* safe, but also to preserve the safety of *staff*, who at times became distressed by family members grief or worried that distraught families might disrupt the resuscitation.

Keeping the patient safe from family members who had or might potentially harm them was an uncommon but important consideration. For example, Michael shared an experience where parents who had remained with their child were later implicated in the death of that child. This example highlighted the importance of careful and ongoing (risk) assessment of all family members who wish to be present during resuscitation, and indeed during any stage of hospitalisation.

> *One instance I can remember … is a non-accidental injury. [We] had both parents at the bedside for a child with quite a severe head injury … the head injury looked like it was going to be un-survivable … there were legal considerations then, coz*

> *we'd had questions about the description of how the injury occurred, and the*
> *seriousness of the injury ... and there were other indications that this child had*
> *suffered quite long term abuse. (Michael: RN)*

The cultural implications of FPDR were also considered in light of Australia's multi-cultural society, and the wide variety of people who present to hospital departments. Participants spoke about people from different cultural backgrounds having varying expectations and reactions to FPDR, highlighting the importance of individual, ongoing assessment and open communication between all family members and health professionals.

> *I do sometimes think that culture has a lot to do with it ... I've had some Italians in*
> *there that throw themselves around, and it's, 'hang on guys; you're going to have*
> *to leave.' But then you have some other cultures where it's actually very quiet.*
> *They will stand back, they will take it all on board and then they will ask you*
> *questions afterwards. (Mandy: RN)*

> *We're very culturally diverse, our areas, so we have some groups who bring a lot*
> *of people, some of them, you know, everyone they know shows up when someone*
> *is unwell, so normally we leave it to the head of the family who comes in.*
> *(Grace: RN)*

The diverse expectations, preferences and needs of *all* family members around FPDR was raised by most participants, and the importance of offering options and supporting informed choices was stressed consistently. However in order to do this, it was first necessary to evaluate the coping mechanisms of family members requesting or being offered FPDR.

Evaluating coping mechanisms

Coping mechanisms of family members who were/wanted to be present during resuscitation were assessed by health professionals, by other family members and by the family member themselves. Health professionals performed this assessment in various ways; including gauging the family member's initial reaction to being invited into the room;

> *I would ask them, would you like to come in? And if they looked shocked and*
> *horrified and terrified at the very thought then that's fine - we'll just back away*

from that. If they look as though they're considering it then I'd go on and explain a
bit more. So I guess I would assess their initial response. (Lauren: Doctor)

The importance of *ongoing* assessment of how family members were coping was also
stressed - something that has been noted previously in the FPDR literature (Oman &
Duran 2010). Some health professionals suggested removing family members from the
resuscitation room if they did not appear to be coping, with the option of returning at a
later time. In the following excerpt, Bella's detailed explanation of her assessment
process demonstrates a considered approach. However, the subjective nature of her
assessment is also evident, highlighting once again the variability of current decision-
making around FPDR.

> *… there's no formalised process. I think you look at how emotional, how distressed*
> *they are. If they come in and they're a complete riot of emotions and distraught,*
> *usually what I'd try and do would be direct them out to a relative waiting area …*
> *then go and see them in a couple of minutes and check on them … and then put it*
> *to them if they wanna come in. Coz they do often come in so hysterical because*
> *it's been so sudden … they haven't quite, had a breath … those sorts of people I try*
> *and direct so they don't come straight in, but they can have a moment to compose*
> *themselves, and then work out what they wanna do from there. (Bella: RN/RM)*

A utilitarian approach to (risk) assessment was evident when health professionals
weighed up the benefits and risks of FPDR, as evidenced by Gemma and Katherine.

> *I s'pose it depends on whether the family members are going to impede or*
> *become a hindrance to the resus, especially if you've got all hands on deck - you*
> *usually don't have a lot of room so it's what resources you have you want to [be*
> *able to] get to fairly quickly. So if you've got people in the way and they can be*
> *more of a hindrance then yeah. I think you've got to weigh it up too, to what suits*
> *in certain environments, the personalities, are they actually going to benefit from*
> *this, will they have closure, and what sort of follow up we have for them. (Gemma:*
> *RN/RM)*

> *It's about decision-making. So if you've got someone that's not reasonably in*
> *control then they need to be out because it's going to impact the team working on*
> *their family. And in the end the priority will always be the patient. (Katherine: RN)*

People who used a utilitarian approach to assessing the suitability of people to participate
in FPDR considered the 'right' decision as one that resulted in the best outcome for the

greatest number of all people involved (Smart & Williams 1973; Beauchamp & Childress 2001; Day 2006). Application of utilitarian theory to FPDR therefore considered whether the outcome of practicing FPDR was better than the outcome of not practicing FPDR. If the outcome was considered to be better if FPDR was practiced (i.e. the benefits outweighed the risks), then practicing FPDR was viewed as the 'right' action (Day 2006).

A significant risk of a utilitarian approach to FPDR was the difficulty in accurately comparing the benefits and risks overall and for individual cases when they were perceived differently by the individual people involved. The symbolic interactionist and social constructionist approach of this research viewed FPDR as a social construction made possible by the perceptions of individuals as they interacted with each other and with their environment. The subjective and interactive nature of what constitutes a 'risk' or 'benefit' thus requires a more considered approach to determining the suitability of FPDR.

I agree with Day (2006) and Timmermans (1999a, 1999b, 2005), who argue that FPDR should be less about 'good outcomes' and more about basic human values. If we start with the utilitarian assumption that family members should be excluded unless we can demonstrate a more beneficial outcome with their presence, the focus remains on the individual patient at the expense of family members. However, if we see the patient as a person who lives as part of an interconnected society with family and community, we can start from a humanistic perspective where family involvement is already valued (Day 2006).

One of the most common 'risks' cited by health professionals when assessing suitability of family members to be present was that they would not be able to cope with resuscitation scenes, and this was sometimes used as a reason to deny FPDR. However, most participants stressed that family members were best placed to know their own coping abilities and should therefore be responsible for choosing the level of family presence they desired.

> I think it's important, depending if the family wants it. I mean some people, my
> mother for example, would have run a million miles from that kind of situation,
> but not me. I wanted to be part of it. (Trevor: FM, Husband)

Some people know they're gonna cope quite well. And then others know they're just not going to. (Mandy: RN)

Some people wouldn't be able to handle it and some people can. Coz I know a lot of blokes, the first time you go near them with a bloody needle and they're gone. (Dooley: FM, Father)

For me, I mean - if he'd died on the table it would have been awful. But I think it would have been worse for a lay person. Because I mean, I've seen deaths on the table. You just sort of cope with it. (Mary: FM, Wife & RN)

The main exception to the widespread philosophical agreement of allowing family members to choose their own level of presence was when the family member was a child. However, there were no consistent recommendations about this, with most participants relying on personal preferences and beliefs to guide their decisions. Some participants, like Grace, preferred the child's family members to make that decision.

I normally leave it up to the family; they know their family best. It's not for me to make those decisions. I'd probably explain what they're going to see when they come in, and some people will go 'Oh they can wait with another relative somewhere else', or I've had children in there before. (Grace: RN)

Other participants gave varying opinions about the suitability of a child being present, once again based on personal preferences and values.

Family who wanted to take young children under 10 in, I would probably recommend not … the middle of a huge trauma resus wouldn't be the place for a child. (Lauren: Doctor)

Very young, you know like 4 or 5, I'm not sure that it's a problem because they see the world in a different light … they're not worried because they're totally fascinated by all the lights, bells and whistles. (Anthony: Doctor)

…we don't have an absolute number. So it really depends on the capacity of the child to understand what's going on. (Darren: RN/NP)

One family member participant spoke at length about the unsuccessful resuscitation of his 14 year old son, who drowned while swimming in a lake with his 12 year old brother. Dooley sent his younger son home, believing he was protecting him from the trauma of watching his older brother being resuscitated. However, rather than feeling protected,

Dooley's younger son was angry for many years about being excluded from the resuscitation scene because he wanted to know what was happening and be with his brother at the end. When asked his opinion about an appropriate age for children to be present, Dooley replied;

> *Oh, that's a hard one. I made that call because I didn't think a 12 year old needs that sort of thing … seeing his own brother dead or anyone else dead for that matter … I think, to a degree, not till they're, 14 or 15, something like that. When you think they can possibly handle something like that a bit better … I made the call and I was wrong, but - it depends, because my [younger] son didn't like the fact that I sent him home and went away with [older son] to the hospital and he didn't know he was dead. (Dooley: FM, Father)*

Determining an appropriate age for FPDR if the family member is a child is complex and requires a holistic and collaborative approach to decision-making. Findings from this study support a considered and informed assessment by family members and health professionals about the benefits and risks along with careful consideration of the child's ability to cope and their own personal, informed preferences for FPDR. No literature could be found relating to the experiences of child family members being present during resuscitation and it was therefore not possible to compare current findings with a wider body of evidence. However, insights can be drawn from the literature surrounding child attendance at funerals.

Much like adults, children grieve in a variety of ways and according to Doka (2000) there is no 'correct' age at which children should attend funerals. Instead, children need the support of family and peers to use their own inherent strengths. Thus, it is not chronological age but cognitive and emotional development that is a better measure of a child's ability to cope with death and grief (Doka 2000). Consideration must also be given to the child's preference around funeral attendance. For example, Søfting, Dyregrov & Dyregrov (2015) interviewed eleven 7-12 year olds who had suffered the loss of a parent or sibling. Most children wanted to see the deceased person and all of them took part in the wake or funeral. The authors concluded that it was very important for the children to be included in the death rituals and be recognised as grievers in the same way as adults in order to legitimatise their status as a 'full' member of the family system. By being

included, the children were given the opportunity to 'see for themselves' what was happening which allowed them to understand and accept the reality of the loss and say goodbye their loved ones.

According to Holland (2010), bereaved children often feel starved of information and control, and having the seriousness of the prognosis hidden from them can increase the impact of the sudden death if their family member dies. Children have similar needs for information and clarity as adults at a level and in language that they (the children) can understand (Holland 2010, p. 11). A lack of communication about death may result in adverse consequences for children (Doka 2000; Toller & McBride 2013), which further supports the holistic and collaborative approach to decision-making around FPDR for children recommended by the current study. The literature outlined above also suggests that assessment of a child's cognitive and emotional development is a more accurate determinant of their ability to cope than their chronological age if they express a preference to be present during resuscitation.

Considering staff comfort and competence

The decision to practice FPDR was impacted considerably by health professionals' level of comfort and competence under observation. Some health professionals were comfortable being observed by family members, even when performing very invasive procedures. While others worried about the impact of performance anxiety on their colleagues and, at times, on themselves.

> *Having other people present, if you've got people who are not sure of their roles, or don't have a good team leader, often they get a little edgy and toey and don't perform as well as they can … Where the team is poorly led, or where you have semi functional team members, that often leads to more questions in the minds of people who have been present. (Neil: RN/NP)*

As a result, some health professionals raised the possibility of excluding family members in order to minimise staff discomfort and potential poor performance. However, they went on to say that excluding family should not be a first resort in response to staff discomfort, and that focus should instead be placed on increasing staff competence and confidence.

> *You could imagine scenarios where that might be a problem. But I can only see it's*
> *a problem if the conduct of the resuscitation falls outside guidelines that someone*
> *with knowledge picks up and … it might be uncomfortable but the solution isn't*
> *not have people there, the solution is to make sure your teams are competent.*
> *(Anthony: Doctor)*

Assessing the suitability of the people involved in resuscitation was an important step in determining the level of family presence enacted. While this assessment was taking place, participants were also assessing suitability of the resuscitation space.

Assessing the space

Health professionals assessed the resuscitation space mostly in terms of safety hazards (i.e. the defibrillator) and having enough room to work unimpeded. Similarly, family members spoke about not wanting to be in the way during a resuscitation event. The importance of being able to work unimpeded has been raised previously in the FPDR literature (refer to appendix 5 on page 257) and was an important factor for health professionals in the current study to be able to focus on life-saving interventions and reduce the risk of injury. However, the outcome of resuscitation space assessments differed considerably in relation to previous ownership claims and the value placed on FPDR. For example, health professionals who did not value FPDR often determined there was not enough room to accommodate family members and used their professional authority and ownership claims in conjunction with this assessment outcome as a reason to deny FPDR. In contrast, health professionals who valued FPDR acknowledged the existence of space limitations but offered suggestions to overcome this potential barrier.

> *We have very small resus areas [but] we make room, you always make room. It*
> *might be right up the back, it might be in an awkward corner but you just work*
> *around it. It's what you do in your normal nursing you know, there's always*
> *someone sitting in front of whatever machine you want or anything you want and*
> *you work around them. (Grace: RN)*

> *Normally you feel like you're a bit stuck for space … but in this case there was*
> *room made for her, and then at any opportunity we'd move her chair closer to her*
> *husband so she could hold his hand and then if we were defibrillating him, we*
> *obviously had to move her back again. (Jane: RN)*

Similar to assessing the people involved, assessment of the resuscitation space involved a series of subjective and value-laden judgements based on personal preferences, past experience and attitudes toward FPDR.

Assessing the context

Assessing the resuscitation context involved considering the circumstances leading up to and surrounding the resuscitation event (including the severity of the patient's injuries and their prognosis), and the nature of resuscitation interventions (including the level of invasiveness).

At times, family members were excluded from the room if the patient's condition appeared reversible; with staff wanting to focus on the patient in a series of life-saving, often invasive interventions. However, if the prognosis was assessed as poor, health professionals considered bringing family members in to be with the patient just before or after they died. For example, Elizabeth was not supportive of FPDR but conceded that family members should be present if the patient died. Whereas Grace, who was supportive of family members being in the room, but away from the patient, went further to encourage physical contact if she knew the patient was going to die.

> *I think, depending on how the resuscitation is going and if we know that there's no hope of success, I think the family member should be allowed into the room. (Elizabeth: RN)*

> *If it's looking very [grim], and we're sort of coming to the end of our treatment, we'll generally bring them up to stand and hold their hand, [to] talk to the patient. (Grace: RN)*

At times, the decision to exclude family members was based on a value-laden assumption that resuscitation scenes would be too traumatic for family members to cope with. However this judgement was often incorrect, with many family members believing *they* were best able to determine their own coping mechanisms, and rationalising that resuscitation scenes were not all the same.

> *I can appreciate from the emergency room's perspective; if it's messy … I can understand why they might want you out. But [my wife] was intact, if you know what I mean. She hadn't been in a traumatic accident … I can imagine if*

> *someone's been mangled in a car accident people might have a bit of queasiness*
> *associated with it. But in the case that I was in, I thought it was fairly my decision*
> *to stay. (Trevor: FM, Husband)*

Some health professionals allowed family presence during *some* interventions but not others. Yet there was no structure or consistency to these decisions, apart from personal preferences and beliefs about what they thought was suitable to observe. For example, Grace and Katherine believed CPR was suitable, but not the insertion of central lines.

> *The only time we don't bring in relatives is during an actual procedure, if we're*
> *actively intubating, if we're putting lines in, you know central lines, thing like that.*
> *We won't usually bring them in during that time, but we'll bring them in during*
> *CPR … (Grace: RN)*

> *So if the patient's in the arrest [CPR phase] they're [FM] generally not too much of*
> *an issue. But if it's that peri-arrest [phase] we'll often, if we've got family in and*
> *we've got an output back and so then we'll start to put in lines and things so -*
> *we'll get them to step out for that part. (Katherine: RN)*

Several health professionals believed *all* facets of CPR were too traumatic for family members to watch, but many others disagreed that resuscitation scenes were too graphic. These diverging views highlighted once again the subjective nature of these assessments and the prevalence of the projection of personal preferences and beliefs onto others during the assessment process.

> *As far as graphic scenes go, I can't really think of much graphic scenes happening*
> *in a resus, you know. I mean everything is done with precision.*
> *(Sally: RN & FM, Sister)*

> *We [are] just jumping on their chest, you know … and it's always messy, it's never*
> *pretty. Their clothes are ripped up high; it's not just a pretty sight. They don't*
> *want that image in their head … I mean we're trying to help the patient but -*
> *sometimes it's just really ugly. (Jackie: RN)*

Many health professionals, while acknowledging the often graphic nature of resuscitation, emphasised the importance of considering family preferences when determining the level of presence. Health professionals maintained that as long as family

members were fully informed about what to expect during the resuscitation event, they were almost always best-placed to know their own coping abilities.

> *So, when they come in and - there's my wife and there's blood all over the place and someone's pushing on her chest and there's obviously open wounds and – they get a little bit distressed about that … But I don't think that we should be making that decision for people, I think we really should be giving them the opportunity [to be present]. (Neil: RN/NP)*

Offering options and supporting informed choices was therefore seen as an important step in the assessment process when determining the level of FPDR and setting boundaries around this practice.

SETTING BOUNDARIES

Setting boundaries involved health professionals imposing a series of conditions around FPDR prior to and during implementation. A similar process of setting pre-requisites was identified during the preliminary literature review (see page 25). Some of the pre-requisites previously identified were similar to those raised by participants in the current study. However, unique to this study was an in-depth examination of how and why these boundaries were set and their subsequent outcomes on clinical practice.

In healthcare settings where FPDR was practiced in an ad-hoc manner or as a result of opportunistic presence, boundaries were set unconsciously and based on personal preferences or setting norms (i.e. this is the way I've/we've always done it). Conversely, in healthcare settings where FPDR was practiced in a more structured and consistent manner, boundaries were set more deliberately in what appeared to be an effort to ensure the best possible outcomes for everyone involved, as exemplified below.

> *… it has to be policy that this [FPDR] is accepted; that should they chose to [be present] that they have that right to be there … certainly it can be very beneficial if you have the right team, and the right people watching … I think that it can be very positive for the family and I think that it's beneficial for staff as much as anybody else to see that, not that they've done the best that they can do but that the best is understood [by FMs]. (Neil: RN/NP)*

However in all settings, boundaries were variable and often dependant on the personal preferences of staff on duty. As outlined previously, health professionals went through a process of assessing the people, the space and the resuscitation context for suitability. The outcome of this assessment then determined the type of boundaries subsequently set and the level of FPDR implemented. For example, health professionals set boundaries around being able to ask family members to leave for certain procedures, being able to delay family presence until staff were ready or until family members were calm, or delaying until staff believed the patient's prognosis was suitable for presence. June referred to this period of setting boundaries as applying 'ground rules', a term that succinctly summarised the views and actions of most health professional participants when setting boundaries.

Some boundaries were physical; such as having enough space for safe presence or being able to limit the number of family members in the room during the resuscitation event. Other boundaries were emotional; for example being able to remove distressed family members from the room to minimise disruptions. A final type of boundary was theoretical; for example where 'setting norms' or 'standard practices' influenced or guided the way in which FPDR was practiced. The following sections outline the way in which boundaries around FPDR were set and maintained by health professionals.

Offering options and supporting informed choices

Health professionals stressed the importance of offering choices and recognising and supporting individual family member preferences around FPDR. While some family members were eager to be present with their loved one during the resuscitation, others preferred to wait in another room and receive regular updates about the patient's condition. The importance of being flexible about the level of FPDR enacted was also highlighted, such as allowing family members to choose their preferred level of presence, or being able to leave the resuscitation room and return if they chose.

> *[FPDR is] variable and quite individual. Some [FMs] are glued to the events; others just find it so overwhelming they will retire, presumably process what's going on and then want to return. Or they'll want to retire and contact other family members, and then return. (Darren: RN/NP)*

There was a particular emphasis on ensuring family members were making an 'informed' choice about whether and to what extent they wished to be present during resuscitation. Health professionals likened these informed choice to informed consent, and stressed the importance of providing adequate information to family members in order to facilitate this process.

> *It's almost like getting an informed consent. That if you describe the nature of the injuries and what the person will potentially see, and that person still says yes, I'm prepared for that, I'm willing to come through with you, well I would be inclined to let that person come through. (Michael: RN)*

Preparing and supporting family members

Preparing and supporting family members was one of the most important boundaries or conditions placed on FPDR. Health professionals stressed the need for a dedicated support person to prepare family members for what they might see, to explain what is happening and to stay with and support family members throughout the resuscitation. This finding supports previous evidence that stresses that the availability of a support person is an important facilitator for FPDR (Holzhauser & Finucane 2007, 2008; Pasquale *et al.* 2011; Porter, Cooper & Sellick 2013; Porter, Cooper & Sellick 2014).

In the current study, the role of the support person was valued so highly that most health professionals who cited multiple benefits of FPDR and/or practiced it consistently for all resuscitation events would not practice FPDR unless a dedicated support person was available. These health professionals claimed that unsupported presence was worse than no presence during resuscitation.

> *… we always allocate someone to them … I mean the person, we don't know what they're seeing, and what they're seeing may or may not be a reality. It's clearly their reality; but how they decipher that is unknown … they need to understand what is happening, otherwise it just becomes an overload of information and situation which they may not be able to decipher, and [they] will put on only the worst interpretation. (Darren: RN/NP)*

Some health professionals went further to say it wasn't enough just to allocate a support person to the family member. It must be the 'right' support person; someone who has the necessary preparation and training to competently support family members.

However, when a dedicated support person was not available (which often occurred during opportunistic presence), some health professionals still practiced FPDR. They suggested ways in which the resuscitation team could support family members and keep them informed about what was happening, while also focusing on patient care.

> *… it's important to explain what's happening, and in fact that helps the resuscitation process anyway; 'we are now gonna do this, and we're gonna use this' … 'we're going to put the tube in now' … 'and we're going to start the heart compressions, someone's gonna put a catheter in to give some medications'. We usually enunciate what we're doing. Not necessarily directly to them but as part of the team process. (Anthony: Doctor)*

Some healthcare settings that practiced FPDR on a regular basis provided a dedicated family support person as part of their standard practice; however the classification and nature of this role varied from setting to setting. In some settings this role was undertaken by junior staff, the scribe nurse or staff members who were called in to assist from another department. More commonly however, this role was undertaken by a senior staff member on duty – either alone or in conjunction with social work staff – so they were able to competently explain what was happening. In all cases, the main function of the dedicated support person was to offer choices about the level of FPDR, to adequately prepare family members for the sights and sounds of resuscitation, and to explain what was happening and support the family member as the resuscitation progressed.

> *I ask them first, 'do you want to go in?' I explain what they might see while they're in there … some people will say 'oh I don't want to go in' or 'I definitely want to go in.' Then I'll take, normally only one or two of the closest relatives in, and straight away I explain what they're seeing. There's that person pushing on their chest and that's making their blood pump around their body, and they've got a tube in their mouth and we're breathing for them … I explain what all the lines are, who different people are, what they're doing. And then I ask them, do you have any questions … and I try to stay with them as much as I can. (Grace: RN)*

However, despite increasing recognition of the importance and value of a family support person during FPDR, designation of this role appears to be a low priority among resuscitation teams (Porter, Cooper & Taylor 2014).

Minimising disruptions

Another important boundary placed on FPDR was allowing family members to be present on the condition that disruptions were kept to a minimum and that health professionals were able to work unimpeded. For example, health professionals imposed a boundary of being able to remove disruptive family members from the resuscitation room. However, on most occasions family members were calm and rarely needed to be evicted. These non-disruptive family members were also able to meet other boundaries such as staying out of the way, watching from a safe distance and not distracting staff, i.e. with loud crying or yelling. When family members did inadvertently get in the way, they were easily moved following staff requests.

> They're [parents] sort of asked to step back so that the resuscitation can take
> place. But they're often still in the unit. We just ask them to move if we feel that
> they're impeding the progress. (Dana: RN/RM)

However, there were infrequent occasions where family members were so disruptive that their presence impeded the resuscitation and distressed staff. Health professionals responded to these disruptions in various ways. Some allocated a support person to calm the family member while others tried to ignore the family member and kept working among the commotion. However, in some situations, the ideal option was to remove the family member from the room – yet this was not always possible.

In the following example, Mandy recounted a distressing experience with a disruptive family member who refused to leave the room. In this case, Mandy and the team were able to continue working amongst the disruption and successfully resuscitated both patients. However, a post resuscitation debrief was necessary to counsel staff. Despite this negative experience, Mandy remained supportive of FPDR and stressed that there were many more benefits than risks. Mandy's example highlights the need for staff to be aware of the unpredictable nature of FPDR and the importance of risk assessment and setting boundaries in order to implement the practice safely and effectively.

> I had a young lady who delivered in the emergency department … she didn't know
> she was pregnant, or hadn't warned anybody. It was premature, probably about
> 32 weeks. So we had two resusses going at the same time, one on the mother and

one on the baby. The young girl's mother was in there, and she was constantly telling us to not work on the baby, not do anything for it. It was ruining her daughter's life, and basically to throw it in the bin. She kept yelling over at us, just telling us to stop, we were going to ruin her daughter's life, and just throw it [the baby] in the bin. It was very distressing. (Mandy: RN)

Delaying FPDR until staff were ready or until the resuscitation context was assessed as suitable was another boundary set by health professionals. For example, as mentioned previously, some health professionals believed certain invasive interventions were not suitable for family members to observe. Others expressed a form of performance anxiety when undertaking certain interventions while being observed by family members. Delaying family presence was therefore a way of health professionals allowing FPDR on their own terms or, as June referred to previously, being able to set the 'ground rules.'

The danger of individual health professionals determining the conditions under which they will or will not practice FPDR (conditional permission) is the wide variation and inconsistency this promotes; because individual preferences are guiding practice instead of standardised evidence-based policies and guidelines.

Practicing within setting norms in the absence of policy

None of the health professionals who took part in this study worked in a setting with a formal FPDR policy, and only one participant (Darren) worked in an ED where FPDR was practiced as standard. However, the extent to which Darren's standard practice was formalised was the inclusion of a 'box' on the advanced life support protocol for staff to tick if a family member was present.

Similar to previous research (see pages 23-26 in the preliminary literature review), some participants in the current study were unsure if their workplace had a formal FPDR policy. Participants in the current study described ad-hoc and inconsistent FPDR practices which highlighted the wide variation within and across healthcare settings in Australia. These practices were often dependant on staff preferences, which at times developed into setting norms. For example, some health professionals claimed there was no policy, but did not allow FPDR as part of their usual practice. Hence, their setting norm was to *deny* FPDR.

There's no written policy; depends on the staff, the situation, the team. (June: RN)

If there is a policy I've never heard of it. It's always case by case coz you look at a situation and say alright, this is what I think it's the best to do. (Jackie: RN)

Other health professionals claimed there was no policy but *did* allow FPDR as part of their usual practice. In other words, FPDR was accepted as a setting norm – yet it wasn't practiced consistently by all staff.

Not that I'm aware of. I think it's just an individual choice, you know, regarding the medical officer and the nursing staff at the time. (Sally: RN & FM, Sister)

No, and it probably varies from person to person. I would say it generally happens on every shift but I couldn't tell you if that's the rule. I know on my shifts, that's the rule, or that's the way I practice and I would say most of our senior nurses are supportive of it too. (Grace: RN)

There isn't any sort of formal policies or procedures around it at our facilities that I'm aware of. So it's really based upon the feelings of the staff involved, to wanna do the best thing for the parents. (Michael: RN)

Some setting norms were viewed as inherent, or what Bella referred to as an 'unspoken practice' among all staff.

… outside the standard unspoken practice of all parents can be there for paediatric resuscitation, which is a general, it's universal wherever I've worked, there's nothing about adults. (Bella: RN/RM)

This universal acceptance of what appears to be an established setting norm can be explained by the social interactionist notion that people within society are continuously fitting their actions into what they and their particular society deem appropriate in a particular situation or context (Blumer 1969; Shalin 1991). Through a process of what Blumer (1969) referred to as collective action, health professionals working in the same setting often fit their lines of action to one another on a day-to-day basis to constantly reinforce a setting norm. As a result, the action appeared to be well established. However, it is important to note that if a procedural norm became re-interpreted (for example if a staff member questioned FPDR practices) there is the potential for the group to change their ideas and in turn their actions.

Formal guidelines and policies were recommended by participants as essential to the successful and widespread implementation of consistent FPDR practices. Formal but flexible guidelines were seen not only as a of way supporting and guiding evidence-based FPDR practices, but to also provide 'permission' or justification to implement a practice that is still viewed by some health professionals as controversial and is strongly resisted by others.

> The onus of having guidelines to say - this is what the hospital sticks by. It's still up to the discretion of the team leader but you know the majority of the times this will happen … I think that if the hospital adopts policy then it's going to make it a lot easier. (Gemma: RN/RM)

> There would probably need to be some sort of written code of practice … it would be nice to have sort of a standard practice across Australia or even just across the state … you know the same standards and opportunities are offered to your patients and your patients' family members. (Jane: RN)

Some health professionals went further to suggest the implementation of position statements from professional nursing and medical bodies in order to facilitate widespread acceptance and implementation of family presence during resuscitation. In most cases, they did not realise that many of these position statements already exist.

> I think it comes down to standardising the processes around it … having policy; recommendations from bodies like the Australian College of Emergency Medicine [ACEM] or other such bodies, you know the College of Emergency Nursing Australasia [CENA] … and suggest this is best practice, and this is how it's done. (Michael: RN)

> … you'd need a position statement from ACEM; you'd need a position statement from CENA. Then from that would come the impetus to develop a policy, because part of a position statement is to make a recommendation about having a certain policy, so that would hopefully, you know, the slow wheels would turn. (Katherine: RN)

The use of evidence-based clinical practice guidelines can translate findings from health research into recommendations for clinical practice (NHMRC 1999) and can improve health outcomes (Buchan *et al.* 2010). However, some health professionals in the current

study warned that the introduction of formal policies and clinical guidelines was sometimes not enough to modify individual and group practices.

Similar concerns about the effectiveness of clinical guidelines to change practice have been raised previously. For example, Greenhalgh *et al.* (2014, p. 2) noted an *'unmanageable and unfathomable'* number of available guidelines and wide variations in implementing evidence-based practices as a significant problem. Other barriers to the implementation of clinical practice guidelines include negative attitudes (Taba *et al.* 2012), insufficient training and limited access to resources (Francke *et al.* 2008; Donnellana, Sweetmana & Shelleyb 2013), and a lack of awareness of the existence of guidelines (Francke *et al.* 2008). These barriers were taken into account when making recommendations regarding the development and implementation of FPDR policies and guidelines - which are detailed in chapter eleven.

Thus far, this chapter has detailed the value-laden judgements being made around FPDR practices. These judgements have included prioritising preferences and rights, assessing suitability and setting boundaries around FPDR. The final value-laden judgement presented in this chapter is protecting others and self.

PROTECTING OTHERS AND SELF

Protecting others and self was often cited as a rationale for denying or limiting FPDR. As participants went through the process of assessing suitability and setting subsequent boundaries, a major consideration in this process was balancing the need to protect others and self from any perceived *risks* of FPDR against the potential *benefits* of FPDR (as detailed in chapter eight).The perceived risks identified in the current study (summarised in table 9 on page 176) were similar to barriers identified previously in the literature (see tables 2 and 3 on pages 33-34). What this study adds is an in-depth examination of how the aim of protecting others and self from these perceived risks impacted subsequent FPDR practices; including how potential risks were minimised or overcome by some health professionals while being used by others as justification to deny FPDR.

Table 9: Perceived risks of FPDR identified in the current study

Perceived Risks	Details about perceived risks and concerns
Inhibiting the resuscitation	Family will be in the way
	Family will interfere / distract from patient care
	Impacting / limiting open communication between staff
	Impacting staff actions i.e. to delay stopping CPR
	Limiting staff coping mechanisms i.e. black humour
	Dividing staff attention between patient and family
	Junior staff not able to acquire new skills
	Room too crowded
	Not being able to remove disruptive family members
Emotional impact	Some family members won't cope with resuscitation scenes
	Family members becoming anxious/distressed/scared
	Long term psychological effects for family members
	Family member reaction making staff anxious or upset
	The burden of presence for family – especially those who are HPs
	Family members may feel obligated to be there
Performance anxiety	Fear of being judged or critiqued
	Fear of looking incompetent
	Feeling anxious and afraid under observation
	Fear of losing control
	Fear of looking unprofessional and disorganised
	Fear of performance being negatively impacted by FPDR
Considering patient rights	Potentially breaching patient privacy/confidentially/dignity
	Advocating for patient treatment preferences
Legal implications	Forensic implications i.e family members caused the arrest
	Worried about being sued
	Worried about family member safety / hazards i.e defibrillator

Focusing on the patient

A focus on saving (protecting) the patient was a priority for all people involved. To that end, participants strove to minimise interruptions to the resuscitation in various ways. Some family members spoke about not wanting to be in the way, and did not enter the resuscitation room for that reason; yet they wanted to remain nearby in order to see the patient if they recovered or to be with the patient if they died.

> *I wouldn't want to interfere or interrupt any of the processes and I would probably be in the way … you know I'd like to be there as soon as possible after either way if you know what I mean. (Rosy: FM, Daughter)*

However, other family members stressed the importance of being there to advocate for the patient and protect their treatment rights and preferences; once again highlighting the importance of offering options for FPDR based on individual preferences and rights.

> *If it was my mother I'd be in there like Flynn saying 'Stop!' Coz (sic) that's her wishes. She does not want to be resuscitated. She's got heart failure. Her distinct wishes are, 'do not resuscitate me!' (June: RN)*

Protecting the patient's privacy and dignity was stressed to a lesser extent than saving their life. However, it was still an important consideration for health professionals when making decisions around FPDR. Privacy was also considered by participants when placing themselves in the hypothetical position of resuscitated patient and deciding whether they would want their family present and why.

> *Maybe my husband, maybe not the kids? That might be more of a privacy, intimacy thing. Because, obviously you're intimate with your husband, but you don't walk naked around your children … you probably wouldn't want your kids to remember you [like that]. (Carol: FM, Mother & RN)*

> *I think maybe that's why we don't have them [FM] in for things that are exposing them [patient] … Because you don't know what the relationship was like between the person and their relative. They may never have seen their mother with no clothes on. And then why is it suddenly ok to have her chest out and someone pushing on it … (Grace: RN)*

Some health professionals denied any form of FPDR in order to eliminate all chances of family members disrupting care; while others placed limits around the level or type of presence, for example by allocating a dedicated support person to stay with family. Either way, the outcome of wanting to protect the patient was impacted by the value placed on FPDR. Health professionals who valued FPDR were able to minimise disruptions and focus on saving the patient while at the same time catering to family needs and preferences. In contrast, health professionals who did not value FPDR denied it under the guise of wanting to protect the patient.

Minimising emotional impacts

Health professionals wanted to protect family members from the emotional impact of being present and from observing potentially distressing resuscitation scenes. However,

while there was a legitimate need to protect *some* family members who did not wish to be present or did not think they would cope with presence – such protection was not necessary in the majority of cases. As discussed previously, some family members had often already seen or even taken part in the resuscitation in the pre-hospital setting and wanted to continue this presence in the acute setting. Other participants believed family members were best placed to determine their own coping abilities and stressed the importance of offering flexible options and supporting whatever level of presence family members chose.

Importantly, none of the family members who had been present during resuscitation regretted it and most participants wanted FPDR for themselves or their family in the future. These findings echoed previous studies that reported unfounded fears that family members would suffer long term emotional affects from FPDR (Robinson *et al.* 1998; Compton *et al.* 2011; Pasquale *et al.* 2011). In addition, a recent randomised controlled trial has demonstrated a measurable benefit from FPDR regarding the long term psychological health of family members (Jabre *et al.* 2014). This finding further supports the notion that family members do not often want or need the paternalistic protection from FPDR that is offered or thrust upon them by some health professionals.

Preserving professional identities

It was not always clear whether participants' actions were aimed toward protecting others (as they claimed), or protecting themselves. For example, some health professionals initially spoke about wanting to protect others; for example protecting patients from disrupted care, or family members from emotional distress. Yet upon deeper examination, it appeared health professionals were often as (and sometimes more) concerned with protecting themselves from many of the performance anxieties outlined previously in table 9 (see page 176). Beyond health professionals' concerns about being judged on their performance was a fear of damaging their professional identify - of no longer being viewed or perceived as confident and competent professionals in control of the care they provide.

> *… during those things [invasive interventions] there's a lot of pressure, on all the team members. Intubation can sometimes be difficult … we don't want families to see us struggling with anything … (Grace: RN)*

Some health professionals were particularly concerned that their ability to communicate with each other would be inhibited with family members present. Further, they believed staff would become anxious about communication limitations and their performance would suffer; which in turn could negatively impact patient care. Another concern was that family members could misinterpret staff communication and become alarmed that health professionals may not be doing everything possible to save the patient.

> *… staff in resus don't really want to be observed by people who don't understand what they're doing … you don't want a family member being there while you go [animatedly] 'Oh shit! Sorry! Forgot about that!' or 'Whoopsy, I've given the wrong drug' or 'Oh crap, I don't know how to use this defib' … and the importance of 'Oh crap, I don't know how to use the defib – oh THAT button' may not have any effect on the outcome at all and may not really be important; but the family members might think that's important … that if you're there to defib, then you KNOW it … (Carol: FM, Mother & RN)*

However, these (often hypothetical) fears were mostly unfounded. Most health professionals claimed their performance was not adversely affected by FPDR and highlighted that it was unlikely family members would be able to accurately critique patient care.

> *There's that fear of failure. There's the fear of maybe not doing everything 100% correctly and having that either observed or examined. Having said that, most family members from the general public wouldn't be able to identify errors or missed steps or all those sorts of things; [so] that's not a fear that's probably well grounded. (Michael: RN)*

Indeed, some health professionals went further to claim that staff were often *more* professional in the presence of a family member. Others questioned the reluctance of health professionals to be observed in practice and recommended that the most effective way to preserve their professional identity was for staff members to be competent and confident in their role.

> *… well if they [staff] don't want them [FMs] watching them - why not? Are they doing something they shouldn't be doing? You know if you're doing your job to the best of your ability then it won't matter who's watching you. (Sally: RN & FM, Sister)*

Some participants went further to talk about open disclosure as an ideal response to errors, rather than hiding them from family by excluding them from the room.

> *Misadventures happen, and my policy is that's it's better to tell people. They're not deliberate acts of badness. They're acts where someone didn't quite have the skill set that was appropriate, and they can have very poor outcomes. But I think it's better to be honest about those things and wear that rather than try and pretend it didn't happen. (Anthony: Doctor)*

However, open disclosure was not a universal recommendation, and some health professionals were reluctant to disclose adverse events in order to preserve the image of the health professional at all cost.

Open disclosure involves an open discussion with a patient and/or family about any incident that resulted in harm and has been adopted by a number of healthcare services both locally and internationally for over two decades (ACoSaQiHC 2013; SA Health 2015). However, despite recent endorsement of a national Australian framework for open disclosure by government ministers and multiple nursing and medical professional organisations (ACoSaQiHC 2013), many health professionals in the current study and in the wider literature were reluctant to engage in open disclosure processes (Johnstone 2008; Byrth & Aromataris 2014). Barriers to open disclosure cited in the literature included fear of legal implications, a reluctance to admit error and uncertainty about what and how much to disclose (Finlay, Stewart & Parker 2013; Byrth & Aromataris 2014). These barriers were similar to those cited by health professionals in the current study as rationales to exclude family members from the resuscitation room.

Minimising the burden of presence

An important consideration for some participants was a desire to protect family members from the burden of presence during resuscitation. While the majority of people in this study expressed a preference to be present at the resuscitation of a loved one, several

people reported a strong inclination *not* to be present. These divergent findings highlighted once again the importance of assessing the suitability of people (including their preferences), before offering flexible options and supporting individual informed choices for FPDR.

Unique to this study was an in-depth examination of the experiences of family members who were also health professionals (HP-FMs) and their opinions about FPDR. Most HP-FMs were passionate about wanting to be present during resuscitation of their loved one, and were willing to use their professional status to gain special access to the patient not afforded general public family members. Some HP-FMs stressed a need to watch over their loved one and ensure that everything possible was done, while others just wanted to be there with and for their loved one.

However, several participants warned that HP-FMs faced an additional burden because of their specialised knowledge and experience, a concern that has been raised previously in the literature (Salmond 2011; Giles & Hall 2014; Giles & Willamson 2015). An example of this additional burden was described in detail by Sally, who was with her sister when she birthed a still-born baby. Sally thought something was wrong during her sister's labour, and believed staff error may have led to the baby's death. However, Sally's sister was not aware of this alleged error, and Sally struggled with this additional knowledge and whether to alert her sister.

> At 1 o'clock in the morning, [the midwife] checked the foetal heart and, to me it was quite slow, and I thought, I hope you're going to get the doctor. Because in my book – and I still maintain this to this day, you know, this baby should have been born at 1 o'clock … I was like three days wondering if I should say anything … so I did tell her [that she thought the staff had made an error] and now I regret telling her because it took four years for the nurses' board to act on anything … I regretted telling her because it took four years for her to get any response, and it prolonged her grieving. (Sally: RN & FM, Sister)

Sally's account highlights the need to recognise that HP-FMs may have different needs and preferences than general-public family members (Salmond 2011; Giles & Hall 2014; Giles & Willamson 2015) and is a reminder of the need for adequate follow-up and support for all family members who are present during a resuscitation event. It is also

important to note that, despite believing staff error had contributed to an adverse outcome for the baby, neither Sally nor her sister considered litigation. Instead, Sally and her sister wanted someone to acknowledge and apologise for the alleged error and, in order to ensure a similar incident did not occur in the future, they reported the case to the Nurses Board for further investigation.

