Parental/carer experiences of Family Huddle participation within a paediatric haematology/ oncology setting

by

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Glossary of Terms

Term	***Definition***
Carer	A carer is *'a person who has responsibility for the care of another'* (Merriam-Webster, 2022, np). Throughout this thesis the terms carer and caregiver have been used interchangeably depending upon the discussion point being considered.
Culture	In anthropology, definitions of culture are plentiful from the very simple through to the complex. The definition of culture within this thesis is defined as *'the way a group of people live – the patterns of human activity and the values and norms that give activity significance'* (Polit & Beck, 2017, p. 274).
Ethnography	Ethnography is *'a branch of human inquiry, associated with anthropology, that focuses on the culture of a group of people, with an effort to understand the worldview and customs of those under study'* (Polit & Beck, 2017, p. 727).
Family Centred Care	All definitions of FCC hold general consensus in placement of the child and family at the centre of care. The Institute for Patient and Family-Centered Care (2018, cited in Al-Motlaq et al., 2019, p. 459) define FCC as *'...an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families'*.
Family Huddle	A Family Huddle refers to *'a semi formal meeting between consumers, caregivers or visitor's (where applicable) and staff on the ward, within a service or unit…to enable shared decision making'.* Regular interval meetings occur supporting principles of Person and Family Centred Care (Ball, 2016, p. 3).
Paediatric	Contemporary literature recognises various overlapping age ranges from birth to adulthood making consensus of a definition of 'paediatric' challenging. For the purposes of this thesis, the definition of paediatric presented by Clark et al. (2015, p. 6) will be used, recognising paediatric patients as ages which *'encompass all individuals who are not yet adults (0 to <18y)'*. Throughout this thesis the terms infant, baby, child and children have been used interchangeably depending upon the discussion point being considered.

Abstract

Background

Hospitalisation of a child with cancer can be an exceptionally stressful time, not only for the child but for members of the entire family unit. With growing awareness globally of the impact of hospitalisation on children, many hospitals are adapting more child friendly spaces. As advocacy for family centred care strengthens, the lived experience of parents of hospitalised children remains at times incongruent with the family centred care approach that continues to be promoted clinically. Family Huddles are one consumer-engagement initiative being introduced to clinical settings in support of family centred care principles. Family huddles are envisaged to enable shared decision making and allow parents and carers a pathway to be heard, to understand what the consumer believes to be important to enhance quality, comfort and safety of care provided. Whilst promotion and implementation of Family Huddles in support of family centred care principles increase, the relationship between advocated practice and actual lived experiences of parents and carers whilst in hospital participating in a Family huddle, is yet to be fully established.

Aim

The aim of this study was to explore what parents and carers of hospitalised children within a paediatric haematology/oncology unit, experience from participating in a Family Huddle.

The specific objectives of the study were:

1. To identify and explore parental/carer experiences/perceptions of a Family Huddle.
2. To identify and explore perceives barriers, motivators, enabling factors and parental/carer willingness to participate in a Family Huddle.
3. To explore and relate how a Family Huddle enhances the principles of family centred care.

Methodology

Full ethical approval for this study was granted by the human research ethics committee of the major metropolitan hospital the study was undertaken within as well as the Flinders University Social and Behavioural Research Ethics Committee. A two-phase qualitative, ethnographic method was utilised to address the aims of this study. Eligibility criteria included parents and carers of hospitalised children within the haematology/oncology unit.

Purposive sampling recruited ten parents to Phase One which consisted of three audio-recorded observed Family Huddles. One parent and one teenaged patient were recruited to Phase Two which comprised semi-structured audio-recorded face-to-face interviews. Audio recordings from observed Family Huddles and face-to-face interviews, were transcribed verbatim by a confidentiality-bound transcriptionist and subsequently thematically analysed in accordance with Braun & Clarke’s (2006) guidelines for thematic analysis. Dedoose™ software was utilised to code and organise data into themes.

Findings

Four primary themes emerged through analysis of transcripts from three observed Family Huddles and one face-to-face interview. The first theme ‘Service accessibility’, encompassed three subthemes including ‘Unit accessibility’, ‘Staff accessibility’ and ‘Connectivity’, and identified parental desire for ease of access to services and physical locations throughout the child’s hospitalisation. ‘Family Centred Care’ illustrated parental desire of physical comfort for the hospitalised child as well as themselves and other members of the family unit. ‘Information sharing’ was deemed vital throughout the period of hospitalisation, with effective two-way communication central to parents obtaining new information and effective communication between parents, patients, and health care professionals. Finally, ‘Role uncertainty’ identified inconsistencies in clinical practice of health professionals as well as inconsistency of nursing expectation of parents, leading to parental role uncertainty and at times frustration. Furthermore, themes generated from this study highlighted the importance of Family Huddle delivery in alignment with the values underpinning Family Huddles, including person and family centred care, partnership, transparency and access to information. Recommendations relating to how organisations and health care professionals can promote and support parental/carer attendance at Family Huddles were made as a result of findings.

Conclusion

This study provides an important first insight to the lived experience of parents of hospitalised children within a haematology/oncology unit, participating in a Family Huddle. Study findings suggest parental participation in Family Huddles offers benefit to parents and patients as consumers and enhances the principles of family centred care. Organisational investment in health care worker professional development of the Family Huddle Framework, may enhance promotion and support of Family Huddle success.

Declaration by Candidate

I certify that this thesis does not incorporate without acknowledgment 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.

Amanda Vickers
Date: 31st March 2022

Acknowledgements

"It always seems impossible, until it's done"

- Nelson Mandela –

Completion of the research process and thesis preparation would not have been possible without the contribution, support, and assistance of others.

Firstly, I would like to extend deep gratitude to the families who volunteered their time and accounts of lived experience to inform this study. Without their valuable contributions, this study would not have been possible.

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To my family and friends for your ongoing encouragement and patience.

Finally, to my children, Athan and Amelia, you bring so much joy to my life. You have both travelled this journey with me and your love has never faltered. This achievement is not solely mine but ours and I am so blessed to have you both by my side. Let this journey instil in you both, the knowledge that with dedication and perseverance, the perceived impossible is possible.

Prologue

As I sat in the doorway of a paediatric patient's room whom I was specialling for the night shift, the clock had no sooner struck 9:30pm and I could hear a small group of parents conversing in the nearby parent's room, a room offered to all parents to seek refreshments and a moment of rest away from their hospitalised child. Present at this small gathering were the same parents from the previous two nights, again conversing about similar topics, except this time with the door again left ajar, the volume of voices was elevated with an undertone of frustration and projecting down the ward's corridor. As parents of infants who were at varying lengths of long stay admissions with their chronically ill infants, their topics of conversation suggested they felt their voices were not being heard. They were tired, fed up and beginning to voice this in a negative manner, speaking poorly of aspects of the health service as well as individual members of the multi-disciplinary health care team, the occasional nurse included. As I sat with my specialled patient, I couldn't help but feel concerned about the increasing tension and frustration voiced by these parents. Mere days later with tensions building, an adhoc meeting was scheduled with an invitation extended to all parents of inpatients on the ward, to come and discuss their concerns, provide feedback and ask questions of the clinical nurse, who was facilitating this session. This would be the catalyst of the subsequent rolling implementation of a hospital wide consumer engagement initiative, now known as a Family Huddle, with a focus on enabling shared decision making, supporting principles of family centred care and aiding parents to have a voice through participation.

I started to wonder what it was like for parents and carers of hospitalised paediatric patients who day in, day out were at the bedside? Some tag teaming with their significant other balancing the care for other children, some working during the day and spending every other spare minute at the bedside, some never leaving the bedside. Why some parents and carers would insist on participating in the care of their child, whilst for others this didn't bring an immediate response? What were these parents needing from the health service, the health care team and me as a paediatric registered nurse, to enable them to feel supported and acknowledged? I knew that to be able to deliver quality family centred care, I needed to better understand what factors were impacting parent and carer experiences in hospital and what could be implemented to enhance their experience while in hospital. It was this process *of reflection, questioning and subsequent discussion with nursing division management, that led me to commence this study, 12 months after implementation of the very first Family Huddle. With no prior formal evaluation of Family Huddle implementation, this study was developed to facilitate formal evaluation of this consumer engagement initiative. One clinical area of the hospital, the haematology/oncology unit where Family Huddles had been embraced, was chosen to conduct this study within.*

Chapter 1: Introduction

1.1 Overview

This thesis presents an ethnographic study that explores parental and carer experiences of Family Huddle participation within a paediatric haematology/oncology clinical setting. This introductory chapter presents a background to the study by describing contemporary considerations of the philosophy of family centred care and implications for parents and carers of hospitalised paediatric patients. It will also outline the research question and objectives, significance of the study, and provide an outline of the thesis structure.

1.2 Background

Between 2013 and 2017, on average approximately 770 children 0-14 years old were newly diagnosed with cancer in Australia (Cancer Council Queensland 2021; Cancer Australia, 2015). Alarmingly by 2021, this increased to an estimated 851 children of the same age being newly diagnosed with cancer (Australian Institute of Health & Welfare, 2021). For those who survive their diagnosis, 2 out of 3 develop life long-term effects from routine treatment (Cancer Australia, 2015; St Baldrick's Foundation 2016). For example, learning disabilities, hearing loss, heart disease, infertility and even secondary cancers contribute to the ongoing issues faced by families, often resulting in numerous hospital admissions over the life of the child.

Hospitalisation of a child with cancer can be an exceptionally stressful time, not only for the child but for members of the entire family unit. With growing awareness globally of the impact of hospitalisation on children, many hospitals are adapting more child friendly spaces (Lambert et al., 2013; Carter et al., 2014; Fraser et al., 2017). Whilst consensus on what constitutes a child friendly space evolves, widespread research recognises the value green spaces have on health and well-being for both children and family members whilst hospitalised (Allahyar & Kazemi, 2021), as well as the views of children being valued in the consultation process (Lambert et al., 2013). Despite attempts of service providers and health professionals to facilitate hospitals being more child friendly, hospitalisation is still associated with 'negative psychosocial sequelae (anxiety, developmental and behavioural changes, post-traumatic stress disorder), due to separation and social disconnection, and loss of power and control,' as well as significant disruption to the family unit (Carter et al., 2014, p. 101).

Health organisations are placing an increasing emphasis on family centred care as the benefits of such models of care continue to emerge (Al-Motlaq et al., 2019; Coyne, 2013; Shields et al., 2012; Sigurdardottir et al., 2016). Family centred care is a means of caring for the emotional and physical well-being of the child and the family unit as a whole, rather than just the individual child. Benefits are reported to include decreased anxiety and emotional distress, accelerated recovery, increased parental satisfaction and confidence, and increased mental health status for both parents and the child as patient (Al-Motlaq et al., 2019; Shields et al. 2012). As advocacy for family centred care has strengthened over the past few decades Uhl et al (2013) acknowledged the 'lived reality' of parents of hospitalised children remains at times a far cry from the family centred care approach that continues to be promoted clinically. Importance lies in facilitating health care professionals to acknowledge the voice of consumers and engage with them within a family centred care model, to identify opportunities to strengthen their ability to act as patient advocate for their child, should they wish.

A 2012 the Cochrane Database presented a systematic review entitled 'Family-centred care for hospitalised children aged 0-12 years (Review)', recognised the significance and importance of inviting families to 'participate actively in the decision-making, planning and provision of their child's care to the extent they choose' (Shields et al., 2012, p. 4). With minimal to zero legal power being afforded to children to make medical decisions, parents primarily hold the authority to make health care decisions on behalf of their child (Sabatello et al., 2018). Having intimate knowledge of the personality, fears and concerns of their child, parents are well placed to advocate for their hospitalised child. Consideration must be given, to what is required to empower parents to assume the role of patient advocate for their hospitalised child. In their systematic review, Shields et al (2012, p. 14) identified the need for more high-quality research in the area of family-centred care, with specific areas for further research including, 'children's knowledge and understanding, satisfaction, parental stress, coping and sense of control'.

Family Huddles are one consumer-engagement initiative being introduced to clinical settings in support of family centred care principles (Ball, 2016). Functioning as a semi-formal meeting between parents/carers and staff, Family Huddles can occur every 2-3 weeks. Parents and carers are welcomed into a private family meeting space where an agenda structures the procession of the Family Huddle, generally over a one-hour period. All forms of communication practices between staff and consumers/caregivers is an obligatory item on the agenda, with further agenda items to be determined in partnership with staff and consumers. The Family Huddle is facilitated and chaired by a staff representative from the unit, usually a manager, clinical lead or clinical coordinator, who also follows-up on actions identified during the Family Huddle. Family Huddles are envisaged to enable shared decision making and allow parents and carers a pathway to be heard. Acknowledging parental voice is intended to facilitate understanding of what the consumer believes to be important to enhancing quality, comfort and safety of care provided (Fernandez & Cameron 2018). In 2016, Family Huddles were introduced to a large metropolitan tertiary paediatric hospital, the first paediatric setting in South Australia and Australia, to introduce Family Huddles to clinical areas. After an initial pilot on a medical/surgical ward for babies from birth to 12 months of age, Family Huddles were further rolled out to other wards and units in the hospital. The haematology/oncology unit commenced regular fortnightly Family Huddles eight months prior. Family Huddles hold promise to strengthen consumer-care provider links and positively impact the holistic child and family unit (Ball, 2016).

1.3 Research question and objectives

This thesis set about to answer the research question "What do parents/carers of hospitalised children within a paediatric haematology/oncology unit, experience from participating in a Family Huddle?"

The specific objectives of the study were:

1. To identify and explore parental/carer experiences/perceptions of a Family Huddle.
2. To identify and explore perceived barriers, motivators, enabling factors and parental/carer willingness to participate in a Family Huddle.
3. To explore and relate how a Family Huddle enhances the principles of family centred care.

1.4 Significance of the study

Whilst promotion and implementation of Family Huddles in support of family centred care principles increase, the relationship between advocated practice and actual lived experiences of parents and carers whilst in hospital participating in a Family huddle, is yet to be fully established (Fraser et al., 2017; Uhl et al., 2013). The purpose of this ethnographic study, therefore, was to explore parental/carer experiences of participating in a Family Huddle in a haematology/oncology unit to generate data rich in lived experience and cultural context, to facilitate validation of their lived experiences, and to in turn, improve parental/carer and paediatric patient experiences whilst hospitalised.

By gaining such insights, this study will endeavour to make recommendations around areas of required support for parents and carers of hospitalised children. Furthermore, recommendations for review may arise related to consumer literature, education specific to Family Huddles, and policy documents specific to the Family Huddle framework and its delivery. In addition, recommendations regarding professional development for members of the multidisciplinary health care team will be made in order to bring about awareness of the benefits of Family Huddle delivery for hospitalised families. Finally, it is hoped that external organisations will recognise the benefits of facilitating the recommendations of this study.

1.5 Outline of the thesis

Six chapters are presented in the following thesis. The introductory chapter contextualises the background, research objectives and significance of the study. Chapter Two presents a literature Scoping Review that explores contemporary literature relevant to the intended study. The Scoping Review provides context to the study and identification of gaps in available literature. Chapter Three outlines the research design and methods and justifies the chosen qualitative paradigm, methodological approach and the selected methods chosen to answer the research question. Ethical considerations of the study are also explored and addressed. Chapter Four presents the findings of the study, guided by identified themes formed throughout the thematic analysis process. Chapter Five critically discusses the findings, strengths, and limitations of the research. Finally, chapter Six summarises the study, provides conclusive statements, in addition to implications for nursing and recommendations for future research.

1.6 Chapter Summary

This introductory chapter has introduced the research study with an aim to explore parental and carer experiences of Family Huddle participation within a paediatric haematology/ oncology clinical setting. Key concepts of family centred care and Family Huddles have been introduced and contextualised. The following chapter will present a scoping review of contemporary literature to consider what is already known about the research topic and identify any gaps in existing literature.

Chapter 2: Scoping Literature Review

2.2. Introduction

In Chapter One, patient advocacy was identified as a significant issue in contemporary paediatric nursing. Furthermore, facilitation of parents and carers as patient advocates, was reported to be inconsistent across some clinical areas (Sabatello et al., 2018; Talley & Zwi 2015). Importance of acknowledging the voice of consumers via initiatives, such as Family Huddles, that align with the principles of family centred care, were identified. In addition, engaging with consumers within a family centred care model, to identify opportunities to strengthen their ability to act as patient advocate for their child, should they wish. Despite identified inconsistencies, initial scans of literature focussing on parental empowerment, satisfaction and patient advocacy combined, yielded the key factors influencing parental and carer decisions to advocate for their hospitalised child, remains under researched and unclear (Shield’s et al., 2012). Consequently, to establish the extent of what already exists in contemporary literature, a scoping review was conducted with a purpose to determine the extent to which parents and carers feel empowered and satisfied to undertake the role of patient advocate for their hospitalised child and identify key factors which facilitate this. In this chapter, the scoping review’s search methods are presented, along with evidence of quality appraisal of included studies, a comprehensive discussion of review findings, limitations of the scoping review and implications for practice. Gaps in the literature will then be identified supporting justification for developed research objectives in chapter three to follow.

2.3. Methods

Two scoping review frameworks were used to guide this review (Arksey & O’Malley 2005; Levac et al., 2010), supported by a literature review on scoping reviews by Colquhoun et al (2014). Originally described by Arksey and O’Malley (2005), the scoping review framework was established to provide a systematic process to map relevant literature in a field of interest. Colquhoun et al (2014) subsequently went on to describe scoping reviews as a method of synthesising literature regardless of study design, to provide a comprehensive summary and synthesis of available research evidence. Whilst consensus of a definition has not been established to date, for the purpose of this review, a definition will be outlined in line with the current best practices for conducting scoping reviews by Colquhoun (2016). Herein, Colquhoun (2016, p. 5) draws upon the definition of scoping reviews as a ‘form of knowledge synthesis that addresses an exploratory research question aimed at mapping key concepts, types of evidence, and gaps in research related to a defined area or field by systematically searching, selecting, and synthesizing existing knowledge'.

Conducting a scoping review was chosen to enable inclusion and examination of all relevant research, irrespective of methodological design. This review followed the five main stages of investigation in line with Arksey and O'Malley's (2005) framework, which include: 1. identifying the research question, 2. identifying relevant studies, 3. study selection, 4. charting the data and finally, 5. collating, summarising and reporting the results. A final sixth optional stage of consultation with stakeholders, was not deemed necessary or relevant to this review.

2.2.1 Identifying research question

Formation of the scoping review's search strategy required the guidance of a carefully constructed research question (Arksey & O'Malley 2005). The research question arose from a desire to understand: *What are the key factors that enable parents and carers to feel empowered and satisfied in their decision-making to advocate for their hospitalised child*?

2.2.2 Identifying relevant studies

Relevant studies were originally sought through a comprehensive search of databases conducted in August 2016. Following a period of time delay awaiting ethical approval and a study intermission, a subsequent search was conducted in October 2021. Key nursing electronic databases were searched including Scopus, Cumulative Index to Allied and Health Literature (CINAHL) and Medline. Given the complexity of the research phenomenon of interest, a Senior Librarian was consulted in the development of a structured database search. The search strategy included a comprehensive list of database search terms using combinations of phrases and keywords, see Table 1, to reduce the number of irrelevant results. With this review focussing on the hospitalised child, in order to capture a paediatric age range from birth up to 18 years of age, search terms included: 'baby', 'babies', 'infan*', 'toddler*', 'child*', 'kid*', 'teen*', 'adolescen*' or 'youth'. Additional search terms focussed on family centred care, hospitalisation, advocacy, parental satisfaction, empowerment and consumer engagement and included: 'hospital*', 'patient*', 'parent*', 'carer', 'caregiver*', 'advoca*', 'empower*', 'satisfaction', ''consumer*', 'engage*', '"family centred care"' and '"family centered care"'. Furthermore, to establish any existence of contemporary research evidence specific to Family

Huddles, the search term of ‘huddle*’ was included. Additional studies were located through hand searching of reference lists of located articles and searching of grey literature.

Table 1. Search Strings.

Database	Search string
Scopus	(TITLE-ABS KEY ((_child*_ OR _infan*_ OR _toddler*_ OR _baby_ OR _babies_ OR _adolescen*_ OR _teen*_ OR _youth_ OR _kid*_) W/3 _hospital*_)) AND ((TITLE-ABS-KEY ((patient* OR _child_ OR _consumer_) W/2 (_advoca*_ OR _engage*_)) OR TITLE-ABS-KEY ((_parent*_ OR _carer_ OR _caregiver*_) W/2 (_empower*_ OR _satisfaction_)) OR TITLE-ABS-KEY (_huddle*_) OR TITLE-ABS-KEY (_{family centred care}_ OR _{family centered care}_))) Limiters: Published date 2010-2021; document type ‘article’; English Language
CINAHL	MH "Child, Hospitalized" OR MH "Infant, Hospitalized" OR MH "Adolescent, Hospitalized"; TI (hospital* N3 (child* OR infan* OR toddler* OR baby OR babies OR adolescen* OR teen* OR youth OR kid*)) OR AB (hospital* N3 (child* OR infan* OR toddler* OR baby OR babies OR adolescen* OR teen* OR youth OR kid*)); S1 OR S2; (MH “Consumer Advocacy”) OR (MH “Child Advocacy”) OR (MH “Family Centered Care”); TI (“family centred care” OR “family centered care” OR huddle*) OR AB (“family centred care” OR “family centered care” OR huddle*); TI ((patient* OR consumer*) N2 (engage* OR advoca*)) OR AB ((patient* OR consumer*) N2 (engage* OR advoca*)); TI ((parent* OR carer OR caregiver*) N2 (empower* OR satisfaction)) OR AB ((parent* OR carer OR caregiver*) N2 (empower* OR satisfaction)); S4 OR S5 OR S6 OR S7; S3 AND S8 Limiters: Published date: 20100101-20211231, English Language
Medline	(MH "Child, Hospitalized") OR (MH "Adolescent, Hospitalized"); TI (hospital* N3 (child* OR infan* OR toddler* OR baby OR babies OR adolescen* OR teen* OR youth OR kid*)) OR AB (hospital* N3 (child* OR infan* OR toddler* OR baby OR babies OR adolescen* OR teen* OR youth OR kid*)); S1 OR S2; (MH “Consumer Advocacy”) OR (MH “Child Advocacy”) OR (MH “Family Centered Care”); TI (“family cent*ed care” OR “family cent*ed care” OR huddle*) OR AB (“family cent*ed care” OR “family cent*ed care” OR huddle*); TI ((patient* OR consumer*) N2 (engage* OR advoca*)) OR AB ((patient* OR consumer*) N2 (engage* OR advoca*)); TI ((parent* OR carer OR caregiver*) N2 (empower* OR satisfaction)) OR AB ((parent* OR carer OR caregiver*) N2 (empower* OR satisfaction)); S4 OR S5 OR S6 OR S7; S3 AND S8 Limiters: Published date: 20100101-20211231, English Language

2.2.3 *Study selection*

Citations were imported into the Covidence web-based application software, to enable the researcher to systematically screen titles and abstracts and enable selection of full-text studies based on inclusion and exclusion criteria outlined in Table 2. Full text review was undertaken on 159 full-text articles. Of these, focus was directed to a non-parent or caregiver role of the hospitalised child (n=61) and/or absence of discussion of parental empowerment, satisfaction, engagement and/or advocacy (n=45). Only one article was identified pertaining to the Family Huddle and was subsequently excluded as this conference abstract had no full-text available (Fernandez & Cameron, 2018). Screening of inclusion tables in each of the three included reviews (Hill et al., 2019; Labrie et al., 2021; & Phiri et al., 2020), identified a duplicate quantitative study (Abuqamar et al., 2015) which had already been identified for inclusion as an independent study. The independent study article was subsequently excluded, along with 8 other duplicate articles, as outlined in Figure 1.

Studies that met inclusion criteria (n=18) reported on factors of parental or caregiver empowerment, satisfaction and/or advocacy for the hospitalised child.

Table 2. Inclusion and Exclusion Criteria.

