TOWARDS AN UNDERSTANDING OF PATIENTS' AND PARTNERS' EXPERIENCES OF BLADDER CANCER

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DEDICATION

'Our lives begin to end the day we become silent about things that matter'

(Martin Luther King, Jr. in Barden 2008, p.16).

This thesis and the work it is derived from is dedicated to the patients, partners and families whose lives have been extraordinarily changed due to a bladder cancer diagnosis, and the ongoing surveillance and treatment usually required to sustain life. In particular, I would like to acknowledge both the participants with bladder cancer and their partners or family members for their participation in this study. Thank you for letting me into your homes and families, and into the very personal aspects of your lives.

I am also grateful to the couples who completed the postal questionnaires. It took me 14 months to find you but eventually patience was repaid when questionnaires started to appear from far and wide. Better late than never.

Thank you to those organizations who allowed me free advertising for participant recruitment in their magazine or website, and to the establishments who allowed my recruitment poster to be placed on their walls. Your support is greatly appreciated.

Susan

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SUMMARY

Bladder cancer (BlCa) is a chronic disease that involves on-going treatment and surveillance. Due to the discomfort and side effects of treatment and surveillance, or radical cystectomy, clinical participants required on-going assistance and care. BlCa is commonly perceived as embarrassing, intrusive and difficult to deal with as it affects daily life within the family, socially, and for employment. Urinary, sexual and bowel dysfunction pose challenges for relationships, social activities and self-esteem.

To date, most BlCa research has used quantitative methodologies to compare types of surgery, treatment regimens or to test new medication or diagnostic instruments. Most studies have focused primarily on muscle invasive bladder cancer, with little known about the lived experiences of participants with non-muscle invasive bladder cancer. Even less qualitative research exists and few studies have included partners, or women with BlCa. This thesis has bridged that gap by using a pragmatic mixed methods research approach over two phases.

In Phase 1, face-to-face interviews were conducted with clinical participants (N = 10) and their partners (N = 10). Participants were interviewed separately allowing for differing perspectives into the experience of living with BlCa. The use of Qualitative Description and thematic analysis exposed four themes of *Physical Responses, Cognitive Reactions, Emotional Reactions,* and *Survival Techniques.* These four themes were first operationalised by mapping them to the four levels of Roy's Adaptation Model to enable quantitative testing and inform the development of a model of care.

In Phase 2 a self-report questionnaire was developed based on the findings of Phase 1 with data collected from 119 clinical participants and 103 partners (N = 102 couples). The questionnaire booklet comprised demographic information and four validated scales (Bladder

Cancer Index, Mini Mental Adjustment to Cancer scale, Psychological Adjustment to Illness Scale, and the Perceptions of Love and Sex Scale).

Using multivariate analysis and structural equation modelling, this study identified various issues relating to the QoL of clinical participants and partners including some undesirable experiences within the healthcare system. Of note was that 30% of participants did not know they had BlCa because the word ‘cancer’ was not used and participants did not understand the medical jargon they heard. There was an absence of information and ongoing support, with a different urologist for every procedure. Surveillance cystoscopy appointment cards sent a month ahead triggered great anxiety among participants whereas others sensed they had fallen through the cracks when such information was not received. However, patients still complained of extended waiting times even when appointments were scheduled.

Of significance is the mediating effects of families and social supports that negated the cognitive distress of clinical participants. Using the models tested, this appeared to be the strongest and most positive adaptive mechanism identified by highlighting the effects of partner support on clinical participants’ acceptance of, and adaptation to, their BlCa. These insights add to the original contribution to knowledge offered by this program of research, which culminated in the proposed six-step model of care. This research has provided a better appreciation of the quality of life of individuals with BlCa and an understanding of the needs of couples, including sensitive family and social needs, and the collaborations required with multidisciplinary teams to assist in the model of care that will allow clinical participants and partners to achieve better adaptation to BlCa.

DECLARATION

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

Susan M Heyes

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The PhD journey is primarily a solo trek, walked, hobbled, or sometimes run, in parallel to others traveling their own journey. We get there in various times for numerous reasons and diverse degrees of difficulty. These may relate to the complexity of the project, time lines, missed social and leisure opportunities with family and friends, or the influences of others be they negative or positive. Similar to the bladder cancer participants, when difficulties arise we look to others traveling the same journey because they seem to be the only people who could possibly understand the rhetoric. Having watched the eyes of others glaze over at the mere utterance of 'PhD,' it is not surprising that PhD candidates cling together and travel in packs.

I have been privileged to meet and associate with PhD candidates who are all brilliant. Particularly, Anna, Pip, Ting and Neti. Well done ladies, due to your brilliance and persistence you truly deserve to be where you are. I have somehow managed to adopt Anna (and Dakota) into more familial roles as they fill my life with understanding, caring, trust, laughter, and cake. You inspired me with your success when I just wanted to get off the PhD train. Thank you for pushing me and believing that I could do it too.

While I stated that the PhD journey is solo, others with whom we have relationships may also be affected by the magnitude of the PhD years. My husband Tom Knight, quite rightly declares that without him I would have starved to death. I know it was difficult to watch me put myself through all the extremely long days with very little sleep, exercise or socialisation. I know that your caring was based on sound health concerns. However, only I knew how much I had to do, and how long it would take for me to understand it, and finally create my vision. That was my way, each one of us has a unique PhD trek. Thank you for listening to the odd rant, getting on with things and picking up the pieces a few times. Mostly, thank you for your constant and total belief in my ability to do this, and telling me so whenever I was doubtful. Jumping ship/train now and passing the baton. LP x

ABBREVIATIONS

A	AUA	American Urological Association
B	BCG	Bacillus Calmette-Guérin
	BCI	Bladder Cancer Index (scale)
	BI	Bladder Intact
	BlCa	Bladder Cancer
	BP	Body Pain
	BPT	Bladder Preservation Therapy
C	CC	Case Control
	CFOT	Cystectomy Following Other Treatment
	CIC	Clean Intermittent Catheterization
	CT	Computed Tomography
	CUS	Cystourethroscopic Surveillance
E	ED	Erectile Dysfunction
	EF	Emotional Function
	EWB	Emotional Well-being
F	FWB	Functional Well-being
G	GP	General Practitioner
H	HCO	Health Care Orientation (PAIS)
	HRQoL	Health Related Quality of Life
I	IC	Ileal Conduit
	IT	Intravesical Therapy
M	MA	Microsatellite Analysis
	MDT	Multi-disciplinary Team
	MIBlCa	Muscle Invasive Bladder Cancer
	Mini-MAC	Mini-Mental Adjustment to Cancer (Scale)
	MMC	Mitomycin C
	MMR	Mixed Methods Research
	MRI	Magnetic Resonance Imaging

N	NMIBlCa	Non-muscle Invasive Bladder Cancer
O	ONB	Orthotopic Neobladder
P	PAIS	Psychological Adjustment to Illness Scale
	PCa	Prostate Cancer
	PF	Physical Function
	PIS	Participant Information Sheet
	PLSS	Perceptions of Love and Sex Scale
	PTSD	Post-traumatic Stress Disorder
	PWB	Physical Well-being
Q	QD	Qualitative Description
	QoL	Quality of Life
R	RAM	Roy’s Adaptation Model
	RARC	Robot-assisted Radical Cystectomy
	RC	Radical Cystectomy
	RE	Role Emotion
	RF	Role Function
	RN	Registered Nurse
S	SA	South Australia
	SCC	Squamous Cell Carcinoma
	SD	Standard Deviation
	SEM	Structural Equation Model
	SF	Sexual Function
	SIC	Self-intermittent Catheterization
	SUI	Stress Urinary Incontinence
	SWB	Social Well-being
T	TCC	Transitional Cell Carcinoma
	Tis	Carcinoma in Situ
	TURBT	Transurethral Resection of Bladder Tumour

U	UD	Urinary Diversion
	UFU	Urinary Frequency and Urgency
	U/O Nurse	Urology-Oncology Nurse
	US	United States
	UTI	Urinary Tract Infection
W	WOC	Wound, Ostomy, Continence (nurse)

PUBLICATIONS ARISING FROM THIS RESEARCH

PEER REVIEWED JOURNAL PUBLICATIONS

Heyes, SM, Harrington A, Bond MJ, Belan I 2016, ‘Family focus on bladder cancer research’, *Australian Nursing & Midwifery Journal*, vol. 23, no. 7 p. 41.

Heyes, SM, Bond, MJ, Harrington A, Belan, I 2016, ‘The relative contributions of function, psychological burden, and partner support to cognitive adaptation in bladder cancer’, *Psycho-Oncology*, vol. 25, pp. 1043-1049, doi: 10.1002/pon.4054.

Heyes, SM, Harrington, A, Bond, MJ, Belan, I 2014ba, ‘The lived experiences of people with bladder cancer and their partners’, *Cancer Nursing Practice*, vol. 13, no. 9, pp. 25-30, doi:10.7748/cnp.13.9.25e1130.

CONFERENCE PROCEEDINGS

Heyes, SM, Bond MJ, Harrington, A, Belan, I 2015 ‘Does Perceived psychological burden explain adaptive outcomes beyond the functional concerns of bladder cancer patients?’ 20th Annual meeting of the Australian and New Zealand Urological Nurses Society (ANZUNS) Conference, Adelaide, April 11th- 13th 2015.

Heyes, SM, Harrington, A, Bond, MJ, Belan, I 2014, ‘An investigation into the experiences of individuals with bladder cancer and their partners/family/caregivers’, Society of Urologic Nursing and Associates (SUNA) Conference, Florida, USA, October 31st-November 3rd, 2014. (Poster presentation)

Heyes, SM, Harrington, A, Bond, MJ, Belan, 2014, ‘How does bladder cancer affect couples and families? Canadian Association of Nursing in Oncology (CANO) Patient Engagement Conference, Quebec City, Canada, October 26-29th, 2014. (Poster presentation)

NONE-PEER REVIEWED PUBLICATION

Heyes, SM 2016, ‘Bladder cancer on the increase’, *Emale improving male health & wellbeing***,** Issue 155, August/September 2016. <http://media.wix.com/ugd/9b1fc5_87442d81ac0d4abda8f128e7d57fca66.pdf>

CHAPTER 1

INTRODUCTION AND OVERVIEW

1.0 INTRODUCTION

Bladder cancer (BlCa) can lead to a lifetime of chronic ill health that may compromise relationships, social activities, and employment. It is characterised by recurrence and progression, resulting in continuing surveillance, treatment, side effects, and complications (Siegel *et al.* 2012; Gilbert *et al.* 2013; Mohamed *et al.* 2012, 2016). However, the research literature primarily focuses on muscle invasive bladder cancer (MIBlCa) patients, or the differential surgical outcomes of such patients (Large *et al*. 2010; Shih & Porter 2011; Vakalopoulos *et al.* 2011; Mohamed *et al.* 2012; Ali *et al.* 2015). There has been less research involving patients with non-muscle invasive bladder cancer (NMIBlCa), the primary theme of which is the medical effects of various non-surgical treatments (Botteman *et al.* 2003; Singer 2013; Kowalkowski *et al.* 2014; Schmidt *et al.* 2015; Mohamed *et al.* 2016).

The lived experiences of those with BlCa remain far from understood, with minimal research from the perspectives of their partners, family or significant others who may be key sources of support (Mohamed *et al.* 2016). Nor can BlCa be compared to any other type of cancer as a way of understanding it. No other cancer concerning both men and women, also involves the type of ongoing surveillance and treatment required of NMIBlCa. Bowel cancer would be a comparison only in relation to the removal of an organ where that organ’s function is then on the outside of the patient, where a bag is attached to the abdomen to collect bodily fluids normally dealt with internally. However, even after surgery, patients with BlCa still require annual surveillance. In addition, BlCa is treated by placing the chemotherapeutic agent or immunotherapy using Bacillus Calmette-Guérin (BCG), directly into the bladder via the urethra, a painful and embarrassing procedure that leaves patients susceptible to infection and strictures which does not occur in other cancers (Arianayagam 2012; Hall *et al.* 2014). Therefore, the current program of research is significant because it specifically seeks to examine the effects of BlCa by acknowledging both the experiences of patients and those who fulfil their supportive care role. No such research that incorporates both MIBlCa and NMIBlCa using a mixed methods research (MMR) approach is believed to have been undertaken previously. Additionally, the manner in which medical practitioners (and the healthcare system generally) may assist in dealing with BlCa is poorly understood. In summary, the key research goal was to identify the factors associated with quality of life (QoL) in the context of BlCa, to assist with the development of a targeted model of care.

1.2 RESEARCH QUESTIONS

The overarching question posed by this research program is:

> *How do the experiences of community-dwelling clinical participants*[1] *with a diagnosis of BlCa, and their partners, affect QoL, and can these experiences inform a model of care?*

This question is addressed in terms of the following issues:

1. What is already known about the effects of living with BlCa?
2. What are the QoL experiences of clinical participants and partners as they adapt to BlCa?
3. What physical and psychosocial experiences are described by clinical participants diagnosed with BlCa and their partners?
4. What elements of the experiences of clinical participants, and their partners, inform a model of care for BlCa?

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[1] Please note that from this point, the person with BlCa is designated ‘clinical participant’ and their significant other is termed ‘partner’. The latter may be in a marital relationship with the clinical participant, but may also be a family member (e.g. son or daughter), friend, or casual caregiver.

1.3 QUALITY OF LIFE

The overall construct to be used to evaluate the effects of BlCa of both clinical participants and their partners is QoL, which acknowledges both medical and non-medical ramifications of a chronic disease such as BlCa. The term QoL was first used in the 1960s to acknowledge that having a *good life* meant more than money and material goods (Ferrans & Powers 1985). It has subsequently been applied in many areas of health including clinical care, research, health promotion, policy, psychology, social sciences, and health economics (Bowling 1995; Gerharz *et al.* 2005a; Gemmill *et al.* 2010). However, while many instruments have been developed to measure QoL, there remains little agreement about its actual definition.

One influential definition is provided by the World Health Organization (WHO):

> *Individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns* (WHOQOL 1994, p. 28; WHO 1997. p. 1).

Further, QoL recognises the interplay between '*…the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of the environment'* (WHOQOL 1994, p. 28; WHO 1997. p. 1).

This reflects that judgments of whether life or health is *good*, are based on all of beliefs, culture and values, using synonyms such as happiness, well-being, physical function, health status and health perception, making QoL a multi-dimensional construct (Post *et al.* 1999; Bahrami 2011). Common dimensions of QoL are physical, psychological, social, and spiritual well-being (Grant *et al*. 2004). Others limit QoL to a functional issue, although this usually embraces all of work, leisure activities, and community involvement (Bowling 1997). A further alternative is the addition of an emotional component (e.g. satisfaction with life, psychological well-being) (Ferrans & Powers 1985; Gerharz *et al*. 2005; Frost *et al.* 2007; Gemmill *et al.* 2010; Bahrami 2011; Mohamed *et al.* 201).

After a diagnosis of cancer, life is often viewed with more depth and complexity, as patients move towards acceptance of their disease (Cecil *et al*. 2010; Bahrami 2011). QoL may therefore need to emphasise fitness and health, the experience of treatment modalities, and future health-related requirements that may result in a more satisfying life (Bowling 1995).

In summary, QoL in this program of research is considered an umbrella construct under which measurable issues related to well-being are positioned. Given the literature relating to chronic disease and cancer specifically, it was determined, that QoL would be defined in terms of four elements: *Physical Well-being, Experiences of the Healthcare System, Psychosocial Well-being,* and *Adaptation to BlCa.*

1.4 THE NATURE OF BLADDER CANCER

BlCa is the 9th most common cancer (7th in men, 17th in women) and the 13th highest cause of cancer deaths (Cheluvappa *et al.* 2014; Ferro *et al*. 2015; Skeldon & Goldenberg 2015). In Australia, BlCa accounts for 2% of all cancers (2.6% in men), which is comparable to other developed countries (Cheluvappa *et al.* 2014). The male: female ratio of prevalence in Australia is 3:1 (Jacobs *et al.* 2010; Turner & Drudge-Coates 2012), but the five-year survival rate is lower in women. Survival is also lower among those with transitional cell carcinoma (TCC) and those who live in a rural location or who are indigenous (Luke *et al.* 2010). Approximately 70% of diagnoses are NMIBlCa. For these patients, recurrence rates are high (50-70%) and progression to MIBlCa occurs in 10-30% of cases (Patel 2009; Arianayagam *et al.* 2011). The remaining 30% of diagnoses are MIBlCa, often associated with metastases and death despite aggressive treatment (Reardon *et al.* 2015). According to the Australian Institute of Health and Welfare B (2012), the outcomes for BlCa have not only not improved but are becoming worse.

1.4.1 Incidence and Prevalence

Common risk factors for BlCa are being male, advanced age, and racial background. For example, people born in Australia are less likely to develop BlCa than are those from English-speaking European countries (Cheluvappa *et al.* 2014). Other risk factors include skin contact or inhalation of aromatic amines, benzene derivatives, aniline dyes, aromatic hydrocarbons, phenacetin, cyclophosphamide, arsenic, and radiotherapy treatment, particularly for gynaecological and prostatic cancers (Olfert *et al.* 2006; Arianayagam *et al.* 2011; Turner & Drudge-Coates 2012). Exposure to these risk factors usually occurs decades before the onset of BlCa. Further, the gender disparity in diagnosis is largely employment-related (Luke *et al.* 2010; AIHW 2012; Cheluvappa *et al.* 2014; Cohn *et al.* 2014; Skeldon & Goldenberg 2015). Many hazardous carcinogens are typically used in industries dominated by men, including the manufacture of rubber and cable, iron and aluminium, tar and gas, and in the print and paint industries (Turner & Drudge-Coats 2012; Colt *et al.* 2014).

Women tend to be at a more advanced stage of BlCa when diagnosed, resulting in poorer survival rates (Henning *et al.* 2013; Noon *et al.* 2013; Cheluvappa *et al.* 2014; Cohn *et al.* 2014). This is generally understood to be due to women experiencing diagnostic delays caused by misdiagnosis of a urinary tract infection (UTI). Few men experience the same situation (Henning *et al.* 2013). It was suggested by Cohn *et al.* (2014, p. 560) that a UTI could be the ‘single strongest independent predictor of delays in diagnosis of bladder cancer after initial presentation with haematuria.’ In women between 40 and 59 years of age, gross haematuria is more likely a positive sign of BlCa (6.4%) compared with men (3.6%), yet men receive a urology referral more quickly than do women. Haematuria in women is commonly mistaken for menstruation, posing further delays in diagnosis (Cohn *et al.* 2014). Women are also more likely to have MIBlCa than men do (Henning *et al.* 2013). Survival and staging variances in women relate to anatomical differences, increased likelihood of cystitis, vascularity, lymph drainage, and higher rates of squamous cell carcinoma (SCC; Luke *et al.* 2010; Henning *et al.* 2013; Cheluvappa *et al.* 2014; Cohn *et al.* 2014).

Age is an independent risk factor for BlCa, with onset predominantly between 50 and 70 years of age (Arianayagam *et al.* 2011; Noon *et al.* 2013; Hall *et al.* 2014). The greatest incidence occurs around 85 years of age, which has been attributed to reduced bladder function and incomplete emptying with age, leaving concentrated carcinogens in the bladder longer. Older patients with reduced bladder function also often restrict fluid intake to prevent incontinence or leakage, with urine remaining in the bladder for longer (Shariat *et al.* 2009).

The most common risk factor for BlCa, however, is smoking. This is due to contact with carcinogens such as polycyclic aromatic hydrocarbons, aromatic amines, and nitrosamines. Outcomes are also worse with an increase in both number of smoking years and number of cigarettes per day (Turner & Drudge-Coates, 2012). The mechanism of action involves the carcinogens inhaled while smoking coming in contact with the urothelial cells of the bladder (Lee *et al.* 2012). Perhaps contrary to expectation, smokers who are younger at diagnosis are less likely to develop MIBlCa compared with people who have never smoked or who are older. This disparity is due to comorbidities that are more common among smokers, for which they present at health facilities for assessment, leading to the co-incidental detection of BlCa (Lee *et al.* 2012).

1.4.2 Diagnosis and Treatment

Diagnosis involves history-taking, physical examination, urinary markers, and flexible cystoscopy (Hall *et al.* 2014; Ferro *et al.* 2015). Intermittent or continuous gross (visible) or microscopic (2-3 drops of blood /high-powered field) haematuria is the first sign of BlCa in most patients, with the amount or duration having little association with disease severity (Turner & Drudge-Coates 2012). Often patients presenting with BlCa have a UTI, so it is worth screening patients with recurrent UTIs (Hall *et al.* 2014). Signs of advanced disease include shortness of breath, anaemia, bone pain, weight loss, unproductive cough, hypocalcaemia, and leg oedema (Turner & Drudge-Coates 2012). Typically, radiological examinations include intravenous urogram, retrograde pyelogram, computed tomography (CT), and magnetic resonance imaging (MRI).

Transurethral resection of bladder tumour (TURBT) provides histopathology for a definitive diagnosis, staging and grading (Jacob *et al.* 2010). A TURBT is performed three monthly for 1-2 years, then at intervals of six or nine months for two years after which annual surveillance is advised unless new tumours appear, in which case the patient recommences three monthly surveillance (Hall *et al.* 2014; Reardon *et al.* 2015). Adjuvant intravesical (inserted into the bladder) chemotherapy (mitomycin C) or immunotherapy using BCG, are often recommended post TURBT. These treatments are used to reduce microscopic tumours circulating, or as a separate regimen including an induction treatment and BCG maintenance therapy at 3,6,12,18,24,30 and 36 months to prevent disease recurrence (Arianayagam 2012; Hall *et al.* 2014).

A radical cystectomy (RC) is considered when a TURBT fails or for continuously recurring and aggressive NMIBlCa (Jacobs *et al.* 2010; Mohamed *et al.* 2016). RC surgery for men involves removing the bladder, prostate, seminal vesicles, ureters and lymph nodes whereas for women the bladder, uterus, urethra, ureters, ovaries, fallopian tubes, cervix, lymph nodes and anterior vagina are excised (Gore *et al.* 2010; Turner & Dredge-Coats 2012). RC is drastic lifesaving surgery with associated physical and psychological complications including urinary, bowel and sexual dysfunction, issues with body image, dependence, impact on relationship, and social problems, which all affect QoL (Brittain & Shaw 2007; Cecil *et al.* 2010; Hedgepeth *et al.* 2010; Kim *et al.* 2012; Meranda 2016). Treatment with intent to cure organ-confined MIBlCa includes either radiotherapy or RC alone, or with chemotherapy (Jacobs *et al.* 2010).

For patients who decline RC or have comorbidities and reduced surgical possibilities, their BlCa can be managed with intravesical therapy regimens (Jacobs *et al.* 2010). In a select group of patients, bladder preservation protocols include TURBT, chemotherapy, and radiotherapy using a multidisciplinary team. Patients who elect to preserve their bladder through intravesical therapy or partial cystectomy often do so to avoid other traditional surgical options in order to retain sexual function approach (Arianayagam 2012; Turner & Dredge-Coats 2012).

1.4.3 Costs of Bladder Cancer Treatment

Available data from the United States (US) Medicare indicates that BlCa is the most expensive cancer per patient, with US$3.4 billion spent annually due to recurrence and high 5-year survival rates (Sievert *et al.* 2009; Guzzo *et al.* 2012; Svatek *et al.* 2014; Danna *et al.* 2016; Meranda 2016). Expenses include TURBT, intravesical chemotherapy, and immunotherapy, surgery and hospital admissions, surveillance and recurrence. Additionally, systemic and medical complications and continued care contribute to the financial costs incurred in diagnosis, treatment, and management (Sievert *et al.* 2009; Skolarus *et al.* 2014; Svatek *et al.* 2014).

1.5 MIXED METHODS RESEARCH

The research questions outlined in 1.2 above will be answered using a Mixed Methods Research (MMR) approach. MMR was chosen for this program of research, as it allows the exploration BlCa experiences from both a qualitative and quantitative perspective. In particular, a sequential, exploratory approach over two phases is used (Figure 1.1), which is most appropriate in model or theory development, or theory testing (Currall & Towler 2003; Morse 2003; Onwuegbuzie & Teddlie 2003).

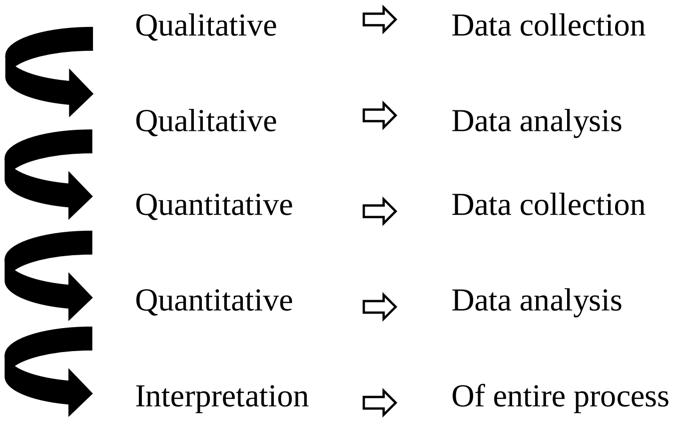

Figure 1.1 *Sequential Exploratory Design*
(adapted from Creswell *et al*. (2003), with permission).

Originally introduced by Jick (1979) in the social sciences as a way to unite qualitative and quantitative paradigms, MMR has steadily grown in popularity, particularly in the health sciences (Maxcy 2003; Tashakkori & Teddlie 2003). MMR aims to identify the true meaning of experiences, with the research question regarded as more important than the paradigm(s) or methodology(ies) employed to answer that question (Tashakkori & Teddlie 2003; Florczak 2014). Use of both qualitative and quantitative methodologies allows the freedom to more fully comprehend the truth of a phenomenon, with each methodology reinforcing, rather than competing with, the other (Tashakkori & Teddlie, 2003; Wheeldon, 2010; Harrits, 2011; Whitehead & Day 2016). That is, the combination of narrative and numerical data in a MMR approach provides triangulation.

1.6 OVERVIEW OF THE RESEARCH PROGRAM

The following subsections provide a brief overview of each chapter of the thesis, describing how the research questions presented in Section 2.0 are addressed.

1.6.1 Chapter 2 - Quality of Life with Bladder Cancer

Chapter 2 comprises a literature review examining the lived experiences of people diagnosed with BlCa (both NMIBlCa and MIBlCa), with a focus on QoL. Relevant findings on the role of partners are also described.

1.6.2 Chapter 3 – The Mixed Methods Research Approach and the Qualitative Methodology and Methods

This chapter further expands on the MMR approach as introduced in Section 5 of this chapter, and provides a detailed examination of the qualitative methodology and methods used.

1.6.3 Chapter 4 - Phase 1 Qualitative Findings

Chapter 4 reports the findings from ten face-to-face interviews with clinical participants regarding their experiences of diagnosis, screening, and treatment for BlCa. Additionally, the findings from ten partners interviewed separately concerning their experiences of living with a person with BlCa augments the narratives of the clinical participants. The aim is to offer a rich, person-centred account of living with BlCa and caring for a person with BlCa.

1.6.4 Chapter 5 – Overview of Phase 1 Findings

Chapter 5 comprises a clarification of the qualitative findings presented in Chapter 4. The objective is to identify the nature of the challenges that both clinical participants and partners face, the relevance to QoL, and their attempt to adapt to BlCa.

1.6.5 Chapter 6 – Phase 2 Proposal

The goal of Chapter 6 is to identify and describe a relevant model of change (adaptation) that might further explain Phase 1 findings. As such, Phase 1 themes are considered potential key elements of a quantitative study that will test the identified model.

1.6.6 Chapter 7 - Phase 2 Quantitative Methods

Chapter 7 describes the methods and instruments used to collect quantitative data. A questionnaire to operationalise the themes identified in Chapters 4 to 6 is described. An explanation of its development in terms of matching themes to quantitative constructs is provided.

1.6.7 Chapter 8 - Phase 2 Quantitative Results

The results of the quantitative study are presented in Chapter 8 for both clinical participants and partners. Importantly, following univariate analyses, the data for clinical participants and partners, respectively, will be used in structural equation modelling (SEM) as an initial test of a model of care based on adaptation to BlCa, as perceived by participants. The potential significance of these results is discussed.

1.6.8 Chapter 9 –Integration Discussion, and Recommendations

Chapter 9 first integrates then discusses the qualitative and quantitative findings from this research. A specific focus is the degree to which these outcomes provide convergent or divergent evidence of the experiences of living with BlCa. A further point of discussion is the extent to which the model of care introduced in Chapter 6 characterises adaptation to BlCa of clinical participants and/or partners. Limitations of the current research are also acknowledged. Chapter 9 then offers suggestions for future research, such as applying the identified model of care in a prospective design.

1.7 CHAPTER SUMMARY

Chapter 1 has introduced the research program. First, the key research questions were presented. Second, the nature of QoL was discussed and the specific meaning to be attributed to QoL in the current research program was introduced (*Physical Well-being*, *Experiences of the Healthcare System*, *Psychosocial Well-being,* and *Adaptation to BlCa*). Further, issues relating to BlCa, such as diagnosis, incidence, prevalence, treatment, and outcomes, were summarised to provide relevant context for this research. MMR was then introduced, with the proposed research adopting an exploratory, sequential mixed methods approach. Finally, a brief description of each of the chapters that follow provided an outline of the thesis.

CHAPTER 2

QUALITY OF LIFE WITH BLADDER CANCER

2.0 INTRODUCTION

Chapter 2 describes the existing literature on the issue of QoL experienced by people with BlCa identified using a systematic process. It includes a commentary on the circumstances of significant others when available. The key sections of Chapter 2 are (1) discussion of the process used to search the literature, (2) critique of the literature (3) synthesis of the literature, (4) discussion of the major issues identified, and (5) an overall summary.

2.1 SEARCH STRATEGY

A systematic search of four databases (CINAHL, Medline, PsycINFO, and Informit) as well as other sources (urology journals, reference lists, and urology websites) was conducted. These four databases were utilized because they include nursing, medical and psychosocial aspects of the disease process and the care required. The extent of this search and key words and MeSH terms used along with their totals are available in Appendix B1 for each database. Keyword searches covered common terms used in both BlCa and QoL studies. The limitations were focused on QoL among individuals with BlCa, with the inclusion criteria being: studies conducted on adults published in English language peer-reviewed journals from 2005 to 2016. Quantitative, qualitative, and mixed methods articles were all included if they met these criteria (see also Table 2.1).

2.1.1 Search Results

The specific search strategy for each of the four databases is detailed in Appendix B1 and the search process is depicted in Figure 2.1. The total number of articles identified from all four databases was 654. However, after reading the article titles many of these studies did not meet at least one of the inclusion criteria or were studies related to breast cancer or prostate cancer (PCa). Additional articles were discarded based on the abstracts that described studies, which were testing an instrument, discussing risk factors, particular treatment regimens or chemotherapy agents or the difference between particular surgical techniques and so did not meet the inclusion criteria. After removing duplicates, the full text of each of the remaining 56 articles was then located and appraised. Of these, 25 articles described studies that met all the inclusion criteria. They comprised of 21 quantitative, three qualitative, and one mixed method study. They had been conducted in the USA (n = 7), Italy (n = 3), Spain (n = 3), Japan (n = 3), China (n = 2), Netherlands (n = 2), and France, Germany, Israel, Canada and Sweden (all n = 1).

Table 2.1 *Inclusion and Exclusion Criteria for the Literature Review*

Inclusion criteria	**Exclusion criteria**
Adults (male and female) diagnosed with NMIBlCa or MIBlCa.	Teenagers or children.
Primary international, peer-reviewed research journal articles.	Secondary articles or non-peer-reviewed studies.
2005-2016.	Prior to 2005.
Experiences of BlCa and QoL outcomes for treatment and surveillance only.	Not related to, or including any other types of cancer, drugs, and surgical techniques comparing one type of diversion with another, test instruments, decision-making algorithms, or risk factors.
Written in the English language.	Not written in the English language.