Unfounded legal implications

Legal implications have been raised previously as a major perceived risk of FPDR. As presented previously in the preliminary literature review (see table 2, page 33), a perceived fear of litigation was one of the most commonly cited barriers in the FPDR research, with 49 studies including a question about litigation in their closed response surveys. However, these fears appear unfounded, with none of these studies reporting litigation incidents as a result of FPDR. Furthermore, during an extensive search of the literature no evidence could be found that supports the notion of litigation resulting from FPDR. Very few participants in the current study mentioned potential litigation of their own accord, and when specifically asked, no participant could recall a situation where a family member had sued and most believed the likelihood of this occurring was remote.

> *I think it's [fear of litigation] overstated and fear-mongering. I think that if people understand what we're doing is everything we possibly can in the circumstances, it's deciphered appropriately and they feel that all of their enquiries are honestly answered then, I think that, I've never had a family member say to me you know 'we're going to sue you' or have had subsequent problems … I think it's a much greater risk that if they are isolated and separated from the events that they can build around that secrecy which just is not there.(Darren: RN/NP)*

Evidence from this current study and the wider literature suggests that concerns about litigation as a result of FPDR are currently unfounded and should not be used as a rationale to deny FPDR. Rather, the implementation of informed and supported FPDR appears to reduce the mystery surrounding resuscitation which in turn could actually reduce litigation risks, something that has been reported previously by Porter, Cooper and Sellick (2014).

CHAPTER SUMMARY

Chapters six, seven, eight and nine provided an in-depth understanding of the major processes enacted by health professionals and family members when deciding to practice or participate in FPDR in an acute healthcare setting. In particular, these chapters have highlighted the subjective nature of current practices in the absence of any formal guidelines and the impact of opportunistic presence. These chapters have also emphasised the significant relationship between valuing and practicing FPDR, and between valuing FPDR and the legitimate power and authority to enforce personal preferences around the practice.

Chapter nine detailed the way in which people involved in a resuscitation event made a series of value-laden judgements in order to determine if and to what extent FPDR would be implemented in a particular setting or context. These judgments included prioritising the preferences and rights of people involved, assessing suitability of the people, the space and the context, and setting boundaries around the level of presence. These value-laden judgments were made in order to protect others and self from potential or perceived risks associated with FPDR, and were enacted in an ad-hoc manner. The cyclic and interconnected nature of these subjective judgements was evident by the varying order in which these decisions were made in different resuscitation contexts. Further, the subjective and value-laden nature of these judgements was evident from the wide variation in practices in the absence of standardised guidelines or policies. The people involved in the decision to practice or participate in FPDR enacted each of these processes in a variety of ways with varying outcomes. These large variations suggest current practices are based mainly on the personal preferences of people with the highest level of perceived or actual power in a particular setting or context.

The interconnected categories and processes examined thus far comprised the central theory of this thesis. Conditional permission was a social construction made possible by the perceptions of individuals and groups as they interacted with each other and with their environment. A theoretical discussion of *the social construction of conditional permission* is presented in the final findings chapter.

Chapter Ten: The Social Construction of Conditional Permission

CHAPTER OVERVIEW

The purpose of this study was to construct a substantive grounded theory of FPDR using the constructivist approach developed by Charmaz (2006, 2014). More specifically, this study examined the factors influencing decision-making around FPDR. Flexible GTM guidelines were used to examine social processes by studying meanings and actions, and to create an abstract, theoretical understanding of the data (Charmaz 2014). The use of GTM allowed me to move beyond exploration and description to the generation of a conceptual theory that explained FPDR from the perspective and in the context of the people who experienced it. Chapters five to nine presented the conceptual categories and properties of the substantive theory. Chapter ten offers a theoretical discussion of the grounded theory and discusses how the theory is situated in and builds upon existing knowledge.

CONSTRUCTING THE SUBSTANTIVE THEORY

The substantive theory developed during this study was *The Social Construction of Conditional Permission*. This theory explains the major social process at work when people were faced with a decision to practice or participate in FPDR. The conceptual model depicted previously as Figure 4 (see page 97) and presented again as Figure 10 (see page 185) was constructed to symbolise and explicate the social processes of the theory. This model depicts the cyclic and inter-connected nature of the processes enacted from the moment a patient required cardiopulmonary resuscitation in the direct or indirect presence of a family member to determine the implementation and type of FPDR.

This theory was constructed using conceptual abstraction (as detailed in chapter four), beginning with and always grounded in the participants perspectives of their own reality of FPDR (Charmaz 2014). Theory construction involved developing abstract concepts and specifying the relationships between them. The theoretical concepts presented in this thesis were constructed as part of an iterative process of going back and forth between

progressively focused data and abstract conceptualisations of them (Bryant & Charmaz 2007b, p. 25).
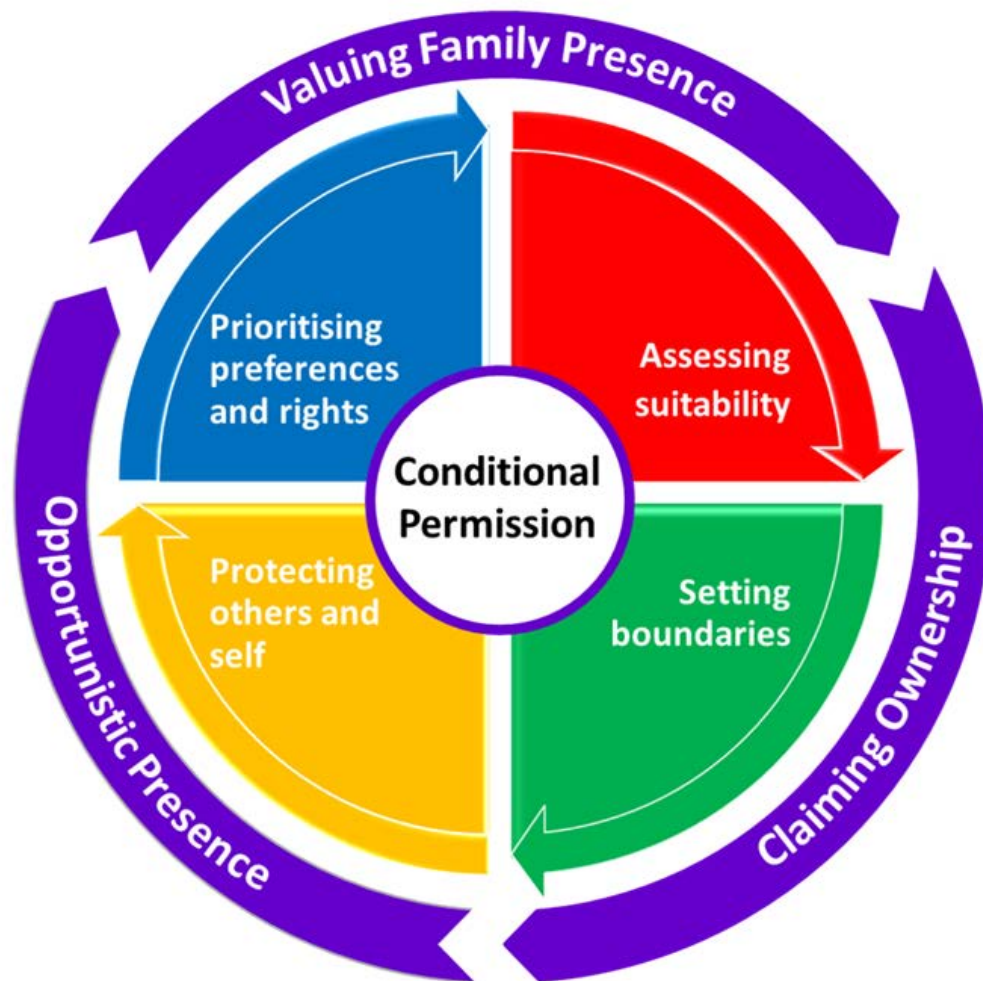
Figure 10: Conceptual model
The Social Construction of Conditional Permission
A grounded theory of family presence during resuscitation

This grounded theory contributes to an understanding of decision-making around FPDR in Australian acute healthcare settings. However, it is important to note that this theory provides an interpretation and conceptual understanding (Charmaz 2014) of FPDR within the contexts outlined in this thesis and therefore may not be applicable to experiences in different contexts. While a central role of GTM is to construct theory, they are not meant to be seen as universal explanations (Bryant 2009). This thesis employs Charmaz's (2014, p 344) theory definition to provide a theoretical explanation of a delimited problem in a particular area that is abstract and interpretivist. As such, the understanding from this

theory relied on my interpretation of the studied phenomenon and used an interpretive approach to theorising in order to allow for indeterminacy, which is compatible with social constructionism and symbolic interactionism.

DEFINING CONDITIONAL PERMISSION

The term 'conditional permission' has been used previously in several contexts outside of healthcare. In the building and construction industry, conditional permission is granted when all specified associated conditions have been satisfied (ProSyst 2015), or as an alternative to outright refusal (defra 2011). Conditional permission has also been discussed in relation to conditional deontic logic - the logical theory of the ethical concepts of permission, disallowal, obligation and (moral) commitment (Rescher & Anderson 1962). However, deontic logic was not relevant to the grounded theory constructed in this thesis because it involves the consideration of what we may, must or should do (Manktelow & Over 1991), rather than what was, is or will actually be the case.

Deontic logic researchers have examined the prediction of conditional permission in relation to pragmatic reasoning or permission schema (Cheng & Holyoak 1985, 1989), social contract theory (Cosmides 1989), and subsequent amalgams of both approaches (Manktelow & Over 1991). The latter researchers defined conditional permission as the action that can be taken if a particular condition is filled; i.e. you may do X if you first do Y. However, in contrast with this thesis, the approaches outlined by deontic researchers focus on testing and predicting what participants would do in response to a 'conditional permission statement.' More specifically, they examined whether participants would be able to correctly choose whether a 'conditional permission' was true or false. The premise of Manktelow and Over's (1991) research was therefore not able to explain the complexities of conditional permission for FPDR. In contrast, the grounded theory constructed in this thesis explains the processes enacted by individuals and groups during the social construction of conditional permission and provided an interpretive understanding of peoples' meanings and actions in relation to FPDR.

In general terms, a 'condition' is a situation that must exist before something else is possible or permitted, while 'conditional' means subject to one or more conditions or requirements being met (Oxford Dictionaries 2015). The term 'permission' describes

the process of officially allowing someone to do a particular thing; or

consent or authorisation (Oxford Dictionaries 2015). The phrase 'officially allowing' in this definition suggests the person providing or granting permission has some form of legitimate power over the person receiving this permission.

Building on these general definitions, conditional permission for FPDR referred to a situation whereby a person with actual or perceived power allowed or invited a family member or significant other to be in the room with the patient during a resuscitation event *if and when* a series of conditions or requirements were first met. Conditional permission was enacted through a series of inter-related processes by the people involved, directly or indirectly, with a resuscitation event. The nature of these conditions, the way in which they were constructed and the factors influencing these constructions were detailed in chapters six to nine. In essence, participants made a series of value-laden judgements that, together, determined the type and level of FPDR that was enacted.

FPDR always required some form of permission (overt, inadvertent or implied) and was always conditional, continually reassessed, and subject to retraction if the established boundaries of conditional permission were breached. The only exception to successful retraction was when family members refused to leave the room (an uncommon response which is discussed later in this chapter). Established boundaries varied widely and were influenced by the subjective attitudes and beliefs of the people setting these boundaries. Health professionals and family members who valued FPDR placed fewer conditions on presence, and were more likely to ensure those conditions could be met in order to ensure FPDR was implemented. Conversely, health professionals and family members who did not value FPDR placed multiple conditions on the practice; sometimes to the extent where meeting them became impossible. Often, the conditions placed on FPDR were used as rationales to justify denying the practice. In essence, conditional permission was impacted most by the extent to which FPDR was valued by individuals and groups who claimed control of permissions.

PERMISSION AS A SOCIAL CONSTRUCT

As stated previously, the term permission describes the process of officially allowing or authorising someone to do a particular thing. Permission has not been previously

discussed as a distinct concept in the FPDR literature. Yet the body of FPDR literature examining attitudes, beliefs and practices is inherently linked to the concept of permission. So too is the endorsement of FPDR from professional organisations, which indicates an implied permission. The language used throughout most published FPDR studies clearly demonstrates a taken-for-granted assumption that health professionals *are* or *should* be in control of whether family members are present during a resuscitation event.

The majority of published FPDR studies included in chapter two were quantitative and used fixed response questionnaires to generate their data. As a result, participants were exposed to the researchers' taken-for-granted meanings as they completed questionnaires. For example, participants were asked if they had or would 'allow', 'permit', 'forbid', 'oppose', 'invite', 'approve' or 'deny' FPDR. Appendix 23 (see page 316) contains a comprehensive summary of the permission terminology used within the FPDR studies included in this thesis. The use of these permission terms supports an inherent assumption (or social norm) that health professionals are in charge of who is or can be present during a resuscitation event. In other words, health professionals were assumed to be in control of permissions for FPDR.

In order to be reflexive about my research and acknowledge my role in the co-construction of this grounded theory (Charmaz 2006, 2014), it was important to acknowledge influences and taken-for-granted meanings that have helped shape the emergent grounded theory. During analysis and theory construction, it became evident to me that the taken-for-granted meanings outlined above and my previous experiences as a registered nurse influenced the wording of my interview questions and the terminology I used during analysis and theory construction.

For example, several of my interview questions asked; 'whose decision do you think it should be whether a family member is allowed to be present during resuscitation?' and 'what are your thoughts about whether family members and/or patients should be given the option to be present during resuscitation of their loved one?' My use of the terms 'allowed' and 'given the option' suggests the granting and receiving of permission from one person or group to another, and may have influenced participant answers. However,

these questions were posed toward the middle and end of interviews - after more open questions had been asked, such as 'can you tell me about your experience of being a family member who was either present or wanting to be present during a resuscitation event' and 'can you tell me about your experience of having a family member present or wanting to be present during an active resuscitation?'

Many participants used permission terminology in response to these open questions, before I had included them in a question. Some health professional participants spoke about 'allowing', 'letting', 'inviting' or 'asking' family members to remain in the room during the resuscitation. Others used less overt permission terms such 'being happy' for family members to be present or 'choosing to leave them in the room.' Family member and patient participants also used permission terminology that indicated an inherent deferral to health professionals, who they viewed as being in charge of permissions around FPDR. For example, *'they haven't offered me that', 'she's not allowed in', 'they won't let her in'* and *'you can't come in.'*

These findings highlight shared, taken-for-granted meanings and assumptions about FPDR permissions between health professionals, family members and patients, and support the wider social construction of 'permission' that is evident in the healthcare system. Traditionally, health professionals are seen as having expert authority and as such are perceived as 'being in charge' in particular contexts. The dominant position of medical knowledge has long been considered an important factor in decision-making in healthcare settings (Freidson 1970a; May 1995; Netherton 1995; Elston 2002; Coombs & Ersser 2004). Further, medical authority is commonly viewed as a type of social authority - where medical professionals can control the actions of others by giving commands; and also as a cultural authority - where medical judgments and definitions of what is real and acceptable are more likely to be accepted by the rest of society as valid and true (Elston 2002).

In the current study, health professionals used their expert, professional authority (May 1995; Kettunen, Poskiparta & Gerlander 2002) to take control of permissions for FPDR. At the same time, family members fit themselves into what has been referred to as the 'normal' or 'expected' role of passive recipients of healthcare (Joseph-Williams, Elwyn &

Edwards 2014). According to Joseph- Williams and colleagues (2014), health consumers often allow or even expect health professionals to make decisions on their behalf, and many consumers are hesitant to question professionals to avoid undermining their status and authority. This reluctance to query authority could explain the often passive acquiescence seen by family members in the current study.

Deference to medical authority has been discussed in the literature for many years. More than half a century ago, Parsons (1951) argued that for the doctor-patient relationship to function effectively, patients need to be assigned a 'sick role' and defer to medical authority. Similarly Freidson, (1970a, 1970b) asserts that medical dominance and authority were the hallmarks of a true profession. However, since that time May (1995) cautions that the exercise of authority by one person over another can restrict freedom and that exerting such authority over another adult may in fact be illegitimate. More recently, there has been a move away from paternalism toward a more patient (and family) centred approach to healthcare (Goodenough & Brysiewicz 2003; Luxford, Gelbsafran & Delblanco 2011). This is being driven in part by increasing public access to specialised information that was previously accessible only by expert professionals, and in part by a growing recognition of consumer rights (Berwick 2009). However, the paternalistic attitude of health professionals 'knowing what's best' for patients and their families is still evident – both in this current study and in the wider literature.

For example, Protheroe and colleagues (2012) reported that patients with chronic illness were reluctant to ask questions about their care, and that many had a preconceived idea not only of what was expected of them as patients but of their expectations of paternalistic care from health professionals. Similarly, Frosch *et al.* (2012) reported that many patients were reluctant to engage in shared decision-making for fear of being labelled 'difficult.' Instead, these patients conformed to socially accepted roles by deferring to their doctors advice. Nyman, Downe & Berg (2011) also wrote about asymmetrical power relationships, describing how expectant parents often felt inferior and exhibited obedient acceptance of health professionals as they waited for 'permission' to enter the labour ward.

Asymmetrical relationships in healthcare have been reported frequently in the literature over many decades (Abbott 1988; Kettunen, Poskiparta & Gerlander 2002; Nyman, Downe & Berg 2011; Rees, Ajjawi & Monrouxe 2013). These asymmetrical relationships are often supported and even perpetuated by health professionals and health consumers. These socially constructed roles and expectations that were evident in the current study exerted a significant impact on the social construction of conditional permission.

THE SOCIAL CONSTRUCTION OF CONDITIONAL PERMISSION

The social constructionist perspective of this research allowed me to examine and interpret the subjective meanings that people attributed to what they said and did in relation to FPDR in order to categorise their experiences (Guba & Lincoln 2005; Charmaz 2014). This approach also allowed me to learn the way in which FPDR was entrenched in larger and often hidden situations and relationships, and highlighted hierarchies of power involved in decision-making around FPDR (Charmaz 2006). This grounded theory study thus elucidated taken-for-granted meanings and assumptions around FPDR practices, and explained the way in which conditional permission was constructed and by whom.

The interconnected processes enacted during the social construction of conditional permission were subjective, variable and dynamic, and reflected the multiple realities of the people involved. People's meanings shaped their actions and their actions conveyed their meanings. Interpretation of these actions helped make taken-for-granted meanings visible as I examined how people interpreted and acted upon the larger social meanings available to them in their particular setting (Charmaz 2004).

When deciding whether to practice or participate in FPDR, people acted according to their interpretations of the phenomenon in a particular context and for a particular set of people. For example, if health professionals believed FPDR was risky or traumatic, they sought to reduce that risk by setting particular boundaries around the type and intensity of presence or by excluding family members from the room altogether. If family members shared this negative interpretation, they were likely to acquiesce to particular boundaries or even complete exclusion. Similarly, if health professionals and family members shared a beneficial interpretation of FPDR, then it was implemented with fewer boundaries and support was provided to overcome any risks or barriers.

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In contrast, there were occasions when meanings and interpretations clashed. This occurred when some individuals and groups believed FPDR to be more beneficial than others or when individuals and group misinterpreted the meanings and interpretations of others. For example, some health professionals excluded family members from the resuscitation room in order to protect them from potentially 'traumatic' scenes. However, family members often did not want or need this protection and wanted to be asked about their own interpretations of what they considered too traumatic for them to observe. In other words, some health professionals used their own meanings and interpretations rather than trying to understand family members' meanings for those same processes.

In addition to being influenced by meanings and interpretations of FPDR, people acted according to their pre-determined social roles and status. Role theory was developed in the 1920s and 1930s (Brookes *et al.* 2007) and is concerned with patterns of human conduct or the roles they play in society - including expectations, identities and social positions. In his writings on role theory, Biddle (1979, 1986) explains that social roles and status' are created through shared expectations for how those roles should act in a particular context. In other words, people learn the behaviours expected of them (as a result of their social roles) by socialising with others. Further, these roles are often associated with a set of people who share a common identity or social position, i.e. health professionals and health consumers. According to Biddle (1979, p. 8) role theory is based on five assumptions;

1) Some behaviours are characteristic of people in a particular context.
2) Roles are associated with a set of people who share a common identity or social position.
3) People are aware of these roles and in some cases their behaviour is impacted by expectations around these social roles.
4) Roles often persist because of the function they provide and because they are often embedded in larger social systems.
5) People must be taught roles (ie must be socialised) and may be happy or unhappy with their subsequent roles.

Role theory has been used previously to explicate relationships between healthcare providers and consumers, including family caregiver role acquisition (Schumacher 1995), community nurse roles in contemporary health systems (Brookes *et al.* 2007) and the nature of consultations between childcare providers and nurse childcare consultants (Crowley 2008). Role theory has also been associated with symbolic interactionism (Biddle 1979; Brookes *et al.* 2007) and as such is a suitable framework to explicate behaviours and decision-making in the current study.

Due to their pre-existing authority and shared expectations of their role, health professionals were automatically perceived as being 'in charge' of who could and could not be present during a resuscitation event. Whereas family members accepted the submissive role of health consumer outlined in the previous section, and acquiesced to health professionals' instructions and commands. These pre-existing social roles and expectations often appeared fixed or static, as the frequently repeated actions and processes enacted as part of the social construction of conditional permission became patterns that were reproduced with minimal effort. As a result, these repeated actions and processes become embedded as routines that formed the current state of knowledge in a particular healthcare setting. According to Andrews (2012), repeated actions are then institutionalised by society to the extent that future generations experience that particular knowledge as objective. This knowledge is then continuously reaffirmed during ongoing interaction between individuals and groups. Similarly, Charmaz (2014, p. 271) argues that people learn and absorb routine meanings and practices during their daily interactions with others. This was certainly evident in the current study. When their FPDR interactions became routine, people were less interpretative about their actions and instead started to follow setting norms without question.

In healthcare settings where FPDR was practiced consistently and the conditions placed on presence were achievable, health professionals and consumers viewed that shared construction as a social norm. Similarly, shared constructions also became a routinised norm in settings that did not practice FPDR. As setting norms become routinised, people were unlikely to change their practices or the meanings those practices had for them

unless those situations became problematised and their habitual responses no longer worked, or when new unanticipated situations or opportunities arose (Charmaz 2014).

Fixed routines were able to be disrupted when people challenged traditional social roles. This occurred when a family member refused to accept that health professionals should automatically be in charge of who has access to the patient, or when health professionals actively involved family members in decisions around FPDR. The subsequent shared decision-making in these cases saw family members and health professionals negotiating a suitable agreed level of FPDR.

Embedded routines were also interrupted as a result of opportunistic presence. Unplanned exposure to FPDR often resulted in people altering their meanings and interpretations of the phenomenon. People's pre-existing fears were often revealed to be unfounded and they re-interpreted FPDR as more beneficial and less risky. As a result, they began to question the traditional roles evident in many health care settings.

FPDR was therefore practiced most successfully in settings where individual meanings were explicated and new shared meanings were established. When this occurred, family members were offered options around FPDR and supported throughout agreed levels of presence. The impact of professional power and authority on decision-making was an important factor in this collaborative approach and the likelihood of success relied on health professionals' willingness to collaborate and engage in a more family/consumer-centred approach to care.

Family-centred care (FCC) emerged in the late twentieth century to involve families in the promotion of health and well-being of their children (American Academy of Pediatrics Committee on Hospital Care 2003). It is now considered an integral dimension of quality health care in all populations (Luxford *et al.* 2010; ACoSaQiHC 2011b; Coyne *et al.* 2011; Luxford, Gelbsafran & Delblanco 2011). FCC builds partnerships between families and health professionals, helps family members feel comfortable in the healthcare setting, recognises their needs and contributions and improves their access to information and to the patient (Cypress 2012). Similarly, consumer-centred care focuses on the importance of partnerships between health services, health professions and health consumers

(ACoSaQiHC 2011b). Standard two of the National Safety and Quality Health Service Standards, *partnering with consumers*, highlights the importance of involving healthcare consumers in decision-making around their own health care (ACoSaQiHC 2011a).

A family/consumer centred approach to FPDR was viewed as an important and achievable goal for many participants in this study. However, while there was evidence of such an approach in some settings, many others fell short of meeting the inherent requirements of this collaborative approach to care.

CHAPTER SUMMARY

This chapter presented the substantive grounded theory that interpreted and explained decision-making around FPDR in acute healthcare settings. Conditional permission was shown to be a social construction made possible by the ongoing interactions and interpretations of people playing a particular role in a particular setting or context. Conditional permission was influenced by people's values and preferences, their previous experiences with FPDR and the pre-existing role and status expectations of individuals and societies. The interconnected processes enacted during the social construction of conditional permission were therefore subjective and dynamic, and reflected the multiple realities of the people involved.

Although some findings in this study were shown to link to existing constructs, this theory is original in how it has used a new approach to interpret and explain rather than merely describe FPDR attitudes and practices. This theory contributes to an enhanced understanding of FPDR practices in Australian acute healthcare settings and offers an explanation for the wide variations and inconsistencies evident within and between health care settings. Construction of this theory and the conceptual model led to new insights into current FPDR practices and has important implications for future practice, education, research and policy around FPDR. The study implications are discussed in the conclusions chapter, along with strengths and limitations of the study and recommendations for future education, practice, policy and research.

Chapter Eleven: Study Conclusions

CHAPTER OVERVIEW

Chapter ten presented the substantive grounded theory of family presence during resuscitation: *The social construction of conditional permission*. This theory captured the meaning and actions of participant experiences and explained the major social process at work when people were faced with a decision to practice or participate in FPDR. This theory offers new insights into attitudes and practices that have not been previously documented in the FPDR literature, and offers an explanation for the wide variation and inconsistencies evident within and between healthcare settings. This final chapter begins with a discussion of the overall study contribution before detailing the strengths and limitations of the research. This is followed by the implications of the study in relation to future research, practice, education and policy development. Chapter eleven finishes with some concluding remarks and the thesis epilogue.

CONTRIBUTION OF THE STUDY

Family presence during resuscitation has been discussed extensively in the literature since the 1980s. The preliminary review presented in chapter two established baseline attitudes, beliefs and practices over several decades - mainly from the perspective of health professionals. There is also a growing body of evidence that FPDR provides important benefits to family members such as helping with closure and grieving, and reducing the incidence of post-traumatic stress disorder (for example see Jabre *et al.* 2014). However, many gaps and inconsistencies were identified that limit our current understanding and effective implementation of FPDR practices. In particular, the literature has not previously examined factors that impact current practices - more specifically, how decisions are made to practice or participate in FPDR. Instead, existing research is significantly skewed toward descriptive, quantitative designs, and has occurred outside Australia in different health care systems and cultures. Despite a growing body of evidence supporting multiple benefits and despite being endorsed by the Australian Resuscitation Council, FPDR is still not practiced widely or consistently in

Australia and most healthcare settings do not appear to have policies in place. This current research was designed to address some of these knowledge gaps.

As stated in chapter one, the aim of this research was to examine factors and perceptions that impacted decisions around FPDR in Australian acute healthcare settings. The aim was deliberately broad in keeping with core GTM tenets and to allow for the flexible and dynamic nature of GTM methods. This study examined and interpreted the socially constructed meanings that formed the experiences of health professionals, family members and patients and the actions that resulted from those meanings.

A constructivist GTM was chosen for this study for its ability to provide a behavioural perspective, enable explanation of behaviour and facilitate the development of a conceptual theory that could be applied in practical situations (Glaser & Strauss 1967; Charmaz 2006). With its theoretical underpinnings of symbolic interactionism and social constructionism, constructivist GTM was particularly suited to this research because it endeavoured to understand and explain the processes people used to construct meaning from their inter-subjective experiences (Charmaz 2004; Suddaby 2006).

The systematic application of core GTM methods and processes during data generation and analysis facilitated the generation and integration of the substantive grounded theory. Chapters five to ten presented the theory, and detailed how this theory is situated in and built upon existing literature. The findings detailed in the substantive theory illustrate new contributions to knowledge and understanding of peoples' FPDR experiences and practices which will have relevance both nationally and internationally. This theory interprets and explains the meanings and actions of health professionals, family members and patients involved in FPDR, and as such the aims of this study have been met. Further, this study provides a unique perspective into the factors impacting FPDR practices from multiple perspectives; something that has not been done previously in Australia. This grounded theory contributes a theoretical understanding of FPDR and also has practical implications for clinical practice, education, research and policy. A discussion of the strengths and limitations of the research is presented in the following sections, followed by the study implications and recommendations.

STRENGTHS OF THE RESEARCH

The systematic and rigorous application of core GTM methods facilitated the construction of a substantive grounded theory that was both grounded in the data and further enhanced during integration of the theory with existing knowledge. Rigorous application and evaluation of the GTM processes and methods employed during this research ensured the final theory demonstrated appropriate credibility, originality, resonance, fit, relevance and practical applicability against established criteria (evaluation and rigour are detailed in chapter four on pages 90-92, and in appendix 22 on page 314). Publication of several peer reviewed methodological articles (Giles, King & de Lacey 2013; Giles, de Lacey & Muir-Cochrane 2016) and the construction of a comprehensive methodological diary (see page 284) further increased the rigour of the study. So too did monthly critical discussions with the study supervisors.

Healthcare participants worked in a variety of acute healthcare settings in five different Australian states and as such provided a rich and varied set of FPDR experiences. The inclusion of several family members who were also registered nurses provided an important and unique perspective of FPDR from multiple roles. Most importantly, all participants had experienced FPDR in some way and were therefore able to contribute to a rich data set around actual as well as hypothetical experiences.

A comprehensive preliminary literature review was undertaken prior to the study in order to fully comprehend the current state of knowledge and to avoid the conceptual and methodological limitations of previous research. As a result, the constructivist grounded theory approach taken in this study was unique and has made an important contribution to the existing body of FPDR knowledge. The grounded theory and conceptual model developed during this study will help to inform education, practice and policy development as well as making important recommendations for future research, both in Australia and internationally.

STUDY LIMITATIONS

Several limitations must be taken into account when interpreting and applying the research findings and final substantive theory. Results from this study also need to be

balanced against related research that was detailed in chapter two and integrated throughout the findings chapters.

The theory constructed during this study provides an interpretation and conceptual understanding of FPDR within acute healthcare settings in Australia and therefore may not be applicable to experiences in different contexts. However, the theory is general enough to have a wide reach and may be useful when considering how conditional permission is constructed and applied in other health-related situations and contexts such as family presence during invasive procedures.

Data was limited to five Australian states and thus may not represent views from people living in other states, nor be transferable to experiences outside Australian healthcare settings and systems. Further, the moderate sample size of this study limits any subsequent claims and recommendations. However, as detailed in chapter four, theoretical saturation was achieved and the sample size was deemed adequate for the claims being made in this thesis.

The aim of this study was to examine FPDR practices from multiple perspectives; including health professionals, family members and patients. While every effort was made to recruit adequate numbers of all three types of participants, the final ratios were skewed toward registered nurses, with only two doctors registering their interest in the study despite widespread advertising among professional publications and organisations. This may reflect a lower level of import placed on FPDR by doctors than nurses; a view which is supported by the wider literature presented in chapter two (see pages 17-18).

Low survival rates made recruitment of resuscitation patients difficult, something that has also been noted previously in the literature. The sole patient recruited into this study provided an important and rarely heard voice to the final theory. However, it is recognised that one patient cannot and does not speak for all potential patients. Family members were also difficult to recruit due to difficulties with gatekeepers and ethics committees in healthcare settings. However, inclusion of the often-missing family member voice in this study provided a vital addition to the theory and ensured multiple role contributions to this social construction were considered.

In-depth interviews were used as the primary method of data generation to facilitate the telling of individual stories and experiences. While the use of observational data may have strengthened the final substantive theory, interview data was deemed the most effective way of addressing the research aims within the constraints of this doctoral research. Furthermore, this thesis met Charmaz's (2014) recommendations for generating 'rich data' in GTM research, which comprises detailed and focused accounts that reveal participants attitudes, beliefs, intentions and actions within the contexts of their experiences. In order to determine the adequacy of data generated for this thesis, I applied Charmaz's (2014, p. 33) criteria for 'rich and sufficient' data which included; sufficient background data, a wide range of participant views and actions, an examination of hidden meanings, sufficient data to reveal changes over time, multiple views of participants' range of actions, data that enabled the development of analytic categories and the ability to make comparisons between the data in order to generate and inform abstraction and conceptualisation of the final theory.

As with all constructivist GTM research, this thesis was a co-construction of knowledge and experiences, and my ongoing interpretations were influenced by my past experiences as a registered nurse and as a family member. In order to address potential bias, I used reflexivity (as detailed in chapter four) to critically examine the research process and to assess how and to what extent my attitudes and experiences may have influenced processes and outcomes. Being actively reflexive during the research process made my personal assumptions explicit and I was able to articulate how prior knowledge and experience influenced data analysis and theory construction.

Despite these limitations, the aim of this study, which was to generate a substantive theory of family presence during resuscitation, was achieved. As a consequence, new knowledge has been generated about this phenomenon that forms a useful and unique addition to the existing body of work. The implications of this new knowledge are presented in the following sections.

IMPLICATIONS OF THE STUDY

The final grounded theory - *the social construction of conditional permission* - has led to an enhanced understanding of FPDR in acute healthcare settings. While this research took

place in an Australian context, the theory is also relevant in an international context due to similarities in healthcare between Australia and many other countries such as the United Kingdom and Canada This research highlights a number of significant implications that are relevant to health professionals, managers, policy makers, health consumers and the general public, both in Australia and internationally. The following discussion details these implications in relation to their contribution to future clinical practice, education, research and policy development.

Education and practice implications

Opportunistic presence was identified as an important facilitator for FPDR in this study and demonstrated how attitudes, and subsequent practices, could be influenced through exposure and role modelling. In particular, health professionals who had never practiced or even thought about FPDR often experienced significant attitude changes following the inadvertent presence of a family member. In the majority of cases, opportunistic presence was a catalyst for people to become more supportive of family presence during future resuscitation events. Building on the influence of opportunistic presence, providing education and awareness about the benefits and risks of FPDR and addressing unsubstantiated fears is an important first step to ensure clinical practice is based on evidence rather than personal preferences.

FPDR requires health professionals to combine high level technical skills with empathy to provide safe, effective and compassionate family/consumer-centred care. It is therefore imperative that health professionals are adequately prepared to cope with all aspects of a resuscitation event that recognises and involves family members as an integral part of the healthcare team. There is a current expectation that resuscitation staff complete regular education and training to maintain and update their skills. The addition of simulation training would expose health professionals to realistic FPDR scenarios and prepare them to work competently and confidently under observation while supporting family members throughout and beyond the resuscitation event.

While the value-laden nature of clinical decision making has been discussed extensively in the literature (refer to page 146), it has not been considered previously in relation to FPDR. This study provided a unique, in-depth examination of the impact of value-laden

judgements on FPDR practices. The subjective nature of these judgements led to wide practice variations based on individual values, preferences and pre-existing expectations around social roles and statuses. However, the implications of value-laden decision-making reach well beyond emergency resuscitative care to a wide range of clinical practices; for example, prescribing antibiotics for very elderly patients and discussions around not-for-resuscitation orders, end-of-life care and organ donation. Many healthcare professionals are not aware of the subjective nature of value-laden decision-making and associate risks - such as the danger of projecting personal preferences and beliefs onto others and making decisions that contradict consumer preferences or beliefs.

Increasing awareness and education around the implications of value-laden clinical decision-making is an important first step to reducing unnecessary practice variations. This education should be implemented both in clinical healthcare settings and undergraduate curriculums. The inclusion of guided clinical decision-making during simulation training could also be offered to encourage consistent and evidence-based practices that are focused on consumer safety and welfare rather than personal preferences and setting norms.

It is understandable that some health professionals are reluctant to practice FPDR due to performance anxiety and fears of being critiqued or judged by family members. However, discomfort and personal preference are not acceptable reasons to exclude family members from the resuscitation room, and in turn from the known benefits of FPDR. Once again, adequate education and training are key to ensuring health professionals are competent and confident to practice FPDR safely and effectively.

Also understandable is the reluctance of some health professionals to surrender a portion of their professional power by sharing ownership of the patient, the space and the resuscitation act with family members. Some staff perceived such ownership sharing as a threat to their professional role/status, and it is important to acknowledge these fears. However, such concerns should not influence practice or impede progress. Society needs to challenge old fashioned views and traditional roles where health professionals are considered all-knowing 'experts' while family members are viewed as submissive recipients of care. Instead, family members and patients should be empowered to

become part of the healthcare team and be involved in end-of-life care decisions if they wish. Shared ownership through partnering with consumers should be highlighted as a way to enhance professionalism, empower family members and promote family-centred care.

Evidence from this study and the wider research highlights the importance of a dedicated support role for family members during FPDR. This study went further to suggest that implementing FPDR in the absence of a support person could do more harm than good. However, in many healthcare settings that practice FPDR, a dedicated support role does not exist consistently or at all. Current barriers to the widespread implementation of a support role include financial limitations, staff shortages and a low value placed on the role and on FPDR in general. However, the increasing body of evidence supporting the benefits of FPDR and the potential harm of forced separation of family members from their loved ones during resuscitation necessitates a rethink of all events.

'Allowing' fathers into labour wards in the western world required a paradigm shift in the 20th century. Many health professionals at the time believed fathers would be in the way, impede the birth and potentially divert staff attention from the mother and baby. Yet, change occurred over time as attitudes shifted and fears were shown to be unfounded. Similarly, there needs to be a widespread paradigm shift among health professionals, managers and policy makers for the 21st century in relation to resuscitation events.

Cardiopulmonary resuscitation has been practiced for many years in an attempt to reverse sudden death, and 'saving the patient' is still prioritised over supporting family members in many healthcare settings. Certainly, when death is reversible and when there is no one available to stay with and support family members, such prioritisation is warranted. However, it is time for all healthcare settings to acknowledge that FPDR has been practiced successfully for almost three decades, and that it is not only possible but desirable to attend to the needs of family members while providing effective resuscitation care.

Consistently low resuscitation survival rates also mean that if FPDR is denied, many family members are missing out being with their loved ones at one of the most important

moments in their lives. Segregation of family members from their dying loved ones violates core family-centred care principles and denies the patient and their families a 'good death.' The family member's inherent right to be with their loved one needs to be recognised and facilitated in the same way as other end-of-life contexts such as palliative care. Health professionals need to stop perceiving unsuccessful resuscitations merely as medical failures and instead seek the opportunity to facilitate the best possible end-of-life event for the patient and their families. Structured yet flexible FPDR guidelines and policies would facilitate the opportunity for health professionals to promote a 'good death' for patients and their families, even in the rush of an unexpected resuscitation event.

Policy implications

Dying should not be thought of as just a biological or medical event. According to the Australian Commission on Safety and Quality in Health Care's National Consensus Statement (ACoSaQiHC 2015) on the essential elements for safe and high quality end-of-life care, dying should be viewed as a normal part of the human experience. In order to deliver safe and high quality end-of-life care, there must be a focus on patient/family-centred care during every resuscitation event. Whenever possible, end-of-life care should be aligned with the values, needs and wishes of the patient and their family. Offering flexible options and supporting individual, informed choices around FPDR would promote these aims.

There is now a significant body of evidence supporting the benefits of FPDR (as discussed in chapter two and throughout the findings chapters), and the practice has been endorsed for many years by professional organisations and resuscitation bodies. Yet the current FPDR practices highlighted in this study and in the wider literature are inconsistent and sporadic, both between and within healthcare setting and between health professionals. The ad-hoc and subjective nature of current FPDR practices in the absence of structured guidelines violates the core principles of evidence-based practice and family-centred care. Policy makers and healthcare systems need to develop a consistent and structured approach to FPDR to ensure family members and patients are

not missing out on known benefits or being harmed by forced separation from loved ones.

The widespread introduction of standardised guidelines would be an effective way to bring about necessary changes to ensure that clinical practice is guided by standards for consumer safety and welfare rather than personal preferences and values. Guidelines would need to be developed in consultation with policy makers, academics, health professionals and the public to ensure care is based on the best available evidence and clinical expertise alongside patient and family preferences. A collaborative approach to policy development would ensure that new guidelines are safe, effective, flexible, realistic and cost effective.

The conceptual grounded theory model developed in this study (see figure 10 on page 185) explains the major social process enacted when health professionals and family members were faced with a decision to practice or participate in FPDR. This model could be used as a framework to assist the development of structured guidelines. To illustrate, the FPDR framework for guideline development depicted in figure 11 (see page 207) was developed using the conceptual grounded theory model. This framework is offered as a starting point for policy makers and health professionals who are interested in developing structured guidelines for FPDR in Australian and international acute healthcare settings.

Recommendations for future research

The current body of FPDR evidence is significantly skewed toward simple descriptive research, examining the attitudes and beliefs of health professionals using closed-response surveys. While these designs can provide useful baseline information about contextual attitudes and beliefs, they do not offer additional insights beyond the current body of knowledge. Future research needs to focus on the planning, implementation and evaluation of FPDR guidelines and practices to guide the development of safe and effective family/consumer-centred care. There is also a need for future research that measures the impact of FPDR on resuscitation processes and outcomes and on family members, patients and health professionals.