Inclusion Criteria	Exclusion Criteria
English language	Non-English language
Primary & Secondary research	Publication year prior to 2010
Published between 2010 and October 2021	Non-parent or Caregiver role/relative of hospitalised child
Mothers, Fathers and Caregivers of hospitalised child	Young person’s over 18 years of age
Target hospitalised age range of birth to 18 years old	Care provision located in non-acute care or community settings
Care provision located in acute-care hospital setting	Study does not describe, explore, or evaluate parental experience of hospitalised child on; parental empowerment, parental satisfaction and/or child/patient/consumer advocacy
Describe, explore or evaluate parental/caregiver experience of hospitalised child on; parental/caregiver empowerment, parental/caregiver satisfaction and/or child/patient/consumer advocacy	

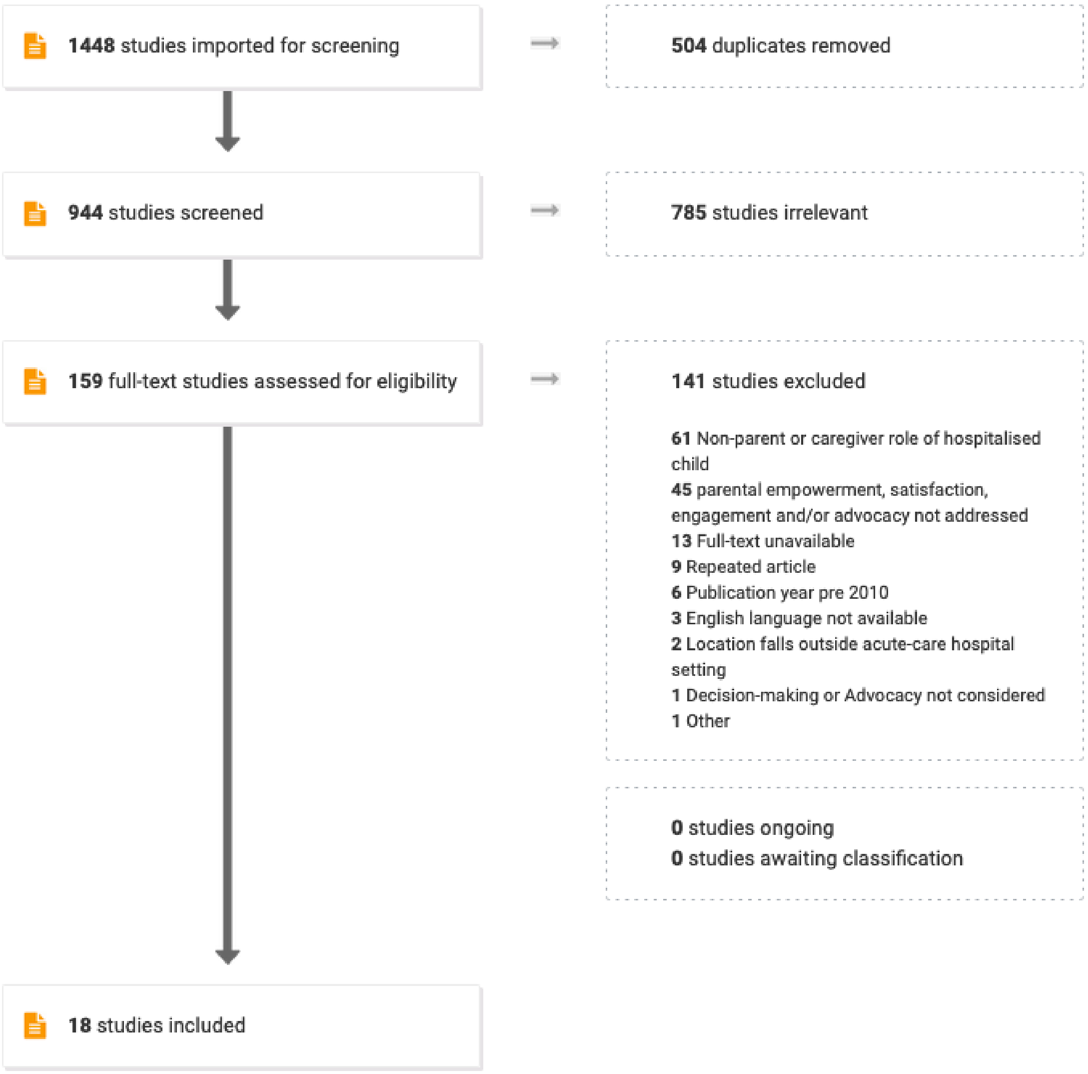

Figure 1. PRISMA Flow diagram

In addition, the methodological rigour of each study that met inclusion criteria, was considered in a final step of quality appraisal by selecting critical appraisal tools to align with the research design of each study. Three qualitative, ten quantitative and two mixed-method studies, in addition to one systematic review and two integrative reviews were included in this review. Critical appraisal of qualitative and quantitative studies was achieved through using critical appraisal tools of the Critical Appraisal Skills Programme (CASP) (2019), with the Mixed-Methods Appraisal Tool (MMAT) utilised for mixed method studies (Hong et al., 2018). The MMAT is a systematic appraisal tool for reviews consisting of a mix of qualitative and quantitative methodological approaches (Hong et al., 2018). Furthermore, these tools were used in combination with the Critical Review Guidelines for Quantitative and Qualitative studies by Whitehead et al., (2020, p. 69-70) to enable assessing of the quality of the studies and subsequent inclusion in the review. For any occurrence of a research design appraisal tool not being available, adaptation of appraisal questions occurred to align with the research design. The CASP checklists and Mixed Methods Appraisal Tool each consisted of a number of critical appraisal items for assessment. The critical appraisal process sought not to exclude studies of poor quality from the discussion, but rather contextualise the evidence (Grant et al., 2017; Lines et al., 2018). A summary of appraisal results can be found in Appendix 1.

The three qualitative studies yielded high levels of rigour against the CASP critical appraisal tool for qualitative research (2018a) with scores of 8.5 to 10 out of a possible 10 points. Research methods included ethnography (Higham & Davies 2022), and descriptive qualitative methodology (Mak et al., 2014; Saria et al., 2019). One study (Saria et al, 2019) did not explicitly identify clear aims for their study, however, did provide commentary of their study describing parent's and nurses' perceptions of the needs of parents, which could infer an aim. Whilst all three studies identified ethical approval was granted to conduct their studies, none of these studies discussed any potential relationship between researchers and participants. Despite this concern, well established research methods were otherwise demonstrated, enhancing confirmability and credibility (Polit & Beck, 2020).

Ten quantitative studies underwent thorough in-depth critical appraisal against the 40 item, Critical Review Guidelines for Quantitative studies tool (Schneider et al., 2020). High levels of rigour were achieved, from 33.5 points (Dadlez et al., 2018) through to 39 (Camur & Karabudak, 2021; Romaniuk et al., 2014) out of a possible 40 points. Two experimental studies reported hypotheses (Camur & Karabudak, 2021; Romaniuk et al., 2014), with the remaining eight descriptive, non or quasi experimental studies stating aims and/or objectives of their study. The main limitations of the quantitative studies were, one identified a small sample limiting generalisability (Krisnana et al., 2019); and one study (Dadlez et al., 2018) did not discuss validity of their data collection instrument. Furthermore, two studies (Foster &Whitehead, 2017; Rostami et al., 2015) did not consider limitations and further gaps of their research.

The two mixed-method studies (Seliner et al., 2016; Uhl et al.,2013) demonstrated high rigour against the Mixed Method Assessment Tool (Hong et al., 2018) in the areas of qualitative, descriptive quantitative and combined mixed methods appraisal. Similarly, the included integrative reviews (Hill et al., 2019; Phiri et al., 2020) and systematic review (Labrie et al., 2021) were thorough and transparent across all criteria of the adapted CASP (2018b) critical appraisal checklist for systematic reviews. One minor area of concern by Labrie et al (2021) was confused wording when addressing potential competing interest, rendering it difficult for the reader to determine the outcome.

The critical appraisal process identified areas of limitation amongst some included studies, however these were not deemed by the researcher to be significant enough to warrant exclusion from the scoping review. Areas of concern resulted from an apparent lack of disclosure of some aspects of detail by the study researchers as opposed to poor study design. In light of a lack of contemporary literature identified throughout the searching process focussing explicitly on factors that enable parents and carers to feel empowered and satisfied in their decision-making to advocate for their hospitalised child, maintaining inclusion was deemed appropriate.

2.2.4 Charting the data

Following the fourth stage of Arksey and O'Malley's (2005) framework, data from included studies were extracted and summarised into a custom-made Excel programme data chart, see Appendix 2 (Levac et al 2010). Data were sorted according to key themes and issues, including a mix of general information about the study and information specific to the study question (Daudt et al, 2013). The data charting form captured: author details, year of publication, location, aims and objectives, sample and setting data, methodology, methods, major findings, rigour and limitations of each study. Where an included study failed to provide one or more criterion, as much availed data as possible was extracted and charted.

2.2.5 *Collating, summarising and reporting the results*

In the absence of standardised reporting guidelines for scoping reviews (Colquhoun, 2016), Levac et al. (2010) and Daudt et al. (2013) recommend thematic analysis and subsequent thematic reporting of data. This approach proves beneficial when attempting to clearly link findings with the identified research question and aims of the scoping review (Daudt et al 2013). Whilst collectively comparing the methods utilised across all included studies was not practical given the methodological perspectives each exhibited (Schneider et al., 2016), comparison of the contexts and concepts of the issues overall across each is achievable.

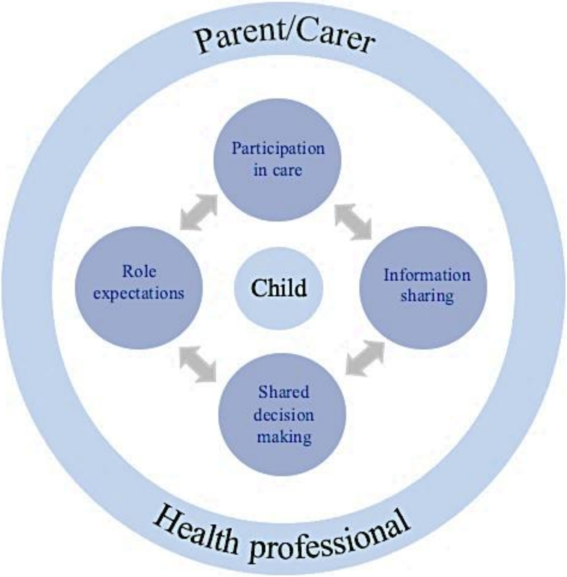

Figure 2. Visual representation of themes

Guided by reflexive thematic analysis principles, each dataset was explored to develop understanding of patterned meaning, grounded in data (Braun et al. 2019). After reading and re-reading each study, coloured codes were applied in an iterative manner, to better capture the developing conceptualisation of the data and to inform identification of emerging themes that reflected key factors influencing parental and/or caregiver decision making to advocate for their hospitalised child. Four distinct themes emerged throughout thematic analysis as important key factors in enabling parents and carers to feel empowered and satisfied in their decision making to advocate for their hospitalised child. Themes have been depicted in Figure 2, and include participation in care, information sharing, shared decision making and role expectations.

2.4. Findings

Eighteen studies were included in this scoping review and were summarised in Appendix 2. Studies emerged from a number of countries including Canada (n=2), China (n=1), Iceland (n=1), Indonesia (n=1), Iran (n=1), Netherlands (n=1), New Zealand (n=1), Poland (n=1), Switzerland (n=1), Tanzania (n=1), Turkey (n=2), United Kingdom (n=1) and the United States of America (n=4). The majority of included studies displayed a combination of themes and were outlined in Appendix 3. Themes will now be discussed in detail below.

2.3.1 Participation in care

Parental participation in care was a prominent theme throughout availed literature (Camur & Karabudak, 2020; Dadlez et al., 2018; Higham & Davies, 2013; Hill et al., 2019; Labrie et al., 2020; Mucuk et al., 2017; Phiri et al., 2020; Romaniuk et al., 2014; Rostami et al., 2015; Saria et al., 2019; Uhl et al., 2013). Parents and carers reported participation in their child's care to be an important aspect of how they experienced their child's hospitalization (Labrie et al., 2021; Phiri et al., 2020; Romaniuk et al., 2014; Uhl et al., 2013). Dadlez et al. (2018, p. 200) declared of their 116 parent participants, all 'uniformly wanted to be involved in their child's care'. Parent's desire to participate in all aspects of their child's care was summed up powerfully in the words of one parent (Uhl et al., 2013, p. 121); *"My son lived for 12 days (after birth). Twice a day, for an hour at a time, we were kicked out (for shift to shift nurse report). So for his 12 days of life, we lost an entire day of his life".*

A parent's experience of participation in care provision in hospital was determined to be an individualised one (Uhl et al.,2013), and one that cannot be presumed. It was important for many parents, to have opportunity to engage in participation and be afforded a choice, a choice to actively participate in cares should they wish (Higham & Davies, 2013; Phiri et al., 2020). Highman & Davies (2013, p. 1394) in their study of fathers' roles during unplanned hospital admissions, identified fathers 'acted as advocates by asking for equipment or supplies or trying to deal what they perceived as inadequacies in the care either the child of mother had received'. For some parents, opportunity to participate in care provision was restricted by the highly acute and technical nature of some care environments i.e., a paediatric intensive care unit which led to reported experiences of frustration, sadness and loss of control (Hill et al., 2019; Labrie et al., 2021). Participation in care led to greater sense of control, increased levels of satisfaction and facilitated some parents to advocate for their child (Hill et al., 2019; Mucuk & Cimke 2017; Rostami et al., 2015).

2.3.2 Information sharing

Consensus amongst parents existed with identification of a required need for sharing and exchange of information regarding the hospitalised child (Foster & Whitehead 2017; Hill et al., 2019; Krisnana et al., 2019; Kuo et al., 2012; Labrie et al., 2021; Mak et al., 2014; Phiri et al., 2020; Saria et al., 2019; Seliner et al., 2016; Svavarsdottir & Sigurdardottir 2013; Uhl et al., 2013). A clear explanation of the diagnosis and treatment plan specifically, was identified as important across four studies (Hill et al., 2019; Kuo et al., 2012; Seliner et al., 2016; Uhl et al., 2013). Knowledge of what was happening with the child was found to facilitate feelings of empowerment (Krisnana et al., 2019; Uhl et al., 2013), and informed decision-making abilities promotes parent-professional partnerships (Foster & Whitehead 2017; Mak et al.,2014; Seliner et al., 2016; Uhl et al., 2013). Uhl et al (2013) went further; identifying in their nine-participant focus group, a lack of knowledge about treatment plans was an important gap in communication that negatively impacted upon parent's confidence and trust in care providers. Furthermore, parents reported experiencing feelings of anger, frustration and irritation when a lack of information provision occurred or was delayed (Hill et al., 2019; Phiri et al., 2020).

Respectful and open communication with nurses and other members of the health care team, assists to allay parents fears and 'provide them with a feeling of security' (Seliner et al., 2016, p. 153). Labrie et al. (2021) highlighted the negative effects of poor communication leading to difficulties in understanding, remembering and processing information. These parents tended to report feelings of being upset, feeling devalued or being uninformed when they were presented with perceived poor communication from staff (Labrie et al., 2021). Quality and relevance of information was regarded more highly by parents than the amount given and was critical to parent's involvement in subsequent decision making (Mak et al., 2014; Svavarsdottir & Sigurdardottir 2013). Quality for parents was signified by treatment specific information and health care provider experience and confidence (Mak et al., 2014; Saria et al., 2019).

2.3.3 Shared decision making

The theme of shared decision making featured in six of the included studies (Foster & Whitehead 2017; Kruszecka-Krowka et al., 2019; Labrie et al., 2021; Mak et al., 2014; Seliner et al., 2016; Uhl et al., 2013). Engagement of parents in the decision-making process was considered an important component of building parental capacity and fostering empowerment (Labrie et al., 2021; Mak et al., 2014; Seliner et al., 2016). This was also echoed in Uhl et al's (2013) mixed method study of insight of parents into patient and family centred care. Feelings of responsibility, knowledge about their child, the protective role and feelings of guilt surrounding their child's illness, were found to fuel parental desire for decision making involvement (Mak et al., 2014; Uhl et al., 2013). Furthermore, in Mak et al's (2014) study, parents reported the importance of health professionals making the decision-making process known to parents, and exchange of information was essential in facilitating partnership in decision making. Seliner et al (2016) recognised for parents, being taken seriously was important in the decision-making process, especially when interdisciplinary decision-making processes occurred. From small decisions to larger ones, parents reported a desire to be involved at all levels of decision-making, and in order to do this clear accurate information provision was key (Uhl et al., 2013).

2.3.4 Role expectations

Role expectations specifically, were considered across three of the included studies of this review (Hill et al., 2019; Romaniuk et al., 2014; Uhl et al., 2013). In their integrative review focussing on family-centred care from the perspective of parents of hospitalised children, Hill et al (2019) highlighted the existing discrepancies between parents being viewed as 'experts' regarding their child and how this expertise is at times ignored. Parents reported feeling pleased, valued and having confidence in health care professionals when their expertise was valued and acknowledged. Some parents perceived an important part of their role was to act as mediator between their child and hospital staff during their stay (Romaniuk et al., 2014). Conversely, a feeling of obligation to relinquish the position of primary caregiver over to nurses and take on a more passive role was reported by some parents (n=9) in Uhl et al's (2013) focus group. Lack of effective communication and poor or minimal information sharing was found to inhibit parental ability to establish clear role expectations with nursing staff (Uhl et al., 2013). For those parents who established some control and influence with health staff, felt a sense of empowerment. This level of empowerment was 'facilitated by knowing what was happening with their children and being involved in their care' (Uhl et al., 2013, p. 126).

Only one randomised-controlled trial met inclusion for this review, with the studies purpose to determine the effect of parental participation in the care of hospitalised children on parent satisfaction and parent and child anxiety (Camur & Karabudak, 2020, p. 6), The results demonstrated a ‘statistically significant difference between intervention groups pre-test and post-test scores on the ‘information’, ‘parental participation’, ‘communication’ and ‘technical skills’ subscales (P <0.001)’. The intervention group received a training programme focussing on communication, teaching of care skills specific to their child’s care needs and ongoing support at the bedside. The intervention group yielded significantly higher satisfaction post-test scores in all four subscales compared to the control group, whereas no statistically significant differences were found pre and post-test in the control group. Overall, the study showed positive effects for both parents and children, of the parent’s participation in care (Camur & Karabudak, 2020).

2.4 Discussion

This review of available contemporary research literature identified a very small amount of qualitative and quantitative research dedicated to parental empowerment, parental satisfaction and parental advocacy of the hospitalised child, in their own right. Furthermore, very little research was located considering the relationship between parental empowerment and satisfaction and the subsequent impact on decision making to advocate for the hospitalised child. Of the available research literature, participation in care, information sharing, shared decision making and role expectations, emerged as four key themes.

Participation in care and information sharing stood out as the strongest themes across eleven studies respectively, as a key facilitator of empowerment and satisfaction to varying degrees (Camur & Karabudak 2020; Dadez et al., 2018; Foster & Whitehead 2017; Higham & Davies 2013; Hill et al., 2019; Krisnana et al., 2019; Kuo et al., 2012; Labrie et al., 2021; Mak et al., 2014; Mucuk et al., 2017; Phiri et al., 2020; Romaniuk et al., 2014; Rostami et al., 2015; Saria et al., 2019; Seliner et al., 2016; Svavarsdottir & Sigurdardottir 2013; Uhl et al., 2013). Active participation in care featured prominently, however the associated studies did not discuss potential factors contributing to parental decision to voluntarily not want to participate in care. Whilst shared decision making and role expectations yielded six and three studies respectively, each contributed to establishing a basis of an initial parental narrative about their ideals of shared decision making and role expectations within the care experience (Foster & Whitehead

2017; Hill et al., 2019; Kruszecka-Krowka et al., 2019; Labrie et al., 2021; Mak et al., 2014; Romananiuk et al., 2014; Seliner et al., 2016; Uhl et al., 2013). Research evidence focussing on role expectations was particularly lacking, highlighting the need for further research to consider not only personal views and accounts from parents and carers of their experiences of role expectations in practice, but the views and accounts from health professionals also.

The identified themes in this review; participation in care, information sharing and shared decision making specifically, are consistent with the philosophy of family centred care, a fundamental approach underpinning health care delivery for children across Western countries, including Australia (Carter et al., 2014). Family centred care has been well recognised, accepted and reported in the literature as the optimal way of caring for hospitalised children and their family (Trajkovski et al. 2012). Family centred care as an approach to care planning and delivery, endorses and promotes shared decision making and involves the family in care provision and ongoing effective communication with families, to ensure care is responsive to their needs and practices (McManus et al. 2020).

This review has established, the four themes of participation in care, information sharing, shared decision making, and role expectations are constructs intertwining with each other to shape the lived experience of the parent, caregiver and child whilst hospitalised. This aligns with Labrie et al's (2021, p. 1542) systematic review of effects of parent-provider communication during infant hospitalisation in the NICU on parents, whereby:

> *"The knowledge parents gained through individual bedside education and group information sessions was empowering, giving parents the confidence to actively participate in their infant' care and build a more trusting relationship with staff".*

Whilst this review has discussed initial indicators of key factors that enable parents and carers to feel empowered and satisfied in their decision-making to advocate for their hospitalised child, the relationship between advocated practice and actual lived experience of parents whilst in hospital requires further focussed exploration (Fraser et al., 2017, Uhl et al., 2013).

This review further established; a lack of research literature exists focussed on Family Huddles. Given Family Huddles were a consumer engagement initiative in its infancy when this research project commenced in 2016, it was unexpected for the researcher, that only one source was identified in database searching in 2021 when the database search was rerun. This further strengthens the need to undertake focussed research into the lived experiences of parents and carers participating in a Family Huddle, to in part explore and relate how a Family Huddle enhances the principles of family centred care.

2.5. Limitations

A number of limitations must be acknowledged when interpreting the findings of this review. Included studies originated from fourteen countries, both developed and developing, where consistency of care provision models cannot be established and may not be comparable. Reviewing the international literature highlighted that some countries have their own customs and policies not congruent with the core principles of family centred care. Furthermore, the settings of each study varied from neonatal intensive care units, paediatric intensive care units, to general paediatric wards and emergency departments, each having their own setting variables for consideration. With none of the included studies carried out in Australia, caution must therefore be applied to dissemination of findings directly to certain contexts, including the Australian setting.

While relevant studies were sought through a systematic search of databases under the guidance of a Senior Librarian experienced in database searching, it is possible in the undertaking of this review that some relevant studies were disregarded. Studies disregarded were done so, if they were not available in English language, were published prior to 2010 and subsequently excluded, or they originated in a non-acute or community setting.

2.6. Implications for practice

To better support parents and carers of hospitalised children in the clinical setting, it is necessary to have access to quality contemporary research. The findings of this review, highlight the need for further research into parental lived experience in hospital. More research is required to further explore key factors and evaluate the relationship between key factors on parental empowerment and satisfaction, and subsequent decision making to advocate for the hospitalised child. In addition, focussed research is required to explore parental and carer experiences of participating in a Family Huddle within the clinical setting. This has the potential to not only improve parent and child experience in hospital and enhance consistency and quality of care, but to develop recommendations at policy level to guide multidisciplinary practice that is evidence based at clinical level.

2.7. Chapter Summary

The intent of this review was to examine available research concerning parental empowerment and satisfaction in the paediatric acute care setting. Moreover, factors impacting upon parental decision making to advocate for the hospitalised child were sought. Literature specific to the issue was limited, however four main themes emerged from the available literature with potential to further contextualise understanding of the lived experiences of parents and their hospitalised child. Whilst the findings of this review suggest parental empowerment and satisfaction are influenced by a number of aforementioned factors, the relationship between the variables has not been clearly ascertained to date. Therefore, further research into this issue is justified. The following chapter outlines the research design and methods utilised, to explore what parents and carers of hospitalised children within a paediatric haematology/oncology unit, experience from participating in a Family Huddle.

Chapter 3: Research Design and Methods

3.1 Introduction

From the Scoping Review in Chapter Two, it is evident that further research is required to better understand the lived experience of parents and carers of hospitalised children who participate in a Family Huddle. The purpose of this chapter is to identify and explore the theoretical underpinnings of the study. Justification for application of the constructivist paradigm and guided by an ethnographic methodology, will be discussed, followed by the methods used to gather, analyse and interpret data.

3.2 Paradigm

The conduct of research in pursuit of new knowledge, must be guided by an appropriate choice of research paradigm. Underpinning of research paradigms by ontological and epistemological positions, shape all aspects of the research process to enable a comprehensive approach to the area of interest (Richardson-Tench et al., 2018). As a worldview and system of beliefs, a paradigm outlines how individual phenomena should be understood and addressed by research whilst also shaping research questions, methods and comprehension of results (Sweet & Davis, 2020). With the purpose of this study to explore what parents and carers of hospitalised children within a paediatric haematology/oncology unit experience from participating in a Family Huddle; it is important to thoroughly consider and select the most appropriate research paradigm for this study in line with its purpose and identified research question. To consider the nature of reality and relationships between researcher and the subjects under study, these philosophical considerations require structured inquiry founded in the positivist and/or constructivist paradigms (Gray & Grove, 2021).

The positivist paradigm emphasises rational and scientific approaches and is aligned closely with quantitative research, a scientific method of research, using deductive reasoning to generate predictions, objective quantifiable data and empirical evidence (Polit & Beck 2017). When researchers aim to search for truth in an objective and measurable manner, the individuals forming a large sample, become subjects through which numerical data is generated, to form a truth that may in turn be generalizable to similar groups (Whitehead et al., 2020).

Conversely, the constructivist paradigm emphasises reality is not fixed but rather adaptable and experienced differently in the minds of subjects living their own reality. Constructivism aligns closely with qualitative research, using inductive reasoning to generate narrative data, subjective in nature and rich in lived experience of those under study (Polit & Beck, 2017). Emphasis of constructivist researchers is placed on ‘the dynamic, holistic, and individual aspects of human life and attempt to capture those aspects in their entirety, within the context of those who are experiencing them’ (Polit & Beck, 2017, p. 35). When little is known about a human phenomenon of interest, qualitative research affords opportunity to explore and make sense of the realities experienced by the participants of the smaller sized sample, and place value in the personal voice, perceptions and in turn the narrative of each individual participant (Whitehead et al., 2020).

Significance for the researcher existed in determining whether the intent of the study was to generate measurable, objective, and uninfluenced data that may be generalised to similar populations, or whether it was to search for a deeper truth, where multiple realities and voices would be instrumental in generating a rich narrative of personal experience (Greenhalgh et al., 2020). The choice of qualitative or quantitative approach to research, must be guided by the purpose of the study and research question. As this study intended to explore the experiences of parents and carers of hospitalised children, and the researcher sought to obtain in-depth subjective narratives from participants in the pursuit of exploration, the constructivist paradigm was considered most aligned with the purpose and identified research question of the study.

3.3 Methodology

Qualitative researchers generally conduct research grounded in holistic perspective, with intent to study phenomena in their natural environment (Greenhalgh et al., 2020). Within the qualitative paradigm, a number of methodologies exist aiming to make sense of the meanings people bring to their experiences. The term methodology refers to the research process and lens through which certain procedures and techniques are used to identify, analyse and interpret data (Sweet & Davis, 2020; Bairagi & Munot, 2019). Some of the main qualitative methodologies include phenomenology, case study, grounded theory and ethnography (Polit & Beck, 2017; Whitehead et al., 2020).

As a methodology, phenomenological research focusses on lived experience and participants interpretations and perceptions of their own experiences. Whilst a beneficial methodology when seeking consciousness and shared meaning (Greenhalgh et al., 2020), the reliance on long duration in-depth interviews as the sole data collection method potentially limiting willingness of participants to volunteer lengthy time to be interviewed, was considered by the researcher to be potentially troublesome in a highly acute and sensitive setting such as a paediatric haematology/oncology ward. Case study might have been a suitable methodological approach, if the purpose of the study was to undertake a detailed investigation intending to explore complex issues of a single event, situation or individual (Yin 2018). With the research objectives seeking to explore multiple facets of Family Huddle delivery, parental/carer experience and alignment with family centred care, the researcher sought a methodological approach that would focus on understanding 'what' the participants have experienced, rather than 'why' as is a common feature in case study research (Polit & Beck, 2017).

Grounded theory researchers seek to understand patterns of human behaviour and interactions in social settings, aimed at generating theory where no prior theory exists (Greenhalgh et al. 2020). Researchers focus on how participants give meaning to their experiences, which fits well with this study, however given this study does not aim to generate theory, it was ruled out as a possible methodology. Finally, ethnography seeks to describe and interpret behaviour within a cultural context to better understand the worldview of those within the culture (Lobiondo-Wood & Haber, 2021). Whilst typically time intensive requiring immersion of the researcher in the cultural setting under study, data sources including for example, observation, in-depth interviews, field notes and artefacts; enable collection of numerous data sets to inform a rich narrative. As this study aimed to identify and explore parental and carer experiences and perceptions of participation within a Family Huddle in a focussed culture setting of a haematology/oncology setting, ethnography was selected as the most appropriate research methodology.

3.3.1 Ethnography

Founded in the early workings of social and cultural anthropologists of the late nineteenth and early twentieth centuries interested in lived engagement, ethnography seeks to immerse the researcher in a position to learn from and understand the worldview of members of a cultural group (Coffey, 2018; Crawford, 2019). This method of research is particularly useful when a rich holistic insight to a cultural group is sought (Polit & Beck, 2017). Culture in ethnographic research, refers to 'the way a group of people live – the patterns of human activity and the values and norms that give activity significance' (Polit & Beck 2017, p. 274). The focus of cultural research ranges from macro level, including broad cultural research as exampled through Indigenous cultural research in Australia, through to micro level or 'focused' ethnographies.