The final 25 studies included 4,361 participants (78% men) whose mean age was 68 years. Two studies recruited only female participants (Bartsch *et al.* 2014; Rouanne *et al.* 2014). Of note is that only one of these studies included caregivers (n = 19; Benner *et al.* 2014). The author(s), year published, country of origin, purpose, and methodology of all included studies are provided in the summary table in Appendix. B2. For the quantitative and mixed methods studies, the sample, instruments used and major results are also presented.

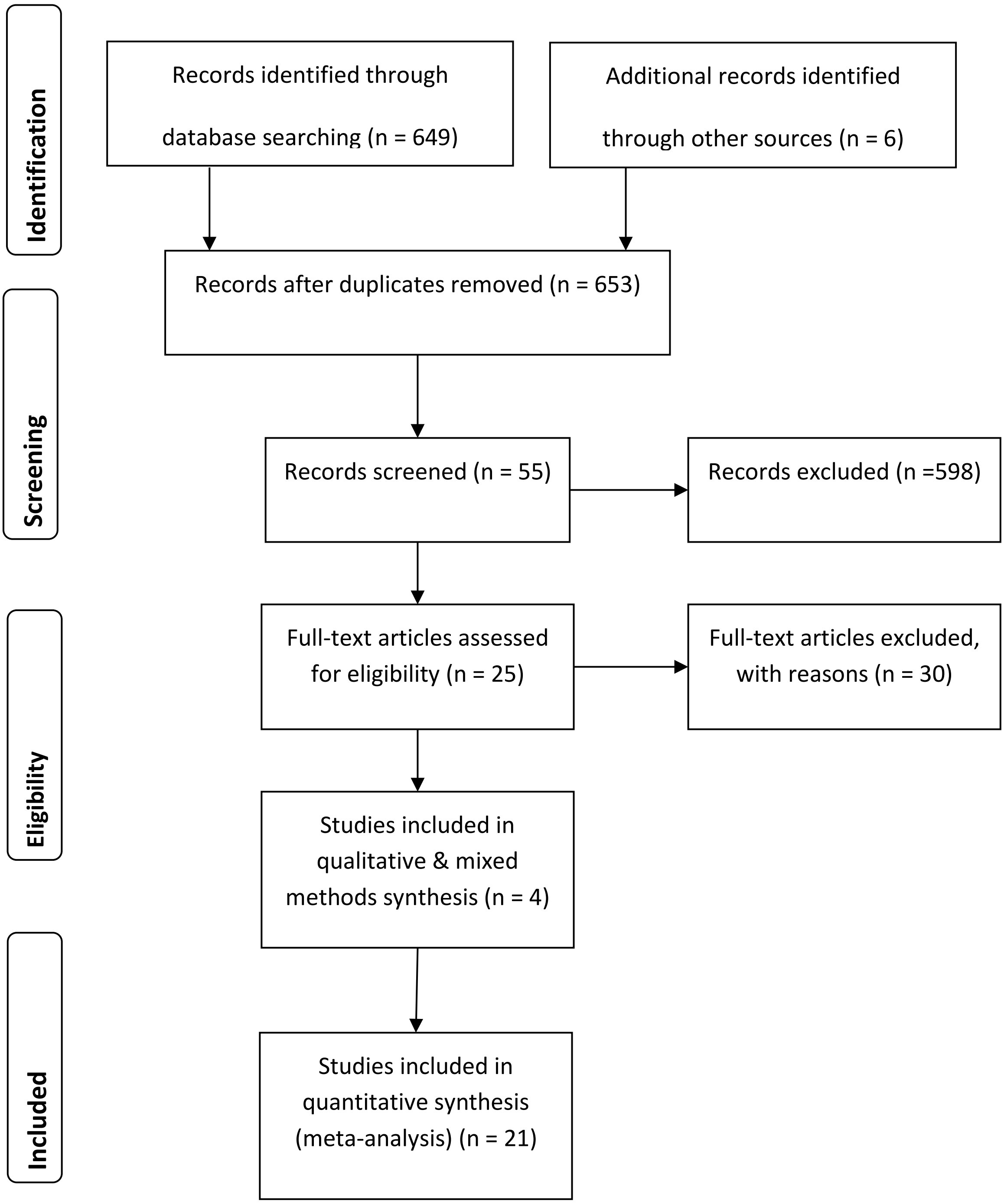

Figure 2.1 *Literature Search Process*

2.2 CRITICAL APPRAISAL

The critical appraisal of literature usually follows a set of standard questions or guidelines that vary according to the research design used. The guidelines applied to the 25 included articles in the current review are those of Schneider (2016) for qualitative and quantitative articles and Long (2005) for mixed methods articles. The specific questions are presented in Appendix B3, and the critical appraisal of individual articles is available in Appendix B4. However, it is important to note that no study met all recommended critical appraisal criteria.

Within the quantitative studies, while titles and abstracts were informative, other areas lacked detailed information. Data collection, data analysis, and results of all quantitative studies scored 86%, 86%, and 85% that is respective of the total scores of 40, being one point for each question in the six sections of the appraisal (see Appendix B4). Information concerning ethical issues was lacking (10 articles) and only two articles provided an adequate description of the instruments used, with one study using a non-validated instrument. Four studies lacked sufficient information about statistical analyses. Nine studies included results that were unexpected and one presented results that were not in agreement with hypotheses. Seven studies did not offer suggestions for future research, three did not identify study limitations, and one did not include implications for healthcare.

Even lower scores were noted for study structure (58%) and sample (57%). The study structure section of the critical appraisal takes into account, for example, literature review, limitation/gap in the review, how the investigation was conducted, and the hypotheses statement and type of hypothesis, whereas the sample describes characteristics of the participants, and appropriateness of the sample for analysis (Appendix B4). Six studies cited literature that was predominantly older than seven years. In four articles, it was not evident that the motivation for the studies came from the literature, and six articles did not address, or failed to highlight, a gap in the literature. Additionally, 11 studies did not specify hypotheses. No *a priori* sample size was determined in 20 studies, whereas the authors of 12 articles noted that a small sample size limited their study.

For the qualitative studies, two of the three did not mention any limitations, with two also failing to provide a complete description of participants. Ethical issues were poorly described, with one study not containing any information concerning ethical considerations, and only consent mentioned in the remaining two. None of the qualitative studies discussed confidentiality or anonymity, nor identified any other ethical issues. One study failed to describe data analytic procedures or include evidence of trustworthiness. Further, despite being a qualitative study, the inclusion criteria also stated that participants should be educated enough to complete a questionnaire. Another study stated that generalisability from the small sample was not possible, even though this is not an aim of qualitative research. Rather, the aim is to seek insight into the personal and unique experiences of people in relation to the phenomenon of interest (Francis *et al*. 2016). Two studies did not mention the researchers' perspectives, nor research bias or imbalance and another did not mention healthcare implications. The mixed methods study did not mention limitations, nor sufficiently describe the setting or provide a full account of potential ethical issues.

In summary, following appraisals using the appropriate tools the quantitative studies with the highest score, and exhibiting the reliability in the rigour of the study (Appendix B4) were by D'Agostino *et al.* (2016) and Allareddy *et al.* (2006), while the studies of Mohamed *et al.* (2014) and Fitch *et al.* (2010) shared the highest scores among the qualitative articles. However, the mixed methods study by Kowalkowski *et al.* (2014) earned the overall, highest total appraisal score across all included studies.

2.3 SYNTHESIS OF INCLUDED STUDIES

Section 2.3 provides a synthesis of the 25 studies that met the inclusion criteria (Table 2.1). QoL was a topic of interest in studies concerning MIBlCa (18 studies) and NMIBlCa (4 studies), with three studies including participants with both MIBlCa and NMIBlCa. Articles that studied MIBlCa focused on RC generally (n = 8), ileal conduit (IC, n = 5) and (n = 4) neobladder procedures specifically. One study of participants with MIBlCa described bladder retention using TURBT, chemotherapy, and radiotherapy. The four studies of NMIBlCa discussed treatment with TURBT, intravesical BCG or chemotherapy, urine analysis and the resulting sexual dysfunction. Of the three studies involving both types of BlCa, one was primarily concerned with QoL immediately following diagnosis whereas the other two examined outcomes after RC compared with those for a participant with a bladder intact (BI).

Among studies of MIBlCa, the outcomes following RC were commonly reported, with focus tending to be which type of surgery might afford a better QoL by comparing surgical diversions. As these studies did not focus on QoL *per se*, but rather, type of surgery, the criteria for inclusion was not met for this review. However, details concerning such studies are summarised in Appendix B5. In short, there is commonly no conclusive evidence that one type of surgical diversion offers better QoL over another (Cerruto *et al.* 2016).

Synthesis of the 25 included articles identified six key topics that dominated the literature. These are *QoL over Time*, *QoL with an Ileal Conduit*, *QoL with a Neobladder, MIBlCa Symptoms and Support, The benefits of conservative treatment over surgical intervention,* and *QoL with a Bladder Intact.*

2.3.1 Quality of Life over Time

Five studies were longitudinal, following participants from either symptom identification or diagnosis to post-surgery, over periods of between six months and nine years. All but one of these studies was quantitative in nature.

Fung *et al.* (2014) conducted the largest study (N = 620 pre-diagnosis, 856 post-diagnosis). This cross-sectional study involved 179 participants who provided both pre- and post-data, comprising measures of physical and mental well-being. It was reported that QoL before diagnosis or surgery was better than post-surgery. Among NMIBlCa participants, a slight reduction in physical well-being (general health, bodily pain, physical function, and role-physical) was noted after diagnosis and remained throughout the nine-year study. Mental well-being such as vitality (feeling full of life vs. being worn out or tired), social function, role-emotion, and mental health was significantly lower for up to five years. Participants with MIBlCa had much better physical well-being before diagnosis than at the end of the studies. After surgery, mental well-being remained the same whereas physical well-being declined, particularly among older patients with comorbidities or of lower socioeconomic status.

In their prospective case control study, Goosens-Laan *et al.* (2014) surveyed 476 participants with haematuria of unknown cause who completed a questionnaire before diagnosis, with 18 later undergoing an RC after diagnosis of MIBlCa. Their health status and sexual function were followed up three times over 12 months, along with a case-control (CC) group. Takenaka *et al.* (2011) used a questionnaire study comprising 86 participants with a neobladder for five years post-surgery assessing general, urinary, and sexual function. Both of these studies reported an improvement in Body Pain (BP) over time, but Role Function (RF), Role Emotion (RE), Functional Well-Being (FWB), and Social Function (SF) all decreased. Takenaka *et al.* (2011) reported that SF was very low five years post-RC, and participants requiring clean intermittent catheterization (CIC), or who were incontinent, had even worse QoL. The cases and controls studied by Goosens-Laan *et al.* (2014) had similar QoL scores prior to diagnosis, although the BlCa cases had lower physical and sexual function after diagnosis, and for up to 12 months.

Mohamed *et al.* (2014) interviewed 30 participants with MIBlCa before and up to 72 months post-surgery using an unspecified qualitative methodology. Unmet informational and supportive needs (medical, psychological, and emotional) were discussed at three time points (at diagnosis, immediately post-operatively, and between six and 72 months post-surgery). Findings suggested that genitourinary complications decreased. However, urinary function, incontinence, loss of control, self-care information deficits, lack of stoma and catheter training, physical, social, and sexual dysfunction, and issues with body image, compounded worry about survival, cancer return, and the aging process. Mohamed *et al.* (2014) believe that the lack of referral for counselling may leave patients feeling that their depression was normal after a diagnosis of cancer and the rigours of treatment. Adding to these physical and psychological problems was a lack of information about medical insurance, post-RC expectations, healing and sexual dysfunction. Specifically, Mohamed *et al.* (2014) highlighted requirements at diagnosis (information about side effects of surgical options, recovery, self-care and medical insurance), post-operative concerns (bowel function, pain, stoma assistance, incontinence and catheters), psychological issues (depression, sexual function, worry, body image), and daily encouragement towards adaptation at survivorship (72 months post-RC). Participants suggested the need for relevant information pamphlets, CDs, and websites with clear communication from medical professionals.

Yuh *et al* (2008) conducted a prospective study with a sample of 34 participants who completed a questionnaire prior to, and up to six months after, robotic-assisted radical cystectomy (RARC). QoL assessment encompassed a range of well-being measures and commenced three weeks prior to surgery, with follow-up at 1, 3 and 6 months post-RARC.

Contrary to other findings, Yuh *et al.* (2008) reported positive QoL outcomes for up to six months. While there was an initial reduction in Physical Well-Being (PWB) for up to a month, all of Emotional Well-Being (EWB), FWB, and Additional Concerns (body image, sexual desire, and gastrointestinal issues) improved after surgery. At six months, all signs of hopelessness, sadness, or anxiety had improved, being attributed to rapid recovery from RARC. Social/family Well-Being (SWB) remained constant, demonstrating the stability of the social supports available to these participants.

2.3.2 Quality of Life with an Ileal Conduit

Five studies focused specifically on QoL (expectations, needs, adaptation, and stoma care) among those with an IC. Again, all but one study used a quantitative methodology (Tal *et al.* 2012; Cerruto *et al.* 2014; Gomez *et al.* 2014; Tejido-Sanchez *et al.* 2014; Liu *et al.* 2016).

In their prospective questionnaire study, Tal *et al.* (2012) sought to clarify who cares for the stoma, how stoma care affects QoL, and predictors of stoma self-care. For 65 participants post-RC, self-care was associated with better QoL, including psychological well-being. Stoma self-care had other benefits, such as independence and feeling less bothersome to caregivers. Women were more likely to care for their own stoma than men, who offered repulsion, avoidance, body image, and denial as reasons for not engaging in self-care. Better post-operative stoma education and skills training, particularly if in place prior to hospital discharge or in the first month post-discharge, were associated with an increased likelihood of self-care. Urologist, urological nurse, or stoma nurse typically provided education.

Gomez *et al.* (2014) used a telephone interview survey with their 37 participants six months post-IC, with stomal self-management associated with improved physical and psychological health and QoL, with 95% of participants reporting *good* QoL and no *poor* QoL. Participants identified patient education and training as important, noting that education of stoma care should preferably commence before surgery or as soon as possible afterwards, given that patients found this training prior to discharge to assist in their adaptation. Ongoing stoma assessment after surgery also allows the identification of complications, with Gomez *et al.* (2014) suggesting that education and counselling for the participant's significant others, might further improve skills, and reduce fears and doubts about the stoma. Transfer to a wound ostomy continence (WOC) nurse in the community was seen as an additional support that improved QoL. Participants who may require more attention and education include the elderly, men, unemployed participants, or those of lower socioeconomic status.

Tejido-Sanchez *et al.* (2014) used a questionnaire study to determine QoL among 59 Spanish participants treated with IC. In general, QoL was worse when treatment included chemotherapy. Further, women undergoing chemotherapy reported mood changes that affected their daily activities. However, these daily activity reductions were not related to mobility issues. Sixty one percent of participants reported stoma complications (e.g. skin problems), lack of social support and poor stoma management skills, predicted worse QoL in terms of depression, anxiety, discomfort, and pain that interfered with personal care. The most problematic complications were stenosis, prolapse, and retraction of the stoma, with infection, leakage, bleeding, hernia, dermatitis, and mucus production, also mentioned.

Liu *et al.* (2016), in their cross-sectional questionnaire survey noted that decline of physical function (PF) adversely affected QoL among 188 participants who were surveyed between 1 month and 2 years post-IC. In particular, sexual dysfunction and lack of sexual satisfaction were associated with poorer psychological well-being and QoL, particularly when linked with reduced urinary function. Being a man over 60 years of age was related to poorer QoL, compared with women or younger patients, in general. Additionally, if these men were unemployed, had financial difficulties or a shorter rehabilitation period they were more likely to experience poorer QoL.

Using grounded theory, Cerruto *et al.* (2014) examined the adaptive behaviours of 30 participants before and after IC, and for up to seven years. They described two main profile groups, a positive profile group (who managed their stoma well, and had good social and PF), and a negative profile group (who experienced worse QoL following their IC, and could not manage their stoma or daily activities). Cerruto *et al.* (2014) also found that a higher household income not only resulted in improved economic and social outcomes, status, and family environment but also improved QoL post-IC. In addition, a prolonged recovery time and employment, was associated with improved PF, value (relationships, isolation, and stigma), confidence, and better social, family and community support. The positive profile group of patients with better QoL tended to be older, with longer follow-up post-IC and fewer complications (Cerruto *et al.* 2014). In later life, stoma-related concerns focused on the loss of a partner, complications, and the insistence on having all required products and equipment with them at all times, limiting the degree and extent of travel.

2.3.3 Quality of Life with a Neobladder

In general, QoL among participants with a neobladder, concentrated on post-operative follow-up (D'Agostino *et al.* 2016), assessment of QoL parameters (Imbimbo *et al.* 2015), and the QoL with respect to women (Bartsch *et al.* 2014; Rouanne *et al.* 2014).

The first study of female patients only (Bartsch *et al.* 2014) used a single centre cohort study to examined urinary function among 56 participants and noted that those with a college degree had worse urinary function and urinary bother scores. These individuals may have had high expectations of the neobladder, yet these were not met by the outcome, and resulted in disappointment. Sixty six percent of participants stated they preferred CIC to the potential for leakage. CIC was the means of emptying the neobladder daily for 44.6% of participants, with 8.6% using CIC once or twice per day, 11.4% three or four times per day, 17.1% more often than 4 times a day. However, 29.6% reported having daily leakage and 35.2% during sleep.

Rouanne *et al* (2014) also studied only women (N = 31) in their single centre questionnaire study, which assessed QoL related to urinary leakage, associated pad use, and the need to self-catheterise. Total continence was reported by 64.5% of participants, with 74% stating that they used no safety pad for leakages during the day (80% during the night). Stress urinary incontinence (SUI) occurred during the daytime for 26% of participants (29% during the night). Further, those who were hyper-continent (29%) reported daily (4-6 times) self-intermittent catheterisation (SIC) and lower QoL. When compared with the general French population, participants had lower physical and mental health, although this was not statistically significant. The majority (58%) reported good quality sexual activity, possibly due to vaginal wall nerve sparing and clitoris vascularization during their RC surgery. Health and well-being were ranked as *good* to *excellent* by 77% of participants, with 71% happy about how they felt and *a little* to *not* embarrassed in their relationships or social situations (80.6%). While this study found that being aged less than 60 years at the time of cystectomy predicted continence, being over 65 years of age was associated with post-operative daytime SUI (Rouanne *et al.* 2014).

In a multicentre cross-sectional questionnaire study, D’Agostino *et al.* (2016) found that long-term QoL among their 171 participants was good despite some negative aspects. For example, experience caring for their neobladder may have helped to improve their independence in performing daily activities in the long term, particularly as perceptions of body image were expected to be better in patients with a neobladder than for those with an external abdominal device. They found that by 5 years post-RC, these positive aspects subsided. Social-emotional related aspects of QoL were also good initially but peaked at 72 months after which there was a sharp decrease, coincidentally with a decline in participant’s social lives. D’Agostino *et al.* (2016) felt this was due to increased urinary symptoms, and associated decrease in the ease with which the neobladder was managed as participants became older. Other negative effects included fatigue, loss of autonomy, sleep disorders, problems emptying the neobladder and sexual dysfunction which increased over time (D'Agostino *et al.* 2016). As participants advanced in years, they had more difficulty managing the regular emptying of the neobladder to prevent leakage, which continues through the night causing sleep problems and fatigue.

Imbimbo *et al.* (2015) conducted a multicentre observational study examining predictors of QoL among 174 participants with a neobladder. They found a number of variables with a negative impact, including advanced age, the presence of comorbidities, urinary incontinence (mostly at night), increasing urinary symptoms, emotional factors and fatigue associated with night time incontinence, or awakening to empty the neobladder. While Imbimbo *et al.* (2015) refuted the suggestion that older patients are not suited to a neobladder. Their study showed that age was an independent predictor of poorer QoL. Even though comorbidities would generally have a negative effect on QoL, they found that patients with peripheral vascular disease had better QoL, attributable to patients' possible acceptance of a chronic disease. Of note is that participants followed-up for at least 36 months reported better QoL.

2.3.4 Muscle Invasive Bladder Cancer Symptoms and Supports

One qualitative study focused on the overall QoL of participants with MIBlCa (Fitch *et al.* 2010), and three quantitative studies examined the effects of nocturnal urinary symptoms (Thulin *et al.* 2010), supports, hope and resilience (Li *et al.* 2016), and the history of symptoms and distress in patients and families (Benner *et al.* 2014).

Fitch *et al.* (2010) used a qualitative descriptive approach and interviewed 22 participants to gain a better understanding of QoL in terms of sexuality, body image, and sense of masculinity or femininity. Participants coped well with the post-surgical period and reported little pain. However, once discharged they could not access the assistance they required, with community nurses or other assistants not being experienced in the necessary care procedures. In fact, participants undertook their own information searches because they believed it was vital for their survival and this need could not be fulfilled by health care professionals. Fitch *et al.* (2010) reported that the opportunity to connect with others experiencing similar issues was important, with family and friends helping to process information received during interactions with health care professionals.

Some participants accepted their BlCa fatalistically and prepared their papers in readiness for death, whereas others mourned the loss of their bladder and surrounding organs (Fitch *et al*. 2010). Urinary and sexual dysfunction were common side effects. Changes to sexual function depended on the type of surgery, stage of life, the importance of sexuality, age, and duration of the relationship. For some, intimacy improved post-surgery and was valued differently to the pre-BlCa period. One man noted that improvements in communication with his spouse made a difference to their intimacy. Others were ill at ease with an unappealing, leaking bag attached to their abdomen, particularly for those who were seeking a new relationship, who did not believe they could feel loved with a stoma. The formation of a stoma raised issues of body image and functioning, mainly among younger participants. The need for new toileting procedures such as catheter use, management of a stoma, urinary leakage, and incontinence, which participants were ill prepared to handle due to a lack of training was discussed by Fitch *et al*. (2010). A stoma was perceived as embarrassing and undignified due to the need for stoma care assistance. Incontinence rendered participants child-like, their autonomy was eliminated rendering them emotionally stressed and unable to cope when leakages occurred.

Thulin *et al.* (2010) recruited 45 participants for their cross-sectional questionnaire study to investigate the effects of sleep disturbance on QoL post-RC, as reported by those with an orthotopic neobladder (37%), continent reservoir (14%), and urostomy (22%). Sleep disturbances were due to urinary leakage and the requirement to empty the neobladder or change protective pads. Many participants set an alarm to allow them to wake and empty their neobladder regularly during the night in the attempt to stop leakages. Sleep disturbances can affect energy, general physical health, and QoL. Thulin *et al.* (2010) emphasised the need for appropriate pre-RC counselling about possible side effects (e.g. sleep disturbances) associated with various diversions. Despite advances in RC procedures, and the expectation that a neobladder promotes better QoL, there remains no agreement about which diversion is best (see Appendix B5).

Li *et al.* (2016) reported a cross-sectional study of 365 Chinese BlCa participants whose overall QoL (e.g. psychological, physiological, financial, and social) was lower than that found in developed countries such as the US. This poorer outcome was attributed to differences in medical systems and regulatory guidelines, and Chinese participants’ inability to access the required hospital care. Conversely, Li *et al.* (2016) noted that participants who exercised were more likely to report a better QoL and a stronger bond with a partner, family, and friends. Those who took part in more activities also had a more positive outlook overall. A better QoL was evident among participants with a higher level of education. That is, better-educated individuals, may have better jobs, earn more money, experience less stress, live in a better housing environment, and so adjust more quickly to their BlCa.

Li *et al.* (2016) recognised that hope and resilience are important factors in adaptation to BlCa as they were associated with a sense of positive well-being, hope for survivorship, and served as resources with which to fight the negative psychological aspects of treatment. For example, mood changes were less evident among participants with more hope. Conversely, poor adaptation to BlCa may be due to a lack of social support, greater psychological distress, depression, and more comorbidities. Older participants (> 75 years of age) had less *fighting spirit*, with poorer prognosis, more psychological distress, and poorer QoL.

In a prospective cohort study, Benner *et al.* (2014) investigated a range of symptoms and distress among BlCa patients and their families during a 6-month period. Thirty-three participants commenced the study but only 22 completed all study requirements. Similarly, only 16 of 19 family caregivers completed the study. For participants, pain and fatigue were both high post-operatively peaking at 4 months and remaining high at six months, with depressive symptoms found to be normal at baseline but increasing between 4 and 6 months. There was no improvement in QoL or spiritual well-being over time. Despite high levels of satisfaction with treatment 30% continued to have incontinence difficulties, sexual dysfunction (10%) and pain (20%). Caregivers perceived only low levels of burden, which did not change over time. However, Benner *et al.* (2014) hypothesised that guilt may have contributed to caused underreporting of burden.

2.3.5 The Benefits of Conservative Treatment over Surgical Intervention

Two studies evaluated QoL among NMIBlCa and MIBlCa participants. Allareddy *et al.* (2006) compared QoL in patients with either MIBlCa and an RC or NMIBlCa and a native bladder. Singer *et al.* (2013) compared individuals with either MIBlCa or NMIBlCa to compare QoL between the two groups and a sample of the local German population.

Allareddy *et al.* (2006) in their cross-sectional questionnaire study, recruited 259 participants, they underwent either RC (n = 82) or conservative therapy (BI; n = 177). Of the former group, 62 had an RC immediately (various surgical diversions) and 20 had a cystectomy following other treatment (CFOT). QoL was similar among these groups, and nor were there differences amongst RC surgical diversions. Similarly, QoL did not differ within groups based on age or time since diagnosis. Participants with an IC were embarrassed (29%) by their stoma and noted difficulties with it (46%), with body image also being a problem for 8.5% of IC participants versus 5% of participants with a BI. Overall, Allareddy *et al.* (2006) found that comorbidities and older age were associated with poorer QoL among participants with a BI. Interest in sex was higher in the BI group, with only 21% disinterested compared with 39% in the RC group. Erectile dysfunction (ED) was experienced by 89% of the RC group and 32% of BI participants.

A cross-sectional questionnaire study was use by Singer *et al.* (2013) in which they recruited 823 participants who were compared with a community sample (n = 2,037). They sought to quantify differences in QoL between those who had received conservative treatment and either a neobladder, IC, or other diversion. Compared with the general population, QoL was worse among participants with either MIBlCa or NMIBlCa across all age groups, along with poorer emotional function (EF) and PF. No QoL differences were noted among participants with MIBlCa or NMIBlCa, even with gender, age, type of treatment or time since surgery taken into account. However, the physical side effects of radiotherapy (constipation, low appetite, more pain), chemo-radiation (pain, nausea and vomiting, dyspnoea), and chemotherapy (dyspnoea and low appetite) had worse effects on QoL for NMIBlCa group, particularly older participants with insomnia and emotional dysfunction. QoL was also worse among women in both groups, and for community members, than for men (Singer *et al.* 2013). Within the MIBlCa group, IC participants reported worse physical and role function, fatigue, loss of appetite and insomnia than those with all other diversions, with men at least 70 years of age or older having worse QoL in terms of insomnia and emotional issues.

2.3.6 Quality of Life with a Bladder Intact

Hashine *et al.* (2008) focused on the QoL (physical and emotional functioning) of participants with MIBlCa who opted for bladder preservation therapy (BPT). In BPT, a TURBT is performed with intra-arterial chemotherapy and radiotherapy. Four studies involving BI participants (with NMIBlCa) examined general QoL (Schmidt *et al.* 2015), sexual dysfunction (Kowalkowski *et al* 2014), the burden of cystoscopy and urinary surveillance (van der Aa *et al.* 2008), and QoL after a TURBT (Yoshimura *et al.* 2005).

Hashine *et al.* (2008) in their cross-sectional, compared the QoL of 33 BPT participants with a comparison group (NMIBlCa, n = 128). Of the BPT participants, 46 had a TURBT twice or more, whereas 74 NMIBlCa participants had BCG treatment, they noted a non-significant poorer QoL in the BPT group. Body pain was worse in this group, as was irritable urinary symptoms and bowel symptoms, largely in participants > 70 years of age. Urinary function and bother caused by urinary symptoms were similar in both groups. Many QoL markers were influenced by age, in BPT participant who were between 70 and 80 years. BPT was preferable to cystectomy due to the decrease in QoL associated with RC surgery and the formation of a urinary diversion. On balance, Hashine *et al.* (2008) concluded that QoL was acceptable for participants with MIBlCa using BPT.

Schmidt *et al.* (2015) conducted a prospective multicentre cohort study to evaluated QoL among 244 participants undergoing TURBT alone (n=144) or in combination with BCG or chemotherapy with mitomycin C (n = 82). Data were collected at baseline, 6 and 12 months. It was noted that there were 32 remissions, whereas 63 participants experienced either recurrence and/or progression of the disease. At both diagnosis and during follow-up, mental health was significantly lower for the BlCa group than for the local population, although it did not worsen over time. Schmidt *et al.* (2015) noted that physical health was unaffected by the diagnosis. No QoL differences were noted for age, gender, education, tumour grade, or comorbidities across the study duration.

According to Schmidt *et al.* (2015), nearly 50% of participants who reported no issues with sexual function at diagnosis had developed sexual dysfunction at 12 months. Among those with moderate dysfunction at diagnosis, 44% had declined further. Participants undergoing TURBT reported decreased sexual function except when in conjunction with mitomycin C, in which case urinary symptoms improved, but bowel symptoms remained stable. Among participants with no initial urinary symptoms, 16% were worse after treatment whereas twothirds of those with moderate to severe urinary symptoms reported similar bowel symptoms. For participants undergoing TURBT plus mitomycin C, Schmidt *et al.* (2015) noted improved mental health and urinary symptoms with BCG treatment associated with fewer bowel symptoms.

Yoshimura *et al.* (2005) in their prospective longitudinal study, assessed the general QoL of 133 participants who underwent at least four TURBTs (designated times 1 to 4). Some also had BCG or mitomycin C. Body Pain measured at Time 1 was similar to the Japanese population norm but elevated among those whose treatment was not curative. Both mental and physical health of participants was worse than the population norm between Times 1 and 3, but both had returned to population equivalence by Time 4. Yoshimura *et al.* (2005) hypothesised that this return to normal levels demonstrated adaptation to BlCa, as the symptoms had perhaps become more manageable.

van der Aa *et al.* (2008) randomised participants with NMIBlCa to either cystourethroscopic surveillance (CUS) 3 monthly for 24 months (n = 108) or microsatellite analysis (MA) of voided urine (n = 93). The latter group also had CUS at 3, 12, and 24 months or if test results indicated the need. Participants completed a questionnaire the week after their CUS or MA on each occasion. For those in the CUS group, pain was assessed at four points (preparation, introduction of the scope, during the CUS and directly afterwards). The MA group reported waiting for their results as *quite* uncomfortable whereas they were satisfied with the MA urine collection process and the healthcare service.

Reported side effects included painful micturition by the CUS group, while both groups noted urinary frequency and urgency (UFU), the need for pain medication or antibiotics, the need for GP follow-up within a week, pain during daily activities, and reduced social activities. Pain was particularly associated with the introduction of the cystoscope for the

CUS group, as it caused an increase in urinary symptoms and the need for pain medication and antibiotics during the following week. CUS participants experienced less burden with age but not number of CUS procedures undertaken. While invasive and painful, CUS may remain the preferred option, as even though it was more burdensome, results are immediate. With MA, the waiting time for results was a perceived burden (19%). This study highlights that surveillance of any type is associated with burden, no matter how innocuous the test, as the proportion of MA participants requiring medication and a general practitioner (GP) visit in the week post-MA was similar to that in the CUS group (van der Aa *et al.* 2008).