This thesis provides an enhanced understanding and valuable insights into how decisions are made to practice or participate in FPDR. Understanding rationales for practice is an important first step when practice changes are needed. Future research could build on this foundation to examine decision-making in different contexts and to explore the lived experience of relevant parties to ensure a holistic and collaborative approach to FPDR. This study also provided a unique, in-depth examination of the impact of value-laden judgements on FPDR practices. Future research could examine how this concept translates to a wide range of clinical practices.

The following recommendations for future research were formulated during the production of this thesis.

- Development, implementation and evaluation of structured but flexible clinical guidelines and policies
- Development and evaluation of FPDR simulation training to ensure health professionals are adequately prepared for their holistic role
- Development and evaluation of dedicated support roles during resuscitation events
- Measuring the emotional and psychological effect of FPDR on family members, patients and health professionals
- Measuring the impact of FPDR on the clinical performance of health professionals
- Exploring the family member role during FPDR to determine their preferences for shared care and decision-making
- Exploring the role of advanced care planning and advanced care directives in relation to FPDR practices
- Exploring ways to improve end-of-life care during/after unsuccessful resuscitation events
- Examining the impact of value-laden judgements on emergency resuscitative care events in relation to family presence and family participation in care.
- Examining the impact of value-laden judgements on a diverse range of clinical care.

Family Presence during Resuscitation Framework for Guideline Development

ESTABLISH PATIENT AND FAMILY PREFERENCES

- Document patient/family FPDR preferences on admission if possible

- If preferences are not already known, ask family members as soon as possible after sudden cardiac arrest

- Acknowledge family members inherent right to be with the patient if desired

- If family do not wish to be present, guide them to a suitable room and provide regular updates

- If family members do wish to be present, perform a risk analysis and negotiate the degree of FPDR implemented

PERFORM RISK ANALYSIS

Assess Suitability

Of the people

- Consider the psychological / emotional state of family members

- Consider the competence and confidence of staff

Of the space/setting

- Assess adjustments needed to make room for family to stand or sit

- Consider potential hazards i.e. defibrillator

Of the resuscitation context

- Consider the severity of injuries and invasiveness of interventions

- Discuss with family to ensure informed FPDR

SET BOUNDARIES FOR FPDR

Negotiate pre-requisites to FPDR with staff and family

- Enough staff available to provide informed, supported FPDR

- Ability to prepare and continually support family members throughout and beyond the event

- Setting the conditions of FPDR according to previous and ongoing risk assessment i.e. asking family to leave for certain interventions or to minimise disruptions

- Allowing family to leave and return as desired

- Setting limits on category and number of FMs

IMPLEMENT ONGOING RISK MANAGEMENT

Protecting patients

- Determining patient preferences if possible

- Protecting privacy and dignity during FPDR

Protecting family members

- Offering options and supporting informed individual choices

- Dedicated support person to provide ongoing explanations and support

- Referring family members to counselling / social worker as needed

Protecting staff

- Education and debrief sessions for FPDR staff

- Involving staff in guideline development

Figure 11: Proposed framework to guide the development of a clinical guideline for FPDR

CONCLUDING REMARKS

Sudden cardiac arrest is the leading cause of death in Australia and impacts millions of people and their families worldwide every year. Despite ongoing advances in resuscitation technology and the implementation of universal CPR, survival rates have remained consistently low for decades. Family presence during resuscitation was introduced in the 1980s so that family could be with their loved ones during their dying minutes and has been practiced successfully for many decades overseas. FPDR has demonstrated many important benefits such as facilitating closure and grieving, and reducing the incidence of post-traumatic stress. Yet in Australia, implementation of the practice is sporadic and inconsistent. This thesis has identified the highly subjective and ad-hoc nature of FPDR practices in Australian acute healthcare settings and the absence of consistent guidelines and policies. Unique to this study was an enhanced understanding of rationales for practice - which were commonly based on personal preferences, past experiences and the inherent value placed on FPDR by individuals and groups. Elucidating the social construction of conditional permission for FPDR has raised important implications for future education, practice, and policy development. Furthermore, this thesis has highlighted the way in which socially constructed meanings and actions can become fixed as part of our social norms and – more importantly – how these meaning and actions can change in order to meet the needs of an evolving society that values family-centred healthcare. More specifically, this thesis identified that awareness, exposure, structure and education are vital to socially constructed changes around FPDR.

In order to provide safe and effective end-of-life care during emergency resuscitative events for patients and their families, we also need to re-contextualise CPR from its current 'high tech' status. There is an urgent need for a more holistic approach to emergency resuscitative events that combines advanced technologies with patient/family-centred care. By excluding family members from the resuscitation room, health professionals are separating family from their dying loved ones at one of the most important periods of their life. But if we include them, we can help family members to make sense of sudden death and allow them to come to terms with losing a loved one.

It is likely that the concept of FPDR will receive increasing attention in Australia in light of the current emphasis on providing high quality end-of-life care and consumer participation in health care. Given the large number of family members affected by the sudden death of a loved one, any attempts to improve care and family support during emergency resuscitative care are both welcome and imperative.

EPILOGUE

I am sometimes discouraged by the reluctance of some health professionals and organisations to implement important clinical change in response to rigorous new evidence. This frustration derives in part from a belief that patients and their families are not receiving the best possible care and in part from feeling powerless to affect change. During the construction of this thesis, I gained significant insight into why people think and act as they do in healthcare environments – both as individuals and as groups. The philosophical and epistemological foundations of this research allowed me to learn the way in which FPDR practices are entrenched in larger and often hidden situations and relationships, and highlighted the hierarchies of power involved in decision-making around FPDR. I learned how social meanings and processes form and reform over time, and how those meaning-making activities largely shape action or inaction. As such, I learned that seemingly fixed healthcare practices around FPDR can be changed if people's meanings and subsequent actions are challenged or disrupted through exposure, education, role modelling, structured guidelines or by challenging traditional social and professional roles. Explicating and challenging existing meanings can expedite new, shared meanings and potentially facilitate a collaborative approach to safe, effective, flexible and family-centred FPDR practices in Australia.

References

Abbott, A 1988, *The system of professions: an essay on the division of expert labor*, University of Chicago Press, Chicago.

Abella, B, Alvarado, J, Myklebust, H, Edelson, D, Barry, A, O'Hearn, N, Vanden Hoek, T & Becker, L 2005, 'Quality of cardiopulmonary resuscitation during in-hospital cardiac arrest', *JAMA,* vol. 293, no. 3, pp. 305-310.

ACHS 2013, *Risk management and quality improvement handbook*, ACHS, Sydney, Australia, viewed 13 April 2015, <www.achs.org.au/>.

ACoSaQiHC 2011a, *National Safety and Quality Health Service Standards*, ACSQHC. Sydney, viewed 8 May 2015, <http://www.safetyandquality.gov.au/wp-content/uploads/2011/09/NSQHS-Standards-Sept-2012.pdf>.

ACoSaQiHC 2011b, *Patient centred care: improving quality and safety through partnerships with patients and consumers,* ACSQHC, Sydney, viewed 8 May 2015, <www.safetyandquality.gov.au>.

ACoSaQiHC 2013, *The Australian open disclosure framework: Better communication, a better way to care*, Australian Open Disclosure Framework, Sydney, viewed 8 May 2015, <http://www.safetyandquality.gov.au/publications/australian-open-disclosure-framework/>.

ACoSaQiHC 2015, *National consensus statement: essential elements for safe and high-quality end-of-life care,* Sydney, Australia, viewed 8 May 2015, <http://www.safetyandquality.gov.au/wp-content/uploads/2014/01/Draft-National-Consensus-Statement-Essential-Elements-for-Safe-and-High-Quality-End-of-Life-Care-in-Acute-Hospitals.pdf>.

AHA 2015a, *Heart attack or sudden cardiac arrest: How are they differen*t?, viewed 9 July 2015, <http://www.heart.org/HEARTORG/Conditions/More/MyHeartandStrokeNews/Heart-Attack-or-Sudden-Cardiac-Arrest-How-Are-They-Different_UCM_440804_Article.jsp>.

AHA 2015b, *History of CPR*, viewed 9 July 2015, <http://www.heart.org/HEARTORG/CPRAndECC/WhatisCPR/CPRFactsandStats/History-of-CPR_UCM_307549_Article.jsp>.

Al-Mutair, AS, Plummer, V & Copnell, B 2012, 'Family presence during resuscitation: a descriptive study of nurses' attitudes from two Saudi hospitals', *Nursing in Critical Care,* vol. 17, no. 2, pp. 90-98.

Albarran, J, Moule, P, Benger, J, Mcmahon-Parkes, K & Lockyer, L 2009, 'Family witnessed resuscitation: the views and preferences of recently resuscitated hospital inpatients, compared to matched controls without the experience of resuscitation survival', *Resuscitation*, vol. 80, no. 9, pp. 1070-1073.

Aldiabat, K & Le Navenec, C 2011, 'Philosophical roots of classical grounded theory: it's foundations in symbolic interactionism', *The Qualitative Report*, vol. 6, no. 4, pp. 1063-1080.

American Academy of Pediatrics Committee on Hospital Care 2003, 'Policy Statement: Family-centred care and the pediatricians role', *Pediatrics*, vol. 112, no. 3, pp. 691-696.

Andrews, T 2012, 'What is social constructionism?', *The Grounded Theory Review*, vol. 11, no. 1, pp. 39-46.

Annells, M 1996, 'Grounded theory method: philosophical perspectives, paradigm of inquiry, and postmodernism', *Qualitative Health Research*, vol. 6, no. 3, pp. 379-393.

Annells, M 2006, 'Triangulation of qualitative approaches: hermeneutical phenomenology and grounded theory', *Journal of Advanced Nursing*, vol. 56, no. 1, pp. 55 - 61.

ARC 2006, *Guideline 1.1. Aims and objectives of the Australian Resuscitation Council*, viewed 10 May 2015, <http://resus.org.au/guidelines/>.

ARC 2012a, *Guideline 8. Cardiopulmonary resuscitation*, viewed 10 May 2015, <http://resus.org.au/guidelines/>.

ARC 2012b, *Guideline 10.5 Legal and ethical issues related to resuscitation,* viewed 11 March 2015, <http://resus.org.au/?wpfb_dl=49>.

Aulisio, M & Arnold, R 2008, 'Role of the ethics committee: helping to address value conflicts or uncertainties', *CHEST*, vol. 134, no. 2, pp. 417-424.

Axelsson, A, Fridlund, B, Moons, P, Martensson, J, Scholte op Reimer, W, Smith, K, Stromberg, A, Thompson, D & Norekval, T 2010, 'European cardiovascular nurses' experiences of and attitudes towards having family members present in the resuscitation room', *European Journal of Cardiovascular Nursing*, vol. 9, no. 1, pp.15-23.

Bacharach, S & Lawler, E 1980, *Power and politics in organisations*, Jossey-Bass, San Francisco, California.

Back, D & Rooke, V 1994, 'The presence of relatives in the resuscitation room', *Nursing Times*, vol. 90, no. 30, pp. 34-35.

Badir, A & Sepit, D 2007, 'Family presence during CPR: a study of the experiences and opinions of Turkish critical care nurses', *International Journal of Nursing Studies*, vol. 44, no. 1, pp. 83-92.

Barbalet, J 2009, *Pragmatism and symbolic interactionism*, in B. Turner (ed), The new Blackwell companion to social theory, Blackwell Publishing Ltd, West Sussex, pp. 199-217.

Barkway, P 2001, 'Michael Crotty and nursing phenomenology: criticism or critique?', *Nursing Inquiry*, vol. 8, no. 3, pp. 191-195.

Barratt, F & Wallis, D 1998, 'Relatives in the resuscitation room: their point of view', *Journal of Accident and Emergency Medicine*, vol. 15, no. 2, pp. 109-111.

Bashayreh, I & Saifan, A 2015, 'Family witnessed resuscitation: through the eyes of family members', *Journal of American Science* , vol. 11, no. 3, pp. 7-15.

Baskett, P, Steen, P & Bossaert, L 2005, 'European Resuscitation Council Guidelines for resuscitation, Section 8. The ethics of resuscitation and end-of-life decisions', *Resuscitation,* vol. 67S1, pp. S171-S180.

Basol, R, Ohman, K, Simones, J & Skillings, K 2009, 'Using research to determine support for a policy on family presence during resuscitation', *Dimensions of Critical Care Nursing*, vol. 28, no. 5, pp. 237-247.

Bassler, P 1999, 'The impact of education on nurses' beliefs regarding family presence in a resuscitation room', *Journal for Nurses in Staff Development,* vol. 15, no. 3, pp. 126-131.

Baumhover, N & Hughes, L 2009, 'Spirituality and support for family presence during invasive procedures and resuscitation in adults', *American Journal of Critical Care*, vol. 18, no. 4, pp. 357-366.

Beauchamp, T & Childress, J 2001, *Principles of biomedical ethics*, 5th edn, Oxford, New York.

Beckman, A, Sloan, B, Moore, G, Cordell, W, Brizendine, E, Boie, E, KJ, K, Goldman, M & Geninati, M 2002, 'Should parents be present during emergency department procedures on children, and who should make that decision? A survey of emergency physician and nurse attitudes', *Academic Emergency Medicine*, vol. 9, no. 2, pp. 154-158.

Benjamin, M, Holger, J & Carr, M 2004, 'Personal preferences regarding family member presence during resuscitation', *Academic Emergency Medicine*, vol. 11, no. 7, pp. 750-753.

Benoliel, JQ 1996, 'Grounded theory and nursing knowledge', *Qualitative Health Research*, vol. 6, no. 3, pp. 406-428.

Berdowski, J, Berg, R, Tijssen, J & Koster, R 2010, 'Global incidences of out of hospital cardiac arrest and survival rates', *Resuscitation*, vol. 81, no. 11, pp. 1479-1487.

Beresford, B & Sloper, T 2008, *Understanding the dynamics of decision making and choice: a scoping study of key psychological theorists to inform the design and analysis of the panel study*, The Publications Office, Social Policy Research Unit Univeristy of York, Heslington, York.

Berger, J, Brody, G, Eisenstein, L & Pollack, S 2004, 'Do potential recipients of cardiopulmonary resuscitation want their family members to attend? A survey of public preferences', *The Journal of Clinical Ethics*, vol. 15, no. 3, pp. 237-242.

Berger, P & Luckman, T 1991, *The social construction of reality*, Penguin Books, London.

Berwick, D 2009, 'What 'patient-centered' should mean: confessions of an extremist', *Health Affairs*, vol. 28, no. 4, pp. w555-w565.

Biddle, B 1979, *Role Theory: Expectations, identities, and behaviors*, Academic Press Inc, New York.

Biddle, B 1986, 'Recent developments in role theory', *Annual Review of Sociology*, vol. 12, pp. 67-92.

Birks, M & Mills, J 2011, *Grounded Theory: a practical guide*, SAGE Publications Ltd, London.

Blumer, H 1954, 'What is wrong with social theory?', *American Sociological* Review, vol. 18, pp. 3-10.

Blumer, H 1969, *Symbolic interactionism: an introduction, an interpretation, an integration*, Prentice Hall Englewood Cliffs, New Jersey.

Boie, E, Moore, G, Brummett, C & Nelson, D 1999, 'Do parents want to be present during invasive procedures performed on their children in the emergency department? A survey of 400 parents', *Annals of Emergency Medicine*, vol. 34, no. 1, pp. 70-74.

Booth, M, Woolrich, L & Kinsella, J 2004, 'Family witnessed resuscitation in UK emergency departments: a survey of practice', *European Journal of Anaesthesiology*, vol. 21, no. 9, pp. 725-728.

Borbasi, S, Wotton, K, Redden, M & Chapman, Y 2005, 'Letting go: a qualitative study of acute care and community nurses' perceptions of a 'good' versus a 'bad' death', *Australian Critical Care,* vol. 18, no. 3, pp. 104-113.

Boyd, R & White, S 2000, 'Does witnessed cardiopulmonary resuscitation alter perceived stress in accident and emergency staff?', *European Journal of Emergency Medicine,* vol. 7, no. 1, pp. 51-53.

Boyde, M, Padget, M, Burmeister, E & Aitken, L 2013, 'In-hospital cardiac arrests: effect of amended Australian Resuscitation Council 2006 guidelines', *Australian Health Review*, vol. 37, no. 2, pp. 178-184.

Bradford, K, Kost, S, Selbst, S, Renwick, A & Pratt, A 2005, 'Family member presence for procedures: the resident's perspective', *Ambulatory Pediatrics*, vol. 5, no. 5, pp. 294-297.

Breckenridge, J, Jones, D, Elliott, I & Nicol, M 2012, 'Choosing a methodological path: reflections on the constructivist turn', *The Grounded Theory Review*, vol. 11, no. 1, pp. 64-71.

Brookes, K, Davidson, P, Daly, J & Halcomb, E 2007, 'Role theory: a framework to investigate the community nurse role in contemporary health care systems', *Contemporary Nurse*, vol. 25, no. 1-2, pp. 146-155.

Bryant, A 2003, 'A constructive/ist response to Glaser', *Forum: Qualitative Social Research*, vol. 4, no. 1, art. 15.

Bryant, A 2009, 'Grounded theory and pragmatism: the curious case of Anselm Strauss', *Forum: Qualitative Social Research*, vol. 10, no. 3, art. 2.

Bryant, A & Charmaz, K 2007a, *Grounded theory in historical perspective: an epistemological account,* in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Inc, London, pp. 31-57.

Bryant, A & Charmaz, K 2007b, *Grounded theory research: methods and practices*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Inc, London, pp. 1-28.

Buchan, H, Currie, K, Lourey, E & Duggan, G 2010, 'Australian clinical practice guidelines - a national study', *Medical Journal of Australia*, vol. 192, no. 9, pp. 490-494.

Bulmer, M 1979, 'Concepts in the analysis of qualitative data', *Sociology Review*, vol. 27, no. 4, pp. 651-677.

Burns, L & Knussen, C 2005, 'False consensus and accuracy of perceptions of nurses regarding universal precaution practices', *Psychology Health & Medicine*, vol. 10, no. 4, pp. 344-354.

Burr, V 2003, *Social constructionism*, 2nd edn, Routledge, London.

Byrne, G & Heyman, R 1997, 'Understanding nurses' communication with patients in accident & emergency departments using a symbolic interactionist perspective', *Journal of Advanced Nursing*, vol. 26, no. 1, pp. 93-100.

Byrth, J & Aromataris, E 2014, 'Health professionals' perceptions and experiences of open disclosure: a systematic review of qualitative evidence', *Joanna Briggs Institute Database of Systematic Reviews and Implementation Report,* vol. 12, no. 5, doi: http://dx.doi.org/10.11124/jbisrir-12014-11552.

Casey, D, Murphy, K, Ni Leime, A, Larkin, P, Payne, S, Froggatt, K & O'Shea, E 2011, 'Dying well: factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland', *Journal of Clinical Nursing*, vol. 20, no. 13-14, pp. 1824-1833.

CASP 2013, 'Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist 31.05.13', viewed 21 April 2011, <http://www.casp-uk.net/#!casp-tools-checklists/c18f8>.

Chalk, A 1995, 'Should relatives be present in the resuscitation room', *Accident and Emergency Nursing*, vol. 3, no. 2, pp. 58-61.

Chapman, R, Bushby, A, Watkins, R & Combs, S 2014, 'Australian emergency department health professionals' reasons to invite or not invite family witnessed resuscitation: a qualitative perspective', *International Emergency Nursing*, vol. 22, no. 1, pp. 18-24.

Chapman, R, Watkins, R, Bushby, A & Combs, S 2012, 'Family-witnessed resuscitation: perceptions of nurses and doctors working in an Australian emergency department,' *ISRN (International Scholarly Research Network) Emergency Medicine*, Article ID 369423, 10 pages.

Chapman, R, Watkins, R, Bushby, A & Combs, S 2013, 'Assessing health professionals' perceptions of family presence during resuscitation: a replication study', *International emergency nursing*, vol. 21, no. 1, pp. 17-25.

Charmaz, K 1980, *The social reality of death: death in contemporary America*, Random House, New York.

Charmaz, K 1990, '"Discovering" chronic illness: using grounded theory', *Social Science and Medicine*, vol. 30, no. 11, pp. 1161-1172.

Charmaz, K 1997, *Good days bad days; the self in chronic illness and time*, Rutgers University Press, New Jersey.

Charmaz, K 2000, *Grounded Theory: Objectivist and constructivist methods*, in N. Denzin and Y. Lincoln (eds), Handbook of qualitative research, SAGE Publications, California, pp. 509-535.

Charmaz, K 2002, 'Stories and silences: disclosure and self in chronic illness', *Qualitative Inquiry*, vol. 8, no. 3, pp. 302-328.

Charmaz, K 2003, *Grounded theory; objectivist and constructivist methods*, in N. Denzin and Y. Lincoln (eds), Strategies of qualitative inquiry, 2nd edn, SAGE Publications Inc, California.

Charmaz, K 2004, 'Premises, principles, and practices in qualitative research: revisiting the foundations', *Qualitative Health Research*, vol. 14, no. 7, pp. 976 -993.

Charmaz, K 2005, *Grounded Theory in the 21st century; applications for advancing social justice studies*, in N. Denzin and Y. Lincoln (eds), The Sage Handbook of Qualitative Research, SAGE Publications Inc, California.

Charmaz, K 2006, *Constructing grounded theory: a practical guide through qualitative analysis*, SAGE Publications Inc, London.

Charmaz, K 2007, *Constructionism and the grounded theory method,* in J. Holstein and J. Gubrium (eds), Handbook of constructionist research, Guilford, New York, pp. 397-421.

Charmaz, K 2008, *A future for symbolic interactionism*, in N. Denzin and J Bingly (eds), Studies in symbolic interactionism, Press Emerald Group Publishing Ltd, vol. 32, pp. 51 - 59.

Charmaz, K 2011, *Grounded theory methods in social justice research*, in N. Denzin and Y. Lincoln (eds), The SAGE handbook of qualitative research, 4th edn, SAGE Publications, London, pp. 359-380.

Charmaz, K 2012, 'The power and potential of grounded theory', *Medical Sociology Online*, vol. 6, no. 3, pp. 2-15.

Charmaz, K 2014, *Constructing Grounded Theory*, 2nd edn, SAGE Publications Inc, London.

Charmaz, K & Mitchell, R 2011, 'The myth of silent authorship: self, substance and style in ethnographic writing', *Symbolic Interaction*, vol. 19, no. 4, pp. 285-302.

Cheng, P & Holyoak, K 1985, 'Pragmatic reasoning schema', *Cognitive Psychology*, vol. 17, no. 4, pp.391-416.

Cheng, P &Holyoak, K 1989, 'On the natural selection of reasoning theories', *Cognition*, vol. 33, no. 3, pp. 285-313.

Chew, KS & Ghani, ZA 2014, 'Attitudes and perceptions of the general Malaysian public regarding family presence during resuscitation', *Singapore Medical Journal*, vol. 55, no. 8, pp. 439-442.

Clark, A 2005, *Situational analysis: grounded theory after the postmodern turn*, SAGE Publications, Thousand Oaks, California.

Clemens, E & Hayes, H 1997, 'Assessing and balancing elder risk, safety and autonomy: decision-making practices of health care professionals', *Home Health Care Quarterly*, vol. 16, no. 3, pp. 3-20.

Compton, S, Levy, P, Griffin, M, Waselewsky, D, Mango, L & Zalenski, R 2011, 'Family-witnessed resuscitation: bereavement outcomes in an urban environment', *Journal of Palliative Medicine*, vol. 14, no. 6, pp. 715-721.

Coombs, M & Ersser, S 2004, 'Medical hegemony in decision-making - a barrier to interdisciplinary working in intensive care?', *Journal of Advanced Nursing*, vol. 46, no. 3, pp. 245-252.

Cooper, H 1998, *Synthesizing research: a guide for literature review,* 3rd edn, SAGE Publications, Thousand Oaks, California.

Corbett, S & Williams, F 2014, 'Striking a professional balance: interactions between nurses and their older rural patients', *British Journal of Community Nursing*, vol. 19, no. 4, pp. 162-167.

Corbin, J & Strauss, A 2008, *Basics of qualitative research*, 3rd edn, SAGE Publications Inc, California.

Cosmides, L 1989, 'The logic of social exchange: Has natural selection shaped how humans reason? Studies with the Wason selection task', *Cognition*, vol. 31, no. 3, pp. 187-276.

Coyne, I, O'Neill, C, Murphy, M, Costello, T & O'Shea, R 2011, 'What does family-centred care mean to nurses and how do they think it could be enhanced in practice', *Journal of Advanced Nursing*, vol. 67, no. 12, pp.2561-2573.

Crotty, M 1998, *The foundations of social research: Meaning and perspective in the research process*. SAGE Publications, London.

Crowley, A 2008, 'Collaborative childcare health consultation: a conceptual model', *JSPN - Journal for Specialists in Paediatric Nursing*, vol. 13, no. 2, pp. 74-88.

Curley, M, Meyer, E, Scoppettuolo, L, McGann, E, Trainor, B, Rachwal, C & Hickey, P 2012, 'Parent presence during invasive procedures and resuscitation: evaluating a clinical practice change', *American Journal of Respiratory and Critical Care Medicine*, vol. 186, no. 11, pp. 1133-1139.

Cypress, B 2012, 'Family presence on rounds', *Dimensions of Critical Care Nursing*, vol. 31, no. 1, pp. 53-64.

Davidson, JE, Buenavista, R, Hobbs, K & Kracht, K 2011, 'Identifying factors inhibiting or enhancing family presence during resuscitation in the emergency department', *Advanced Emergency Nursing Journal*, vol. 33, no. 4, pp. 336-343.

Davidson, JE, Savidan, K, Barker, N, Warmuth, N & Degen-De Cort, A 2014, 'Using evidence to overcome obstacles to family presence', *Critical Care Nursing Quarterly*, vol. 37, no. 4, pp. 407-421.

Day, L 2006, 'Family involvement in critical care: shortcomings of a utilitarian justification', *American Journal of Critical Care*, vol. 15, no. 2, pp. 223-225.

de Beer, J & Moleki, M 2012, 'Critical care nurses' perceptions of family witnessed resuscitation in the united kingdom of Saudi Arabia', *Africa Journal of Nursing and Midwifery*, vol. 14, no. 1, pp. 105-115.

defra. 2011, 'Planning system: a farmers guide (02PD00188). Conditional permission', viewed 2 June 2015, <http://adlib.everysite.co.uk/adlib/defra/content.aspx?doc=20064&id=125945>.

Demir, F 2008, 'Presence of patients' families during cardiopulmonary resuscitation: physicians and nurses' opinions', *Journal of Advanced Nursing*, vol. 63, no. 4, pp. 409-416.

Denzin, N & Lincoln, Y (eds) 2005, *The sage handbook of qualitative research*, 3rd edn, SAGE Publications, California.

Denzin, N & Lincoln, Y (eds) 2008, *The landscape of qualitative research*, 3rd edn, SAGE Publications, California.

Dey, I 2007, *Grounding categories*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE publications Ltd, London, pp. 167-190.

Doka, KJ (Ed). 2000, *Living with grief; children, adolescents, and loss*, Hospital Foundation of America, Routledge.

Donnellana, C, Sweetmana, S & Shelleyb, E 2013, 'Implementing clinical guidelines in stroke: A qualitative study of perceived facilitators and barriers', *Health Policy*, vol. 111, no. 3, pp. 234-244.

Doyle, C, Post, H, Burney, R, Maino, J, Keefe, M, Rhee, K & Arbor, A 1987, 'Family participation during resuscitation: an option', *Annals of Emergency Medicine*, vol. 16, no. 6, pp. 673-675.

Duran, C, Oman, K, Jordan, J, Koziel, V & Szymanski 2007, 'Attitudes toward and beliefs about family presence: a survey of healthcare providers, patients' families, and patients', *American Journal of Critical Care*, vol. 16, pp. 270-282.

Dwyer, T 2015, 'Predictors of public support for family presence during cardiopulmonary resuscitation: a population based study', *International Journal of Nursing Studies*, vol. 52, no. 2, pp.1064-1070.

Edley, N 2001. 'Unravelling social constructionism', *Theory and Psychology*, vol. 11, no. 3, pp. 433-441.

Egemen, A, Ikizoglu, T, Karapinar, B, Cosar, H & Karapinar, D 2006, 'Parental presence during invasive procedures and resuscitation; Attitudes of health care professionals in Turkey', *Pediatric Emergency Care*, vol. 22, no. 4, pp. 230-234.

Ehlenbach, W, Barnato, A, Curtis, J, Kreuter, W, Koepsell, T, Deyo, R & Stapleton, R 2009, 'Epidemiologic study of in-hospital cardiopulmonary resuscitation in the elderly', *New England Journal of Medicine*, vol. 361, no. 1, pp. 22-31.

Eichhorn, D, Meyers, T, Guzzetta, C, Clark, A, Klein, J & Calvin, A 2001, 'Family presence during invasive procedures and resuscitation: hearing the voice of the patient', *American Journal of Nursing*, vol. 101, no. 5, pp. 48-55.

Elliott, D 2007, *Reviewing the literature*, in Z. Schneider, D. Whitehead, D. Elliott, G. Libiondo-Wood and J. Haber (eds), Nursing and midwifery research: methods and appraisal for evidence-based practice, Mosby Elsevier, New South Wales, pp. 46-61.

Ellison, S 2003, 'Nurses' attitudes toward family presence during resuscitative efforts and invasive procedures', *Journal of Emergency Nursing*, vol. 29, no. 6, pp. 515-521.

Elston, M 2002, *The politics of professional power*, in M. Bury, M. Calnan and J. Gabe (eds) The sociology of the health service, Routledge,Taylor and Francis Group, London, pp. 58-88.

Ersoy, G & Yanturali, S 2006, 'Family witness resuscitation. Allow or deny? Which is true?', *International Journal of Nursing Studies*, vol. 43, no. 5, pp. 653 - 654.

Fallis, W, McClement, S & Pereira, A 2008, 'Family presence during resuscitation: a survey of Canadian critical care nurses' practices and perceptions', *CACCN*, vol. 19, no. 3, pp. 22-28.

Feagan, LM & Fisher, NJ 2011, 'The Impact of education on provider attitudes toward family-witnessed resuscitation', *Journal of Emergency Nursing*, vol. 37, no. 3, pp. 231-239.

Fein, J, Ganesh, J & Alpern, E 2004, 'Medical staff attitudes toward family presence during paediatric procedures', *Pediatric Emergency Care*, vol. 20, no. 4, pp. 224-227.

Fernandez, R, Compton, S, Jones, K & Velilla, M 2009, 'The presence of a family witness impacts physician performance during simulated codes', *Critical Care Medicine*, vol. 37, no. 6, pp. 1956-1960.

Fields, J, Copp, M & Kleinman, S 2006, *Symbolic interactionism, inequality, and emotions*, in J. Stets and J. Turner (eds), Handbook of the sociology of emotions, Springer, New York, pp. 63-83.

Fine, G 1993, 'The sad demise, mysterious disappearance, and glorious triumph of symbolic interactionism', *Annual Review of Sociology*, vol. 19, pp. 61-87.

Finlay, A, Stewart, C & Parker, M 2013, 'Open disclosure: ethical, professional and legal obligations, and the way forward for regulation', *The Medical Journal of Australia*, vol. 198, no. 8, pp. 445-448.

Fisher, C, Lindhorst, H, Matthews, T, Munroe, D, Paulin, D & Scott, D 2008, 'Nursing staff attitudes and behaviours regarding family presence in the hospital setting', *Journal of Advanced Nursing*, vol. 54, no. 6, pp. 615-624.

Fontana, A & Frey, J 2005, The interview: from natural stance to political involvement, in N. Denzin and Y. Lincoln (eds), The SAGE book of qualitative research, 3rd edn, SAGE Publications Inc, California, pp. 695-727.

Franck, L, Oulton, K & Bruce, E 2012, 'Parental involvement in neonatal pain management: An empirical and conceptual update', *Journal of Nursing Scholarship*, vol. 44, no. 1, pp. 45-54.

Francke, A, Smit, M, de Veer, A & Mistiaen, P 2008, 'Factors influencing the implementation of clinical guidelines for health care professionals: A systematic meta-review', *BMC Medical Informatics and Decision Making,* vol. 8, no. 38, doi:10.1186/1472-6947-1188-1138.

Freidson, E 1970a, *Profession of medicine: A study of the sociology of applied knowledge*, Harper and Row, New York.

Freidson, E 1970b, *Professional dominance: the social structure of medical care*, Aldine Publishing Co, New York.

French, J & Raven, B 1959, *The bases of social power*, in D. Cartwright (ed), Studies in social power, Ann Arbor, Michigan, pp. 259-269

Frick, W 2009, 'Principals' value-informed decision making, intrapersonal moral discord, and pathways to resolution: the complexities of moral leadership praxis', *Journal of Educational Administration*, vol. 47, no. 1, pp. 50-74.

Frosch, D, May, S, Rendle, K, Tietbohl, C & Elwyn, G 2012, 'Authoritarian physicians and patients' fear of being labeled 'difficult' among key obstacles to shared decision making', *Health Affairs*, vol. 31, no. 5, pp. 1030-1038.

Fulbrook, P, Albarran, J & Latour, J 2005, 'A European survey of critical care nurses' attitudes and experiences of having family members present during cardiopulmonary resuscitation', *International Journal of Nursing Studies*, vol. 42, no. 5, pp. 557-568.

Fulbrook, P, Latour, J, Albarran, J, de Graaf, W, Lynch, F, Devictor, D & Norekval, T 2007, 'The presence of family members during cardiopulmonary resuscitation: European federation of Critical Care Nursing associations, European society of pediatric and neonatal intensive care and European society of cardiology council on cardiovascular nursing and allied health professions joint position statement', *European Journal of Cardiovascular Nursing*, vol. 6, no. 4, pp. 255 -258.

Ganz, F & Yoffe, F 2012, 'Intensive care nurses' perspectives of family-centred care and their attitudes towards family presence during resuscitation', *Journal of Cardiovascular Nursing*, vol. 27, no. 3, pp. 220-227.

Gibson, B 2007, Accommodating critical theory, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications, London, pp. 436 - 453.

Giles, T, de Lacey, S & Muir-Cochrane, E 2016, 'Coding, constant comparisons and core categories: a worked example for novice constructivist grounded theorists', *Advances in Nursing Science*, (accepted for publication 20 August 2015).

Giles, T, de Lacey, S & Muir-Cochrane, E 2015, 'Family presence during resuscitation; who decides and how?' Nurses and Midwives Research Symposium, South Australian Department of Health, Adelaide, South Australia, May 2015.

Giles, T & Hall, K 2014, 'Qualitative systematic review: the unique experiences of the nurse-family member when a loved one is admitted with a critical illness', *Journal of Advanced Nursing*, vol. 70, no. 7, pp. 1451-1464.

Giles, T, King, L & de Lacey, S 2013, 'The timing of the literature review in grounded theory research: an open mind versus an empty head', *Advances in Nursing Science*, vol. 36, no. 2, pp. E29-E40.

Giles, T & Willamson, V 2015, 'Torn between dual roles: the experiences of nurse-family members when a loved one is hospitalised in a critical condition', *Journal of Clinical Nursing* IN PRESS: doi: 10.1111/jocn.12900.

Gilovich, T 1990, 'Differential construal and the false consensus effect', *Journal of Personality and Social Psychology*, vol. 59, no. 4, pp. 623-634.

Glaser, B 1978, *Theoretical sensitivity*, The Sociology Press, Mill Valley, California.

Glaser, B 1992, *Basics of grounded theory analysis: emergence vs forcing*, The Sociology Press, Mill Valley, California.

Glaser, B 1998, *Doing grounded theory; issues and discussions*, The Sociology Press, Mill Valley, California.

Glaser, B 2001, *The grounded theory perspective: conceptualisation contrasted with description*, The Sociology Press, Mill Valley, California.

Glaser, B 2002, 'Constructivist grounded theory?', *Forum: Qualitative Social Research*, vol. 3, no. 3, art. 12.

Glaser, B 2004, 'Remodeling grounded theory', *Forum: Qualitative Social Research*, vol. 5, no. 2, art. 4.

Glaser, B & Strauss, A 1965, *Awareness of Dying*, Aldine Publishing Company, New York.

Glaser, B & Strauss, A 1967, *The Discovery of Grounded Theory*, Aldine Publishing Company, New York.

Glaser, B & Strauss, A 1968, *Time for dying*, Aldine Publishing Company, Chicago.

Glaser, B & Strauss, A 1971, *Status passage*, Aldine Atherton, Chicago.

Gold, K, Gorenflo, D, Schwenk, T & Bratton, S 2006, 'Physician experience with family presence during cardiopulmonary resuscitation in children', *Pediatric Critical Care Medicine*, vol. 7, no. 5, pp. 428-433.

Goldberger, Z, Chan, P, Berg, R, Kronick, S, Cooke, C, Lu, M, Banerjee, M, Hayward, R, Krumholz, H & Nallamothu, B 2012, 'Duration of resuscitation efforts and survival after in-hospital cardiac arrest: an observational study', *The Lancet*, vol. 380, no. 9852, pp. 1473-1481.

Goldberger, Z, Nallamothu, B, Nicol, G, Chan, P, Curtis, J & Cooke, C 2015, 'Policies allowing family presence during resuscitation and patterns of care during in-hospital arrest', *Circulation: Cardiovascular Quality and Outcomes*, vol. 8, no. 3, pp. 226-234.

Goldenberg, M 2013, 'How can feminist theories of evidence assist clinical reasoning and decision-making', *Social Epistemology: A Journal of Knowledge, Culture and Policy*, vol. 29, no. 1, pp. 3-30.

Goodenough, T & Brysiewicz, P 2003, 'Witnessed resuscitation - exploring the attitudes and practices of the emergency staff working in Level 1 emergency departments in the province of KwaZulu-Natal.' *Curationis*, vol. 26, no. 2, pp. 56-63.

Gordon, E, Kramer, E, Couper, I & Brysiewicz, P 2011, 'Family-witnessed resuscitation in emergency departments: doctors' attitudes and practices', *South African Medical Journal. Suid-Afrikaanse Tydskrif Vir Geneeskunde*, vol. 101, no. 10, pp. 765-767.

Grbich, C 2010, *Integrated methods in health research*, in P. Liamputtong (ed), Research methods in health: foundations for evidence-based practice, Oxford Univeristy Press, South Melbourne, pp. 317-330.

Greckhamer, T & Koro-Ljungberg, M 2005, 'The erosion of a method: examples from grounded theory', *International Journal of Qualitative Studies in Education*, vol. 18, no. 6, pp. 729-750.

Greenhalgh, T, Howick, J & Maskrey, N 2014, 'Evidence based medicine: a movement in crisis?', *British Medical Journal*, vol. 348, no. g3725, doi: 3710.1136/bmj.g3725.

Grice, A, Picton, P & Deakin, C 2003, 'Study examining attitudes of staff, patients and relatives to witnessed resuscitation in adult intensive care units', *British Journal of Anaesthesia*, vol. 91, no. 6, pp. 820-824.

Guba, E & Lincoln, Y 1989, *Fourth Generation Evaluation*, SAGE Publications, Newbury Park.

Guba, E & Lincoln, Y 2005, *Paradigmatic contraversies, contradictions, and emerging confluences*, in N. Denzin and Y. Lincoln (eds), The SAGE handbook of qualitative research, 3rd edn, SAGE Publications, California, pp. 191-215.

Gunes, U & Zaybak, A 2009, 'A study of Turkish critical care nurses' perspectives regarding family-witnessed resuscitation', *Journal of Clinical Nursing*, vol. 18, no. 20, pp. 2907-2915.

Guyatt, G, Haynes, R, Jaeschke, R, Cook, D, Lee Green, L, Naylor, C, Wilson, M & Richardson, W 2000, 'Users' guides to the medical literature XXV. Evidence-based medicine: principles for applying the users' guides to patient care', *JAMA: The Journal of the American Medical Association*, vol. 284, no 10, pp. 1290-1296.

Hallgrimsdottir, E 2000, 'Accident and emergency nurses' perceptions and experiences of caring for families', *Journal of Clinical Nursing*, vol. 9, no. 4, pp. 611-619.

Hammersley, M & Traianou, A 2012, *Ethics in qualitative research; controversies and contexts*, SAGE Publications Ltd, London.

Hammersly, M 1992, *What's wrong with ethnography?,* Routledge, London.

Hanson, C & Strawser, D 1992, 'Family presence during cardiopulmonary resuscitation; Foote Hospital emergency department's nine-year perspective', *Journal of Emergency Nursing*, vol. 18, no. 2, pp. 104-106.

Harvey, ME & Pattison, HM 2012, 'Being there: a qualitative interview study with fathers present during the resuscitation of their baby at delivery', *Arch Dis Child Fetal Neonatal Education* March vol. 97, no. 6, pp. F1 - F5.

Havugitanga, P & Brysiewicz, P 2014, 'Exploring healthcare professionals' perceptions regarding family-witnessed resuscitation in a hospital in Kigali, Rwanda', *Southern African Journal of Critical Care*, vol. 30, no. 1, pp. 18-21.

Hayajneh, F 2013, 'Jordanian professional nurses' attitudes and experiences of having family members present during cardiopulmonary resuscitation of adult patients', *Critical Care Nursing Quarterly*, Apr-Jun, vol. 36, no. 2, pp.218-227.