Familiarity with the field and reflexivity are key principles in focussed ethnography, with reflexivity becoming imperative to challenge the researcher's preunderstanding when entering a field to avoid any bias within the field being explored (Mølgaard et al. 2022). Focussed ethnographies explore narrowly defined social phenomenon and cultures, including smaller units within a culture and has a focussed field of enquiry (Bikker et al., 2017; Crawford, 2019; Polit & Beck, 2017). Data collection is targeted and short term with visits to the field tailored to a particular time frame or events. This focus enables the relevant results on the pre-defined topic to be obtained. This aligns well with the focus of this study, with participants of a Family Huddle making up a focussed group within the cultural setting of a haematology/oncology unit. In this focussed ethnographic study, the researcher sought to explore both *etic*, 'the outsiders' interpretation of the culture's experiences – the words and concepts they use to refer to the same phenomena' (Polit & Beck 2017, p. 274), and *emic*, or insiders' perspectives of carefully selected participants.

3.4 Methods of data collection

3.4.1 Sampling and recruitment of participants

Purposive sampling was used during the study for potential recruitment of parents and carers of hospitalised children within the haematology/oncology unit, as study participants. This method of sampling facilitates selection of a variety of participants who are knowledgeable about the culture of the haematology/oncology ward and participation in the phenomenon under study, being the Family Huddle (Moser & Korstjens, 2018). Support of the Unit's Nursing Service Director was sought as an informant to assess suitability of involving patients' families and to function as a conduit between researcher and potential participants. This was vital given the highly acute and sensitive nature of a paediatric haematology/oncology ward, including for example instances of active chemotherapy infusion and/or palliation of paediatric patients in the unit.

Sample size in qualitative research is dependent upon various factors, including information needs and achievement of data saturation (Polit & Beck, 2017). The researcher intended to undertake a minimum of three observed Family Huddles in Phase One and then review obtained data before proceeding with planning of further observed Family Huddles if required. The researcher intended to achieve a minimum of three face-to-face interviews in Phase Two, noting the acuteness and sensitivity of a haematology/oncology ward would render this desire completely dependent upon parental willingness.

In preparation for recruitment of participants the researcher spent time in the haematology/oncology unit establishing research study information displays consisting of an A3 sized information poster with identical A4 flyers and information packs. Information packs contained an A4 flyer (Appendix 4) along with a letter of introduction (Appendix 5) and participant information sheets for the observed Family huddle (Appendix 6) and face-to-face interview (Appendix 7). Consultation with the Nursing Service Director culminated in two locations for the displays being selected: within the parent room and in the unit's, reception waiting area. It was deemed most respectful and unobtrusive to allow potential participants to obtain an information pack from the display stand, to view the enclosed information in their own time without interruption. The researcher communicated with potential participants in person to discuss the study and consent procedures, only once voluntary communication was initiated by the potential participant to the researcher via email or phone contact.

3.4.2 Inclusion criteria

Mothers, fathers, and carers of hospitalised children aged 0-17 years with a cancer/haematological disorder admitted to the haematology/oncology unit, were eligible to participate in the study if they were willing to voluntarily participate in an observed Family Huddle. Due to the nature of the Family Huddle and face-to-face interview requiring conversation in English, being the researchers only spoken language, potential participants who were unable to read, write and speak English were excluded from potential participation.

3.5 Facilitating data collection

To establish a rich exploration, several data sources are often relied upon in ethnographic research including but not limited to, participant observation, field notes, in-depth interviews, artefacts and physical evidence (Whitehead et al., 2020). Coffey (2018) specifically recognises participant observation as the vital starting point for data generation in ethnographic research. The researcher established two phases of data collection for this study: Phase One being attendance at an observed Family Huddle (focus group) and Phase Two being an optional one-on-one face-to-face follow-up interview, post Family Huddle attendance.

3.5.1 Phase One

Phase One of the study was an observed Family Huddle (focus group). The researcher took on an overt passive observer role for the duration of the observed Family Huddle. A unit representative from the haematology/oncology unit, facilitated each session, which routinely ran for 30 to 60 minutes duration. The unit representative conducted a walk around of the unit prior to Family Huddle commencement, to recruit attendees to the Family Huddle. The Family Huddle portfolio was held by the same unit representative who undertook the session approximately every three weeks. Consistency of facilitator was important to minimise influence of variables within the Family Huddle. Audio recordings were taken on two separate recording devices, for the duration of the observed Family Huddle. Audio recording each session facilitated increased rigour and validity by way of objectively and comprehensively recording data that was then later transcribed verbatim by a confidentiality bounded transcriptionist, to be referred to for accurate representation and clarity (DeJonckheere & Vaughn, 2019). This also enabled the researcher to be immersed wholly in the authentic moment of the observed Family Huddle. Double checking of the transcription then occurred by the researcher comparing the transcription to the audio recording.

The researcher wrote down time stamped de-identifiable field notes during the session in a field diary. This included observations about participant behaviour and expressiveness as well as hand drawn diagrams of participant seated positioning during the session as well as layout of the parent room, being the location for the observed Family Huddles. Coffey (2018, p. 48) recognises the value of field notes as ‘textual representations of the field, crafted and made by the ethnographer, drawing on literary conventions to produce thick description, situating actions and interactions in contexts that render them meaningful to those not familiar with the setting’. Observation of participants throughout the Family Huddle was important to gain deeper understanding of human behaviours and the social interactions within the group (Polit & Beck, 2017). Time stamping field notes enabled cross-referencing against the audio recording to enhance clarity and context (Coffey, 2018).

To ensure access to Family Huddles for individuals not wishing to participate in the study, the term ‘observed Family Huddle’ was utilised to distinguish sessions occurring as part of the study, compared to routine unit Family Huddles. This delineation was identified clearly in information packs and unit displays and communicated verbally to unit inpatients and their families throughout the six months duration the researcher had presence within the haematology/oncology unit. Delineation was established especially for the collection of data.

3.5.2 Phase Two

During Phase Two, a face-to-face interview was conducted for any participant of the observed Family Huddle in Phase One, who consented voluntarily to taking part in Phase Two. The semi-structured interview, with a duration of up to 60 minutes, was conducted in a suitable private location chosen by the participant, within the grounds of the hospital. Audio recordings were taken on two separate recording devices, for the duration of the face-to-face interview and later transcribed verbatim by a confidentiality bounded transcriptionist. Audio recording of the interview enabled the researcher to be immersed in the conversation and able to make short notes rather than having focus taken away from the lived experience being shared by the participant (Coffey, 2018; Polit & Beck, 2017). As with Phase One, double checking of transcription then occurred by the researcher comparing the transcription to the audio recording.

Semi-structured interviews were selected to align with a desire to capture an emic worldview, after having built rapport and dialogue with the participant (DeJonckheere & Vaughn, 2019). A semi-structured interview question sheet (Appendix 8) enabled the researcher to ask open ended questions aligned with the objectives of the study whilst also affording opportunity to delve deeper into topics being discussed (Whitehead et al., 2020) including issues raised during the observed Family Huddle. Specifically, open-ended questions around experiences and perceptions of participating in a Family Huddle, identifying, and exploring perceived barriers, motivators, enabling factors and willingness for participation and finally how a Family Huddle enhances the principles of family centred care. Interview questions were informed by the person and family centred care charter of the Organisation and discussed with the supervisory research team prior to delivery to research participants.

Whilst the researcher intended to achieve a minimum of three face-to-face interviews in Phase Two, communication with several potential participants saw only one participant progressing to this stage of their own volition. Whilst not reaching the preferred three face-to-face interviews, the one completed interview yielded highly valuable insightful data for analysis.

The one face-to-face interview undertaken as part of this study, occurred in a patient's room at the request of the father as participant. The father wished to stay close to his daughter whilst being interviewed and his daughter wished to contribute to the discussion. To maintain safety for the patient who was connected to an intravenous infusion during the interview, the unit representative also attended and sat in on the face-to-face interview. This not only maintained safety for the patient, but also enhanced a building of rapport and ease with the participant and his daughter, who were already familiar with the unit representative.

3.6 Ethical considerations

In line with the National Health and Medical Research Councils' National Statement on Ethical Conduct in Human Research (2018) and requirements for human participants, this research project was granted full ethical approval in the first instance by the ethics committee of the major metropolitan hospital the study was undertaken within. The first submission for ethical approval was granted conditionally pending minor changes to wording in participant information sheets. Once rectified and resubmitted, full ethical approval was granted (Appendix 9). At completion of this process, a copy of this full ethical approval was submitted to the Flinders University Social and Behavioural Research Ethics Committee, at which time, further full ethical approval was granted by Flinders University, Project Number: OH-00218 (Appendix 10).

An amendment was subsequently submitted to the ethics committee of the major metropolitan hospital the study was undertaken within, to obtain approval for inclusion of the data obtained from the fourteen-year-old patient. The teenaged patient was present during the face-to-face interview conducted between her father and the researcher. Consideration must be given by the ethics committee to the level of maturity of the child or young person as participant, 'including implications for whether his or her consent is necessary and/or sufficient to authorise participation' (NHMRC, 2018, p. 65). With clear verbal articulated audio recorded consent from the father as participant and his teenaged daughter as inpatient, at the time of interview, approval was granted by the ethics committee for inclusion of the patients' data availed on the audio recording during the face-to-face interview (Appendix 11).

3.6.1 Confidentiality and anonymity

To ensure private information was not misused and confidentiality was maintained, only the primary researcher had access to participants' personal identifiable information. Via the participant information sheet (Appendix 6 and 7) participants were assured they would not be individually identifiable in any publications and pseudonym use would occur after de-identification of all availed data. All electronic data was stored on the researcher's password protected computer with hardcopy data stored in a lockable filing cabinet in the researcher's lockable single office for a five-year period, after which time it would be destroyed or deleted. Given the nature of a focus group participation in Phase One and face-to-face interviews in Phase Two, participants were informed anonymity could not be guaranteed. In line with mandatory reporting requirements in South Australia and the Children and Young People (Safety) Act 2017 (Government of South Australia, 2021), participants were informed of the legal requirement for sharing of personal information to third parties if a mandatory notification was required as a result of information shared during either phase of the study.

Confidentiality was further maintained by having the transcriptionist complete a transcription services confidentiality agreement, established by Flinders University's Social and Behavioural Research Ethics Committee.

3.6.2 Consent

Informed consent was obtained from all participants in Phase One and Phase Two of the study. To ensure safeguarding of participants, voluntary participation in research must be informed by sufficient information and 'requires an adequate understanding of the purpose, methods, demands, risks and potential benefits of the research' (NHMRC, 2018, p. 16). Each participant who agreed to participate in the study were required to read the information sheets for Phase One and Two in full and ask any follow-up questions they may have before proceeding to complete written consent. Each participant was required to sign a written consent for both Phase One (Appendix 12) and Phase Two (Appendix 13) separately indicating their understanding of the implications of the study, with informed knowledge they were free to withdraw their consent at any point.

3.7 Analysis of data

Qualitative data analysis sets about organising, providing structure to and generating meaning from data (Polit & Beck, 2017). In qualitative research however there is no single universal approach to data analysis (Whitehead et al., 2020). Researchers, therefore, must carefully plan and reflect upon the preferred data analysis framework and maintain transparency throughout the data analysis process. Nowell et al (2017, p. 1) recognise the necessity for qualitative data analysis to be ‘conducted in a precise, consistent, and exhaustive manner through recording, systematizing, and disclosing the methods of analysis with enough detail to enable the reader to determine whether the process is credible’.

Data analysis in ethnographic research should be flexible and systematic (Coffey, 2018) with Reeves et al (2013) delving further to suggest three distinct aspects of ethnographic data analysis: description, analysis and interpretation. Description involves treating the data as fact, analysis includes ‘examining relationships, factors and linkages across the data points’, and interpretation builds understanding of the data beyond the factual data points and analysis (Reeves et al., 2013, p. e1370). Whilst some researchers such as Reeves et al (2013) attempt to identify processes for analysing ethnographic data, no consensus for a mandatory method of analysing ethnographic data currently exists (Coffey, 2018).

Utilising well known and regarded strategies such as thematic analysis, has been recommended as a primary foundational method for analysing ethnographic and qualitative data more generally (Coffey, 2018). Specifically, Braun and Clarkes’ (2006) six phased thematic analysis step-by-step process has been used successfully for qualitative analysis in recent ethnographic studies (Chin, Lopez & Tan, 2019; Griffin & Bryan, 2021; Ihlebaek, 2020), providing a process for identifying, analysing, reporting themes and interpreting aspects of the research data. As this method of thematic analysis offers a more accessible form of analysis particularly for those just starting out in their research endeavours (Braun & Clarke, 2006). Therefore, the researcher elected to proceed with Braun and Clarkes method of thematic analysis to examine differing perspectives of participants and generate rich insights. The more recent work of Nowell et al. (2017) further enhanced Braun and Clarkes stages of thematic analysis by aiming to meet trustworthiness in each stage and was also utilised in support of thematic analysis within this study.

Phase One: Data familiarisation

During this study, the researcher enlisted, a university referred, remunerated professional transcriptionist to transcribe verbatim, all audio recordings of the three observed Family Huddles and one face-to-face interview. Verbatim transcription is considered to provide the ‘best database for analysis’ (Merriam & Tisdell 2016, p 131) and aides immersion of the researcher in obtained data. High quality transcripts assist in establishing methodological rigour (Polit & Beck, 2017). The researcher immersed themself in obtained data including field notes and transcripts by reading and re-reading them over in an effort to begin to search for meaning and patterns in data and makes initial notes for subsequent coding (Braun & Clarke, 2006).

Phase Two: Generating initial codes

Systematically working through the entire data set enabled organising of data into meaningful groups (Braun & Clarke, 2006). The Dedoose™ web-based application was used to organise data and facilitate the generation and collation of codes. Dedoose™ was the preferred coding application with its documented strength in qualitative data analysis and ability to upload a wide variety of data sets from text and audio to videos and images (Northwestern University, 2022). To minimise any risk of the researcher being removed from aspects of data coding and the analysis process, the researcher undertook Dedoose™ training sessions prior to data analysis commencing.

Phase Three: Searching for themes

On completion and collation of initial coding, focus was directed to analysis at a broader level of themes. Codes were sorted into potential themes and thematic mapping enabled visual representation of codes combining to form an overarching theme. Braun and Clarke (2006) recognise the benefit of visual representations including tables and/or mind maps to inform this process.

Phase Four: Reviewing themes

Following initial coding and subsequent mapping of initial broader themes, it was important to further review and explore potential overarching themes and sub-themes within them. Reading and re-reading of coded data extracts occurred for each theme to determine if a ‘coherent pattern’ could be established (Braun & Clarke 2006, p. 91). Where this was not evident, reworking of the theme occurred to establish accurateness and furthermore, any additional data that had been missed previously in earlier stages was considered for coding. Overarching themes and potential sub-themes were discussed with project supervisors before proceeding to defining and naming of major themes (Braun & Clarke, 2006).

Phase Five: Defining and naming of themes

As each theme was identified, it was necessary to clearly outline the intent of each theme and determine 'what aspect of the data each theme' captured (Braun & Clarke 2006, p. 92). A detailed analysis of each theme occurred accompanied by the story each theme set about telling. Moving back and forth between phases four and five was necessary to minimise overlapping of themes and ensure each theme fit with the overall story being told and was aligned well with the purpose and objectives of the study. Checking of transcripts was also an important to ensure consistency between themes and obtained data (Arksey & O'Malley, 2005).

Phase Six: Producing the report

Final analysis and documenting the lived story were done in a way which demonstrates merit and validity of analysis (Braun & Clarke, 2006). Sufficient evidence which captured the essence and prevalence of each identified theme was extracted from transcripts. This enabled accurate depiction of the narrative and communication of an argument for each theme in line with the overall research question and in direct response to the identified project objectives.

3.8 Establishing trustworthiness

Rigor and validity are concepts traditionally used to establish the quality of quantitative studies. They are generally not, however, considered appropriate for methodologies aligned to the constructivist paradigm (Polit & Beck, 2017). Development of standards for establishing trustworthiness in qualitative research have however been established, that parallel the standards of reliability and validity, so often addressed in quantitative research (Polit & Beck, 2017). Polit and Beck (2017, p. 787) recognise for qualitative work to be good, requires it to be 'descriptively sound and explicit and interpretively rich and innovative'. To meet this standard, this study adopted the framework established by Lincoln and Guba (1985 in Nowell et al. 2017) for establishing trustworthiness in qualitative research, specifically addressing the four criteria of *credibility, transferability, dependability,* and *confirmability*.

3.8.1 Credibility

Credibility within a study is established when congruence exists between study findings and reality. As the researcher attempted to understand the perspectives of the participants involved in participation of a Family Huddle, it was important for the researcher to be able to 'present a holistic interpretation of what is happening' (Merriam & Tisdell, 2016, p. 244). Several techniques suggested by Lincoln & Guba (1985 in Nowell et al., 2017) were utilised by the researcher to address credibility, including long periods of engagement with participants being a fitting aspect of ethnographic research, peer debriefing and reflexivity.

Peer debriefing of the researcher with supervisors throughout the analysis stage invited constructive feedback based on their own research conduction expertise. It also enabled identification of potential errors in the analysis process (Polit & Beck, 2017) which in turn facilitated the researcher to review study methods and subsequently strengthen posed arguments.

Reflexivity in ethnographic research requires placement of the researcher at the centre of inquiry and consideration of potential impacts of the researchers' presences on obtained data sets (Nowell et al., 2017; Reeves et al., 2013). A reflexive journal was maintained throughout the study to record internal and external dialogue, and document the researchers' reflections including relating to values, beliefs, and thoughts about the research process. Furthermore, the researcher also declared their background prior to commencement of the study.

3.8.2 Transferability

In qualitative research, transferability is concerned with generalisability of findings and the extent to which findings can be applied to other contexts (Merriam & Tisdall, 2016; Nowell et al., 2017). It was therefore imperative the researcher provided rich and thick descriptions of findings, for readers to be able to self-determine whether transferability to their own site or circumstance is appropriate. In this process onus of responsibility is transferred from the researcher to the reader (Nowell et al., 2017).

3.8.3 Dependability

Determining whether research results are consistent with collected data is a vital process of the research, to be able to assure the reader the results are dependable and consistent with collected data (Merriam & Tisdall, 2016). Strategies employed to ensure dependability and consistency included data triangulation and peer examination by members of the supervisory team, as previously addressed within *3.8.1 credibility*: and an audit trail.

Creating an audit trail availed the evidence used to reach decisions regarding theoretical and methodological issues throughout the study (Nowell et al., 2017). This was important to enable subsequent researchers' ability to follow the decision trail to 'arrive at the same or comparable, but not contradictory, conclusions' (Nowell et al., 2017, p. 3). The audit trail required records of raw data, field notes, transcripts of audio recordings and ongoing entries of the reflexive journal.

3.8.4 Confirmability

Confirmability established that the interpretations of the researcher were derived directly from the data sets obtained from participants. Guba and Lincoln (1989) conclude confirmability is reached, once credibility, transferability and dependability are all reached. Koch (1994) identified the importance for others in understanding why and how decisions were made throughout the research process and an audit trail enabled this. A clear audit trail was availed by the researcher to demonstrate how conclusions and interpretations have been reached (Nowell et al., 2017).

3.9 Chapter Summary

This chapter has identified and explored focussed ethnography as the methodological approach, and the methods used to successfully gather, analyse and interpret data. Ethical considerations of the study were addressed along with the four key aspects of establishing trustworthiness of findings: credibility, transferability, dependability, and confirmability. The following chapter will present a description summary of study participants along with identification and discussion of the primary and sub-themes within the findings of the study.

Chapter 4: Findings

4.1. Introduction

Chapter Four presents the findings of the ethnographic study undertaken to explore parental and carer experiences of Family Huddle participation within a paediatric haematology/oncology setting. An overview of participant demographics from Phase One and Phase Two of the study will firstly be presented along with a visualisation of a Family Huddle. Themes arising from thematic analysis will then be identified and explored. Quotations from participants have been included to enhance aspects raised within each theme.

4.2. Participant Profiles

Participants in this study were parents, of paediatric patients aged two to fifteen years, who were inpatients of the haematology/oncology unit. All paediatric patients in this study, were admitted under the oncology specialist team. Two fathers and eight mothers participated in Phase One of the study: the observed Family Huddle. Of the three observed Family Huddles, participant numbers were six, three and two participants respectively and were held in three separate months from late 2019 to the middle of 2020. One father attended two observed Family Huddles, with all other participants attending one each. Each participant attended the observed Family Huddle without the presence of the patient's other parent. Therefore, Phase one examined the lived experience of a parent of ten paediatric patients overall. The durations of each observed Family Huddle were 33 minutes, 20 minutes and 22 minutes respectively.

One father who participated in Phase One agreed to participate in Phase Two: a semi-structured face-to-face interview. One teenaged patient participated in Phase Two alongside her father. Whilst the teenaged patient was not the targeted participant in line with the research objectives, the interview was undertaken at the request of the father and daughter and ethical approval was amended to accommodate this. The patient contributed rich insight in support of her father's responses, which to disregard would detract substantially from communicating the lived experience of this family. The duration of the face-to-face interview was thirty-one minutes.

Table 3 further identifies demographic information of participants. Given the intimate size of the haematology/oncology unit, to maintain privacy of participants, a pseudonym has been assigned and ages of participants and their child not identified.

Table 3. Summary of participant characteristics.

Participant pseudonym	Mother/Father Carer	Phase One: Observed Family Huddle 1	Phase One: Observed Family Huddle 2	Phase One: Observed Family Huddle 3	Phase Two: Face-to-face interview
Kylie	Mother	√			
Melissa	Mother	√			
Kate	Mother	√			
Stephanie	Mother	√			
Jack	Father	√			√
Rebecca	Mother	√			
Nicole	Mother		√		
Claire	Mother		√		
Alex	Father		√	√	
Bree	Mother			√	

4.3. The Family Huddle Environment

Individual patient rooms stem the length of one side of a long corridor within the haematology/oncology unit. Across the corridor lay the parent room, where parents could retreat for a moment of refreshment and time out away from their hospitalised child. The parent room was the location chosen to accommodate all Family Huddles to the time of data collection, within the unit. For consistency, this location also was used for the observed Family Huddles.

The parent room consisted of a small kitchenette and fridge/freezer, a two-person blue couch, two small round tables with the odd chair tucked underneath, and a stack of chairs in the corner. Walls were filled with posters, notices, and a television. A small stand of magazines and books was located in one corner. Sounds of patient bells, monitor alarms, parent and nurse chatter adorned the surrounding space cutting through any momentary silence the room possessed. A sketch of the parent room layout can be seen in Figures 3 and 4. To enable depiction of inward and outward views of the parent room, the corridor wall has been illustrated transparently. In reality the corridor wall is not transparent, but opaque.

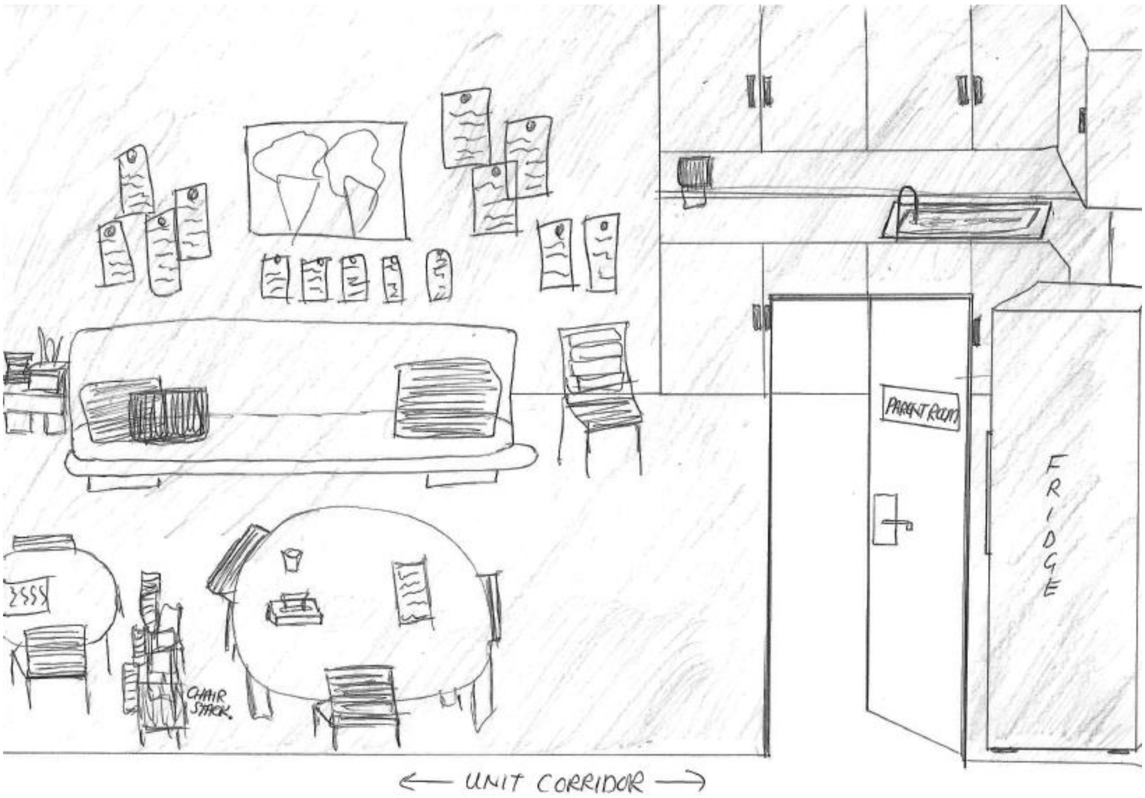

Figure 3. Inward view of Parent Room

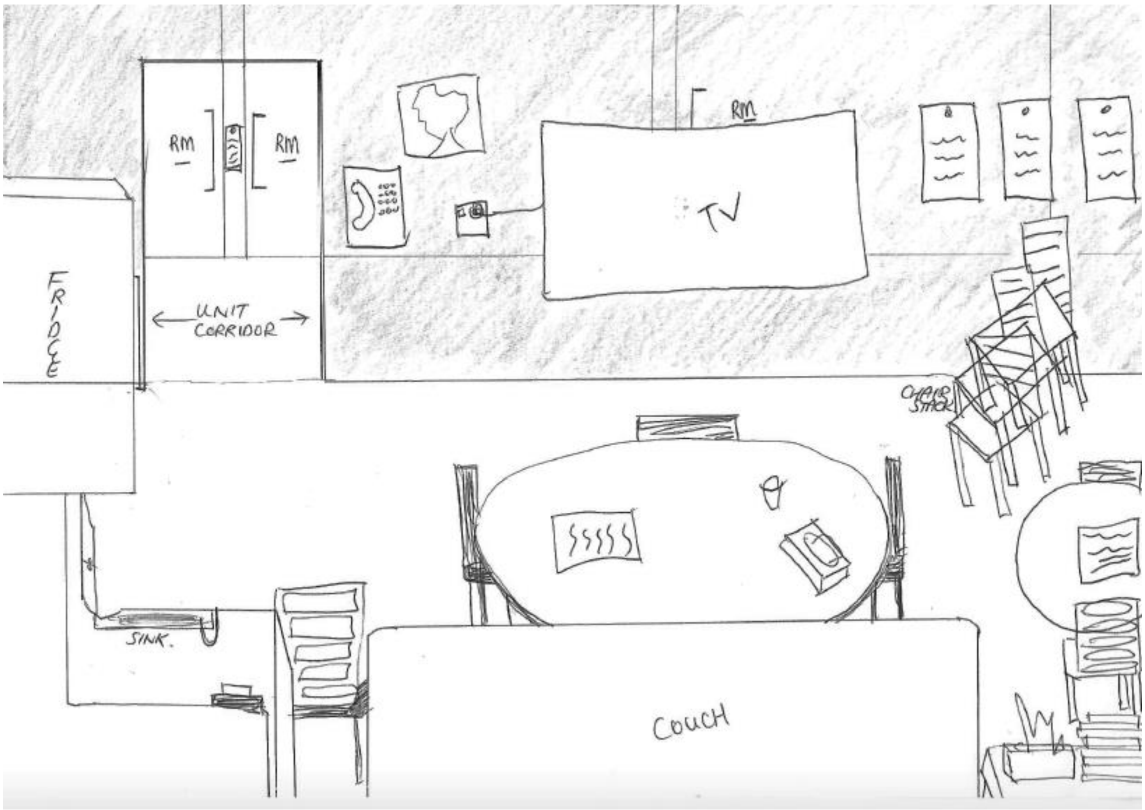

Figure 4. Outward view of Parent Room

4.4. Major Findings

Four primary themes emerged through analysis of transcripts generated from the observed Family Huddles and face-to-face interview. Primary themes included, ‘Service accessibility’, ‘Family centred comfort’, ‘Role uncertainty’, and ‘Information sharing’. Three subthemes emerged within the primary theme of ‘Service accessibility’, namely, ‘Unit accessibility’, ‘Staff accessibility’ and ‘Connectivity’. Presented findings often aligned with a number of themes, as themes were found to be often interconnected, rather than independent stand-alone themes. A visual representation of primary themes and interconnections between them, is presented in Figure 5.