Kowalkowski *et al.* (2014) conducted a mixed methods study investigating sexual dysfunction in among 117 participants with NMIBlCa in the quantitative arm (Study 1) and 26 participants in the qualitative arm (Study 2). Study 1 highlighted that BlCa treatment had significantly disrupted relationships (55.3%), reduced sexual activity (38.8%; women 56%), and resulted in ED (60%), ejaculatory dysfunction (43.1%), and vaginal dryness (62.5%). Participants also expressed concern about contaminating their partner with BlCa (23.2%). Although sexual function and activity were compromised for many, among those who openly discussed these issues with their partner (20%), half found the conversation beneficial. Higher levels of partner communication were associated with *a little* or *quite a bit/very much* sexual activity, and sexual abstinence in those with *poor* communication with their partner.

Study 2 similarly highlighted that 30% of participants were scared of contaminating their partner with BlCa or the intravesical treatment agent, causing them to cease sexual activity. Kowalkowski *et al.* (2014) reported sexual dysfunction, decline in intimacy or divorce, and other adverse effects of BlCa on relationships. Again, however, improved communication was noted to be helpful. Other relationship problems were due to urinary and bowel dysfunction. Kowalkowski *et al.* (2014) demonstrated the impact of sexual dysfunction and fear that may negatively influence relationships, particularly women. The decline in sexual activity and close relationships decreases QoL and is associated with further psychological and emotional issues around loss, grief, and vulnerability.

2.4 DISCUSSION OF SYNTHESIS

Section 2.3 summarised evidence concerning the QoL of people with NMIBlCa or MIBlCa who underwent either conservative or surgical treatment. The following eight issues were identified consistently (1) diagnosis and treatment modality over time (2) physical functioning, (3) psychological state, (4) sexual functioning, (5) the role of partners and support generally, (6) social functioning, (7) the healthcare system, and (8) age and gender.

Generally, diagnosis and treatment of BlCa was associated with a reduction in QoL (Yuh *et al.* 2008; Singer *et al.* 2013; Cerruto *et al.* 2014; Fung *et al.* 2014; Gomez *et al.* 2014), particularly for those undergoing RC (Goosens-Laan *et al.* 2014). While some improvements in physical symptoms and psychological well-being post-treatment were noted (including social, psychological, physical, urinary, and sexual function), these too tend to decline over time (Takenaka *et al.* 2011; Fung *et al.* 2014; Rouanne *et al.* 2014; D'Agostino *et al.* 2016). Mohamed *et al.* (2014) highlighted other negative outcomes such as depression, poor body image issues, and an inability to adjust to changes in daily living.

QoL changes were, to some extent, associated with the type of BlCa and its treatment. In terms of MIBlCa and NMIBlCa there was no apparent difference in QoL in terms of age, gender, or treatment or over time, except among people undergoing radiotherapy, chemo-radiation or chemotherapy alone, particularly older participants or those with existing psychological issues (Singer *et al.* 2013). This subset suffered a more substantial reduction in QoL. Similarly, Allareddy *et al.* (2006) did not find QoL differences between those with a BI and those undergoing surgery. Nor were there QoL associations with age or time since diagnosis, although participants with comorbidities who were older did have worse QoL.

A decline in physical functioning was a key aspect of reduced QoL, many studies noted that QoL was affected by urinary and bowel dysfunction, CIC, skin problems, stoma care, pain, fatigue, sleep disorders, leakages, and incontinence (Yuh *et al.* 2008; Fung *et al.* 2014; Cerruto *et al.* 2014; Gomez *et al.* 2014). However, conservative treatment including mitomycin C, improved sexual function among those with NMIBlCa (Schmidt *et al.* 2015).

Poorer QoL was also associated with worse psychological health (Gomez *et al.* 2014), as reflected by reduced role function, poor body image, and self-esteem generally, increased worry, mood disorders, anxiety, depression, more perceived burden, distress and stigma (Allareddy *et al.* 2006; Fitch *et al.* 2010; Benner *et al.* 2014; Mohamed *et al.* 2014; Imbimbo *et al.* 2015). However, Schmidt *et al.* (2015) found that mental function improved following treatment for NMIBlCa that included mitomycin C.

Sexual functioning was noted to deteriorate after diagnosis and treatment (Cerruto *et al.* 2014), contributing to relationship strain and poorer QoL. However, Allareddy *et al.* (2006) found that interest in sex was higher among those with a BI whereas ED was worse following surgery. Fitch *et al.* (2010) suggested that partners who communicated about sexual dysfunction experienced better relationships and hence improved QoL. Along with the recommendation that counselling includes partners (Fitch *et al.* 2010; Thulin *et al.* 2010), Li *et al.* (2016) discussed the potential benefits of exercising with a partner, family, or friends to improve QoL and social functioning.

Issues involving social functioning included employment, financial problems, dependence, embarrassment, and loneliness. Participants with better QoL had attained a higher level of education, reporting better social functioning and physical outcomes associated with better jobs, higher income, social status, and family environment (Cerruto *et al.* 2014; Li *et al.* 2016; Liu *et al* 2016). In China, the burden of illness falls on the family due to the one child policy, and spiritual beliefs that include family members caring for each other (Liu *et al* 2016). Conversely, Bartsch *et al.* (2014) claimed that individuals with a higher level of education had poorer physical and psychological QoL, and attributed this finding to higher expectations of better-educated participants.

Despite interactions with the healthcare system being perceived favourably, Benner *et al.* (2014) found that many participants had substantial unmet needs throughout their treatment. D'Agostino *et al.* (2016) stated that pre-surgery education explaining the positive and negative aspects of a neobladder and CIC might encourage active participation in treatment decision-making, with the potential to improve QoL. Fitch *et al.* (2010) remarked that participants felt healthcare professionals could not meet their informational or training needs, and that a trusted partners or friends may offer valuable support during such interaction.

Treatment interventions that improved QoL included training with a stomal nurse to enhance stomal self-care, confidence, and adaptation (Tal *et al.* 2012; Cerruto *et al.* 2014; Gomez *et al.* 2014). In addition, having > 36 months of follow-up after surgery also helped to promote QoL (Imbimbo *et al.* 2015). Future recommendations suggested by participants included clear communication from healthcare professionals, better access to information pamphlets, CDs, websites, post-surgical information, with resources relating to diet, infection, wound care, home care, and follow-up plans, along with awareness campaigns, posters, books, and patient education packages (Fitch *et al* 2010; Mohamed *et al.* 2014). Other recommendations were to make members of the public more aware of BlCa signs, symptoms, and risk factors.

Many studies identified the relationship between QoL and older age. Liu *et al.* (2016) found that younger participants experienced better QoL than their older male participants. Being 60 to 65 years at diagnosis was predictive of continence, whereas being 65 to 70 years of age was indicative of decreased physical and psychological functioning and QoL, with further reduction after age 70 (Allareddy *et al.* 2016; Hashine *et al.* 2008; Singer *et al.* 2013; Rouanne *et al.* 2014; Imbimbo *et al.* 2015; Li *et al.* 2016). Yet body image was better among older participants indicating that such individuals either adapted to their new body, (e.g. stoma appearance), or simply had a lack of interest (Tal *et al.* 2012; D'Agostino *et al.* 2016). Allareddy *et al*. (2006) found a poorer QoL was evident among older participants with NMIBlCa undergoing cystoscopic surveillance and TURBT. This finding is not surprising given the continuous nature of surveillance and treatment. Imbimbo *et al.* (2015) noted that poorer QoL was linked to older age for participants with a neobladder, suggesting that older participants should be counselled about their prognosis once a neobladder is formed. Finally, Singer *et al.* (2013) found that women with BlCa experienced a worse QoL than men.

2.5 CHAPTER SUMMARY

Chapter 2 presented a systematic review of the QoL issues associated with BlCa. Section 2.2 highlighted the lack of study details including methodological approach, hypotheses, ethical issues, data collection and analysis, the use of validated instruments, participant description, sample size, limitations and recommendations. Few studies focused on NMIBlCa despite NMIBlCa accounting for 70% of BlCa diagnoses, and these studies commonly focused on the social component. The fact that only three qualitative studies were found to include in this review suggest there is a knowledge gap about the lived experiences of people with BlCa. Similarly, there is limited information about women with BlCa and the roles played by partners. Knowledge about BlCa would be enhanced by further qualitative research into the experiences of couples facing BlCa and how they adapt to BlCa in their lives. Additionally, quantitative research using validated tools which do not merely report on MIBlCa, or the QoL variances between surgical procedures, would add insight into the difficulties of living with both types of BlCa through all treatment modalities. The following chapter introduces Phase 1, and presents a detailed description of the mixed methods approach.

PHASE 1

'Every thinker puts some portion of an apparently stable world in peril and no one can wholly predict what will emerge in its place."

John Dewey, Experience and Nature (2008, p. 173).

CHAPTER 3

THE MIXED METHODS RESEARCH APPROACH, QUALITATIVE METHODOLOGY AND METHODS

3.0 INTRODUCTION

This chapter examines the mixed methods approach used in this program of research and explicates the qualitative methodology and methods utilised. While the MMR approach was briefly introduced in Chapter1, the theoretical and philosophical framework underpinning this research is elaborated further in this Chapter. In particular, the use of pragmatism as a philosophical framework for sequential exploratory research using a MMR approach is discussed. Furthermore, the methodology of Qualitative Description (QD) is applied, as it is particularly appropriate to use in MMR because it also aligns with a pragmatic lens. The Phase 1 methods are then presented, including the research context, ethical considerations, recruitment of clinical participants and partners, data collection procedures, data analysis and trustworthiness. The QD findings are then detailed in Chapter 4.

3.1 THE MIXED METHODS RESEARCH APPROACH

This program of research uses the theoretical and philosophical approach of pragmatism to explore the experiences of individuals who have been diagnosed with BlCa. The primary aim was to gain an understanding of their QoL. In MMR, no particular methodology is valued more than another is, but rather the research seeks to identify the truth using techniques that best fit that context (Lincoln & Guba 1985). Pragmatism is appropriate in research where the overarching question dictates that an exploration of different worldviews is essential to understanding the complexities of a phenomenon (Tashakkori & Teddlie 2003).

Phase 1 adopts the constructivist paradigm that assumes an emphasis on in-depth understanding of human experiences for which the researcher uses inductive reasoning and flexibility (Whitehead *et al.* 2016). Phase 2 then utilises the quantitative paradigm for which deductive reasoning, and instruments capture the meaning of the data. Key to quantitative research is instrument quality and suitability (Castro *et al.* 2010; Leech *et al.* 2010).

According to Fetters *et al.* (2013), integration of the qualitative findings and quantitative results is built into the design when using an exploratory sequential MMR approach. At the methods level, integration can occur through a *merging* technique when using a multistage framework, whereby the qualitative findings are reported followed by the quantitative results which are later merged (Tashakkori & Teddlie 2003; Fetters *et al.* 2013). At this level, the *building* technique is represented by the qualitative findings of Phase 1 informing the formulation of the questionnaire in Phase 2, where Phase 2 *builds* upon Phase 1 findings.

3.2 PRAGMATISM

Morgan (2014) describes pragmatism as a series of questions used to guide enquiry and argues that classical pragmatists question why it matters to conduct research in a particular manner. According to Dewy (2008), pragmatism highlights the experiences of humans with feelings both causing and resulting from those experiences. Human experiences relate to the origins of personal beliefs and the significance of actions. All experiences, beliefs, and actions require interpretation (Dewey 2008). Research is an enquiry that seeks to rectify a problem through action, by asking and answering questions and developing theory for the benefit of others (Feilzer 2010; Morgan 2014). It is suggested that choices such as determining which research problem to prioritise, or which methods to use, are pragmatically determined as ‘pragmatism concentrates on beliefs that are more directly connected to actions’ (Morgan 2014, p. 1051). In other words, based on our belief systems, we choose what we think is the right way to conduct research for the desired outcome.

The origins of pragmatism stem from Peirce, James, Dewy, Mead, and Bentley [1838-1957] who were American philosophers during the period of social reform in the US (Rosenthall 1986; Maxcy 2003). These philosophers disagreed with the notion that *scientific* methods were the only way to derive information, and instead conducted their research by using enquiry based on real life experiences and aimed at unearthing truth (Rosenthall 1986; Albrecht 2006; Snowden & Atkinson 2012). Pragmatism was revived by Rorty [1979] who believed in 'language and context' rather than 'thought and objects or mind and behaviour' (Maxcy 2003, p. 79). Building on Dewey's earlier work, Rorty advocated '… a mixture of methods deployed on a problematic situation … to aid action' (Maxcy 2003, pp. 79-80).

Pragmatism involves discarding absolutes and *a priori* knowledge and engaging in problem solving instead by seeking a thorough understanding of experiences (Florczak 2014). Tashakkori and Teddlie (2003), and more recently, Whitehead and Day (2016) suggested the use of pragmatism as a third paradigm to assist in overcoming tensions between qualitative and quantitative paradigms. Table 3.1 compares these three methodologies in terms of fundamental assumptions. Pragmatism positions the research problem as the priority, rather than the paradigm or methodology and embraces the chosen methods without judgement (Denzin 2010; Wheeldon 2010; Harrits 2011; Richardson-Tench *et al.* 2014).

Onwuegbuzie and Leech (2005) suggest that pragmatic researchers are better able to conduct holistic research, use qualitative research to inform quantitative studies, and offer descriptive and empirical precision and focus. Pragmatic researchers are encouraged to remain flexible to the setting, participants, and phenomenon under scrutiny, while being wary of new data from various sources that might unexpectedly surface (Feilzer 2010). The main obligation of researchers is to understanding that '… any knowledge produced through research is relative and not absolute …', that life and people are unpredictable, and the role of the researcher is to remain '… curious and adaptable …' (Feilzer 2010, p. 14).

Table 3.1 *Pragmatism and Alternative Research Methodologies.*

Approach	Data and theory construction	Procedural relationships	Inferences from the data
Qualitative	Induction	Subjectivity	Contextual
Quantitative	Deduction	Objectivity	Generality
Pragmatism	Abduction	Intersubjectivity	Transferability

Note: *Reproduced from Morgan (2007, p.71) with the permission of DL Morgan and Sage Publishing (01/07/2016).*

To summarise, pragmatism emphasises the importance of the outcome rather than the method used to arrive at that outcome, and the subjective nature of study design and interpretation (Creswell 2004). More specifically, in the current study pragmatism is used as a world view and a framework on which to hang the components of both qualitative and quantitative research methodologies. The goal is for research to be of assistance and answer the original overarching question while remembering that '… all knowledge is knowledge from some point of view …' (Feilzer 2010, p. 8). Paradigms may change over time, as do assumptions concerning knowledge and reality, they are modified to fit a changing society and its needs (Roy 1987; Greene & Caracelli 2003; Albrecht 2006). Guba (1990, p. 17), reminds us that 'Having the term not cast in stone is intellectually useful and allows for reshaping understandings'

3.3 PHASE 1 METHODOLOGY: QUALITATIVE DESCRIPTION

Qualitative Description (QD) is a specific pragmatic methodology that facilitates the study of the phenomenon of interest without prior agenda or knowledge as it is devoted to a 'comprehensive summary of events in … everyday terms' without the requirement of further theories (Sandelowski 2000 p.334). QD is a methodology in its own right, in which the researcher attempts to remain true to describing an event or phenomenon without the need for other constructs, frameworks or philosophies (Sandelowski 2000; Whitehead *et al.* 2016). QD seeks to characterise the *viewpoints* of participants in a manner in which most people observing the same event would provide a similar description (Sandelowski 2000; Vaismoradi *et al.* 2013, p. 398). QD is an appropriate methodology for use in inductive research (e.g. characterising people's experiences of BlCa).

Sandelowski (2010) has defined QD as the least interpretive and least theoretical of the naturalistic qualitative methodologies. However, she warns that the researcher cannot commit to QD without at least a personal theoretical standpoint, and that in fact no researcher can so naively approach research. QD is based on the supposition that the data are honest and truthful or '*factist,'* and that the findings are representative of methods as '*living entities that resist simple classification*' (Sandelowski 2010, pp. 80, 83).

Whereas Interpretive Description (ID) utilises a theoretical framework, and extends the study's findings beyond the participant's descriptions to an interpretation of the described phenomenon, where abstract ideas assist visualisation of a new meaning (Thorne *et al.* 2004; Thorne 2008; Thorne *et al.* 2012). According to Thorne *et al.* (2004, p.7), ID uses a '… *critical examination within methodological guidelines*…' consistent with disciplinary nursing procedures where a '*new truth*' is generated as an version of the described phenomenon, arrived at through iterative, concurrent data collection and analysis (Thorne *et al.* 2004; Thorne 2008; Thorne *et al.* 2010; Thorne *et al.* 2012).

It is appropriate in QD to use a purposive, maximum variation recruitment strategy to enable all possible components of a phenomenon to be represented (Sandelowski 2000; Neergaard *et al.* 2009). This technique has guided Phase 1 participant selection, with the emphasis of the recruitment process being on gender, age, length of time since BlCa diagnosis, and inclusion of participants who have undergone all possible treatment modalities.

A QD personal face-to-face interview allows a participant's story to emerge naturally during conversation using open-ended questions with a *what, who, where,* and *why* focus. Further, Neergaard *et al.* (2009, p.53) suggest that an open-ended interview guide is particularly important when focusing on a research area about which little is known or an area that is '*amenable to intervention.*' However, the researcher may also ask participants to explain experiences using prompts such as '*tell me …*' (Sandelowski 2000; Patton 2015). The researcher must trust that the *story* progresses to a suitably credible outcome.

The goal of transcription and analysis is to preserve participants' experiences using their own words without interpretation and staying true to their story (Neergaard *et al.* 2009). However, inadvertent interpretation may occur if decisions are made about the importance of one piece of datum over another, even though the accuracy of the description may not be altered (Sandelowski 2000; Whitehead *et al.* 2016). Neergaard *et al.* (2009, p.53) and Vaismoradi *et al.* (2013, p.399) refer to this as '*low-inference interpretation.*' Thematic analysis is the appropriate approach for use in low-inference interpretation of data, where little previous information exists, or where a comprehensive description of findings from interviews is required (Vaismoradi *et al.* 2013). Such analysis results in important patterns in the data that relate to the research question being highlighted and recorded as themes (Neergaard *et al.* 2009; Vaismoradi *et al.* 2013).

Further, according to Neergaard *et al.* (2009, p. 55), QD '… *helps to focus on the experiences of patients, relatives and professionals and their views on the patient-professional interaction and the organisation of the health care system.*' In particular, QD is amenable for use in the assessment of needs, questionnaire development, MMR, and the firsthand consideration of 'patients', partners' and professionals' experiences' the outcomes of which might lead to further exploration based on these initial findings (Neergaard *et al.* 2009, p. 56). Research concerning a phenomenon about which little is known can be assisted by having more than one account of that phenomenon available (Sandelowski 2000). In Phase 1 of the current research, the same phenomenon is represented by two different perspectives, also known as a Rashomon effect (Sandelowski 2000). That is, both clinical participants and partners provided separate views unique to them as individuals, even though they were discussing the same diagnosis, treatment, and side effects of BlCa.

3.4 PHASE 1 METHODS

The following section first discusses the context in which the QD-based phase was located. Second, the various ethical implications in relation to these methods are reported. An explanation of the participant recruitment, data collection, data analysis methods, and the concepts of trustworthiness as it pertains to this study follow.

3.4.1 Research Context

Phase 1 of this research involved interviews about the experience of BlCa. The clinical participants for this phase were identified from the database of a 300-bed tertiary acute care public hospital in Adelaide, South Australia (SA).

3.4.2 Ethical Considerations

Study approval was sought and approved from the head of the Urology Department (Appendix C1), and the hospital Director of Nursing and Patient Services (Appendix C2). There is a letter from the database manager (Appendix C3), the University Manager of Insurance and Risk (Appendix C4), and the Southern Adelaide Clinical Human Research Ethics Committee, application number 453.11 (Appendix C 5).

3.4.2.1 Informed Consent

Informed consent requires that potential participants clearly understand their rights and obligations (Polit & Beck 2008; Kvale & Brinkmann 2009). Clinical participants who met the inclusion criteria (Table 3.2) were sent a Letter of Introduction inviting them to participate

(Appendix C6), a Clinical Participant Information Sheet (Appendix C7) and a Partner Information Sheet (Appendix C8). At the interview, a verbal explanation of the study was also provided prior to either a Clinical Participant Consent Form (Appendix C9) or Partner Consent Form (Appendix C10) being signed. This explanation included the type of data to be collected, that the interview would be audio recorded for transcription, and that data dissemination would include publication in a thesis, journals and conference proceedings.

3.4.2.2 Confidentiality and Anonymity

Each participant was allocated a pseudonym and reference number to maintain confidentiality and anonymity (Woods & Lakeman 2016; Polit & Beck 2008; Woods & Lakeman 2016). These issues are particularly important in personal interviews as participants' own words and personal profiles require de-identification prior to dissemination of findings. Information concerning confidentiality was included in the verbal introduction to the study and the Participant Information Sheets (Kvale & Brinkmann 2009). This included that participation was voluntary, and that responses and personal details would remain anonymous. It was explained to participants that their data would be given a pseudonym and that once their personal information was combined with the data of other participants, that their personal details will become unidentifiable. Additionally, participants were advised that data would be stored in a locked cabinet, in a secured room.

3.4.2.3 Risk of Harm

While the risk of harm was considered minimal, there was a potential for some participants to feel vulnerable when discussing personal information (Woods & Lakeman 2016). In the event of distress, arrangements were made for a counsellor to be available, or a list of counsellors would be provided. Despite modest evidence of distress, all participants stated they felt comfortable at the end of their interview. In cases where participants became emotional and were unable to continue, the interview and audio recorder were paused until the participant could recommence. During these pauses, participants were consoled and encouraged to discuss their emotions. For some, the interview was the first time they had had the opportunity to discuss the BlCa diagnosis and treatment. All participants also received contact information for Lifeline on their Participant Information Sheets and a contact number for the researcher should they have further questions (Polit & Beck 2008; Kvale & Brinkmann 2009). In the event that another health problem was disclosed during interviews, participants would have been advised to seek professional medical advice from their GP. If it were relevant, arrangements were made to refer participants to the hospital's Urology Department Clinical Practice Consultant (Urology/Continence) for further assessment.

3.4.2.4 Participants' Rights

All participants have the right to fair treatment including the right to refuse to continue with the interview without reprisal. Further, it is important to respect the range of cultural lifestyles, beliefs, and habits that may be encountered among participants (Polit & Beck 2008). Patton (2015) advises that participants are unlikely to divulge personal information if they are uncomfortable or feel insecure. Therefore, an atmosphere of mutual trust was promoted during interviews. Participants had the right to refuse to answer individual questions, or to terminate the interview on request. For example, a participant might state '*that's all I want to say about that*' or '*next question?*' at which point the next interview question was posed.

3.4.3 Participant Recruitment Process

The database manager and hospital case-mix manager assisted in compiling a list of BlCa patients. A manual check of individual medical records was used to identify whether potential participants met the inclusion criteria (Table 3.2). In line with QD, a purposive recruitment strategy was used to select participants, focusing on gender, age, type of treatment and time since diagnosis. The aim was to recruit both men and women, though as explained in Chapter 1 (1.4.1 Incidence and Prevalence) BlCa is more prevalent among men (Turner 2009; Jacobs *et al*. 2010; Arianayagam *et al.* 2011). Inclusion criteria included adults with a diagnosis of BlCa, able to provide consent in English and who had no cognitive impairment. A significant other ('partner') also had to agree to participate, and both were required to discuss their BlCa experiences. During their recruitment, participants' were made aware that his/her partner's involvement was also required. Recruitment ceased after 10 clinical participants were recruited as the combination of clinical participants and their partners who agreed to be involved, made an appropriate QD sample of 20 participants.

Table 3.2 *Phase 1 Inclusion and Exclusion Criteria*

Inclusion criteria	**Exclusion criteria**
Adult men and women.	Persons under 18 years of age.
Diagnosis of BlCa.	No diagnosis of BlCa.
Ability to give consent in English.	Inability to speak and write in English.
No evidence of cognitive impairment.	Any evidence of cognitive impairment.
Partners' willingness to participate.	No partner willing to participate.
Ability to discuss BlCa experiences.	Inability to discuss BlCa experiences.

3.4.4 Participant Summary

Nine heterosexual couples (married or defacto) and one couple comprising a clinical participant and her daughter-in-law were recruited. Two of the marriages were to a second partner. There were nine participants who were in the middle to older age group and one younger participants. The participants were Caucasian (n=6 Australian, n = 3, Welsh, n=1 Polish), and educated to middle secondary school level. The names of the highest year attained at high school have been changed from the original to the current education terms used in Australia. Two couples were self-employed and ran their businesses together, while half of the participants were retired.

The ten clinical participants were born over a six-decade period including the 1920s (n = 2), 1930s (n = 1), 1940s (n = 3), 1950s (n = 2), 1960s (n = 1), and 1970s (n = 1). Table 3.3 summarises the ages of participants and partners at the time of interview, age at diagnosis, and years with BlCa. Table 3.4 presents demographic information for clinical participants and partners. Consistent with the literature there were seven male and three female clinical participants (Arianayagam *et al.* 2011). The smoking years reported by clinical participants ranged from 4 to 62 years with a median of 29 years. Two participants (Dennis and Eddie) had lived in a range of locations since their BlCa diagnosis so their medical records did not necessarily include details of treatment undertaken interstate and overseas.

Table 3.3 *Summary of Phase 1 Clinical Participants*.

Characteristic (years)	**Median (years)**	**Range (years)**
Age at interview	66.8	41 - 86
Age at diagnosis	52.5	32 - 79
Years with BlCa	9.0	3 - 24
Partner’s age at interview	61.0	53 - 75

Table 3.5 presents the demographic information for partners including age, relationship to the clinical participant, education level, employment, nationality, and length of the relationship with the clinical participant.

3.4.5 Data Collection

Phase 1 data collection used an in-depth, semi-structured, open-ended interview question guide (Appendix C11, C12). Depoy and Gitlin (2005) recommend that interview questions define the phenomenon under study, explore relationships among phenomena, or test existing theory in relation to the research question. For the current enquiry, the interview guides for both clinical participants and partners were informed by the literature review (Chapter 2).

Table 3.4 *Demographic Information for Clinical Participants*.

Pseudonym	Age	Education	Employment	Nationality	Smoking years	Native Bladder/ Cystectomy
Alicia	41	Year 12	Unemployed/Homemaker	Australian	20	Native Bladder
Barry	62	Post-graduate	Self employed	Australian	40	Cystectomy
Charles	76	Trade school	Retired	Australian/German	10-15	Cystectomy (Neobladder)
Dennis	71	Military College	Retired	Australian	38	Native Bladder
Eddie	61	Year 10	Disability pension	Australian/British	26	Native Bladder
Frank	85	Year 11	Retired	Polish	47	Native Bladder
Gareth	49	Bachelor degree	Engineer	Australian	4	Native Bladder
Heather	65	Year 9	Retired	Australian	45	Native Bladder
Ian	72	Grammar school	Self employed	Welsh	62	Native Bladder
Jose	86	Year 9	Aged pensioner	Australian	20	Cystectomy

Table 3.5 *Demographic Information for Partners*.

Pseudonym	Age	Relationship	Education	Employment	Nationality	Years together
Allen	53	Husband	Year 11	Information technology	Australian	14
Barbara	56	Partner	Year 12	Self employed	Australian/Italian	30
Carol	69	Wife	Year 10	Retired	Australian	26
Debbie	54	Wife	College	Registered Nurse	Australian	26
Enid	61	Wife	Year 10	Carer	Australian	-
Flo	77	Wife	Year 11	Retired	Welsh	58
Grace	47	Wife	Bachelor degree	Administration	Australian	27
Henry	67	Husband	Year 7	Retired	Australian	46
Ida	67	Wife	-	Self employed	Welsh	-
Jean	61	Daughter-in-law	Year 11	Retired	Australian	42

The two guides sought identical information, varying only in the use of the third person in the case of the partners. That is, their perceptions and experiences were related to the diagnosis and treatment of their clinical participant's BlCa. Both interview guides sought information about the pre-diagnosis period. Asking what had led each clinical participant to the urologist. Details of the specific diagnosis were obtained, including the tests undertaken and any immediate concerns. Ongoing treatment issues were discussed which not only enquired about the physical processes but also any psychosocial effects and concerns. In addition, participants were asked about their experiences with the healthcare system.

Interviews took place in the most convenient location for participants. This was mostly in their home or a private room in the hospital. All interviews took approximately one hour and were audio-recorded. The researcher transcribed some interviews, but a professional transcriber was also used. All audio-recordings were transcribed verbatim including non-verbal involuntary sounds (e.g. laughter or crying) to maintain the exact meaning and expressions used by participants in line with QD (Oliver *et al.* 2005; Braun & Clarke 2006). Transcripts were then read while listening to the audio recordings to ensure an exact match.

Finally, transcripts were provided to participants to verify that the contents were correct. They were advised to return the transcript in the reply-paid envelope supplied within a month or it would be assumed that they were in agreement with the contents. Five participants returned transcripts with the only amendment being a request to change a number that had been misquoted. Another couple both sent individual notes regarding their thoughts and feelings since their interviews, along with their hope that benefits would come from the research. No participant asked to be withdrawn from the study.

3.4.6 Data Analysis

Analysis often begins prior to transcription as data sorting and filtering may commence during an interview (Depoy & Gitlin 2005). Such early feelings, thoughts and presumptions may be supported by notes or ‘memos’ made during the interviews which can assist the researcher in the later analysis (Depoy & Gitlin 2005). These memos could include the demeanour of the participant, their body language and the concepts to which they kept returning or which seemed most important to them and why. However, the formal transcribing and checking of transcripts increases the depth and breadth of the researcher’s understanding of the discourse represented (Braun & Clarke 2006).

Transcription and analysis were conducted consecutively, leading to a more focused and interactive process (Sandelowski 2000; DePoy & Gitlin 2005; Vaismoradi *et al.* 2013). The six-step model described by Braun and Clarke (2006) was used to interpret the analysis of the transcripts (Table 3.6). Based on thematic analysis, this model assists in maintaining the meaning of participants’ words and is particularly beneficial for use with the pragmatic approach of MMR. Braun and Clarke (2006) add that thematic analysis has the advantage of being flexible, rather than having a particular epistemological or theoretical focus.

Table 3.6 *Six-Step Thematic Analysis*

Steps	**Explanation of the thematic analysis process**
1	Become familiar with the data, transcribe audio recordings, read, and re-read the data noting ideas.
2	Generate initial open codes, the data set in systematic logical manner.
3	Collate codes into potential themes; group all relevant data for each theme.
4	Review the themes and check that themes and codes relate (Step 1), and are suitable for the data set (Step 2), draw an analytical thematic map.
5	Define and name themes, refine and analyse each theme and other related findings.
6	Write the analysis report using the most compelling extracts, which should relate to the research question and literature.

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Step 1 involved reading and re-reading the transcripts noting recurring concepts. Step 2 comprised the initial nomination of open codes from these notes. There were 45 open codes identified (Appendix D3), these tended to be concerning what participants had been through, issues they did not know about, how they felt about what had happened to them and concerns for themselves and their family in the future. The collation of codes (Step 3) involved highlighting text in assorted colours to indicate individual themes. Using a cut-and-paste technique, text of the same colour was grouped and given an interim name (Step 4). These groupings were reviewed to confirm the similarity of text within each and endorse the final name of each category (Step 5).

Finally, upon re-reading the transcripts and categories it was determined that four key themes were evident within the data. The topics discussed by participants were related to their *Physical Responses* to their treatment and side effects, their *Cognitive Reactions* to their diagnosis, living and coping with a new situation and information, the *Emotional Reactions* to cancer and treatment including the affect to their lives and the *Survival Techniques* they utilised to deal with BlCa daily. The original refined categories identified were then termed 17 sub-themes (Appendix D5), with each of the four final themes containing between three and five sub-themes (Table 3.7). Finally, the text within themes was reviewed with the most informative sections of dialogue used to illustrate the meaning of each theme (Step 6). Some sections of text appeared relevant to more than one theme and were therefore difficult to separate, leading to final crosschecking to ensure logic and fit and that a grouping was not nominated as a theme or sub-theme without substantial evidence.