Hearns, G, Klein, M, Trousdale, W, Ulrich, C, Butcher, D, Miewald, C, Lindstrom, R, Eftekhary, S, Rosinski, J, Gómez-Ramírez, O & Procyk, A 2010, 'Development of a support tool for complex decision-making in the provision of rural maternity care', *Health Policy*, vol. 5, no. 3, pp. 82-96.

Helmer, S, Smith, S, Dort, J, Shapiro, W & Katan, B 2000, 'Family presence during trauma resuscitation: a survey of AAST and ENA members', *The Journal of Trauma: Injury, Infection and Critical Care*, vol. 48, no. 6, pp. 1015-1024.

Hernandez, C & Andrews, T 2012, 'Commentary on "constructing new theory for identifying students with emotional disturbances"', *The Grounded Theory Review*, vol. 11, no. 1, pp. 59-63.

Hesse-Biber, S 2007, *Teaching grounded theory*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Ltd, London, pp. 311-338.

Higgs, J, Horsfall, D & Grace, S, Eds. 2009, *Writing qualitative research on practice. Practice, education, work and society,* Sense Publishers, Rotterdam.

Holland, J 2010, 'Should children attend their parent's funerals?' *Pastoral Care in Education: An International Journal of Personal, Social and Emotional Development*, vol. 22, no. 1, pp. 10-14.

Holton, J 2007, *The coding process and its challenges*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Ltd, London, pp. 265-289.

Holzhauser, K and Finucane, J 2007, 'Staff attitudes to family presence during resuscitation Part A: An interventional study', *Australasian Emergency Nursing Journal*, vol. 10, no. 3, pp. 124-133.

Holzhauser, K & Finucane, J 2008, 'Part B: A survey of staff attitudes immediately after post-resuscitation to family presence during resuscitation', *Australasian Emergency Nursing Journal*, vol 11, no. 3, pp. 114-122.

Holzhauser, K, Finucane, J & De Vries, S 2005, 'Family presence during resuscitation: a randomised controlled trial of the impact of family presence', *Australasian Emergency Nursing Journal*, vol. 8, no. 4, pp. 139 - 147.

Hood, J 2007, Orthodoxy vs. power: the defining traits of grounded theory, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Ltd, London, pp. 151-164.

Hung, M & Pang, S 2010, 'Family presence preference when patients are receiving resuscitation in an accident and emergency department', *Journal of Advanced Nursing*, vol. 67, no. 1, pp. 56-67.

Isoardi, J, Slabbert, N & Treston, G 2005, 'Witnessing invasive paediatric procedures, including resuscitation, in the emergency department: a parental perspective', *Emergency Medicine Australasia*, vol. 17, pp. 244-248.

Itzhaki, M, Bar-Tal, Y & Barnoy, S 2011, 'Reactions of staff members and lay people to family presence during resuscitation: the effect of visible bleeding, resuscitation outcome and gender', *Journal of Advanced Nursing*, vol. 68, no. 9, pp. 1967-1977.

Jabre, P, Tazarourte, K, Azoulay, E, Borron, SW, Belpomme, V, Jacob, L, Bertrand, L, Lapostolle, F, Combes, X, Galinski, M, Pinaud, V, Destefano, C, Normand, D, Beltramini, A, Assez, N, Vivien, B, Vicaut, E & Adnet, F 2014, 'Offering the opportunity for family to be present during cardiopulmonary resuscitation: 1-year assessment', *Intensive Care Medicine*, vol. 40, no. 7, pp. 981-987.

James, J, Cottle, E & Hodge, RD 2011, 'Registered nurse and health care Chaplains experiences of providing the family support person role during family witnessed resuscitation', *Intensive & Critical Care Nursing*, vol. 27, no. 1, pp. 19-26.

Jarvis, A 1998, 'Parental presence during resuscitation: attitudes of staff on a paediatric intensive care unit', *Intensive and Critical Care Nursing*, vol. 4, no. 1, pp. 3-7.

Jeon, Y 2004, 'The application of grounded theory and symbolic interactionism', *Scandanavian Journal of Caring Science*, vol. 18, no. 3, pp. 249-256.

Jirojwong, S, Hohnson, M & Welch, A 2011, *Research methods in nursing and midwifery; pathways to evidence based practice*, Oxford University Press, South Melbourne.

Johnson, S, Bautista, C, Hong, S, Weissfeld, L & White, D 2011, 'An empirical study of surrogates' preferred level of control over value-laden life support decisions in intensive care units', *American Journal of Respiratory Critical Care Medicine*, vol. 183, no. 7, pp. 915-921.

Johnstone, M 2008, 'Clinical risk management and the ethics of open disclosure: Part I. Benefits and risks to patient safety', *Australasian Emergency Nursing Journal*, vol. 11, no. 2, pp. 88-94.

Jones, BL, Parker-Raley, J, Maxson, T & Brown, C 2011, 'Understanding health care professionals' views of family presence during pediatric resuscitation', *American Journal of Critical Care : an official publication, American Association of Critical-Care Nurses*, vol. 20, no. 3, pp. 199-207.

Joseph-Williams, N, Elwyn, G & Edwards, A 2014, 'Knowledge is not power for patients: A systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making', *Patient Education and Counselling*, vol. 94, no. 3, pp. 291-309.

Kelle, U 2007, The development of categories: different approaches in grounded theory, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Ltd, London, pp. 191-213.

Kelly, B, Rid, A & Wendler, D 2012, 'Systematic review: individuals' goals for surrogate decision-making', *Journal of the American Geriatrics Society*, vol. 60, no. 5, pp. 884-895.

Kennedy, T & Lingard, L 2006, 'Making sense of grounded theory in medical education', *Medical Education*, vol. 40, no. 2, pp. 101-108.

Kettunen, T, Poskiparta, M & Gerlander, M 2002, 'Nurse-patient power relationship: preliminary evidence of patients' power messages', *Patient Education and Counselling*, vol. 47, no. 2, pp. 101-113.

Kianmehr, N, Mofidi, M, Rahmani, H & Shahin, Y 2010, 'The attitudes of team members towards family presence during hospital-based CPR: a study based in the Muslim setting of four Iranian teaching hospital', *Journal of the Royal College of Physicians Edinburgh*, vol. 40, no. 1, pp. 4-8.

King, N & Horrocks, C , 2010, *Interviews in qualitative research*, SAGE Publications, London.

Kirchoff, C, Stegmaier, J, Buhmann, S, Leidel, B, Biberthaler, P, Mutschler, W & Kanz, K 2007, 'Trauma surgeons' attitude towards family presence during trauma resuscitation: a nationwide survey', *Resuscitation*, vol. 75, no. 2, pp. 267-275.

Klein, M, Trousdale, W & Ulrich, C 2010, 'Development of a support tool for complex decision-making in the provision of rural maternity care', *Healthcare Policy*, vol. 5, no. 3, pp. 82-96.

Knott, A & Kee, C 2005, 'Nurses' beliefs about family presence during resuscitation', *Applied Nursing Research*, vol. 18, no. 4, pp. 192-198.

Koberich, S, Kaltwasser, A, Rothaug, O & Albarran, J 2010, 'Family witnessed resuscitation - experience and attitudes of German intensive care nurses', *British Association of Critical Care Nurses*, vol. 15, no. 5, pp. 241-250.

Kon, A 2010, 'The shared decision-making continuum', *JAMA*, vol. 304, no. 8, pp. 903-904.

Kosowan, S & Jensen, L 2011, 'Family presence during resuscitation: cardiac health care professionals' perspectives', *Canadian Journal of Cardiovascular Nursing*, vol. 21, no. 3, pp. 23-29.

Kotkis, D & Tabak, N 2008, 'Family presence during invasive procedures and resuscitation procedures: the attitudes of Israeli emergency nurses', *The Open Ethics Journal*, vol. 2, pp. 13-17.

Kuzin, J, Yborra, J, Taylor, M, Chang, A, Altman, C, Whitney, G & Mott, A 2007, 'Family-member presence during interventions in the intensive care unit: perceptions of pediatric cardiac intensive care providers', *Pediatrics*, vol. 120, no. 4, pp. e895-e901.

Kvale, S & Brinkman, S 2009, *Interviews; learning the craft of qualitative research interviewing*, 2nd edn, SAGE Publications, California.

Lam, D, Wong, S, Hui, H, Lee, W & So, K 2007, 'Attitudes of doctors and nurses to family presence during paediatric cardiopulmonary resuscitation', *Hong Kong Journal of Paediatrics*, vol. 12, no. 4, pp. 253-259.

Lederman, Z, Garasic, M & Piperberg, M 2014, 'Family presence during cardiopulmonary resuscitation: who should decide?', *Journal of Medical Ethics*, vol. 40, no. 5, pp. 315-319.

Lederman, Z & Wacht, O 2014, 'Family presence during resuscitation: attitudes of Yale-New Haven Hospital staff', *Yale Journal of Biology & Medicine*, vol. 87, no. 1, pp. 63-72.

Lempert, LB 2007, *Asking questions of the data: memo writing in the grounded theory tradition*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Ltd, London, pp 245-264.

Leske, JS, McAndrew, NS & Brasel, KJ 2013, 'Experiences of families when present during resuscitation in the emergency department after trauma', *Journal of Trauma Nursing*, vol. 20, no. 2, pp. 77-85.

Letts, L, Wilkins, S, Law, M, Stewart, D, Bosch, J & Westmorland, M 2007, 'Critical Review Form - Qualitative Studies (Version 2.0)', *McMaster University Occupational Therapy Evidence-Based Practice Research Group,* viewed 21 April 2011, <http://www.srs-mcmaster.ca/Portals/20/pdf/ebp/qualreview_version2.0.pdf>.

Leung, NY & Chow, SKY 2012, 'Attitudes of healthcare staff and patients' family members towards family presence during resuscitation in adult critical care units', *Journal of Clinical Nursing*, vol. 21, no. 13-14, pp. 2083-2093.

Levinson, M & Mills, A 2014, 'Cardiopulmonary resuscitation - time for a change in the paradigm?', *Medical Journal of Australia*, vol. 201, no. 3, pp. 152-154.

Liamputtong, P 2009, *Qualitative research methods*, 3rd edn, Oxford University Press, Sydney.

Liamputtong, P 2010, *Research methods in health: foundations for evidence-based practice*, Oxford University Press, Sydney.

Lowry, E 2012, '"It's just what we do": a qualitative study of emergency nurses working with well-established family presence protocol', *Journal of Emergency Nursing*, vol. 38, no. 4, pp. 329-334.

Luckett, T, Bhattarai, P, Phillips, J, Agar, M, Currow, D, Krastev, Y & Davidson, P 2015, 'Advance care planning in 21st Century Australia: A systematic review and appraisal of online advance care directive templates against National Framework criteria', *Australian Health Review* AH14187, June 1, doi: 10.1071/AH14187, [Epub ahead of print].

Lunenburg, F 2012, 'Power and leadership: an influence process', *International Journal of Management, Business, and Administration*, vol. 15, no. 1, pp. 1-9.

Luxford, K, Gelbsafran, D & Delblanco, T 2011, 'Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience', *International Journal for Quality in Health Care*, mzr024, vol. 23, pp. 510-515.

Luxford, K, Piper, D, Dunbar, N & Poole, N 2010, *Patient-centred care: improving quality and safety by focusing care on patients,* ACoSQiHC, Sydney, Biotext, Canberra.

Macdonald, M, Liben, S, Carnevale, F & Cohen, S 2012, 'An office or a bedroom? Challenges for family-centred care in the pediatric intensive care unit', *Journal of Child Health Care*, vol. 16, no. 3, pp. 237-249.

MacLean, S, Guzzetta, C, White, C, Fontaine, D, Eichorn, D, Meyers, T & Desy, P 2003, 'Family presence during cardiopulmonary resuscitation and invasive procedures: practices of critical care and emergency nurses', *American Journal of Critical Care*, vol. 12, no. 3, pp. 246-257.

Macy, C, Lampe, E, O'Neil, B, Swor, R, Zalenski, R & Compton, S 2005, 'The relationship between the hospital setting and perceptions of family-witnessed resuscitation in the emergency department', *Resuscitation*, vol. 70, no. 1, pp. 74-79.

Madden, E & Condon, C 2007, 'Emergency nurses' current practices and understandings of family presence during CPR', *Journal of Emergency Nursing*, vol. 33, no. 5, pp. 43- 440.

Mahabir, D & Sammy, I 2012, 'Attitudes of ED staff to the presence of family during cardiopulmonary resuscitation: a Trinadad and Tobago perspective', *Emergency Medicine Journal*, vol. 29, no. 10, pp. 817-820.

Maner, J, Kenrick, D, Vaughn Becker, D, Robertson, T, Hofer, B, Neuberg, S, Delton, A, Butner, J & Schaller, M 2005, 'Functional projection: How fundamental social motives can bias interpersonal perception', *Journal of Personality and Social Psychology*, vol. 88, no. 1, pp. 63-78.

Mangurten, J, Scott, S, Guzzetta, C, Clark, A, Vinson, L, Sperry, J, Hicks, B & Voelmeck, W 2006, 'Effects of family presence during resuscitation and invasive procedures in a paediatric emergency department', *Journal of Emergency Nursing*, vol. 32, no. 3, pp. 225-233.

Manktelow, K & Over, D 1991, 'Social roles and utilities in reasoning with deontic conditionals', *Cognition*, vol. 39, no. 2, pp. 85-105.

Maxton, F 2008, 'Parental presence during resuscitation in the PICU: the parents' experience. Sharing and surviving the resuscitation: a phenomenological study', *Journal of Clinical Nursing*, vol. 17, no. 23, pp. 3168-3176.

May, C 1992, 'Individual care? Power and subjectivity in therapeutic relationships', *Sociology*, vol. 26, no. 4, pp. 589-602.

May, L 1995, 'Challenging medical authority: The refusal of treatment by Christian Scientists', *The Hastings Center Report*, vol. 25, no. 1, pp. 15-21.

Mazer, M, Cox, L & Capon, J 2006, 'The public's attitude and perception concerning witnessed cardiopulmonary resuscitation', *Critical Care Medicine*, vol. 34, no. 12, pp. 2925-2928.

McCall, G & Simmons, J 1966, *Identities and interactions*, The Free Press, New York.

McCallin, A 2003a, 'Designing a grounded theory study: some practicalities', *Nursing in Critical Care*, vol. 8, no. 5, pp. 203-208.

McCallin, A 2003b, 'Grappling with the literature in a grounded theory study', *Contemporary Nurse*, vol. 15, no. 1-2, pp. 61-69.

McCann, T & Clark, E 2003a, 'Grounded theory in nursing research: part 1 - methodology', *Nurse Researcher*, vol. 11, no. 2, pp. 7-18.

McCann, T & Clark, E 2003b, 'Grounded theory in nursing research: part 2 - critique', *Nurse Researcher*, vol. 11, no. 2, pp. 19-28.

McClement, S, Fallis, W & Pereira, A 2009, 'Family presence during resuscitation: Canadian critical care nurses' perspectives', *Journal of Nursing Scholarship*, vol. 41, no. 3, pp. 233-240.

McClenathan, B, Torrington, K & Uyehara, C 2002, 'Family member presence during cardiopulmonary resuscitation: a survey of US and International critical care professionals', *CHEST*, vol. 122, no. 6, pp. 2204-2211.

McGahey-Oakland, P, Lieder, H, Young, A & Jefferson, L 2007, 'Family experiences during resuscitation at a children's hospital emergency department', *Journal of Pediatric Health Care*, vol. 21, no. 4, pp. 217-225.

McGhee, G, Marland, G & Atkinson, J 2007, 'Grounded theory research: literature reviewing and reflexivity', *Journal of Advanced Nursing*, vol. 60, no. 3, pp. 334-342.

McLaren, K, Lord, J, Murray, S, Levy, M, Ciechanowski, P, Markman, J, Ratzliff, A, Grodesky, M & Cowley, D 2013, 'Ownership of patient care: a behavioural definition and stepwise approach to diagnosing problems in trainees', *Perspective in Medical Education*, vol. 2, no. 2, pp. 72-86.

McMahon-Parkes, K, Moule, P, Benger, J & Albarran, J 2009, 'The views and preferences of resuscitated and non-resuscitated patients towards family-witnessed resuscitation: A qualitative study', *International Journal of Nursing Studies*, vol. 46, no. 2, pp. 220-229.

Mead, G 1962, *Mind, self, and society*, Univeristy of Chicago Press, Chicago.

Melnyk, B, Gallagher-Ford, L, Long, L & Fineout-Overholt, E 2014, 'The establishment of evidence-based practice competencies for practicing registered nurses and advanced practice nurses in

real-world clinical settings: proficiencies to improve healthcare quality, reliability, patient outcomes, and costs', *Worldviews on Evidence-Based Nursing*, vol. 11, no. 1, pp. 5-15.

Melnyk, BM & Fineout-Overholt, E 2011, *Evidence-based practice in nursing and healthcare; a guide to best practice*, Wolters Kluwer Health / Lippincott Williams & Wilkins, Philadelphia.

Meltzer, B, Petras, J & Reynolds, L 1975, *Symbolic interactionism: genesis, varieties and criticism*, Routledge & Kegan Paul Ltd, London.

Meyers, T, Eichorn, D & Guzzetta, C 1998, 'Do families want to be present during CPR? A retrospective survey', *Journal of Emergency Nursing*, vol. 24, no. 5, pp. 400-405.

Meyers, T, Eichorn, D, Guzzetta, C, Clark, A, Klein, J, Taliaferro, E & Calvin, A 2000, 'Family presence during invasive procedures and resuscitation: the experience of family members, nurses, and physicians', *American Journal of Nursing*, vol. 100, no. 2, pp. 32-43.

Mian, P, Warchal, S, Whitney, S, Fitzmaurice, J & Tancredi, D 2007, 'Impact of a multifaceted intervention on nurses' and physicians' attitudes and behaviours toward family presence during resuscitation', *Critical Care Nurse*, vol. 27, no. 1, pp. 51-61.

Miller, J & Stiles, A 2009, 'Family presence during resuscitation and invasive procedures: the nurse experience', *Qualitative Health Research*, vol. 19, no. 10, pp. 143- 1442.

Mills, J, Bonner, A & Francis, K 2006a, 'Adopting a constructivist approach to grounded theory: implications for research design', *International Journal of Nursing Practice*, vol. 12, no. 1, pp. 8-13.

Mills, J, Bonner, A & Francis, K 2006b, 'The development of constructivist grounded theory.' *International Journal of Qualitative Research*, vol. 5, no. 1, pp. 25-35.

Minichiello, V, Aroni, R & Hays, T 2008, *In-depth interviewing*, 3rd edn, Pearson Education Australia, Sydney.

Mintzberg, H 1983, *Power in and around organizations*, Prentice-Hall, Englewood Cliffs, New Jersey.

Mitchell, M & Lynch, M 1997, 'Should relatives be allowed in the resuscitation room?', *Journal of Accident and Emergency Nursing*, vol. 14, no. 6, pp. 366-369.

Monks, J & Flynn, M 2014, 'Care, compassions and competence in critical care: a qualitative exploration of nurses' experiences of family witnessed resuscitation', *Intensive and Critical Care Nursing*, vol. 30, no. 6, pp. 353-359.

Morrison, L, Kierzek, G, Diekema, D, Sayre, M, Silvers, S, Idris, A & Mancini, M 2010, 'American Heart Association guidelines for cardiopulmonary resuscitation and emergency cardiovascular care: Part 3, Ethics', *Circulation*, vol. 22, no. 18, suppl. 3, pp. S665-S675.

Morse, J (2007), *Sampling in grounded theory*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Inc, London, pp. 229-244.

Mortelmans, L, Broeckhoven, V, Van Boxstael, S, De Cauwer, H, Verfaillie, L, Van Hellemond, P, Van Colen, S & Cas, W 2010, 'Patients' and relatives' view on witnessed resuscitation in the emergency department: a prospective study', *European Journal of Emergency Medicine*, vol. 17, no. 4, pp. 203-207.

Mortelmans, L, Cas, W, Van Hellemond, P & De Cauwer, H 2009, 'Should relatives witness resuscitation in the emergency department? The point of view of the Belgian emergency department staff', *European Journal of Emergency Medicine*, vol. 16, no. 2, pp. 87-91.

Nagy, S, Mills, J, Waters, D & Birks, M 2010, *Using research in healthcare practice*, Lippincott Williams and Wilkins Pty Ltd, Broadway, Australia.

Nancarrow, S & Borthwick, A 2005, 'Dynamic professional boundaries in the healthcare workforce', *Sociology of Health & Illness*, vol. 27, no. 7, pp. 897-919.

National Advanced Care Directives Working Group 2011, *A national framework for advanced care directives,* The Clinical Technical and Ethical Principle Committee of the Australian Health Ministers' Advisory Council, viewed 13 may 2015, <http://www.health.wa.gov.au/advancecareplanning/docs/AdvanceCareDirectives2011.pdf>

Needle, J, Mularski, R, Nguyen, T & Fromme, E 2012, 'Influence of personal preferences for life-sustaining treatment on medical decision making among pediatric intensivists', *Critical Care Medicine*, vol. 40, no. 8, pp. 2464-2469.

Nelson, K 2004, 'Consumer decision making and image theory: understanding value-laden decisions', *Journal of Consumer Psychology*, vol. 14, no. 1&2, pp. 28 -40.

Netherton, S 1995, *The Sociology of Health and Illness*, Polity Press, Cambridge.

NHMRC 1999, *A guide to the development, implementation and evaluation of clinical practice guidelines,* NHMRC, Canberra, viewed 10 June 2014 <https://www.nhmrc.gov.au/guidelines-publications/cp30>.

NHMRC 2009, *National Health and Medical Research Council additional levels of evidence and grades for recommendations for developers of guidelines*, viewed 13 November 2011, <http://www.nhmrc.gov.au/_files_nhmrc/file/guidelines/stage_2_consultation_levels_and_grades.pdf>.

NHMRC, ARC & AVCC 2007, *National statement on ethical conduct in human research*, Canberra, Australian Government, viewed 12 April 2013, <http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72_national_statement_130207.pdf>

Nichol, G, Thomas, E, Callaway, C, Hedges, J, Powell, J, Aufderheide, T, Rea, T, Lowe, R, Brown, T, Dreyer, J, Davis, D, Idris, A & Stiell, I 2008, 'Regional variation in out-of-hospital cardiac arrest incidence and outcome', *JAMA*, vol. 300, no. 12, pp. 1423-1431.

Nielsen, J 2012, 'Co-opting science: a preliminary study of how students invoke science in value-laden discussions', *International Journal of Science Education*, vol. 34, no. 2, pp. 275-299.

Nykiel, L, Denicke, R, Schneider, R, Jett, K, Denicke, S, Kunish, K, Sampson, A & Williams, J 2011, 'Evidence-based practice and family presence: paving the path for bedside nurse scientists', *Journal of Emergency Nursing*, vol 37, no. 1, pp. 9-16.

Nyman, V, Downe, S & Berg, M 2011, 'Waiting for permission to enter the labour ward world: First time parents' experiences of the first encounter on a labour ward', *Sexual and Reproductive Healthcare*, vol. 2, pp. 129-134.

O'Brien, J & Fothergill-Bourbonnais, F 2004, 'The experience of trauma resuscitation in the emergency department: themes from seven patients', *Journal of Emergency Nursing*, vol. 30, no. 3, pp. 216-224.

O'Brien, M, Creamer, K, Hill, E & Welham, J 2002, 'Tolerance of family presence during pediatric cardiopulmonary resuscitation: a snapshop of military and civilian pediatricians, nurses and residents', *Pediatric Emergency Care*, vol. 18, no. 6, pp. 409-413.

Oberle, K & Hughes, D 2001, 'Doctors' and nurses' perceptions of ethical problems in end-of-life decisions', *Journal of Advanced Nursing*, vol. 33, no. 6, pp. 707-715.

Oman, K & Duran, C 2010, 'Health care providers' evaluation of family presence during resuscitation', *Journal of Emergency Nursing*, vol. 36, no. 6, pp. 524 -533.

Omran, S, Al Ali, N & Alshahrani, H 2015, 'Acute care nurses' attitudes toward family presence during cardio-pulmonary resuscitation in the Kingdom of Saudi Arabia', *Clinical Nursing Studies*, vol. 3, no. 3, pp. 69-75.

Ong, M, Chan, Y, Srither, D & Lim, Y 2004, 'Asian medical staff attitudes towards witnessed resuscitation', *Resuscitation*, vol. 60, no. 1, pp. 45-50.

Ong, M, Chung, W & Mei, J 2007, 'Comparing attitudes of the public and medical staff towards witnessed resuscitation in Asian populations', *Resuscitation*, vol. 73, no. 1, pp. 103-108.

Oxford Dictionaries 2015, available online, <http://www.oxforddictionaries.com/>.

Parsons, T 1951, *The social system*, Free Press, Glencoe, Illenois.

Pasquale, M, Pasquale, M, Baga, L, Eid, S & Leske, J 2011, 'Family presence during trauma resuscitation: ready for primetime', *The Journal of Trauma: Injury, Infection and Critical Care*, vol. 69, no. 5, pp. 1092-1100.

Perry, S 2009, 'Support for parents witnessing resuscitation: nurses perspectives', *Nursing Children and Young People*, vol. 21, no. 6, pp. 26-31.

Polit, DF & Beck, CT 2010, *Essentials of nursing research*, Wolters Kluwer / Lippincott Williams & Wilkins, Philadelphia.

Porter, J, Cooper, S & Taylor, B 2014, 'Emergency resuscitation team roles: what constitutes a team and who's looking after the patient', *Journal of Nursing Education and Practice*, vol. 4, no. 4, pp. 124-132.

Porter, J, Cooper, S & Taylor, B 2015, 'Family presence during resuscitation (FPDR): a survey of emergency personnel in Victoria, Australia', *Australasian Emergency Nursing Journal*, vol. 18, no. 2, pp. 98-105.

Porter, J, Cooper, SJ & Sellick, K 2013, 'Attitudes, implementation and practice of family presence during resuscitation (FPDR): a quantitative literature review', *International Emergency Nursing*, vol. 21, no. 1, pp. 26-34.

Porter, JE, Cooper, SJ & Sellick, K 2014, 'Family presence during resuscitation (FPDR): Perceived benefits, barriers and enablers to implementation and practice', *International Emergency Nursing*, vol. 22, no. 2, pp. 69-74.

Post, H 1989, 'Letting a family in during a code', *Nursing,* vol. 19, no. 3*,* pp. 43-46.

Power, N & Franck, L 2008, 'Parent participation in the care of hospitalized children: a systematic review', *Journal of Advanced Nursing*, vol. 62, no. 6, pp. 622-641.

ProSyst. 2015, 'Conditional permission admin.' ProSyst Developer Zone, viewed 12 April 2015, https://dz.prosyst.com/pdoc/mBS_SDK_7.3.0/modules/framework/system/system/permissions/conditionalpermission.html>.

Protheroe, J, Brooks, H, Chew-Graham, C, Gardner, C & Rogers, A 2012, '"Permission to participate?" A qualitative study of participation in patients from differing socio-economic backgrounds', *Journal of Health Psychology*, vol. 18, no. 8, pp. 1046-1055.

Quint, J 1967, *The nurse and the dying patient*, Macmillan, New York.

Redley, B & Hood, K 1996, 'Staff attitudes towards family presence during resuscitation', *Accident and Emergency Nursing*, vol. 4, no. 3, pp. 145-151.

Rees, C, Ajjawi, R & Monrouxe, L 2013, 'The construction of power in family medicine bedside teaching: a video observation study', *Medical Education*, vol. 47, no. 2, pp. 154-165.

Rescher, N & Anderson, AR 1962, 'Conditional permission in deontic logic', *Philosophical Studies*, vol. 13, vol. 1-2, pp. 1-8.

Robinson, S, Mackenzie-Ross, S, Hewson, G, Egleston, C & Prevost, A 1998, 'Psychological effect of witnessed resuscitation on bereaved relatives', *The Lancet*, vol. 352, no. 9128, pp. 614-617.

Ross, L, Greene, D & House, P 1977, 'The "false consensus effect": An egocentric bias in social perception and attribution processes', *Journal of Experimental Social Psychology*, vol. 13, no. 3, pp. 279-301.

Rousseau, P 2004, 'Social invitations, time constraints, and professional distance.' *American Journal of Hospice & Palliative Care*, vol. 21, no. 1, pp. 17-18.

SA Health 2015, *Open disclosure*, Government of South Australia, Department of Health and Ageing, viewed 8 May 2015, <http://www.sahealth.sa.gov.au/wps/wcm/connect/public+content/sa+health+internet/clinical+r esources/safety+and+quality/governance+for+safety+and+quality+in+health+service+organisatio ns/open+disclosure>.

Sackett, D, Richardson, W, Rosenberg, W & Haynes, RB 2000, *Evidence-based medicine. How to practice and teach EBM*, Churchill Livingstone, New York.

Sackett, D, Rosenberg, W, Gray, J, Haynes, R & Richardson, W 1996, 'Evidence based medicine: what it is and what it isn't', *Brittish Medical Journal*, vol. 312, no. 7023, p. 71.

Salmond, S 2011, 'When the family member is a nurse: the role and needs of nurse family members during critical illness of a loved one', *Intensive and Critical Care Nursing*, vol. 27, no. 1, pp. 10-18.

Salvini, A 2010, 'Symbolic interactionism and social network analysis: an uncertain encounter', *Symbolic Interaction*, vol. 33, no. 3, pp. 364-388.

Sasson, C, Rogers, M, Dahl, J & Kellermann, A 2010, 'Predictors of survival from out-of-hospital cardiac arrest: a systematic review and meta-analysis', *Circulation. Cardiovascular quality and outcomes,* vol. 3, no. 1, pp. 63-81.

Sayre, M, Koster, R, Botha, M, Cave, D, Cudnik, M, Handley, A, Hatanaka, T, Hazinski, M, Jacobs, I, Monsieurs, K, Morley, P, Nolan, J & Travers, A 2010, 'Part 5: adult basic life support: 2010 international consensus on cardiopulmonary resuscitation and emergency cardiovascular care science with treatment recommendations', *Circulation*, vol. 122, no. 16, Suppl 2, pp. S298 -324.

SBREC 2007, *Ethical Guidelines for Social and Behavioural Research - Information for Researchers/Supervisors*, Flinders University, viewed 2 Jan 2011, <http://www.flinders.edu.au/about_research_files/Documents/Info%20for%20Research/Ethics% 20and%20Biosafety/SBREC/EthicsGuidelines.pdf>.

Schneider, Z, Whitehead, D & Elliot, D 2007, *Nursing and midwifery research; methods and appraisal for evidence-based practice*, 3rd edn, Elsevier Australia, Marrickville, NSW.

Schneider, Z & Whitehead, D 2013, *Nursing and midwifery research; methods and appraisal for evidence-based practice*, 4th edn, Elsevier Australia, Chatswood, NSW.

Schumacher, K 1995, 'Family caregiver role aquisition: role-making through situated interaction', *Scholarly Inquiry for Nursing Practice: An International Journal*, vol. 9, no. 3, pp. 211-226.

Seidman, J 2009, 'Valuing and caring', *Theoria*, vol. 75, no. 4, pp. 272-303.

Shalin, D 1986, 'Pragmatism and social interactionism', *American Sociological Review*, vol. 51, no. 1, pp. 9-29.

Shalin, D 1991, 'The pragmatic origins of symbolic interactionism and the crisis of classical science', *Symbolic Interaction*, vol. 12, no. 1, pp. 223-251.

Shalowitz, D, Garrett-Mayer, E & Wendler, D 2006, 'The accuracy of surrogate decision makers: a systematic review', *Archives of Internal Medicine*, vol. 166, no. 5, pp. 493-497.

Sharp, D 2007, 'ANMC national guidelines on boundaries of professional practice for nurses and midwives', *Contemporary Nurse: A Journal for the Australian Nursing Profession*, vol. 26, no. 2, pp. 157-160.

Sheng, C, Lim, C & Rashidi, A 2010, 'A multi-center study on the attitudes of Malaysian emergency health care staff towards allowing family presence during resuscitation of adult patients', *Internal Journal of Emergency Medicine*, vol. 3, no. 4, pp. 287-291.

Sherman, S, Presson, C & Chassin, L 1984, 'Mechanisms underlying the false consensus effect: The special role of threats to the self', *Personality and Social Psychology Bulletin*, vol. 10, no. 1, pp. 127-138.

Shields, L 2010, 'Questioning family-centred care', *Journal of Clinical Nursing*, vol. 19, no. 17-18, pp. 2629-2638.

Shields, L, Kristensson-Hallstrom, I, Kristjansdottir, G & Hunter, J 2003, 'Who owns the child in hospital? A preliminary discussion', *Journal of Advanced Nursing*, vol. 41, no. 3, pp. 213-222.

Skeat, J 2010, *Using grounded theory in health research*, in P. Liamputtong (ed), Research methods in health; foundations for evidence-based practice, Oxford University Press, Melbourne, pp. 106-122.

Slovic, P 2001, 'The risk game', *Journal of Hazardous Materials*, vol. 86, no. 1, pp. 17 - 24.

Slovic, P & Gregory, R 1999*, Risk analysis, decisional analysis, and the social context for risk decision making*, in Shanteau, J, Mellers, B, Schum, D (eds), Decision Science and Technology; reflections on the Contributions of Ward Edwards, Kluwer, Boston, pp 353-365.

Smart, J & Williams, B 1973, *Utilitarianism for and against*, Cambridge University Press, Cambridge, UK.

Smith, J, Cheater, F, Chatwin, J & Bekker, H 2009, 'Parents' involvement in decisions when their child is admitted to hospital with suspected shunt malformation; study protocol', *Journal of Advanced Nursing*, vol. 65, no. 10, pp. 2198 - 2207.

Smith, R 2000, 'A good death: an important aim for health services and for us all', *BMJ*, vol. 320, no. 7228, pp. 129-130.

Snow, D 2001, 'Extending and broadening Blumer's conceptualization of symbolic interactionism', *Symbolic Interaction*, vol. 24, no. 3, pp. 367-377.

Søfting, GH, Dyregrov, A & Dyregrov, K 2015, 'Because I'm also part of the family. Children's participation in rituals after the loss of a parent or sibling: a qualitative study from the children's perspective', *OMEGA-Journal of Death and Dying*, viewed 4 September 2015 <http://ome.sagepub.com/content/early/2015/03/20/0030222815575898.full.pdf> doi: 10.1177/0030222815575898.

Soleimanpour, H, Behringer, W, Tabrizi, J, Sarahrudi, K, Golzari, SE, Hajdu, S, Rasouli, M, Nikakhtar, M & Esfanjani, R 2015, 'An analytical comparison of the opinions of physicians working in emergency and trauma surgery departments at Tabriz and Vienna medical universities regarding family presence during resuscitation', *PLoS ONE*, vol. 10, no. 4, doi:0123710.0121371/journal.pone.0123765.

St John Ambulance Australia, ARC & NHFoA 2012, *Early access to defibrillation*, viewed 9 July 2015, <http://www.heartfoundation.org.au/SiteCollectionDocuments/EAD-joint-statement-2012-update.pdf>.

Stern, P 2007, *On solid ground: essential properties for growing grounded theory*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Ltd, London, pp. 114-126.

Strauss, A 1987, *Qualitative analysis for social scientists*, Cambridge University Press, Melbourne.

Strauss, A & Corbin, J 1990, *Basics of qualitative research: techniques and procedurs for developing grounded theory*, 1st edn SAGE Publications, London.

Strauss, A & Corbin, J 1998, Basics of qualitative research; techniques and procedures for developing grounded theory, 2nd edn, SAGE Publications Inc, California.

Stryker, S 1987, 'The vitalization of symbolic interactionism', *Social Psychology Quarterly*, vol. 50, no. 1, pp. 83-94.

Suddaby, R 2006, 'From the editors: what grounded theory is not', *Academy of Management Journal*, vol. 49, no. 4, pp. 633-642.

Svenson, O 2003, Values, affect and processes in human decision making: a differentiation and consolidation theory perspective, in S. Scheider and J. Shanteau (eds), Emerging perspectives on judgement and decision research, Cambridge University Press, Cambridge, pp. 287-326.

Taba, P, Rosenthal, M, Habicht, J, Tarien, H, Mathiesen, M, Hill, S & Bero, L 2012, 'Barriers and facilitators to the implementation of clinical practice guidelines: A cross-sectional survey among physicians in Estonia', *BMC Health Services Research*, vol. 12, vol. 455, doi:10.1186/1472-6963-12-455.

Taraghi, Z, Ehteramalsadat, I, Yaghoobi, T, Noroozinejad, F, Naseri, F, Baghernejad, S & Mohammadpour, R 2014, 'A comparison of the attitudes towards family members witness during CPR', *Global Journal on Advances Pure and Applied Sciences*, vol. 4, pp. 132-140.

Taylor, B, Kermode, S & Roberts, K 2011, *Research in nursing: evidence for best practice*, Cengage Learning Australia Pty Ltd Sydney.

Tercier, J 2008, *The lips of the dead and the "kiss of life;" the comtemporary deathbed and the aesthetic of CPR*, in Wong, YS & Sayer, D (eds), Twenty years of the Journal of Sociology: challenging the field, vol. 2, Blackwell Publishing, UK, doi: 10.1002/9781444309720.ch6.

Timmermans, S 1996, 'Saving lives or saving multiple identities? The double dynamic of resuscititation scripts', *Social Studies of Science*, vol. 26, no. 4, pp. 767-797.

Timmermans, S 1997, 'High touch in high tech: the presence of relatives and friends during resuscitative efforts', *Scholarly Inquiry for Nursing Practice: An International Journal*, vol. 11, no. 2, pp. 153-168.

Timmermans, S 1998, 'Resuscitation technology in the emergency department: towards a dignified death', *Sociology of Health and Illness*, vol. 20, no. 2, pp. 144-167.

Timmermans, S 1999a, *Sudden death and the myth of CPR*, Temple University Press, Philadelphia, USA.

Timmermans, S 1999b, 'When death isn't dead: implicit social rationing during resuscitative efforts', *Sociological Inquiry*, vol. 69, no. 1, pp. 51-75.

Timmermans, S 2005, 'Death brokering: constructing culturally appropriate deaths', *Sociology of Health and Illness*, vol. 27, no. 7, pp. 993-1013.

Tinsley, C, Hill, J, Shah, J, Zimmerman, G, Wilson, M, Freier, K & Abd-Allah, S 2008, 'Experiences of families during cardiopulmonary resuscitation in a paediatric intensive care unit', *Pediatrics*, vol. 122, no. 4, pp. e799-e804.

Tomlinson, K, Golden, I, Mallory, J & Comer, L 2010, 'Family presence during adult resuscitation; a survey of emergency department registered nurses and staff attitudes', *Advanced Emergency Nursing Journal*, vol. 32, no. 1, pp. 46-58.

Toller, PW & McBride MC 2013, 'Enacting privacy rules and protecting disclosure recipients: parents' communication with children following the death of a family member', *Communication Faculty Publications,* Paper 25, viewed 3 September 2015, <http://digitalcommons.unomaha.edu/commfacpub/25>.

Tudor, K, Berger, J, Polivka, BJ, Chlebowy, R & Thomas, B 2014, 'Nurses' perceptions of family presence during resuscitation', *American Journal of Critical Care*, vol. 23, no. 6, pp. e88-96.

Turner, B 1987, *Medical power and social knowledge*, SAGE publications, London.

Twibell, R, Siela, D, Riwitis, C, Wheatley, J, Riegle, T, Bousman, D, Cable, S, Caudill, P, Harrigan, S, Hollars, R, Johnson, D & Neal, A 2008, 'Nurses' perceptions of their self-confidence and the benefits and risks of family presence during resuscitation', *American Journal of Critical Care*, vol. 17, no. 2, pp. 101-111.

Urquhart, C 2007, *The evolving nature of grounded theory method: the case of the information systems discipline*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE Publications Ltd, London, pp. 339-360.

Van Eaton, E, Horvath, K & Pellegrini, C 2005, 'Professionalism and the shift mentality. How to reconcile patient ownership with limited work hours', *JAMA Surgery*, vol. 140, no. 3, pp. 230-235.

Vavarouta, A, Xanthos, T, Papadimitriou, L, Kouskouni, E & Iacovidou, N 2011, 'Family presence during resuscitation and invasive procedures: physicians' and nurses' attitudes working in pediatric departments in Greece', *Resuscitation*, vol. 82, no. 6, pp. 713-716.

Vermeulen, H, Ubbink, D, de Zwart, F, Goossens, A & de Vos, R 2007, 'Preferences of patients, doctors, and nurses regarding wound dressing characteristics: a conjoint analysis', *Wound Repair and Regeneration*, vol. 15, no. 3, pp. 302-307.

Wacht, O, Dopelt, K, Snir, Y & Davidovitch, N 2010, 'Attitudes of emergency department staff toward family presence during resuscitation', *IMAJ - Israel Medical Association Journal*, vol. 12, no. 6, pp. 366-370.

Wagner, J 2004, 'Lived experience of critically ill patients' family members during cardiopulmonary resuscitation', *American Association of Critical Care Nurses*, vol. 13, no. 5, pp. 416-419.

Warren, C & Xavier Karner, T 2010, *Discovering qualitative methods; field research, interviews and analysis*, Oxford University Press, New York.

Waseem, M & Ryan, M 2003, 'Parental presence during invasive procedures in children: What is the physician's perspective?', *Southern Medical Association*, vol. 96, no. 9, pp. 884-887.