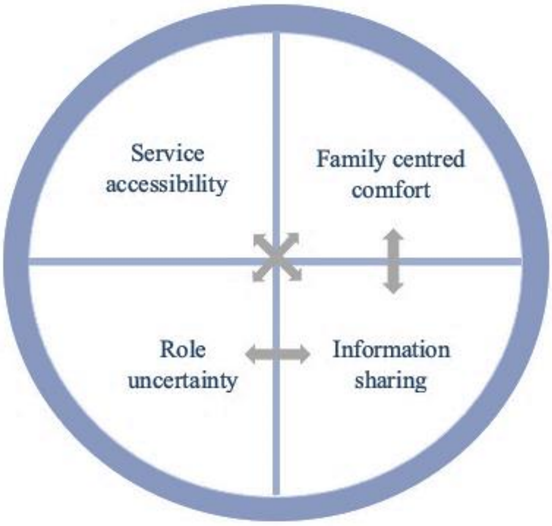

Figure 5. Visual Representation of Themes

4.5. Themes

4.5.1 Service accessibility

The first primary theme ‘Service accessibility’, arose out of parental desire for ease of access to services and physical locations throughout their child’s hospitalisation. Within this primary theme, are three subthemes including ‘Unit accessibility’, ‘Staff accessibility’ and ‘Connectivity’. Each sub-theme will now be explored with quotations from participants included to enhance the rich narrative.

Unit accessibility

Ease of accessibility to the unit was seen as important for parents, who would leave their child’s bedside to exit the unit for differing periods of time. Unit doors locking upon exiting, often resulted in parents returning and waiting for an extended period of time after pushing the door buzzer for re-entry. Kylie explained: *"Especially when they're doing their rounds or they're going around delivering stuff, sometimes 10-15 minutes you could be there just pushing it and waiting"*. Parental agreement ensued along with a sense of uncertainty: *"You don't know how long to leave it before you press that button again"* (Rebecca). Melissa expressed her anxiety an extended period standing at the entry to the unit caused her:

> *"I know when I was staying with K before, they were busy so I had to wait and I knew he was a bit distressed that day so it made me anxious as well, so I can imagine other parents being stressed waiting for long periods by the door to be let in"* (Melissa).

The unit representative facilitating the observed Family Huddle shared with the participants:

> *"Something that we could look into...security cards to come in and out of the ward...so that you're not having to wait at the entrance which can be a bit time consuming sometimes depending on how many nurses are on and how busy the ward is"*.

This was received well by participants in attendance with affirming nods of heads and Melissa expressing: *"I think that's a really good idea"*.

In addition, accessibility to locations within the unit were also raised. Location of the parent's room relative to patient rooms was identified by Claire and Jack as significant, when deciding accessibility and attendance to a Family Huddle. Figures 3 and 4, shown on page 34, depict the proximity of individual patient rooms down one side of the unit's corridor. This aligns parallel directly opposite the parent room. This was significant for Claire who stated*: "Because it is so close to the rooms it's almost a bit more comforting because you know your child's close by"*. Jack also stated: *"During admissions my wife or I will attend a Family Huddle if A is resting. I'm not so sure I would attend if it were held further away"*. Jack continued: *"I think it's reasonably central to both ends so from that perspective alone it's perfect really, but there might be people that disagree with that as well"*.

In consideration of the sizing of the parent room, Jack expressed: *"Look if it was a little bigger in a perfect world it would be fantastic, but it is what it is, and I think it does the job. It's better than nothing"*. Jack continued: *"Earlier I was in the parent room and there was another parent in there and the doctor came in to speak to the parent and I straight away felt like, okay I need* *to move out, so I can see how other parents might not feel they can relax entirely in there [the parent room] sometimes".*

Staff accessibility

In addition to ease of unit accessibility concerns for parents, timely access to staff within the unit was a reoccurring theme across all observed Family Huddles and the face-to-face interview. Lack of chemotherapy staff on a given shift was identified as a contributory factor to time taken away from nursing staff to tend to call bells, which was an area of ongoing concern.

> *"Even B, she sort of said, 'Mum tell them next time at the huddle', because they only have so many chemo trained staff I understand that they put so many on, but then there's two staffing that have to go and deliver all the chemos (sic) here. It's you push the buzzer, and you can be waiting and waiting and waiting because they're off doing chemo. B's waited for up to an hour for a nurse or they say they're going to come back and they don't and I get that they get busy and they forget, I do get that"* (Stephanie).

Accounts of piling up used bed pans were reported in patient rooms and many times a buzzer not answered for extended periods of time. Bree shared the anxiety her daughter experienced when Bree returned to the unit after a short trip home: *"There was like an hour gap before I came in, so she was by herself. She's pushed the buzzer and they haven't come straight away, and she was panicking and then when I got there, she just burst out crying".*

The workload demands of staff with procedures such as chemotherapy and having to escort patients to other areas of the hospital for salt baths, left reduced time to tend to the holistic care needs of paediatric patients. In the words of Aria, a teenaged patient who contributed to the face-to-face interview with her father Jack:

> *"I wanted to say about like maybe more staffing for things. Like especially if I'm here for 5 nights or if I'm here for long periods of time, sometimes I want to get out just even to go down to the café or the play deck or something just to get out for my mental health too. Because being cooped up in this room unable to go and especially if I'm like connected to this [intravenous therapy] sometimes...a nurse has to come with me"* (Aria).

Whilst staffing concerns were reoccurring, all parents also expressed their appreciation and acknowledged the hard-working nature of nurses and doctors. Alex for example stated: *"It's* *good to say your appreciation with the nurses and my experience with them have been fantastic for me I can't fault them".* Claire supported this notion and also shared her only concern being *"staffing...it's the amount of staff and it's not their fault".*

Connectivity

For families frequenting the haematology/oncology unit, connectivity to Wi-Fi and the internet was a daily occurrence. Wi-Fi enabled patients and families to connect their electronic devices such as smartphones and laptops wirelessly to the internet. During one observed Family Huddle, the unit representative explained: *"We never used to have internet at all and then through the Family Huddle parents would say it would be really useful to have W-Fi and internet access and so then we got this service for families, through their feedback".*

When connections became patchy due to presence in lead lined rooms, or lagging due to high usage, frustrations of patients were experienced.

> Nicole explained: *"Especially when you have a full ward, because you've got so many people using it, it just sort of, it's intermittent sometimes which J finds frustrating. She gets very frustrated".*

As consensus of ongoing interruption to internet connection was reached, the impact on teenagers was particularly prominent in discussions. Alex felt *"teenagers are a lot more hard done by when it's not operating. I assume for the younger kids they are a little less impacted, but I could be wrong".* During the face-to-face interview alongside her father, Aria shared:

> *"Especially sitting in a hospital, it does get pretty boring, and you want to be able to do something and being able to watch a movie or TV show it distracts you. That's what I experience here, it does get boring, especially if you're sitting in bed all day long".* Aria continued: *"The DVD's they've got here, they're good, but it does get boring after a while if you've seen all of them".*

Parents put forth suggestions to the unit representative for Wi-Fi boosters to increase access for patients and families to the internet. This was noted for follow-up by the unit representative who advised this would be listed on the agenda and a further update would be provided at the next Family Huddle. The hospital school internet was also put forth as an alternative by the unit representative, with a suggestion of posters to be placed in each patient's room advising how to access the hospital school's internet after hours. This suggestion was well received.

4.5.2 Family centred comfort

Another primary theme, ‘family centred comfort’, arose from parental desire of comfort for their hospitalised child. For children who are undergoing chemotherapy and on intravenous therapy, the need to urinate more frequently is a common occurrence. The first two observed Family Huddles saw consensus from parents regarding the poor quality of toilet paper provided within the unit. Jack shared: *“Well my daughter would like me to mention that we’ve had to bring toilet rolls in sometimes”*. Nicole also shared: *“Yeah because it’s thin. They [the hospital] think they’re saving money but in the long run the amount that you have to use it’s not saving money, is it?”*.

> *“When you’re on a drip and going to the toilet every 40 minutes or so, my daughter I get it, she complains all the time about the toilet paper, all the time. She just finds it coarse after a while like when you’re having to go so often it starts to hurt. And I think with everything else they’re going through; they should be comfortable”* (Kate).

During the third observed Family Huddle, the unit representative provided an update to parents in attendance regarding a trial of new toilet paper.

> *“So, we’ve got some newer toilet paper. Some feedback that we’ve had through the Family Huddle is that the toilet paper that is in the patient rooms...is really quite rough and really thin. So, we trialled a new one through the hospital which wasn’t very soft still, but we have got some new ones donated so we’re just going to try and see how we sustain that”* (Unit representative).

Parents agreed the new trialled donated toilet paper was well received by patients and parents alike and *“much softer and more comfortable”* (Claire). Speaking of the toilet paper Jack stated: *“They’re pretty stoked with the toilet paper, well she [his daughter Aria] is”*.

Seating comfort was also considered, with the unit representative sharing: *“chairs in the clinic and unit are quite uncomfortable to sit on, so that’s something that we’re looking into at the moment about how we can get some different ones for parents to trial”*. Following introduction of new chairs for trial, positive feedback was received from parents. Nicole stated: *“They’re heaps comfier especially when you’re sitting there all day”*.

> *“J likes those chairs too and it’s good, instead of sitting in the bed all the time she gets out of the bed now, whereas before she won’t because there was no recline on the chair, or she’d pinch my bed, not that mines comfier but to her it is”* (Claire).

In addition, comfort for parents themselves and other family members was considered important particularly in light of admissions across a number of days or weeks. Facilities provided for parents were considered by some parents to be inadequate to meet their needs. Lack of space in the parent room fridge/freezer and coffee brand supplies impacted parents' money expenditure whilst hospitalised and limited ability to bring in their choice of food and beverages. Bree shared:

> *"You need a bigger fridge. Sorry, but you need a bigger fridge. When the place is full there is no room in there. I know the space [parent room] is quite small, but they need a bigger fridge, especially for parents who want to bring meals in from home so they don't have to buy at the cafeteria all the time, you can't because there's no room there to"* (Bree).

Kate explained: *"I know last time when we were here the fridge was packed but the freezer was only half full, so almost you'd say half the freezer would probably be enough and bigger fridge capacity".* Whilst the majority of parents agreed the sizing of the fridge limited ability to bring food options in, Rebecca was a little less concerned: *"You can usually find somewhere to squeeze it in. I don't know, I just don't sweat the small stuff, I guess. Maybe it really bothers a lot of people, especially if they are here long term"*.

4.5.3 Information sharing

'Information sharing' was considered by parents to be vital throughout the period of hospitalisation. Whether communicating information about health status or providing feedback, two-way dialogue and sharing of information between parents and healthcare professionals, to keep parents informed was deemed valuable. When speaking about music therapy for example, Alex asked: *"Can we find out when and how often she [the music therapist] visits? Even if an information flyer was put up in the parent room would be good"*. Bree also shared:

> *"Does she get really busy? Because I know S loves seeing her, that's her favourite thing, like she's not interested in any of these other people, but she loves seeing her. We just don't really get to see her much or know when she is coming"* (Bree).

For Jack, throughout his face-to-face interview, he shared insights to the value he sees in attending Family Huddles. Having attended three previously, Jack indicated attendance at Family Huddles was *"a good opportunity for parents...not just parents but everyone to raise concerns and actually get some outcomes"*. It provides opportunity for parents to bring concerns raised by their child. *"Parents will come and say, 'my daughter wants this raised' or* *'this is what my son said'"* (Jack). Aria also suggested: *"It would be good to have maybe like a survey sheet for feedback, so I [as the patient] could write down things I want mum and dad to bring up at the Family Huddle. That way they don't have to try and remember it all"*.

Attendance at Family Huddles helps parents to obtain new information and *"helps general communication and probably getting things off your chest too. Having that two-way sort of feedback as well, like us as parents feeding both positives and negatives back is good"* (Jack).

> *"Most times, dads are going to not be the full-time carer and working, so opportunities are a lot less to be able to provide the feedback or get some sort of questions answered, so I like to get to a Family Huddle when I can and if the timings right. And if you get a little bit out of it, those things are massive to us"* (Jack).
>
> Aria shared: *"One outcome we got from the Family Huddle was the disabled parking permit. It's for free so you don't have to pay for it so that's one good thing we got out of the Family Huddle because one of the parents said about it to mum"* (Aria).

Having the choice to participate in a Family Huddle was welcomed by parents, knowing *"if you don't want to utilise it then that's okay too"* (Claire). Many parents felt it was beneficial to meet other parents, converse and share experiences with others who are going through a similar experience of a child hospitalised within the haematology/oncology unit. *"Because they [the other parents] know, because they understand and they're in the same position"* (Jack).

4.5.4 Role uncertainty

The final primary theme of 'Role uncertainty' arises from confusion caused through inconsistencies of individual health professionals and their care practices. Inconsistency of expectation placed on parents, was experienced by all parents on one or more occasions during their child's hospitalisation. A desire for standardised expectations was identified as important to parents.

> *"Something that would've helped me...like kind of more standardised ways of how if your child's having a procedure in clinic for example, some kind of process so it's consistent, between the different nurses. I've had ones where you don't know where to sit and you're kind of in a weird space because you have to be there with your child and it's hard because you feel like you need a role because you're in the room. Your role is like to comfort but then your kind of like, am I in the way? Some of them are really casual about it...other nurses don't want you near them or talking to them.*

> *Just if there was consistency, a process so that you're not in this vulnerable state and you want to have a role"* (Nicole).

Other accounts included parents feeling the need to seek permission to speak. *"Sometimes that nurse didn't want me to talk"* (Melissa). Not knowing where to sit or if being seated was permitted caused uncertainty. Alex stated: *"It's okay as long as you don't feel as if you're doing the wrong thing so you just kind of need to know what is my role?"*. Rebecca agreed: *"So long as you don't feel you're doing something wrong and people aren't getting angry with you"*.

> *"I think the hardest part for us is that everyone has different expectations of what they want us to do. Some of you want us to change a nappy every four hours during chemo and then others are like, well as long as you're changing it regularly enough then that's fine. Some things are different to every nurse and so it's very hard to know what you're meant to be doing"* (Kate).

The unit representative acknowledged that uncertainty or confusion may arise for parents. *"I think sometimes we forget a bit what it's like for you guys [the parents]. You know, we know what we're doing [the nurses] and what is to happen but sometimes we forget what it's like for you guys. I will certainly feed this back to the staff to be aware of"* (Unit representative).

4.6. Chapter Summary

The purpose of this study was to explore what parents/carers of hospitalised children within a paediatric haematology/oncology unit, experience from participating in a Family Huddle. An exploration of findings was provided within this chapter, having arisen from three observed Family Huddles and one face-to-face interview where parents were afforded opportunity to share their lived experience. The findings from this study revealed that the ten parent participants experienced several challenges and uncertainties during the period of hospitalisation of their child in the haematology/oncology unit. Participation in Family Huddles identified four primary areas of parental concern. Service accessibility, inclusive of unit accessibility, staff accessibility and connectivity, impacted the overall day to day lived experience of patients and parents alike, including likelihood of attending a Family Huddle. Family centred comfort indicated a need for improved care consumables and equipment for patients and families. Information sharing highlighted the benefits of two-way communication including parental feedback, improvements to service provision and keeping patients and parents informed via information provision. Finally, 'Role uncertainty' demonstrated that inconsistency of nurse to parent expectation, can lead to parental uncertainty, confusion, and feelings of judgement.

Chapter Five will consider the significance of these findings and how they compare with contemporary literature. Family Huddle participation and its relationship to the principles of family centred care will also be discussed. Strengths and limitations, of the study and its findings, will then be presented.

Chapter 5: Discussion

5.1. Introduction

Previous chapters demonstrated that there was a lack of identified literature that explored parental lived experiences of participating in a Family Huddle. Therefore, the aim of this study was to explore what parents/carers of hospitalised children within a paediatric haematology/oncology unit, experience from participating in a Family Huddle. To satisfy this aim, three objectives were established: to identify and explore 1) parental/carer experiences/perceptions of a Family Huddle; and 2) perceived barriers, motivators, enabling factors and parental/carer willingness to participate in a Family Huddle. The final objective was: 3) to explore and relate how a Family Huddle enhances the principles of family centred care. Chapter Four presented the findings in relation to these aims and objectives and identified four emerging primary themes of; ‘Service accessibility’, ‘Family centred comfort’, ‘Information sharing’ and ‘Role uncertainty’. Positive and negative aspects of lived parental experience existed throughout identified themes. This chapter will provide a discussion of the study’s major findings, with each primary theme presented in turn, and explore their significance informed by contemporary literature. Finally, the study’s strengths and limitations will then be identified.

5.2. Service accessibility

Existing literature supports the premise that hospitalisation of a child whether planned or unplanned, can be an exceptionally stressful event for the entire family unit (Fraser et al., 2014; Luczynski, 2020; Uhl et al., 2013). The primary theme of ‘Service accessibility’ identified three sub themes of; ‘Unit accessibility’, ‘Staff accessibility’ and ‘Connectivity’, that had the potential to contribute additional stressors to parents within this study. Reported stressors and anxiety for many of the parents, arose from delayed access to the unit, chemotherapy accredited nurse staffing shortages and interrupted connectivity to Wi-Fi and the internet. This to varying degrees detrimentally impacted parents lived experience within the unit, in addition to that at times of their hospitalised child. This is consistent with the work of Luczynski (2020) exploring adolescents’ need for patient and family centred care in an adult hospital environment. Specifically, parental support may still be required by adolescents. In addition, facilities for parents to stay including a kitchen and lounge facilities would have a beneficial impact by affording families opportunity to rest, to ‘be together and support each other’ and may decrease anxiety (Luczynski, 2020, p. 27).

Locality of the parent room was identified as an enabler of parental attendance at a Family Huddle. The parent room positioned in close proximity to patient rooms, instilled a sense of comfort and security for parents. The thought of the Family Huddle being held farther away, led some parents to indicate the likelihood of their attendance would diminish in such circumstances. Existing literature identified, for some hospitalised children, separation from parents and family members in an unfamiliar hospital setting could increase anxiety for the child and subsequently the parent and family members (Carter et al., 2014). Furthermore, families valued close proximity to their child or adolescent (Luczynski, 2020). Proximity of the parent room further away from patient rooms, therefore, was deemed a potential barrier to Family Huddle attendance for parents, whose child was experiencing a degree of separation anxiety.

The internet has emerged as one of the most common ways children and adolescents interact socially (McDool et al., 2020; Luczynski, 2020). Furthermore, for children and adolescents with health problems, accessing condition specific information through the internet has been shown to be a highly acceptable way for information to be obtained (Carter et al., 2014). When considering the purpose of Family Huddles, two aspects include a mutual understanding of optimal ward functionality, and identification of quality improvement projects (Ball, 2016). Implementation of free Wi-Fi and internet within the unit was achieved as a direct result of parental feedback received at previous Family Huddles. This in turn demonstrated a benefit of parental attendance, sharing of experiences and parental feedback, to inform mutual understanding and contribute to quality improvement within the unit. This process demonstrates organisational acknowledgement of the parental voice in this instance, and positively validates parental lived experience within the unit.

5.3. Family centred comfort

Parental desire to be an active participant in the care of their hospitalised child, has long been established in literature (Coyne 2013; Gill et al., 2012; Shields et al., 2012). Furthermore, the way in which parents have participated in their child’s care, has been seen as an important aspect of how the child experienced their period of hospitalisation (LaBrie et al., 2021; Phiri et al., 2020; Romaniuk et al., 2014; Uhl et al., 2013). Part of this need to be an active participant in their child’s care, was evident in this study through parental desire to achieve comfort, not only for their child, but also the family unit. Within the literature, one notion of comfort which aligns well with the philosophy of family centred care, relates to ‘having the needs for relief, ease, and transcendence addressed in the four contexts of holistic human experience: physical, psychospiritual, sociocultural, and environmental’ (Pinto et al., 2017, p. 7).

Within this study, parents played an active role to address the comfort needs of their hospitalised child. During Family Huddles parents were afforded opportunity to feedback areas of concern regarding the holistic care and comfort needs of their child and family. Just as parent feedback achieved quality improvement within the theme of service accessibility, this too occurred across comfort needs of the child and family. Parental feedback at Family Huddles regarding coarseness of toilet paper for example, yielded a trial of new toilet paper, improving comfort and satisfaction for patients and families alike. This was well received by patients and parents and reinforced the value of parental voice and sharing their lived experience.

5.4. Information sharing

The theme of ‘Information sharing’ refers to parental desire to both share information with others and to receive information, throughout the period of hospitalisation. This emerging theme is consistent with findings of the Scoping Review in Chapter Two of this thesis. The Scoping Review identified a clearly established need by parents, for sharing and exchange of information regarding the hospitalised child (Foster & Whitehead 2017; Hill et al., 2019; Krisnana et al., 2019; Kuo et al., 2012; Labrie et al., 2021; Mak et al., 2014; Phiri et al., 2020; Saria et al., 2019; Seliner et al., 2016; Svavarsdottir & Sigurdardottir 2013; Uhl et al., 2013). Whilst there are several structured ways in which information can be shared within a health service (Carter et al., 2014), there are also less formal and less structured settings within which information sharing can take place, including a Family Huddle.

Within this study, the Family Huddle was carried out in part, in line with two of its identified purposes. These two purposes being, ‘to provide information to consumers and caregivers within a ward environment’ and ‘to provide caregivers and consumers the opportunity to discuss any issues or questions related to the ward environment and suggestions for improvement’ (Ball, 2016, p. 3). The intent of Family Huddles was clear, and parents appreciated the opportunity to have open respectful dialogue with fellow parents and the unit representative. Attendance and participation within a Family Huddle afforded parents opportunity to raise concerns and achieve outcomes and debrief with fellow parents who had shared similar experiences of a child hospitalised with a cancer diagnosis. Furthermore, parents were able to exercise their right of choice, in choosing when and if they wished to participate or not.

Two-way dialogue between parents in attendance at the Family Huddle and the unit representative, enabled sharing of constructive feedback and areas of potential quality improvement. In addition, as new initiatives such as free Wi-Fi and internet for example, were rolled out based on previous parental feedback, the potential of enablement for future re-attendance at Family Huddles of parents strengthened. Indication of this strengthening was identified in parental feedback via their observation of feedback in action and voicing their belief that through feedback at Family Huddles, positive changes have been and could be made within the unit.

As parental engagement in the Family Huddle process continued, so too did the sharing of messages and lists given to parents by their hospitalised child to discuss at the Family Huddle. Once considered passive and silent recipients of care (Carter et al., 2014), children and adolescents are increasingly being listened to as their participation in their own self care is encouraged. Throughout the Family Huddle process parents frequently assumed the role of messenger or acted as a conduit to inform the health service of feedback informed by the lived experience of their child, thereby validating to varying degrees the voice of the child.

5.5. Role uncertainty

Hospitalisation of a child requires adaptation of parents to an environment shared with health professionals. This adaptation demands changes to occur in roles, responsibilities, power, and authority, as families try and engage and adapt to function successfully in partnership with the health care team (Carter et al., 2014). The nurse/family working relationship is impacted by power and control which can at times be challenging for all parties involved. Existing literature identifies a lack of effective communication, and poor or minimal information sharing inhibits parental ability to establish clear role expectations with nursing staff (Uhl et al., 2013). These findings are consistent with findings within this study relating specifically to parental role uncertainty. Parents reported feelings of confusion and frustration with a strong desire for consistency of expectation placed on parents by nursing staff. The need for standardised expectations was shared within the Family Huddle forum and acknowledged by the Clinical Nurse as an identified issue requiring further consideration and addressing at staff level.

5.6. Significance of the findings to family centred care

Family centred care is recognised as the most common philosophical approach underpinning health care delivery for children and adolescents in the Western World (Carter et al., 2014). All definitions of family centred care hold general consensus in placement of the child and family at the centre of care. The Institute for Patient and Family-Centred Care (2018, cited in Al-Motlaq et al., 2019, p. 459) define family centred care as '...an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families. According to Kuo et al., (2012, p. 298) general principles of family centred care focus on; information sharing, respect and honouring differences, working in partnership, negotiation and care in the context of family.