3.5 TRUSTWORTHINESS

Unlike the expected rigour of quantitative research that stems from the use of particular measures, instruments or cause and effect, qualitative research is compelled to demonstrate trustworthiness (Sandelowski 1986; Vaismoradi *et al.* 2013). *Goodness* should be evident in all aspects of a qualitative enquiry including motivations, beliefs, and assumptions, manner of working, research procedure, and findings, continuing throughout and remaining central to the researcher (Sandelowski 1986; Emden & Sandelowski 1998; Tobin & Beagley 2003).

Phase 1 incorporated the criteria of credibility, auditability, fittingness, and confirmability as forms of trustworthiness (Rolfe 2006; Harding & Whitehead 2016). These criteria promoted transparent believability, demonstrated by using detailed documentation, vivid description, visible decision-making and an audit trail, which allows transferability of the research (Lincoln & Guba 1985; Rolfe 2006). Verification of accurately transcribed interviews (member checking) was demonstrated by returning the transcribed interviews to participants who were able to check the accuracy and appropriateness of their transcripts and provide feedback (Harding & Whitehead 2016). According to Vaismoradi *et al.* (2013), the trustworthiness of study findings is the ability to use those outcomes to improve clinical practice because of the generation of a new and innovative understanding of the phenomena.

3.5.1 Credibility

The credibility and validity of a study is demonstrated through the descriptions of analytical coding, grouping of categories and formation of themes. Credibility is assessed by the validity of the participants own words collected from interview transcripts and used to describe their everyday world (Tong *et al.* 2007). Member checking increases credibility as transcripts returned to the participant for their judgement of whether the representation of their story, through an interview, has been correctly portrayed (Sandelowski 1986; Tong *et al.* 2007; Harding & Whitehead 2016). Credibility is also evident when using an audit trail and peer debrief (Tobin & Begley 2003; Rolfe 2006).

3.5.2 Auditability

Auditability refers to the ability of a reader to follow logically, the formulation of a study from the inception or research question through the recruitment of participants, collection of data and analysis (Tobin & Begley 2003; Rolfe 2006). Tracing the signposts, the reader should be led through the research and left with a feeling that this description is adequately conveyed, and that the findings have been interpreted in a dependable and reliable manner. Sandelowski (1986) suggests that the research manuscript is where the auditability of the study is verified. These accounts and explanations of the study background, researcher views, and purpose for the study, participant recruitment, and clear explanations of the data collection and analysis, and techniques used are elements of auditability.

3.5.3 Fittingness

Fittingness denotes the collection of information and documents pertaining to the study, which show a clear path of data collection that is in accordance with the qualitative methodology (Sandelowski 1986; Carlson 2010). This audit trail of information invariably relates to descriptions of the participants and the collection of data. In this QD phase, interview audio recordings, transcripts of interviews, field notes, records, analysis drafts, notes and interpretations are used as elements of fittingness in that another researcher or practitioner might follow this path and transfer or replicate this study in another context, or use it in their own practice (Harding & Whitehead 2016).

3.5.4 Confirmability

The confirmability of a study relies on objectivity and open display of all the steps applied. It depends on clearly presenting that the data originated in the study and relates to the phenomenon described. In so doing, the confirmation of credibility, auditability, and fittingness are reflected (Tobin & Begley 2003; Rolfe 2006; Harding & Whitehead 2016).

3.6 CHAPTER SUMMARY

This chapter has explained the use of a MMR approach that is guided by pragmatism, and has discussed the qualitative methodology of QD. The methods employed in Phase 1, including the research context, ethical considerations (i.e. informed consent, confidentiality and anonymity, risk of harm, participant's rights), and the recruitment process were also described. The use of interviews as a data collection technique, and the thematic analysis of the resulting transcripts are in line with QD. Additionally, the concept of trustworthiness has been clarified in terms of credibility, auditability fittingness, and confirmability. The four main themes identified from the data were summarised, and are further explored in Chapter 4 in which the specific findings from the ten clinical participants and their ten partners are presented. A discussion of these findings follows in Chapter 5.

Table 3.7 *Final Themes and Sub-Themes Derived by Thematic Analysis.*

Themes	**Sub-themes**
Physical Responses	Treatment and side effects Continence matters Discomfort On-going needs
Cognitive Reactions	Diagnosis and information A life overshadowed Public persona Talking it over (P)
Emotional Reactions	Anxiety and shock Life supports Sexuality and loving relationships Embarrassment and intrusiveness The nature of care
Survival techniques	Acceptance Having faith Avoidance, denial and distancing

Note: *(P) = partners' only responses.*

CHAPTER 4

QUALITATIVE FINDINGS: CLINICAL PARTICIPANTS AND PARTNERS

4.0 INTRODUCTION

Chapter 3 described the methodology and methods of Phase 1. Chapter 4 now presents a more detailed information about themes identified in Table 3.7 to characterise the experiences of both clinical participants and partners as they dealt with BlCa, including the dialogue used to express those experiences. The key themes to emerge were Physical Responses, Cognitive Reactions, Emotional Reactions, and Survival Techniques. The evidence obtained from clinical participants and/or partners is presented for each of these themes in the following sections, with further discussion provided in Chapter 5.

4.1 PHYSICAL RESPONSES

Although treatment and surveillance of BlCa varied for these participants, nearly all experienced side effects, such as discomfort and incontinence. The general management of on-going needs was a requirement for all participants. The needs of partners were also disclosed, as was their struggle to cope with their daily life when faced with BlCa.

4.1.1 Treatment and Side Effects

Of note in regard to treatment are the stories of Dennis and Eddie who had diagnoses of longer standing than the other clinical participants. Eddie had aggressive BlCa and had cystoscopies every three months for the first 14 of the last 22 years.

> *They got to the stage with me they didn't bother going in and had* [have] *a look. I'm straight in, anaesthetic, to be removed …* (L59-61). *… the bleeding, the pain, the anaesthetics … it does get you down and … you get a bit sick of it …* (L73-74) *… just get over one lot and then you've got to go in and start all over again … after a few years it does wear you down …* (L41-42).

Eddie had BCG treatment, which was ceased due to a reaction, and chemotherapy had been unsuccessful. Eventually he managed to stretch out the time between cystoscopies and *get on top of it,* which he believed was due to taking apricot kernels. Eddie experienced vomiting due to the anaesthetic, therefore extending his hospital stays. He was allergic to Zofran and had malignant hyperthermia. On one occasion, the urologist said, '*well I thought we was going to lose you a couple of times there yesterday … whatever you do never take that stuff again*' (L679-681). Enid was horrified on each occasion:

> *… I'd go in there to visit him and one time I went in … and there was panic stations all over the place and he'd got that cold that they nearly lost him, he nearly died of* [sic] *hypothermia …. Eddie never understood that from my point of view 'cause he'd just have everybody buzzing around him … and I come in and find out I nearly lost my husband* (L125-30). *… when he's in hospital I can't do nothing. That helplessness … that's … part of it and having no control … helplessness and no control …* (L797-800).

Dennis had had BlCa for 24 years, requiring 40 to50 cystoscopies. *'… I've been … going through the treadmill … since with these treatments'* (L367-368). He had been treated with both chemotherapy and BCG, but his third session of BCG Dennis suffered 'great angst physically' so it was decided to extend the treatment interval to fortnightly. This intolerance was particularly difficult to deal with when it left Dennis with urinary frequency and urgency (UFU) for a year. Dennis's high-powered career left him with little time to recover from procedures or to deal with his BlCa, and forced him to shorten nine weeks of chemotherapy to six. Dennis later took up positions in a rural location, interstate and then overseas before he finally listened to his doctors and retired on medical grounds in his 50s. When the couple resided in a rural location, Dennis flew to the city for treatment, involving hospital admissions of four to seven days. He admitted that even though the BCG he had three years earlier had an adverse effect on his QoL, there might have been some benefits (see also Section 4.1.2). Dennis reflected that:

> *… the number of times that I've had catheters and … instruments and other bits and pieces going back and forth … I'm surprised I've still got a penis and I'm surprised I've still got a bladder* (L1264-1267).

It took Barry a year to recover from his cystectomy, with six-monthly checks initially for five years with x-rays, CT and blood tests, and an annual appointment to examine his urethra. When Barry received his diagnosis, he was *'horrified, the prospect of a … bag … was awful but the alternatives to having an internal bladder construction were worse'* (L145-147). Barry remarked that the *'way I used to run my life before, and the way I run it now, that is by far the biggest difference and it has been somewhat difficult to cope with'* (L871-874).

In contrast, when Charles had his cystectomy he opted for a neobladder. He said *'… I had the … bladder removed prostate the appendix and some lymph nodes. … then … a new bladder reconstructed from a …. six inch … piece of small bowel …'* (L19-21). After discharge, Charles was re-admitted for another five days due to an infection. He had at least 20 more cystoscopies, with some at three- or six-monthly intervals.

After the urologist was unable to remove all of Jose's BlCa with a TURBT, she opted for a cystectomy. Her son-in-law advised that it would be difficult to endure weeks of radiation therapy or chemotherapy and Jose did not want to undergo the side effects of chemotherapy that her daughter had endured for breast cancer. The pre-cystectomy check is very thorough to ensure the patient is fit enough to endure the extensive procedure, and Jose particularly enjoyed going using the treadmill as part of the rigorous testing.

Heather had a cystoscopy every three months for at least two years and '*… got sick of it …*' (L33). She was having a cystoscopy, going home after a tumour was located and returning a couple of weeks later for an anaesthetic and TURBT to remove the tumour(s). That was when she said '*… I was sick of it and I said to Henry … I don't care if I die I've had enough of this …*' (L41-442). Eventually the surgeon recognised her emotional state and booked Heather in for an anaesthetic each time rather than go '*through that trauma of having the Flexi (cystoscope), seeing it [tumour] on the screen … and then wait to have it removed*' (L46-47).

After ten weeks of BCG treatments, Heather's BlCa was clear but she was told '*you'll come here every year now for the rest of your life*' (L72-73).

Alicia and Heather still become uptight when their appointment card arrives for their check cystoscopy. Heather said '*… when I get that letter and then for that next month at odd times it's … I hope it's clear, I hope it's clear …*' (L753-754). She said that Henry '*… knows that when I've got that letter that I start to clam up, go inward …*' (L882-883). In contrast, Ian stated he did not *'think about it too much only when they send me the letter to say you've got another bloody cystoscopy* [laughter]' (L458-459). For Ian, the worst part was having chemotherapy. He was concerned about having to *'hang on to it for two hours … I was … afraid it* [catheter] *was gunna fall out* [laughter]*'* (L77-89).

Due to scarring caused by their procedures, a number of men (Barry, Charles, Dennis, Frank, and Gareth) had undergone a urethrotomy due to obstructed urine flow. Charles was told his *'urethra was like a … pin hole. It took me about … 20 minutes, half an hour to … urinate'* (L576-577). Charles started catheterising twice a week for that reason, then once a week, to monthly and currently six-monthly. Dennis said *'he* [urologist] *has to basically ream that* [urethra] *to open that up … so that I can urinate with a flow as against a dribble'* (L1280-1281). He had this procedure with almost every cystoscopy. In contrast, following a number of cystoscopies and TURBTs Frank had BCG and radiotherapy treatment five days a week for six weeks but reported no side effects.

4.1.2 Continence Matters

When Dennis's intolerant bladder caused him to urinate three times an hour, 24 hours a day he said that *'life's pretty … crappy …'* (L78). At that stage, Dennis refused to leave home because of his constant need to use the toilet. He knew where all the public toilets were in his local area. However, even a trip to the hardware store was difficult, as he had to make a toilet stop on the way there and on the way back, or stop the car and run into the bushes. Dennis had also stopped playing bowls due to the tradition of an after-game beer.

Dennis was displeased when he had to argue to see an incontinence nurse. When he finally did, Dennis was supplied with various products to help him control his urgency and incontinence. He tried a leg bag and Urodome, which became jammed with clots and *'blew off in the bed'* (L538). He remembered driving home with *'nappies on to stop anything leaking …'* (L309). Finally, Debbie put him on Prostate-Eze and after two years, he found that he was not getting up as often during the night. He remained unsure as to whether the improvement could be attributed to the Prostate-Eze or the drastic effects of the BCG and chemotherapy on his bladder. During the time Dennis experienced UFU, the effect on his QoL made Debbie think *'what kind of life is that?'*(L226). That period was *'very disruptive'* (L471) to the family, with their lives revolving around toilets. It was important to get out of the house but dealing with the toilet and Dennis's bladder were all-consuming.

Heather had terrible half-hourly UFU in the early stages of her diagnosis. At one point, she said *'… it would be like a person that's got incontinence … there's no way that you can hold it you just wet yourself …'* (L284-285). Heather talked about being incontinent at work, on the train or the bus, in the car and of running behind a bush to relieve herself. She said:

> *… coming home … on the bus with my daughter … I just sat there and I couldn't do anything I just wet myself … it's … embarrassing … but what can you do about it, you can't, there's nothing you can do, you can't control it …* (L327-330).

Heather often had to tell Henry that she had just wet her pants when they were out. Heather commented that now there are a lot more continence products available but back then she would carry packs of tissues and a change of clothing wherever she went. Heather spoke about the incontinence being inconvenient and *'… not being in control of your body …*

because you can't control it … there's nothing you can physically do to stop it …' (L768-870). She disclosed her vigilance in checking for blood:

> *… every time you go to the toilet you're always checking to make sure … it's just something once you've had it you just automatically. Most people would just go to the toilet and that's it but every time I go … I make sure that I check to make sure there's no blood anywhere … and I'll probably continue to do that until I die. … I check to make sure that there's no blood on the paper … so it's always there in the back of your mind or if you get an ache or a pain …* (L593-604). *… just a reflex action to check because I think I need to know straight away …* (L926-928).

Henry said the urge to urinate would hit Heather suddenly and she would need to run. He recalled her telling him how embarrassing it was, but she would laugh about it later. He felt that Heather had taken her incontinence well and did not stress about it as *'it just happens there's nothing you can do about it ...'* (L530).

After Barry's cystectomy, he experienced several problems with equipment and said that over the years, his body shape had changed and the appliance flanges bent or misbehaved. Due to being a restless sleeper, he changed the type of overnight bag he had been using. He admitted that a continence nurse should reassess him to decide which type of equipment would be most suitable. While accidents had become infrequent, he still had *dedicated under-bed linen* in the form of absorbent Kylie material in case of leakage. When first experiencing leakages, Barry was *'… horrified that this is the future … it calmed down … but … initially … I though oh no this is awful I don't really want to live like that'* (L744-746). He said that he was aware of the stoma all the time though admitted that he did not always carry spare equipment or clothing, and had at times been caught short and embarrassed. Barbara believed Barry was in *'denial'* (L834) about leakages saying it had *'taken him years'* (L838) to admit that he needs to carry supplies. Barbara knew that he could get pants and jeans custom-made that were wider at the top to accommodate the stoma bag, but Barry *'… doesn't want to know'* (L1021) or listen to her advice. However, when Barry has a leakage or a bag bursts in public or at their shop, *'he panics and gets angry'* (L1027). Barbara reported her own medical problems and felt that being ill at the same time allowed them both to better understand what the other was going through and that *'it's all plumbing … put it into perspective'* (1164).

Eddie's UFU left him going to the toilet every hour though it could be every 10, 15 or 20 minutes. He said that the frequency was urgent with no warning and often made him run. Consequently, he managed little sleep. Eddie discussed how he would try to focus his mind on training his bladder. Even though it was painful, he would hold on to control the urge. He said the need to urinate was there all the time and he did not quite have control. He would constantly visit the toilet at shopping centres, and found holidaying with a caravan more convenient because it has a toilet. At night, Eddie would lie in bed and not get up to the toilet upon first feeling the urge *'… because if I do that … you are giving in to it and therefore it just dominates so much …'* (L930-931). He mentioned a loss of sensation. He could no longer feel himself urinating so had to turn the light on which woke him up more. While Eddie monitored his fluid intake, he said his body would suffer without enough hydration and he would get a headache. It was a matter of *'… when you've gotta go, you've gotta go'* (L950).

Since her cystectomy Jose had managed well with her appliance though sometimes had a leakage problem. Jose had difficulties with her overnight bag due to turning over too quickly in bed, and used a rubber sheet underneath her bed linen for protection as she had experienced a few accidents. She revealed that sometimes the bag could become buckled, particularly when lifting her leg too high, such as when getting into a car. Jose had not changed her style of clothing much, but preferred long jumpers or loose blouses to wearing a belt or tight clothes around her waist. Jose had given up wearing pantihose because if she had a leakage it came *'right over the top of everything, that's more you have to pull down …'* (L258). She learnt that it was easier to wears short socks and trousers instead. Jose was also careful with fluids particularly when travelling by bus. Jose carries spare equipment and clothing at all times, which she refers to as her 'bag of tricks'.

After Frank’s TURBT, his bladder was very weak, and he would wet the bed at night causing him to move into another bedroom so as not to disturb Flo. However, when he woke up with blood and urine in the bed *‘she had to get up and change the bed’* (L438). For a while, Frank had a bucket next to the bed because of the UFU. He said it had quietened down now, though he still goes to the toilet up to four times at night. Changing bed sheets through the night was Flo’s main problem, as she struggled to cope with the demands of the washing. She said Frank bought pads to wear which gave him a sense of security, especially when he left the house. However, Frank found the incontinence difficult and embarrassing. They did not get any outside help because Flo felt that Frank would be embarrassed if someone witnessed his incontinence. Even when Frank visited a continence nurse, he asked Flo to stay outside and wait. Flo watched Frank’s self-esteem decline to an abnormal low through the worst of his incontinence. She likened his incontinence to menstruation to play it down and make Frank feel better. Learning self-catheterisation had greatly improved Frank’s circumstances.

Alicia attributed her frequent urination to childbirth on three occasions:

> *… a pretty common mum thing as well and of course I try and practise not going and trying to keep it longer and longer … but I guess it probably doesn’t help* [laughter] *… I just make sure that if I’m going somewhere that there’s facilities* [laughter] *not too far away if I need them …* (L446-451).

According to Carol, Charles had bed-wetting accidents when he initially became accustomed to his neobladder but that leakages had become rare. When night-time leakage began, Charles had gone to the chemist and bought Depend Guards to solve the problem. Charles was still using pads and did not seek help for his incontinence.

4.1.3 Discomfort

Barry had two months of chemotherapy prior to his cystectomy, almost five months after his BlCa diagnosis. He talked about having a catheter:

> *… they whack a dirty great catheter up your old fella …* (L104-105) *and … they kept that in for 18 hours and … constantly trying to reject it and … it’s excruciating* (L115-116).

Alicia, Heather, Dennis, Eddie and Gareth all commented that some doctors were not very gentle during their cystoscopy and that even inserting the anaesthetic gel prior could be excruciating. There were references made about doctors who were rougher and caused more pain. Heather questioned if it was how they view women that caused them to be so rough, though some of the men made similar comments. Eddie said *'it's a lot of pushing and shoving around with a rigid* [cystoscope] *you do get a lot of pain and … problems'* (L138-140). He was often in so much pain following a cystoscopy that when urinating he would stamp his feet on the floor to take his mind off the pain, *'anything to concentrate away from the pain'* (L152). Eddie also described the pain when going over a bump in the road as an aching in his bladder when it was full and of blockages that were *'the worst because that hurt like hell'* (L793-794). Even having wind or ejaculating hurt, with Eddie commenting that ejaculation was more like burning and took *'… the pleasure out of it'* (L832). He also mentioned how cold it was in theatre *'freezing cold … then they're putting cold anaesthetic on … you go … I don't want to do this'* [laughter] (L1119-1121).

Gareth had a stent inserted because one of the tumours excised was near a drain from his kidney and the stent was to maintain patency for a month to allow the wound site to heal properly. The stent restricted his movements, bled, was painful and hindered his performance at work. Gareth was happy to have it removed but he had experienced pain and discomfort during the stent removal.

Charles also mentioned pain associated with sex, with his doctor having discussed injections to assist with erectile function after his cystectomy:

> *… wasn't really successful …. I … used to be in pain a couple of hours afterward … it wasn't very nice so it's pretty well non-existent now* (L684). *I was in pain a couple of hours after lying in bed … it wasn't really enjoyable …* (L747-748).

Conversely, Jose had minimal pain following her cystectomy and recovered in six weeks. However, she acquired a painful hernia next to her stoma sometime later from lifting large pot plants. Ian reported no *‘pain whatsoever of any description … the only discomfort I had was after the op when they had the catheter in’* (L85-86).

4.1.4 On-Going Needs

While some clinical participants had great need for counselling and support a minority did not and thought it was now too late. Ida felt Ian would not have attended any counselling session nor talked to others about his BlCa. Ian commented that ‘I feel if you do that it’s just people … whinging’ (L165).

Due to employment difficulties, Eddie and Barry also suffered some financial hardship. After Centrelink denied Eddie’s initial application, he eventually had a disability pension approved on appeal because he provided evidence of the aggressive nature of his BlCa. In Barry’s case, the hospital was reluctant to give any practical supports after he was discharged. He asked for a shower chair and frame, but the hospital said he should just manage. However, he did acknowledge *‘I don’t seriously think there was anything they could have done more than they did’* (L342-343). Barry and Barbara did get some government support for their school aged children and Barry’s medical costs and medications were covered by a health care card.

Gareth was disappointed with the lack of information and the way in which he was informed of his BlCa diagnosis. He said it was all straightforward as far as the follow-up cystoscopies were concerned and that he did not think the service required improvement. However, Grace mentioned the lack of information for partners. Therefore, it was important to attend appointments because *‘they’re certainly not going to seek you out. You’ve still got to keep everything going’* (L375). If she did not attend with Gareth, she received information from him second-hand but he was often still feeling the effects of drugs and could not remember what he had been told. Grace was not included in any discussions about Gareth coming home, such as whether she was ready for him or whether she would be there to look after him. Whenever she rang the hospital staff told her what time Gareth would return from theatre, but when she arrived at the nominated time, she would be told *'no he's not back yet'* (L578) as if her time did not matter. With two young children at the time, she said *'Everything's still got to keep functioning at school and activities'* (L377). However, although Grace commented that Gareth's BlCa was '... *not good and he's had a recurrence which is not good'* (L560), she saw BlCa as being less serious than Gareth's bowel cancer. She added that the whole experience had been *'interesting, you find out what you can cope with. I've realised I'm much stronger than I ever thought I was'* (L696-7). Grace was also glad that the current research was investigating the partner's perspective.

Jose was thankful for the stoma nurse who visited her after discharge and gave her more confidence in caring for her stoma. After her recovery, Jose moved home and said that the community ileostomy group she sometimes attended helped with problems, was supportive and group members had the opportunity to learn from each other. Her daughter-in-law Jean picks up Jose's ostomy supplies, which saves her $11 in postage. Jose had assistance with shopping and fortnightly cleaning.

Dennis questioned why there were a range of supports for many illnesses (even marital difficulties), but nothing for people with BlCa. Due to his PTSD Dennis visited a psychologist with whom he discussed his BlCa and its effects on his life. Mostly Dennis felt that the hospital did not care for his needs regarding information, support, respect, or follow-up. While Dennis appreciated that the urology department was very busy, he became frustrated with the system when appointments were not organised for the correct times, and when there were constant delays because he had been *forgotten*, despite attending the reception desk twice. In relation to the couple's needs, Dennis's partner Debbie said that '...

it would have been wonderful to have … something available … a counsellor … to talk things through with … might have saved a lot of my hair loss' (L592-4). She continued that no one had offered counselling or informed them of support groups, but she was keen to know how others coped with BlCa and its effects on their families. Debbie commented it would be helpful to gain a different perspective on BlCa by putting:

> *… some other things in place to help … with coping skills to … understand a bit more …* (L627-8). *There's a lot of things that could be done that we've … been thinking it would be good if …* (L1630-31).

Debbie hoped something would come from this research and somebody would take:

> *… notice of the fact that you fall through the loop … as far as … having a support network … there's a lot … of support … out there for … breast cancer … to … have understanding of that, I don't find that with bladder cancer…*(L1623-1628).

Flo felt that partners were not included in medical care as *'you don't come into it at all'* (L585-6) and *'the wife should have more knowledge of what bladder cancer is'* (L284). Although they received a leaflet about BlCa, she said there should be more information for partners. She agreed that for some people a support group might be helpful to find out information from others. While this may have been useful in the beginning, it was now too late because *'I've been through it all'* (L307). Flo said they felt alone at first, and although Frank read about BlCa, there was no one with whom he could discuss his concerns. They could ask questions when they saw the urologist, but Flo said the doctors were busy and *'you don't absorb it till you come out … it don't all sink in, you just hear the cancer*' (L328-30). Flo insisted she accompany Frank to appointments saying, *'look what you don't hear, I hear'* (L331-332). She believed that it would have been helpful if they could have spoken to someone else after seeing the urologist to ensure they understood any matters discussed and explain things to them without being rushed. Flo also stated that no one had enquired about how she was or how they were coping as a couple.

Enid had never been involved in Eddie's BlCa, stating that only in recent years had *'doctors … encouraged wives to go along'* (L934), and she did not *'feel part of it'* (L935). Enid's frustration came from not having the information she required and feeling on the outside, particularly when the hospital did not contact her about Eddie's difficulties in theatre. Finally, Henry noted that someone needs to talk to and support partners, giving them required information or they may be *'left in the dark'* (L10335) when *'they need to know'* (L1041).

4.2 COGNITIVE REACTIONS

All participants revealed their reactions to the BlCa diagnosis in terms of what they thought about this life-changing event. The following discussions highlight these cognitive reactions and the extent to which appropriate information was available upon diagnosis of BlCa, along with the ways in which people coped with a life overshadowed by the disease including the need to prepare for the worst. Participants' public lives (social activities, sports, and employment) were important reminders of the difficulties they faced daily. Many partners had a greater need for 'talking it over' than clinical participants did, in order to process issues relating to BlCa and enable them to offer appropriate support.

4.2.1 Diagnosis and Information

All clinical participants had been on a continuous cycle of regular cystoscopies, TUBTs, chemotherapy, radiation therapy, or BCG installations, with three participants unable to retain their bladder. Although the onset and diagnosis of BlCa took various forms, all clinical participants began with a cystoscopy for diagnosis and/or treatment after most participants had observed visible blood in the urine (haematuria). While participants commonly received information about BlCa from their urologist and nurses in the urology clinic, Alicia and Barry admitted to surfing the net for information. However, Alicia found this approach 'awful', and Barry's daughter had warned him of *quack.com* on the web.

Misdiagnosis and/or delays in diagnosis caused a sense of urgency. For some participants that moment was one that they will never forget, whereas others struggled to remember exactly what occurred such was their shock. Further, some urologists used terms that were not understood. Participants did understand what *cancer* meant, but *polyp*, *carcinoma* and *tumour* were often not clearly recognised as synonyms for *cancer*. This lack of understanding is portrayed in the following participants' recollections.

Alicia was young to receive a BlCa diagnosis at the age of 32. After giving birth to her third child, a ureterocele was observed. Alicia's BlCa was discovered when she returned to hospital to have this repaired. Alicia stated:

> *… my last cystoscopy the doctor said that you have bladder cancer and I thought well no one has ever actually … said that to me before it was weird. … what I had done, it just said stage one … carcinoma … and they never ever, ever anywhere mentioned the word cancer … it was just a kick in the face almost … that that's what it is but no one's talked about it that way before so it was weird …* (L 17-26).

Even so, Alicia described her surgeons as 'amazing' in how they dealt with her and acknowledged the non-medical terminology used with her when describing her procedures. Alicia was reassured that it was *slow growing,* and nothing would suddenly appear in three months before her next cystoscopy. She mentioned that some written information on her type of BlCa needs would have be helpful. Like her urologist, this couple did not use the word cancer, particularly in front of their children. Rather, a *little spot* had been removed.

Gareth had a sudden onset of painless haematuria. Following his cystoscopy and TURBT, Gareth heard nothing further from the hospital after his discharged home. On this basis, he believed that he was all right and the problem had been rectified. However, Gareth had been diagnosed with bowel cancer four years prior and when attending a regular bowel check-up, he mentioned the cystoscopy. His bowel specialist looked up Gareth's results and informed him that he had BlCa. Gareth said '*So … I never really found out what it was they just said …*

they removed tumour or a growth … so … the information was a bit vague …' (L35-37). Gareth was disappointed that he did not receive earlier information about the cystoscopy result and Grace, his partner, felt that '*it could've been handled better'* (L62-63).

Eddie was living in a rural location when his haematuria and subsequent medical appointments began. When he later began experiencing back pain, he visited his GP who sent Eddie for an x-ray. Upon his return to the GP Eddie asked about the x-ray but was told not to worry as all cancer patients were sent for that x-ray. Eddie's response was:

> *I didn't know I was a cancer patient and it horrified me … and really knocked the stuffing out of me* (L475-477). *… I first got told … in recovery … he told me they found one the size of a 50-cent piece plus … quite a few … smaller ones …. plus some polyps. Well he never mentioned cancer …* (L463-467).

Eddie's diagnosis was also delayed because for two years doctors thought that a previously diagnosed blood disease was the cause of his haematuria. Eddie was not forthcoming about his BlCa but over time, he found that when questioned, if he disclosed details of his BlCa friends or acquaintances would then leave him alone:

> *… one time … I said, 'I've got bladder cancer' and the person just shut up. They didn't want to know anymore because cancer is this…dreaded thing. … I just tell people I've got bladder cancer and … 90% of the time they just shut up and change the subject* (L535-541).

The lack of information provided to Eddie led him to believe that his symptoms, such as his urethra narrowing (in fact due to scarring caused by BlCa procedures), could be PCa. Eddie said that what he knew now after 22 years of BlCa ought to have been explained to him from the beginning. There was not enough information or support, and counselling would have helped to alleviate the stress experienced by and his partner. Over time, Eddie had gathered information from doctors, nurses and from books but he did not search the internet. Eddie enjoyed watching his cystoscopy being conducted because it increased his understanding, and urologists assisted by pointing things out on the monitor.

During the 18-month delay in Eddie’s realisation that he had BlCa, his partner Enid felt sure that he did in fact have cancer and was concerned that he did not seem to understand. She said that he *‘nearly fell through the floor’* when he finally realised and it was a *‘pretty emotional battle at the time’* (L 44-45). As Eddie was ‘*not very good at asking questions*’ (L599) at urology appointments Enid made ‘*suggestions*’ (L606) of topics that Eddie could ask so he was more prepared for his urology appointments.

Every doctor Barry saw for 18 months diagnosed him with a urinary tract infection. After numerous courses of antibiotics and various tests with negative results, he was referred to a urologist and diagnosed with BlCa. In contrast to Alicia, Gareth, and Eddie, Barry’s diagnosis was clearly stated in non-medical language, being described as looking like cauliflower stalks growing in his bladder. Barry appreciated the way the urologist and stoma nurse had spoken to him and found them to be very helpful.

Barry and his partner Barbara knew little about BlCa, so it was a huge learning curve for them. Barbara felt that it was not necessary for a doctor to deliver the medical information, as long as it was from a medical person and was clear. More information about the *plumbing* aspect post-cystectomy including how Barry’s new *plumbing* worked, availability of products, more appropriate clothing and *‘what’s available to help later’* (L1107-8) would have assisted. Barry’s sexual dysfunction and frustration post-cystectomy left Barbara feeling that she ought to find strategies to assist their sexual relationship. Though it would be ‘… *a bit tricky … he’s got the problem … and they need to check him, not me … it’s probably something … I might have to deal with* (L688-89). Barbara felt compelled to seek information because *‘if you don’t … ask, you’re not going to get’* (L170), *‘people are going to think everything’s okay … so if you’ve got problems you need to let them know’* (L1295-6).