Waters, M & Crook, R 1989, *Sociology one; principles of sociological analysis for Australians*, Longman Cheshire Pty Ltd, Melbourne.

Watson, G 2004, *Free agency*, in Agency and Answerability, Clarendon Press, Oxford, pp. 13 - 32.

Webb, C 1992, 'The use of the first person in academic writing: objectivity, language and gatekeeping', *Journal of Advanced Nursing*, vol. 17, no. 6, pp. 747-752.

Weber, M 1962, *Basic concepts in sociology*, Peter Owen Limited, London.

Weinberg, D 2009, *Social constructionism*, in B. Turner (ed), The new Blackwell companion to social theory, Blackwell Publishing Ltd, West Sussex, pp. 281-299.

Weslien, M & Nilstun, T 2003, 'Family presence during CPR - the experiences and attitudes of code team members', *Nordic Journal of Nursing Research*, vol. 23, no. 1, pp. 31-34.

Weslien, M, Nilstun, T, Lundqvist, A & Fridlund, B 2005, 'When the unreal becomes real: family members' experiences of cardiac arrest', *British Association of Critical Care Nurses*, vol. 10, no. 1, pp. 15-22.

Weslien, M, Nilstun, T, Lundqvist, A & Fridlund, B 2006, 'Narratives about resuscitation - family members differ about presence', *European Journal of Cardiovascular Nursing*, vol. 5, no. 1, pp. 68-74.

Wiener, C 2007, *Making teams work in conducting grounded theory*, in A. Bryant and K. Charmaz (eds), The SAGE handbook of grounded theory, SAGE publications Ltd, London, pp. 293-310.

Williams, B, Lewis, D, Burgio, K & Goode, P 2012, '"Wrapped in their arms." Next of kin's perceptions of how hospital nursing staff support family presence before, during and after death of a loved one', *Journal of Hospice & Palliative Nursing*, vol. 14, no. 8, pp. 41-550.

Yanturali, S, Ersoy, G, Yuruktumen, A, Aksay, E, Suner, S, Sonmez, Y, Oray, D, Colak, N & Cimrin, A 2005, 'A national survey of Turkish emergency physicians perspectives regarding family witnessed cardiopulmonary resuscitation', *International Journal of Clinical Practice*, vol. 59, no. 4, pp. 441-446.

Yedidia, M, Lipkin, M, Schwartz, M & Hirschkorn, C 1993, 'Doctors as workers: work-hour regulations and interns' perceptions of responsibility, quality of care, and training', *Journal of General Internal Medicine*, vol. 8, no. 8, pp. 429- 435.

Zakaria, M & Siddique, M 2008, 'Presence of family members during cardio-pulmonary resuscitation after necessary amendments', *Journal of Pakistan Medical Association*, vol. 58, no. 11, pp. 632-635.

Zavotsky, KE, McCoy, J, Bell, G, Haussman, K, Joiner, J, Marcoux, KK, Magarelli, K, Mahoney, K, Maldonado, L, Mastro, KA, Milloria, A, Tamburri, LM & Tortajada, D , 2014, 'Resuscitation team perceptions of family presence during CPR', *Advanced Emergency Nursing Journal*, vol. 36, no. 4, pp. 325-334.

A comprehensive search of the literature was undertaken between May 2011 and November 2011 (and updated during June 2014 and June 2015). The review began by searching electronic databases CINAHL, Proquest, Journals@Ovid, SCOPUS, Cochrane Library and Google Scholar, using the following search terms and phrases; *family presence during resuscitation, family presence during cardiopulmonary resuscitation, family witnessed resuscitation, family witnessed cardiopulmonary resuscitation, parental presence during resuscitation, parental presence during cardiopulmonary resuscitation, family presence* AND *resuscitation, parent* presence* AND *resuscitation.* This search yielded several thousand articles on FPDR which were then refined as described in the following sections in an attempt to include only primary research studies.

Hand searching was then undertaken which involved reviewing the bibliographical details of published studies, PhD dissertations, review papers and position statements and guidelines in order to locate additional relevant literature. Several more primary studies were accessed using this strategy and from professional colleagues. In order to ensure all relevant primary studies were retrieved, all 120 electronic databases in the Flinders University Library online catalogue were searched using the same key words and phrases listed above, with 34 of these databases yielding literature relating to FPDR.

No date restrictions were applied to the search and all relevant studies since the seminal FPDR study was published in 1987 (Doyle *et al.* 1987) were retrieved. This decision was made to allow an in-depth exploration of the developing phenomenon and practice of FPDR from its inception through to current practices.

Once retrieved, each abstract was read and duplicate studies were removed. Studies that were not relevant to the review aims and objectives, and those that failed to meet the inclusion criteria (listed in appendix table 1 on page 230) were also removed. Several methodological restrictions were applied to the search. Opinion pieces using anecdotal evidence, case-study examples from clinical practice and conference abstracts and proceedings were excluded because it was not possible to determine study rigour and findings were scantly reported and added little to the analysis and discussion. Secondary sources such as literature reviews were also excluded in keeping with recommendations that a well-conducted literature review contains mainly published primary sources (Taylor Kermode & Roberts 2011) so it is not reliant on the interpretation of secondary sources and has gone through a peer review process. For this reason unpublished theses were also excluded from the review.

Appendix Table 1: Inclusion and exclusion criteria applied to the literature search

Inclusion criteria	Exclusion Criteria
Original (primary) research	Literature reviews and case studies
Studies published in English	Studies published in languages other than English
Acute care settings	Aged care settings and out of hospital settings
Main focus is on family presence during CPR	Main focus on IP/ trauma resuscitation, not CPR
Dual focus but main focus on FPDR	Dual focus but main focus on FPDIP's
Patients from all age groups included	Child family members
Attitudes, beliefs of relevant HP, patients and FM	HP groups must include nurses and/or doctors
All methodologies included	Opinion pieces, anecdotes, clinical exemplars
No time restrictions applied	Unpublished theses
No geographical restrictions applied	Participants included HP students only
Rural and metropolitan settings included	Pre-hospital setting

Table key: CPR = cardiopulmonary resuscitation; FPDR = family presence during resuscitation; FPDIP = family presence during invasive procedures; HP = health care professional; FM = family members; IP = invasive procedures; trauma resuscitations excluding CPR

INTRODUCTION

Contentious debate has taken place about the role of the literature review in grounded theory research ever since the publication of *The discovery of Grounded Theory.*[1] Concerns have been raised about how researchers should approach the related literature,[2] with timing of the literature review in grounded theory research an issue of ongoing confusion and misunderstandings.[3-12] Conflicting advice, in particular the commonly held belief that *all* grounded theorists should delay the literature review until during or after data collection, can lead to inexperienced researchers becoming confused and in some cases discounting grounded theory as a potential methodology.[13]

The timing of the literature review is often influenced by the researcher's epistemological perspective, and previous background and knowledge in the study area.[6] In quantitative research the review is undertaken prior to data collection to guide the development of the research question and the methods used, and to provide the rationale for future research by considering previous gaps and inconsistencies.[14] The guidelines about the use of the literature review in qualitative research differ, with some approaches recommending delay of the review until after data collection.[14] One research approach that sometimes recommends postponing the literature review is grounded theory.

Two broad perspectives about the timing of the literature review in grounded theory are apparent in the literature; 1) to delay the literature review until after data collection and analysis begins, and in some cases until codes and categories begin to emerge, or 2) to undertake a preliminary literature review prior to the study and then either expand this review or write a secondary review during data collection and analysis. Few articles and texts discuss this issue in depth, and most sources offer conflicting advice which contributes to the ongoing confusion about the 'correct' use of the literature in grounded theory research. This article provides a critical review of the extant literature and debate about the timing of the literature review and makes recommendations for researchers to consider when planning their grounded theory studies.

HISTORICAL POSITIONING OF THE LITERATURE REVIEW IN GROUNDED THEORY RESEARCH

Several styles of grounded theory have been developed and used over the years, each reflecting the epistemological underpinnings of the researchers developing these styles. Literature plays an important and varied role in grounded theory research[15] depending on the chosen style. The following section explores historical and current recommendations and rationales about use of literature in grounded theory research by Glaser and Strauss,[1] Glaser,[16-18] Strauss and Corbin[15,19-21] and Charmaz. [2,4,22,23]

Glaser and Strauss

The recommendation to delay reviewing the literature until after data collection begins, or even until after the substantive theory has been generated, first arose in relation to the classical grounded theory method developed by Barney Glaser and Anselm Strauss.[1] In *The Discovery of Grounded Theory* Glaser and Strauss advised researchers to 'literally ignore the literature and fact on the area under study, in order to ensure that the emergence of categories will not be contaminated by concepts more suited to different areas.'[1] (p37) They assured readers that similarities and differences with the literature could be established after the analytic core of categories has emerged.

However, several contradictions to this advice are evident further along in the text. The first of these is their recommendation that researchers should be sufficiently theoretically sensitive in order to conceptualise and formulate a theory as it emerges from the data.[1] (p 46) They acknowledge that researchers have previous knowledge in their substantive area (p 92), and advise that the theoretical sensitivity developed over many years within the researcher can be used to generate his specific theory if 'the fit and relevance to the data are emergent' (p46). This begs the question - exactly how can this sensitivity be developed without knowledge of existing literature? The second contradiction is evident in their chapter about new sources of qualitative data. Here, Glaser and Strauss[1] agree that documents 'may be used – especially in the early days of research – to help the researcher understand the substantive area he has decided to study … and help him formulate his earliest hypotheses' (p 162).

In light of this contradictory advice within their co-authored text, it is not surprising then that Glaser and Strauss went on to make opposing recommendations about the timing of the literature review in grounded theory research in their subsequent publications. These differences are explored below.

Glaser

Since the publication of *The Discovery of Grounded Theory* Glaser has maintained that the literature should not be reviewed prior to the study for fear of contaminating, constraining, inhibiting or impeding the researcher's analysis of theoretical codes emerging from the data.[16-18] More specifically Glaser advises 'do not do a literature review in the substantive area and related areas where the research is to be done; and when the grounded theory is nearly completed during sorting and writing up, then the literature search in the substantive area can be accomplished and woven into the theory as more data for constant comparison'.[17] (p 67) Glaser's claim that the researcher in traditional or classical grounded theory must be a *tabula rasa* (or blank slate) when beginning a study however is at odds with some of his writings in *Theoretical Sensitivity*.[24] In this text Glaser alludes to possessing prior knowledge of the research issue when he writes 'it is necessary for the grounded theorist to know many theoretical codes in order to be sensitive to rendering explicitly the subtleties of the relationship in his data' (p 72). This leads us to question, as Charmaz[4] does, how researchers could know these theoretical codes if they are not part of their existing knowledge. If the researcher *does* know these codes as Glaser suggests, this implies knowledge of the relevant literature.

Glaser also acknowledged the problems of presenting a research proposal to dissertation committees and funding agencies in light of recommendations to delay the literature review until after analysis. Glaser

concedes that if a preliminary literature review is necessary to satisfy university requirements then it should be done, recommending that researchers not waste time and 'do what people want.'[17] (p 72) He assures us that concepts from the literature 'will constantly be corrected, put in perspective and proportioned in relevance by the constant comparative method.'[17] (p72), and falsify, confirm or extend the applicability of the theory to the substantive area under study.

Strauss and Corbin

While Glaser remains adamant about delaying the literature review in grounded theory research to this day, Strauss appears to have changed his view over time. Strauss (together with Glaser) also initially advocated delaying the literature review,[1] but later Strauss suggests they may have overemphasised the inductive aspects of grounded theory in their earlier work.[21] Strauss also acknowledges that his earlier advice to delay the literature review applied less so to experienced researchers. Strauss indicates that experienced researchers are able to subject a theoretical statement to comparative analysis and would be capable of questioning whether such a decision would hold true under different conditions.[20] In his later works with Corbin,[15,19,21] Strauss highlights both the advantages and disadvantages of the initial literature review stating that while there is a risk that familiarity with the relevant literature can block creativity, familiarity can also enhance sensitivity to subtle nuances in data.[21]

In *Basics of Qualitative Research* Strauss and Corbin[15] acknowledged that researchers bring with them life experience and knowledge of related literature. They stress the importance of acknowledging and using that knowledge to enhance theoretical sensitivity, stimulate research questions and direct theoretical sampling. Strauss and Corbin elaborate on these recommendations in the second[21] and third[19] editions of their text, adding that before a research project begins the literature can formulate questions that 'act as a stepping off point' during initial observations and interviews, and during data analysis can stimulate questions about 'what is going on' with the data.[21] (p 51) In these later editions they also maintain that the literature can help the researcher to assist theoretical sampling, and add that it can direct the researcher to situations they might not have considered otherwise. Strauss and Corbin[21] conclude that if the researcher is careful not to allow the literature to stand between themselves and the data, it can also be used as an analytic tool to foster conceptualisation.

Charmaz

One of the founders of a constructivist approach to grounded theory research and a previous student of Glaser, Kathy Charmaz[4] presents her version of grounded theory as a return to the classic statements of the past century, which have been re-examined through a methodological lens of the present century. In *Constructing Grounded Theory*[4] Charmaz writes that institutional and ethical requirements often dictate the need for a preliminary literature review but warns if the literature is reviewed *in-depth* prior to data collection, the novice researcher may be influenced by existing theories and force data into pre-existing categories.[4,23] However Charmaz fails to define exactly what an in-depth review consists of in such a study. Together with Antony Bryant[2] Charmaz later acknowledges that advice to delay the literature review usually comes from experienced researchers who have extensive knowledge of the literature and general familiarity with key topics and concepts.[2] This knowledge in effect becomes *a literature review on tap*, a concept that is mentioned again later in this paper in relation to Glaser.

Although Charmaz believes grounded theory research aims to minimise pre-conceived ideas about the research problem and data, she concedes that each person brings a past to the present and will most certainly bring pre-conceived knowledge and ideas to their research.[22] In her later collaboration with Antony Bryant,[2] Charmaz contends that a researcher should account for these pre-conceived ideas in some way and not simply ignore them. Together they recommend a balance between using the literature to provide a beginning framework to the research study and having a level of understanding to provide an orientation to the research. On the latter point they cite Lempert[25] who strongly advocates a preliminary literature review in order to avoid ignorance of existing evidence and to participate in the current theoretical conversation, while maintaining that the review does not have to define your research.

Charmaz's constructivist view therefore appears to allow a preliminary literature review prior to the study, which is then put aside and 'allowed to lie fallow' until the researcher has begun to develop categories during analysis.[4] (p 166) She asserts that during data collection and analysis, 'completing a thorough, sharply focused literature review strengthens your argument – and your credibility.'[4] (p 166) This secondary literature review provides a place to engage with the ideas and research in the areas relevant to the grounded theory, and helps the researcher position the study and clarify its contribution to knowledge.[4]

THE ONGOING LITERATURE REVIEW DEBATE

One of the most often cited rationales for delaying the review is to ensure that the emergent theory will be grounded in the data rather than being forced to fit into a pre-conceived theory.[1,4,6,15-17,20,26,27] Glaser[17] famously stated that *everything is data*, something to be constantly compared and analysed with everything else that is data. Many researchers have interpreted this statement in different ways, with some arguing that the data Glaser refers to includes literature that may have been examined at some time before or during the study. The following discussion focuses on the apparent contradiction that exists between recommendations made by Glaser and Strauss about the use of literature in grounded theory and their own research practices.

Glasserian and Straussarian Grounded Theory: Recommendations versus Practice

As far back as the 1970's, Blumer[28] argued that Glaser and Strauss's original tabula rasa view of inquiry was open to serious doubt. More recently, Mills and colleagues[7] and Dey[29] argue that Glaser could not have really thought it possible to begin a research study with an actual blank slate. Indeed, few researchers today begin a study with no knowledge of a topic due to the enormous amounts of information available freely online, and experts argue that exposure to this knowledge cannot be simply put aside and forgotten.[3,10,22]

While they originally warned against engaging with the literature prior to beginning a study, it appears that both Glaser and Strauss did not always follow their own advice. It has been said[30] that Glaser provided ambiguous advice about the timing of the literature review to his students, such as advising them *not* to review the literature prior to data analysis but not actually telling them *when* they should review it. Some students reported being increasingly frustrated that their analysis was hampered by their poor knowledge of the literature while at the same time Glaser used the huge amount of data in his head

(referred to by his students as a *literature review on tap*) to identify categories and enhance his theoretical sensitivity.[30]

Strauss too did not always appear to follow his original advice of avoiding the literature prior to a study, with a previous student attributing Strauss's skill in analysis and coding to his wide experience and reading.[31] Wiener goes on to say that while studying with Strauss, she and Strauss both found the literature useful from the very beginning of their research to widen their horizons and enrich their interviews. Wiener claimed that rather than avoiding the literature, they used it extensively and in fact remaining current was the pressing challenge of their research.[31]

The differing opinions of the founders of grounded theory discussed so far have already highlighted conflicting and at times confusing advice regarding *what extent* the literature should be scrutinised, and exactly *when* it should be reviewed. Many authors have contributed to this timing debate. Some have supported Glaser's approach of delaying the literature review until after analysis begins and in some cases until codes and categories begin to emerge, while others defend their use of literature at any point from the very beginning of the research onwards. Some of the most common concerns about undertaking a preliminary literature review are discussed below along with strategies to ensure these issues do not adversely affect or bias the research process or outcomes.

Dealing with Preconceptions

Delaying the literature review in grounded theory studies has been recommended in the past to avoid the influence of previous knowledge, values, beliefs and experiences on the research. This was thought to decrease any chance of personal bias, which some people maintain was to gain credibility with researchers who use quantitative or positivistic methods.[32] It has since been said that grounded theory (and in particular constructivist grounded theory) has moved beyond the positivist stance that we should come to the data with a clear mind and no pre-conceptions.[12]

The fundamental tenet of grounded theory research to minimise pre-conceived ideas about the research problem and data is being questioned more and more in the literature. Bryant[3] contends that the belief that researchers can approach a topic without any preconceptions or having rid themselves of all prejudices and bias is now largely derided by many experts. Rather than being thought of as disadvantageous and undesirable, it is argued that *a priori assumptions* should not only be expected, but in fact welcomed as a way of making the study worthwhile and possible.[33] Bryant agrees that sometimes it is precisely someone's prejudices (in the sense of prior judgements) that can lead to innovative insights.[3] He also argues that if we move away from the idea of grounded theory as a purely inductive process and instead stress the ways that 'theoretical sensitivity can be encouraged and advanced as a form of abduction' then whether or not we use existing literature at the beginning of a study loses relevance.[3] (p 14) In other words it is possible to access existing knowledge without 'being trapped in the view that it represents the final truth in the area.'[34] (p 341)

Evidence suggests that forcing pre-conceived ideas on the data from existing literature can be minimised or even avoided with careful thought and planning. For example McCallin[11] used classical grounded theory in her nursing research, but undertook a pre-study literature review in order to satisfy university

authorities and ethics committees. She avoided literature she considered had the potential to emerge as a significant concept, but justified her significant reading in other related areas. McCallin used Glaser's argument that *any literature is data* that can be neutralised or integrated using the constant comparison method if the researcher can put aside personal perspectives in order to understand the participant's viewpoint.[11] More recently, several lecturers in Health Studies presented opposing approaches to using the literature in grounded theory research. McGhee et al. concluded that the use of literature or any other pre-knowledge should not prevent a grounded theory emerging if reflexivity is used to prevent prior knowledge distorting the researcher's perception of the data.[6]

Reflexivity in Grounded Theory Research

The constant comparison method of grounded theory where emergent themes are grounded in the data rather than gained from pre-conceived concepts requires a consciously reflective process called reflexivity.[6] Reflexivity is a process during which a researcher overtly scrutinises his or her research experiences, decisions and interpretations in order to allow the reader to assess to what extent the researcher's interests, positions and assumptions influenced the research.[2] Glaser[18] does not appear to believe reflexivity to be an appropriate grounded theory strategy, warning that it will lead to 'reflexivity paralysis' (p 47) during analysis. However Corbin and Strauss[19] argue that reflexivity is now considered an essential part of the grounded theory research process. They state the meaning a researcher gives to reflexivity and the extent to which it is used varies depending on their philosophical orientations and perceived degree of relevance. Using a constructivist approach, Charmaz[4] believes grounded theorists are obligated to incorporate reflexivity into their research design, arguing that we are 'part of our constructed theory and this theory reflects the vantage points inherent on our varied experience, whether or not we are aware of them.' (p 149)

Reflexivity acknowledges that the researcher as an individual, with a particular background and social identity, will inevitably influence the research process and should be subject to the same critical analysis and scrutiny as the research itself.[2,4,3] Reflexivity can make research findings more credible by making explicit the researcher's contribution to the interpretive process through self-critical appraisal and self-awareness.[35]

Self-awareness expressed through analytic memo-writing is integral to the process of reflexivity, making personal assumptions explicit and enabling a *turning back* on initial reactions to the data.[36] In other words reflexivity requires the researcher to develop a self-aware, self-questioning approach and be prepared to allow prejudices to be eliminated by data that oppose them.[6,37] Corbin wrote about how self-reflection allowed her to identify when she was slanting the data, at times noting that her memos were more reflective of her emotional response to the data rather than a conceptualization of what the respondents were telling her. This allowed her to go back and re-analyse the data and increase the truthfulness and credibility of the findings.[19]

McGhee and colleagues[6] argue that reflexivity can prevent a researcher who is already very familiar with the literature on the study topic from distorting perceptions of the data, or forcing pre-conceived concepts and theories. The fear that a researcher might stifle their analysis can also be addressed by being self-aware and able to appreciate other theories without imposing them on the data.[34] Reflexivity therefore can

allow researchers to be informed by and build on previous knowledge gained through a literature review without assuming that concepts discovered in the preliminary literature review would be the only solution to a research problem.[9,38]

An Empty Head versus an Open Mind

Pre-conceived ideas themselves then are not the problem, but rather how they are dealt with by the grounded theory researcher in order to minimise bias and avoid imposing existing theories on the data. As we have already shown, a blank slate is neither desirable nor possible,[39] and instead the main goal should be that the researcher does not start with an existing theory to prove or disprove but rather allows theories to emerge from the data.[4]

More and more experts are now questioning the recommendation to avoid the literature at the beginning of a grounded theory study, arguing that we can never enter a research area with an empty head, but that we can try to approach research with an open mind.[3,40] It could in fact be argued that the researcher is no more likely to adversely influence the inductive research process by prior reading of the literature than from any knowledge gained through professional experience.[41] In addition, knowledge and concepts drawn from the immediate field can provide a useful guide to analysis provided we keep an open mind about their cogency and relevance to the data.[40]

Preconceptions are acknowledged and accepted by many experts as unavoidable and by some as necessary to contribute to the worth of the study. Their acceptance adds weight to the argument in favour of a preliminary literature review in grounded theory research. The point therefore is not to avoid pre-conceptions, but to ensure they are well-grounded in arguments and evidence and always subject to further investigation, revision and refutation.[42] It is therefore important for researchers to account for their pre-conceived ideas in some way,[2] and openly acknowledge the influence of prior work in their perspective of what is emerging from the data.[4]

Using the Constant Comparative Technique to deal with Pre-conceptions

Researchers have used Glaser's[17] *all is data* tenet to justify their use of literature in grounded theory research in many different ways. For example, McCallin[11] (p 66) used classical grounded theory for her dissertation, yet conducted a preliminary search of relevant literature which she concedes was not strictly in accordance with the grounded theory style used. She argued that some sense of direction was needed to satisfy university and ethics committees, and that any literature was data which according to Glaser could be neutralised or integrated as long as it was constantly compared with emerging concepts.

Although Urquhart[43] delayed the bulk of her literature review while using a classical grounded theory approach, she developed a preliminary theoretical framework using minimal aspects of the literature, arguing that this framework increased her theoretical sensitivity. Urquhart claimed her thinking was not overly coloured by this literature because she took an inductive rather than a deductive approach and listened to the data rather than imposing pre-conceived ideas on the data. She also used the constant comparative approach to confirm, deny or extend the applicability of the theory to the substantive area under study.[43]

The constant comparison used in grounded theory research therefore validates, modifies, or rejects the researcher's observations. For the researcher with professional experience in the substantive field of research or in-depth knowledge of the related literature, constant comparison is a valuable feature of the grounded theory method to reduce the risk of bias-induced interpretations and analysis of the data.[39]

TO REVIEW OR NOT TO REVIEW

Two broad perspectives have been explored in this paper concerning the timing of the literature review in grounded theory; 1) to delay the literature review until after data collection and analysis begin, and in some cases until theoretical codes and categories begin to emerge, or 2) to undertake a preliminary literature review prior to the study and then either expand this review or write a secondary review during data collection and analysis. Advocates of the delayed literature review seem concerned primarily with avoiding pre-conceived ideas and assumptions, while those recommending a preliminary literature review argue that any concerns can be overcome with correct and transparent techniques and procedures. Table 1 presents rationales for and against a preliminary review of the literature in grounded theory research. We argue that the evidence favours a preliminary review of the literature, and provide a detailed discussion of the rationales that support our position below.

Table 1: Rationales for the timing of the literature review in Grounded Theory Research

Timing of the review	Rationale
Preliminary review	Become familiar with the literature and identify gaps [6, 21, 25, 31, 40, 46]
	Identify new approaches the researcher might not have otherwise considered [21]
	Stimulate research questions [6, 15, 21]
	Provide justification, background and framework for the study and demonstrate the potential of new knowledge [2, 5, 6, 18, 25]
	Meet ethics committee requirements [6, 18]
	Avoid conceptual and methodological pitfalls of previous studies [5, 6, 25]
	Gain a critical knowledge of key concepts [5, 6, 25]
	Direct theoretical sampling [6, 15, 21]
	Enhance theoretical sensitivity [3, 5, 6, 15, 21, 25, 31, 40, 48, 49]
	Provide secondary source of data to stimulate thinking [6, 15, 21]
Delayed review	To be strictly in keeping with a post-positivist ontology of Classic GT [6, 27]
	Avoid recognised or unrecognised assumptions and preconceptions [6, 23, 27, 42]
	Avoid being constrained, contaminated, inhibited or blocked [1, 6, 15, 16, 20, 21, 23, 24, 27, 42]
	Prevent generating a focus from the literature rather than from the emerging data; avoid forcing data into pre-conceived categories [1, 6, 15, 16, 17, 20, 21, 24, 27, 41]
	Avoid being 'stuck' with a lot of information outside data analysis categories [42, 45]

To Meet Committee Requirements and Assist with Methodological Choices

Most ethics committees and funding agencies demand a thorough literature review prior to collecting data,[6,8,11] which is a compelling reason for many researchers (particularly PhD students) to undertake a preliminary review. Some Departments of Health also argue that research which needlessly duplicates other work is unethical,[44] further supporting a preliminary review to ensure that research adds to the body of evidence rather than just replicating it.

A preliminary review allows the researcher to become familiar with the literature and gain a comprehensive knowledge of the key concepts and issues seminal to the topic at hand.[6] Some experts warn that it can be hard to know which literature is relevant for the initial review[42,43] while others point out that the researcher may be stuck with information that lies outside of the analysis of the gathered data.[45] (p 123) However, other grounded theory researchers may choose to review the literature prior to the study because they have not yet chosen their methodology and therefore all literature is relevant at this stage in order to guide methodological choices.[6,32]

The literature can be used to identify that a new approach is needed to solve an old problem even though it has been well studied in the past.[6,19,46] Marland[6] found this to be true when he was able to develop a theory free of the methodological and conceptual pitfalls of previous studies whilst also bridging perceived gaps in existing knowledge. He argued that his preliminary review of the literature was vital to demonstrate his proposed approach had not been taken before and therefore the result would constitute a unique addition to knowledge.[6]

To Identify Current Knowledge and Gaps in the Literature and help Formulate Questions

Hutchinson[47] believes a literature review should precede data collection and analysis to identify current gaps in knowledge and help provide a rationale for the proposed research. This preliminary review can sensitize concepts and add to conceptual clarity. McCallin[11] and McGhee et al[6] agree that a preliminary review is necessary at the very least to determine whether the proposed study or something similar has been done before.

Sound preliminary work can demonstrate that researchers know exactly what they are doing even if they do not know exactly what they are looking for.[11] A literature review as an orientating process can be useful to ensure researchers know about current thinking, without taking a position on the research to be done.[34] At the beginning of a project, the literature is also useful to help formulate questions that act as a stepping off point during initial observations and interviews.[21] Then as the study progresses the literature becomes an effective analytical tool to stimulate thinking.

To Enhance Theoretical Sensitivity

Glaser and Strauss have both noted that grounded theory methods seem to be easier to use when the researcher is sensitive through having professional experience or knowledge about the study field.[1,17] Theoretical sensitivity, a major tenet of grounded theory, relates to the ability to have insight, to understand and give meaning to the data, and to detach the relevant from the irrelevant[5,15,21]

With these purposes in mind, some experts advocate an early review of the literature in order to enhance theoretical sensitivity.[6,25,48,49] Gibson goes further to question how researchers can be expected to develop theoretical sensitivity *without* some familiarity with the relevant literature[49] The theoretical sensitivity gained by an initial review of the literature can help emphasize the need to not be guided by an existing conceptual framework, and to demonstrate that the research question would be likely to generate new knowledge.[6]

Lempert[25] used the literature extensively during data collection, coding, memo writing and write up. He argued that 'in order to participate in the current theoretical conversation, I need to understand it. I must recognise that what may seem like a totally new idea to me – an innovative breakthrough in my research – may simply be a reflection of my ignorance of the present conversation.' (p 254)

A preliminary review of the literature can therefore be used to enhance sensitivity and to help researchers know the types of themes and categories to look for during analysis. Researchers must be careful to ensure that themes and categories from the literature actually exist in their own data to avoid imposing pre-existing ideas and theories.[5,21] However, if used reflexively, a preliminary literature review can enhance a research study without defining it.[25]

DISCUSSION

Grounded theory research is continually evolving and different styles are used by researchers throughout the world. Whatever style is used, a defining feature of grounded theory is that emergent categories and themes arise from and are thus grounded in the data rather than being imposed on the data from existing evidence and theories. Some experts (most notably Barney Glaser) argue that reviewing the literature prior to beginning a grounded theory study threatens this defining feature by causing the researcher to force preconceived ideas on the data. However we agree instead that a constructivist grounded theory style has moved beyond the positivist stance that we should come to the data with a clear mind and no pre-conceptions.[12] We believe the use of literature or any other pre-knowledge should not prevent a grounded theory emerging if: reflexivity is used to prevent prior knowledge distorting the researcher's perception of the data;[6] essential grounded theory methods are used consistently and correctly; and the entire process is transparent.

There is a growing body of evidence that supports a preliminary literature review to contextualise the background, identify knowledge gaps, avoid conceptual and methodological pitfalls of previous research, satisfy ethical committees, provide a rationale for the study, stimulate research questions and enhance theoretical sensitivity (refer again to table 1). We agree with Charmaz that the preliminary literature review should then be put aside and be 'allowed to lie fallow'[4] (p 166) until data analysis begins.

A secondary review of the literature during data collection and analysis can link existing research and theory with the concepts, constructs and properties of the new research,[47] and validate emerging theory.[21,34,50] Charmaz asserts that during data collection and analysis, 'completing a thorough, sharply focused literature review strengthens your argument – and your credibility.'[4] (p 166) This second literature review provides a place to engage with the ideas and research in the areas relevant to the

grounded theory, and allows researchers to situate their work among and within the body of related literature and demonstrate how they built upon and went further than previous research.[4,45]

CONCLUSION

The timing of the literature review in grounded theory research has been an issue of ongoing debate since its inception in the 1960's. Previous recommendations to delay the review of the literature in order to minimise pre-conceived ideas and bias are questioned by experts who argue that such pre-conceptions are unavoidable. There is now a considerable body of evidence arguing a preliminary review of the literature does not jeopardise the rigour of grounded theory research. Rather it can be seen to enhance creativity, theoretical sensitivity and rigour. Previous knowledge and experience can lead to innovative insights. However it is important for researchers to openly acknowledge the influence of prior work in their perspective of what is emerging from their own data. The recommendation from this paper therefore is not to avoid pre-conceptions, but to ensure that they are well-grounded in arguments and evidence and always subject to further investigation, revision and refutation. If used reflexively, a preliminary literature review can enhance grounded theory research without defining it.

Conflicts of Interest

There are no conflicts of interest to declare.

REFERENCES

1. Glaser B, Strauss A. The Discovery of Grounded Theory. New York: Aldine Publishing Company; 1967.
2. Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE Publications Inc; 2007.
3. Bryant A. Grounded theory and pragmatism: the curious case of Anselm Strauss. *Forum: Qualitative Social Research* 2009;10:Available online: htpp://www.qualitative-research.net/index/php/fqs/article/view/1358/2850. Accessed 15 May 2012.
4. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London: Sage; 2006.
5. McCann T, Clark E. Grounded theory in nursing research: Part 1 - methodology. *Nurse Researcher.* 2003;11:7 - 18.
6. McGhee G, Marland G, Atkinson J. Grounded theory research: literature reviewing and reflexivity. *Journal of Advanced Nursing.* 2007;60:334 - 42.
7. Mills J, Bonner A, Francis K. The development of constructivist grounded theory. *International Journal of Qualitative Research.* 2006;5:March 2006.
8. Skeat J. Using grounded theory in health research. In: Liamputtong P, ed. Research methods in health; foundations for evidence-based practice. Melbourne: Oxford University Press; 2010.
9. Strubing J. Research as pragmatic problem-solving: the pragmatist roots of empirically-grounded theorising. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE Publications Ltd; 2007: 580-602.
10. McCallin A. Designing a grounded theory study: some practicalities. *Nursing in Critical Care.* 2003;8:203 - 8.
11. McCallin A. Grappling with the literature in a grounded theory study. *Contemporary Nurse.* 2003;15:61 - 9.
12. Kennedy T, Lingard L. Making sense of grounded theory in medical education. *Medical Education.* 2006;40:101 - 8.
13. Kelle U. The development of categories: different approaches in grounded theory. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE Publications Ltd; 2007: 191-213
14. Taylor B, Kermode S, Roberts K. Research in nursing: evidence for best practice. 4th ed. Sydney: Cengage Learning Australia Pty Ltd; 2011.
15. Strauss A, Corbin J. Basics of qualitative research: techniques and procedures for developing grounded theory, 2nd edition. London: SAGE Publications; 1990.
16. Glaser B. Basics of grounded theory analysis: emergence vs forcing. Mills Valley California: Sociology Press; 1992.
17. Glaser B. Doing grounded theory; issues and discussions. California: Sociology Press; 1998.

18. Glaser B. The grounded theory perspective: conceptualisation contrasted with description. Mill Valley California: Sociology Press; 2001.
19. Corbin J, Strauss A. Basics of qualitative research; 3rd edition. California: SAGE Publications Inc; 2008.
20. Strauss A. Qualitative analysis for social scientists. Melbourne: Cambridge University Press; 1987.
21. Strauss A, Corbin J. Basics of qualitative research; techniques and procedures for developing grounded theory; 2nd Edition. California: SAGE Publications Inc; 1998.
22. Charmaz K. Grounded Theory in the 21st century; applications for advancing social justice studies. In: Denzin N, Lincoln Y, eds. The Sage Handbook of Qualitative Research. 3rd ed. California: Sage Publications Inc; 2005.
23. Charmaz K. 'Discovering' chronic illness: using grounded theory. *Social Science and Medicine*. 1990;30:1161 - 72.
24. Glaser B. Theoretical sensitivity. Mill Valley, CA: The Sociology Press; 1978.
25. Lempert LB. Asking questions of the data: memo writing in the grounded theory tradition. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE Publications Ltd; 2007.
26. Hickey G. The use of literature in gounded theory. *Nursing Times Research*. 1997;2:371 - 8.
27. Holton J. The coding process and its challenges. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE Publications Ltd; 2007.
28. Blumer M. Concepts in the analysis of qualitative data. Sociology Review 1979;27:651 - 77.
29. Dey I. Grounding grounded theory. San Diego: Academic Press; 1999.
30. Covan E. The discovery of grounded theory in practice: the legacy of multiple mentors. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE publications Ltd; 2007: 58-74.
31. Wiener C. Making teams work in conducting grounded theory. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE publications Ltd; 2007: 293-310.
32. Cutcliffe J. Methodological issues in grounded theory. *Journal of Advanced Nursing*. 2000;31:1476 - 84.
33. Thomas G, James D. Reinventing grounded theory: some questions about theory, ground and discovery. *British Educational Research Journal*. 2006;32:767 - 95.
34. Urquhart C. The evolving nature of grounded theory method: the case of the information systems discipline. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE Publications Ltd; 2007: 339-360.
35. Liamputtong P. Qualitative research methods; 3rd Edition. 3rd ed. Sydney: Oxford University Press; 2009.
36. Birks M, Mills J. Grounded Theory: a practical guide. London: SAGE Publications Ltd; 2011.
37. Liamputtong P, ed. Research methods in health: foundations for evidence-based practice. Sydney: Oxford University Press; 2010.
38. Walsham G. Interpretive case studies in IS research: nature and method. *European Journal of Information Systems*. 1995;4:74 - 81.
39. Fernandez W. The grounded theory method and case study data in IS research: issues and design. In: Information Systems Foundations: Constructing and Criticising Workshop; 2004; The Australian National University; 2004. p. 43 - 59.
40. Dey I. Grounding categories. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE publications Ltd; 2007: 167-190.
41. Procter S. The contribution of inductive and deductive theory to the development of practitioner knowledge. London: Chapman and Hall; 1995.
42. Dick B. What can grounded theorists and action researchers learn from each other? In: Bryant A, Charmaz K, eds. The SAGE handbook of Grounded Theory. London: SAGE Publications Ltd; 2007: 398-416.
43. Urquhart C. An encounter with grounded theory: tackling the practical and philosophical issues. In: Trauth E, ed. Qualitative research in IS: Issues and trends. Hershey PA: Idea Group Publishing; 2001.
44. Walker W. Witnessed resuscitation: a conceptual exploration. Birmingham: The Univeristy of Birmingham; 2010.
45. Stern P. On solid ground: essential properties for growing grounded theory. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE Publications Ltd; 2007: 114-126.
46. Backman K, Kyngas A. Challenges of the grounded theory approach to a novice researcher. *Nursing and Health Sciences*. 1999;1:147 - 53.
47. Hutchinson SA. Grounded theory: The method. New York: National League for Nursing Press; 1993.
48. Carpenter DR. Grounded theory research approach. Philadelphia: Lippincott; 1999.
49. Gibson B. Accommodating critical theory. In: Bryant A, Charmaz K, eds. The SAGE handbook of grounded theory. London: SAGE Publications; 2007: 436-453.
50. McCann T, Clark E. Grounded theory in nursing research: part 2 - critique. *Nurse Researcher*. 2003;11:19 - 28.
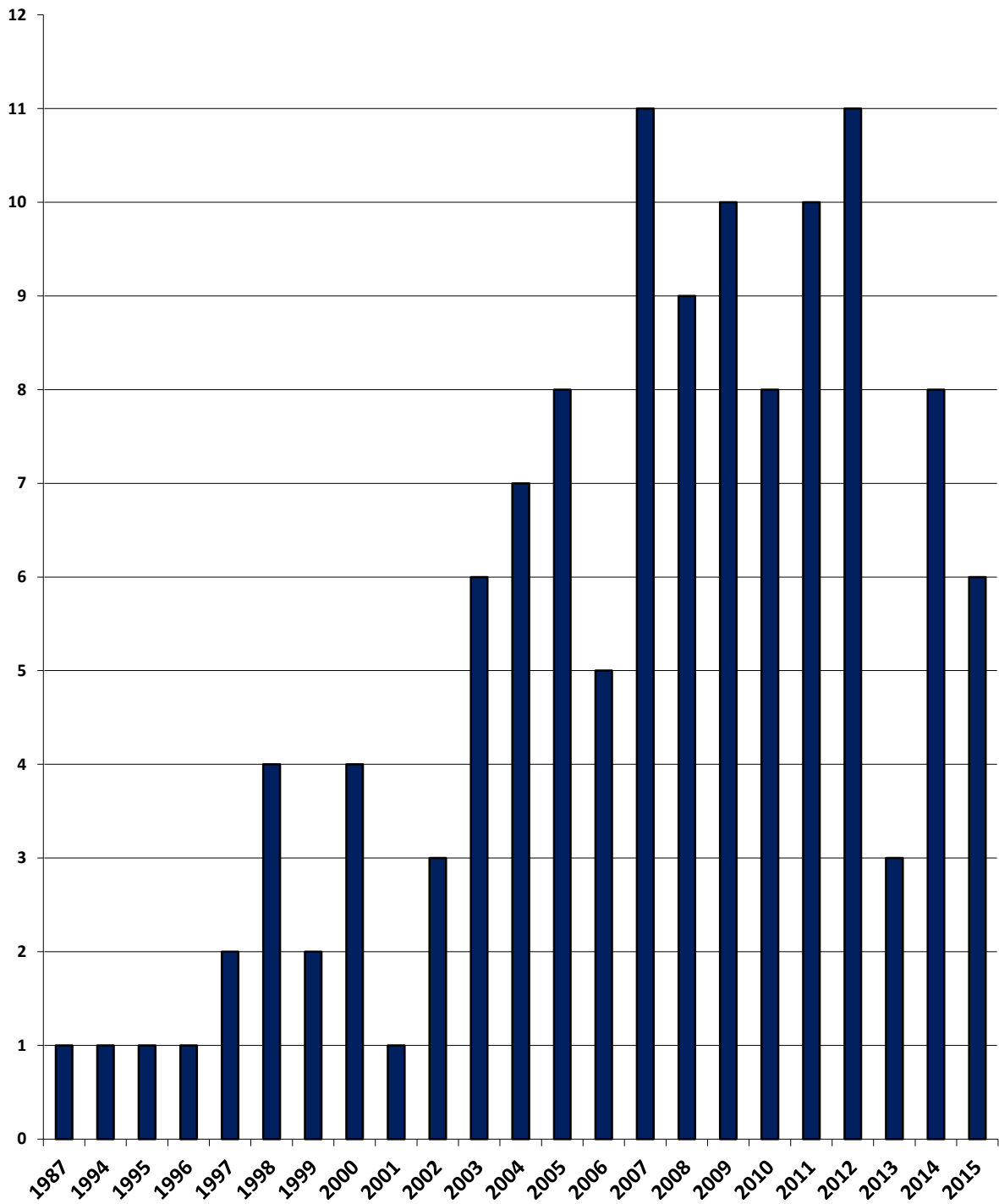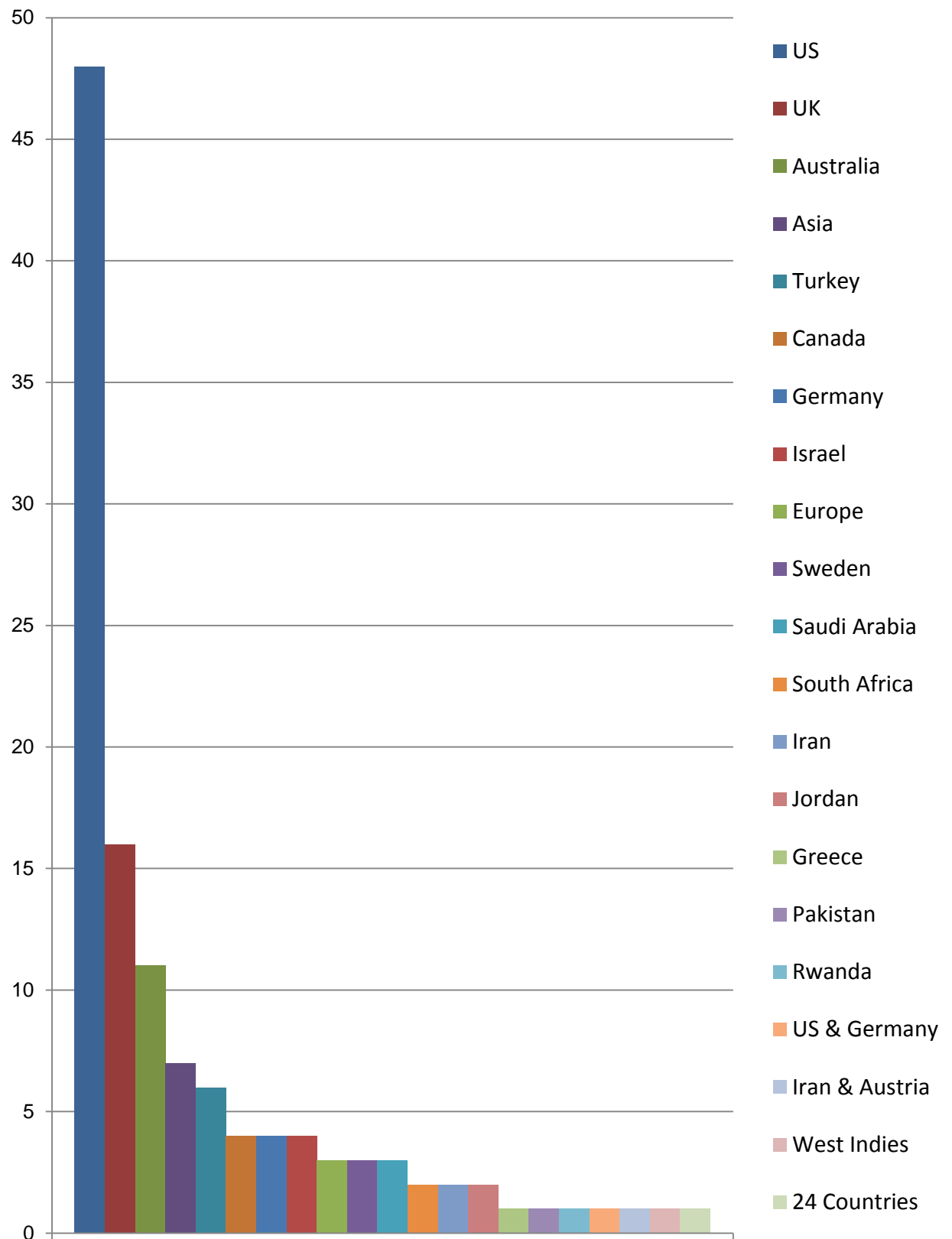
Appendix Figure 1: Number of FPDR studies published each year since 1987 (n = 122)