Themes generated from this study highlight the importance of Family Huddle delivery in alignment with the values underpinning Family Huddles. These values are formed on the principles of; person and family centred care, partnership, transparency, and access to information (Ball, 2016). Parents who participated in this study, were successfully able to share feedback of their lived experiences and build supportive rapports with fellow unit parents. They were also able to contribute purposefully and constructively to quality improvement within the unit in the areas of; service accessibility, family centred comfort, information sharing and role uncertainty.

5.7. Strengths and limitations

Strengths

This study was the first known research undertaken to explore what parents/carers of hospitalised children within a paediatric haematology/oncology unit, experience from participating in a Family Huddle. The findings, therefore, form an initial insight to the lived experience of parents participating in a Family Huddle. Opportunity exists to utilise the findings as a basis to inform clinical education of health care professionals of the benefits of Family Huddle conduction in hospital ward and unit settings.

Another strength of this study is the contribution of two fathers to Phase One being the observed Family Huddle, and one of these fathers subsequently participating in Phase Two, the face-to-face interview. There is often a paucity of research of viewpoints of fathers focussing on the care of the child. The insight provided by both fathers in this study, contributes significantly to the richness of the lived parental experience of fathers.

This research was conducted as part of a master's program, by a researcher who is considered a novice. Despite this, the ongoing supervision, discussion with and expert guidance by three supervisors experienced in research conduction, maximised credibility and rigour of the study.

Limitations

Ethnographic research uses the researcher as the instrument in data collection. Therefore, a risk of bias exists if the researcher's ability to identify and record observations is impaired or swayed. Using reflexivity, the researcher was able to minimise the risk of bias. Reflexivity required the researcher to carefully consider each step during the conduction of the study and how their own perspective may influence the data (Greenhalgh et al., 2020). Furthermore, the researchers own reflections were challenged by sharing thoughts and reflections with the supervisory team which fostered an approach of curiosity and open-mindedness.

Sample size in qualitative research is dependent upon a number of factors including information needs and achievement of data saturation (Polit & Beck, 2018). Whilst the researcher intended to undertake a minimum of three face-to-face interviews in Phase Two, only one face-to-face interview was achieved. As the acuteness and sensitivity of a haematology/oncology unit, the researcher understood at commencement of the study that parental willingness to participate in a face-to-face interview, may have been challenging. Given this was the first research of its kind exploring parental participation in Family Huddles, the single face-to-face interview was considered a promising starting point for emergence of the lived experience of parents.

All participants of this study self-identified as 'parents' of the hospitalised child. There were no self-identified 'carers' in the participant group, therefore comparison cannot be made of the parent experience to that of a carer of a hospitalised child. This does afford opportunity for future research, should a comparison be deemed necessary. Despite the new findings gathered from this study, in view of several limitations, caution should be applied when interpreting results.

5.8. Chapter Summary

This chapter provided a discussion of the study’s major findings. Given this study was the first of its kind exploring parental experiences of participation within a Family Huddle, opportunity to compare to existing literature was limited. Through this study, parental experiences and perceptions of a Family Huddle have been considered and explored. Barriers, motivators, enabling factors and parental willingness to participate in a Family Huddle have been established. Furthermore, consideration of how a Family Huddle enhances the principles of family centred care has been addressed. Finally, the strengths and limitations of this study have been presented for consideration during the interpretation of results. The following chapter will conclude this thesis, with incorporation of implications for nursing and recommendations for future research.

Chapter 6: Conclusion

6.1. Introduction

With no existing literature exploring parental lived experience of participating in a Family Huddle, this research study was necessary to generate a narrative, rich in parental lived experience and cultural context. Qualitative ethnographic methodology, therefore, was used with an aim to explore parental/carer experiences of participating in a Family Huddle within a haematology/oncology unit. This concluding chapter will provide a summary of the findings of this research study. Implications relating to current nursing practice will then be identified and discussed, followed by suggestions for possible areas of future research.

6.2. Summary of study findings

This study set about achieving a clear aim and objectives. To recap, the study objectives included identifying and exploring parental/carer experiences/perceptions of a Family Huddle. Furthermore, perceived barriers, motivators, enabling factors and willingness to participate in a Family Huddle were sought. Finally, to explore and relate how a Family Huddle enhanced the principles of family centred care. Facilitated by qualitative design, the intended aim and objectives of this study were met. The study findings were summarised into four primary themes of: ‘Service accessibility’, ‘Family centred comfort’, ‘Information sharing’ and ‘Role uncertainty’. The first theme ‘Service accessibility’, encompassed three subthemes including ‘Unit accessibility’, ‘Staff accessibility’ and ‘Connectivity’, and identified parental desire for ease of access to services and physical locations throughout the child’s hospitalisation. ‘Family Centred Care’ illustrated parental desire of physical comfort for the hospitalised child as well as themselves and other members of the family unit. ‘Information sharing’ was deemed vital throughout the period of hospitalisation, with effective two-way communication central to parents obtaining new information and effective communication between parents, patients, and health care professionals. Finally, ‘Role uncertainty’ identified inconsistencies in clinical practice of health professionals as well as inconsistency of nursing expectation of parents, leading to parental role uncertainty and at times frustration. Furthermore, themes generated from this study highlighted the importance of Family Huddle delivery in alignment with the values underpinning Family Huddles, including person and family centred care, partnership, transparency and access to information (Ball, 2016). From the identified themes in this study, several areas arose for consideration of implications for nursing and recommendations to clinical nursing practice. Identification of implications for nursing and recommendations for changes to clinical nursing practice will now be considered, with intent to facilitate enhancement of the lived experience of parents and carers during periods of a child's hospitalisation.

6.3. Implications for nursing practice

This study explored many important aspects of what it is like for a parent of a hospitalised child, participating in a Family Huddle within a haematology/oncology unit in a paediatric setting. A number of implications for nursing practice and recommendations have arisen from the findings of this study. Implications for nursing practice and recommendations will now be addressed below.

Family Huddle Framework review

In 2016, the organisation under study, developed and endorsed a Family Huddle Framework underpinned by the values of person and family-centred care, partnership, transparency and access to information (Ball, 2016). With the last review of the Family Huddle Framework occurring in 2016, recommendation would be for the organisations' Consumer and Community Engagement Unit to undertake a review of the framework. A review of the framework would enable the ongoing implementation and review of Family Huddles to maintain contemporariness. Furthermore, the framework should be informed by and align with the more recently published strategic direction of the organisation (Women's and Children's Health Network, 2020). Organisations wanting to adopt Family Huddles within their settings, should do so informed by an organisation specific evidence-based framework, aligned to their strategic direction. Furthermore, organisations should be committed to professional development of staff, both prior to Family Huddle commencement and throughout delivery.

Professional development of health care staff

The Family Huddle Framework envisions engagement and effective communication of staff with consumers and caregivers across the continuum of the child's hospitalisation (Ball, 2016). Whilst one or two staff representatives may be designated within each area to facilitate a Family Huddle, all staff hold responsibility to promote and inform consumers of the presence of Family Huddles within the ward/unit. To empower staff to promote Family Huddles to consumers, all staff must be informed of the benefits of Family Huddle participation for parents and carers.

Professional development should focus on discussion of the purpose, scope and intent, values underpinning and process of a Family Huddle.

Promotion of Family Huddles

It was evident in this study that the unit representative of the Family Huddle doing a round of the unit prior to Family Huddle commencement, was one effective method of recruiting attendees to a Family Huddle. For parents and carers as consumers to engage in the Family Huddle process, adequate ongoing promotion of Family Huddles is required. This will require evidence-based promotional materials placed throughout the unit/ward to share a clear timetable for upcoming Family Huddles. In addition to, provision of Family Huddle literature or audio-visual materials to families as part of the admission process to the unit/ward, may increase knowledge of Family Huddle delivery. A Family Huddle information brochure accompanying admission packs can be explained by the admitting staff member with the parents/carers to maximise understanding on the purpose of a Family Huddle. Furthermore, information of upcoming Family Huddle sessions may be shared within ward/unit parent groups online as appropriate.

Implementation of Patient Huddles

Desire of the teenaged patient to participate in this study and share her interest to attend what she termed a ‘patient huddle’, highlighted the importance of the voice and lived experience of the child. Furthermore, parents shared the feedback of their hospitalised child who wanted specific issues raised at the Family Huddle. It, therefore, would be useful for organisations to consider the appropriateness of a patient huddle. A patient huddle, for attendance by hospitalised children and adolescents, may enable the sharing of experiences and enable feedback, much the same way Family Huddles are delivered. Attendance at patient huddles, may also offer opportunity for peer support and information sharing. Information sharing could include distribution and discussion of support materials from organisations such as Canteen, an Australian not-for-profit organisation that provides free and tailored support to young people and their families impacted by cancer (Canteen, 2021).

Location of the Family Huddle

Consideration of the Family Huddle location to maximise attendance opportunity, is necessary. It was evident from parental feedback during this study that factors including location of patient to parent, and to a lesser extent the size of the room, is important. Parent’s felt more at ease to attend a Family Huddle when they were in close proximity to their hospitalised child. Organisations looking to implement Family Huddles, therefore, should consider appropriate facilities such as seating, location and size of room, to enhance opportunity for parental/carer presence at a Family Huddle.

Connectivity to free Wi-Fi

Access to Wi-Fi and the internet emerged as an important enabler for maintenance of social interaction and connectedness of the hospitalised child with friends and family. Furthermore, it was considered a means to continue educational activities, as well as a source of entertainment for the hospitalised child and family members throughout the period of hospitalisation. Access for consumers, particularly those facing lengthy periods of hospitalisation, to free Wi-Fi would be advantageous. Where a hospital school exists within an organisation, instructions for ward/unit staff to connect patients to the hospital school’s Wi-Fi connection would be recommended, particularly after hours when access to hospital school staff is not available.

Family Huddle feedback loop

The benefit of two-way information sharing between parents and the unit representative was clear during the Family Huddle process. Parental feedback at Family Huddles informed review of care provisions and services, resulting in for example, implementation of free Wi-Fi for consumers, new recliner chairs and greater quality toilet paper for use by hospitalised children. Parental feedback via a Family Huddle to inform the lived care experience of the hospitalised child is important. Furthermore, feedback to parents from the unit representative to provide updates resulting from parental feedback and suggestions is equally as important. Implementation of a Family Huddle folder to provide documented feedback to parents would be recommended, enabling parents unable to attend an upcoming Family Huddle, to have access to suggestion or feedback updates from the ward/unit.

6.4. Recommendations for future research

This study is the first of its kind researching the parental experience of participation within a Family Huddle within a haematology/oncology unit. Whist this study has achieved its aim and objectives, there is certainly scope for further research to explore the lived experience of parents and patients as consumers, participating in a Family Huddle within the clinical setting. The following recommendations for future research can be made from this thesis:

1) Studies to explore the experiences of carers of hospitalised children participating in a Family Huddle.

2) Studies to examine consumer engagement with Family Huddles over a longer duration of time and organisation wide, rather than solely unit/ward specific.

3) Studies to determine parental satisfaction and empowerment from participation in a Family Huddle using a validated satisfaction and/or empowerment tool.

4) A mixed-method study to evaluate adolescent participation and satisfaction in a patient huddle (if deemed ethically appropriate by individual organisations).

5) Studies to determine health care professionals' knowledge of and willingness to promote Family Huddle participation to consumers of the organisation.

6.5. Chapter Summary

Using a qualitative ethnographic design, this study has provided an initial insight into the experiences of parents of hospitalised children within a paediatric haematology/oncology unit, participating in a Family Huddle. Unique insight into a number of themes occurred, specifically; 'Service accessibility', 'Family centred comfort', 'Information sharing' and 'Role uncertainty'. The study's findings suggest parental participation in Family Huddles offers benefit to parents as consumers and enhances the principles of family centred care. Whilst the first study of its kind exploring parental participation in a Family Huddle, it is hoped identified future research will further strengthen the need for Family Huddle and potentially patient huddle promotion and participation moving forward.

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Appendix 1: Critical appraisal tables of included studies and reviews

Summary of critical appraisal of included qualitative studies:
Adapted from Critical Appraisal Skills Programme (CASP) (2018a), 'Ten questions to help you make sense of qualitative research'

Author & date	**Highman & Davies** **2013**	**Mak, Hiebert Murphy, Walker & Altman** **2014**	**Saria, Mselle & Siceloff** **2019**
Q.1 Was there a clear statement of the aims of the research?	Y	Y	N
Q.2 Is a qualitative methodology appropriate?	Y	Y	Y
Q.3 Was the research design appropriate to address the aims of the research?	Y	Y	C
Q.4 Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y
Q.5 Was the data collected in a way that addressed the research issue?	Y	Y	Y
Q.6 Has the relationship between researcher and participants been adequately considered?	Y	Y	Y
Q.7 Have ethical issues been taken into consideration?	Y	Y	Y
Q.8 Was the data analysis sufficiently rigorous?	Y	Y	Y
Q.9 Is there a clear statement of findings?	Y	Y	Y
Q.10 How valuable is the research?	Y	Y	Y

Key: *Yes = Y, No = N, Can't Tell = C*

Summary of critical appraisal of included quantitative studies:
Adapted verbatim from Critical Review Guidelines for Quantitative Studies (Whitehead et al., 2020, p.70)

Critical Review Guidelines for Quantitative Studies

The Title and Abstract

a. Is the title of the research paper congruent with the text?
b. Were the aims and/or objectives stated? What are they?
c. Did the abstract contain sufficient information about the stages of the research process (e.g., aims, hypothesis, research approach, sample, instruments, and findings)?

Structuring the Study

a. Is the motivation for the study demonstrated through the literature review?
b. Is the literature cited current, relevant and comprehensive? Are the references recent?
c. Are the stated limitations and gaps in the reviewed literature appropriate and convincing?
d. How was the investigation carried out?
e. Is the hypothesis stated?
f. Which hypothesis is stated: the scientific hypothesis or the null hypothesis?
g. Does the hypothesis indicate that the researcher is interested in testing for differences between groups or in testing for relationships?

The Sample

a. Is the sample described?
b. Is the sample size large enough to prevent an extreme score from affecting the summary statistics used?
c. How was the sample size determined?
d. Was the sample size appropriate for the analyses used?

Data Collection

a. How were the data collected (questionnaires or other data collection tools)?
b. Who collected the data?
c. Are the data adequately described?
d. What is the origin of the measurement instruments?
e. Are the instruments adequately described?
f. How were the data collection instruments validated?
g. How was the reliability of the measurement instruments assessed?
h. Were ethical issues discussed?

Data Analysis

a. Are descriptive or inferential statistics reported?
b. What tests were used to analyse the data: parametric or non-parametric?
c. Were the descriptive statistics/inferential statistics appropriate to the level of measurement for each variable?
d. Were the appropriate tests used to analyse the data?
e. What is the level of measurement chosen for the independent and dependent variables?
f. Were the statistics appropriate for the research question and design?
g. Are there appropriate summary statistics for each major variable?
h. Were the statistics primarily descriptive, correlational, or inferential?
i. Identify the outcome of each statistical analysis.
j. Explain the meaning of each outcome.

Findings

a. Were the findings expected? Which findings were not expected?
b. Is there enough information present to judge the results?
c. Are the results clearly and completely stated?
d. Describe the researcher's report of the findings.
e. Identify any limitations or gaps in the study.
f. Were suggestions for further research made?
g. Did the researcher mention the implications of the study for healthcare?
h. Was there sufficient information in the report to permit replication of the study

Summary of critical appraisal of included quantitative studies:
Adapted verbatim from Critical Review Guidelines for Quantitative Studies (Whitehead et al., 2020, p.70)

Author & date	**Çamur & Karabudak** **2020**	**Dadlez, Bisono, Williams, Rosenthal & Hametz** **2018**	**Foster &Whitehead** **2017**	**Krisnana, Sulistyarini, Rachmawati, Sufyanti Arief & Dwi Kurnia** **2019**	**Kruszecka-Krówka, Smoleń, Cepuch, Piskorz-Ogórek, Perek & Gniadek** **2019**
Title/abstract					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	Y	Y
c	Y	N	Y	Y	Y
Study structure					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
e	Y	N	N	N	N
f	Y	N	N	N	N
g	Y	N	N	N	N
Sample					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	C	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	N	Y
Data collection					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
e	Y	Y	Y	Y	Y
f	Y	C	Y	Y	Y
g	Y	Y	Y	Y	C
h	Y	Y	Y	Y	Y
Analysis					
a	Y	Y	Y	Y	Y
b	Y	N	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
e	Y	Y	Y	Y	Y
f	Y	Y	Y	Y	Y
g	Y	N	Y	Y	Y
h	Y	Y	Y	Y	Y
i	Y	Y	Y	Y	Y
j	Y	Y	Y	Y	Y
Findings					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
e	Y	Y	N	Y	Y
f	N	Y	Y	N	Y
g	Y	Y	Y	Y	Y
h	Y	Y	Y	Y	Y

Key: *Yes = Y, No = N, Can't Tell = C*

Summary of critical appraisal of included quantitative studies continued..
Adapted from Critical Review Guidelines for Quantitative Studies (Whitehead et al., 2020, p. 70)

Author & date	**Kuo, Sisterhen, Sigrest, Biazo, Aitken & Smith** **2012**	**Mucuk & Cimke** **2017**	**Romaniuk, O'Mara & Akhtar-Danesh** **2014**	**Rostami, Syed Hassan, Yaghami, Ismaeil & Saundi** **2012**	**Svavarsdottir & Sigurdardottir** **2013**
Title/abstract					
a	Y	Y	Y	Y	Y
b	C	Y	Y	Y	Y
c	N	Y	Y	Y	Y
Study structure					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
e	N	N	Y	N	N
f	N	N	C	N	N
g	N	N	Y	N	N
Sample					
a	Y	Y	Y	Y	Y
b	Y	C	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
Data collection					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
e	Y	Y	Y	Y	Y
f	Y	Y	Y	Y	Y
g	Y	Y	Y	Y	Y
h	Y	Y	Y	Y	Y
Analysis					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
e	Y	Y	Y	Y	Y
f	Y	Y	Y	Y	Y
g	Y	Y	Y	Y	Y
h	Y	Y	Y	Y	Y
i	Y	Y	Y	Y	Y
j	Y	Y	Y	Y	Y
Findings					
a	Y	Y	Y	Y	Y
b	Y	Y	Y	Y	Y
c	Y	Y	Y	Y	Y
d	Y	Y	Y	Y	Y
e	Y	N	Y	N	Y
f	Y	N	Y	Y	N
g	Y	Y	Y	Y	Y
h	Y	Y	Y	Y	Y

Key: *Yes = Y, No = N, Can't Tell = C*

Summary of critical appraisal of included mixed method studies:
Adapted from Mixed Method Appraisal Tool (Hong et al., 2018)

	Author & date	**Seliner, Latal & Spirig** **2016**	**Uhl, Fisher, Docherty & Brandon** **2013**
Screening questions (for all types)	S1. Are there clear research questions?	**Y**	**Y**
	S2. Do the collected data allow to address the research questions?	**Y**	**Y**
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?	**Y**	**Y**
	1.2. Are the qualitative data collection methods adequate to address the research question?	**Y**	**Y**
	1.3. Are the findings adequately derived from the data?	**Y**	**Y**
	1.4. Is the interpretation of results sufficiently substantiated by data?	**Y**	**Y**
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	**Y**	**Y**
2. Quantitative RCTs	2.1. Is randomization appropriately performed?	-	-
	2.2. Are the groups comparable at baseline?	-	-
	2.3. Are there complete outcome data?	-	-
	2.4. Are outcome assessors blinded to the intervention provided?	-	-
	2.5 Did the participants adhere to the assigned intervention?	-	-
3. Quantitative Non-randomised	3.1. Are the participants representative of the target population?	-	-
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	-	-
	3.3. Are there complete outcome data?	-	-
	3.4. Are the confounders accounted for in the design and analysis?	-	-
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	-	-
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?	**Y**	**Y**
	4.2. Is the sample representative of the target population?	**Y**	**Y**
	4.3. Are the measurements appropriate?	**Y**	**Y**
	4.4. Is the risk of nonresponse bias low?	**Y**	**Y**
	4.5. Is the statistical analysis appropriate to answer the research question?	**Y**	**Y**
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	**Y**	**Y**
	5.2. Are the different components of the study effectively integrated to answer the research question?	**Y**	**Y**
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	**Y**	**Y**
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	**Y**	**Y**
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	**Y**	**Y**

Key: *Yes = Y, No = N, Can't Tell = C, Not applicable = -*

Summary of critical appraisal of included reviews:
Adapted from Critical Appraisal Skills Programme (CASP) (2018b), '10 questions to help you make sense of a Systematic Review'

Author & date	**Hill, Knafl &Santacroce** **2019**	**Labrie, van Veenendaal, Ludolph, Ket, van der Schnoor & van Kempen** **2021**	**Phiri, Chan & Wong** **2020**
Q.1 Did the review address a clearly focused question?	Y	Y	Y
Q.2 Did the authors look for the right type of papers?	Y	Y	Y
Q.3 Do you think all the important, relevant studies were included?	Y	Y	Y
Q.4 Did the review's authors do enough to assess quality of the individual studies?	Y	Y	Y
Q.5 If the results of the review have been combined, was it reasonable to do so?	Y	Y	Y
Q.6 What are the overall results of the review?	Y	Y	Y
Q.7 How precise are the results?	Y	Y	Y
Q.8 Can the results be applied to the local population?	Y	Y	Y
Q.9 Were all important outcomes considered?	Y	Y	Y
Q.10 Are the benefits worth the harms and costs?	Y	Y	Y

Key: *Yes = Y, No = N, Can't Tell = C*

Appendix 2: Summary table of included studies

Author and Date	Aim/Objectives	Sample and Setting	Methodology and Methods	Major Findings	Rigour and Limitations
Çamur & Karabudak **2020** **Turkey**	To determine the effect of parental participation in the care of hospitalized children on parent satisfaction and parent and child anxiety.	Participants n=122 parents of children 8 years to 18 years of age Setting Paediatric clinic of State hospital admitted >48 hours	Quantitative: Randomised controlled trial	- Statistically significant difference between pre-test and post-test scores on the 'information', 'parental participation', 'communication' and 'technical skills' subscales (*p* <0.001) for intervention group. - Post-test scores of 'emotional needs' and 'general satisfaction' subscales significantly higher in intervention group (*p* <0.001).	Thesis work with single researcher for data collection, therefore not blinded. Patient profile = low socio-economic impacting generalizability.
Dadlez, Bisono, Williams, Rosenthal & Hametz **2018** **United States of America**	To evaluate parents' preferences surrounding decision-making for their children and whom parents would like to include (self, other parent, and extended family).	Participants n=116 parents (106 mothers, 10 fathers) of children aged 7 years and below. Setting Inpatient service of children's hospital	Quantitative: Survey	- 99% parents agreed they themselves should participate in medical decision-making. - 76% agreed or strongly agreed that they would want to take "greater control" in decision-making if the child's condition were to worsen. - Clinical acuity and the perception of increased risk associated with the decision, may add tension to the decision-making process. With increased risk, parents may want to share the burden of the decision with others.	Participants paid $25 as time compensation. No limitations identified by researchers.
Foster &Whitehead **2017** **New Zealand**	To identify parents' and staff's perceptions of parent's needs during a paediatric high-dependency unit admission and the relationships between needs, socio-demographic and clinical variables and explored if these perceptions have changed.	Participants n=104 parents (86 mothers, 18 fathers) of children newborn to 15 years of age n= 88 nursing staff Setting Single Paediatric High Dependency Unit that facilitates Family Centred Care.	Quantitative: Cross-sectional descriptive correlational design	- Parents placed informational needs as more important (*P* = 0.014), met and needed than staff. - The domains most influenced (*P* = <0.05) by demographic variables were support, information, and resources with treatment and to be trusted the least represented. - Targeting care to align with the domains rated as highly important by parents and increasing staff awareness of positive health care delivery will sequentially influence parent and staff satisfaction.	No limitations identified by researchers.
Highman & Davies **2013** **United Kingdom**	To gain an increased understanding of fathers' experiences during their child's stay in hospital as an unplanned admission for acute illness or injury.	Participants n=12 fathers of children newborn to 16 years of age n= 7 qualified children's nurses Setting Two children's wards of a district general hospital	Qualitative: Ethnography Critical realist approach Semi-structured interviews 150 hours of ethnographic observation	- Fathers want to be present with their sick child in hospital yet face challenges in doing so. - Fathers observed undertaking protective roles including being strong and advocacy. - Fathers acted as advocates by asking for equipment or supplies and dealing with perceived care inadequacies - One father advocated actively by recommending use of a pain assessment scale for his child.	Information needs not considered. Small sample size

Author and Date	Aim/Objectives	Sample and Setting	Methodology and Methods	Major Findings	Rigour and Limitations
Hill, Knafl &Santacroce **2019** **United States of America**	To examine the extent to which published research articles concerning parent perspectives on their involvement in the child's care in a PICU demonstrate implementation of the four core concepts of FCC.	Participants Setting n/a	Integrative review: n= 32 qualitative/mixed methods n=17 quantitative	- Concepts of respect and dignity, information sharing, and participation were well represented in the literature, as parents reported having both met and unmet needs in relation to FCC. - Similar to the type and amount of information preferred, parents expressed satisfaction and dissatisfaction with communication in the Paediatric Intensive Care Unit. - Parents reported that participating in medical rounds about their child provided opportunities to receive and exchange information.	Authors of included studies may have only reported on data relevant to their research question and in turn parent report data specific to FCC concepts may not have been included in their results.
Krisnana, Sulistyarini, Rachmawati, Sufyanti Arief & Dwi Kurnia **2019** **Indonesia**	To analyze the effect of a parenting empowerment module, with the aim of reducing the stress experiences by mothers of children suffering from leukemia.	Participants n=60 mothers of children Setting Paediatric Oncology ward	Quantitative: Quasi-experimental Pre-test/post-test control group	- Cognitive empowerment can improve the understanding of parents caring for leukemic children and reduces the level of stress associated with hospitalization. - The Family Centered Empowerment Module (FACE) can reduce stress levels in parents of children with leukemia. - Information about nutritional needs,prevention of infection, and prevention of bleeding can increase parental knowledge, giving parents confidence to care for their own children.	Age demographics of children not identified Small sample size
Kruszecka-Krówka, Smoleń, Cepuch, Piskorz-Ogórek, Perek & Gniadek **2019** **Poland**	The assessment of determinants of parental satisfaction with nursing care in paediatric wards.	Participants n= 336 parents (284 mothers, 52 fathers) of children 0 to 16 years of age Setting General paediatric and specialist (non-surgical) departments at University Children's Hospital and Provincial Specialist Children's Hospital	Quantitative: Questionnaire	- Parents of children admitted to the hospital in an emergency mode, gave lower score for the individual criteria of satisfaction with care (I "Information", II "Care and Treatment", IV "Parental participation") and general satisfaction with care. - Parents of children diagnosed with post-trauma conditions reported a lower satisfaction level within the main criterion I "Information" than parents of children with another type of clinical diagnosis (p= 0.011). - An emergency admission to the hospital, does not allow for the physical and mental preparation of parents and children for hospitalisation, hindering the process of adaptation and causing fear, which may have an impact on the satisfaction with nursing services. - The age of the child, the mode of admission and education of the respondents are significant predictors of parental satisfaction with nursing care.	Researchers identify results should be treated as preliminary only. Emotional state of participant not considered during study.