For months Jose's GP also kept diagnosing a urinary tract infection for which she was prescribed antibiotics. On one occasion, the GP conducted a urine analysis as usual but left the dipstick in longer while he washed his hands and upon his return discovered blood in her urine. Jose went straight to another doctor who referred her to a urologist. She had a cystoscopy and TURBT and within six weeks had had a cystectomy. Jose's daughter-in-law Jean stated that their family received a thorough explanation from the urologist. They felt having *'a doctor like that behind you … makes all the difference'* (L555).

Charles visited his GP because he had symptoms suggestive of PCa. Therefore, a diagnosis of BlCa was a surprise. He commented that more information before his cystectomy particularly concerning the inability to ejaculate and the rapid decline in sexual function would have been preferable. He was happy with how the nurse had taught him to catheterise his neobladder and was amused by the cross the stoma nurse had drawn on his abdomen the night before his cystectomy. His partner Carol said it was a relief when Charles was diagnosed. Although unpleasant, at least they knew what was wrong. Carol did not ask for information and stated that everything she knew came from Charles, *'I accept what I'm told'* (L39). Often the lack of information left participants unaware of what could occur in the future. Carol confirmed *'we've heard that … cancer does move along … into other parts'* (L412-13), though they were still surprised when four years post-cystectomy, Charles had to have a kidney removed.

Dennis was also disappointed with the lack of information following procedures and believed the urologist should have given him advice. No one had explained the consequences of not maintaining regular surveillance (*check)* cystoscopies, for example. Dennis believed that his treatment had cured him so when he moved interstate he did not seek another urologist until he suddenly started bleeding one day in the middle of a meeting. His partner Debbie found it helpful that another urologist had shown them images of Dennis's BlCa. She felt under pressured to know more because of her healthcare background and researched BlCa because

Dennis *'wants to block out'* (L206) things. Debbie wanted to talk with other families dealing with BlCa to hear how they dealt with it and the effects it had on them. Sensing that firsthand experience was better than reading medical leaflets *'…that's all a bit matter of fact'* (L1466).

Debbie would have preferred to discuss long-term medical options right from the beginning, as follow-up appointments were too short leaving little time to make enquires. Therefore, Debbie accompanied Dennis to appointments to assist with collecting information. She said that he has *'things on his mind … but often doesn't vocalize'* (L1398) them. Even when they had a written list of questions, when they got to the urologist's office *'you forget things or you're just there to hear what they have to say and … don't state … things that are … on your mind'* (L1366-1368), resulting in them feeling that the doctors left them in the dark.

Frank knew about BlCa, but not the distinct types, and found the consequences of MIBlCa to be confronting, so he was grateful to be diagnosed with NMIBlCa. Frank knew a couple of people with BlCa and was encouraged by the fact that they continued to live fulfilling lives 10 to 15 years post-diagnosis. He thought that if it is *'caught in time it's not as dangerous'* (L237) as other cancers. His partner Flo thought it prudent for couples to talk to someone sometime after the diagnosis to *'… give you time to absorb it and then ask questions …'* (L336). Information given at the time was not completely absorbed.

In contrast, Heather was happy with the information she had been given, and did not require every detail. However, her partner Henry accused her of not asking enough questions. Heather said she was curious in relation to the cystoscopy and would be interested in watching one [on the monitor]. During a conversation with another woman in the waiting room, Heather learned that this woman had been clear of BlCa for a few years before it returned, which scared her as she had also been clear and did not realise BlCa could recur.

Ian had never heard of BlCa so when he saw blood in his urine he thought that he had strained himself lifting something heavy. He was happy with the information he received from a registered nurse (RN) and was reassured that his BlCa was only tiny. Ian did not tell people about his BlCa and thought that some people like to '*brag about their illnesses*', so the couple had only informed their children. If someone did ask, Ian was happy to talk about his diagnosis but commented that that only happens when waiting at the urology clinic.

4.2.2 A Life Overshadowed

Thoughts of death followed a BlCa diagnosis. Inconvenience, time *wasted*, and *bother* were associated with procedures, the need for which overshadowed and dominated the lives of participants. The word *cancer* was equated with death, both in the eyes of participants and their family and friends who were often too scared to visit. For example, the fear of death for Barry was particularly strong when he compared himself with fit friends of the same age. Barry and Barbara were concerned that he would not survive his cystectomy and Barbara felt that [death] could happen any time as *'you don't really want things to rule your life and you … make it so that it rules your life as little as possible'* (L859-60).

After Charles had a cystectomy, his cancer metastasised resulting in the removal of a kidney. At that point, his doctor warned him to get his *'… affairs in order* [laughter] *and well I'm still here'* (L92-93) after eight years. For Grace, suggestions of death came from her mother who was '*… a negative person … had him* [Gareth] *dead and buried, and I … had to say to her 'if you can't be positive then you can't come around'* (L221-4).

Dennis's bladder 'intolerance' from BCG treatment left him with UFU. As a result, he felt isolated and anti-social because he refused to leave home due to *'the need to be at the toilet'* (L97). Thinking of the future, Dennis asked *'… what support is there available for my partner when I pass on?'* (L484-485). Dennis and Debbie had been together for 26 years and he wanted another 20. Dennis felt that his death would have a huge effect on Debbie and questioned what might happen if he lost his bladder or if BlCa killed him. Debbie's initial reaction to her husband's diagnosis was that *she* had received the death sentence. After having lived with Dennis's BlCa for quarter of a century, she now realised that cancer is not necessarily a death sentence unlike *'it was 30 or 40 years ago … people had no real hope. Whereas I see there's a lot of hope now'* (L1589-91). Debbie was initially distressed and scared at the thought of bringing up their children alone. She was young and had just given birth at the time, so the responsibility appeared daunting.

When Heather was first diagnosed she was fine until she got home and started to question *why me?* Having BlCa had made Heather realise that:

> *I could not be here in a few years' time … it makes you realise life is short … you have to really … love your partner, love each other all the time … and not let stupid things get in the way …* (L903-906).

After having three-monthly cystoscopies for up to three years, Heather experienced UFU and *'got sick of it'* (L33). It was a difficult time for her husband Henry as initially Heather said, *'I don't want to die, I'm too young'* (L82-3). When she was later having regular cystoscopies and TURBTs along with severe incontinence, Heather said the opposite, *'I just want to die … I don't care if I die'* (L870-2). Henry thought that Heather should get her affairs in order:

> *Well if you want to die, just die, … make sure you've got your will all paid out and done and everything …* (L876-878) *… well just … die then will you for God's sake … if you're going to die hurry up and do it …* (886).

Henry revealed his use of reverse psychology because '*if I agree, it can be wrong and if I disagree … it can be wrong so it didn't matter …*' [Laughter] (L891-3).

After his BlCa diagnosis, Frank '*… prepared all the papers and things I ... even* [laugh] *… paid for the grave …*' (L163-164). Flo said there were few plots left at a nearby cemetery and she wanted him to be within walking distance to visit. Frank commented '*… I try to prepare* *everything so … my wife doesn't have too much trouble … that she has enough money and everything else to go with it …'* (L177-179). Frank's thoughts of dying later reduced in intensity. Flo said, '*that's passed … he really thought he didn't have long …'* (L527).

Eddie felt that the early stages of not knowing were particularly difficult and that counselling would have '*taken a lot of pain away and a lot of fear*' (L1132). Eddie found the diagnosis of BlCa very difficult to comprehend and he experienced suicidal ideation:

> *… so basically, you think cancer, okay I'm gunna die … that's what everybody seems to think … I can't remember how long I … went through that. It was a while … to the extent where … I was driving … and … no police out there [in the country] so foot goes to the floor* [laugh] *… there's a bend in front of me … and I thought I can't take the bend at this speed. Then I thought what's it matter I'm dying anyway. … I didn't care … and I thought what's going on. … so, we had … a few sessions at home … tears … and all the rest of it …* (L485-498).

Eddie's partner Enid was *'terrified that … I'd lose him'* (L379-80). She was mainly stunned at Eddie's suicidal ideation and worse, not telling her of those thoughts for so long. The effects of that event strained their relationship for some time. The lingering emotion stayed evident during their separate interviews when each recalled the events from their own perspective.

Eddie explained his BlCa procedures comprised of a pre-surgery anaesthetic examination the week prior to his cystoscopy. If more tumours were diagnosed during the cystoscopy, he was discharged home to return for a TURBT with a general anaesthetic the following week. Eddie said that by the time he had been through all of that and recovered, it was almost time to go back for his next pre-clinic check-up. For Eddie, *'it got very monotonous. It dominates your life … it does wear you down …'* (L40-41). He believed that the hardest part was *'… revolving your life around going into hospital every three months …'* (L179-180), *'… dominates life so much'* (L842) which included employment and social activities. The couple's sex life even revolved around cystoscopies, rather than being a natural occurrence. UFU was the *'… most dominating thing because that was consistent …'* (L906).

Jose had adapted well to her stoma and had very few concerns, apart from its position being bothersome. While she was given some placement options by the stoma nurse, the size of her breasts was never considered. To see her stoma Jose had to move a breast out of the way. She did not think there was anywhere else to place the stoma more conveniently, but this daily problem was not acknowledged. Jose feared being diagnosed with another type of cancer, or having her BlCa return, and thought most people with cancer would have similar fears. Jose was an active octogenarian who said *'… well … I'd hate to find it somewhere else … I'm too busy, I haven't got time …'* [laughter] (L660).

All clinical participants often talked about *time* or duration in their interviews, knowing the date of their diagnosis and first cystoscopy, and the duration of any delay in their diagnosis. Time was also mentioned with respect to how many weeks until the next cystoscopy, how many cystoscopies they had had, how many were clear, and the amount of time between tests. They discussed how long they waited, time taken for recovery, how many doses of treatment, how long the treatment took, how many times and for how long they were hospitalised. Additionally, participants discussed how far they had travelled for treatment and how long that took. They knew how many times they had been catheterised, and how long it had taken for the pain or side effects to subside. There were aware of how many times they had been to the reception desk to question how much longer they would have to wait for their treatment, and how much leave from work was required. They knew when their next cystoscopy was due and to ring the clinic if their appointment had not been confirmed one-month prior. Four male clinical participants were particularly vocal about the time they spent waiting:

> *Barry: … for a two-minute examination that takes me the best part of half a day … you get in the list … wait for things, one thing about medical treatment in the hospital system … is you learn patience. You get to do a lot of waiting …* (L510-512). *I had a lot of good books … for the first … examination I was in at … eight in the morning … and … taken into surgery about 3 …* (L517-119).

> *Dennis: You have an appointment for 1 o'clock and when at 10 past four you go up to the counter and say I've been up here twice already can you tell me what's going on? "We forgot you"* (L390-392).
>
> *Ian: … if I'm havin' that done at one o'clock why on earth, it's ten past one [laughter] what am I…doing sat here… I'm thinkin' why don't they … hurry up so's I can get out of here … (L480-483). … it's only the nuisance of havin' to go down there wasting my … time … I could be doin' … something recreational instead* [laughter] (L605-607).
>
> *Gareth: … you …sit there 'cause you can wait for well over an hour up to … two hours last time because they were running late. It's quite tedious sitting there* (L186-188).

Gareth realised there were many patients to look after but was frustrated by always waiting at least an hour longer than expected. Ian was more concerned with having to *'traipse down there and 'ave a couple hours off'* (L691) which was *'more of a nuisance than anything else'* (L693). Even having the procedures and the catheter was a *'damn nuisance …'* (L87).

4.2.3 Public Persona

While BlCa had effects on the employment, sporting and social activities of all participants, not all effects were necessarily problematic. Dennis found that the constant UFU had made him very antisocial. Due to the possibility of appearing weak or having his diagnosis held against him, Dennis could not let anyone know of his BlCa because at work *'I felt an obligation to be at work doing what I was paid to do and being sick wasn't … part of the mantra'* (L701-703). Dennis never took enough time off work to recover following procedures, and cut courses of treatment short or dismissed follow-up appointments. Continuing with surveillance and treatments was also difficult when Dennis lived rurally and overseas. Since his retirement and recent 'all clear', Dennis had resumed playing bowls, joined a gym, and started walking with Debbie after having become sedentary.

According to Debbie, Dennis dealt with his BlCa stoically, not allowing it to interfere with his life. She felt his training was *'… about facing stiff things that come … your way … not running away from it … just dealing with it as it comes'* (L71-3). Debbie was amazed by his rapid recovery that limited the effects of BlCa on employment and social activities. However, during the year of Dennis's severe UFU, venturing out of the house was problematic. Still, Debbie talked him into going on an overseas holiday to take his mind off it. Some problems occurred on a bus trip when Dennis left the bus to use the facilities. The driver became angry and nearly left him behind because it was not a scheduled stop. Debbie defended Dennis to the driver explaining *'… you have no idea how difficult it's been for him to hold on …'* (L670-671). Though a lot of their time was focused on finding a toilet, Debbie said *'it was … good for him to do something completely different'* (L685-6). Dennis called it their *toilet tour*. Even during the two-hour flight, Dennis was waiting for the seat-belt sign to turn off so that he could use the toilet, afraid that he might embarrass himself. Dennis surprised Debbie when he retired, she commented *'the way that we had ordered our lives … changed overnight because he … wasn't going back … and … I became the breadwinner'* (L1161).

Some participants had to restrict their activities due to reduced physical health associated with BlCa. Eddie mentioned that due to three-monthly cystoscopies, treatment, and UFU dominating his life he had little time for work, holidays, or socialising. Even going to the shopping centre could be difficult and Eddie found it awkward to explain to his grandchildren why he could not pick them up sometimes. Enid said that BlCa:

> *… dominated our* lives (L147). *… he got to a point where he'd had enough of it and … I can understand that … invasion of your … body it … affected our lives, we lived around that …* (354-356).

Jose was no longer confident to swing a golf club and had given up sports. Given her post-cystectomy hernia, she felt that the bowling ball was too heavy for her now. While she had enjoyed swimming, Jose envisaged her stoma pouch floating past her eyes, and gave that up too. Yet according to her daughter-in-law Jean, having a cystectomy had not slowed Jose down. Jose was heavily involved in community committees and had a wide group of friends with whom she went on outings. Jose did not like going far from home but had completed a lengthy train trip, *'… she wanted to do it so she did … nothing stops her'* (L396).

BlCa had not affected Heather’s social life, most of which involved family. Business hours were long, leaving little free time anyway. Heather and Henry had been on few holidays, for which Heather said the most important aspect was to be near a toilet. Henry remembered the stage during which Heather did not want to go anywhere. He was unsure whether it was due to her constant need for a toilet or because she was still smoking, and would go for a cigarette. The couple had recently retired but Henry said that work had helped Heather with any physical pain or psychological issues and *‘… helped to relieve the frustrations…’* (L603).

Alicia was not employed at the time of her interview but was employed when she was first diagnosed. Her employers were very good about her having time off for a cystoscopy. When Alicia had an anaesthetic, she took more time off work but said *‘… it’s only one day every three to six months’* (L438). Alicia’s social life was limited more by having three children than by BlCa. Allen’s employers were accepting of his time off to pick Alicia up from hospital and he said that BlCa had not affected their social life or holidays.

Gareth’s employers also understood, so he would leave work at lunchtime to go for his cystoscopy. However, he was not happy about having time off when he had the stent because he was unable to walk, jog, or climb ladders, as he would normally be required to do so at work. Grace’s employers understood her need for time off work when Gareth had a cystoscopy or TURBT. BlCa had not adversely affected the couple’s social life or their holiday plans. Unlike other participants, Grace felt that receiving the appointment card for the next cystoscopy a month prior helped them to plan work, social events, and holidays.

Barry was self-employed and worked from home until he became so sick prior to his cystectomy leaving him to potter around the house as a ‘*house husband for most of that time’* (L221). After his surgery, the couple bought a business, to run together, with Barry working six days a week since the purchase seven years ago. Barry remarked that bending and crouching to unpack boxes of stock sometimes put pressure on his pouch and made the adhesive come unstuck or caused it to burst. He had some embarrassing moments with leakage during social occasions but did not let that stop him. Barbara felt that starting their business helped Barry and was akin to therapy. She thought he would be *'sitting reading a book or … newspaper all day and getting more and more depressed … that would have been the end of him'* (L938-40). Barbara talked about the difficulties of socialising and going on holidays since Barry's cystectomy:

> *… you've got … things that you've got to…adapt to knowing that if you go on holidays you've got to make sure that you pack everything…even…visiting someone, you … pack things up and … bring them with you, whereas before you wouldn't have … (L816-20). … going over to people's houses … he doesn't like to think about bringing things along. … I think … it's … denial … where you don't want to admit that … something could … start leaking, so he wouldn't bring things along with him. Now he's starting to get … better with it, but it's taken him years (L832-8).*

Ian and Ida were also self-employed. When Ian had time off work for a cystoscopy, he would start work earlier the following day. In contrast to other participants, Ian and Ida found the manner in which cystoscopy appointments were made, difficult to manage due to their business commitments. The clinic asks patients to telephone after 3pm on the day before to be allocated an appointment time. Ian said that was not much time to change clients' meetings for the next day or to get someone else to assist, stating *'you've got to organise your life around that for a day and sometimes it's awkward'* (L199). Ida questioned why the hospital could not give a time when they issue the appointment dates.

Charles was a very active man, riding his bicycle to most chemotherapy appointments. He played competitive squash and said that his BlCa and cystectomy had not interfered with any of his activities. At the time of his diagnosis, Charles and Carol had both retired. Carol recalled that even though Charles had felt sick after treatments it had not interfered with his bike rides. Having a cystectomy and neobladder had not impeded the couple's social life, or their holiday plans overseas. In contrast, Frank's limited physical capacity meant that excursions were car trips to the shops or church. Flo said they previously travelled overseas every two years. However, since Frank's diagnosis they had not been away. They socialised mostly at home, but Frank could go out for lunch because he could rest at home afterwards.

4.2.4 Talking it Over

Many partners discussed the need for *talking it over*. Initially Debbie and Grace's husbands were unable to discuss their BlCa but over time, they became more open about their health issues. After 20 years of marriage, Grace understood that Gareth did not talk much but he became noticeably quiet after his BlCa diagnosis. Grace knew his brain would have been racing, thinking about it, but since then a positive side effect was that Gareth had become *'quite open, for him'* (L543) in talking things over.

Dennis was now able to discuss his BlCa with others, particularly anybody in need of information and counselling. Though Debbie felt that sometimes he told friends too much and thought they *'… don't really need to hear all this'* (L509). Initially, talking about BlCa was difficult but since Dennis's visits to a psychologist, discussions were more open. Debbie explained to their children the things that were affecting Dennis's behaviour. She said their family worked around Dennis, with his life revolving around toilets. Dennis focused on his symptoms, making it difficult to discuss anything else. The family frequently dealt with being *'snapped at … without really understanding why'* (L479-80). Debbie said that discussing his BlCa was now cathartic for Dennis and that he:

> *… has come out with a lot more these days that he used to … suppress (L516-517). … it's all very close to home and you're trying to deal with our own issues of how you're coping with it too as well as being a support to the person who's going through what they are. …. Trying to keep everything together can be a real struggle (L632-636). You all get thrown in … the deep end together … you … either sink or swim (L645-646).*

Further, Debbie believed that having someone to talk to about having a cystectomy would make Dennis more comfortable about having the surgery when the time came. She felt they should have been *'put in touch with someone who's been through things previously'* (L1440-1441). Debbie's interview stopped when she became upset talking about sexual issues and the love in their relationship. After we discussed what she had been struggling with over the years, she recovered and resumed the interview. Debbie felt that the outpouring of emotion was because *'it's* [the interview] *a chance to discuss things that you don't normally discuss'* (L805-6). She admitted that she should have seen a counsellor a long time ago and that it *'… probably would be wise to see somebody'* (L817) particularly considering the benefit Dennis had gained from his counsellor. She said, *'I don't think I've ever really had anybody that I could discuss it with … there's not been anybody to turn to'* (L138-44), neither had anybody asked her *'What are you coping with … here?'* (L142-3).

Heather's stubbornness, independence, and inability to discuss issues caused disharmony in their marriage. Their children had asked Henry why he stayed, and he revealed that he had come close to leaving. His faith had kept him there and one day he sat Heather down and had a *'D & M* [deep and meaningful] *with her'* (L104), saying *'we can't keep going like this'* (L106). He had turned to a nurse friend who could explain the medical side of what Heather was going through and listen because he believed it was important to talk things over.

Enid was emotional when Eddie told her of his suicidal ideation that made it *'a bit tender talking to each other'* (L51). Her reaction was to telephone a Cancer Helpline on Eddie's behalf, with the advice being to go back to the doctor for further explanation and information. After doing so Eddie *'slowly came to terms with it'* (L89-90) but Enid said, *'we were a long time before we … actually talked to one another about it'* (L90-91). She was also concerned that Eddie only had her to talk to, but he was not inclined to have someone else that close. Enid found it difficult to discuss sexual issues, and was not always receptive to do so, whereas Eddie was more *'forthcoming on those things'* (L719). Eddie was not bothered about discussing his BlCa now because *'people back off'* (L916), *'I don't back off when people talk about that now, I suppose that's helped us'* (L923-4).

When Barry had chemotherapy, Barbara said she could see his chin through his beard. Barry and a friend, who was also undergoing chemotherapy, went and *'bought a … beret so they can … go to art shows* [laughter]' (L280). Barbara thought it *'amazing … being able to keep that sense of humour'* (L276). She had two close friends with whom she could discuss Barry's BlCa, knowing that the information would remain private. Barbara said that BlCa *'changes you in that you're learning … from things … and if you've learnt something new, it always changes you'* (L798-9). Keeping a sense of humour and perspective were important to her. Conversely, Charles and Carol did not discuss BlCa unless Charles had just had a urology appointment. Charles played sport with some nurses who Carol believed did discuss his BlCa. Carol believed that Charles thought about cancer as his brother died of it 20 years ago.

4.3 EMOTIONAL REACTIONS

A third theme identified concerned the emotional reactions expressed by participants toward BlCa. This included initial anxiety and shock, with the thoughts of clinical participants turning to the important people in their lives likely to provide support to them, and the effects BlCa may have on their loving and sexual relationships including 'macho' reactions of some male clinical participant. The embarrassment and intrusiveness associated with tests and treatment and the care received were further emotional topics. Partners described their reactions to BlCa as 'shock,' 'surprise,' being 'stunned' and 'devastated.' They were 'worried,' 'nervous,' 'stressed,' 'apprehensive,' 'emotional,' 'terrified,' and 'frightened.'

4.3.1 Anxiety and Shock

Alicia was shocked and scared by her diagnosis. She and her partner Allen had lost parents and family to cancer, so she had witnessed the effects of chemotherapy and radiation therapy, which she was glad were not recommended for her. Alicia worried about those treatment options as *'… it's always gunna be … there … what happens … if I have to start having chemotherapy or I … hold my bladder outside my body in a plastic bag …'* (L502-504).

Barry said *'… they didn't give me any option but to remove it which was scary …'* and he was *'… absolutely horrified'* (L94-95). One of Barry's biggest concerns was his needle phobia:

> *I've had a phobia of injection or any sort of penetration of skin, cut, anything … and I … became a pincushion … I had blood tests all the time … injections frequently, … shunts put in, I … did a lot of cat scans. I had contrast material put in lots of that … saline drips and I never thought I'd be able to cope with any of that but I sort of figured I had to so I just got used to it* (L294-300).

His partner Barbara recalled that Barry was *'fairly apprehensive'* (L513) when preparing for his cystectomy but *'once you'd set your mind to, okay it's got to be done, that's it then you can deal with it'* (L514-5). Barbara became teary during her interview, stating *'I get a bit emotional now … looking back on it all'* (L1405-6). Barbara let her emotions flow but did not allow herself that luxury at the time of Barry's diagnosis, testing and surgery. Barbara did not get emotional in front of Barry as she felt *'… it wouldn't have helped the situation*' (L1439). For Barbara, it was often difficult to know if Barry was unwell due to his depression, BlCa or newly diagnosed diabetes. She felt the depression was not *'letting him … look at his health problems in … a logical light'* (L57-58). Buying their businesses '… *forced him into … concentrating on something else … not … being able to look … inside all the time'* (L111-113). Barry's anxiety was represented as anger. In particular, he had a 'bug bear' about the cost of parking when he went for chemotherapy:

> *… I was probably more angry at the expense of that than anything else … bloody hell I come down here and do this stuff and you charge me 20 bucks parking and … that was cheap because they* [nurses] *organised a cheap deal … for chemo patients … I got angry at that* (L413-420).

Dennis moved through an array of emotions and felt angst after his BCG treatments because of the UFU and the fear of incontinence. Dennis had run out of BCG and chemotherapy options and said '*… we really need to talk about them removing my bladder which has caused me great concern …*' (L27-28). Due to Dennis's intolerant bladder, he spent 12 months feeling '*… that I had been … left adrift in this sea of despair …*' (L995-996). Dennis was tired, depressed and angry '*… because you can't cope and … you become antisocial because you don't want to … go out … because you're saying, 'where's the toilet?'* (L118-120). Dennis became so 'god damn dog tired' that he would explode and go into what he called the *black dog* where he would remove himself to the bedroom. He even described throwing a piece of furniture on the floor to '*… get rid of some of that anger that built up inside …*' (L1124-1125). Dennis was disturbed by sexual issues as he found it '*… frustrating because … you can't … maintain an erection and you cannot ejaculate …*' (L1200-1201). Dennis suffered from post-traumatic stress disorder (PTSD) as well as depression. He said:

> *… your emotions go from the highs and the lows. The high is when you're told everything's fine. The lows are when you're told it's not … and then you need to go through another series of treatments … your mental health … can have some pretty dark spots … particularly when you're on chemotherapy* (L 477-480).

Dennis was angry about the lack of care and staff shortages. He felt '*… you've just become a number … you're being put through … a processing line …*' (L407-408). 'I *was so jacked off with the way I felt I … wasn't being treated correctly or being valued …*' (L1009-1010). He realised that the urology department was *swamped*, but was disgruntled at not being able to speak to his urologist after the procedure about his concerns. He was disappointed when he did not receive an appointment card when a surveillance cystoscopy was due '*… I felt like … I had fallen off … the list or fallen off something …*' (L384-385) questioning, '*How do you meet the need of someone who's … agitated about their normal daily life …?*' (L555-556).

Debbie was devastated at Dennis's diagnosis because '*somebody that you love has got what feels like a death sentence*' (L6-7). She had given Dennis information to read about having a cystectomy but '*that starts to make him panic a bit too and it probably doesn't help his* *emotional and mental health*' (L208-9). She worried about the amount of general anaesthetics Dennis had received and believed he was at risk every time. Debbie was particularly concerned after Dennis had a TURBT and had aspirated several times in recovery. She had to drive him home afterwards as they lived in the country at that time. When their children were younger, Debbie recalled they had no real concept of why their Dad was so grumpy but by the time they were teenagers, they related his moods to his procedures and understood 'just don't talk to Dad … keep your distance … try to be a bit more sympathetic' (L114-115). Debbie commented that on the days prior to Dennis's cystoscopy:

> *… he'd get tense and agro and you're trying to calm him … it's understandable he would feel that way but it all became a bit self-focused and still does* (L96-99). *… coming up for a check-up … he gets a bit down and depressed, where he's been really quite on top of things …* (L726-727). *Everything's fine and then suddenly … he'll be really down and flat and doesn't want to get close* (L733-735).

Dennis suffered from side effects of BCG treatments resulting in pain, acute UFU, isolation, and incontinence. '*So, in no uncertain terms did he* [Dennis] *let him* [urologist] *know … that things were getting … very tedious and … he needed help'* (L1371-2). Debbie said *'he* [Dennis] *was quite depressed about it … it's not easy … to talk with him about anything …'* (L463-5). His concerns were his BlCa and the location of the nearest toilet. As a couple, they had been through difficulties over the 24 years since Dennis's diagnosis, Debbie noted that:

> *… I suppose we don't harbour a lot of ill will or feeling, and I think that counts a lot towards your own … health and well-being … 'cause I think that would serve no … useful purpose …* (L1660-1669).

Eddie found the constant cycle of cystoscopies depressing as '*… every three months, with … bleeding … pain … anaesthetic …that does get you down …*' (L72-74). Enid worried about the amount of anaesthetics and the side effects of drugs, particularly Eddie's near death from a reaction to Zofran, which terrified her. There had been other occasions in theatre that made Enid feel worried and on the *'outer'* (L299) as nobody told her what was happening. '*I get emotional about it* [Eddies' incidents in theatre] *I was terrified … I'd lose him*' (L379-380).

Heather recalled earlier stages of her BlCa when the side effects seemed endless causing her to have a 'slow wick.' Though she rarely cried, she was very upset and suffered from mood swings, flying off the handle, and getting picky*, and niggly*. She told Henry *'… I don't care if I die … I'm sick of this I don't want to keep going on like this …'* (L424). Heather found the continual cystoscopies difficult and emotional, but looking at others with cancer, she said:

> *… they've had to go through a lot more than what I did, but I suppose when you're going through it yourself you don't think about that, you just think … I'm sick of going in and having this done all the time …* (L428-430).

Henry found the early years particularly difficult as Heather would be *'fairly tense and concerned'* (L54). It was an emotional time for the couple and Henry felt *'my whole world's falling around me … what do I do, where do I go?'* (L738-739). It was like *'living with two different people'* (L89) due to the personality and character changes Heather experienced. Henry complained that she was *'not the person I married … and it got … quite tense … things that happened … was totally out of character for her'* (L100-104). It progressed to the point where he nearly left the marriage, which their children found justifiable. Occasionally Heather had said *'it's alright for you, it's not your body, it's my body'* (L238). Her attitude was so negative that their son, who *'was hurting for his mother'* (L302), argued *'if you don't change your attitude … you might as well die … because you're killing all of us'* (L294-295).

Frank was shocked and scared to see blood flowing out of him and found the prospect of having his bladder removed and collecting his urine in a bag, confronted. Saying '*… not that, I don't want that … if I have to die I have to die*' (L405). Given the shock of Frank's BlCa Flo felt it would have been helpful to have support from others going through the same thing. Flo said that before his BlCa and chemotherapy Frank was a *'very placid man, well I can see nerves now, … he gets upset he don't scream or shout but he gets upset'* (L368-369). There were *'times, especially in the beginning that it's a heavy type of burden … on you, not on* *him, on you'* (L628-629). After Frank's initial cystoscopy, she recalled that *'He just couldn't hold his water and … he was afraid he was going to be like that his life'* (L192-193).

A cystectomy was not Jose's main worry. She was more concerned with living and handling her appliance correctly. '*When it comes to doing it you … try not to panic. Am I doing it … right … as much as they tell you it's … up to you to handle …'* (L465-467) after discharge. On reflection, Jose was angry about the neglect of her first GP who did not spend enough time with her, the result being that her self-esteem had 'gone right down'. She said he *'… was too quick, in and out, he double-books a lot … I was cross with him …'* (L409-410).

Similarly, Gareth had difficulty in the early stages and discussed not knowing the extent of his BlCa, or his chances of survival. Grace felt that he worried *'more than he would let on, I'm sure he does* [worry] *but he certainly doesn't voice that to me'* (L317). The couple were shocked further when after five years of having been clear of BlCa, more tumours were found on a routine surveillance cystoscopy. Grace commented *'… that's always the concern, it's always in the back of your mind, and I would have to imagine it's always in the back of his mind'* (L562-4). She was particularly angry when she arrived to pick Gareth up after a procedure only to spend hours waiting for a shift change and drugs to arrive before they could leave. She thought it would be more prudent to call her when he was ready to leave.