Appendix Figure 2: Published FPDR studies according to country of origin (n = 122)

Policy Status	Number	Studies in each category (n=122)
Policy existed at time of study	15	Al-Mutair, Plummer & Copnell 2012; Baumhover & Hughes 2009; Boyd & White 2000; Davidson *et al.* 2011; Doyle *et al.* 1987; Eichorn *et al.* 2001; Hayajneh 2013; Lowry 2012; Mangurten *et al.* 2006; Maxton 2008; Mian *et al.* 2007; Oman & Duran 2010; Pasquale *et al.* 2011; Tinsley *et al.* 2008; Zavotsky *et al.* 2014
Policy existed in some study settings	11	Axelsson *et al.* 2010; Booth, Woolrich & Kinsella 2004; Duran *et al.* 2007; Fallis, McClement & Pereira 2008; Fulbrook, Albarran & Latour 2005; Fulbrook *et al.* 2007; Gold *et al.* 2006; Goldberger *et al.* 2015; Kuzin *et al.* 2007; MacLean *et al.* 2003; Mortelmans *et al.* 2009
No policy existed at time of study	24	Badir & Sepit 2007; Bassler 1999; Chapman *et al.* 2014; Demir 2008; Goodenough & Brysiewicz 2003; Grice, Picton & Deakin 2003; Gunes & Zaybak 2009; Hallgrimsdottir 2000; Havugitanga & Brysiewicz 2014; Itzhaki, Bar-Tal & Barnoy 2011; Kianmehr *et al.* 2010; Kotkis & Tabak 2008; Lederman & Wacht 2014; Madden & Condon 2007; McGahey-Oakland *et al.* 2007; Monks & Flynn 2014; Nykiel *et al.* 2011; Timmermans 1997; Tomlinson *et al.* 2010; Twibell *et al.* 2008; Vavarouta *et al.* 2011; Wacht *et al.* 2010; Weslien *et al.* 2005; Weslien *et al.* 2006
Policy was not mentioned in the research article	64	Albarran *et al.* 2009; Back & Rooke 1994; Barratt & Wallis 1998; Beckman *et al.* 2002; Benjamin, Holger & Carr 2004; Berger *et al.* 2004; Boie *et al.* 1999; Bradford *et al.* 2005; Chalk 1995; Chapman *et al.* 2012; Chapman *et al.* 2013; Compton *et al.* 2011; de Beer & Moleki 2012; Egemen *et al.* 2006; Ellison 2003; Ersoy *et al.* 2006; Fein, Ganesh & Alpern 2004; Fernandez *et al.* 2009; Ganz & Yoffe 2012; Gordon *et al.* 2011; Harvey & Pattison 2012; Helmer *et al.* 2000; Holzhauser, Finucane & De Vries 2005; Holzhauser & Finucane 2007; Holzhauser & Finucane 2008; Hung & Pang 2010; Isoardi, Slabbert & Treston 2005; James, Cottle & Hodge 2011; Jarvis 1998; Jones *et al.* 2011; Kirchoff *et al.* 2007; Knott & Kee 2005; Koberich *et al.* 2012; Kosowan & Jensen 2011; Lam *et al.* 2007; Leske, McAndrew & Brasel 2013; Leung & Chow 2012; Macy *et al.* 2005; Mahabir & Sammy 2012; McClement, Fallis & Pereira 2009; McClenathan, Torrington & Uyehara 2002; Mcmahon-Parkes *et al.* 2009; Meyers, Eichorn & Guzzetta 1998; Miller & Stiles 2009; Mitchell & Lynch 1997; Monks & Flynn 2014; Mortelmans *et al.* 2010; O'Brien *et al.* 2002; O'Brien & Fothergill-Bourbonnais 2004; Omran, Ali & Alshahrani 2015; Ong *et al.* 2004; Ong, Chung & Mei 2007; Perry 2009; Porter, Cooper & Taylor 2015; Redley & Hood 1996; Robinson *et al.* 1998; Sheng, Lim & Rashidi 2010; Soleimanpour *et al.* 2015; Tudor *et al.* 2014; Wagner 2004; Waseem & Ryan 2003; Weslien & Nilstun 2003; Yanturali *et al.* 2005; Zakaria & Siddique 2008
Policy implemented after the study	4	Basol *et al.* 2009; Curley *et al.* 2012; Feagan & Fischer 2011; Meyers *et al.* 2000
Not relevant (General Public QA)	3	Chew & Ghani 2014; Dwyer 2015; Mazer, Cox & Capon 2006;
Researcher unsure if policy existed	1	Bashayreh & Saifan 2015

Please note that within all tables in the appendices, author details are presented alphabetically for ease of identification.

Health professionals self-reported practices relating to FPDR in health care settings with a formal policy

Country	Setting	HPs who claim they work with a formal policy	HPs who have invited FPDR	HPs who have previously experienced FPDR	FM who requested to be present for resus	Study
Europe	Conference (Cardiac nurses)	7%	13%	44%	22%	Axelsson *et al.* 2010
UK	162 ED's (nurses & physicians)	11%	50%	-	-	Booth *et al.* 2004
USA	One hospital, multiple units	5%	-	66%	-	Duran *et al.* 2007
Canada	Online survey (Crit Care nurses)	8%	65% (have or would)	-	18.5%	Fallis *et al.* 2008
Europe	Conference (critical care nurses)	5.7%	12%	46.8%	28.2%	Fulbrook *et al.* 2005
Europe	Conference (critical care nurses)	2%	36.3%	70.1%	50%	Fulbrook *et al.* 2007
USA	Postal survey (physicians)	9%	-	83%	-	Gold *et al.* 2006
Jordan	Critical care/non CC	8.1%	2.3%	64%	61%	Hayajneh 2013
Germany	Conference (ICU nurses)	6%	0.6%	42.2%	10.2%	Koberich *et al.* 2010
24 countries	Online survey	12% do not have a policy	-	-	-	Kuzin *et al.* 2007
USA	Postal QA (critical care & ED nurses)	5%	36%	-	31%	MacLean *et al.* 2003
Germany	85 ED's (managers)	2%	-	80%	41%	Mortelmans *et al.* 2009

PERCEIVED BARRIER	No. of studies	SOURCE
PERCEIVED BARRIERS RELATING TO HEALTH PROFESSIONALS		
Fear of litigation	49	Al-Mutair 2012; Axelsson *et al.* 2010; Badir & Sepit 2007; Booth Woolrich & Kinsella 2004; Bradford *et al.* 2005; Chapman *et al.* 2012; Chapman *et al.* 2013; Chew & Ghani 2014; Demir 2008; Ellison 2003; Fallis McClement & Pereira 2008; Fein Ganesh & Alpern 2004; Fernandez *et al.* 2009; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Gordon *et al.* 2011; Grice Picton & Deakin 2003; Gunes & Zaybak 2009; Helmer *et al.* 2000; Holzhauser & Finucane 2007; Jones *et al.* 2011; Kianmehr *et al.* 2010; Kirchoff *et al.* 2007; Kosowan & Jensen 2011; Lam *et al.* 2007; Lederman & Wacht 2014; Leung & Chow 2012; Lowry 2012; MacLean *et al.* 2003; Macy *et al.* 2006; Madden & Condon 2007; Mahabir & Sammy 2012; McClement Fallis & Pereira 2009; McClenathan Torrington & Uyehara 2002; Mian *et al.* 2007; Mitchell & Lynch 1997; Meyers *et al.* 2000; Mortelmans 2009; Ong *et al.* 2004; Porter, Cooper & Taylor 2015; Redley & Hood 1996; Soleimanpour *et al.* 2015; Timmermans 1997; Tomlinson *et al.* 2010; Twibell *et al.* 2008; Tudor *et al.* 2014; Vavarouta *et al.* 2011; Wacht *et al.* 2010; Yanturali *et al.* 2005
FM could interfere, argue, be disruptive, interrupt care	43	Axelsson *et al.* 2010; Back & Rooke 1994; Badir & Sepit 2007; Booth Woolrich & Kinsella 2004; Chapman *et al.* 2012; Chapman *et al.* 2013; Chapman *et al.* 2014; Chew & Ghani 2014; Curley *et al.* 2012; de Beer & Moleki 2012; Demir 2008; Doyle *et al.* 1987; Dwyer 2015; Duran *et al.* 2007; Egemen *et al.* 2006; Fallis McClement & Pereira 2008; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Ganz & Yoffe 2012; Grice Picton & Deakin 2003; Goodenough & Brysiewicz 2003; Gunes & Zaybak 2009; Hayajneb 2013; Holzhauser & Finucane 2008; Jarvis 1998; Koberich *et al.* 2010; Kosowan & Jensen 2011; Mahabir & Sammy 2012; McClement Fallis & Pereira 2009; McClenathan Torrington & Uyehara 2002; Meyers *et al.* 2000; Mitchell & Lynch 1997; Nykiel *et al.* 2011; Oman & Duran 2010; Omran, Ali & Alshahrani 2015; Ong *et al.* 2004; Redley & Hood 1996; Taraghi *et al.* 2014; Timmermans 1997; Tomlinson *et al.* 2010; Twibell *et al.* 2008; Tudor *et al.* 2014; Zakaria & Siddique 2008
Increased stress and emotional trauma for HPs	40	Al-Mutair 2012; Badir & Sepit 2007; Bradford *et al.* 2005; Davidson *et al.* 2011; de Beer & Moleki 2012; Demir 2008; Doyle *et al.* 1987; Duran *et al.* 2007; Fallis McClement & Pereira 2008; Fein Ganesh & Alpern 2004; Goodenough & Brysiewicz 2003; Helmer *et al.* 2000; Grice Picton & Deakin 2003; Holzhauser & Finucane 2007; Jarvis 1998; Kianmehr *et al.* 2010; Kirchoff *et al.* 2007; Knott & Kee 2005; Kosowan & Jensen 2011; Lam *et al.* 2007; Leung & Chow 2012; MacLean *et al.* 2003; Macy *et al.* 2006; Madden & Condon 2007; Mahabir & Sammy 2012; McClement Fallis & Pereira 2009; Mian *et al.* 2007; Monks & Flynn 2014; Nykiel *et al.* 2011; Ong *et al.* 2004; Perry 2009; Redley & Hood 1996; Soleimanpour *et al.* 2015; Taraghi *et al.* 2014; Timmermans 1997; Tomlinson *et al.* 2010; Vavarouta *et al.* 2011; Wacht *et al.* 2010; Waseem & Ryan 2003; Yanturali *et al.* 2005
Team/HPs performance could be negatively affected	37	Al-Mutair 2012; Axelsson *et al.* 2010; Back & Rooke 1994; Basol *et al.* 2009; Bradford *et al.* 2005; Demir 2008; Doyle *et al.* 1987; Duran *et al.* 2007; Fein Ganesh & Alpern 2004; Fernandez *et al.* 2009; Goodenough & Brysiewicz 2003; Gordon *et al.* 2011; Grice Picton & Deakin 2003; Gunes & Zaybak 2009; Havugitanga & Brysiewicz 2014; Helmer *et al.* 2000; Holzhauser & Finucane 2007; Jarvis 1998; Kianmehr *et al.* 2010; Kirchoff *et al.* 2007; Koberich *et al.* 2010; Kosowan & Jensen 2011; Lam *et al.* 2007; Lederman & Wacht 2014; Leung & Chow 2012; Madden & Condon 2007; MacLean *et al.* 2003; Macy *et al.* 2006; McClement Fallis & Pereira 2009; Omran, Ali & Alshahrani 2015; Redley & Hood 1996; Soleimanpour *et al.* 2015; Taraghi *et al.* 2014; Tomlinson *et al.* 2010; Twibell *et al.* 2008; Tudor *et al.* 2014; Yanturali *et al.* 2005
Resuscitation may be prolonged, difficulty stopping resuscitation	25	Al-Mutair 2012; Axelsson *et al.* 2010; Badir & Sepit 2007; Chapman *et al.* 2014; Curley *et al.* 2012; de Beer & Moleki 2012; Demir 2008; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Ganz & Yoffee 2012; Gordon *et al.* 2011; Gunes & Zaybak 2009; Havugitanga & Brysiewicz 2014; Helmer *et al.* 2000; Holzhauser & Finucane 2008; Kianmehr *et al.* 2010; Lam *et al.* 2007; Mahabir & Sammy 2012; Meyers *et al.* 2000; Mitchell & Lynch 1997; Mortelmans 2009; Porter, Cooper & Taylor 2015; Soleimanpour *et al.* 2015; Taraghi *et al.* 2014; Yanturali *et al.* 2005

No support person available, not enough staff	22	Al-Mutair 2012; Axelsson *et al.* 2010; Back & Rooke 1994; Badir & Sepit 2007; Bassler 1999; Booth Woolrich & Kinsella 2004;Chalk 1995; Davidson *et al.* 2011; Ellison 2003; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Ganz & Yoffe 2012; Gordon *et al.* 2011; Grice Picton & Deakin 2003; Gunes & Zaybak 2009; Hallgrimsdottir 2009; Jarvis 1998; Koberich *et al.* 2010; Lam *et al.* 2007; MacLean *et al.* 2003; Wacht *et al.* 2010; Weslein & Nilstun 2003
Performance anxiety, difficult to concentrate or make decisions	20	Chapman *et al.* 2014;Doyle *et al.* 1987; Duran *et al.* 2007; Ellison 2003; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Ganz & Yoffe 2012; Gunes & Zaybak 2009; Havugitanga & Brysiewicz 2014; Holzhauser & Finucane 2008; Jones *et al.* 2011; Koberich *et al.* 2010; Knott & Kee 2005; McClement Fallis & Pereira 2009; McClenathan Torrington & Uyehara 2002; Meyers *et al.* 2000; Monks & Flynn 2014; Omran, Ali & Alshahrani 2015; Vavarouta *et al.* 2011; Waseem & Ryan 2003
Space limitations	20	Axelsson *et al.* 2010; Badir & Sepit 2007; Bassler 1999; Booth Woolrich & Kinsella 2004; Davidson *et al.* 2011; Demir 2008; Ellison 2003; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Gordon *et al.* 2011; Koberich *et al.* 2010; Knott & Kee 2005; Lederman & Wacht 2014; MacLean *et al.* 2003; Macy *et al.* 2006; McClement Fallis & Pereira 2009; Nykiel *et al.* 2011; Ong *et al.* 2004; Timmermans 1997; Zakaria & Siddique 2008
Staff reluctance to practice FPDR	11	Booth Woolrich & Kinsella 2004; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Ganz & Yoffe 2012; Grice Picton & Deakin 2003; Goodenough & Brysiewicz 2003; Gunes & Zaybak 2009; Hallgrimsdottir 2009; Koberich *et al.* 2010; Miller & Stiles 2009; Redley & Hood 1996
Staff worried they may say something inappropriate	10	Axelsson *et al.* 2010; Back & Rooke 1994; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Ganz & Yoffe 2012; Koberich *et al.* 2010; McClement Fallis & Pereira 2009; Mitchell & Lynch 1997; Weslein & Nilstun 2003; Zakaria & Siddique 2008
Staff worried about being seen as inexperienced, doing something wrong	8	Bradford *et al.* 2005; Duran *et al.* 2007; Knott & Kee 2005; Lowry 2012; Madden & Condon 2007; McClement Fallis & Pereira 2009; Timmermans 1997; Weslein & Nilstun 2003
May inhibit communication between team members	7	Duran *et al.* 2007; Fallis McClement & Pereira 2008; Kirchoff *et al.* 2007; Lederman & Wacht 2014; McClement Fallis & Pereira 2009; Oman & Duran 2010; Tudor *et al.* 2014;
May affect staff training opportunities	7	Bradford *et al.* 2005; Curley *et al.* 2012; Fein Ganesh & Alpern 2004; Jarvis 1998; Macy *et al.* 2006; Mian *et al.* 2007; Vavarouta *et al.* 2011
Focus distracted from pt	6	Bassler 1999; Booth Woolrich & Kinsella 2004; Demir 2008; Duran *et al.* 2007; Knott & Kee 2005; McClement Fallis & Pereira 2009

PERCEIVED BARRIERS RELATING TO PATIENTS		
Concerns about confidentiality	14	Al-Mutair 2012; Axelsson *et al.* 2010; Badir & Sepit 2007; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Gunes & Zaybak 2009; Hayajneb 2013; Koberich *et al.* 2010; Lam *et al.* 2007; Leung & Chow 2012; Mian *et al.* 2007; Porter, Cooper & Taylor 2015; Soleimanpour *et al.* 2015; Tomlinson *et al.* 2010
Concern for patient privacy, dignity	10	Bassler 1999; Chapman *et al.* 2014; Chew & Ghani 2014; Gordon *et al.* 2011; Grice Picton & Deakin 2003; Lowry 2012; MacLean *et al.* 2003; Timmermans 1997; Tomlinson *et al.* 2010; Weslein & Nilstun 2003
Staff believe FP NOT beneficial to patient	7	Al-Mutair 2012; Axelsson *et al.* 2010; Badir & Sepit 2007; Chapman *et al.* 2012; Fulbrook Albarran & Latour 2004; Gunes & Zaybak 2009; Holzhauser & Finucane 2008
No consent from patient	3	Chapman *et al.* 2012; Jarvis 1998; Lam *et al.* 2007
PERCEIVED BARRIERS RELATING TO FAMILY MEMBERS		
Too distressing, traumatic for FM	47	Al-Mutair 2012; Axelsson *et al.* 2010; Badir & Sepit 2007; Booth Woolrich & Kinsella 2004; Chew & Ghani 2014; Davidson *et al.* 2011; Demir 2008; Dwyer 2015; Duran *et al.* 2007; Fallis McClement & Pereira 2008; Fernandez *et al.* 2009; Ganz & Yoffe 2012; Goodenough & Brysiewicz 2003; Gordon *et al.* 2011; Grice Picton & Deakin 2003; Gunes & Zaybak 2009; Havugitanga & Brysiewicz 2014; Holzhauser & Finucane 2007; Holzhauser & Finucane 2008; Jarvis 1998; Jones *et al.* 2011; Kirchoff *et al.* 2007; Koberich *et al.* 2010; Knott & Kee 2005; Lam *et al.* 2007; Leung & Chow 2012; Lederman & Wacht 2014; Lowry 2012; Macy *et al.* 2006; Mahabir & Sammy 2012; McClement Fallis & Pereira 2009; McClenathan Torrington & Uyehara 2002; Meyers *et al.* 2000; Mian *et al.* 2007; Mitchell & Lynch 1997; Mortelmans 2009; Nykiel *et al.* 2011; Oman & Duran 2010; Omran, Ali & Alshahrani 2015; Ong *et al.* 2004; Soleimanpour *et al.* 2015; Timmermans 1997; Vavarouta *et al.* 2011; Wacht *et al.* 2010; Weslein & Nilstun 2003; Yanturali *et al.* 2005; Zakaria & Siddique 2008
Staff worried FM may not understand and consider CPR offensive or chaotic	20	Badir & Sepit 2007; Demir 2008; Ellison 2003; Fernandez *et al.* 2009; Fulbrook Albarran & Latour 2004; Ganz & Yoffe 2012;Goodenough & Brysiewicz 2003; Grice Picton & Deakin 2003; Holzhauser & Finucane 2007; Kianmehr *et al.* 2010; Knott & Kee 2005; Lam *et al.* 2007; Lowry 2012; MacLean *et al.* 2003; Meyers *et al.* 2000; Mitchell & Lynch 1997; Omran, Ali & Alshahrani 2015; Redley & Hood 1996; Soleimanpour *et al.* 2015; Weslein & Nilstun 2003
Potential long term psychological effects	15	Axelsson *et al.* 2010; Badir & Sepit 2007; Chapman *et al.* 2012; Chapman *et al.* 2013; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Grice Picton & Deakin 2003; Gunes & Zaybak 2009; Holzhauser & Finucane 2007; Lederman & Wacht 2014; Meyers *et al.* 2000; Mitchell & Lynch 1997; Omran, Ali & Alshahrani 2015; Twibell *et al.* 2008; Tudor *et al.* 2014
Unpleasant/traumatic memories of patient	11	Duran *et al.* 2007; Ellison 2003; Fein Ganesh & Alpern 2004; Goodenough & Brysiewicz 2003; Grice Picton & Deakin 2003; Holzhauser & Finucane 2007; Jarvis 1998; Knott & Kee 2005; Lowry 2012; Omran, Ali & Alshahrani 2015; Timmermans 1997
FM may panic	3	Chapman *et al.* 2013; Twibell *et al.* 2008; Tudor *et al.* 2014
FM do not ask for FPDR	1	Booth Woolrich & Kinsella 2004
FM do not arrive in time	1	Timmermans 1997

PERCEIVED FACILITATOR	NO.	SOURCE
Family facilitator / support person	22	Al-Mutair 2012; Bassler 2009; Fein Ganesh & Alpern 2004; Fernandez *et al.* 2009; Fulbrook Albarran & Latour 2004; Gordon *et al.* 2011; Hallgrimsdottir 2009; Holzhauser & Finucane 2007; Jarvis 1998; Jarvis 1998; Koberich *et al.* 2010; Knott & Kee 2005; Kosowan & Jensen 2011; Lam *et al.* 2007; Lowry 2012; MacLean *et al.* 2003; McClement Fallis & Pereira 2009; Meyers *et al.* 2000; Oman & Duran 2010; Perry 2009; Porter, Cooper & Taylor 2015; Weslein & Nilstun 2003
Existing policies, guidelines and conditions	14	Bassler 2009; Fallis McClement & Pereira 2008; Fein Ganesh & Alpern 2004; Fernandez *et al.* 2009; Hallgrimsdottir 2009; Jarvis 1998;Knott & Kee 2005; Lam *et al.* 2007; MacLean *et al.* 2003; Madden & Condon 2007; Meyers *et al.* 2000; McClement Fallis & Pereira 2009; Tomlinson *et al.* 2010; Zakaria & Siddique 2008
Staff education and support	11	Davidson *et al.* 2011; Ellison 2003; Fein Ganesh & Alpern 2004; Madden & Condon 2007; Mian *et al.* 2007; Mitchell & Lynch 1997; Mortelmans 2009; Mortelmans 2009; Ong *et al.* 2004; Perry 2009; Tomlinson *et al.* 2010
Previous experience with FPDR	4	Duran *et al.* 2007; Macy *et al.* 2006; Mitchell & Lynch 1997; Perry 2009
Consensus among staff	2	Madden & Condon 2007; Tomlinson *et al.* 2010

Perceived Benefit	No.	Source
PERCEIVED BENEFITS FOR THE PATIENT		
FM can provide support to patient	8	Basol *et al.* 2009; Ellison 2003; Holzhauser & Finucane 2007; Holzhauser & Finucane 2008; Lowry 2012; MacLean *et al.* 2003; Meyers *et al.* 2000; Miller & Stiles 2009
Personalises, humanises the patient	6	Davidson *et al.* 2011; Doyle *et al.* 1987; McClement Fallis & Pereira 2009; Meyers *et al.* 2000; Monks & Flynn 2014; Oman & Duran 2010
FP is beneficial for the patient	4	Fein Ganesh & Alpern 2004; MacLean *et al.* 2003; Meyers *et al.* 2000; Zakaria & Siddique 2008
FM can advocate for the patient	2	Ellison 2003; Meyers *et al.* 2000
Provides holistic care	1	Basol *et al.* 2009
PERCEIVED BENEFITS FOR FAMILY MEMBERS		
Help FM with the grieving process	34	Axelsson *et al.* 2010; Badir & Sepit 2007; Bashayreh & Saifan 2015; Booth Woolrich & Kinsella 2004; Chalk 1995; Chapman *et al.* 2012; Chapman *et al.* 2013; Chapman *et al.* 2014; Chew & Ghani 2014; Davidson *et al.* 2011; de Beer & Moleki 2012; Ellison 2003; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Grice Picton & Deakin 2003; Gunes & Zaybak 2009; Holzhauser & Finucane 2007; Jarvis 1998; Kianmehr *et al.* 2010; Knott & Kee 2005; Lam *et al.* 2007; Leung & Chow 2012; MacLean *et al.* 2003; Mahabir & Sammy 2012; Mitchell & Lynch 1997; Mortelmans 2009; Ong Chung & Mei 2007; Porter, Cooper & Taylor 2015; Soleimanpour *et al.* 2015; Taraghi *et al.* 2014; Twibell *et al.* 2008; Tudor *et al.* 2014; Weslein & Nilstun 2003; Zakaria & Siddique 2008
Help FM know/see everything was done	32	Axelsson *et al.* 2010; Badir & Sepit 2007; Booth Woolrich & Kinsella 2004; Chapman *et al.* 2014; Chew & Ghani 2014; Davidson *et al.* 2011; de Beer & Moleki 2012; Demir 2008; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Ganz & Yoffe 2012; Grice Picton & Deakin 2003; Gunes & Zaybak 2009; Havugitanga & Brysiewicz 2014; Holzhauser & Finucane 2008; Jarvis 1998; Knott & Kee 2005; Lam *et al.* 2007; Leske, McAndrew & Brasel 2013; Lowry 2012; MacLean *et al.* 2003; McClement Fallis & Pereira 2009; Meyers *et al.* 2000; Miller & Stiles 2009; Oman & Duran 2010; Ong Chung & Mei 2007; Ong *et al.* 2004; Porter, Cooper & Taylor 2015; Taraghi *et al.* 2014; Timmermans 1997; Weslein & Nilstun 2003; Zakaria & Siddique 2008
FM can share last moments with loved one	14	Axelsson *et al.* 2010; Bashayreh & Saifan 2015; Dwyer 2015; Ellison 2003; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Grice Picton & Deakin 2003; Holzhauser & Finucane 2007; Lam *et al.* 2007; Leung & Chow 2012; McClement Fallis & Pereira 2009; Meyers *et al.* 2000; Timmermans 1997; Zakaria & Siddique 2008
Closure for FM, ability to say goodbye, helps them accept the death	13	Booth Woolrich & Kinsella 2004; Davidson *et al.* 2011; de Beer & Moleki 2012; Demir 2008; Fulbrook Albarran & Latour 2004; Knott & Kee 2005; MacLean *et al.* 2003; Meyers *et al.* 2000; Miller & Stiles 2009; Oman & Duran 2010; Porter, Cooper & Taylor 2015; Weslein & Nilstun 2003; Yanturali *et al.* 2005

Prevents a distorted image of CPR, allows a more realistic view	11	Axelsson *et al.* 2101; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Grice Picton & Deakin 2003; Holzhauser & Finucane 2008; Jarvis 1998; Knott & Kee 2005; Lowry 2012; McClement Fallis & Pereira 2009; Soleimanpour *et al.* 2015; Timmermans 1997
Staff can provide support to FM	6	Davidson *et al.* 2011; Leske, McAndrew & Brasel 2013; Lowry 2012; MacLean *et al.* 2003; McClement Fallis & Pereira 2009; Miller & Stiles 2009
FM can be informed of patient progress	5	Havugitanga & Brysiewicz 2014; Lam *et al.* 2007; Leung & Chow 2012; MacLean *et al.* 2003; Tudor *et al.* 2014
Can decrease FM anxiety	4	Basol *et al.* 2009; Holzhauser & Finucane 2007; Holzhauser & Finucane 2008; Meyers *et al.* 2000
Helps FM to adjust to the illness	3	Holzhauser & Finucane 2007; MacLean *et al.* 2003; Meyers *et al.* 2000
Enables FM to give last religious rites	2	Bashayreh & Saifan 2015; Chew & Ghani 2014
Decreases fear of the unknown	2	Fein Ganesh & Alpern 2004; McClement Fallis & Pereira 2009
FM will suffer fewer psychological complications	1	Fallis McClement & Pereira 2008
PERCEIVED BENEFITS FOR HEALTH PROFESSIONALS		
FM more likely to accept treatment withdrawal	9	Al-Mutair 2012; Axelsson *et al.* 2101; Badir & Sepit 2007; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Gunes & Zaybak 2009; Koberich *et al.* 2010; McClement Fallis & Pereira 2009; Miller & Stiles 2009
Team performance positively affected, improves professional behaviour	9	Axelsson *et al.* 2010; Demir 2008; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Jones *et al.* 2011; Lowry 2012; McClement Fallis & Pereira 2009; Meyers *et al.* 2000; Porter, Cooper & Taylor 2015
FM more satisfied with care, appreciate HPs efforts	6	Fallis McClement & Pereira 2008; Knott & Kee 2005; McClement Fallis & Pereira 2009; Meyers *et al.* 2000; Miller & Stiles 2009; Twibell *et al.* 2008
Reduces litigation	5	Grice Picton & Deakin 2003; Jarvis 1998; Jones *et al.* 2011; Meyers *et al.* 2000; Yanturali *et al.* 2005
Easier to tell FM the outcome	2	Holzhauser & Finucane 2008; Yanturali *et al.* 2005

PERCEIVED BENEFITS FOR HEALTH CARE PROFESSIONALS AND FAMILY MEMBERS		
Creates a stronger bond between FM and HPs	12	Axelsson *et al.* 2010; Chew & Ghani 2014; Fulbrook Albarran & Latour 2004; Fulbrook Latour & Albarran 2007; Gunes & Zaybak 2009; Havugitanga & Brysiewicz 2014; Leske, McAndrew & Brasel 2013; Miller & Stiles 2009; Ong Chung & Mei 2007; Monks & Flynn 2014; Twibell *et al.* 2008; Tudor *et al.* 2014;
FM can provide information, help make decisions	8	Basol *et al.* 2009; Chapman *et al.* 2014; Grice Picton & Deakin 2003; Holzhauser & Finucane 2008; MacLean *et al.* 2003; Meyers *et al.* 2000; Miller & Stiles 2009; Mortelmans 2009
FM included as part of the team	5	Holzhauser & Finucane 2007; Jones *et al.* 2011; Koberich *et al.* 2010; Lowry 2012; Miller & Stiles 2009
Can enhance communication between staff and FM	3	Ellison 2003; Tudor *et al.* 2014;Yanturali *et al.* 2005

FINAL APPROVAL NOTICE

Project No.:	**5890**

Project Title:	Factors and perceptions that impact on decision-making about Family Presence during Resuscitation in an acute care setting

Principal Researcher:	Mrs Tracey Giles

Email:	tracey.giles@flinders.edu.au

Address:	School of Nursing and Midwifery

Approval Date:	27 November 2012	Ethics Approval Expiry Date:	**31 December 2018**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
   Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

   - all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.

   - the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.

   - the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

   This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. **Annual Progress / Final Reports**
   In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress report must be submitted each year on the **27 November** (approval anniversary date) for the duration of the ethics approval using the annual progress / final report pro forma. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request <u>and</u> an annual report.

Your first report is due on **27 November 2013** or on completion of the project, whichever is the earliest.

3.   Modifications to Project
Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such matters include:

- proposed changes to the research protocol;
- proposed changes to participant recruitment methods;
- amendments to participant documentation and/or research tools;
- extension of ethics approval expiry date; and
- changes to the research team (addition, removals, supervisor changes).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form to the Executive Officer. Please note that extension of time requests should be submitted <u>prior</u> to the Ethics Approval Expiry Date listed on this notice.

<u>Change of Contact Details</u>
Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4.   Adverse Events and/or Complaints
Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforseen event occurs that may affect the ethical acceptability of the project.

Andrea Fiegert
Executive Officer
Social and Behavioural Research Ethics Committee

c.c   Dr Lindy King
            Dr Sheryl de Lacey

Andrea Fiegert (nee Mather)
Executive Officer, Social and Behavioural Research Ethics Committee
Research Services Office |Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001
P: +61 8 8201-3116 | F: +61 8 8201-2035 |Web: Social and Behavioural Research Ethics Committee

Dear Sir / Madam,

This letter is to introduce Ms Tracey Giles who is a Lecturer and PhD student in the School of Nursing and Midwifery, Flinders University. Tracey will produce her student card which carries a photograph as proof of her identity.

Tracey is undertaking research exploring the factors and perceptions that impact decision-making about Family Presence during Resuscitation in an acute care (hospital) setting.

- <u>Family Presence during Resuscitation</u> refers to the situation where a family member or significant other (eg partner, loved one) is present in the resuscitation room at one point or continuously during a cardiopulmonary resuscitation attempt by health professionals in an acute care setting including the emergency department, intensive care unit, coronary care unit and any other ward in a hospital setting.

- <u>Health Professional</u> refers to registered nurses and medical doctors who have performed CPR on a patient while on duty in an acute care setting where a family member (or significant other) was present in the resuscitation room, or wanted to be present.

- <u>Family Member</u> refers to a family member or significant other who was present in the resuscitation room (or wanted to be) in an acute care setting during active cardiopulmonary resuscitation (CPR) of their family member (or significant other).

- <u>Former Patient</u> refers to a person who underwent CPR in an acute care setting who had a family member (or significant other) present in the room during that resuscitation, or would have liked a family member to be present.

You are invited to volunteer to be part of this research project by granting an interview lasting approximately 60 minutes. Following the interview some participants may be invited to take part in a follow up interview of 30 – 45 minutes or to be part of a focus group[16] lasting approximately 60 - 90 minutes.

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[16] Focus groups were included in the ethics application (and associated documents) because they were considered as a possible means of data generation. While writing the ethics application, I observed recommendations from GTM experts to ensure ethics approval was broad and allowed for all possible means of data generation. However, following the completion of 27 interviews with 28 people and emergence of the core category, my PhD supervisors and I decided that focus groups would not add anything further to the emerging theory.

Be assured that any information provided will be treated in the strictest confidence. Your name will not be used in the resulting thesis, research report or other publications, and it will not be possible to identify you in these reports and publications. You are free to discontinue your participation at any time during the interview or focus group, or to decline to answer particular questions.

Tracey intends to audio-record the interviews and focus groups and will seek your consent for this on the attached form. By signing this form you will also be agreeing to the use of the recording and transcription in preparing the thesis, research report or other publications, on condition that your name and identity is not revealed. The recording and transcript will also be available to Tracey's supervisors under the same conditions of confidentiality. Transcription of the interviews and focus groups will be performed by Tracey and by a professional transcription service that is bound by the same confidentiality conditions as the researchers; therefore your identity and responses will remain confidential.

Any enquiries you may have concerning this project can be directed to me at the address provided above or by telephone on 82015907 or by email at eimear.muircochrane@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely,

Professor Eimear Muir-Cochrane

Chair of Nursing (Mental Health Nursing)

School of Nursing and Midwifery

Flinders University

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5890). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

Research Project Title:
Factors and perceptions that impact decision-making about Family Presence during Resuscitation in acute care settings.

Why is this research being done?
This study will explore the experiences, attitudes and beliefs of health professionals, family members and former patients who have experienced family presence during resuscitation in an acute care setting. A specific aim of the research is to find out what influences decision-making around whether to participate in or allow family presence during resuscitation.

Who can participate in the research?

Family Presence during Resuscitation refers to the situation where a family member or significant other (eg partner, loved one) is present in the resuscitation room at one point or continuously during a cardiopulmonary resuscitation attempt by health professionals in an acute care setting including the Emergency Department, Intensive Care Unit, Coronary Care Unit and any other ward in a hospital setting.

Three types of participants are eligible to take part in the research

1. Health Professionals refers to registered nurses and medical doctors with a minimum of 2 years' experience post completing their degree and who have ever performed CPR on a patient while on duty in an acute care setting with a family member (or significant other) present in the resuscitation room or who wanted to be present in the room.

2. Family Member refers to a family member or significant other who has ever been present in the resuscitation room (or wanted to be present) in an acute care setting during active cardiopulmonary resuscitation (CPR) of their family member (or significant other).

3. Former Patient refers to a person who has ever required CPR in an acute care setting who had a family member (or significant other) present in the room during that resuscitation, or wanted them to be present.

What choices do I have?
Participation in this research is entirely your choice. Whether or not you agree to participate, your decision will not disadvantage you in any way. By returning the signed consent form, you are agreeing to take part in the research. You are free to discontinue your participation at any time during the interview or focus group, and you can decline to answer particular questions.

If I agree to participate what will I be asked to do?
You will be invited to take part in a face to face interview with the researcher at a mutually convenient location. You may also be invited to take part in a follow up interview or a focus group, again at a mutually convenient location with the same researcher.

How much time will it take?
The initial interview will take between approximately 60 minutes and any follow-up interviews will take between 30 – 45 minutes. The focus group will take approximately 60 - 90 minutes.