Author and Date	Aim/Objectives	Sample and Setting	Methodology and Methods	Major Findings	Rigour and Limitations
Kuo, Sisterhen, Sigrest, Biazo, Aitken & Smith **2012** **United States of America**	To examine the association of Family Centred Rounds with family experiences and health services use.	Participants n=140 parents Setting Unit-based general paediatric ward at Arkansas Children's Hospital	Quantitative: Prospective cohort study	- Compared with non-Family-Centred Rounds, FCR families were more likely to report consistent medical information (P < .001), the option of discussing care plan (P < .001), doctors listening carefully (P <.01) and doctors showing respect (P < .001).	Participants paid $10 gift card to local department store. Age range of children not identified. Nursing care not considered
Labrie, van Veenendaal, Ludolph, Ket, van der Schnoor & van Kempen **2021** **Netherlands**	To synthesize and analyse the literature on the effects of parent-provider communication during infant hospitalization in the neonatal (intensive) care unit (NICU) on parent-related outcomes.	Participants Setting n/a	Systematic Review with meta-synthesis and narrative synthesis n= 54 qualitative n=19 quantitative n= 4 mixed methods	- Parent-provider communication is a crucial determinant for parental well-being and satisfaction with care, during and following infant hospitalization in the NICU. - The effects of communication on parents' knowledge pertained to the extent to which parents understood their infant's situation and developed the skills to provide care.	Several findings are specific to NICU context.
Mak, Hiebert-Murphy, Walker & Altman **2014** **Canada**	To understand parent's experiences in, and perspectives on, decision making regarding child anxiety treatment, including information needs.	Participants n=19 parents (16 mothers, 3 fathers) of children 4 years to 18 years Setting Paediatric mental health anxiety service in a public hospital	Qualitative: Semi-structured interviews	- The need for an exchange of information is essential for partnership in decision making. - Parents report a strong desire to maintain control over making final decision regarding the care for the child.	Generalizability reduced by small sample size. Results restricted to parents of a child receiving treatment for anxiety. Non-English-speaking parents not represented.
Mucuk & Cimke **2017** **Turkey**	To explore the relationship between overall satisfaction and family centred care, parent participation and demographic characters.	Participants n=285 mothers Setting Tertiary children's hospital	Quantitative: Descriptive	- Pediatric Quality of Life Inventory Health Care Satisfaction Scale and Family-Centred Care Scale scores increased at significant levels in cases where mothers were informed about the health care activities for the child, shown how to do activities, and were given feedback (*p* <0.000). - Strong positive relationship between the mothers PQoLIHCSS and FCCS scores (*p* <0.001).	Age of hospitalised children not identified. No fathers as participants. Researcher identified results only generalisable to study setting.
Phiri, Chan & Wong **2020** **China**	To report on the scope of FCC practices, implementation of FFC, and to identify barriers and facilitators influencing the implementation of FCC for hospitalised children and their families in paediatric wards in developing countries.	Participants n= 1228 parents Setting Paediatric inpatient settings such as surgical, medical, oncology, orthopaedic, nutrition rehab, PICU, NICUs	Integrative review: n= 10 quantitative n= 1 qualitative	- FCC practice and research are in infancy stage in developing countries. - There is limited understanding on scope of FCC practices, the needs of parents and children, and the influence of facilitators and barriers. - Communication in FCC enhances rapport, trust and partnerships between nurses and family members.	Sole focus on 'developing countries' – 'developed' countries excluded from inclusion. Few studies met the inclusion criteria and therefore the included studies may not be very representative of developing countries.

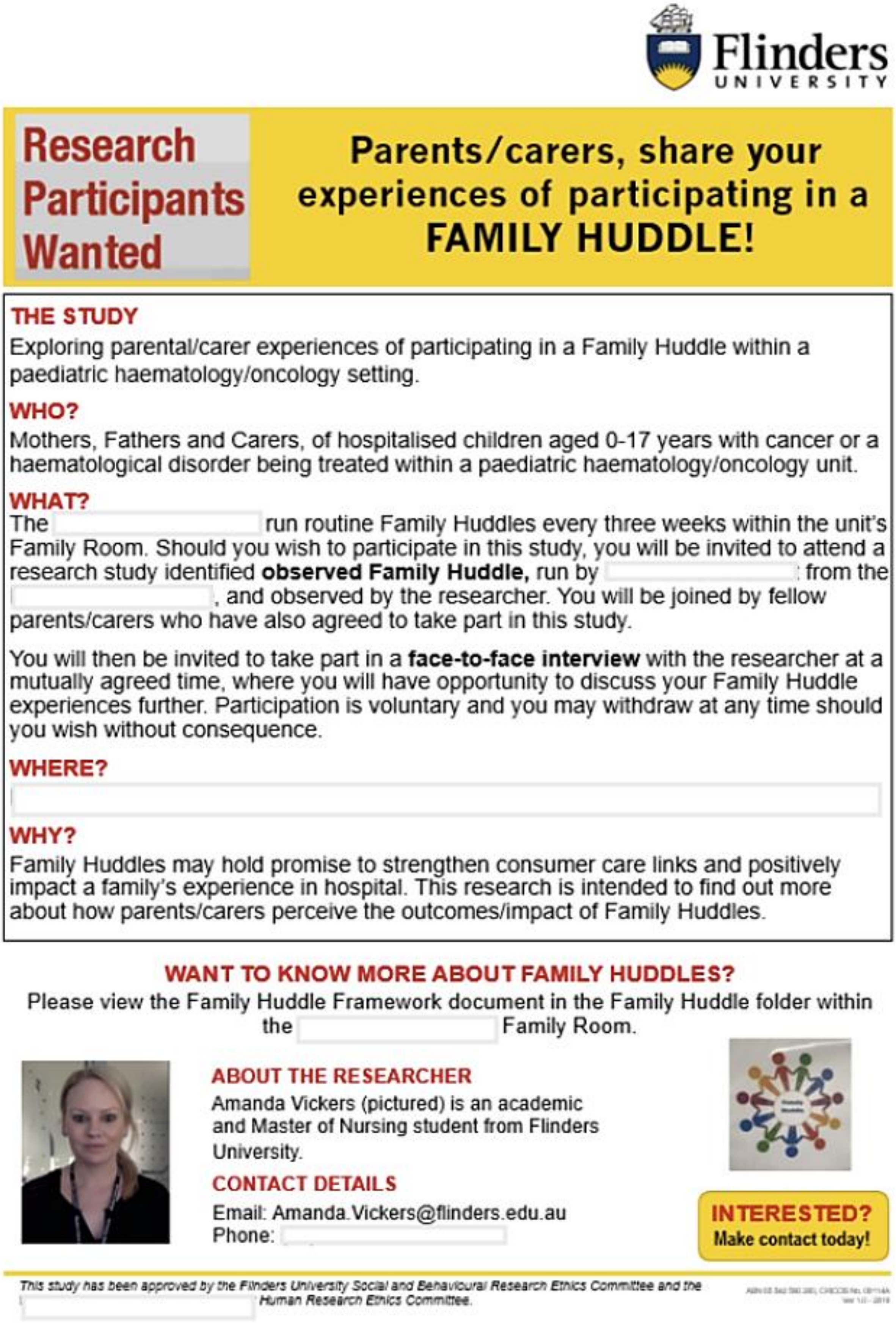
Author and Date	Aim/Objectives	Sample and Setting	Methodology and Methods	Major Findings	Rigour and Limitations
Romaniuk, O'Mara & Akhtar-Danesh **2014** **Canada**	To examine the congruency between parents' actual level of participation and their desired level of participation.	Participants n= 191 parents (161 mothers, 24 fathers, 6 others) of children 0 to 12 years of age Setting Two inpatient units in a pediatric tertiary care hospital	Quantitative: Cross-sectional design Questionnaire	- Parents responses suggested a desire to advocate for the child was not always fulfilled. - A difference exists between parents' actual participation and their desired participation, with the majority of parents reporting a desired participation higher that their actual participation. - 74.9% had negative congruency scores, indicating their desired participation was higher than actual participation.	Potential for social desirability response bias if participants believed that "good" parents should participate in their child's care and should want to do so.
Rostami, Syed Hassan, Yaghami, Ismaeil & Saundi **2012** **Iran**	To determine the effects of FCC on the satisfaction of parents of children hospitalised in 2012 in the pediatric ward.	Participants n= 70 mothers of children aged 0 to 3 years of age Setting Paediatric ward of Razi Hospital, Iran	Quantitative: Quasi-experimental Control group/Intervention group = FCC	- In the FCC group, the mean score of satisfaction among the parents was 20 out of 90 before the intervention, but after the FCC method was used, it increased to 83.2 out of 90. - A significant difference was found between the scores of satisfaction for the control and experimental groups ($p<0.001$) and all parents of children in the experimental group expressed high satisfaction.	No limitations identified by researchers.
Saria, Mselle & Siceloff **2019** **Tanzania**	To describe parents' and nurses' perceptions of the needs of parents, with a primary focus in their engagement in care and the psychological support they receive with caring for their critically ill hospitalized child.	Participants n= 24 parents of children 1 month to 12 years of age Setting Burns unit, paediatric ward, and surgical intensive care unit of Kilimanjaro Christian Medical Centre	Qualitative: 5 focus groups	- Parents involvement in their child's care reduces anxiety and allows parents to feel supported and empowered, enhancing their coping mechanisms. - Both parent's and nurses identified the importance of providing adequate information about the child's progress. - Encouraging and involving parents in the care of their children and having flexible visiting time for parents was vital when caring for critically ill children.	Analysis of Focus Group Discussions occurred from in English from translated transcripts, which may affect the quality of accounts as some words were not translatable in meaning from Kiswahili language to English.
Seliner, Latal & Spirig **2016** **Switzerland**	To assess parental burden of care, satisfaction with family-centred care, and quality of life (HRQoL) of parents and their hospitalized children with profound intellectual and multiple disabilities (PIMD) and determine the relationship among these factors.	Participants n= 117 parents (98 mothers, 19 fathers) of children 1 to 18 years of age Setting Six pediatric units of a Swiss University Children's Hospital (Internal Medicine, Surgery, Intermediate Care, Rehab)	Mixed methods: Cross-sectional survey including qualitative components	- Parents appraised the level of family-centered care, as fair to moderate. Their data indicated deficits in all five domains, particularly regarding the provision of either general or specific information. - Qualitative results showed parents struggling to safeguard their children and worrying more about the child's wellbeing. - A substantial impact on burden of care and parental health related quality of life was established. - Parents expressed their need for timely and comprehensible information in order to understand the treatment process and have some control over it.	Generalizability of results impacted by 25 parents declining for unknown reasons and 18 for reasons of associated stress – response rate 63%.

Author and Date	Aim/Objectives	Sample and Setting	Methodology and Methods	Major Findings	Rigour and Limitations
Svavarsdottir & Sigurdardottir **2013** **Iceland**	To evaluate the benefits of a brief therapeutic conversation intervention for families of children and adolescents in active cancer treatment on perceived family support and on expressive family functioning.	Participants n= 19 parents (9 mothers, 10 fathers) of children 0 to 18 years Setting Inpatient cancer unit and day treatment cancer unit	Quantitative: Quasi-experimental Pre and Post-test	- Primary caregivers perceived significantly higher family support after the intervention (family therapeutic conversation intervention (FAM-TCI)) compared to before. - Partner caregivers (in this case fathers only) did not report a significant increase in their perception on family support. - After FAM-TCI, partner caregivers did not find they were getting better support from nurses, such as information sharing, or having better access to resources.	Small sample size
Uhl, Fisher, Docherty & Brandon **2013** **United States of America**	To describe parents' care experiences during hospitalization of their children. To identify strategies that could improve the provision of patient and family-centred care.	Participants n= 134 parents undertaking survey (107 mothers, 27 fathers) n=9 focus groups Setting Paediatric public hospital	Mixed Methods: Qualitative descriptive focus groups & quantitative survey method	- Empowerment increased by ability to have influence and control over relationships with health professionals. - Positive & negative hospital experiences influence empowerment. - Lack of knowledge about treatment plan, an important gap in communication. - Accurate information is vital to confidence and satisfaction. - On admission only 52% of parents reported receiving welcome information. - 73% of parents felt the quality of care was excellent.	Generalizability reduced by small sample size & low response rate 10.2%. Unable to determine non-English speaking parents' representation.

Appendix 3: Summary of included themes

Theme	**n =**	**Sources**
Participation in care	11	Camur & Karabudak 2020; Dadez et al., 2018; Higham & Davies 2013; Hill et al., 2019; Labrie et al., 2021; Mucuk et al., 2017; Phiri et al., 2020; Romaniuk et al., 2014; Rostami et al., 2015; Saria et al., 2019; Uhl et al., 2013
Information sharing	10	Foster & Whitehead 2017; Hill et al., 2019; Krisnana et al., 2019; Kuo et al., 2012; Mak et al., 2014; Phiri et al., 2020; Saria et al., 2019; Seliner et al., 2016; Svavarsdottir & Sigurdardottir 2013; Uhl et al., 2013
Shared decision making	6	Foster & Whitehead 2017; Kruszecka-Krowka et al., 2019; Labrie et al., 2021; Mak et al., 2014; Seliner et al., 2016; Uhl et al., 2013
Role expectations	3	Hill et al., 2019; Romaniuk et al., 2014; Uhl et al., 2013

Appendix 4: Research information flyer



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Research Participants Wanted

Parents/carers, share your experiences of participating in a FAMILY HUDDLE!

THE STUDY

Exploring parental/carer experiences of participating in a Family Huddle within a paediatric haematology/oncology setting.

WHO?

Mothers, Fathers and Carers, of hospitalised children aged 0-17 years with cancer or a haematological disorder being treated within a paediatric haematology/oncology unit.

WHAT?

The [redacted] run routine Family Huddles every three weeks within the unit's Family Room. Should you wish to participate in this study, you will be invited to attend a research study identified **observed Family Huddle,** run by [redacted] from the [redacted], and observed by the researcher. You will be joined by fellow parents/carers who have also agreed to take part in this study.

You will then be invited to take part in a **face-to-face interview** with the researcher at a mutually agreed time, where you will have opportunity to discuss your Family Huddle experiences further. Participation is voluntary and you may withdraw at any time should you wish without consequence.

WHERE?

[redacted]

WHY?

Family Huddles may hold promise to strengthen consumer care links and positively impact a family's experience in hospital. This research is intended to find out more about how parents/carers perceive the outcomes/impact of Family Huddles.

WANT TO KNOW MORE ABOUT FAMILY HUDDLES?

Please view the Family Huddle Framework document in the Family Huddle folder within the [redacted] Family Room.

ABOUT THE RESEARCHER

Amanda Vickers (pictured) is an academic and Master of Nursing student from Flinders University.

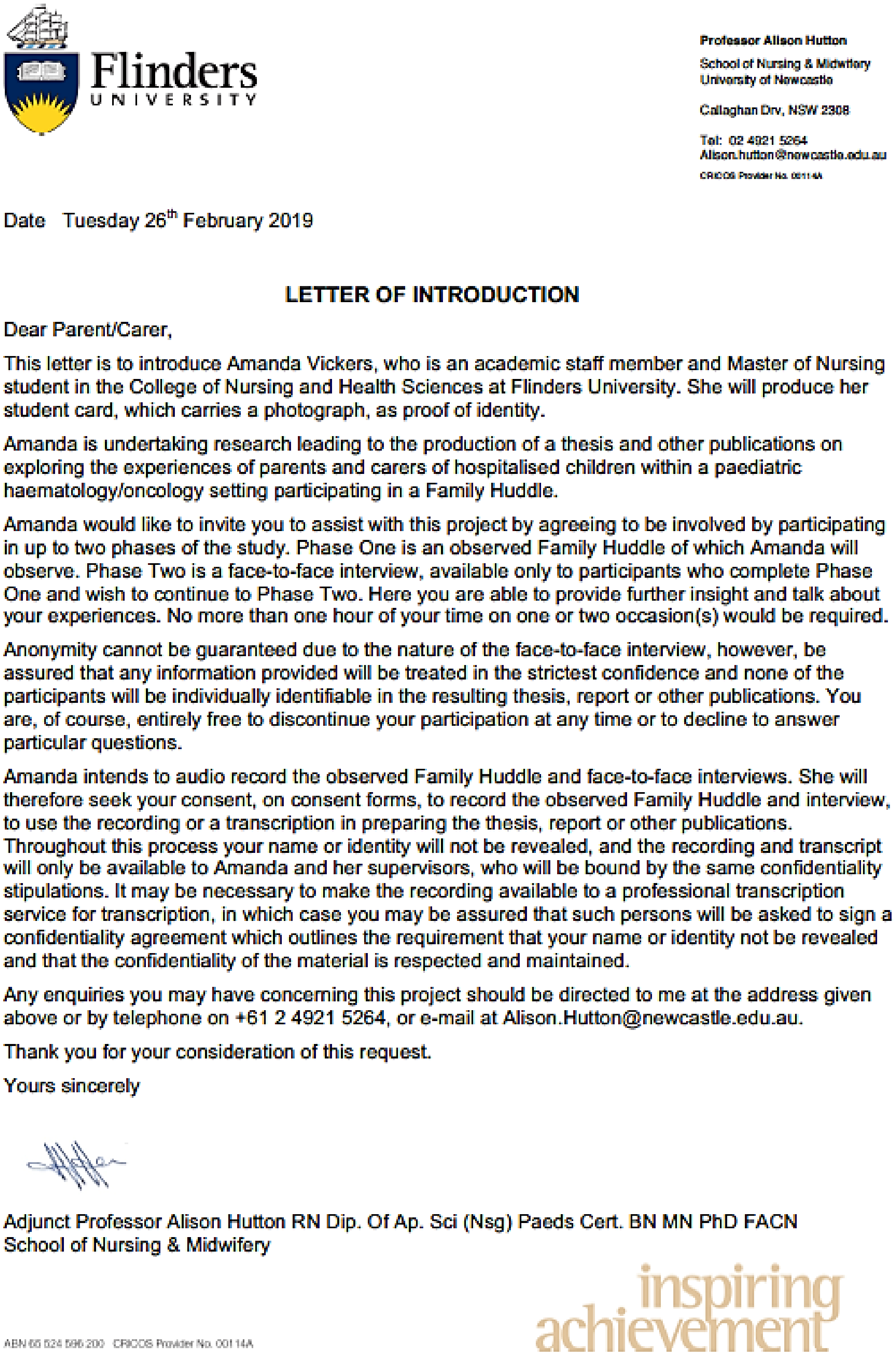
CONTACT DETAILS

Email: Amanda.Vickers@flinders.edu.au
Phone: [redacted]

INTERESTED?
Make contact today!

This study has been approved by the Flinders University Social and Behavioural Research Ethics Committee and the [redacted] *Human Research Ethics Committee.*

Appendix 5: Letter of introduction



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Professor Alison Hutton
School of Nursing & Midwifery
University of Newcastle

Callaghan Drv, NSW 2308

Tel: 02 4921 5264
Alison.hutton@newcastle.edu.au

CRICOS Provider No. 00114A

Date Tuesday 26th February 2019

LETTER OF INTRODUCTION

Dear Parent/Carer,

This letter is to introduce Amanda Vickers, who is an academic staff member and Master of Nursing student in the College of Nursing and Health Sciences at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.

Amanda is undertaking research leading to the production of a thesis and other publications on exploring the experiences of parents and carers of hospitalised children within a paediatric haematology/oncology setting participating in a Family Huddle.

Amanda would like to invite you to assist with this project by agreeing to be involved by participating in up to two phases of the study. Phase One is an observed Family Huddle of which Amanda will observe. Phase Two is a face-to-face interview, available only to participants who complete Phase One and wish to continue to Phase Two. Here you are able to provide further insight and talk about your experiences. No more than one hour of your time on one or two occasion(s) would be required.

Anonymity cannot be guaranteed due to the nature of the face-to-face interview, however, be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. You are, of course, entirely free to discontinue your participation at any time or to decline to answer particular questions.

Amanda intends to audio record the observed Family Huddle and face-to-face interviews. She will therefore seek your consent, on consent forms, to record the observed Family Huddle and interview, to use the recording or a transcription in preparing the thesis, report or other publications. Throughout this process your name or identity will not be revealed, and the recording and transcript will only be available to Amanda and her supervisors, who will be bound by the same confidentiality stipulations. It may be necessary to make the recording available to a professional transcription service for transcription, in which case you may be assured that such persons will be asked to sign a confidentiality agreement which outlines the requirement that your name or identity not be revealed and that the confidentiality of the material is respected and maintained.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on +61 2 4921 5264, or e-mail at Alison.Hutton@newcastle.edu.au.

Thank you for your consideration of this request.

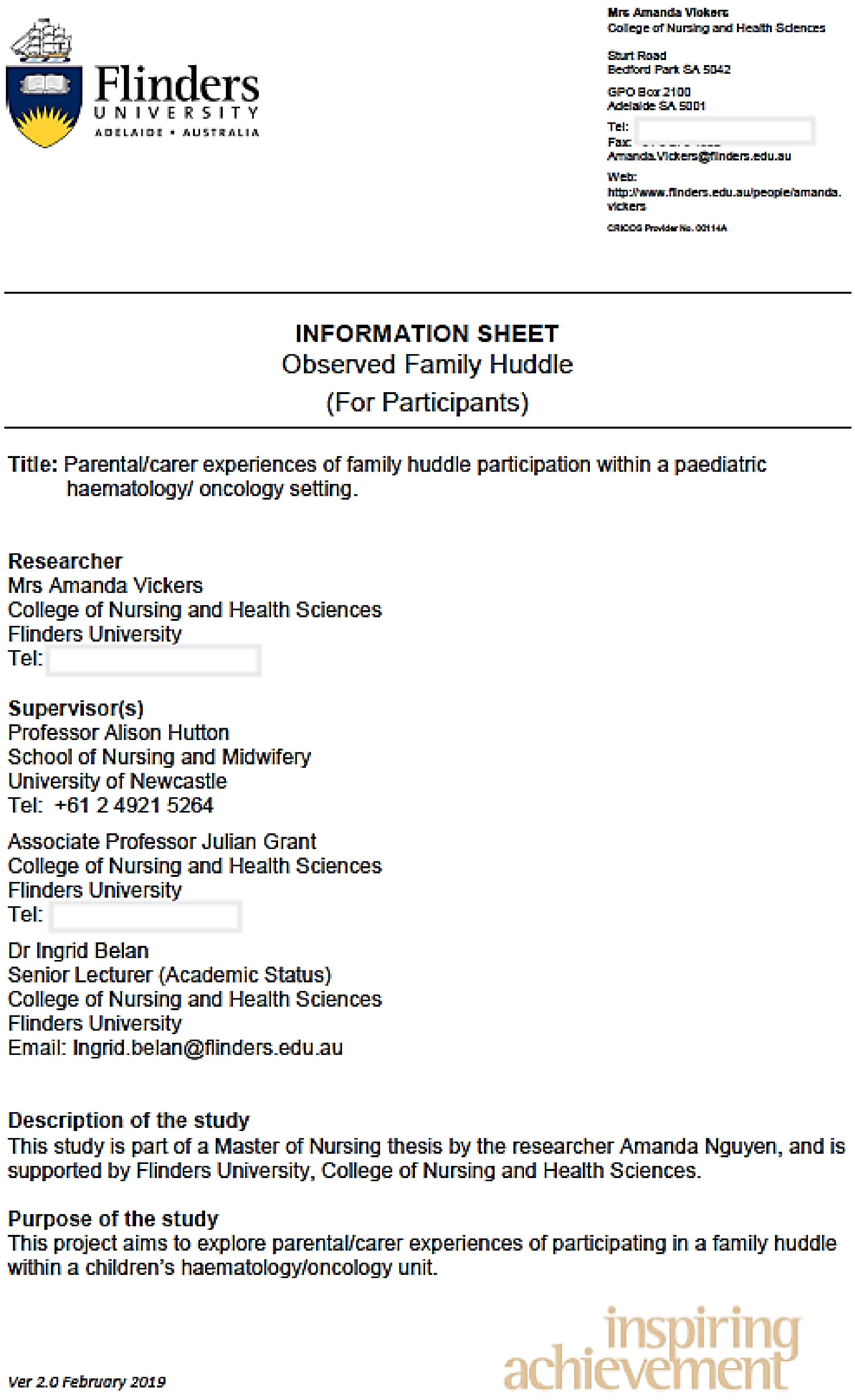
Yours sincerely

Adjunct Professor Alison Hutton RN Dip. Of Ap. Sci (Nsg) Paeds Cert. BN MN PhD FACN
School of Nursing & Midwifery

inspiring achievement

ABN 65 524 596 200 CRICOS Provider No. 00114A

Appendix 6: Information sheet: Observed Family Huddle



Mrs Amanda Vickers
College of Nursing and Health Sciences

Sturt Road
Bedford Park SA 5042

GPO Box 2100
Adelaide SA 5001

Tel: [redacted]
Fax:
Amanda.Vickers@flinders.edu.au

Web:
http://www.flinders.edu.au/people/amanda.vickers

CRICOS Provider No. 00114A

INFORMATION SHEET
Observed Family Huddle
(For Participants)

Title: Parental/carer experiences of family huddle participation within a paediatric haematology/ oncology setting.

Researcher
Mrs Amanda Vickers
College of Nursing and Health Sciences
Flinders University
Tel: [redacted]

Supervisor(s)
Professor Alison Hutton
School of Nursing and Midwifery
University of Newcastle
Tel: +61 2 4921 5264

Associate Professor Julian Grant
College of Nursing and Health Sciences
Flinders University
Tel: [redacted]

Dr Ingrid Belan
Senior Lecturer (Academic Status)
College of Nursing and Health Sciences
Flinders University
Email: Ingrid.belan@flinders.edu.au

Description of the study
This study is part of a Master of Nursing thesis by the researcher Amanda Nguyen, and is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study
This project aims to explore parental/carer experiences of participating in a family huddle within a children's haematology/oncology unit.

Ver 2.0 February 2019

inspiring achievement

In particular, we wish to explore: parental/carer experiences and perceptions of participating in a family huddle; perceived barriers, motivators, enabling factors and parental willingness; and how a family huddle enhances the principles of family centred care.