There was difficulty accepting a cancer diagnosis for those who had otherwise remained well. Ian's BlCa diagnosis made him realise he was not '… *the person that gets away with everything 'cause that's what I thought all my life …*' (L196-197). After all the 'fiddling around inside' Ian thought discomfort was due to the procedures and resultant scar tissue. According to Ida, the word cancer meant *'well that's it'* (L18) so she thought that Ian would have been *'a bit teary … he said he wasn't'* (L17). After treatment, he was *'a bit impatient…'* (L86) and *'he's* [sic] *temper would be a little bit more than usual'* (L88). Ida said Ian was impatient and grumbled when his appointment card arrived for his next cystoscopy but she compared BlCa with family issues including the death of a grandchild for perspective.

4.3.2 Life Supports

Jose's family cared for her during her recovery from surgery and her daughter-in-law Jean continued to collect stoma appliances and take Jose to regular ileostomy group meetings. Jose is a very social person and spends time with friends, *the girls* and as a member of community committees. A number of relatives had been through cancer, so they were not new to the cancer support role. Jean said they were just all glad that Jose had survived as they realised the outcome could have been a lot worse.

Barry remarked how amazing and supportive his partner was. She accompanied him to all his appointments, stayed with him during chemotherapy sessions and took time off work when he needed her with him. *'She was a brick, just unbelievably good, incredibly supportive …'* (L213) admitting that he was not '*the easiest person to live with for quite a long time*' (L592-593). Barry had a particular friend who visited weekly to play cards and chat. Barry felt that *'most people who knew sort of stayed away … I think they were all a bit scared that they'd turn up and I'd … be dead* [laughter]*'* (L570-571). Barbara's family had been struck by various illnesses that had left her believing that illness was just something to deal with. Of Barry's BlCa, she said *'we got through it* [laughter] *that's about the main thing but it was difficult'* (79-80). She felt that it was best to remain calm when supporting someone going through tests and procedures as they may become more emotional and find it harder to cope:

> *… a … friend of mine … who's a nurse and … come … over so that he could just … whinge at her, which was just wonderful. … I think that helped a lot. Just having someone to complain to and who knew what … he was talking about … I think that's useful… because he's not always wanted to talk to me about it, … that's fine as long as he's talking … to somebody* (L228-236).

Having young children at the time gave Barry another focus as he always had something to watch them doing. For a short while after Barry's cystectomy Barbara assisted by preparing his stoma bag, cutting the circles out to the correct size then leaving him to apply the bag. She felt the main change in their relationship was being more considerate of each other.

Heather agreed that having cancer is *'like you've got the plague and they* [family and friends] *don't know how to speak to you'* (L466-467). Henry and their family were supportive and optimistic about her abilities to get through it, but Heather found it difficult to speak to others about her BlCa, sensing that it had changed her. She said Henry was *'very patient … I couldn't ask for a … better husband'* (L884) and that she had apologised to him for her inability to talk to him and her moods during the course of her BlCa. Henry and Heather shared a property with their daughter's family because their daughter wanted to reside more closely to provide support. However, these living arrangements became difficult at times due to Heather's moods. Henry wanted to speak to Heather's doctor about her BlCa but she would not allow him to accompany her to medical appointments or be involved in her care. He felt it would be easier to support Heather with open, communication because without that *'you don't know … if I say this am I supporting her or am I working against her'* (L919-920).

Ian's children warned him not to strain himself and always rang to enquire about his tests. However, they realised that the whole story would come from Ida. She agreed that their children were supportive and asked about Ian. Ida was aware when something was wrong with Ian, but he reassured her '*nothing to worry about … everything's alright'* (L301-302).

Debbie was caring and supportive of Dennis and accompanied him to most appointments. She asked the more in-depth technical questions and Dennis appreciated her going to listen to what the doctor had to say, and look at the images and diagrams. Dennis thought it was important for Debbie to go to some of his psychologist appointments too because '*he … can* *give you some strategies and … I think it's also important to hear how the other half of the relationship is… what she could … maybe use as a strategy*' (L1115-1117). Their children call Dennis after procedures and offer the 'appropriate words' with the couple supportive of a son-in-law recently diagnosed with BlCa. Dennis and Debbie offered advice and information but the young couple were not realistic about the younger man's BlCa prognosis:

> *… if you've got that … network around you and your family cares, that sees you through and makes you optimistic about life* (L1625-1627). *… somebody who's just there for your emotional wellbeing I think … would help a lot of people going through what they do* (L1616-1617). *… sometimes you … lean heavily on other support networks to get you through … I'm thankful for what we … have in our lives … how Dennis and I've grown through … difficult times … it's made us closer … and as a family too* (L1692-1699).

Eddie had undergone cystoscopies for over twenty years, during that time he experienced adverse drug reactions which Enid found difficult and stressful. To cope and take her mind off him she needed someone with her, and often felt *separated from it* particularly as she was not informed of the drug reactions at the time. In addition, as the carer for Eddie's mother, Enid could not travel across town to accompany him to tests. However, in the beginning of his BlCa when they had limited information and support, Enid insisted that Eddie speak to someone regarding his BlCa. Eddie was quite emotional when explaining that one-day Enid approached him holding the phone saying that the woman from Lifeline wanted to speak to him. Enid said '*… none of them* [family] *understood what we were going through'* (L136).

Frank's wife Flo visited him twice a day in hospital and their two daughters and grandsons visited regularly. Frank said Flo was quite a bit younger, full of energy, and still healthy. Therefore, she was able to care for Frank at home and did everything including cooking, cleaning and gardening. Frank did not want to tell their daughters about his BlCa but Flo had chided '*They've got to know'* (L339). Although their girls had been supportive and caring, it had been hard for them, and the youngest took the diagnosis quite hard. Flo had to talk to her saying *'you're not helping us, we've got to cope and we want strength'* (L57). Flo tried to *'buck him up'* (L68) by playing things down and *'not making it bigger … in his mind…'* (L143). They did not require outside assistance because they had family support and friends so someone was available to take them shopping. However, Frank was adamant that no one could stay with him when Flo went out. In supporting her husband through his incontinence, Flo reassured him *'look, don't worry about it, that's small things in life'* (L206).

Cancer was not new to Gareth's family. His previous colon cancer, and another relative's cancer journey, had given their family valuable coping experiences to assist with his BlCa diagnosis. Friends were also supportive by offering to drive the children to and from school. While their son had not expressed concerns for his own health, Grace said their daughter had. Grace explained to the children that Gareth and his relative had genetic testing and there was no familial link. *'So, yes you've got to be more cautious than everybody else but it's not definite'* (L201-202) and she tried to downplay the issue. Grace said while friends dropped by to offer support, a visit from a particular friend made an impact on her and made her conscious of what other people were going through. Grace explained that her friend had:

> *… brought me flowers and that made all the difference, … so then when she was going through something a bit later on I did the same thing, I sent her flowers and said, 'a really good friend did this for me'. So now when I talk to people if their partners have … something, anything, it's … like that's really bad but 'how are you?' because I know how difficult it can be because you've just got to sit and watch* (L360-367).

Grace said that when people were offering support she appreciated it but became tired of talking on the phone. Learning from her own experiences, she started to use her mobile phone texting function to let others know she was there for them, without them having to talk to her. Grace noted even Gareth's father, who did not like hospitals or the word *cancer*, had visited.

Carol visited Charles in hospital with their children and grandchildren. Charles thought that passing time might be hard for Carol because she was alone. However, Carol managed to stay busy and family visited her. Carol knew the children were around if she needed them but *'they weren't sitting in my pocket all the time'* (L204-205). Charles did not have much time to deal with his cystectomy because six weeks later Carol had heart surgery and *'… the boot was on the other foot'* (L432), neither of them had much time to think about being sick.

Alicia's mother had died from cancer since Alicia's BlCa diagnosis and Allen's mother had died from cancer, so he only had Alicia and his oldest daughter, with whom to discuss Alicia's BlCa situation. He said they had not discussed BlCa much other than at the time of diagnosis, but he believed Alicia had confided in her sister and her father. He stated that he had *'been through everything with her … I'm always there for her'* (232).

4.3.3 Sexuality, and Loving Relationships

Barry stated that in the 24 hours before his cystectomy, he and Barbara *'made the most of the last … opportunity'* (L442-443). He said that they do have *sexual encounters,* but they are unfulfilling. He felt that Barbara did not get enough from him. While he could satisfy himself, he could not explain to Barbara what he needed. They knew impotence was possible and the doctor had prescribed *'the little blue pills on the off chance they might work, but they didn't'* (L468-470). Towards the end of his hospital stay Barry started to have emotional problems when he thought about body image and he always made sure he was wearing a t-shirt to bed because he felt embarrassed about his stoma. Barry noted that the lack of sexual activity had been the most significant change in his attitude to life:

> *… the thing I miss the most is having a proper sexual relationship, that's never been able to happen … but that's … probably … well, undoubtedly the biggest thing* (L432-434).

Barbara understood that Barry's sexual dysfunction was *'very upsetting for him'* (L606) and *'the worst problem …'* (L615-616). Barry had not dealt with it and to Barbara sex was:

> *... not something that … I need … It doesn't bother me but I know it bothers him … so if it's going to bother one of us, then it's … a problem* (L622-4).

Barbara hoped that *'one day maybe he'll deal with it'* (L630). When asked what part sex played in their relationship Barbara said:

> *… it was part of it … but … if you don't get along as … friends … the sex part doesn't make any difference. …* (L733-734). *I'm not the one who's … got the stoma so I don't know how it … feels* (896-897).

Allen only stated that there had been no impact on his intimate relationship or sexuality with Alicia since her BlCa diagnosis, and Alicia agreed. She remarked that her cystoscopies did not affect their sex life except when she had an anaesthetic and they abstained for a few days.

When Charles had his cystectomy and lost his sexual function, he felt that maybe he did not think about it enough before his operation and *'it would be nice if it was ... still normal'* (L683). Charles had not expected his sex life to diminish as it had. He had about ten attempts using injections but that left him in pain for a couple of hours afterwards and he did not have a complete erection. Charles believed that Carol would probably like things back to 'normal' too. When discussing the issue with a specialist he said:

> *… I was … 64 and … the specialist in … that field said to me … that sometimes people at 60 don't … practise sex anymore* [laughter] *… so in his opinion maybe I … shouldn't have worried too much about it* [laughter] (L753-757). *Well my opinion, I wish I could … put me back to normal but … well I can't …* (L770).

Charles had tried Viagra after his cystectomy, but the effect lasted '*for too long … for hours … we … discontinued that … it wasn't very good for him*' (L331-333). Carol had accepted the situation. '*I guess I sorted it out because I'm … older … I'm not a young … person … and that's life*' (L338-340). Carol was not concerned by the loss of their sex life stating that she was '*too old … to worry about … those sort of things now*' (L356). She realised that Charles felt differently but that '*as a couple … you just have to accept that*' (L367-368).

After 24 years of BlCa treatments Dennis had sexual problems. Apart from when he had chemotherapy and had to abstain, Dennis said that the frequency of their sexual activity had reduced from three times a week when they were younger to once every three weeks now.

Dennis spoke to a few doctors and tried Cialis to maintain an erection. He found it astonishing that Cialis was available under the hospital system but only one script with five repeats every six months. '*So, it means in fact that you're allowed … to have intercourse … at least once every 10 days*' (L1197-1198). Even if he was able to maintain an erection, Dennis could not ejaculate. In fact, the only way he could maintain an erection was by standing or kneeling because if he lay down he lost it in seconds.

In the week of their interviews, this couple had had a confronting discussion about love and sex. Debbie thought Dennis was pushing her away because he was always too tired or emotionally distant. In fact, he was embarrassed because he could not have a 'proper' sexual relationship with her. On several occasions, he had taken Viagra without telling Debbie. He still loved her, found her attractive, and felt the same heightened chemistry between them. When he told Debbie his feelings and that he had taken Viagra without telling her, Debbie understood why sometimes he was able to perform and other times he could not, and realised his embarrassment. Dennis had concerns for the future:

> *what knocks you is that you're … told it's a very serious operation and you'll cut nerves …that … means … you'll lose your … sexual prowess or your sexual needs … 'cause all the nerves are gone and you think … hang on this is getting … quite serious* (L184-188).

Debbie said that Dennis carried the weight of worrying about what would happen if he had a cystectomy in the future and that he had commented *'I can understand if you don't want to be with me anymore'* (L761). Those types of comments made Debbie feel:

> *… quite sad … we've been through so much and a sexual relationship's only a part of that* (L766-767) *… you learn to adapt … it makes you realise the important things in life … here I go again* [crying] (L1614-16).

Conversely, Eddie laughingly commented that he and Enid made sure to have sex before he went into hospital for treatment because for about a week afterwards they needed to abstain. *'If you're too soon it hurts, it burns'* (L826) and *'being a bloke you want to know it still works'* [laughter] (L833-834). After Eddie had his TURBT, the couple could not have sex for up to 14 days. Enid *'always made him wait that long 'cause I've always felt that he wasn't well enough to be doing anything … and it used to hurt him …'* (L166-8). Enid thought he had a painful sensation on ejaculation *'so there was a certain amount of tension'* (L177).

Gareth stated that his relationship with Grace was fine and that *'in a way probably might … be a … bit closer just because of the dramas that we've had'* (L375-376). Similar to other men, Gareth wanted to make sure everything still worked but Grace was more concerned about Gareth's welfare after his procedures. Their experiences with Gareth's bowel cancer and then his BlCa made Grace think it *'… in some ways brought us closer together'* (L348) *'… it's an extreme way to cement your relationship …'* (L352).

As for Frank and Flo's sexual relationship, Frank stated that it was *'… rather … dicey at the moment …'* (L426). There had been no sexual intimacy since Frank's diagnosis though they had always been very close. Frank was under the impression that he could give Flo BlCa by having sex with her. She knew that BlCa developed and *'… you can't catch it …'* (L220). She had tried to talk to Frank about it but believed *'… an erection is hard for him and he feels embarrassed … he feels he's not a man …'* (L251-252).

Heather felt that sexual activity slows down with age and that they did not have intercourse for a while following a cystoscopy but *'still have an active sex life'* (L695). At one stage, their relationship was more platonic, but Heather seemed to be the perfect dutiful wife in all areas except the bedroom. When Heather returned from working overseas for 12 months '… *it just kicked something back into gear again in … our marriage'* (L702-703). Although Henry spoke about the negative effect BlCa had on Heather's character and demeanour, he praised her abilities and pride in her personal presentation.

Some men were eager to recommence sexual activity as soon as possible following their procedures to ensure their masculinity was intact. Female partners viewed this as typically *macho*. Enid thought it was due to the treatment involving a man's '*main part, and that gets treated as just another injury*' [laughter] (L1037-8), '*all there exposed*' (L1043).

Barbara had difficulty knowing exactly how Barry was coping or '*how much of a front he was putting on for everybody*' (L334-5). Barry struggled to deal with his sexual dysfunction and Barbara thought the 'macho' element played a part because sex had been important to him. Barry was stubborn about any change, even refusing to change his clothing style post-cystectomy, yet Barbara knew there was clothing that was more appropriate with a stoma.

Gareth had not mentioned how painful his urinary stent was until after it was removed, and Grace was sure that he still lived with symptoms. For Grace, the best thing to arise from a BlCa diagnosis was '*that now he does go to the doctor if he's got any concerns, whereas years ago he wouldn't …*' (L710-1). Grace did not believe that Gareth would have attended a support group even if there were one because he was very young to have BlCa. Other patients would be a lot older, with BlCa being the only thing they would have in common. Both of Gareth's cancers were more common in older people so he was always the youngest patient in clinics. Grace thought he found this difficult to cope with, saying that Gareth was such a '*… gentleman, and looks after me, which is wonderful, but sometimes "I can do it, you don't have to do everything" …*' (L698-700).

Dennis detested cystoscopies under local anaesthetic because '*it was invasive … it dealt with his manhood*' (L82), and he loathed the idea that a '*stranger was handling him*' (L86). Debbie commented that Dennis was isolated after treatment due to UFU and incontinence:

> *… it's really good we've got a shed here. He likes to go down to the shed* (L703-4). *Sheds'* [are] *an important place for a man … he needs time out sometimes he'll go down there and just tinker and … sort it. Can't find a thing in that shed but Dennis is always sorting it …* (L708-11).

Apart from sorting out his affairs and paperwork, when Frank was quite ill in hospital, he would tell friends not to come and visit. Flo felt that this was because he did not want people to see him like ‘that’ (frail and ill). He even sent family away after five minutes of their arrival. *‘He was always the rock … I said to him “well it’s my turn now”’* [laughter] (514-515). Like Barry and Gareth, Frank was *‘putting on a brave front’* (L652). Similarly, it was approximately three weeks after Ian started losing blood when he finally told his partner Ida, and even then, she had to force him to visit the doctor. Mimicking her husband, she said *‘…’cause can’t be anything wrong with me, I’m a perfect man …’* (L11-2).

4.3.4 Embarrassment and Intrusiveness

Participants discussed their embarrassment and the intrusiveness of BlCa treatment and surveillance. Alicia found the cystoscopies ‘horrible’ and ‘humiliating.’ The worst part was having five or six different doctors and a room full of strangers. She recognised that they were all professionals but the experience was awful:

> *… you’re lying there with a big sheet and all that’s open is this little gap with your private bits and you’ve got your legs in the air … it’s just like, oh … kill me now because … I was so embarrassed …* (L196-198).

Dennis’s urinary frequency made him frightened of wetting and embarrassing himself. He found the cystoscopies ‘disconcerting’ and detested ‘being interfered with’. Dennis combated the problem by having a general anaesthetic every time he had a cystoscopy so he was oblivious to what was happening to him:

> *… the doctors said that you could do this under a local and invariably each time that I allowed that to happen … I found that quite… painful and … disconcerting …* (L312-317). *… the embarrassment of having your legs up in stirrups as if you’re giving birth … I didn’t want to know … so I switched off …* (L323-325).

Charles explained how it felt to have a nurse training him to self-catheterise:

> *… a little bit embarrassing … when you have a female nurse showing you how to do it … After the urethrotomy I had the catheter … in and it was bleeding so the nurses looked after it … you get used to it … When you’re crook you don’t seem to worry about that too much …* (L612-617).

In contrast, Ian was surprised that he was not embarrassed:

> *… Ida and I are not people that undress in front of each other or … anybody else … I knew they had to do it … to fix me so … no embarrassment whatsoever … I suppose before it happens to you you've never … thought about showin' your private parts to anyone or never had to …* (L705-710).

4.3.5 The Nature of Care

Continuity of care from medical staff and having a partner who cared for them were important topics for clinical participants. In general, they appreciated the excellent treatment they received. Ian felt that the nursing staff and treatment were very good and that he was fully informed. Likewise, Heather thought that care was amazing even though she was a public patient. She could not speak highly enough of the friendly and courteous staff.

Alicia discussed having a different doctor for each procedure. She had the *'same doctor the last four or five times, it's a man but still the same person … more comfortable'* (L205-206). She remarked that the nurses were wonderful, and that she had received special care due to being a novelty because of her young age. She said *'… the prep nurses are lovely and they're all really helpful … they keep it light hearted ... 'cause I'm usually the youngest one there …'* (L533-535). Alicia said that her urologist *'… sits next to me and he explains … what we've just done and what's gunna happen again …'* (L545-546). Alicia always had someone there to hold her hand and comfort her. Allen did not meet Alicia's doctors but dropped her and picked her up at the hospital if she had a general anaesthetic, as Alicia required little care.

Eddie found that *'you very rarely have the same doctor. You seem to have somebody different all the time …'* (L1075-1076). During a move interstate, it took Eddie months to get into the health care system and on one occasion, a doctor did not believe that he had BlCa. By the time he had the proof for her and had a cystoscopy, he had quite a few more tumours and required a TURBT. Eddie was pleased when the nursing staff remembered him on his return to SA. Enid did whatever was required to assist Eddie through the worst of his BlCa including helping him out of bed, cooking and serving meals to him in bed when required, and had done so for decades without additional support. The couple was happy to return to SA because the staff knew Eddie, and they appreciated the helpful medical staff.

Gareth said, *'Virtually every time I go I see somebody different that does the procedure so … they have to look at your notes to find out what's happened …'* (L99-101). Grace felt the BlCa monitoring by the hospital was excellent which reassured her there would be early detection of any further developments. Much to Gareth's frustration, Grace insisted he did nothing when he came home after his BlCa treatment, but he was uncomfortable being fussed over.

Dennis alleged he was in the urology clinic so often that he was on a first name basis with the nurses. After his original urologist moved hospitals, Dennis could not recall another urologist sitting down and describing what had happened or what needed to occur. He commented that on a few occasions a nurse rang a couple of days after his procedure to ask how he was. Dennis received a phone call *telling* him when he was having BCG treatment rather than discussing BCG as an option. When Dennis had side effects from his BCG treatments Debbie recalled that *'he was told to keep going … when he was asking for help … it wasn't there'* (L251-253). Another time when he had a blood clot blocking his catheter, the nurses were:

> *… on to it all night it … seemed they didn't really know what they were doing 'cause by the morning they were told … no you shouldn't have been doing that ... washout all night … then it doesn't get a chance to heal …*(L315-19).

No specialist or registrar spoke to them after Dennis's procedure and they had to ask an intern, who was not caring for Dennis, about the outcome of his cystoscopy. Debbie felt that management, care and follow-up were poor. That was the last of three adverse events, which culminated in the couple not wanting to go back. In terms of caring, Dennis spoke about the people from his church, who supported Debbie and included him in their prayers.

Barry had a different opinion, stating that staff were *'just magnificent'* and that he was very *'excited about how good they were'* (L899-903). Barbara said the *'nurses were … wonderful … you couldn't ask for nicer … they'd bend over backward … just lovely … no complaints there … and the doctors were really good'* (L1539-43).

Charles looked embarrassed when admitting that he did not mind going into hospital. The staff were very good and he *'enjoyed … getting looked after'* (L287). Carol agreed that the hospital staff were very good and Charles was *'well looked after'* (L491). She thought that most people complain when they are ill and Charles was no different.

Frank was happy with his treatment and thought the nurses were polite and helpful, except one who was not doing her job. When visiting another hospital, he noted that the carpet and toilet were dirty, and used urine bottles lined the bathroom floor. He believed the nurse was a student who *had no idea*. Flo described her method of caring for Frank that was quite different from other partners. Flo assisted his recovery by getting:

> *… every vegetable under the sun I could think of and I boiled them … I made soup for him … every time he got … hungry I gave him this, he ate a little, and often …* (L23-29).

Flo believed that the soup gave Frank the stamina to get through his radiotherapy treatments and recalled the specialist's surprise at Frank's recovery. Frank was upset watching Flo gardening and doing all of the chores around the house because he was the man and should be caring for her. Flo said *'that's nothing, when I can't do it I'll sit down'* [laughter] (L171-2).

Jose said information in the form of reading material was available from the urologist and Jean recalled the stoma nurse had started visiting before Jose's operation, with that care continuing when Jose was in hospital and for a brief time after discharge. Jose's care in hospital was very good and they felt lucky to have had that compared with what others had.

4.4 SURVIVAL TECHNIQUES

Participants dealt with BlCa in numerous ways. While the clinical participants all said they accepted their diagnosis, treatment, and ongoing surveillance in an almost stoic manner, often they contradicted themselves with other behaviours or views on BlCa so that is seemed that in fact, they did not live that acceptance. in reality. Finding something (e.g. alternative treatment or foods) or someone to have faith or trust in, helped some participants whereas others completely denied the effects of BlCa on their lives. Partners accepted their situation and that of their loved one and the struggles they faced. However, sometimes they had to distance themselves from dealing with BlCa, to enable them to get on with other daily chores and to cope with the situation.

4.4.1 Acceptance

Participants made comments about accepting the situation they were in with BlCa and their inability to change the situation. Heather had been teary and thinking ‘why me’. She said, *‘there’s nothing you can do about it, you just have to … get on with it’* (L203-204). She put that behind her and no longer thinks about it but at the time, it was a huge dilemma.

Alicia felt it could be a lot ‘scarier’ but knowing she only had check-ups every three months was a *‘small price to pay’* (L125-127). She *‘got over it … I accepted it very quickly’* (L138) because the urologist had explained that her BlCa was only small. She was confident that when she went back in three months she would not be ‘really sick’ and that *‘these things happen* [laughter] *can’t do much about it’* (L291-292). Alicia thought she had been *lucky*. Allen’s philosophy was to *‘just take it as it comes …’* (L102). He felt previous experiences such as his parent’s death prepared him for dealing with ill health, *‘I’ve been that sort of person that just accepts it … takes what comes and try being supportive’* (L105-106).

With his supportive partner, Barry only took a few months to come to terms with his stoma. Barry did not think he could cope but *'figured I had to so I just got used to it'* (L298-299) and that they '*… just live with it…'* (L877). Barbara felt that BlCa introduced things into their lives that they had to *'…adapt to…'* (L819) which changed various aspects of their lives and *'…expectations change…'* (L825). She confided that *'…you change certain aspects of your life … to allow for all of that…'* (826), and had to *'accept that … he's obviously not happy … about it … but we can still … do things…'* (L901-2). Barbara felt they had dealt with Barry's BlCa diagnosis, and in doing so had tried to keep their family life normal, particularly because of the children. Barry had changed since his cystectomy and sexual dysfunction, which Barbara had noticed and accepted because *'…everybody changes … over the years … both of us have … you factor in things that have happened…'* (L753). Barbara thought that maintaining her *'…just deal with it…'* (L1390) philosophy had assisted Barry.

Eddie was *'…sick of it … what else do you do …there's no alternative. You've got to have it* [tumour] *removed'* (L74-75). Numerous times Eddie said that BlCa was just one of those things with which to cope. Cystoscopies, TURBTs, and watching for blood in his urine were about learning to live with BlCa. To get through the times when it dominated his life he said:

> *So therefore, … you just live with it. You go, well that's life … you see some people around the place and … you know, a lot worse'* (L211-214). *… if you do it properly, it makes you stronger'* (L843), *…it's just one of those things … I've been going through this for so many years and … it's just a part of … life …* (L1241-1243).

Likewise, Enid felt Eddie *'slowly came to terms …'* (L90) with BlCa, and that '*… you get used to it I suppose … it becomes part of … life and we just accept it'* (L652-3). She dealt with it by putting things to the back of her mind and got '*… on with it … there's nothing you can do about it, so you have to live with it'* (L856-7).

Frank denied any side effects or pain and apart from hospital visits he said that life was quite normal. He believed that Flo accepted it too. Flo '*… accepted everything … I'm that type of* *person … I accepted that this was it … there was nothing you could do, just get him better that's all …'* (L738-739). She coped by making life easier for Frank who had now accepted BlCa and his need for treatment. He said:

> *We just accept it as this has to be and that's it. There's nothing I can do about it* (L430-431). *…when it comes to that you've got to accept …that it is natural* (L452-453). *… just have to manage it the way things are now …* (L461). *I accept it that I had it, I accept that I know that they cured it … but if there's any chance of it coming back again … I am convinced … that everything's okay now … with the help of hospital … that is not come back and I survive* (L503-508).

Jose accepted her BlCa diagnosis and surgery. She thought she would have been lucky if she did not get cancer with a son and daughter having already died from it. Her sentiment was *'if it's got to be done, it's got to be done'* (L87). Regarding her incontinence, she said *'that's what happens, you just have to accept it, you're still here'* (L479-480). When she was told about the cystectomy she *'accepted it, I didn't look for anything else'* (L539) and the family had accepted it too. *'… if my feet don't hit the floor in the morning I won't know anything about it, other than that, I've got my day planned'* (L717-719). According to Jose's daughter-in-law Jean, the speed with which it occurred was appropriate because it left little time for Jose to think it over, and Jose likes to get things done in a timely manner so it suited her:

> *… she never said "oh I've got to have this, I've got to do that" ... never felt sorry for herself, "why me", all that sort of stuff, I didn't hear that from her …* (L413-416).

Even though it had been an inconvenience Dennis saw other people in the waiting room and felt that he was not '*so badly off by comparison*' (L188). He said '*you just have to deal with those things and you've got to be standing up straight and tall … saying … this is the way it is*' (L889-892). According to Debbie, Dennis faced BlCa stoically, just as he dealt with any stressful event. Debbie understood that Dennis was accustomed to facing the worst of issues without emotion and just dealing with it, treating it as another job to get on with and fix. She thought if Dennis needed a cystectomy '*if that's the way it has to be then, I guess we really need to accept that*' (L227), '*you learn to adapt …*' (L1611-612).

Except for the sexual dysfunction, Charles said that his life was uneventful. Carol accepted his sexual dysfunction and when things went wrong for Charles *'… you can only hope for the best …'* (L39), and kept herself busy to cope. She commented:

> *… as a couple … you … have to accept that …* (L361-2), *… everything inside … him wasn't … as it was originally … but … accepting … he's had that done and … you get on with life as best you can* (L390-391).

Carol believed that staying active was better than sitting and thinking about their situation. With cooking, gardening and bike rides, they continued with life taking one day at a time.

4.4.2 Having Faith

Gareth's partner Grace was the only person who did not talk about having faith. While several BlCa participants had great faith in their urologist, Eddie, Heather and Dennis had faith in products they were taking to control their BlCa. Eddie had seen an association between taking the apricot kernels and increased time between cystoscopies, compared with when he was interstate and could not find any apricot kernels and coincidentally, a lot more tumours appeared. He said even though they tasted awful '*kernels control it but it doesn't fix it'* (L423). Eddie said that it is *'better to do that than come in here every three months and go through all the rigmarole'* (L329-330). Adding that:

> *… in your mind you hope that … you've got on top of it, you've got rid of it …* (L442-443) *… you've just gotta have faith* (L977). *… the most important thing is to … be there for your treatments and to trust the people that are treating you …* (L1157-1158) *… you need to give yourself peace of mind and know that … you have got a future and that … they're doing everything they can …* (L1205-1207).

Enid agreed with Eddie on the effects of the apricot kernels, and thought the combination of apricot kernels, vitamins and a healthy diet and life style were the key.

Henry insisted that Heather also try apricot kernels. She said they were foul and *'they didn't do any good'* (L56). Heather's faith was in taking cranberry juice but due to the high cost she switched to cranberry tablets and advocated drinking plenty of fluids. Heather said:

> *… I'm just glad that it's clear and hope it stays that way …* (L747), *… I'm … thankful that its … clear it's like a weight lifts off you …* (L752-753). *… there is always that little niggle in the back that it could come back and I just hope and pray that it doesn't …* (L923-924). *… I just keep hoping and praying that it will stay that way …* (L917).

Henry held religious beliefs and prayed for Heather saying '*… faith really has carried me through those years …'* (L160) of Heather's BlCa. Belief in the future, moving forward, and letting go of the past were crucial for him as he tried to stay positive and give Heather hope. He believed that she could now see there was someone looking after her because her BlCa was under control. Henry believed *'for better for worse'* (L180) and that they would '*come out the other side'* (L183). He also added *'go but I by the grace of God … I could've easy … gone for a walk ... permanently'* (451-452). Henry knew that the woman he was dealing with was not Heather and stayed until the worst of her BlCa side effects, and Heather's moods had passed. The worst was over, and Henry felt they were finally comfortable with each other.

Dennis had faith in the urologist he had originally seen, but who had moved to a private hospital. A couple of years ago Dennis met up with this original urologist and called this experience a 'god incident'. He had a 'corridor consultation' after which Dennis moved under the urologist's care and changed hospital. '*He has now been treating me and … I'm feeling a hell of a lot better …'* (L107). However, during the 'dark spots' associated with chemotherapy Dennis started to question his spiritual faith, even though he was very grateful for the support of members of his church group. When Dennis was feeling low, he said that Debbie would shake him out of it saying, *'it's not that bad and we'll pray'* (L1121). Dennis also had faith in Prostate-Eze that Debbie had recommended. His doctor said that *'it might work for one in five people and if it's working for you keep taking it'* (L71-72).