What will happen if I wish to withdraw from the study?
Participation in this research project is entirely voluntary. If you decide at any point to withdraw from the interview or focus group you will be free to do so without any disadvantage or repercussion. If you do not want to answer certain questions during the interview or focus group your decision will be respected.

After the interview / focus group you will be asked if you would like to view your typed transcript before data analysis begins. If you elect to view your transcript, once you have agreed to the content you will be asked again if you are happy for your transcript to be included in the research project. After that time you will no longer be able to withdraw your transcript from the research project.

How will the information provided by me be used?
The information gained from your responses will be collated together with that of other interview / focus group participants. It will then be analysed to form a thesis which is part of the requirements of the PhD degree at Flinders University School of Nursing and Midwifery. The findings from this study will also be published in professional journals and research reports. You will be offered a digital copy of the final research report.

How will my privacy be protected?
Your identity will remain confidential at all times. During interviews / focus groups you will use a pseudonym and this pseudonym will be used in all subsequent reports and publications to ensure that you cannot be identified in any way. Your age, gender and participant type (eg Health Professional, Family Member, Former Patient) will be used when discussing the findings but the names of any Health Care Institutions will not be used. Instead they will be referred to generically; for example 'a large metropolitan hospital'.

All collected data will be stored in a locked filing cabinet when in print form, and password protected when in digital form. Only the researcher, the researcher's supervisors and a professional transcription service will have access to the data. All people with access to the data are bound by the same confidentially conditions as the researcher.

How will the data be stored?
Digital data will be stored in a password protected format. Any paper based data will be stored in a locked filing cabinet at the School of Nursing and Midwifery Flinders University. All data pertaining to this study will be destroyed after 5 years.

What should I do with the consent form after I have signed it?
Please bring your consent form with you when you attend the interview / focus group. You will be asked to sign two copies of the consent form and you should keep a copy of the signed consent form and the information sheet for your own records.

Will I be paid for my participation in the study?
No you will not receive payment for your participation in this study.

What are the benefits and risks of taking part in the study?
Family Presence during Resuscitation (FPDR) has been shown to provide many benefits such as helping with the grieving process, decreasing fear of the unknown, family being able to support

and be with the patient in a time of need, and promoting holistic and family-centred care. Yet FPDR is not widely practiced in Australia and there are no national policies. By taking part in this research study, you have the opportunity to share your attitudes, beliefs and experiences about FPDR and contribute to the development of recommendations about FPDR in South Australia. This in turn may influence the development of standard policies and procedures to guide practice to ensure the best level of family centred care is offered to relevant patients and their family members.

Because you will be reminiscing about an experience that involves a serious illness and or death, you may become upset during the interview / focus group. Please be assured that you will be free to stop the interview / focus group at any time. It is a priority of the researcher that you remain emotionally safe during the interview / focus group. Free confidential counselling services are available from Lifeline. This service can be accessed by phoning 13 11 14 or by visiting the website at http://www.lifeline.org.au   You will also be given the opportunity to debrief at the end of the interview / focus group with the researcher who is a Registered Nurse.

During the focus groups, four to six people will be sharing their experiences and beliefs with each other. To protect your privacy, at the beginning of the focus group participants will be informed of the rights and responsibilities of group members in relation to confidentiality of each individual member of the group. Participants will be asked to sign a consent form that outlines these conditions prior to the focus group commencing. The researcher will explain that the focus group is being carried out in order to explore and understand both similar and different experiences, attitudes and beliefs and not to pass judgement. The researcher will facilitate the discussion in such a way to allow all participants to contribute and ask that personal and/or judgement statements are ceased should they occur.

Who should I contact if I have any questions about the study?
For further information or if you have any questions please contact Tracey Giles using the details provided below.

Thank you for considering this invitation.

Principal Researcher
Tracey Giles
RN, GradCert HDN, MN, MCNA, PhD Candidate
Phone: 8201 3481
Email: tracey.giles@flinders.edu.au

Principal Supervisor
Professor Eimear Muir-Cochrane
BSc Hons RN (University of London), Grad Dip Adult Ed. (UniSa), MNS (Deakin), PhD (RMIT)
FACMHN, Credentialed Mental Health Nurse
Chair of Nursing (Mental Health Nursing)
Phone: 82015907
Email: eimear.muir-cochrane@flinders.edu.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5890). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

CONSENT FORM FOR PARTICIPATION IN RESEARCH (By in-depth interview)

> **Factors and perceptions that impact on decision-making about**
>
> **Family Presence during Resuscitation in an acute care setting**

I ....

being over the age of 18 years hereby consent to participate in the research project on *Family Presence during Resuscitation.*

1. I have read the information provided in the letter of introduction and information sheet

2. Details of procedures and any risks have been explained to my satisfaction.

3. I agree to audio recording of my information and participation.

4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.

5. I understand that:

    - I may not directly benefit from taking part in this research.

    - I am free to decline to answer particular questions

    - I am free to withdraw from the project at any time prior to the commencement of data analysis.

    - I will be asked if I would like to view my typed transcript of the interview. Once I have agreed to the content of this transcript, I will be asked again if I am happy for this transcript to be included in the research project. After this time I understand that I will no longer be able to withdraw my transcript from the research project

    - While the information gained in this study will be published as explained in the information letter, I will not be identified, and individual information will remain confidential.

    - Confidentiality will be maintained by the use of a pseudonym in all subsequent writing up and publication of data.

    - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the interview session without disadvantage.

I understand the conditions outlined above and consent to participate in this research project.

**Participant's
signature……………………………………………………………………………………….Date…………………..**

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

**Researcher's
name……………………………..……………………………………………………………………………………**

**Researcher's
signature……………………………………………………………………………………….Date…………………..**

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5890). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

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Demographic Questionnaire for participants who have experienced FPDR

1   Name (pseudonym) of interviewee

2   Age

3   Gender

4   Ethnicity

5   Education

6   Occupation

7   Years since qualified (for health care professionals)

8   Relationship to person being resuscitated (for family members)

9   Relationship to the family member present (for former patients)

10   Are you happy to be contacted again for a follow up interview

11   Preferred contact information

INTERVIEW QUESTIONS	POSSIBLE PROMPTS
Can you tell me about your experience of having a family member present or wanting to be present during an active resuscitation?	• How long ago? Which department? Ie ED • Events that led up to the FM being/wanting FPDR? • What relationship did the FM/s have to patient? • Was the FM in the room before or enter the room after? • Who else was in the room during the resus? • Did the patient survive? • What was your interaction like with the FMs during and after the resus? • Was there anyone supporting FM during the resus?
Whose decision was it for the FM to be present or not present?	• How was the decision made? What do you think contributed to this decision? • Did everyone in the room agree with the decision? Did you?
Can you tell me your thoughts about whether FMs should be given the option to be present during resuscitation of their loved one?	• What factors do you think would affect your decision?
Can you tell me your thoughts about whether patients should be given the option to have FMs present if they required resuscitation?	• What factors would affect or change your decision?
Ultimately – whose decision do you think it should be whether a FM is present during resuscitation	• FM, Patient, Registered Nurse, Medical Doctor, Policy? Other?
As you look back on the resuscitation – are there any events that stand out in your mind?	• What do you remember most about the resuscitation with the FM in the room / or wanting to be in the room and not being permitted?
Tell me about whether you want <u>your FM</u> / loved one present if <u>you</u> needed resuscitation?	• What would impact this decision if anything?
Tell me about whether <u>you would want to be present</u> if your loved one required resuscitation?	• What would impact this decision if anything?
Thinking back on your experience – is there anything you would change if you were in this situation again?	• Could you tell me the most important thing you learned?
Is there anything else you would like to tell me about?	• About your experience? Your thoughts on FPDR in general? • Were you aware of FPDR before this interview? • How – if at all – have your feelings changed about FPDR since your experience? • What do you think were the advantages and disadvantages of FPDR? • Have you ever talked about FPDR with anyone?
Is there anything you would like to ask me?	
Would you like to check your transcript?	

Thank you so much for your time and for sharing your experiences about FPDR.

INTERVIEW QUESTIONS	POSSIBLE PROMPTS
Can you tell me about your experience of having a family member present or wanting to be present during resuscitation?	• What was your interaction with FMs during/ after resus? • Who provided information to the FMs? • Was there anyone supporting FMs during the resus? • Is this the first time you have had a FM present during a resus? How often does it occur?
Whose decision was it for the FM to be present or not present?	• How was the decision made? What do you think contributed to this decision? • Did everyone in the room agree with the decision? • ***If FMs are already present are you/HP more likely to allow them to stay?**
*What do you think drives different decision-making and practices between clinical settings that will or will not allow FPDR	
What are your thoughts about whether <u>FMs and or patients</u> should be given the option to be present during resuscitation of their loved one?	• What factors do you think would affect your decision?
Ultimately – whose decision do you think it should be whether a FM is allowed to be present during resuscitation	• FM, Patient, Registered Nurse, Medical Doctor, Hospital or unit Policy? Other?
As you look back on the resuscitation – are there any events that stand out in your mind? Is there anything you would change?	• What do you remember most about the resuscitation with the FM in the room / or wanting to be in the room and not being permitted?
Would you want <u>your FM</u> / loved one present if <u>you</u> needed resuscitation? What is the reason for your answer?	• What would impact this decision if anything?
Would <u>you want to be present</u> if your loved one required resuscitation? What is the reason for your answer?	• What would impact this decision if anything?
* In your opinion what would need to happen for FPDR to occur as standard practice?	• In your health care setting? In all health care settings?
Is there anything else you would like to tell me?	• About your experience? Your thoughts on FPDR in general? • Were you aware of FPDR before this interview? • How – if at all – have your feelings changed about FPDR since your experience? • Advantages and disadvantages of FPDR? • *Who do you think FPDR is for? • Have you ever talked about the FM being present during the resus with anyone?
Is there anything you would like to ask me?	
Would you like me to send you the transcript to check?	

Thank you so much for your time and for sharing your experiences about FPDR.

Type of theoretical memo	Initial theoretical memo written after initial coding
Topic of memo	Second interview, RN 'Elizabeth'
Date memo was written	21st October 2013

Initial Theoretical Memo (abbreviated version)

I noted quite a few similarities between the attitudes and beliefs expressed by Jackie and Elizabeth. They work in health care settings where there is no policy or standard practice, do not allow FPDR and prefer FMs to wait quietly in a separate room. They also experienced a situation where a FM was present during the resuscitation because it was *unexpected.* In Jackie's case the FMs stayed for the entire resus because *no one remembered to ask them to leave*, whereas for Elizabeth, the FM was *asked to leave* almost immediately and did so without hesitation but asked for regular updates on the patient's status.

Like Jackie, Elizabeth appeared to have an internal conflict between her desire to *protect family members* from 'graphic' resuscitation scenes while at the same time considering family centred care and the *rights of family members* present. For example, Elizabeth believed the resus would be too traumatic for FMs to witness and worried about the long term effects. Yet she also spoke about family centred care and stated that if FMs and the patient wanted FPDR then it *should* be allowed - but that it never was.

Similarly, Elizabeth presented conflicting reasons for not wanting FMs present. At times she spoke about wanting to *protect FMs* from the resuscitation, but at other times seemed more concerned about *protecting HPs* from distressed or disruptive family members, or being 'watched' and 'judged' by family members, particular those who are also HPs and possess specialised knowledge against which to measure staff performance.

In keeping with GTM methodology, I referred back to what Jackie had shared during the first interview about not allowing Nurse-FMs into the resus room, but *making special allowances* if they worked in the same hospital. When asked if she agreed with this opinion, Elizabeth was emphatic that Nurse-FMs should never be present because they

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would *'judge' the resus* team and *make them uncomfortable*. However, when asked whether a Doctor-FM would be allowed to stay, Elizabeth conceded they would. In other words, Elizabeth would not allow a Nurse-FM to stay for fear of being judged by someone with specialised knowledge, but would allow a Doctor-FM to stay despite them possessing as much if not more specialised knowledge and potentially judging HPs in the same way.

Jackie's and Elizabeth's views raise an interesting point about *power in health care settings.* Who holds the power to be present? Who holds the power to decide? What is the source of this power? Under what circumstances will a FM be awarded the 'special privilege' of being present when others in that same setting are not permitted? I need to follow this up with future participants to see whether certain HP statuses are consistently afforded *special privileges* and whether the anxiety that may arise from being 'watched' and 'judged' by a HP is always overridden by the fear of denying a *'powerful' HP* (in this case a doctor) to be present during the resus when other HPs (in this case a nurse) are not.

While Jackie and Elizabeth appeared to have different personal beliefs about whether FPDR should be allowed, upon closer examination these beliefs were more similar than they first appeared. Both Jackie and Elizabeth spoke about how FMs and patients should be (in theory) given the option of FPDR. However, in reality, neither RN practiced FPDR and instead quite emphatically stated they would always prefer to ask the FM to leave.

When asked specifically about a FM asking permission to stay, Elizabeth said for her to even consider this request the FM would have to be able to demonstrate they would not be emotional, both for their own wellbeing but also in order to avoid HPs having to deal with an anxious and potential disruptive FM in the room in an already *'uncontrolled' environment*. It is interesting that Elizabeth inferred she does not wish to deal with 'emotional' FMs, and yet it would be very unusual for a FM to **not** be emotional with their loved one in a critical condition. Are nurses reluctant to deal with an 'emotional' FM at a time when they themselves are feeling emotional and stressed and *out of control*? During Jackie's interview, she implied a *loss of control* during a resuscitation that would be exacerbated by the presence of a FM. Elizabeth spoke even more overtly about a loss of control, emphasising that allowing FP into an already uncontrolled environment would

cause even more disruption for the already anxious HPs, which in turn would make them even more anxious. She also emphasised that FM should not be privy to HPs in an uncontrolled situation, which again raises the issue of performance anxiety.

It is likely that Elizabeth's attitudes and beliefs about not wanting FPDR stems from her *own personal experiences* about what FMs should and should not be exposed to, and also her *preferences* as a nurse. In other words, because she (a nurse) does not feel she would cope emotionally with being present, she does not believe anyone else will. In addition, because she does not like being 'watched' when attending to a patient, she herself did not feel comfortable to 'watch' her own HPs during her husband's admission. In a sense, she may be *'projecting' her own beliefs* onto other FMs. In both settings, the decision to not allow FPDR appears to be based on the *personal opinions of HPs*, which have developed over time into a *non-formal but standardised practice* of not allowing FM to be present. In both settings, beliefs about what could or should happen are quite different to what actually happens in practice. *Personal beliefs and preferences* therefore appear to play a significant role in decision-making among other participants also. The more supportive HPs are of FPDR, the more likely they are to overcome barriers to make it happen. This requires further exploration in future interviews.

Type of theoretical memo	Initial memo written immediately after initial coding
Topic of memo	Eighth interview 'Mandy' RN
Date memo was written	15th November 2013

Initial Theoretical Memo (Abbreviated version)

Mandy spoke about positive and negative experiences with FPDR but overall believed it was beneficial, not only to FMs but also patients and HPs. Mandy acknowledged that not all FMs would be suitable or even want to be present, but repeatedly stressed the importance of offering the option of being present. While most of her experiences had been positive, Mandy also shared a particularly distressing situation where a disruptive FM asked HPs to stop resuscitation on a new born because she wanted the baby to die, telling HPs repeatedly to 'throw it in the bin.' HPs tried to remove her from the room, but were unsuccessful.

Mandy's experience once again raised the importance of *assessing the suitability* of FMs to stay. According to participants, this is vital because some FMs may not be able to cope with graphic resuscitation images, while others may become disruptive and hamper HPs efforts. However Mandy maintained throughout the interview that despite the potential disadvantages of having FM there, the option to stay should be offered to all suitable FMs.

Some of the previous RN participants (particularly Jackie and Elizabeth) have shared feelings of intimidation as a result of a Nurse-FM's presence. Yet Mandy, Sally and Dana were unaffected by this, stressing that as long as they were doing their job, they did not mind who was watching. This raises questions about why some RNs appear to be affected by *performance anxiety* while others do not. Length of service does not appear to be a factor because, while Jackie was only 3 years post registration, Elizabeth had been an RN for many years. Further exploration of performance anxiety is warranted in future interviews.

Once again the issue of *power in health care settings* emerged in relation to whose decision it would be to allow FMs to stay. Mandy currently works night duty in a rural hospital and as such is the senior HPs member present on all shifts. As such she makes

the decision to allow FMs to stay – but she also spoke about gaining retrospective support for this decision from the doctor once they arrived.

A strong theme to emerge from this interview was the fact that if FMs were *already present*, they were more likely to be allowed to stay. Interestingly, all participants so far have verbally identified FMs as the most important person when making the decision to stay or go. Yet in practice, the final decision appears to rest with HPs, who provide *'permission'* for FMs to stay or ask them to leave. Once again, this comes down to *ownership of the space and of the patient*, and I suspect this will be a key theme in future interviews. Once again HPs were seen to *focus on the patient* as their number one priority and then attend to *FMs as a secondary duty*. Understandably, when there are limited HPs to attend to the needs of the critically ill patient, FMs are often forgotten and left unattended. Interestingly though, Mandy was not concerned with an *unaccompanied FM* watching from the back of the room so long as they stayed *'out of the way'*.

This interview once again highlighted the importance of the FM playing their *'role'* correctly and highlights the difference between a 'good' FM and 'bad' FM. However some RNs are so afraid that all FMs will be 'bad' - they do not allow <u>any</u> FMs to be present, while others appear to deny FPDR due to performance anxiety. Others still appear to base their decision to deny FPDR on their own *personal preferences* which they project onto the FM. The overall sense from this interview was that Mandy's *positive attitude toward FPDR* strongly impacts her decision to offer FMs the option to be present. Despite some bad experiences with disruptive FMs, Mandy believes the *benefits of FPDR outweigh the risks*. In addition, because of her positive attitude and the belief that FPDR is every FMs right, Mandy overcomes any potential barriers by *assessing FMs for suitability*, and by *providing explanations and information to the FM* to ensure they have an adequate understanding of what could happen, what is going to happen, and what did happen.

Type of theoretical memo	Theoretical Memo
Topic of memo	Free writing exercise at 3 Day GTM Master Class with Professor Kathy Charmaz, Melbourne, March 2014.
Date memo written	18th March 2014

PROTECTING OTHERS (free writing exercise)

'Protecting others,' is about protecting people from certain situations that might cause them discomfort. There are three groups of people who are being protected in regards to FPDR – the patient, the HPs and FMs. This tentative category also overlaps several others; 'holding *decisional power'* and '*ownership of the space*.'

First and foremost, HPs are protecting themselves and their colleagues from being observed, often for fear of being judged by family member- who in this case may be seen as 'outsiders.' In order to protect themselves, HPs are claiming ownership of the resuscitation space, and as such are making decisions about who can and cannot be let into the resus room. In our current health care settings, there is a distinctive *power imbalance* between HPs and health care consumers. As such, HPs often make *unilateral decisions* about what they believe is best for the patient and for the family - this paternalistic ethos seems to be driving many of the decisions made by HPs under the guise of 'protecting others.'

Protecting HPs seems to be a significant factor impacting whether FMs are let in to observe a resuscitation. When HPs are comfortable and confident in their own practice, they are more likely to allow FMs to observe them in practice. Conversely, HPs members who are not confident in their practice do not seem to be comfortable being observed, and were much more likely to feel they were being judged by observers. Not only did they exclude FMs to protect themselves from being observed, they also appeared to be projecting this need for protection onto their colleague. Similarly, HPs who were confident and comfortable in their practice -while they acknowledged that not all HPs may feel this way -expected them to increase their competence and overcome this performance anxiety.

HPs who were reluctant to allow FPDR justified this stance by explaining they were protecting FMs from graphic resus scenes. As such they were making a judgement about

the fact that those FMs needed protection. What they did not take into account was that often family members did not want protection and had in fact already seen (and participated in) the resus in their home. By making this judgement on the FMs behalf, they were almost *disempowering* FMs. HPs were not trusting the FM's ability to assess their own coping mechanisms and were instead enforcing the paternalistic attitudes that exist in healthcare.

I think HPs were sometimes using the notion of 'protecting' FMs almost as an 'excuse' to exclude them from the room, and that they were in fact protecting themselves from being observed, from appearing to lose control, from having to justify their actions/practices and to ensure they were not observed making mistakes. Several HPs also mentioned that fact that they were protecting their patient's privacy but also about protecting FMs from…

(The writing exercise ended here).

Question guide for follow up interviews

1. Since we last spoke, have your views about FPDR changed? What do you think is the reason for this?

2. Do you think decisions about FPDR are made consciously or unconsciously? What is the reason for your response?

3. Who do you think FPDR is for and why?

4. Can you please read the matrix[17] on the following page which summarises some of the decision-making processes used by the people in this study.

    a. What are your thoughts about the matrix?

5. Can you please read the table[18] on the following page which represents the criteria used by the people in this study to make decisions about FPDR

    a. What are your thoughts about the table?

6. Do you have anything else you would like to add about FPDR?

Thank you so much for your time and participation in this study.

---

[17] This matrix can be found on page 139 of the thesis.
[18] This table can be found in appendix 19.

Value judgements used by study participants for decision-making related to FPDR

VALUE JUDGEMENTS	TOPIC OF JUDGEMENT	SOME EXAMPLES OF HOW PEOPLE APPLIED THEIR VALUE JUDGEMENTS TO EITHER ALLOW OR DENY FPDR
Prioritising preferences, rights and needs	Of the Patient	• Protecting the patient as a priority • Protecting privacy, confidentiality • Valuing the benefits of FPDR for patient
	Of HPs	• Preference to be unobserved / unimpeded • HPs preferences to allow/deny FPDR
	Of Family members	• Valuing the benefits of FPDR for FM • Respecting FM right to choose whether they want to be present and level of presence • FM best placed to know patient preferences
Assessing suitability	Context	• Intervention being witnessed (deciding what is suitable for observation; CPR, defib, invasive procedures, traumatic injuries) • Policy or procedure supporting practice • Working within setting 'norms' • Cultural implications
	Setting	• Safety of the setting (defib, radiation, trip hazards etc) • Space limitations – will FP impede resus
	People	• FM preferences to stay or go • FM ability to cope / level of distress • FM risk of becoming disruptive • FM involvement in cause of illness • Patients' preferences for FPDR • HPs ability/willingness to be observed • HPs competence under observation
Setting boundaries	Physical	• HPs being able to control the environment • Limiting the number of FM present • Having enough HPs • Having space available • FM staying out of the way • Delaying FP until patient presentable/stable
	Emotional	• Conditional permission (FM remaining calm) • Preparing and supporting FM for presence • HPs supporting/removing distressed FM • FM deciding which other FM can be present • Patient wanting only some FM present
	Theoretical	• Watching from a 'safe' distance • Being present but not involved • Being able to remove disruptive FM • Asking FM to leave for certain procedures • Differences between FP for child/adult resus • Weighing up risks and benefits of FPDR

ACTIVITY	DESCRIPTION
Initial Sampling	Sampling from a specific population of people who have experienced FPDR commenced September 2013
One-on-one, in-depth interviews	In-depth, semi-structured interviews (commenced October 2013)
Initial memo writing	I wrote initial memos after each interview to allow me to start thinking about important recurring statements and concepts and to start comparing participant experiences and views.
Developing important recurring themes and concepts	After interview 4 (Dana), several key themes and codes were identified: Already being present, Being assessed as 'suitable' to stay, Ownership - of the patient /the space, Ability to support parents/FMs, Positive attitudes toward FPDR (this later became valuing Family Presence)
Further interviews, ongoing constant comparisons	With each subsequent interview I compared recurring, important themes between and within the same interview. I also started to modify and focus the interview questions.
Ongoing interviews, initial coding, constant comparisons	After interview 6, (Sally) I revisited the GTM literature to ensure I was following correct processes. I also sought feedback from my PhD supervisors about future processes.
Key factor emerged as a potential tentative category	During interview 12 (Darren) I realised an *in vivo statement* about *valuing FPDR* was an important recurring process throughout the 11 previous interviews. I raised this code to a tentative category to check, and found this tentative category within the remaining interviews.
Focused sampling – adding paramedics	During interview 3 (Trevor) it first became apparent that paramedics play an important role in directing FMs upon arrival to hospital. Following interview 12 (Darren), I made a note to interview paramedics about their experiences.
Ongoing interviews, initial coding, constant comparisons.	During interviews 13 – 21 (December 10th 2013 to April 23rd 2014), I continued to compare interview with interview, and compared recurring/important themes between interviews.
Attending to emergent areas of possible theoretical interest	I continued to modify/focus interview questions. Started focused coding by treating recurring interview statements as 'theoretically plausible.' (Charmaz 2006).
Focused coding	March/April 2014 I re-coded all interview transcripts thus far and made a list of recurring / important codes.
Attended a 3 day Master Class with Kathy Charmaz (Melbourne, March 17th – 19th 2014)	I was able to further develop my initial coding, focused coding, constant comparisons and theoretical memo writing. I also used mind map clustering and free writing to increase the level of abstraction in my memoing and analysis.
Development of focused codes and tentative categories	Tentative categories became more focused, some major codes collapsed to form categories to test. Tentative categories at this stage. 1) Valuing FPDR, 2) Protecting others, 3) Holding decisional power, 4) Claiming ownership
Focused coding against tentative categories and the emerging properties of each category	Constant comparative method used to refine and redevelop five tentative categories. 1) Valuing FPDR, 2)protecting self and others, 3) Holding and relinquishing decisional power (initially Holding decisional power), 4)Practicing within setting norms, 5)Claiming ownership
Identifying category properties and conditions	I constructed a list of all tentative categories and their properties and the conditions under which the properties exist

Focused coding	April 2014: Focused coding of interviews 2, 3, 4, 5, 6 against current tentative categories. The tentative categories and properties were evident in and fit into each interview.
Discussion of tentative categories	Discussion of tentative categories took place with principal PhD supervisor to increase transparency and study rigour
Focused coding against each tentative category	Focused coding of interview against each tentative category. Theoretical memo written after each category was coded.
Purposive sampling **Theoretical sampling**	Purposive sampling, but also theoretical sampling was undertaken (interviews conducted with 3 paramedics) to develop the properties of one tentative category Holding & Relinquishing Decisional Power – 'Being present by default'
Refining Categories and subcategories **Constant comparisons**	Following interview 21 I considered that **'Ownership of the space'** should be moved to fit under **'Holding and Relinquishing Decisional Power.'** I changed the category of **'Protecting self and others'** to **'Protecting others and self'**
Theoretical Memos **(Constant comparisons)**	I am continuing to develop each category / code through memo writing (what Charmaz (2014) refers to as 'rendering the data'). Theorising about the links between 1) valuing FPDR, 2) holding and relinquishing decisional power, 3) protecting self and others, 4) practising within setting norms, 5) setting boundaries, 6) default presence and 7) claiming ownership.
Theoretical sampling	Interview 24 with Carol focused on developing the properties of the tentative categories.
Clustering using lists and diagrams **(Constant comparisons)**	May 8th 2014: Re-considered sub categories and categories in order to determine how they fit together using clustering lists, then memoing. I was initially unable to decide how the tentative category of **'Valuing FPDR'** fit with the sub-categories I had allocated: *Attitudes, weighing benefits and risks, personal experiences and beliefs, prioritising preferences/rights/needs, and dealing with barriers.*
	When I considered Charmaz's question **Under what circumstances do priorities change?** I realised that all of the other subcategories I had placed under **'Valuing FPDR'** now answered this question. I therefore made them <u>properties</u> of **'prioritising preferences/rights/needs.'** I realised that **'Valuing FPDR'** – which I had until now considered to be a major category – now also fit within **'prioritising preferences/rights/needs'** as a <u>property</u> to explain **Under what circumstances do priorities change?**
	I now had seven major categories – all with developing properties.1) Prioritising preferences, rights and needs, 2) Assessing suitability, 3) Protecting others and self, 4) Claiming ownership, 5) Being present by default, 6) Setting boundaries, 7) Experiencing power differentials
Constant comparisons	9th May 2014: I re-read through Interviews 1 – 23 searching for every process and situation where participants talked about **Decisional Power**. I realised there were more variables at work than just **holding and relinquishing decisional power**. I would need to develop an overarching title for this category that has a better fit. Possibly **The fluctuating nature of decisional power.**
Refining Codes and Categories **Constant comparisons**	May 19th 2014: I merged some categories. **My most recent list of categories is**: 1) The fluctuating nature of decisional power, 2) Experiencing power differentials, 3) Claiming ownership, 4) Being

	present by default, 5) Protecting others and self, 6) Assessing suitability, 7) Prioritising preferences, rights and needs, 8) Setting boundaries.
	I then collapsed some categories: Numbers 1, 2, and 3 are about **power,** Numbers 6, 7, 8, are all about **making judgements**. Number 4 is first about **opportunistic presence** but then becomes about **making judgements** (and also about having the **power** to exert those **judgements**). Number 5 – I am not sure where this fits in yet?
Diagramming	May 23rd 2014: Diagramming helped me redefine the categories and determine which can be subsumed by others, which stand alone, and how they all fit together. Note: An example of my diagramming is included at the end of this methodological diary.
Refining major categories and their properties	June 20th 2014: Considering connections between **'making judgements'** and **'power differentials'** and **'valuing FPDR.'**
Diagramming	As I continued to compare phrases, codes and processes I realised that every person in every decision-making situation was **making value laden judgements along a power continuum".**
Literature review (secondary)	October 2014: Consulting the decision-making literature to consider my findings against existing knowledge
Follow-up interviews with several key participants Theoretical Sampling	November 2014: I wrote several broad follow up questions in order to saturate the properties of my categories and also to evaluate the key findings.
Theoretical Saturation **Addressing the completeness of data collection** **Study rigour**	I determined that after 27 interviews with 25 participants I have reached theoretical saturation (by saturating the properties of my core categories) and I have also addressed Charmaz and Glaser's criteria for study rigour.
	In order to pay respect to my participants for their time and valuable input, I sent all participants who were not re-interviewed a copy of the decision matrix and the value judgement table.
A plan for writing up the theory	December 2014: I need to undertake a **secondary literature review,** sorting and re-ordering (and possible renaming) of my core categories and theory properties.
Theoretical analysis	December 2014: Literature search, **'value-laden' decision-making**. Many articles related to risk assessment, risk management. In my study – **assessing suitability is a type of risk assessment that is also value based**. This requires further exploration during the secondary review.
Analysing data, Sorting, ordering, integrating memos, codes, categories	December 2nd 2014: Two previous categories, *Setting Boundaries* and *Assessing Suitability* can be consumed by a higher category *Giving & Receiving Conditional Permission.*
Refining the categories and properties	**December 2014:** GIVING AND RECEIVING CONDITIONAL PERMISSION (category) • Prioritising preferences rights and needs (property) • Setting Boundaries (property) • Assessing suitability (property) • Protecting others and self (property) THE FLUCTUATING NATURE OF DECISIONAL POWER (category) • Experiencing power differentials (property) – include legitimate power versus perceived power here • Power versus opportunity – or Opportunistic presence (property)

- Claiming ownership of the patient, the space and the resus act (property)

As I continue to analyse and sort the data and write the theory, I may reorder these categories / properties

Updating the preliminary literature review	I completed my preliminary literature review in 2012. Given the nature of thesis expectations – I completed a literature search update in November, December 2014 that covered the years 2011 – 2014. I was therefore careful to wait until AFTER my core categories emerged before I went back to update my preliminary review.
Renaming and reordering categories	Feb 2015: Two major categories merged into one core process (category) **Major category = conditional permission** Feb 2015 – May 2015: I wrote an article for peer review publication detailing the analysis and emergence of the core category in order to strengthen the analysis and increase transparency.
Renaming the core category to improve fit and resonance	April 2015: Constant comparisons allowed me to progress the emergence of conceptual data and to compare the final analyses with relevant theoretical and research literature.
Theoretical Integration	May 2015: As I continue to reflect on the major processes at play for participants - I realise that the subjective nature of every action and process enacted by participants is a **social construction** as they engage in meaning making through their interactions with each other. The name of the grounded theory is thus **'The social construction of conditional permission.'** and the core category is **conditional permission.**
Writing the theory	Writing the theory was an iterative process – going back and forth between sections and chapters to revise the emergent theory and theoretical integration using the extant literature.

Diagram of major tentative categories: version 4. May 23rd 2014.

Aug 20 2015 04:34:32:071PM
RE: ANS1088R1, entitled "Coding, constant comparisons and core categories: a worked example for novice constructivist grounded theorists."

This is to let you know that I have received your revised manuscript, and I am delighted to let you know that it is accepted for ANS as a "General Topic" article. Thank you for your thoughtful response to the reviewer comments.

Your article will be scheduled to be published in a future issue of ANS. The exact issue in which it will appear has not yet been determined; I will notify you of acceptance for publication in a specific issue within the next 2 to 6 months.

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Advances in Nursing Science
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Article accepted for publication 20 August 2015, Advances in Nursing Science Journal.

Title: Coding, constant comparisons and core categories: a worked example for novice constructivist grounded theorists.

Introduction

Grounded Theory Method (GTM) is one of the most widely used qualitative research methodologies across a variety of disciplines.[1] The increasing use of GTM in nursing research has directed attention on the quality of studies using this approach and the credibility of subsequent study findings.[2] In order to provide safe and effective evidence-based care, clinicians must be able to access rigorous research in their related fields. Yet many researchers who claim to be using GTM fail to apply the core tenets of this methodology/methods package[1,3], possibly due to an inadequate understanding of the approach.

Whilst GTM has been described extensively in the literature, less attention has been given to providing practical examples of the key methods and processes inherent to this research approach. In particular there are limited worked examples that track the development of initial and focused codes, through to the construction of tentative and major categories and emergence of the core category. The purpose of this paper is to offer a step-by-step example of how a grounded theory develops and is systematically constructed.

Grounded theory method (GTM) is a research methodology used to create substantive theories through inductive and abductive data analysis, rather than hypothetical deductions.[3,4] More specifically, GTM is a research/methods package which includes the cyclic application of '…data collection, coding and analysing through memoing, theoretical sampling and sorting to writing, using the constant comparative method.'[5(p12)] At its core, GTM aims to understand behaviour and meanings that participants give to their experiences in a particular setting.[6] Further, the aim is to generate conceptual theories that explain a phenomenon from the perspective and in the context of the people who experienced it[7] that can be applied to practical situations.[4]

Since its inception in the late 1960's GTM has evolved from positivist beginnings[4] to a constructivist paradigm.[3] Charmaz's constructivist approach adopts the methodological strategies developed by an objectivist Glaser, while also building on the social constructionism that underpinned Strauss's symbolic interactionist perspective.[8,9]

Charmaz's approach also incorporates Strauss's emphasis on meaning and action inherent in pragmatist traditions.[3] As such, Charmaz's constructivist approach actively repositions the researcher as a co-constructor of experience and meaning.[8,10]

According to Charmaz[3], researchers construct grounded theories through their past and present interactions with people, their personal perspectives and their research practices. A constructivist approach therefore allows a representation of experience rather than an exact replication of it[3] and sees the researcher as an interpreter during analysis rather than the ultimate authority in defining the data.[1 (p52)]

A constructivist approach to GTM starts with the lived experience, then asks how participants constructed that experience.[8,11] The researcher can then explore how and why participants constructed meanings and actions in certain situations, while keeping in mind that the resultant theory is itself an interpretation that is dependent on the researcher's view.[8, 11-14] Using this approach, what researchers see and hear will depend on their past experiences and interests, their prior interpretation of the phenomenon, the research context, the researcher-participant relationship, and the methods of generating and recording the data.[8,10] As such, the researcher should treat the research process itself as a social construction, and scrutinise all research decisions and directions.[9]

Charmaz's GTM comprises systematic yet flexible guidelines for collecting and analysing (primarily qualitative) data in order to construct theories that are grounded in the data.[3,4] A key feature of this method is the concurrent collection and analysis of data, with each informing and focusing the other; this allows analysis to become progressively more theoretical as the research progresses.[3,4] Other core tenets include theoretical sampling, constant comparison of data to theoretical categories, writing theoretical memos and a focus on the development of theory through theoretical saturation of categories rather than through substantive verification.[15] Each of these core GTM tenets are discussed and exemplified within this paper.

Stern[16] believed GTMs are difficult to explain in writing because of the multitude of different methods used and because the analytical activity required is a primarily cerebral process. Many experts agree that the best way to learn GTM is by doing GTM[16-18], and from our personal experience this is certainly true. Further, we believe that detailed worked examples from grounded theorists can help elucidate analysis, category development and theory building for novice researchers.

The study - a grounded theory of family presence during resuscitation

This article details the data analysis phase of a constructivist grounded theory study that examined decision-making around family presence during cardiopulmonary resuscitation. Our initial research question was 'what factors impact decision-making around family presence during resuscitation in an acute care setting.' Our example depicts the methods and processes undertaken to construct the substantive grounded theory *'The Social Construction of Conditional Permission.'* This article traces the construction of the core category *'Conditional Permission'* from initial and focused codes, subcategories and properties, through to its position in the final substantive grounded theory.

Family presence during resuscitation (FPDR) is the practice where family members or loved ones are in a location where they can see and sometimes touch the patient during active cardiopulmonary resuscitation.[19-21] FPDR is a contentious area of practice that has attracted widespread international debate.[22] Despite support for the practice from the Australian Resuscitation Council,[23] European Resuscitation Council,[24] the American Heart Association,[25] and increasingly from the public,[26-28] views among health care professionals remain divided - with support for the practice ranging from 3% to 98% in surveys.[22,29]

International research suggests there are multiple benefits for family members who are present during resuscitation of a loved one. Yet health professionals continue to report concerns and anxieties about FPDR and many hospitals do not have written policies to guide this practice. Many of the reported barriers seem to be based on perceptions of negative outcomes rather than on actual events and the influence of personal values and preferences appear to be an important consideration in the decision to practice FPDR. The possibility that individual value systems may have a considerable impact on FPDR practices warranted further investigation in order to examine how decisions are influenced in relation to FPDR, and the rationales behind these decisions.

The aim of this study was to examine decision making by health care professionals and family members in relation to family presence during resuscitation in an acute care setting.

This doctoral study was conducted by the lead author, and supervised by the co-authors. The study was approved by the relevant Social and Behavioural Research Ethics Committee, conducted in accordance with the Australian Code for the Responsible Conduct of Research, and ethically reviewed and monitored in accordance with the National Statement on Ethical Conduct in Research.[30] Pseudonyms were allocated to

promote confidentiality and any events and experiences that could potentially identify participants have been de-identified, including workplaces and specialties.