Why am I being invited to participate?
We are looking for parents/carers, of children aged 0-17 years with cancer/ haematological disorder being treated within a children's haematology/oncology unit.

What will I be asked to do?
You are invited to attend an observed family huddle in the haematology/oncology unit led by a [redacted] of this unit. The researcher will not be actively participating in the observed family huddle but rather observing from a distance and writing down notes about what she may see, hear or feel in the private meeting environment. The observed family huddle will be attended by other parents/carers from the same unit who have consented to take part in this part of the study. During the observed family huddle, you will be invited by the [redacted] to share anything you may wish to bring to the attention of unit management and/or fellow parents/carers in attendance. The term 'observed family huddle' is being used throughout this project, to distinguish the family huddles being observed as part of this project, from those routine family huddles that will continue within the [redacted] not involved in this project.

Participation is entirely voluntary. The observed family huddle will take about 45-60 minutes. The observed family huddle will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the audio recording will be listened to by the transcriber, transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by the participant.

What benefit will I gain from being involved in this study?
The sharing of your experiences will provide an opportunity for you to have your experiences validated. You may find you are able to strengthen your support networks through the sharing of experiences with other parents/carers from your unit. Your ability to advocate for your child may be strengthened and you have a unique opportunity to gain insight to the research process. By sharing your experiences, you will be contributing to research that aims to strengthen consumer and care provider links and positively impact the overall experience of children and their families within the [redacted] Centre.

Will I be identifiable by being involved in this study?
Anonymity cannot be guaranteed due to the nature of the family huddle and participants conversing face to face with fellow participants, however, be assured that any information provided will be treated in the strictest confidence and you will not be individually identifiable in the resulting thesis, report or other publications. Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such requests to

access information are rare; however, we have an obligation to inform you of this possibility.

We recommend not to use any identifiable features such as names or ages when speaking in the family huddle, however should any identifiable features be audio recorded, they will be removed during the transcription process and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way at the College of Nursing and Health Sciences Flinders University, with access restricted to relevant researchers and supervisors bound by the same confidentiality conditions as the researcher.

Are there any risks or discomforts if I am involved?
The researcher anticipates few risks from your involvement in the study. However, given the nature of the project, some participants may experience emotional discomfort. If this happens you are free to exit the observed family huddle at any time. Furthermore, if you become visibly upset during an observed family huddle, audio recording and observations will cease immediately, and the researcher will exit the Family Huddle.

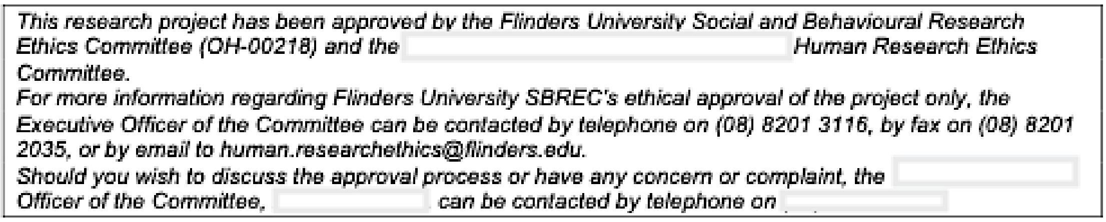
In the event of emotional discomfort or distress during or after the observed family huddle, you may contact the researcher who will make availability to meet and debrief with you and/ or organise for a representative from the hospital's social work department to provide support/counselling to you at no charge. After hours please call Lifeline's 24 hours support service on 131114 or visit their website at https://www.lifeline.org.au .The researcher will make every effort to avoid misunderstanding and misrepresentations of the findings.

How do I agree to participate?
Participation is voluntary. You are free to withdraw from participation in the observed family huddle at any time without consequence. Please be aware, should you participate in the observed family huddle and on completion wish to withdraw from the study, you will not be able to withdraw provided information or ask that the audio recording be stopped.

A consent form will be provided to you once you have made initial contact with the researcher and she has discussed the project with you. If you agree to participate you will be required to read and sign the form and the researcher will collect the consent form from you. Please be aware you are welcome to attend more than one family huddle during your time in the unit. Should you wish to do this, a new consent form will be required each time, available from the researcher.

How will I receive feedback?
On completion of this study, a digital copy of the final research report will be available to all participants upon request of the researcher by the participant.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

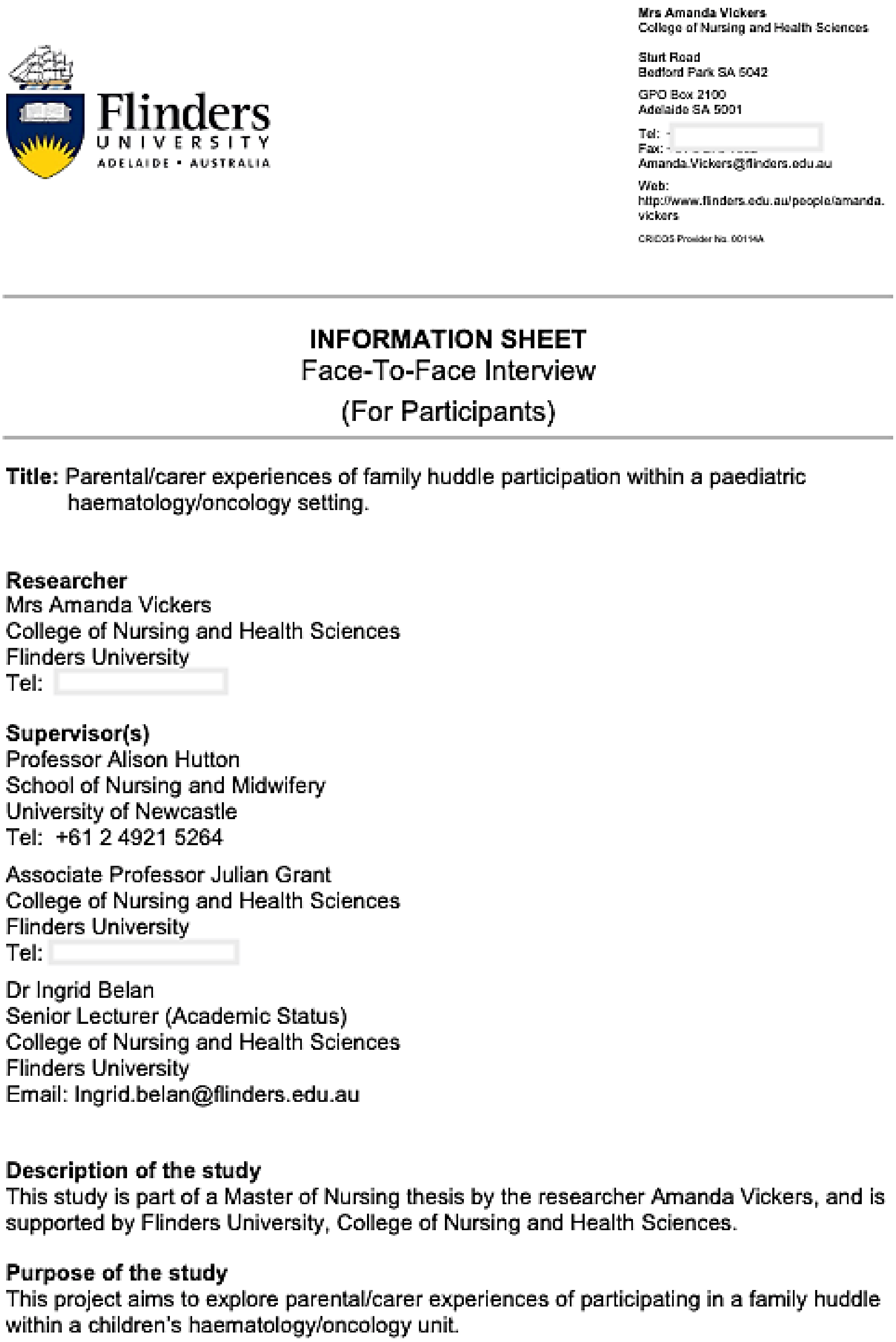


This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (OH-00218) and the [redacted] *Human Research Ethics Committee.*

For more information regarding Flinders University SBREC's ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.

Should you wish to discuss the approval process or have any concern or complaint, the [redacted] *Officer of the Committee,* [redacted] *can be contacted by telephone on* [redacted]

Appendix 7: Information sheet: Face-to-face interview



Mrs Amanda Vickers
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Fax: -
Amanda.Vickers@flinders.edu.au

Web:
http://www.flinders.edu.au/people/amanda.vickers

CRICOS Provider No. 00114A

INFORMATION SHEET
Face-To-Face Interview
(For Participants)

Title: Parental/carer experiences of family huddle participation within a paediatric haematology/oncology setting.

Researcher
Mrs Amanda Vickers
College of Nursing and Health Sciences
Flinders University
Tel: [redacted]

Supervisor(s)
Professor Alison Hutton
School of Nursing and Midwifery
University of Newcastle
Tel: +61 2 4921 5264

Associate Professor Julian Grant
College of Nursing and Health Sciences
Flinders University
Tel: [redacted]

Dr Ingrid Belan
Senior Lecturer (Academic Status)
College of Nursing and Health Sciences
Flinders University
Email: Ingrid.belan@flinders.edu.au

Description of the study
This study is part of a Master of Nursing thesis by the researcher Amanda Vickers, and is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study
This project aims to explore parental/carer experiences of participating in a family huddle within a children's haematology/oncology unit.

In particular, we wish to explore: parental/carer experiences and perceptions of participating in a family huddle; perceived barriers, motivators, enabling factors and parental willingness; and how a family huddle enhances the principles of family centred care.

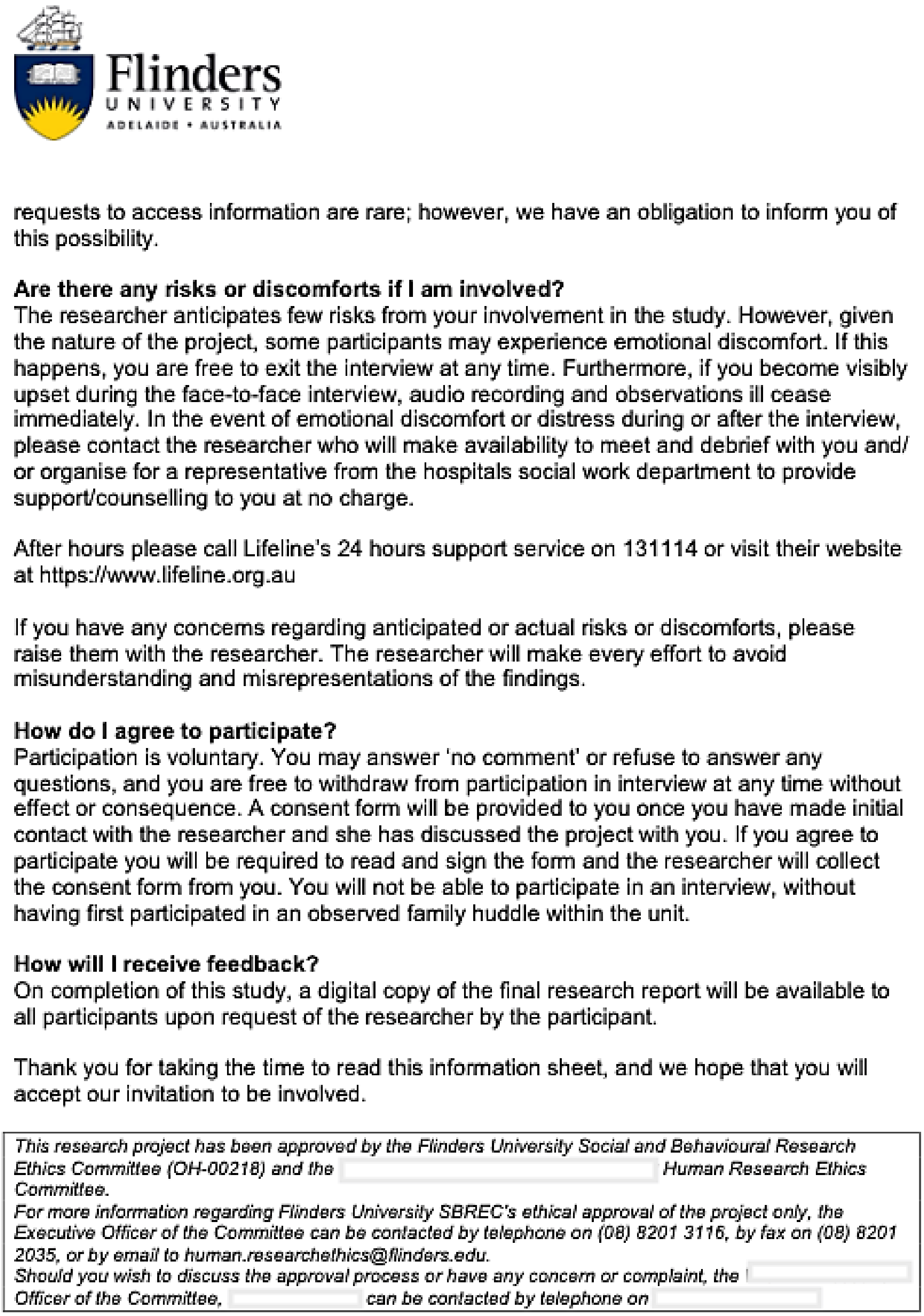
Why am I being invited to participate?
We are looking for parents/carers, of children aged 0-17 years with cancer/ haematological disorder being treated within a children's haematology/oncology unit.

What will I be asked to do?
You are invited to attend an observed family huddle in the haematology/oncology unit led by a [redacted] of this unit. The researcher will not be actively participating in the observed family huddle but rather observing from a distance and writing down notes about what she may see, hear or feel in the private meeting environment. The observed family huddle will be attended by other parents/carers from the same unit who have consented to take part in this part of the study. During the observed family huddle, you will be invited by the [redacted] to share anything you may wish to bring to the attention of unit management and/or fellow parents/carers in attendance. The term 'observed family huddle' is being used throughout this project, to distinguish the family huddles being observed as part of this project, from those routine family huddles that will continue within the [redacted] not involved in this project.

Participation is entirely voluntary. The observed family huddle will take about 45-60 minutes. The observed family huddle will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the audio recording will be listened to by the transcriber, transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by the participant.

What benefit will I gain from being involved in this study?
The sharing of your experiences will provide an opportunity for you to have your experiences validated. You may find you are able to strengthen your support networks through the sharing of experiences with other parents/carers from your unit. Your ability to advocate for your child may be strengthened and you have a unique opportunity to gain insight to the research process. By sharing your experiences, you will be contributing to research that aims to strengthen consumer and care provider links and positively impact the overall experience of children and their families within the [redacted] Centre.

Will I be identifiable by being involved in this study?
Anonymity cannot be guaranteed due to the nature of the family huddle and participants conversing face to face with fellow participants, however, be assured that any information provided will be treated in the strictest confidence and you will not be individually identifiable in the resulting thesis, report or other publications. Your information will remain confidential except in the case of a legal requirement to pass on personal information to authorised third parties. This requirement is standard and applies to information collected both in research and non-research situations. Such requests to



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requests to access information are rare; however, we have an obligation to inform you of this possibility.

Are there any risks or discomforts if I am involved?
The researcher anticipates few risks from your involvement in the study. However, given the nature of the project, some participants may experience emotional discomfort. If this happens, you are free to exit the interview at any time. Furthermore, if you become visibly upset during the face-to-face interview, audio recording and observations ill cease immediately. In the event of emotional discomfort or distress during or after the interview, please contact the researcher who will make availability to meet and debrief with you and/ or organise for a representative from the hospitals social work department to provide support/counselling to you at no charge.

After hours please call Lifeline's 24 hours support service on 131114 or visit their website at https://www.lifeline.org.au

If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher. The researcher will make every effort to avoid misunderstanding and misrepresentations of the findings.

How do I agree to participate?
Participation is voluntary. You may answer 'no comment' or refuse to answer any questions, and you are free to withdraw from participation in interview at any time without effect or consequence. A consent form will be provided to you once you have made initial contact with the researcher and she has discussed the project with you. If you agree to participate you will be required to read and sign the form and the researcher will collect the consent form from you. You will not be able to participate in an interview, without having first participated in an observed family huddle within the unit.

How will I receive feedback?
On completion of this study, a digital copy of the final research report will be available to all participants upon request of the researcher by the participant.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (OH-00218) and the [redacted] Human Research Ethics Committee.
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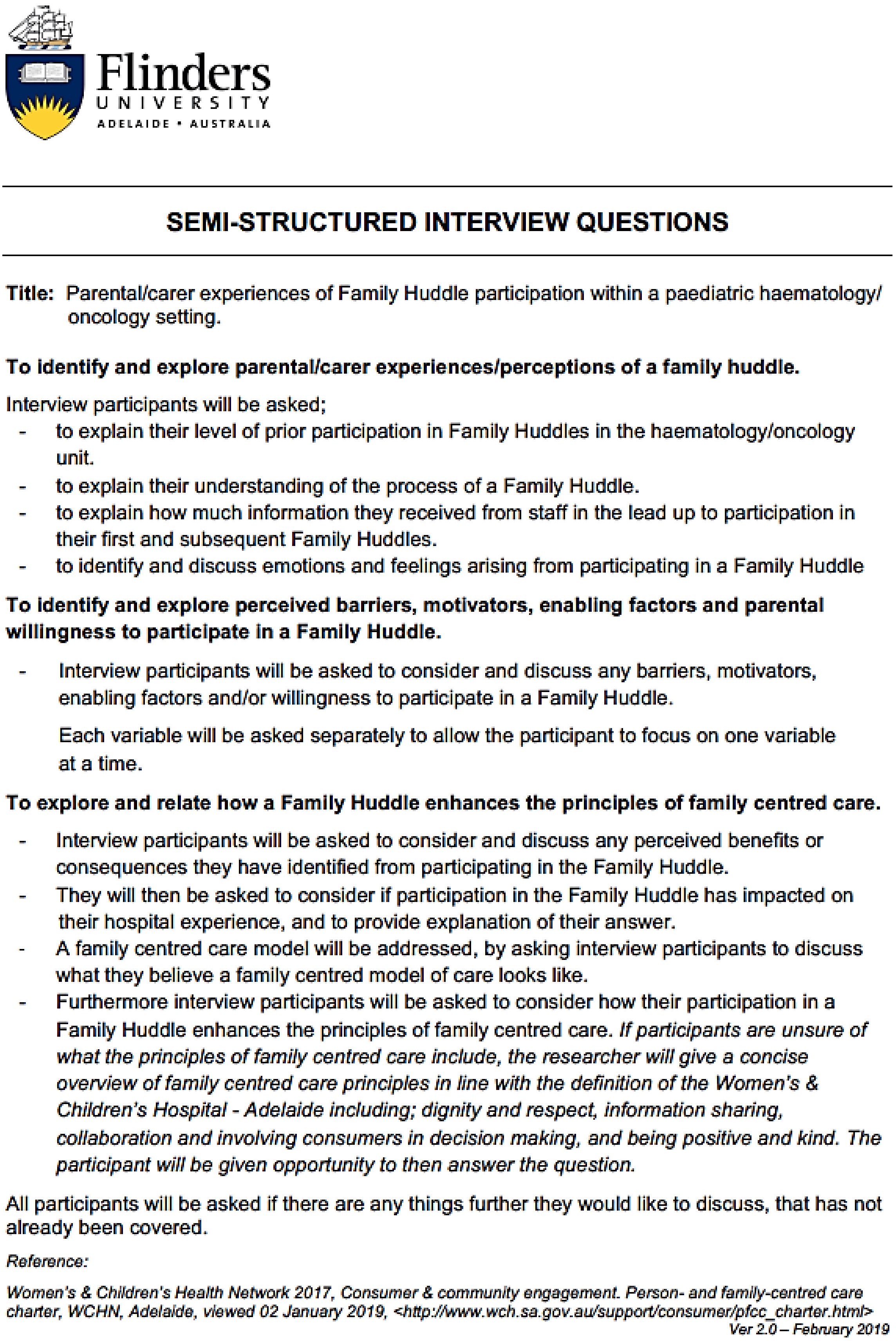
Appendix 8: Interview guide



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SEMI-STRUCTURED INTERVIEW QUESTIONS

Title: Parental/carer experiences of Family Huddle participation within a paediatric haematology/oncology setting.

To identify and explore parental/carer experiences/perceptions of a family huddle.

Interview participants will be asked;

- to explain their level of prior participation in Family Huddles in the haematology/oncology unit.
- to explain their understanding of the process of a Family Huddle.
- to explain how much information they received from staff in the lead up to participation in their first and subsequent Family Huddles.
- to identify and discuss emotions and feelings arising from participating in a Family Huddle

To identify and explore perceived barriers, motivators, enabling factors and parental willingness to participate in a Family Huddle.

- Interview participants will be asked to consider and discuss any barriers, motivators, enabling factors and/or willingness to participate in a Family Huddle.

  Each variable will be asked separately to allow the participant to focus on one variable at a time.

To explore and relate how a Family Huddle enhances the principles of family centred care.

- Interview participants will be asked to consider and discuss any perceived benefits or consequences they have identified from participating in the Family Huddle.
- They will then be asked to consider if participation in the Family Huddle has impacted on their hospital experience, and to provide explanation of their answer.
- A family centred care model will be addressed, by asking interview participants to discuss what they believe a family centred model of care looks like.
- Furthermore interview participants will be asked to consider how their participation in a Family Huddle enhances the principles of family centred care. *If participants are unsure of what the principles of family centred care include, the researcher will give a concise overview of family centred care principles in line with the definition of the Women's & Children's Hospital - Adelaide including; dignity and respect, information sharing, collaboration and involving consumers in decision making, and being positive and kind. The participant will be given opportunity to then answer the question.*

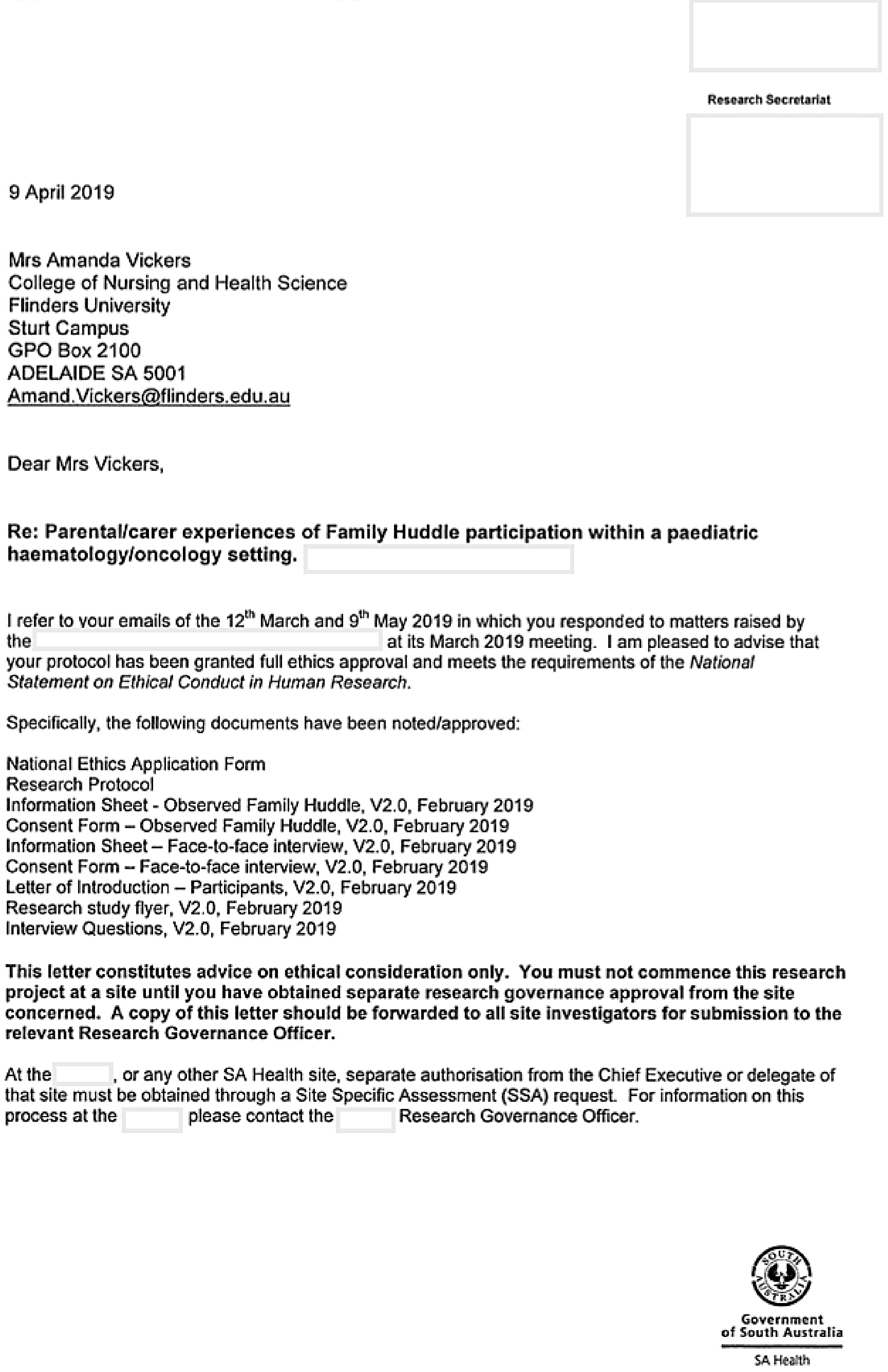
All participants will be asked if there are any things further they would like to discuss, that has not already been covered.

Reference:

Women's & Children's Health Network 2017, Consumer & community engagement. Person- and family-centred care charter, WCHN, Adelaide, viewed 02 January 2019, <http://www.wch.sa.gov.au/support/consumer/pfcc_charter.html>

Ver 2.0 – February 2019

Appendix 9: Letter of ethical approval – Initial



[redacted]

Research Secretariat

[redacted]

9 April 2019

Mrs Amanda Vickers
College of Nursing and Health Science
Flinders University
Sturt Campus
GPO Box 2100
ADELAIDE SA 5001
Amand.Vickers@flinders.edu.au

Dear Mrs Vickers,

Re: Parental/carer experiences of Family Huddle participation within a paediatric haematology/oncology setting. [redacted]

I refer to your emails of the 12th March and 9th May 2019 in which you responded to matters raised by the [redacted] at its March 2019 meeting. I am pleased to advise that your protocol has been granted full ethics approval and meets the requirements of the *National Statement on Ethical Conduct in Human Research*.