Debbie felt '*… it was like a gift from God'* (L334) when they found Dennis's original urologist. They drew on their *'inner strength … we've relied heavily on our faith … we've prayed a lot together ...'* (L1604-1606). Prayer support also came from family and friends who helped them to '*… maintain … faith in God'* (L1660). Debbie said, *'it hasn't always been the way I expected it would go'* (L1176), and that loving each other was most important, *'tolerate the … ups and downs … if you have the inner strength you can rise above it'* (L1611-1613).

Charles never became upset or had any major concerns. He was fit and had a good positive attitude. *'I never thought that … I'm going to not be here'* (L182). He trusted the medical staff as *'they would know best … they would know better than I would'* (L560-561), *'you have to trust your … specialists, whoever is … treating you'* (L826-827). Charles felt relieved that his experiences had not been too difficult. [The] *'whole experience has, well it's been an experience put it that way ... and it hasn't always been unpleasant'* (L816-817). Carol did not want to be *'looking on the wrong side of the fence all the time'* (L39-40), *'I'm presuming you've got to look on the bright side … and that's his … idea as well'* (L101-2).

Frank had *'so much faith in doctor* [s]*'* (L1590) and was quite relaxed after his cystoscopy because he knew that he was receiving suitable care. Frank was happy that his BlCa was not muscle invasive that would have required a cystectomy. He considered himself *lucky* it had not spread too far. Flo felt that Frank's BlCa had made them both stronger and compared to other cancer patients they had seen Flo believed *'I'm lucky…'* (L376).

Jose also believed she was in good, capable hands and that if *'I didn't come out of it I wouldn't have known anyway'* (L365-366) and *'…thank God that we've got clever doctors'* (L826). Given that Jose had gone *'into it with a good frame of mind'* (L327), her family were confident she would pull through because she was fit, healthy and had a good outlook on life.

Ian felt that *'those good people down there are gunna make sure I'm okay for the next rest of however long I live and I'm happy with that'* (L685-686). Ida's faith was that he would *'be fixed one way or another'* (L28). In the meantime, she kept herself very busy. Ida did not think about Ian's BlCa or worry like him because they were confident that his BlCa had gone.

Alicia hoped that after so long her BlCa would not come back, *'… so it was a bit of a … bummer …'* (L285-286) when it returned and she went back to three-monthly cystoscopies. She said *'I'm not worried about it now because I know that I'm gunna win this. If I wasn't doing this* [treatment] *then … I would be … a bit more concerned'* (L330-331). Allen hoped that one-day Alicia's BlCa would *'go away'* (L199), but until then they stayed positive.

Ian and Alicia took comfort that their BlCa was only very small and easily treated. Ian used that information to reassure his family so they did not make a fuss. Barry's partner Barbara felt that maintaining a sense of humour was an imperative because *'… there's always a funny side … you've always got to look at it … optimistically …'* (L255-6). However, every time Barry's results were clear she said, *'It's a relief …'* (L1499).

4.4.3 Avoidance, Denial and Distancing

Dennis, Eddie, Ian, Alicia and Frank either denied the severity of their disease or avoided talking about it or its cause. Partners distanced themselves in order to continue with the smooth running of their lives. For example, Grace admitted that as a couple they had hidden their true emotions about what they were going through with Gareth's BlCa.

Heather was so independent that she took herself to appointments because she had to deal with her BlCa alone. She was not forthcoming with information, so Henry was left to guess what she was going through. He had to *'ride it through, that's all I could do'* (L817) because *'If your partner's not talking … you ... think man … it's a hard road to walk'* (L832-3).

The embarrassment related to cystoscopies, such as being in the 'birthing' position, and then hearing the 'bad news' when more tumours were found, was unbearable for Dennis. To avoid dealing with those issues, he chose to have a general anaesthetic every time, '*I didn't want to know about it so I switched off*' (L324-325). Feeling well, Dennis discontinued the urology appointments after his tumours were removed and he thought that he was cancer free. Two years later he was in a much worse situation. When he was going through the phase of UFU he would avoid dealing with or seeing anybody for 24 hours and told everyone '*don't anyone come into the room, leave me alone*' (L625-626). Even in the early days when he was having bladder washouts Dennis noted he '*couldn't understand why I was there so long because I was fit and healthy rearing to go home and get back to work*' (L697-698). Dennis spoke of his son-in-law's BlCa diagnosis, saying that the younger man was in denial. When it was put to Dennis that he knew all about that, he admitted to the denial and likened it to going bald in that '*there's nothing much I can do to stop it*' (L1264). He continued:

> *… it's got to be happening to somebody else and not me …* (L757-758) *… it's a bloke thing … that I have had all the treatment and I'm back at work …* (L763-764) *… that's right, I'm fire proof, which you're not …* (L769).

Debbie distanced herself from Dennis's BlCa in her efforts to maintain control of the children and house *'… keeping things going …'* (L126) and *'… to keep everything together …'* (L626). She accused him of playing *'out of sight's out of mind'* (L356) when he failed to maintain regular check-ups. In the past, he had put his health *'on the back burner and … chosen not to look at it'* (L1138). She believed that Dennis would rather *'face it when we come to it rather than think ahead'* (L1404-5). She was frustrated watching their daughter and son-in-law going down the same road with the young couple denying the existence of a BlCa diagnosis.

Eddie admitted to being *pigheaded* and reluctant to visit the doctor unless Enid insisted. With his UFU he would not get up to urinate immediately because that was giving in to it. Additionally, despite 26 years of smoking a pipe and cigars, Eddie did not believe that they caused his BlCa because he did not inhale them, it was different because he enjoyed it, they were like 'an old friend' and he 'smoked for pleasure'. Enid also used distraction to take her mind off Eddie when he was undergoing procedures, she could not cope with what could happen to him. Occasionally, she had to put it to the back of her mind and get on with life.

Similarly, Ian denied that smoking caused his BlCa and he had plenty of reasons:

> *… why do you say smokin' because almost everyone that has bladder cancer smokes?* (L834) *I been smokin' since I was ten,* [62 years] *and when I retire … when I'm getting bored out of our skulls we decided to take up* [occupation] *… the cancer came four years after I started work as a* [occupation] *so it could be the chemicals …* (L861-865).

Further, Ian suggested that it would have happened years ago if it was smoking related. He was not going to give up smoking because *'I'm selfish'* and *'I like it'* (L838), adding that he had more chance of dying on the road given the kilometres that he drove every week and *'not from a simple little bladder cancer'* (L276). When first diagnosed with BlCa Ian thought *'they're wrong'* (L352) and *'I can't have it, can't be me* [laughter]*'* (L188). Ian thought the hospital did such an excellent job with treatment that his BlCa would not come back and he was *'fixed … once and for all'* (L815) and he never heard of it recurring. His partner Ida had smoked since she was sixteen and, like Ian, denied the damage that smoking could cause. Ida claimed that they were unaffected by BlCa, and it was like *'water off a duck's back'* (L 317) when people talk to Ian about his smoking.

Alicia made similar comments about the insignificance of her BlCa:

> *… we've never actually said … that I've got cancer because it's not it's been … they had a spot and they got rid of it and that was the end of it … initially so it's not its … just … a recurring spot ... that's all* [laughter] (L47). *I have a little spot that I have to go and get removed I'm not gunna hide anything from them* [children] *… if it was a serious cancer that I had then I would tell them because I don't believe in keeping them in the dark but it's not that. Well I don't think it's that ...* (L323-326).

Frank smoked for 47 years but denied that smoking caused either his BlCa or respiratory problems. Instead, he blamed treatment undertaken for Gravis disease. Frank developed a rash and underwent phototherapy. During treatment, he noticed a sign advising *'cover your testicles … because it can cause cancer'* (L282-283). Frank took this precaution at subsequent treatments, but told his doctor about the phototherapy when he developed BlCa asking if that could be the cause. Frank's doctor said it was '… impossible… ' but Frank was adamant that:

> *'… I couldn't prove it or anything … I suppose that it could. Because otherwise I don't know what else could … all of a sudden cause … bladder cancer'* (L295-29).

Flo took everything with a *'… pinch of salt …'* (L628) when dealing with Frank's BlCa. She believed that after radiation therapy they [people with BlCa] *'can't get upset because their nerves are shot to pieces'* (L631). Frank denied any difficulties from his treatment but Flo could see that he was *'putting on a brave front'* (L652).

Barbara felt that Barry would *'…like to be in denial of the whole thing'* (L8567). While they did not want BlCa to rule their lives, they needed to at least *'pretend it doesn't'* (L861) without acting as if it does not exist. As to Barry admitting to his depression, BlCa, leakages and how he handled his stoma, she commented numerous times in many ways throughout her interview that *'… he doesn't want to know …* [laughter]*'* (L1022).

4.5 CHAPTER SUMMARY

This chapter has described the findings of interviews with ten clinical participants and ten partners. Using the participants' own voices within these findings has emphasised both the meaning and sentiment behind their responses. In summary, the themes identified may be characterised as *Physical Responses, Cognitive Reactions*, *Emotional Reactions*, and *Survival Techniques*. *Physical Responses* highlighted differences in experience based on treatment and side effects. *Cognitive Reactions* described the different thoughts and beliefs about BlCa. *Emotional Reactions* highlighted the classic responses (e.g. anxiety and shock), to chronic illness including the BlCa-specific emotions of embarrassment and intrusiveness. The latter were more of a concern for participants with NMIBlCa than MIBlCa as the former participants were still undergoing regular invasive surveillance and treatment. Finally, *Survival Techniques* documented the different strategies used by clinical participants and their partners to deal with BlCa on a day-to-day basis. A discussion of these findings is contained in the follows in Chapter 5.

CHAPTER 5

OVERVIEW OF PHASE 1 FINDINGS

5.0 INTRODUCTION

The purpose of the first applied stage of this program of research was to gain insight into the experiences of people diagnosed with BlCa and their partners. As reported in Chapter 3, a thematic analysis identified four themes (reproduced as Table 5.1), while Chapter 4 presented the findings that led to these themes. The purpose of Chapter 5 is to describe the implications of these themes as evidence of the physical and psychosocial experiences of clinical participants with BlCa and their partners, the effect of these experiences on QoL, and their relevance to a potential model of care.

Table 5.1 *Themes and Sub-Themes Emerging from the Thematic Analysis*.

Themes	**Sub-themes**
Physical Responses	Treatment and side effects Continence matters Discomfort On-going needs
Cognitive Reactions	Diagnosis and information A life overshadowed Public persona Talking it over (P)
Emotional Reactions	Anxiety and shock Life supports Sexuality and loving relationships Embarrassment and intrusiveness The nature of care
Survival Techniques	Acceptance Having faith Avoidance, denial and distancing

Note: *(P) = partners' only responses.*

The following commentary considers the four themes that arose from the thematic analysis of participant’s interviews. These themes portrayed the impact that BlCa had had on participant’s daily lives and the subsequent effect on their QoL. It has been acknowledged (Chapter 2) that little qualitative research exists concerning BlCa, and that the effects of NMIBlCa on participants and the effects that BlCa has on partners is limited. Therefore, the ability to explain these themes further considering the current literature, is restricted. However, where such connections with BlCa research exist, they are acknowledged. Other literature is also referred to in this chapter when connections between the current findings and cognate areas of enquiry (e.g. PCa, which shares some similarities regarding sexual dysfunction in men) are known to exist. Due to this literature coming from various other areas of research it did not meet the inclusion criteria for the literature review in Chapter 2, though remains relevant to the topics and another illustration of the lack of research and information concerning individuals living with BlCa and their partners with which to explain and understand the findings from this first phase.

5.1 PHYSICAL RESPONSES

Several *Physical Responses*, which arose primarily from *Treatment and Side Effects* associated with BlCa, were identified in both the current findings and the literature review. Participants were surprised initially by the sudden onset of tests, treatment, and side effects, which varied depending on type of BlCa, treatment modality, length of time since diagnosis and disease severity. Clinical participants experienced discomfort particularly when the disease was of a more aggressive nature and when side effects were more severe and persistent. Many of these physical responses affected participants’ abilities to adapt to this chronic disease as they impacted every aspect of their lives.

The key *Physical Responses* concerned urinary and sexual dysfunction. It is worthy to note that disorders of the bowel were not discussed during interviews despite bowel dysfunction being a common side effect of BlCa treatment (Hedgepeth *et al.* 2010; Jacobs *et al.* 2010; Mohamed *et al*. 2012; Turner & Dredge-Coats 2012). It is unknown whether this was an intentional or aversive measure on the part of participants or another source of embarrassment to discuss this side effect. Clinical participants in the current study were watchful with fluid intake, location of toilets and frequency with which their stoma or neobladder was emptied. To that end, many ceased social activities that might involve drinking due to the high possibility of incontinence.

Continence Matters, were significant concern for clinical participants. For example, Josie mentioned wearing dark trousers so that any leakages might be less noticeable. Heather spoke of wetting herself walking down the street, on the bus and various other places but just getting on with it. Barry spoke about IC leakage and being ill-prepared for those events. Dennis and Eddie discussed their UFU. For Dennis, these symptoms caused him to become isolated as he ceased sporting activities and limited ventures away from the home to places with handy toilet stops on the way. Fitch *et al.* (2010) found that participants faced various new toileting practices such as changing stoma appliances, dealing with catheterisation, urinary leakage and incontinence, which were testing and problematic when participants had not been educated on how to cope with them. One of their participants bought all black pants so that leakage might be less noticeable, whereas another participant spoke about going around *wetting yourself,* very much like Jose's and Heather's experiences.

Studies have found that participants with day-time incontinence feel forced to deal with their private waste publicly, causing embarrassment, stigma and a reduced sense of adulthood (Rouanne *et al.* 2014; Goosens-Laan *et al.* 2014; Benner *et al.* 2014; Imbimbo *et al.* 2015). When investigating the unmet informational and supportive care needs of clinical participants, Mohamed *et al*. (2014) found urinary complications (e.g. CIC, incontinence, catheter care, lack of information and training, and body image issues) to be primary unmet care needs. Fitch *et al.* (2010) noted that younger participants or those with an IC experienced more negative body image issues and functional changes that were more obvious, with discomfort associated with participants’ ages, and ability to cope with a changed body.

A disheartening side effect for male clinical participants was sexual dysfunction. On numerous occasions Charles said he wished he could still be *normal*. This sentiment was also mentioned by Fitch *et al.* (2010) whose participants voiced grief at the loss of sexual function. In the current study, Dennis, Barry, and Charles were frustrated with their inability to perform due to ED. These men tried various pills and painful injections that nevertheless failed to facilitate sexual arousal or ejaculation. Even more of the male participants had a painful burning sensation with ejaculation. While this physical side of sexual dysfunction warrants commentary here, the topic of sexuality also appears below in the section dealing with *Emotional Reactions,* because it considers participants’ loving relationships more specifically (section 5.2). Takenaka *et al.* (2011) studied the urinary and sexual function of participants with a neobladder. Over time, pain dissipated but functional roles and emotional issues were worse with a low point for sexual function at five years post-RC. Incontinence and need for CIC led to an even worse QoL. Goosens-Laan *et al.* (2014) also noted a decline in physical and sexual function post-diagnosis for up to 12 months.

The physical capacity of some current participants deteriorated so much they were barely able to cope with a trip to the shop or church and mostly spent time with family. Brittain and Shaw’s (2007) study on partner’s perspective of incontinence also found that couples became socially restricted. According to Liu *et al.* (2016), sexual and urinary dysfunction, particularly among unemployed men above 60 years of age, was associated with poorer QoL outcomes. While some studies found improvements in physical function post-treatment, they tend to be unsustainable and gradually decline (Takenaka *et al.* 2011; Fung *et al.* 2014; Rouanne *et al.* 2014; D’Agostino *et al.* 2016). Such deterioration also led to a decline in general QoL (Yuh *et al.* 2008; Fung *et al.* 2014; Gomez *et al.* 2014). In contrast, Rouanne *et al.* (2014) stated that the level of sexual activity was good for most of their all-female cohort and attributed that to their nerve-sparing surgery.

5.2 COGNITIVE REACTIONS

Participants' physical side effects altered their ways of thinking or being in their normal daily lives. Such reactions were indicative of how BlCa overshadowed their lives, affecting many aspects of daily living and thus, negatively affecting their QoL. One of the more noteworthy negative findings of the current research was the poor communication from urologists. Alicia, Eddie and Gareth did not realise they had cancer because other words like carcinoma, tumour or polyp were used (see Chapter 4.2.1). With confusing terminology resulting in participants being unaware of their BlCa diagnosis, which they did not realise until much later. This information was a surprise and left them feeling quite helpless. Fitch *et al.* (2010) also had a participant who was told that he had a *malignant tumour,* but he was not sure if that meant cancer. He was further confused when three doctors who saw him at separate times each provided conflicting information. Thorne *et al.* (2010, p.750) noted that one of their participants had a 'lymphoma' but was not sure that that meant he had cancer as the communication was unclear and medical *jargon* was used.

Despite having haematuria, many participants did not expect their BlCa diagnosis. The surprise caught participants unaware and they failed to take in all the information given at the time. The current study highlights the importance of diagnostic information, future treatments and prognosis which should be communicated using easily understandable terminology, for all those involved. Schaepe (2011) likened a cancer diagnosis to a two-part trauma involving the initial receipt of the unwelcome news, and then the subsequent dissemination of this information to a partner and family. Participants also carried the emotional weight of what their future was about to become. In contrast, Smith *et al.* (2012) found that a partner's presence at the time of diagnosis was not necessarily a positive experience as a partner's anxiety, particularly in close relationships, could escalate the anguish faced by the clinical participant. Brown *et al*. (2011) found that over half of their participants were happy with how they received their diagnosis, but complaints included using jargon a lack of privacy.

There were delays in diagnosis for some participants due to the presence of a UTI and not being immediately referred to the urologist. Turner and Drudge-Coates (2012) and Hall *et al.* (2014) also recognised that some participants who presented with BlCa had a UTI, and suggested routinely screening for BlCa among patients with recurrent UTIs. Delays in diagnosis have occurred more frequently for women. Henning *et al.* (2013) attributed this finding to women being more likely to experience a UTI. Most participants in the current study recognised haematuria as being a concern and sought medical assistance immediately.

Jacobsen *et al.* (2013) learnt that participants were so stressed about their diagnosis they did not appreciate all the information given by their physician and often misunderstood the severity of their situation. Participants who had less chance of improvement and recovery were not able to recollect what they were told. With retention becoming even worse upon receipt of more information. Furthermore, participants process the terminal impact of their disease at a much slower rate and may need to be told many times before they start to comprehend their situation. Questions may be asked repeatedly in hopeful anticipation of a more positive prognosis (Jacobsen *et al.* 2013). While studies have reported participants' requests for more information (Fitch *et al* 2010; Mohamed *et al.* 2014), Brown *et al*. (2011) found evidence of a preference for less information due to the worry and fear associated with knowing more. Unlike other participants in the current research, Heather did not *require every detail like some people*, she had all the information required and refused Henry's request that she seek more. Barbara repeatedly stated that she would like to have better understood Barry's new *plumbing* since his IC and Debbie reflected that, at one appointment with the urologist, they were shown images of Dennis's BlCa which gave them a clearer understanding of what was happening.

Participants sought information in various forms (verbal, written and visual using non-medical terminology) and in clearly understandable terms. Visual images of BlCa and associated bodily changes could give participants a clearer indication of their disease progression, and assist them to better understand the adverse effects of treatment. Likewise, more accurate insight into their prognosis and probable future health issues could help to alleviate fears. Some participants commented on how beneficial but also overwhelming the various forms of information were. Studies outlining cancer diagnosis and communication between patients and physicians also report misinterpretation (Thorne *et al.* 2010; Jacobsen *et al.* 2013; Rossen *et al.* 2016). The issues to be considered include the time taken on the part of the participant to process and remember diagnostic information, and the most helpful ways in which to impart such information by practitioners. This varies widely depending on the discipline of the physician, their own comfort with the topic, and their experience in the role (Thorne *et al.* 2010; Jacobsen *et al.* 2013; Rossen *et al.* 2016).

Fitch *et al*. (2010) found that participants required BlCa information that included signs, symptoms, risk factors, post-surgical information, awareness campaigns, posters, books and patient education packages, particularly post-surgical information with a follow-up plan at discharge. Partners in the current study were also concerned that their clinical participant received vital information when they were still under the influence of drugs from a procedure and did not understand, or clearly remember, the information given. Couples also repeatedly asked to speak to others who were going through BlCa but that request was never realised.

Both members of the dyad in the current study emphasised the need to speak to others who were experiencing BlCa. Fitch *et al.* (2010) found that this task was left up to their participants, and that word of mouth was used to locate information, urologists, and to *connect* with other BlCa patients. Thorne *et al.* (2010) and Brown *et al*. (2011) stated that participants requested their healthcare practitioners discuss treatment and prognosis during the diagnostic consultation. More specifically, they sought clear communication, wanted to feel assured of their doctors' skills, be actively involved in decision making, and to be given a sense of hope. These participants appreciated time and privacy to digest the information received and to generate questions. Thorne *et al*. (2010) noted that their participants appreciated a seamless transition of care from the physician to another clinical team member to regain composure, ask further questions, and clarify information before leaving the clinic.

Eddie spoke at length about *A Life Overshadowed* by BlCa and the degree to which his thinking about sex, employment, social events and holidays were affected. Heather and Dennis's lives were dominated by the urinary side effects of BlCa. Other couples perceived threat associated with the aggressive nature of the cancer, with the constant need for treatment and surveillance. Three monthly cystoscopies and TURBTs were disruptive and made employment and socialising difficult. The time taken for tests and treatment was displeasing as their lives seemed to turn into a ticking clock of treatment time slots, sequences and intervals, while continued incontinence and UFU made for antisocial isolation.

Some participants believed that their partner was *putting on a brave front*, and a few admitted they were hiding their own true feelings to protect the other from additional worrying. Clinical participants felt fearful of the possibility of a cystectomy in the future, collecting their urine in a plastic bag, having to undergo treatments they perceived to be worse than what they had already experienced, fear of the cancer returning after receiving the all clear, and death. These findings mirror those of Tobin and Begley (2008) who explored the experience of being given a cancer diagnosis, and whose participants also feared pain, uncertainty, future disability and death. In the current study, Frank would rather have died than have a cystectomy, which was a fear also realised by Alicia, Dennis and Heather.

Talking it Over allowed partners to maintain communication and information about their clinical participant's progress and problems. However, male spouses were unable to discuss the intimate and emotional details, a finding commonly related to men and health (Oliffe 2004; Cecil *et al.* 2010; Heyes *et al.* 2010, 2011; Oliffe & Greaves 2012). The emotional burden was then left on the shoulders of partners who became tearful when sharing their fears and anxieties during their interviews. For two couples, marital disharmony resulting from poor communication, was a hurdle that nearly broke their relationships.

Gilbert *et al*. (2013) reported that increased communication, closeness, mutual emotional states and efforts to understand, appeared to enrich relationships for couples experiencing BlCa. Fitch *et al.* (2010) found that acceptance of changed sexual function related to type of surgery, age and stage of life, the importance of the sexual relationship, and the length of that relationship. For some, intimacy improved or had a different value, some had better communication with their partner after their surgery or treatment, whereas others found it difficult to come to terms with a stoma and a leaking bag (Fitch *et al.* 2010).

Only Dennis mentioned visiting a counsellor from whom he received considerable psychological assistance. Partners (Debbie, Barbara, Grace, Enid, and Flo) either stated that there should be someone available with whom to discuss BlCa after the diagnosis, or that they should have contacted a counsellor to share concerns, as they had no one with whom to discuss BlCa. According to Mohamed *et al*. (2014) urinary and sexual complications and dysfunction compounded concerns regarding survival and the possible return of cancer. They found the lack of counselling for their participants concerning and that it could have left them believing that their level of depression was normal. It was suggesting that counselling needs to be routinely practiced for participants with BlCa. Fitch *et al.* (2010) also recommended counselling that includes partners.

5.3 EMOTIONAL REACTIONS

Participants in the current study also revealed their anxiety when their next surveillance cystoscopy appointment card arrived one month prior to the appointment. Heather and Alicia commented that the arrival of the card was associated with reminders of their cancer, their own frailty, the embarrassment, the perceived intrusion to their body and the speculation over a possible poor test result. Debbie also commented on the change of behaviour in Dennis when his appointment card arrived, and he became anxious about the outcomes of his next surveillance cystoscopy. A search of the literature failed to find similar reports of anxiety triggered by a cystoscopy appointment notification. However, in the breast cancer literature similar psychological effects have been noted among women notified to return to the clinic after mammographic screening (Baines *et al.* 1990; Barton *et al.* 2001). These women were anxious and frightened, and many participants stated they had *sensed* their breast cancer diagnosis. These call-backs were related to results (some of which were false positives), an appointment card which distressed BlCa participants was only a reminder of further surveillance. Not surprisingly, participants advocated that limiting the length of time between receipt of the recall notification and the appointment could reduce their anxiety (Thorne *et al.* 1990; Barton *et al.* 2001; Brett & Austoker 2001; Pineault 2007; Sherman *et al.* 2013).

In contrast to this fear of the arriving appointment card, Dennis and Eddie became anxious when their appointment card did not arrive, because they felt that they had *fallen off the list* or *through the cracks*. Participants concluded that it was up to them to keep track of their appointments. They were angry and frustrated at the hospital system, the staff shortages, being on a *processing line*, not being listened to when they knew something was wrong, and dealing with embarrassment, pain, and discomfort.

This reaction, to both the arrival and non-arrival of an appointment card, were of great concern to participants. Also, the arrival of the card one month prior, but then having to telephone the clinic the day before to confirm an actual appointment time, seemed at odds with other patient priorities. The participants' comments indicate that this appointment process was frustrating and particularly inconvenient for some as it did not allow time for rearranging other responsibilities. Given this dynamic, the percentage of *no-shows* to the surveillance cystoscopy *processing line* would be of interest to know.

Partners discussed the moods and emotions experienced by clinical participants and the effects on the family. Children had to learn to be more sympathetic and family members gave the clinical participant space and time for recovery when consumed by the side effects of treatment and surveillance. The *Life Supports* for clinical participants were their partners, family and friends who cared for them and shared their worry of every test or treatment. Clinical participants were frank and effusive about how their spouses assisted them to get through the worst times, and how much family and friends had worried, as reported similarly by Fitch *et al*. (2010). All participants acknowledged and understood the fear and discomfort associated with social interactions, with some friends withdrawing completely.

Sexuality and *Loving Relationships* were discussed by couples. Dennis's sexual dysfunction had become problematic for his relationship with Debbie. Couples discussed sexual dysfunction, for example, from the perspectives of male clinical participants who still desired a satisfying sexual relationship, and female partners who valued the closeness in the relationship. Indeed, ED and inability to ejaculate were frustrating and caused substantial distress among male clinical participants. Female partners' views differed, as they focused on the length and quality of their relationships rather than the sexual aspect. Female partners were concerned with the love in their relationship and the life and family they had built together. For partners the demise of the physical, sexual act was not as important as having their clinical participant alive and supportive of their romantic relationship. To reduce relationships to their ability to perform sexually would be misleading as sexual activity per se was not the focus for female partners.

Partners' perspectives regarding BlCa were not evident in previous literature, but those of clinical participants were. Cerruto *et al.* (2014) noted the decline in sexual function occurring post-diagnosis and treatment that placed more strain on relationships and negatively affected QoL. In addition, Goosens-Laan *et al.* (2014) surveyed patients with haematuria prior to diagnoses and found that those eventually diagnosed with BlCa had reported a reduction in sexual function which remained after diagnosis for 12 months. While exploring unmet informational and supportive care needs of participants with MIBlCa, Mohamed *et al.* (2014) found that sexual dysfunction was a concern as was the absence of information which provoked anxiousness. A reduction in sexual function and satisfaction was linked with worse psychological outcomes (Liu *et al.* 2016). However, most women undergoing RC with nerve-sparing techniques in the study conducted by Liu *et al.* (2016), reported good sexual relationships. Fitch *et al.* (2010) noted that improved communication between couples assisted the relationship tensions caused by sexual dysfunction and burden. Kowalkowski *et al.* (2014) found similar sexual dysfunction issues in both their quantitative and qualitative phases. Their study uncovered the fear clinical participants experienced when they believed that they could contaminate their partner with BlCa or treatment agents, which caused many to cease sexual activity. In comparison, half of the Schmidt *et al.'s* (2015) participants with NMIBlCa had no sexual dysfunction.

Participants made observations about their interactions with the healthcare system, medical practitioners, other healthcare professionals, and healthcare facilities across multiple themes that were difficult to dissect due to the overlap of information. Such comments pertained to *Physical Responses*, *Cognitive Reactions* and *Emotional Reactions*. This section is formed from a set of aggregated comments around the *Nature of Care* that includes the healthcare system, partner involvement and clinical participant’s perspectives, and offers a more comprehensive understanding of these experiences.

During their interviews participants began their *story* from a pre-diagnosis point when symptoms and medical appointments commenced. This reference point represented the start of their interactions with the healthcare system that assisted a few but missed the needs of many. Participants discussed tests, clinics, times, misdiagnoses, care providers skills, delays or disorganisation, that were all mentioned as part of the build-up to hearing the diagnosis of BlCa. These issues formed a negative context for the presentation of the diagnosis as a lengthy wait for a definitive diagnosis has been noted to increase patient’s anxiety (Barrass & Wood 2013). Barry, Charles and Jose enduring diagnostic delays and downplaying of their symptoms. A similar *shock* and *fear* reported in the current study was expressed by participants in other studies too (Fitch *et al.* 2010; Williams *et al.* 2014) and they reported hiding their emotions to appear stronger and better able to cope with their diagnosis and treatment. Schaepe (2011) found that prior interactions with the clinic, care provider or hospital, affected the way participants received and reacted to their cancer diagnosis. It was noted that participants who felt they had been mistreated, misdiagnosed, kept waiting, or had their symptoms trivialised, expected future care would be similar (Tobin & Begley 2008; Jacobsen *et al.* 2013). They also knew that timely treatment would be imperative.

In the current study participants were generally pleased with the care received from medical and nursing staff, though several complaints related to *The Nature of Care* were voiced by participants. For example, most participants found rough and painful cystoscopies to be unpleasant. Another concern was the lack of continuity of medical care. For example, participants found it unnerving that they did not see the same doctor twice, particularly given the intimate and embarrassing nature of treatment and surveillance that were delivered via the urethra in cases of NMIBlCa.

Debbie complained about the communication after she telephoned the hospital for a time to collect Dennis post-procedure. When she arrived, he was not back from theatre and they had to wait a long time for drugs to arrive. She felt that it would be better use of her time if the hospital let her know when he was ready, then she could leave work to pick him up rather than wait around for hospital staff to get organised. Grace stated that she was *told* that Gareth was coming home but no one asked her if she was ready, or felt capable of caring for him.

Other problems included patients believing that they were not being adequately informed or heard. When Dennis started his BCG treatment he was telephoned and *told* that he was starting it, without discussion of options or side effects. Later when Dennis was suffering from severe side effects of BCG therapy no one listened to him for some time before his BCG regimen was adjusted. Because of these severe side effects, Dennis had UFU and incontinence and had to argue to see a continence nurse for assistance. Equally, Charles was not aware of the sexual dysfunction associated with the formation of his neobladder and stated that he did not feel fully informed about this impact. D’Agostino *et al.* (2016) suggested that pre-surgery education explaining the positive and negative aspects of a neobladder and CIC might encourage patients’ active participation in treatment decision-making, which may improve their QoL.

Partners attended medical meetings to record information on behalf of their clinical participant or simply listen to the advice given, in the hope of maximise the information retained. As Flo insisted to Frank, *what you don’t hear I hear*. However, couples often felt that they could not ask questions during urology appointments as visits were too brief, leaving couples feeling rushed with questions unanswered. Similar findings were reported by

Fitch *et al*. (2010) whose participants also wrote lists of questions they needed to ask the urologist. A male participant said he and his wife compared notes after his urology appointment also used websites to obtain further information (Fitch *et al*. 2010). Participants in other studies believed that information was vital for their survival, but doubted the abilities of healthcare professionals to meet such needs or provide the required support (Wenger & Oliffe 2014; Rossen *et al.* 2016). Instead, they relied on partners or friends to assist during interactions with healthcare professionals and located information on the internet.