In the study, health care professionals (registered nurses, doctors and paramedics), family members and surviving resuscitation patients were interviewed by the lead author. A flexible interview guide was used to explore participant experiences.[3] Open ended questions included; Can you tell me about your experience of having/being a family member present or wanting to be present during an active resuscitation? Can you tell me your thoughts about whether family members should be given the option to be present during resuscitation of their loved one? As you look back on the resuscitation are there any events that stand out in your mind? As recommended by Charmaz,[3] questions were not asked in a linear fashion and in some cases not all questions within the guide were posed. Instead, questions were used to guide each interview in order to learn about individual participants' attitudes, beliefs, experiences and actions.[8]

Comparisons of knowledge, truth and reality over time and across cultures make it quite clear that there have been and continue to be very different interpretations of the same phenomena.[14] For example, the meaning of 'marriage' has changed over time and differs significantly between countries and cultures. Relativism then is necessary to account for the fact that different people inhabit different worlds with diverse ways of knowing. As such, in keeping with a constructivist approach to GTM[3] narration and description of the in-depth interviews in this study was not seen as a straight forward representation of reality. Rather, when the researchers described something, they were reporting on (and therefore interpreting) how something was seen and reacted to and therefore meaningfully constructed within a particular community or society.[14]

Data analysis began after the first interview to facilitate simultaneous collection, coding and analysis of the data, and to provide the focus for subsequent data collection as per GTM requirements.[3,4]

Constructing the core category

The core category constructed in this study was *'Conditional Permission.'* This article does not present detailed findings from the study, but instead describes *how* the core category was constructed and traces how initial and then focused codes were elevated to tentative categories which were then refined into the final core category. The GTM process is not

linear; so while the methods used are presented in a linear fashion within this article they were applied in a cyclical process (see Figure 1) in line with GTM tenets.[3]
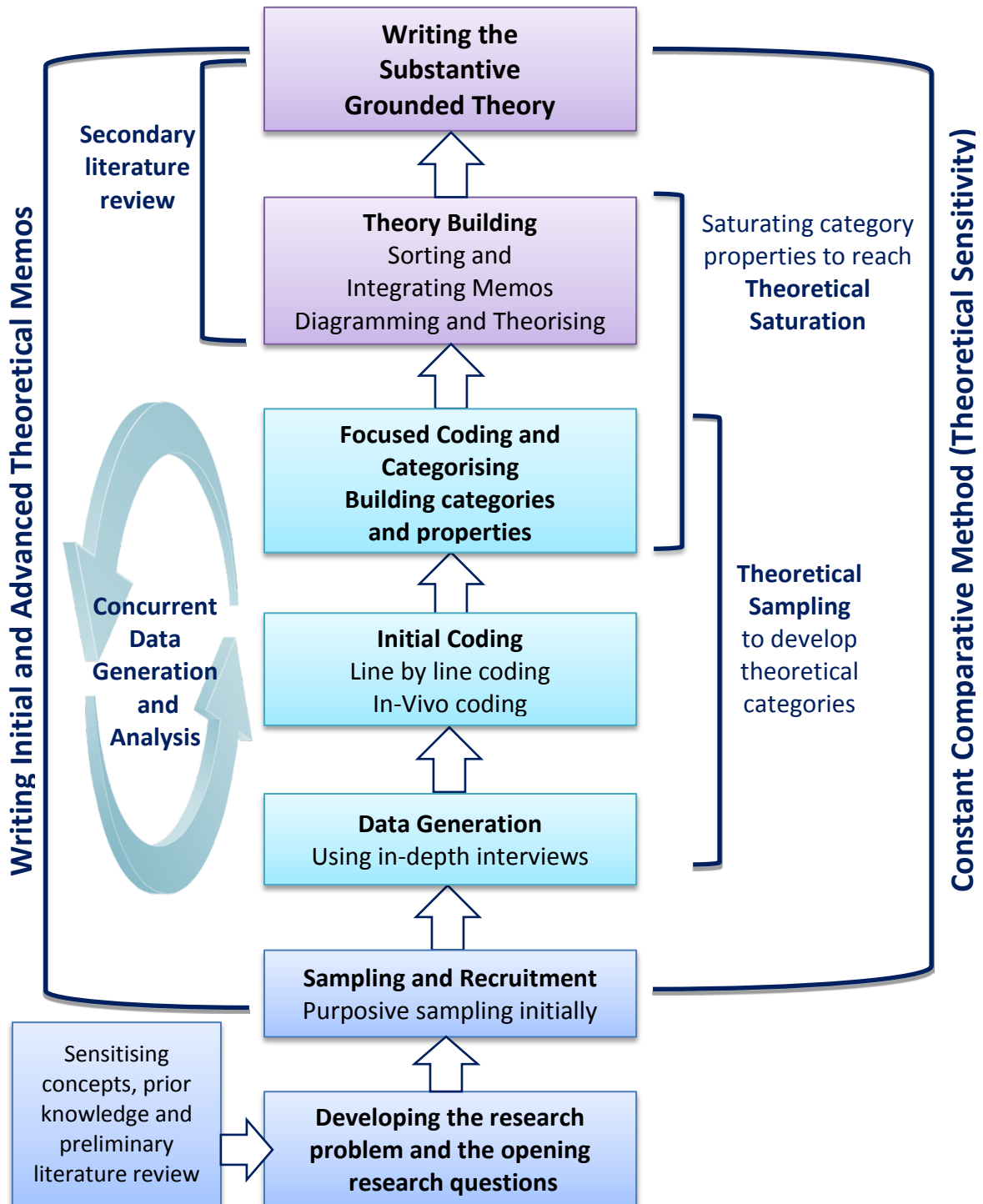

Figure 1: Grounded theory processes and methods used to guide the current study

Coding the data

GTM coding allows researchers to define what is happening in the data and begin to understand its meaning.[8] A constructivist approach to GTM acknowledges that codes are *constructed* by the researcher because they are interpreting and naming what they see in the data based on their previous knowledge and experience.[3] Coding for processes, actions and meanings breaks the data up into their properties or components, and defines the actions that shape or support these data.[31] Close attention to correct GTM coding methods in this study ensured implementation of a core grounded theory mandate - to study the emerging data.[6] Complete interview transcripts were coded by the lead author to provide a deep understanding of the phenomenon and to generate ideas that might otherwise have been missed.[8] The transcripts were typed into a word document table with two columns; one column contained the interview transcription while the other column was used to enter the codes. The initial and focused coding phases described by Charmaz[3,8] were employed during analysis.

Initial coding

Initial coding took place immediately after each interview to comply with a core GTM tenet – simultaneous data collection and analysis.[3,4] During initial coding, each line of the interview transcript was allocated a short label (code) that both summarised and accounted for each portion of data.[3,4] This initial coding was done quickly and spontaneously to prompt analytic thinking about the data, while at the same time engaging in reflexivity (detailed later in the article) to avoid forcing the data into preconceived codes.[8] Initial line by line coding kept the researcher studying the data in order to start to build ideas inductively while at the same time limiting the researcher from imposing existing theories or their own beliefs on the data.[32] This form of coding therefore helped the researcher remain attuned to participant's views of their own realities rather than assuming the researcher and participants shared the same views and worlds.

Examples of initial codes generated from the analysis are included in Table 1. In order to facilitate effective coding and to ensure the codes fit the data rather than forcing the data - initial codes were kept simple and precise, using gerunds (the verb form of nouns) to preserve actions while continually comparing data with data from subsequent interviews.[8] Initial codes assisted the separation of data into tentative categories and enabled the researcher to see processes and actions in the data.[8]

As depicted in Table 1, the initial codes allocated immediately after the first interview were too lengthy, too descriptive and lacked the analytical grab required in a grounded theory study. These initial codes were therefore treated as provisional and comparative in order to remain open to other analytic possibilities.[3]

Table 1: Initial codes allocated immediately after the first interview and initial codes allocated when the interview was re-coded after the first five interviews had taken place.

Interview Excerpt - Interview 1 with 'Jackie' Registered Nurse	Initial Codes immediately after the first interview	Initial codes after re-coding the interview
…we would normally not allow the family member to come in but because they were there all along and we were trying to fix the problem quickly, we kind of forgot about them and they were there for most part of the resus…No-one really made the decision to let them stay, coz usually we never let them stay…They don't really have a choice… If anything is about to happen we say can you excuse us we are about to do a resus can you just step outside we'll come and get you when we're ready	Family members usually not permitted in room FM already present Staff focusing on saving the patient Staff forgetting about family members Excluding Family Members as standard practice Family members not being given a choice Asking FM to leave the room FMs waiting away from resus until staff ready	Practicing within setting norms Already being present Placing patient needs above Family Members Practicing within setting norms Delaying presence until staff ready

While coding the first five interviews, the lead author gained confidence and skill in the initial coding process and thus re-coded the interview transcripts available to that time to improve the analytical fit of initial codes. The codes allocated during the second initial coding attempt demonstrated a higher level of conceptual abstraction and included codes from subsequent interviews as part of the constant comparative analysis process inherent to GTM research. Table 1 shows the difference between the first and second attempts at initial coding of the first interview.

As initial coding progressed, codes that were interpreted by the lead researcher to most closely fit the data were compared with further data to explore and develop these codes.[3] Codes that most closely fit the data were those that explicated how people enacted or responded to FPDR, what meanings they held toward those events and the way in which those actions and meanings evolved.[3] Some codes were reworded later to improve their fit or the degree to which they captured and condensed participants meanings and actions.[8] For example, some codes from Table 1 (third column) were renamed as the study progressed. The initial code *'already being present'* was raised to a focused code in order to explore this process further as the analysis progressed. The focused code *'already being present'* was renamed later in the analysis to *'opportunistic presence'* (because it conceptualised a wider range of experiences, rather than merely describing an action or process) and became a sub-category of the core category *'conditional permission.'* Further and more detailed examples of focused coding are presented in the following section.

As the analysis progressed, line by line coding identified and defined significant actions/processes, as well as the role participants played within these processes and their beliefs concerning them.[3,8] Line by line coding also provided insight very early on in the research into the kind of data that needed to be collected next. For example, two initial codes from Table 1 *'already being present'* and *'delaying FPDR'* were both raised to the level of focused code in order to explore these processes further. This was accomplished in two ways – by looking for these processes in previous transcripts and by modifying interview questions in order to examine these (and other) processes in subsequent interviews as part of the theoretical sampling process.[3,31]

Focused Coding

As depicted previously in Figure 1, moving from initial coding to focused coding was not a linear process. During the coding process the lead researcher moved back and forth between initial and focused coding whenever new threads for analysis became apparent.[3,8] The codes developed during focused coding were more selective and conceptual than the initial coding examples presented in Table 1.

The purpose of focused coding was to synthesise and explain larger segments of the data.[3,8] This was achieved by identifying the most significant and/or frequent initial codes – raising them to the level of focused codes - then using those focused codes to sift through large amounts of data. Further data were then compared to these focused codes in order to

refine them. Focused coding was used to move across interviews and compare people's experiences, actions and interpretations. This process determined the adequacy of the earlier codes and some codes were subsequently re-named to improve their fit. This re-naming highlights initial and focused coding as emergent processes, which is consistent with the logic of GTM.[3]

During focused coding a decision was made (using theoretical sensitivity and reflexivity) about which of the initial codes made the most analytic sense to categorise the data incisively and completely.[3] For example, several initial codes previously presented in Table 1 were subsequently developed into focused codes as depicted in Table 2. The initial code *'placing patient needs above family members'* to the focused code *'prioritising preferences rights and needs'* and the initial code *'delaying presence until staff ready'* was changed to the focused code *'protecting others and self.'* Constant comparison of data with data, and codes with data, allowed the lead researcher to continually refine these codes and check to what extent they were able to account for other data. As a result the codes became more analytical and theoretical, which allowed the lead researcher to achieve a higher level of abstraction and conceptual analysis.

Table 2: Focused codes constructed from initial codes during the study

INITIAL CODE (Selected Examples)	FOCUSED CODE (Selected Examples)
Placing patient needs above family members	Prioritising preferences rights and needs
Staff deciding 'what's best' for patient/families	
Respecting individual preferences	Supporting informed choices
Allowing family member to choose level of FPDR	
Personal preferences impacting staff practices	Staff preferences impacting practice
Staff prioritising staff preferences	
Deciding if prognosis suitable for family presence	Assessing prognoses
Delaying family presence until patient condition suitable	
Delaying family presence until staff are ready / in control	Protecting others and self
Determining FM coping abilities	
FM watching from a distance	Watching from a safe distance
Being aware of forensic or legal implications	
FM staying out of the way	Minimising disruptions
Being able to remove disruptive FMs	
Preparing and supporting FM	Informed supported presence
Having a dedicated support person available	

As focused codes were constructed during the analysis process, the lead author combed through interview transcripts looking for incidents in the data where these processes/actions were evident. If these processes/actions are not evident, Charmaz[3] recommends asking focused questions in subsequent interviews to determine whether those processes or actions could explain participant experiences. Using theoretical sensitivity, ongoing decisions were made about the suitability of each of the focused codes to adequately explain and categorise what was actually happening every time a decision was made about whether to practice family presence during resuscitation.

Engaging in focused coding allowed the researcher to do two things; to determine the adequacy and conceptual strength of the initial codes allocated to the data, and to consider which focused codes could be raised to the level of tentative category to be tested against further data using the constant comparative analysis method detailed in the following section.[3] Two of the focused codes in Table 2 that were treated as tentative categories - *'prioritising preferences rights and needs'* and *'protecting others and self'* - subsequently became sub-categories of the core category (discussed later in the article).

Constant comparative analysis method

One of the core tenets of GTM research is the constant comparative analysis method that was first described by Glaser and Strauss.[4] Charmaz[8(p187)] defined the constant comparative method as *'a method of analysis that generates successively more abstract concepts … through inductive processes of comparing data with data, data with category, category with category and category with concept'*. Throughout the analytic process in this study, constant comparative analyses were used to; a) compare different people's beliefs, actions and experiences, b) compare data from the same individuals with themselves at different points in time, c) compare incident with incident, d) compare codes with categories, e) compare categories with other categories, and f) to compare categories with memos.[33(p515)]

An example of constant comparative analysis during the focused coding phase of this study involved using the focused code *'watching from a safe distance'* to compare different participant accounts in relation to this process. The interview excerpts presented in Table 3 demonstrate how the process *'watching from a safe distance'* was experienced and recounted by several different participants, and tracks the emergence of this focused code from initial codes.

PEER REVIEWED ARTICLE: CODING, CONSTANT COMPARISONS AND CORE CATEGORIES:

The constant comparative method was used throughout all stages of analysis to recognise similarities and differences in the data, to refine emerging concepts,[34] to progress the emergence of conceptual data[33] and to compare the final analyses with relevant theoretical and research literature.[31] These constant comparisons were reflected upon when writing theoretical memos (detailed later in this article) which helped to develop interpretations of the data, focus further data collection as well as inform and refine the developing theoretical analysis.[33(p509)]

Table 3: Constant comparisons of the same process between interview participants

EXCERPT (Selected examples)	INITIAL CODE	FOCUSED CODE
… they're [FM] sort of asked to step back so that the care can be given and the resuscitation can take place. But they're often, they're often still in the unit. We just ask them to move, *if* we feel that they're impeding the progress. (Dana: Registered Nurse/Midwife)	Staying out of the way Stepping back	Watching from a safe distance
The husband, we actually just popped him off to one side. I actually said to him, "If you want to stay that is fine. But we do need you to keep out of the way." … So basically we just popped him off to one side. He was out of the way of the actual action, and he just kept out of the way but he watched everything. (Mandy: Registered Nurse)	Staying out of the way Stepping back	
I have been cautious about how close family members get because there's forensic implications. So there may be implications at the scene of assault, or of actual murder … but I've never actually had a family member be removed. (Darren: Nurse Practitioner)	Watching from a distance – forensic implications	
… generally they'll stand towards the foot of the bed near the scribe nurse … um generally we'll bring a chair in, they can sit in a chair if they choose to, sort of out of the way at the back. (Grace: Registered Nurse)	Staying out of the way	

Theoretical sensitivity and reflexivity

Theoretical sensitivity relates to the researcher's ability to have insight, to understand and give meaning to the data, and to separate what is relevant from what is irrelevant.[35-37] The lead author used professional knowledge and experience (both her own and her

supervisors') as sources of theoretical sensitivity throughout the study, while at the same time using reflexivity to avoid being blocked by these previous experiences.[37] A preliminary review of the literature was undertaken at the beginning of the study to gain and apply theoretical insight to the study phenomenon. The use of literature in GTM lies outside the scope of this particular article. However, the lead author published a detailed critique and discussion of their use of the literature in GTM that novice researchers may find useful.[38]

The lead author was aware that what was seen and heard during data generation and analysis was dependent upon prior knowledge, past experiences, interests and prior interpretation of the phenomenon.[8,10,39] In order to learn the meaning that participants attributed to their beliefs, actions and experiences, and to minimise bias and to avoid imposing preconceived ideas on the data, the lead researcher was actively reflexive about her own meaning for those same beliefs, actions and experiences. This reflexivity was engaged through the systematic writing of analytic theoretical memos and through discussion between the lead author and PhD supervisors.

Memo writing

Memo writing (memoing) is a core tenet of GTM research.[3,4,37] Memoing was undertaken throughout this study to actively interact with the data, speed analytic momentum, question and clarify what was emerging from the data, see data and codes in new ways and increase the level of abstraction.[8,31] Memoing was also used to demonstrate rigour and trustworthiness, providing an audit trail of the evolving theory and documenting the lead author's thinking and decision making throughout the study.[7]

Memos were written immediately after each interview to prompt reflection upon and critique of the interview process. Such writing prompted thinking about important recurring statements/concepts and allowed comparisons between participant experiences and views – all of which were necessary to help direct and focus further data collection.[8] Memoing also allowed the lead author to specify the conditions under which a process arose, persisted or changed and to ask various questions of the data such as who was involved, how, when, why, what they did and the consequences of their actions.[31] The following memo (excerpt) was written immediately after the eighth interview with registered nurse 'Mandy.'

> *This raised an issue that many participants, including Mandy, have mentioned – the importance of assessing the suitability of the FM to stay. According to participants, assessing FM's suitability is vital because some may not be able to cope with graphic resuscitation images, while others may become disruptive and hamper staff efforts. However, Mandy maintained throughout the interview that despite the potential disadvantages of having FMs there, the option to stay should be offered to all suitable Family Members.*

While writing this memo, an important focused code, *'assessing suitability,'* was first constructed to explain a recurring process that was evident (but not yet named) in the first eight interviews. This code was then raised to a tentative category in order to explore the related processes further.[3] Previous and subsequent interviews were examined with this tentative category in mind and multiple examples of *'assessing suitability'* were found. For example:

> *We dragged her off the bed; we moved the bed away so they had a nice open space to work with …. and the head paramedic said 'you OK with this?' and I said 'yeah.' (Trevor, Family Member (husband), Interview 3)*

> *I would ask them, would you like to come in. And if they looked shocked and horrified and terrified at the very thought then that's fine, we'll just back away from that. If they look as though they're considering it then I'd go on and explain a bit more. So I guess I would assess their initial response. (Lauren, Doctor, Interview 11)*

> *If they come in and they're a complete riot of emotions and distraught, usually what I'd try and do would be direct them out to a relative waiting area … then go and see them in a couple of minutes and check on them and see how they're going, and then put it to them if they wanna come in. (Bella, Registered Nurse, Interview 17)*

As the study progressed, memos were written to describe how categories and sub-categories emerged, evolved and inter-related, and to refine conceptual categories.[8(p81)] For example, the following memo excerpt depicts how the lead author considered the relationship between *'assessing suitability'* and other focused codes and tentative categories such as *'valuing family presence.'*

The significance and ordering of each focused code and tentative category is becoming both more and less clear. I previously hypothesised that the value someone placed on FPDR would impact the extent to which they would overcome barriers to allow and even invite FPDR - the greater the value a person assigned to FPDR, the harder they would work to ensure it took place. For example, Darren valued FPDR so highly for its perceived benefits that he worked hard to overcome barriers such as staff attitudes, space limitations and staff shortages. He also assessed the context, setting and people involved to determine whether FPDR was suitable, and ensured that people who chose to accept the offer of presence were adequately prepared.

Theoretical sampling

In keeping with the logic and inherent requirements of GTM research, theoretical sampling was used to develop and refine the properties of the developing categories,[3] which in turn increased category precision and made the analysis more abstract.[8] Theoretical sampling was also used to demonstrate links between categories, and participants for whom particular concepts appeared significant were asked to add their experiences to the existing data set about a particular concept or category. For example during Interview 12 it first became apparent that *'valuing FPDR'* was an important tentative category that required further exploration in subsequent interviews. After exploring this category with subsequent participants, the significance of *'valuing FPDR'* to the emerging theory became apparent, as depicted in the previous memo.

As data generation and analysis progressed, the range of interview topics and questions became progressively narrower in order to gather specific data to develop the emerging theory.[8] For example, questions were added to the interview guide relating to who FPDR is for and what drives different decision making and practices between clinical settings that do and do not allow FPDR.

Category development and refinement

The development of categories was made possible by making constant comparisons and writing theoretical memos about the analysis as described in the previous sections. After the first 10 interviews, five tentative categories had emerged; 1) valuing family presence, 2) protecting self and others, 3) holding decisional power, 4) practicing within setting norms and 5) claiming ownership.

All interviews to that point in time, as well as subsequent interviews, were re-coded against these tentative categories to determine their fit. Some tentative category names were subsequently changed to encompass the data more completely. For example, *'holding decisional power'* was re-named *'holding and relinquishing decisional power'* in order to fully account for the different experiences involving power differentials. One of these tentative categories *'practicing within setting norms'* later became a property/condition of a new category rather than being considered a category of its own. In other words, the tentative category *'practicing within setting norms'* became a property of the new category *'setting boundaries.'*

After 20 interviews, eight major categories had been constructed; 1) prioritising preferences, rights and needs, 2) assessing suitability, 3) protecting others and self, 4) claiming ownership, 5) being present by default, 6) setting boundaries, 7) experiencing power differentials and 8) valuing family presence.

Further memoing and constant comparisons facilitated the continual refinement of categories, subcategories and properties, and helped determine which categories could be subsumed by others, which categories could stand alone, and how they all fit together. The following memo excerpt details the analytical thinking behind the construction and ordering of some of these new categories, subcategories and properties.

> *I was initially unable to decide how the tentative category 'Valuing FPDR' fit with the sub-categories I had allocated to it; Attitudes, weighing benefits and risks, personal experiences and beliefs, prioritising preferences/rights/needs, and dealing with barriers. I realised the subcategories I had allocated to 'Valuing FPDR' were all related to the question 'under what circumstances do priorities change?'[2] I therefore made them properties of the category 'prioritising preferences, rights, needs.' I realised 'Valuing FPDR' now also fits within 'prioritising preferences, rights, needs' however this relationship requires further exploration.*

Diagramming and tabling were also used to re-order and refine the major categories. For example, during the construction of Table 4, it became apparent how the core categories/processes identified thus far (highlighted in capital letters in table 4) were related, and the order in which these processes occurred during a resuscitation event became clearer. It also became evident that some categories were properties rather than stand-alone categories. For example at this stage, *'experiencing power differentials'* was

identified as a condition under which many of the other core processes (categories) took place and was therefore no longer considered to be a category.

The categories presented in Table 4 all impacted the decision to allow or deny family presence during resuscitation in an acute care setting. However at this point in the analysis, the core category had not yet emerged from the data and the properties of the study categories had not yet been saturated. Data generation and analysis therefore continued until theoretical saturation occurred.

Table 4: Diagramming and tabling to redefine and reorder categories and subcategories

CATEGORY	EXPLANATION
CLAIMING OWNERSHIP Experiencing power differentials	Claiming ownership of the space, the patient and the resuscitation act. Someone says who can and cannot be present; someone else complies or refuses. Claiming ownership is closely related to power and authority. Whoever is considered to have the most power successfully claims ownership.
Being present by default (*later re-named) OPPORTUNISTIC PRESENCE	If are already present, a person's chance of remaining in the resuscitation room increases. Once already present, that person is either permitted to stay or asked to leave. If asked to leave they either comply or refuse Or the person stays by default because no-one asked them to leave
PRIORITISING PREFERENCES, RIGHTS AND NEEDS ASSESSING SUITABILITY SETTING BOUNDARIES VALUING FAMILY PRESENCE	Assessing who and what situation is suitable, and then setting boundaries around permissions (PROVISIONAL PERMISSION) based on the priority placed on that person's preferences rights and needs. The value placed on family presence during resuscitation determines how this prioritisation is done and influences the assessment and boundaries set.
PROTECTING OTHERS AND SELF	Protecting family members from resuscitation scenes – whether they want this protection or not. Protecting staff from being observed and potentially judged. The level of protection judged to be required influences the other processes at play.

Theoretical saturation

Data generation in GTM research continues until subsequent data is yielding scant/no new information and further generation would not add anything useful to the study. Theoretical saturation occurs when the category properties are saturated rather than the data itself.[4,8] After 24 interviews with 25 participants (a husband and wife team were interviewed together), a major/core process emerged that was subsequently developed into the core category. The lead author then re-interviewed three key participants (a registered nurse, doctor and family member) in order to fully saturate the properties of each major category. Existing transcripts were also re-coded against the major categories as part of the theoretical saturation process. As analysis progressed, the lead researcher continued to refine categories and re-order them as the final substantive theory was constructed.

Emergence of the core category

During the processes of refining the major categories (see Table 4), the lead author used the phrase *'provisional permission'* to explain four of the major categories; 1) prioritising preferences, rights and needs, 2) assessing suitability, 3) setting boundaries, and 4) valuing family presence. At the time, this term did not resonate with the lead author and further interviews were conducted. However, during the final interview and subsequent theoretical memo construction, the phrase *'conditional permission'* prompted further refinement of categories and sub-categories that led to the emergence of the core category, as evidenced in the following memo excerpt.

> *I have used the term 'conditional permission' as a code/category previously when analysing data. However during this interview I suddenly realised my two previous categories of Setting Boundaries and Assessing suitability can both be subsumed by a higher category - Constructing Conditional Permission. Thus 'conditional permission' becomes the category and Setting Boundaries and Assessing suitability become the subcategories, along with the other already existing subcategory of prioritising preferences rights and needs.*

The systematic application of the grounded theory methods and processes detailed in this article thus facilitated the emergence of the core category *conditional permission.* Table 5 traces the evolution of this core category from related initial and focused codes, and depicts the relationship between this core category and its sub-categories. The core category - *conditional permission* - explained the major process at work when health care professionals and family members were involved in decision making around whether to allow or deny family presence during resuscitation.

Table 5: Development of the major category – 'Conditional Permission'

INITIAL CODE EXAMPLES	FOCUSED CODE EXAMPLES	SUBCATEGORY (Properties)	CATEGORY
Placing patient needs above FMs	Making value judgments	**Prioritising preferences, rights, needs**	**Conditional Permission**
Staff deciding 'what's best' for patient/FM			
Respecting individual preferences	Supporting informed choices		
Allowing FM to choose level of FPDR			
Personal preferences impacting staff practices	Staff preferences impacting practice		
Staff prioritising staff preferences			
Deciding if prognosis suitable for FP	Assessing prognosis	**Assessing Suitability (context, setting, people)**	
Delaying FP until patient condition suitable			
Delaying FP until staff are ready / in control	Delaying presence	**Protecting others and self**	
Determining FM coping abilities			
FM watching from a distance	Watching from a safe distance	**Setting Boundaries (physical, emotional, theoretical)**	
Being aware of forensic implications			
FM staying out of the way	Minimising disruptions		
Being able to remove disruptive FMs			
Preparing and supporting FM	Informed supported presence		
Having a dedicated support person available			

FM, Family Members; FPDR, family presence during resuscitation; FP, family presence

As mentioned previously, the aim of this article was not to present detailed findings from the study; but instead to describe *how* the core category was constructed. However, a brief explanation of the substantive grounded theory is presented below to further elucidate the relationship between the grounded theory, the core category and its properties.

Conditional Permission: A Grounded Theory of Family Presence during Resuscitation

According to Charmaz[3(p344)] a substantive grounded theory is a *'theoretical interpretation or explanation of a delimited problem in a particular area.'* Charmaz's definition of theory emphasises a theoretical understanding that is abstract and interpretivist, where the understanding from the theory relies on the theorist's interpretation of the studied phenomenon.

The systematic application of the grounded theory methods and process detailed throughout this paper facilitated the emergence of a core category (process) and substantive grounded theory which created an abstract understanding of the data.[3] The grounded theory developed in this study accounted for most of the relevant behaviour when people were deciding to practice or participate in FPDR. As such, this grounded theory meets the requirements of theory construction outlined by Charmaz[3,8] and Glaser and Strauss.[4] During the final stages of analysis and writing of the theory as part of the doctoral thesis, existing literature was accessed by the lead author to support the emerging theory,[3,4,37] to situate the theory within the body of related literature and to demonstrate how the current study built upon this body of evidence.[3,11,16]

The substantive theory developed during this study was *The Social Construction of Conditional Permission.* This theory captured the patterns of meanings and actions that reflected participant experiences, and explained the major social processes at work when people were faced with a decision to practice or participate in FPDR. The core category, *conditional permission,* comprised several major processes. These processes were enacted by participants in a cyclic and interconnected manner in order to determine the level of *conditional permission* for each FPDR event.

In the absence of formal policies or guidelines, the *value* placed on family presence by health care professionals and family members had a significant impact on decision making - demonstrated by particular groups claiming ownership of the patient, the setting and the resuscitation act. Groups who claimed ownership were then able to determine or construct *'conditional permission'* for FPDR by prioritising individual preferences, rights and needs,

assessing suitability of the setting and the people involved, and setting physical, emotional and theoretical boundaries around that presence, while at the same time protecting others and self from potential risks.

FPDR always required some form of permission (inadvertent or implied), and was always conditional, continually reassessed, and subject to retraction if the established boundaries of conditional permission were breached. Established boundaries varied widely and were influenced by the subjective attitudes and beliefs of the people setting these boundaries. Health professionals and family members who valued FPDR placed fewer conditions on presence, and were more likely to ensure those conditions could be met in order to ensure FPDR was implemented. Conversely, health professionals and family members who did not value FPDR placed multiple conditions on the practice; sometimes to the extent where meeting them became impossible. Often, the conditions placed on FPDR were used as rationales to justify denying the practice. In essence, c*onditional permission* was impacted most by the extent to which FPDR was valued by individuals and groups who claimed control of permissions.

Our research indicates a strong need for formal protocols and associated education to ensure that clinical practice is guided by evidence and standards for consumer safety and welfare rather than by personal values and preferences of the individuals 'in charge' of permissions.

Conclusion

GTM research is being increasingly employed to contribute to the current body of nursing knowledge due to its ability to explain behaviour and facilitate the advancement of conceptual theories that can be applied in practical situations. As such, attention to study rigour is imperative to ensure subsequent clinical practice is safe, effective and based on the best available empirical evidence. Appropriate rigour and enhanced transferability of findings can be strengthened by the systematic application of the core GTM methods and procedures that have been detailed and exemplified in this article. Researchers using grounded theory methods can also strengthen the knowledge claims of their research if they are explicit about the way in which they employed core methods to construct their grounded theory. This article provides a worked example of the systematic application of grounded theory methods and processes and traced the construction of the core category *'Conditional Permission'* from initial and focused codes, subcategories and properties,

through to its position in the final substantive grounded theory. Such elucidation of data from initial codes to substantive category can assist novice researchers to develop rigorous analytic techniques in order to strengthen their study outcomes.

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References

1. Bryant A, Charmaz K. Introduction. Grounded theory research: methods and practices. In: The SAGE handbook of grounded theory. Bryant A, Charmaz K, eds. London, England: SAGE publications inc; 2007: 1-28.

2. Elliot N, Lazenbatt A. How to recognise a 'quality' grounded theory research study. Australian Journal of Advanced Nursing. 2005. 22(3): 48-52.

3. Charmaz K. Constructing Grounded Theory, 2nd Edition. London, England: SAGE publications; 2014.

4. Glaser B, Strauss A. The Discovery of Grounded Theory. New York: Aldine Publishing Company; 1967.

5. Glaser B. Doing grounded theory; issues and discussions. California: Sociology Press; 1998.

6. Glaser B. Theoretical sensitivity. Mill Valley, CA: The Sociology Press; 1978.

7. Birks M, Mills J. Grounded Theory: a practical guide. London, England: SAGE Publications; 2011.

8. Charmaz K. Constructing grounded theory: a practical guide through qualitative analysis. London, England: Sage Publications; 2006.

9. Charmaz, K. Constructionism and the grounded theory method. In: Handbook of constructionist research. Holstein J, Gubrium J, eds. New York: Guilford; 2007: 397 - 421.

10. Charmaz K. Grounded theory methods in social justice research. In: The SAGE handbook of qualitative research, 4th edition. Denzin N, Lincoln Y, eds. London, England: SAGE Publications; 2011: 359 - 380.

11. Charmaz K. Discovering' chronic illness: using grounded theory. Social Science and Medicine. 1990; 30(11): 1161 - 1172.

12. Charmaz K. Good days bad days; the self in chronic illness and time. New Jersey: Rutgers University Press; 1997.

13. Charmaz K. Premises, principles, and practices in qualitative research: revisiting the foundations. Qualitative Health Research. 2004; 14(7): 976 - 993.

14.   Crotty M. The foundations of social research: Meaning and perspective in the research process. London, England: Sage Publications; 1998.

15.   Hood J. Orthodoxy vs. power: the defining traits of grounded theory. In: The SAGE handbook of grounded theory. Bryant A, Charmaz K, eds. London, England: SAGE Publications; 2007: 151-164.

16.   Stern P. On solid ground: essential properties for growing grounded theory. In: The SAGE handbook of grounded theory. Bryant A, Charmaz K, eds. London, England: SAGE Publications; 2007: 114-126.

17.   Chew, KS, Ghani, ZA. Attitudes and perceptions of the general Malaysian public regarding family presence during resuscitation. Singapore Medical Journal. 2014; 55(8): 439-442.

18.   Glaser, B. The novice GT researcher. Grounded Theory Review, 2009. 8(2): http://groundedtheoryreview.com/2009/06/30/914/ Accessed May 2, 2015.

19.   Chapman, R, Bushby, A, Watkins, R, Combs, S. Australian Emergency Department health professionals' reasons to invite or not invite family witnessed resuscitation: a qualitative perspective. International Emergency Nursing. 2014; 22(1): 18-24.

20.   Lederman, Z, Garasic, M, Piperberg, M. Family presence during cardiopulmonary resuscitation: who should decide? Journal of Medical Ethics. 2014; 40(5): 315 - 319.

21.   Tudor, K, Berger, J, Polivka, BJ, Chlebowy, R, Thomas, B. Nurses' perceptions of family presence during resuscitation. American Journal of Critical Care. 2014: 23(6): e88-96.

22.   McMahon-Parkes, K, Moule, P, Benger, J, Albarran, JW. The views and preferences of resuscitated and non-resuscitated patients towards family-witnessed resuscitation: A qualitative study. International Journal of Nursing Studies. 2009; 46: 220 - 229.

23.   Australian Resuscitation Council, Legal and ethical issues related to resuscitation. Guideline 10.5, 2012; Available online http://resus.org.au/?wpfb_dl=49 Accessed March 11, 2015.

24.   Baskett, P, Steen, P, Bossaert, L. European Resuscitation Council Guidelines for resuscitation, Section 8. The ethics of resuscitation and end-of-life decisions. Resuscitation. 2005; 67S1: S171-S180.

25.   Morrison, L, Kierzek, G, Diekema, DS, Sayre, MR, Silvers, SM, Idris, AH, Mancini, ME. 2010 American Heart Association Guidelines for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care: Part 3, Ethics. Circulation. 2010; 22: S665-S675.

26.   Bashayreh I, Saifan A. Family witnessed resuscitation: through the eyes of family members. Journal of American Science. 2015; 11(3): 7-15.

27.   Dwyer T. Predictors of public support for family presence during cardiopulmonary resuscitation: a population based study. International Journal of Nursing Studies. 2015; 52: 1064-1070.

28.   Leung NY, Chow SK. Attitudes of healthcare staff and patients' family members towards family presence during resuscitation in adult critical care units. Journal of Clinical Nursing. 2012; 21(13-14): 2083 - 2093.

29.   Sachetti, A, Guzzetta, C, Harris, R. Family presence during resuscitation attempts and invasive procedures: Is there science behind the emotion? Clinical Paediatric emergency Medicine. 2003; 4: 292 - 296.

30.   National Health and Medical Research Council, Australian Research Council, and Australian Vice-Chancellors Committee, National statement on ethical conduct in human research. Australian Government, Canberra. 2007: Available http://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/e72_national_statement_130207.pdf Accessed April 12, 2015.

31.   Charmaz, K. The power and potential of grounded theory. Medical Sociology Online. 2012; 6(3): 2 - 15.

32.   Charmaz K, Grounded theory; objectivist and constructivist methods, in Strategies of qualitative inquiry. 2nd edition. Denzin N, Lincoln Y, eds. SAGE Publications Inc; California: 2003

33.   Charmaz K. Grounded Theory: Objectivist and constructivist methods. In: Handbook of Qualitative Research. Denzin N, Lincoln Y, eds. California: SAGE; 2000: 509 - 535.

34.   Wiener C. Making teams work in conducting grounded theory. In: The SAGE handbook of grounded theory. Bryant A, Charmaz K, eds. London, England: SAGE publications;.2007: 293-310.

35.   McCann, T, Clark, E. Grounded theory in nursing research: part 3 - application. Nurse Researcher. 2003; 11(2): 29-39.

36.   Strauss A, Corbin J. Basics of qualitative research: techniques and procedurs for developing grounded theory, 1st edition. London, England: SAGE Publications; 1990.

37.   Strauss A, Corbin J. Basics of qualitative research; techniques and procedures for developing grounded theory; 2nd Edition. California: SAGE Publications Inc; 1998.

38.   Giles T, King L, de Lacey S. The timing of the literature review in grounded theory research: an open mind versus an empty head. Advances in Nursing Science. 2013; 36(2): E29 - E40.

39.   Charmaz K. Grounded Theory in the 21st century; applications for advancing social justice studies. In: The Sage Handbook of Qualitative Research. 3rd Edition. N. Denzin N, Lincoln Y, eds. California: SAGE Publications Inc; 2005

CRITERIA	HOW THE CRITERIA WERE MET IN THE CURRENT STUDY
Credibility	
Intimate familiarity with the topic achieved	Previous knowledge and experience, a comprehensive preliminary literature review, multiple in-depth interviews, the constant comparative method, and a secondary literature review all contributed to intimate familiarity with the phenomenon
Sufficient data generated to warrant claims	27 in-depth interviews with 25 participants – all with personal experiences relevant to the research aims
Systematic comparisons made between incidents and categories	The constant comparative method was used throughout the research, together with memoing in order to systematically compare data with data, data with incidents and processes, codes with categories etc as outlined earlier in this chapter
Strong logical links made between data, the argument and the analysis	Constant comparisons in conjunction with memoing, diagramming and dialoguing are presented throughout the thesis and within the appendices
Enough evidence provided for the claims to allow the reader to form an independent assessment of credibility and agree with the claims?	The thesis contains a comprehensive audit trail that would allow the reader to independently assess credibility of the research processes and findings and draw the same or similar conclusions.
Originality	
Categories are fresh, offer new insights	The core categories offer insights that both support and build upon the current body of knowledge
The analysis provides new conceptual rendering of the data	All stages of analysis are transparent and provide examples of conceptual analysis and theorising
The social and theoretical significance has been considered	Both the theoretical significance and social and practical implications have been considered and are presented within the findings / discussion chapters
The theory challenges, extends refines current ideas, concepts, practise	The substantive grounded theory offer insights that both challenge and support current theories, and build upon the current body of knowledge

Resonance

The categories portray the fullness of the studied experience	Multiple in-depth interviews exploring the phenomenon from multiple perspectives provide a full and robust presentation and analysis of the studied experience
Both liminal and taken for granted meanings have been revealed	This was addressed during the in-depth interviews by ensuring that taken-for-granted meanings and beliefs were clarified with participants
Links made between larger collectives and individual lives when data indicated	In keeping with the symbolic interactionist perspective used for this research, both individual and collective interpretations and constructions of meaning have been considered
The Grounded Theory make sense to participants	Participants who viewed preliminary findings could see the relevance to both themselves and others. For example Carol could easily place herself in the 'high power' quadrant of the findings matrix. 'Yeah – that's probably where I sat. And perhaps because of my, familiarity with emergency departments and resus and, and, and sort of hospital procedures – perhaps that, made me feel like I had more, more power in that situation. And because I'm a leader in that situation, quite frequently.' Carol could see where HPs and family members would fit within the matrix, and also how value judgements could be applied in various FPDR scenarios.
The analysis offer participants deeper insights about their lives and worlds	June stated, 'It *really* made sense, and that's why, it wasn't until we were talking about it – I thought – I looked at that [the findings matrix] and went 'Of *course*!' It just clicked in my brain, what I was thinking. I hadn't, conceptualised it that way before. But seeing it written that way, made a lot of sense.'

Usefulness

The analysis offers implications that people can use in their everyday worlds	The findings provide pragmatic implications that could be used to formulate relevant policies around FPDR
The analytic categories suggest generic processes	The core categories are sufficiently generic to allow application to decision-making in other contexts
The analysis could spark further research in other substantive areas	The substantive grounded theory could be applied and built upon in subsequent research into decision-making in many different health care contexts
The research contributes to knowledge and to making a better world	The substantive grounded theory builds upon our current body of knowledge and offers useful and importance insights into decision-making around FPDR

Terminology	Study
Allow, Allowing, Not allowed	Al-Mutair *et al.* 2012, Basol *et al.* 2009, Bassler 1999, Beckman 2002, Booth *et al.* 2004, Chalk 1995, Davidson *et al.* 2011, Jarvis 1998; Hallgrimsdottir 2000; Helmer *et al.* 2000; Ellison 2003; Goldberger *et al.* 2015; Goodenough & Brysiewicz 2003; Fernandez 2004; Gold *et al.* 2006; Kuzin *et al.* 2007; Kotkis & Tabak 2008; Gunes & Zaybak 2009; Koberich *et al.* 2010; Gordon *et al.* 2011; Jones *et al.* 2011; Kosowan & Jensen 2011; Lam *et al.* 2007; MacLean *et al.* 2003; Lowry 2012; McClenathan *et a..* 2002; Miller & Stiles 2009; O'Brien *et al.* 2002; Omran, Ali & Alshahrani 2015; Ong *et al.* 2004; Porter, Cooper & Taylor 2015; Sheng *et al.* 2010; Soleimanpour *et al.* 2015; Yanturali *et al.* 2005; Waseem & Ryan 2003
Given the option, opportunity, choice	Basol *et al.* 2009; Bassler 1999; Chapman *et al.* 2012, Feagan & Fisher 2011; Fulbrook, Latour & Albarran *et al.* 2006; Kianmehr *et al.* 2010; Kosowan & Jensen 2011; Mortelmans *et al.* 2009; Nykiel *et al.* 2011; Twibell *et al.* 2008
Consider inviting	Axelsson at al 2010; Badir & Sepit 2007; Fallis, McClement & Pereira 2008; Ganz & Yoffe 2012; Koberich *et al.* 2010; Redley & Hood 1996
Excluded	Holzhauser & Finucane 2008; Jarvis 1998; Lam, Wong *et al.* 2007
Permission, Permit	Booth *et al.* 2004, Davidson *et al.* 2011, Demir 2008, Mian *et al.* 2007; Waseem & Ryan 2003; Weslien & Nilstun 2003
Oppose or favour	Jones *et al.* 2011; Lynch *et al.* 2008, McClenathan *et al.* 2002
Forbid	Gold *et al.* 2006
Deny / denied	Ellison 2003; Bashayreh & Saifan 2015
Support	Vavarouta *et al.* 2011
Appropriate / acceptable	Baumhover & Hughes 2009; Macy *et al.* 2005
Approve / not approve	Egemen *et al.* 2006, Kirchoff *et al.* 2007; Soleimanpour *et al.* 2015