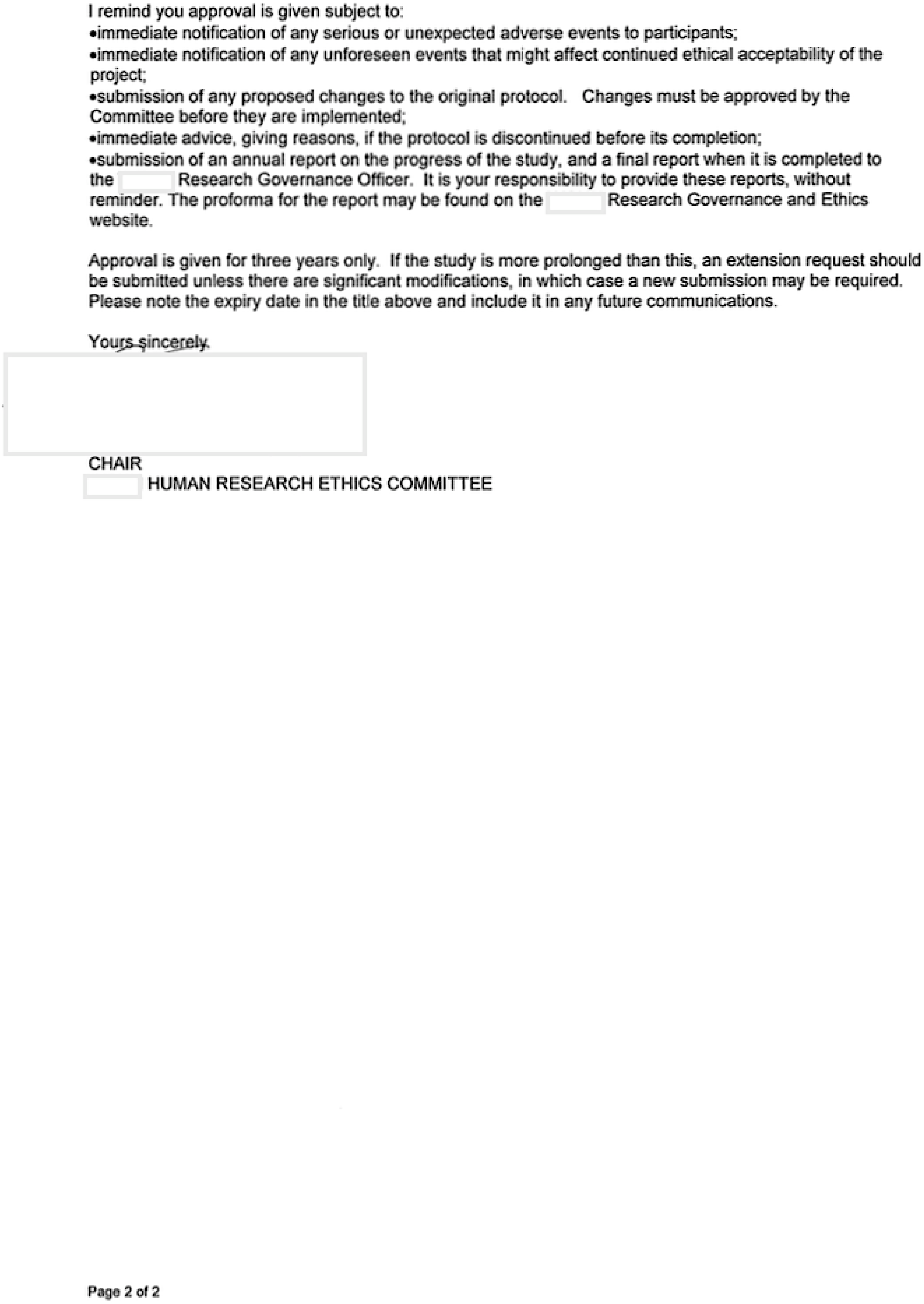
Specifically, the following documents have been noted/approved:

National Ethics Application Form
Research Protocol
Information Sheet - Observed Family Huddle, V2.0, February 2019
Consent Form – Observed Family Huddle, V2.0, February 2019
Information Sheet – Face-to-face interview, V2.0, February 2019
Consent Form – Face-to-face interview, V2.0, February 2019
Letter of Introduction – Participants, V2.0, February 2019
Research study flyer, V2.0, February 2019
Interview Questions, V2.0, February 2019

This letter constitutes advice on ethical consideration only. You must not commence this research project at a site until you have obtained separate research governance approval from the site concerned. A copy of this letter should be forwarded to all site investigators for submission to the relevant Research Governance Officer.

At the [redacted], or any other SA Health site, separate authorisation from the Chief Executive or delegate of that site must be obtained through a Site Specific Assessment (SSA) request. For information on this process at the [redacted] please contact the [redacted] Research Governance Officer.

Government
of South Australia
SA Health



I remind you approval is given subject to:

- immediate notification of any serious or unexpected adverse events to participants;
- immediate notification of any unforeseen events that might affect continued ethical acceptability of the project;
- submission of any proposed changes to the original protocol. Changes must be approved by the Committee before they are implemented;
- immediate advice, giving reasons, if the protocol is discontinued before its completion;
- submission of an annual report on the progress of the study, and a final report when it is completed to the [redacted] Research Governance Officer. It is your responsibility to provide these reports, without reminder. The proforma for the report may be found on the [redacted] Research Governance and Ethics website.

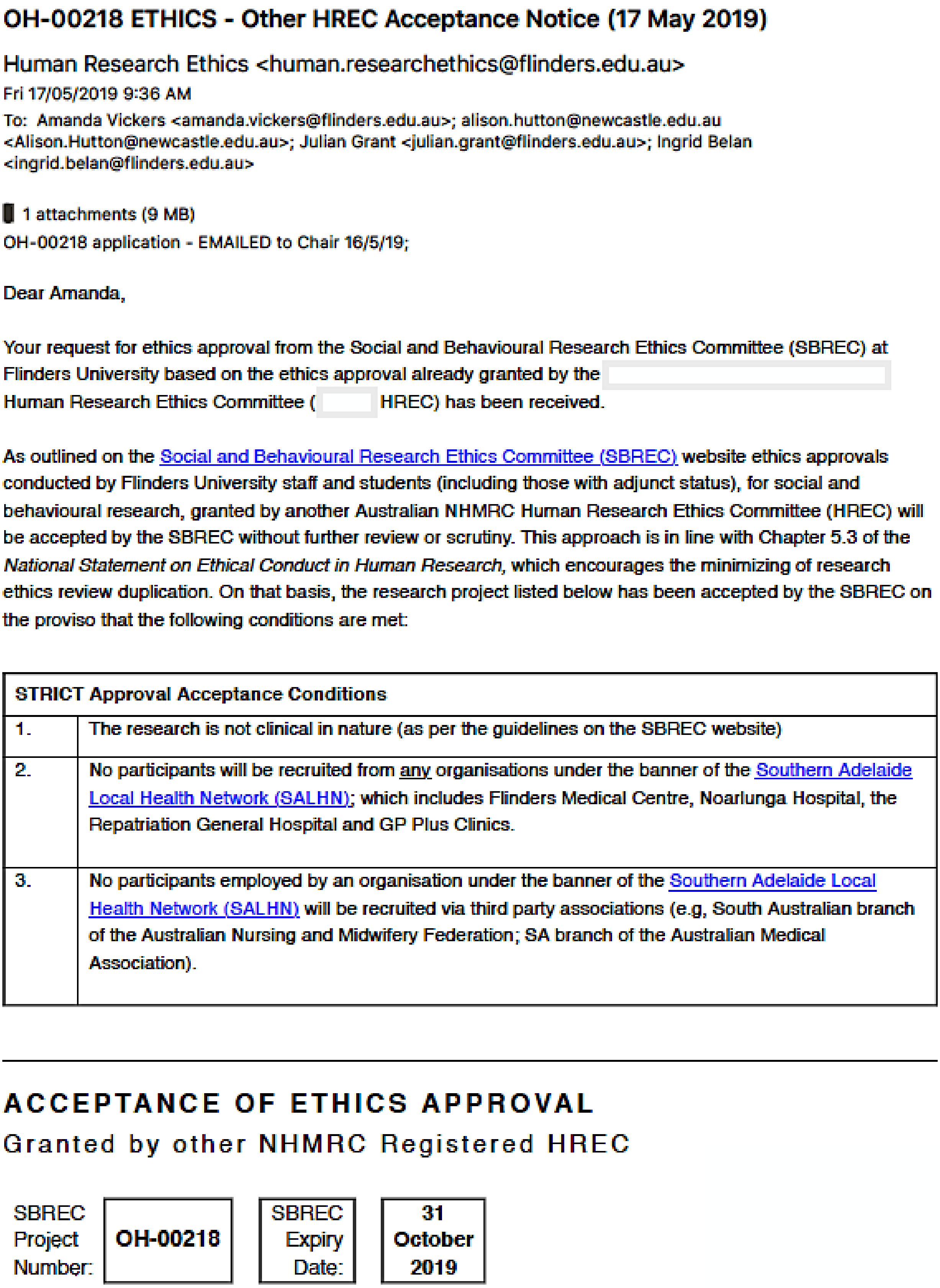
Approval is given for three years only. If the study is more prolonged than this, an extension request should be submitted unless there are significant modifications, in which case a new submission may be required. Please note the expiry date in the title above and include it in any future communications.

Yours sincerely

[redacted]

CHAIR
[redacted] HUMAN RESEARCH ETHICS COMMITTEE

Appendix 10: SBREC Ethical approval



OH-00218 ETHICS - Other HREC Acceptance Notice (17 May 2019)

Human Research Ethics <human.researchethics@flinders.edu.au>
Fri 17/05/2019 9:36 AM
To: Amanda Vickers <amanda.vickers@flinders.edu.au>; alison.hutton@newcastle.edu.au <Alison.Hutton@newcastle.edu.au>; Julian Grant <julian.grant@flinders.edu.au>; Ingrid Belan <ingrid.belan@flinders.edu.au>

1 attachments (9 MB)
OH-00218 application - EMAILED to Chair 16/5/19;

Dear Amanda,

Your request for ethics approval from the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University based on the ethics approval already granted by the [redacted] Human Research Ethics Committee ([redacted] HREC) has been received.

As outlined on the Social and Behavioural Research Ethics Committee (SBREC) website ethics approvals conducted by Flinders University staff and students (including those with adjunct status), for social and behavioural research, granted by another Australian NHMRC Human Research Ethics Committee (HREC) will be accepted by the SBREC without further review or scrutiny. This approach is in line with Chapter 5.3 of the *National Statement on Ethical Conduct in Human Research*, which encourages the minimizing of research ethics review duplication. On that basis, the research project listed below has been accepted by the SBREC on the proviso that the following conditions are met:

STRICT Approval Acceptance Conditions	
1.	The research is not clinical in nature (as per the guidelines on the SBREC website)
2.	No participants will be recruited from any organisations under the banner of the Southern Adelaide Local Health Network (SALHN); which includes Flinders Medical Centre, Noarlunga Hospital, the Repatriation General Hospital and GP Plus Clinics.
3.	No participants employed by an organisation under the banner of the Southern Adelaide Local Health Network (SALHN) will be recruited via third party associations (e.g, South Australian branch of the Australian Nursing and Midwifery Federation; SA branch of the Australian Medical Association).

ACCEPTANCE OF ETHICS APPROVAL

Granted by other NHMRC Registered HREC

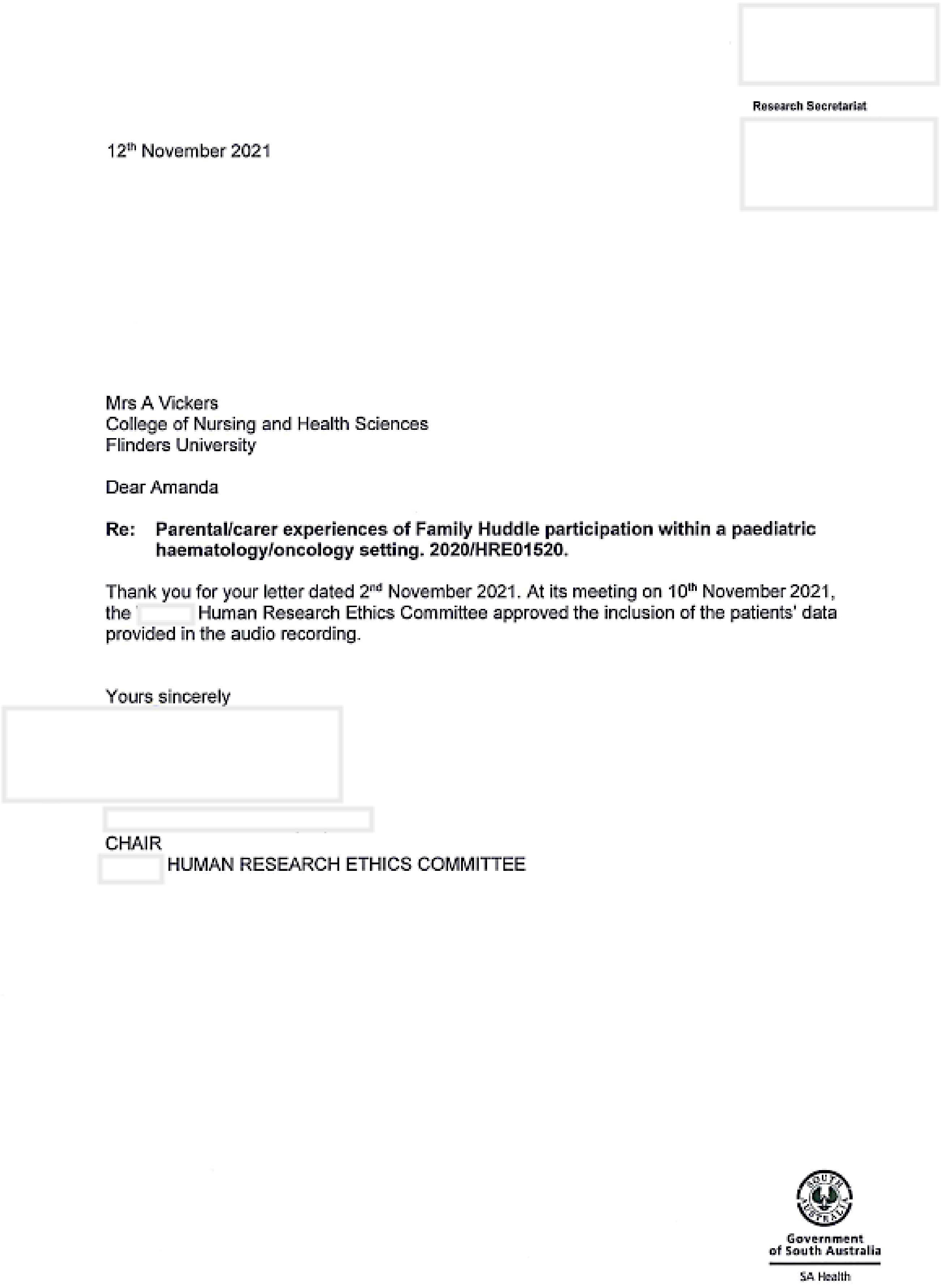
SBREC Project Number:	**OH-00218**	SBREC Expiry Date:	**31 October 2019**

Other HREC approval number:	HREC/18. /18	
Ethics approval granted by:		
Project Title:	Parental / carer experiences of Family Huddle participation within a paediatric haematology / oncology setting	
Flinders University Researcher:	Mrs Amanda Vickers (formerly Nguyen)	Please note that the Flinders University researcher has been listed as principal researcher (even if they are not on the application) for the purposes of this SBREC approval.
School / Dept	College of Nursing and Health Sciences	
Email:	amanda.nguyen@flinders.edu.au	
Date approval accepted:	17 May 2019	

Please note the researcher responsibilities below that need to be adhere to meet the requirements of this Acceptance Notice:

Researcher Responsibilities	
1.	Flinders University Letterhead If the principal researcher is a Flinders University staff or student researcher, it is a requirement that all documentation to be distributed to potential participants is placed on Flinders University letterhead. Please submit a copy of all participant documentation on the Flinders University letterhead if you have not already done so. If a Flinders University researcher is not listed as the principal researcher than documentation does not need to be placed on Flinders University letterhead.

Appendix 11: Letter of ethical approval – Amendment



[redacted]

Research Secretariat

[redacted]

12th November 2021

Mrs A Vickers
College of Nursing and Health Sciences
Flinders University

Dear Amanda

Re: Parental/carer experiences of Family Huddle participation within a paediatric haematology/oncology setting. 2020/HRE01520.

Thank you for your letter dated 2nd November 2021. At its meeting on 10th November 2021, the [redacted] Human Research Ethics Committee approved the inclusion of the patients' data provided in the audio recording.

Yours sincerely

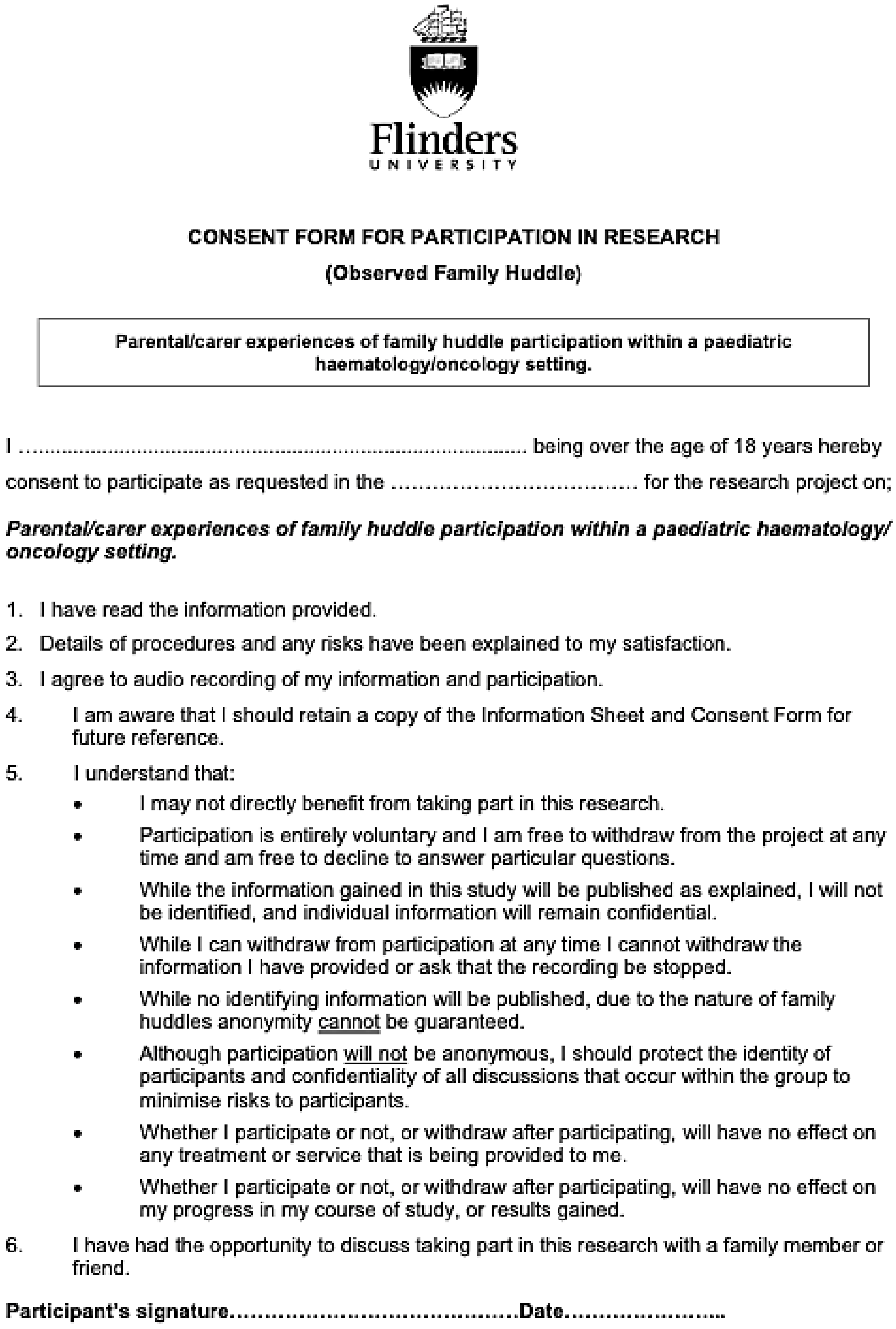
[redacted]

[redacted]

CHAIR
[redacted] HUMAN RESEARCH ETHICS COMMITTEE

Government
of South Australia
SA Health

Appendix 12: Consent form – Observed Family Huddle



Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(Observed Family Huddle)

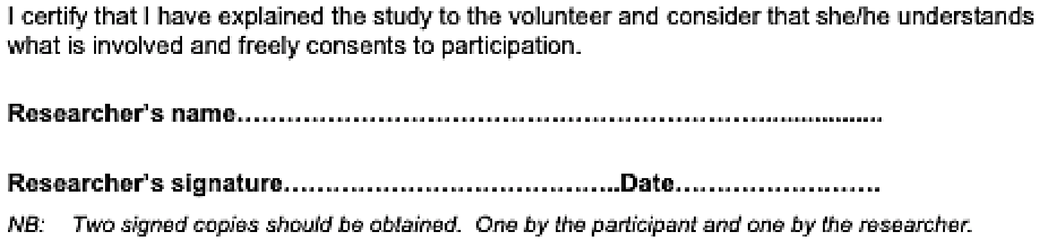
Parental/carer experiences of family huddle participation within a paediatric haematology/oncology setting.

I .... being over the age of 18 years hereby consent to participate as requested in the .... for the research project on;

Parental/carer experiences of family huddle participation within a paediatric haematology/ oncology setting.

1. I have read the information provided.
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.
   - Participation is entirely voluntary and I am free to withdraw from the project at any time and am free to decline to answer particular questions.
   - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
   - While I can withdraw from participation at any time I cannot withdraw the information I have provided or ask that the recording be stopped.
   - While no identifying information will be published, due to the nature of family huddles anonymity cannot be guaranteed.
   - Although participation will not be anonymous, I should protect the identity of participants and confidentiality of all discussions that occur within the group to minimise risks to participants.
   - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
   - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my course of study, or results gained.
6. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's signature...Date.......................



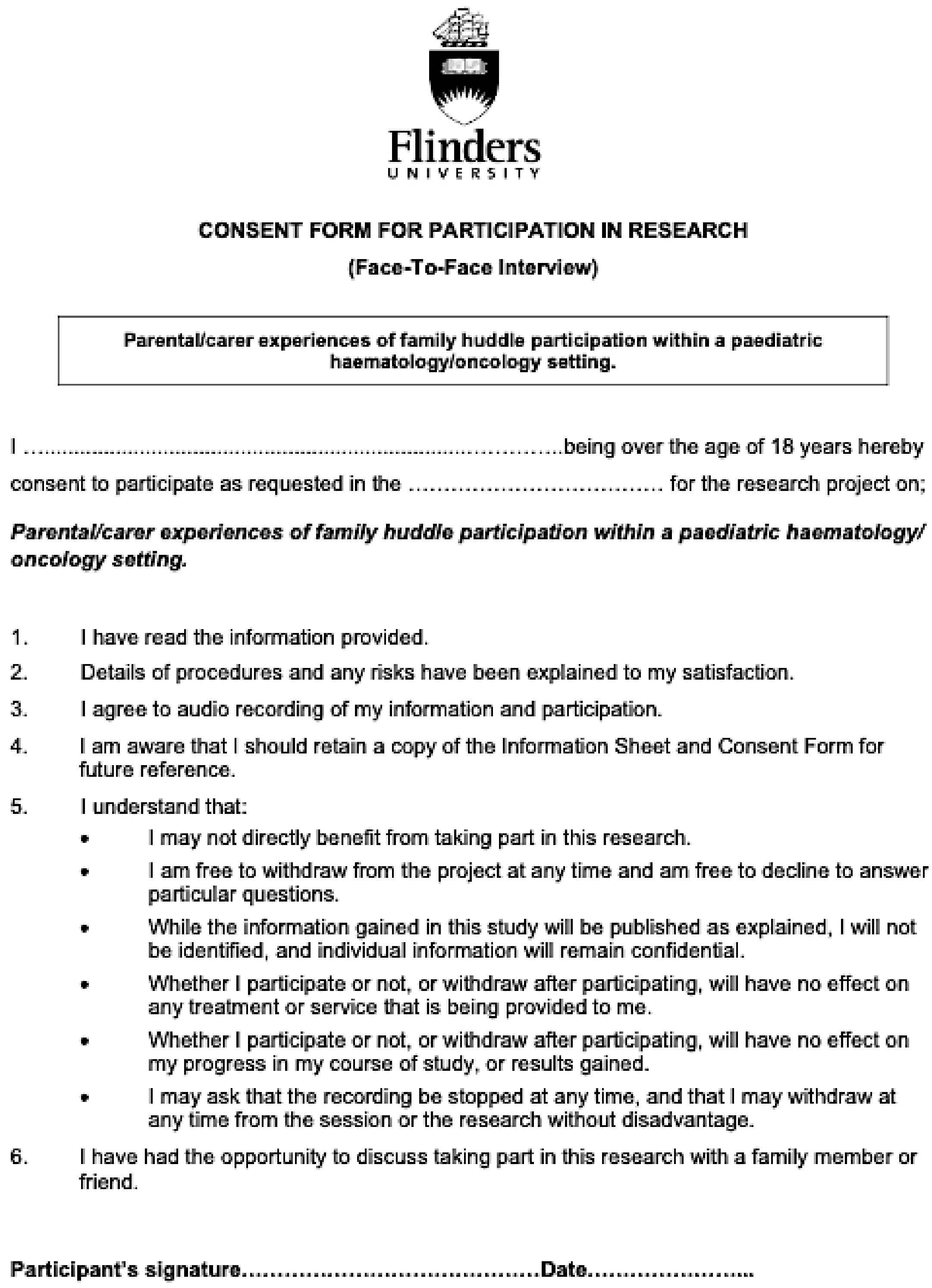
I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name……………………………………………………………..................

Researcher's signature…………………………………..Date…………………….

NB: Two signed copies should be obtained. One by the participant and one by the researcher.

Appendix 13: Consent form – Face-to-face interview



Flinders
UNIVERSITY

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(Face-To-Face Interview)

Parental/carer experiences of family huddle participation within a paediatric haematology/oncology setting.

I ………………………………………………………………………being over the age of 18 years hereby consent to participate as requested in the ……………………………… for the research project on;

Parental/carer experiences of family huddle participation within a paediatric haematology/ oncology setting.

1. I have read the information provided.
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 withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my course of study, or results gained.
    - I may ask that the recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
6. I have had the opportunity to discuss taking part in this research with a family member or friend.

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**…………………….

NB: Two signed copies should be obtained. One by the participant and one by the researcher.