In this study, partners felt that counselling or learning coping skills would have been of benefit. Participants wanted to know how other families coped, to learn coping skills, and to form support networks. Partners' healthcare needs included information, counselling and support, inclusion, and they expected some respect for their role as carer and loved one. Partners felt that it was important to have someone with whom to discuss the consequences of living with a person diagnosed with BlCa. They worried about being the only person to whom the clinical participant could confide his/her fears and anxieties. The intimate nature of BlCa, and lack of understanding from others, prevented discussions about BlCa issues. Additionally, they requested contact with a support group even though no such group exists in SA yet, but participants had to find out this information for themselves.

5. 4 SURVIVAL TECHNIQUES

The ability of both clinical participants and partners to adapt to BlCa was the final theme identified. Both members of the dyads in this study expressed their acceptance of BlCa with statements such as *there's nothing you could do*, *these things happen*, *can't do much about it*, and *what else can you do*. When treatments or surgery were suggested, they said *if it has to be done, it's got to be done,* they *accepted it*, *we just accepted it,* and *I accepted it had to be done*. Comments about incontinence included, *that's what happens*, *you have to accept it*, *it's one of those things*, *part of living with it*, *this is the way it is*, and *you just have to get on with* *it*. Despite such acceptance, many participants were emotional and teary during their interview, particularly Barbara, Debbie, Eddie, Ida, Frank and Grace.

There were certainly many comments (Barbara, Barry, Grace, and Flo) about people *putting on a brave face* for the benefit of their spouse, particularly by *playing things down*. This approach was noted by Cecil *et al.* (2010) in discussing men's sense of masculinity regarding cancer. A study by Williams *et al.* (2014), concerning carers of a spouse with PCa, found that their participants also *downplayed* the situation so that as a couple they could move on with their lives. According to Fife (2005), adaptation can only occur when the individual has control of their coping methods, self-perception, social standing and threats to health. When applying these criteria to the current study, one clinical participant (Jose) and four partners (Allen, Carol, Jean and Barbara may be considered close to achieving, or have achieved adaptation to BlCa.

Rather than displaying either acceptance or denial, some participants sought alternative sources of assistance (e.g. herbs, apricot kernels, cranberry juice, and non-prescription medications), or placed implicit trust in their specialist. Others relied on religious beliefs and faith, which assisted them to get through their ordeal and helped them to survive. Mao *et al.* (2010) noted that enhanced spiritual awareness can convert cancer into a more considerable experience by increasing closeness with others and improving positive attitudes. They found an association between spirituality and the use of complementary alternative medicine in cancer survivors with improvement in QoL and in the outlook on sickness and health. However, Davison and Jhangri (2012) found that in the case of patients with kidney disease, QoL was assisted by emotional well-being but that psychosocial domain changes remained independent of spirituality.

A cancer diagnosis can have many different complex effects on individuals, their relationships and their social environment. According to Fife (2005) and Mao *et al.* (2010) understanding these factors is crucial for the individual's adaptation to illness, particularly when cancer treatment is often traumatic and can be difficult in which to find meaning. The everyday lives of four clinical participants (Charles, Dennis, Eddie and Gareth) and four partners (Debbie, Flo, Grace and Enid) remained compromised as they appeared to not yet have adapted to BlCa.

At times, the words used by some participants sounded as if they were at war, fighting a deadly enemy with comments like … *this isn't the end,* … *not giving in to it, I'm gunna win this* and you … *take control* … otherwise *it dominates*. Further, while talking about her incontinence and how it occurred in public locations, Heather stated that *it was like someone who was incontinent*. Surely, it was not *like* someone who was incontinent, as she *was* incontinent. While Henry believed that Heather accepted her incontinence and took it in her stride, and she mentioned the jokes they made about it. Nevertheless, in other ways, Heather's incontinence seemed to be denied. Heather distanced herself from her problems by engaging with their business and family. She also denied Henry and her family any involvement in her BlCa care and appointments, yet her moods adversely affected her entire family almost to dissolution at times according to Henry. Similarly, Barry's reluctance to prepare adequately for a possible leakage when away from home, or change anything in his life related to his stoma, was another example of denial and distancing from the problem. Barbara was concerned about Barry's attitude towards his stoma and lack of pre-planning or use of available resources.

Alicia and Ian repeatedly spoke about being *reassured* that they had a *small spot* that was *slow growing* and believed they would know in plenty of time if their situation became worse. Upon hearing the diagnosis, Schaepe (2011) found that participants and families tended to hold on to certain phrases well after the moment of diagnosis and into the treatment protocol. These phrases were of a qualifying nature such as *very treatable, high risk, good kind* and *cancer of choice* when referring to the least problematic form of cancer. Alicia and Ian held on to these positive terms to convince themselves that their BlCa did not represent much of a concern. Alicia also commented that it was just a spot she has removed every three months (for years) and Ian was sure that he had had the treatment and was now cured as he had never heard of BlCa recurring. Ian also did not believe that smoking caused BlCa saying that people only cited smoking as a cause because most people diagnosed with BlCa happened to smoke. He believed this observation did not make smoking the cause, and so Ian and Ida continued to smoke.

A strategy used by partners to enable them to get on with caring for the needs of their whole family included distancing from the issues associated with BlCa, and avoidance of the problems, and the person connected to it. It allowed partners time and space to care for their own needs when they required distraction from emotional times and events they found difficult to process. Five clinical participants (Alicia, Barry, Frank, Heather and Ian) and two partners (Henry and Ida) appeared to be failing to adapt to the presence of BlCa in their lives.

5.5 CHAPTER SUMMARY

Phase 1 has explored the unique QoL experiences of both clinical participants and partners as they attempt to adapt to BlCa. The clinical participants varied in unique ways from the type of BlCa, treatment undertaken and their ages which crossed a six-decade period. This maximum variation sample is recommended for a QD study of an exploratory nature.

There was a resonance between the four pillars representing QoL, as presented in Chapter 1 (*Physical Well-being, Experiences of the Healthcare System, Psychosocial Well-being,* and *Adaptation to BlCa)* and many of the themes to emerge from the findings of Chapter 4, as discussed further here. Aspects of *Experiences of the Healthcare System* were diverse, expressed in multiple themes and more clearly in *The Nature of Care.* While some of these were complaints of inconvenience, they added up to an overall negative appraisal of the healthcare system particularly in terms of communication and information. *Psychosocial Well-being* has aligned with the themes of Cognitive and Emotional Reactions and *Adaptation to BlCa* might also describe the sentiments expressed in Survival Techniques. Overall, the defining characteristics of QoL appeared relevant to the current research context.

Chapter 6 follows with a proposal to further explore the importance of the Phase 1 findings with a view to answering question four and articulating a model of care.

4. What elements of the experiences of clinical participants, and their partners, inform a model of care for BlCa?

More specifically, to evaluate whether Physical *Experiences, Cognitive and Emotional Reactions*, and *Survival Techniques* comprise a framework of adaptation to chronic illness. That is, consideration is given to the ways in which the physical constraints and psychosocial reactions of clinical participants and partners impact on their adaptation to BlCa in the context of the constant need for interactions with the healthcare system?

CHAPTER 6

PHASE 2 PROPOSAL

6.0 INTRODUCTION

Chapter 5 presented a detailed discussion of the findings of Phase 1. Using a QD methodology, face-to-face interviews highlighted the physical, healthcare, psychosocial and survivorship needs of participants with emphasis on the behaviours they reported. Overall, the findings showed differences in how participants adapted to BlCa and in their available resources, and support requirements. Formally, these experiences were termed *Physical Experiences, Healthcare Needs, Cognitive and Emotional Reactions,* and *Survival Techniques*. However, these observations emerged within a qualitative context of personal and subjective perspectives that may not be relevant to the population (Francis *et al.* 2016). Therefore, to test their relevance, a quantitative study is proposed as part of a this mixed methods research approach.

The goal of Chapter 6 is to incorporate the experiences explored in Phase 1 into an appropriate model and to provide an integrated commentary on the QoL of clinical participants and their partners. That is, further examination of the effects of BlCa on participants' QoL requires an appropriate framework to complement and expand the Phase 1 findings. First, however, brief consideration is given to potential areas of research appropriate for such a model or framework. The chosen model is then tested empirically in Phase 2.

6.1 ADAPTATION IN BLADDER CANCER

A summary of the findings from Chapter 5 suggests that by seeking to understand the experiences of participants it is possible to gain a better appreciation of their attempts to adapt to BlCa. This includes adaptation to a set of rules and procedures required by the healthcare system, often found by participants to be annoying and frustrating. Further, physical, and psychosocial concomitants of BlCa also compromised participants' ability to adapt to BlCa. Indeed, the theme of *Survival Techniques* allowed the description of three levels of adaptation among participants (Section 5.4). Therefore, it may be assumed that interactions between *Healthcare Needs, Physical Responses,* and *Psychosocial Reactions* (Cognitive and Emotional Reactions) are important contributors to *Survival Techniques* as an indication of QoL. On balance, these themes have indicated that the area of research focus from which an appropriate model might emerge is that of adaptation to chronic illness. In the case of clinical participants and partners, several changes had taken place following diagnosis that affected participants' behaviours, cognitions, and affect concerning life and the disease process, which could contribute to either adaptation or maladaptation to BlCa.

Lazarus and Folkman (1984, p.182) describe adaptation as the ability to '… *survive and flourish*' which encompasses the biological basis for adaptation in a '… *physical and social environment*'. They noted that being content with life and social activity, including family, friends, employment, and emotions, play a role in adaptation, with '… *social functioning, morale, and somatic health …*' as elements of '*major long-term adaptational outcomes*' (Lazarus & Folkman 1984, p. 182). The relationship between these three areas is multifaceted and Lazarus and Folkman (1984, p. 225) warn that:

> *… good functioning in one sphere may be directly related to poor functioning in another and that good functioning in one area does not necessarily mean that the person is functioning well in all areas.*

Therefore, (mal) adaptation would seem to stem from the inability to adjust physically and/or psychosocially to the threatening stimulus or event. A number of psychological and nursing theories may provide an appropriate framework in which to test this proposition.

6.2 MODELS OF ADAPTATION

The goal for Phase 2 was to identify and test an appropriate model of adaptation that could accommodate the specific themes identified as relevant to the current context of BlCa. The theory behind conceptual models is of both a philosophical and scientific nature, and includes terminology that describes both the phenomenon, and the relationships between sub-elements of the phenomenon (Clarke *et al.* 2011). Within a discipline, conceptual models act as roadmaps for development of the direction, shape, and strength of a theory (Nuamah *et al.* 1999). A number of potentially applicable models are reviewed briefly in this section.

6.2.1 The Grief Cycle by Kübler-Ross

Kübler-Ross (1969, 1970) noted the difficulty doctors faced when dealing with terminally ill patients and identified the emotional states through which patients progressed at this time (denial, anger, bargaining, depression, and acceptance). Later she suggested that this cycle was also relevant to the receipt of bad news, including the diagnosis of a chronic illness such as cancer. An extended version of the model comprises an initial *Shock* stage upon hearing the bad news and a *Testing* (finding realistic answers) stage, prior to acceptance. With acceptance as the outcome, her cycle of emotional states may be considered a model of adaptation. Indeed, all of the diagnosis, treatment, side effects, possible regression of disease, and disease recurrence are encompassed. However, the movement of patients through this framework may not be linear, and it fails to include the themes of psychosocial support and healthcare interactions that appear important in the current program. Furthermore, it has been suggested by Telford *et al.* (2006), that the specific stages proposed by Kübler-Ross (1969, 1970) may prompt healthcare professionals to expect a particular behaviour at a given time rather than attend to the actual experiences of the patient. They add that the generalisations of the Kübler-Ross (1969, 1970) model do not allow for the various pathological and psychological experiences, nor the patients' attempts to adjust to their chronic illness. When the patient does not appear to be moving towards the correct stage, they may be labelled as being in *Denial* rather than actually struggling to meet an idealistic stage (Kingsbury 2000). These labels are judgements made by healthcare professional and society, which are counterproductive for patients with chronic disease as they are well aware that they do not meet the norms in society leaving them with a sense of negativity and fragility rather than moving towards positive adaptation (Kingsbury 2000; Telford *et al.* 2006). For these reasons, the Kübler-Ross model was not considered further for the current research.

6.2.2 Taylor's Cognitive Adaptation Model

Taylor (1983) described how patients could improve on previous psychological functioning in the face of tragedy or bad news (e.g. a diagnosis of BlCa) by using a cognitive adaptation method (finding meaning, mastery, and self-esteem). She defines adaptation as a process of accepting a threatening event that relies on coming to terms with that threat through finding '*meaning … regaining mastery over the event, in particular and over … life … to feel good …. despite the setback*' (Taylor 1983, p. 1161). Doing so enhances the understanding of what effect the negative event is likely to have on the individual's life. Mastery is a process of gaining a sense of control over the event. Information and control might see the individual make lifestyle or health changes, to reduce the possibility of a recurrence. Self-enhancement or self-esteem can also assist meaning and mastery by allowing individuals to feel better about themselves. Taylor (1983 p. 1161) noted that *'… social comparisons …'* are the key mechanism by which this occurs. For example, patients diagnosed with cancer may observe another person in a worse situation because their cancer is of a more advanced stage or more aggressive. Their own circumstances therefore become more acceptable, leading to increased meaning and mastery, and patients are considered to demonstrate '*psychological adjustment*' (Taylor 1983, p. 1163).

In the current research, the threatening event is the BlCa diagnosis. Finding meaning may involve determining why the person has BlCa, the cause(s), its potential course and what that means in the participant's life (Taylor 1983). In gaining control, participants might question what is to come of their life and how they might overcome and manage the problems faced with BlCa. However, Fournier *et al.* (2002, p.1165), advise that the '… *illusion of invulnerability*…' might delay and impede the patient's movement towards positive healthy behaviour. They warn that patients with chronic diseases may be limited in their ability to gain the control described by Taylor (1983), due to the illness characteristics (Fournier *et al.* 2002). While this model is attractive at some levels, its focus on social comparison rather than social support, and a lack of acknowledgement of environmental issues such as healthcare interactions, suggest that this model may not provide the appropriate framework.

6.2.3 Roy's Adaptation Model (RAM)

Philosophically, RAM views people as self-contained entities with individual needs, yet mutually dependent on the shared and common needs of others (Roy 1976, 1984, 1988). Development of RAM was influenced by Systems Theories (Von Bertalanffy 1968) and Adaptation Level Theory (Helson 1964). According to Roy, as biopsychosocial beings we continually interact with the environment in which we live with our ever-changing environment defined as being any '… *conditions, circumstances and influences that … affect … development and behavior*' (Roy *et al.* 2009, p. 209).

RAM focuses specifically on the means by which a person might respond and adapt to challenging circumstances, with adaptation implying an integration of both the person and relevant environmental stimuli (Roy & Corliss 1993; Roy 2011a, 2014). When applied to its original nursing context RAM portrays goals as '… *promoting adaptation in a changing environment*' (Roy 1987, p. 46). According to Clarke *et al.* (2011, p. 338) '… *the main concept of the model, adaptation, gives the model underlying spirits of unity and hope … it is* *profoundly an idea of continual transformation toward some potential end.*' RAM is conceptualised as an inputs-throughputs-outputs model with the portrayal of patients' circumstances, cognitions, affect, and behaviours using the categories of *Environmental Stimuli, Control Process, Adaptive Modes*, and *Adaptation Levels*.

While each of the models described above has the potential to characterise adaptation to BlCa, the general focus of RAM on personal circumstances and environmental stimuli appears most relevant. The core classifications of RAM (see also Table 6.1) allow the specific mapping of the physical, cognitive, emotional and survival techniques described by participants in Phase 1. Therefore, RAM was chosen as the most appropriate theoretical model with which to explore further the identified BlCa experiences.

6.3 MAPPING RAM TO PHASE 1 FINDINGS

The following section provides an explanation of the connections between each level of RAM and the Phase 1 themes, along with an introduction to alternative nomenclature for the different levels of RAM. Various authors have described *Environmental Stimuli* as *Input*(*s*), *Control Process* as *Coping mechanism*(*s*), *Adaptive Modes* as *Bio-psycho-social behavioural response*(*s*), and *Adaptation* Levels as *Output*(*s*) (Lefaiver *et al.* 207; Weinert *et al.* 2008; Weiland 2010; Phillips 2011). Table 6.2 summarises the use of alternative RAM labels.

6.3.1 Environmental Stimuli

The first level of RAM consists of Focal, Contextual, and Residual *Environmental Stimuli* (termed *Inputs*), which are either internal or external to the individual (Roy & Corliss 1993; Roy *et al.* 2009, Roy 2014). Focal Stimuli are concerns that are immediately confronting and a priority following a negative event. Contextual Stimuli include all other known stimuli that may affect adaptation, whereas Residual Stimuli are unknown (Roy & Corliss 1993; Roy *et al.* 2009, 2014). In the current research, *Environmental Stimuli* equate to the Chapter 4

Table 6.1 Roy’s Adaptation Model (RAM)

ENVIRONMENTAL STIMULI	Focal Stimuli	Most confronting problem or issue.
	Contextual Stimuli	Other positive/negative contributions to focal stimuli.
	Residual Stimuli	Unknown stimuli.
CONTROL PROCESS	Regulator	Innate coping process (genetically determined, automatic; endocrine, neural). Acquired coping process (learned or developed).
	Cognator	Perception and information, learning, emotion and judgement. Emotional and intellectual responses to stimuli.
ADAPTIVE MODES	Physiologic Mode	Endocrine and neurological responses (oxygen, nutrition, elimination, activity, and rest). Responses to physical and fiscal resources required to meet basic needs.
	Self-Concept Mode	Body sensation and physical aspects of self-image. Moral, spiritual, ethical integrity.
	Interdependence Mode	Relationships with significant others involving giving and receiving of love, respect and value, social support and nurturing relationships that give a sense of security.
	Role Function Mode	Social role, behaviour, and integrity (meeting obligations, freely choosing activities). Involves spouse/partner, parent, sibling, occupation, age, gender, developmental stage.
ADAPTATION LEVELS	Integrated Process	Life meets needs and stimulates human system integrity.
	Compensatory Process	Coping process, challenges to life.
	Compromised Process	Inadequate life processes that do not promote adaptation, growth, or mastery.

Table 6.2 Integration of Phase 1 Themes and RAM

RAM (with alternative labelling of components)			**Phase 1 Themes**
Environmental Stimuli	Focal Stimuli	**Input(s)**	Treatment and side effects
	Contextual Stimuli		Anxiety and shock; A life overshadowed
	Residual Stimuli		The nature of care
Control Process	Regulator	**Coping mechanism(s)**	Continence matters
	Cognator		Diagnosis and information; Talking it over (P)
Adaptive Modes	Physiologic Mode	**Bio-psycho-social behavioural response(s)**	Discomfort; On-going needs
	Self-Concept Mode		Embarrassment and intrusiveness
	Interdependence Mode		Life supports; Sexuality and loving
	Role Function Mode		Public persona
Adaptation Levels	Integrated	**Output(s)**	Acceptance
	Compensatory		Having faith
	Compromised		Avoidance, denial and distancing

Note: *(P) = partners' only responses*

findings of *Treatments and Side Effects* associated with BlCa, the *Anxiety and Shock* related to the experience of testing and treatment, the sense of *A Life Overshadowed* by BlCa, and the *Nature of Care* required that might influence the degree of adaptation. The role of *Environmental Stimuli* is to trigger the *Control Process*, which is the second level of RAM (Roy 1987, 1988; Silva 1987; Roy & Corliss 1993; DeSanto-Madeya & Fawcett, 2009).

6.3.2 Control Process

The *Control Process* is a *Coping Mechanism* classified as either *Regulator or Cognator* (Roy 1987, 1988; Roy & Corliss 1993; Phillips 2006). The *Regulator* describes automatic physical responses to the *Environmental Stimuli*, which occur via neural, chemical, or endocrine system changes (Roy 1987, 1988; Roy & Corliss 1993; Moreno *et al*. 2009). The *Cognator* subsystem concerns perceptions and information processing, learning, judgment and emotions (Roy 1987, 1988; Roy & Corliss 1993). The *Control Processes* comprise the *Continence Matters* and *Cognitive Reactions* associated with *Diagnosis and Information*, and the ability to *Talk It Over* as identified in Chapter 4.

6.3.3 Adaptive Modes

Behaviours initiated at the *Control Process* level manifest in the *Adaptive Modes* or *Bio-psycho-social Behavioural Responses* (DeSanto-Madeya & Fawcett 2009; Moreno *et al.* 2009; Phillips 2010; Roy 2011a). There are four *Adaptive Modes*. The *Physiological Mode* refers to chemical responses to stimuli and the requirements to meet basic human needs (e.g. oxygen, food, rest). *Self-Concept Mode* includes beliefs and feelings about the self at a particular time (Phillips 2006, 2010; Roy 2011a). *Interdependence Mode* includes partner and family relationships, social supports and the ability to give and receive love and respect from others. *Role Function Mode* describes the person’s ability to enact their usual, socially prescribed role (Roy 1987, 1988).

A Phase 1 theme associated with the *Physiological Mode* is the *Discomfort* experienced with emphasis placed on the *On-going Needs* of clinical participants and their requirement for external supports, counselling, and assistance. The *Self-concept Mode* is exhibited in the overwhelming *Embarrassment and Intrusiveness* of treatment and surveillance. The *Interdependence Mode* is highlighted through clinical participants and partners having different interpretations of *Sexuality and Loving*, and through the clinical participants' partners, family, and friends as *Life Supports*. The *Role Function Mode* is illustrated by disruption to all facets of clinical participants' lives (family, employment, social activities, hobbies and sporting pursuits) comprising their *Public Persona*.

6.3.4 Adaptation Levels

The combination of behaviours expressed in the *Adaptive Modes* is reflected in the *Adaptation Levels* (*Outputs*) of RAM. This is essentially the degree of demonstrated adaptation by the individual, defined as either *Integrated, Compensatory* or *Compromised* (Roy 1987, 1988; Roy & Corliss 1993). *Integration* reflects satisfactory adaptation, with most needs being met by the social and physical environment. The *Compensatory* level implies that the negative event (BlCa) is still presenting challenges in everyday life. Those at the *Compromised* level are demonstrating unsuccessful adaptation to their new social and physical environment (Roy 1987, 1988; Roy & Corliss 1993). Therefore, the *Adaptation Levels* of RAM reflect the degree to which BlCa participants expressed successful adaptation and *Acceptance* of BlCa, *Having Faith* in their ability to get through with the help of others, dietary supplements or faith, and the degree of *Avoidance, Denial, and Distancing.*

6.4 OTHER RELEVANT APPLICATIONS OF RAM

Since its inception four decades ago, the use of RAM has grown in both research and nursing practice particular, with changes reflecting contemporary interpretations of patient care, including the acknowledgement of evidence-based practice. However, the central proposition remains that humans (patients) seek to adapt in response to an aversive stimulus or stimuli, which initiates a coping process that affects behaviour (Roy 1987; Roy & Corliss 1993; Nuamah *et al.* 1999; Perrett 2007). According to Roy (2011b), RAM describes the objectives (across the model's four levels) that might assist patients and families as they seek effective adaptation to a diagnosis.

Nurses, researchers, and academics have all utilised RAM across a diverse range of medical contexts. For example, it has become a guide to understanding the needs of surgical patients' spouses (Silva 1987) and adaptation to chronic illness (Pollock 1993; Weinert *et al*. 2008). RAM has been used to understand the QoL of cancer patients (Nuamah *et al*. 1999) including children (Yeh 2001, 2002, 2003), the QoL of men receiving prostate cancer treatment (McCaughan *et al.* 2013), physical activity and cancer (Courneya 2011), lung transplant candidates and their caregivers (Lefaiver *et al.* 2007) and adaptation after liver transplantation (Ordin *et al.* 2013). RAM has also been applied to research on death and dying, spirituality at the end of life, and life closure (Dobratz 2002, 2004, 2011, 2014, 2016) and spirituality in critical care (Weiland 2010). Other studies have focused on role function and stress among caregivers (Lotus Shyu 2000; Tsai 2003), the perspectives of patients' families (Hanna & Roy 2001), and women's adjustment to diabetes (Willoughby *et al.* 2000).

Further applications of RAM include studies of cancer survivorship (Peck 2008), combat-related PTSD (Nayback 2009), and the development of an antenatal assessment instrument (Lee *et al.* 2011). Other uses include measuring the internalized stigma of HIV/AIDS (Phillips 2011), management of Bulimia Nervosa (Seah & Tham 2015), and adaptation of new registered nurses during their orientation period (Ashton 2015) and utilised in qualitative research to describe the experiences of participants adaptation (Fawcett 2006; Perrett 2007).

The preceding summary highlights a number of applications of RAM relating primarily to its use in the nursing care of patients and/or families. Table 6.3 presents additional studies particularly of a seminal nature that have utilised RAM, serving to illustrate a number of alternative operationalisations of the four core levels of RAM that have appeared in applied research over time and across contexts. RAM's values and philosophical assumptions of 'veritivity and humanism' (Hanna 2012, 2013) continue to be expounded. Roy herself has continued to write about the use of RAM in research (Roy 1976, 1984; Roy *et al.* 2009), by providing philosophical assumptions (Roy 1988), a theoretical update, and knowledge for clinical practice (Roy & Corliss 1993). RAM has also been extended to meet changing global needs (Roy 2011a, 2011b). Thus, RAM remains an appropriate framework for assessing adaptation to health challenges such as those faced by patients with BlCa and their partners.

6.5 CHAPTER SUMMARY

The purpose of Chapter 6 was to identify a framework or model of change that might explain further the findings from Phase 1. A general focus on adaptation to BlCa was depicted through themes derived from the Phase 1 thematic analysis and discussion. When reviewing frameworks and models applicable for use in a quantitative study, the emergent themes clearly aligned most appropriately with those of RAM (Roy 1987). To provide further evidence of the relevance of the Phase 1 findings, the RAM framework will now be applied to help operationalise the qualitative findings into measurable constructs (Chapter 7), the results of which are to be presented in Chapter 8. Such evidence might enable the development of a model of care to help meet the needs of future patients and partners.

Table 6.3 Pivotal Studies Demonstrating the Changing Operational Use of RAM

Citation		Ashton (2015)	Seah and Tham (2015)	Topaz *et al*. (2014)	Lee *et al*. (2011)
Aim and Participants		Workplace adaptation among new RNs (N = 250)	Management of Bulimia Nervosa (N = 1)	Construction of a theory of successful aging (N = 0)	Development of an antenatal assessment instrument (N = 0)
Environmental Stimuli	Focal Stimuli	✓	✗	✓	✓
	Contextual Stimuli	✓	✗	✓	✗
	Residual Stimuli	✓	✗	✓	✗
Control Process	Regulator	✗	✗	✓	✓
	Cognator	✗	✗	✓	✓
Adaptive Modes	Physiological Mode	✗	✓	✓	✗
	Self-concept Mode	✗	✗	✓	✓
	Role Function	✗	✗	✓	✗
	Interdependence Mode	✗	✗	✓	✗
Adaptation Levels	Integrated	✓	✓	✓	✓
	Compensatory	✓	✓	✗	✗
	Compromised	✓	✓	✓	✓

Table 6.3 Pivotal Studies Demonstrating the Changing Operational Use of RAM (continued …)

Citation		Phillips (2011)	Weiland (2010)	Weinert *et al.* (2008)	Lefaiver *et al.* (2007)
Aim and Participants		Internalized stigma of HIV/AIDS (N = 0)	Integration of spirituality into critical care (N = 1)	Women's adaptation to chronic illness (N = 861)	QoL of lung cancer patients; relationships with carers (unknown)
Environmental Stimuli	Focal Stimuli	✓	✓	✓	✓
	Contextual Stimuli	✓	✓	✓	✗
	Residual Stimuli	✗	✓	✓	✗
Control Processes	Regulator	✓	✓	✗	✗
	Cognator	✗	✓	✗	✗
Adaptive Modes	Physiological Mode	✗	✗	✗	✓
	Self-concept Mode	✓	✓	✓	✓
	Role Function	✗	✗	✓	✓
	Interdependence Mode	✗	✗	✓	✓
Adaptation Levels	Integrated	✗	✓	✓	✗
	Compensatory	✗	✗	✗	✗
	Compromised	✓	✓	✗	✗

Table 6.3 Pivotal Studies Demonstrating the Changing Operational Use of RAM (continued …)

	Citation	Lotus-Shyu (2000)	Nuamah *et al*. (1999)	Pollock (1993)	Silva (1987)
	Aim and Participants	Roles of caregivers and receivers at discharge (N = 28)	HRQoL theory for cancer patients (N = 375)	Adaptation to chronic illness (N = 597)	Needs of spouses of surgical patients (N = 75)
Environmental Stimuli	Focal Stimuli	✓	✓	✓	✓
	Contextual Stimuli	✓	✓	✓	✗
	Residual Stimuli	✓	✓	✓	✗
Control Processes	Regulator	✗	✗	✓	✗
	Cognator	✗	✗	✓	✗
Adaptive Modes	Physiological Mode	✗	✓	✓	✓
	Self-concept Mode	✗	✓	✓	✗
	Role Function	✓	✓	✓	✗
	Interdependence Mode	✗	✓	✓	✓
Adaptation Levels	Integrated	✗	✗	✗	✗
	Compensatory	✗	✗	✗	✗
	Compromised	✗	✗	✗	✗

PHASE 2

'Not everything that can be counted counts and not everything that counts can be counted'

Cameron (1963, p. 13).

CHAPTER 7

QUANTITATIVE METHODS

7.0 INTRODUCTION

The previous chapters covering Phase 1 of this research program highlighted the expectations of both clinical participants and partners as they travel through the BlCa trajectory. The themes derived from in-depth interviews with 20 participants were noted to resonate with Roy's Adaptation Model (RAM; Roy 1976, 1984), which is a nursing theory of adaptation to chronic illness. In order to explore further the relevance of RAM in the BlCa context, Phase 2 of this study tested applicable elements of RAM quantitatively. This chapter describes the setting, ethical considerations, participant recruitment, and instruments used in Phase 2.

7.1 DESIGN AND SETTING

Phase 2 comprised a single time point cross sectional survey which was conducted in the southern suburbs of Adelaide, South Australia. It encompasses the South Australian State Government's Southern Adelaide Local Health Network (SALHN) administrative division.

7.2 ETHICAL CONSIDERATIONS

Approval for Phase 2 was sought from and granted by both the Social and Behavioural Research Ethics Committee of Flinders University for community-based participants (Project no. 5956, Appendix E1) and the Southern Adelaide Clinic Human Research Ethics Committee (Project no. 453.11, Appendix C4, C5) for participants sourced from a hospital database. In all cases potential participants were provided with a Letter of Introduction to Participants (Appendix E2) and a Participant Information Sheet (PIS; Appendix E3) which fully outlined the purpose of the study and the participant's obligations. Informed consent was assumed when the participants returned their completed questionnaire. No concerns were raised by participants during recruitment. It was acknowledged that participants may become upset while completing the questionnaire and re-living theirs or their partner's BlCa health issues. The PIS stated that a counsellor would be arranged if required and it contained the Lifeline contact phone number.

7.3 PARTICIPANTS AND RECRUITMENT PROCEDURES

To be included in this study, participants had to be at least 18 years of age, with a confirmed diagnosis of BlCa. The spouse, other family member, or friend of the person with BlCa (partner), were also recruited. There was a requirement to be able to read and write English to allow them to understand the Information Sheet and complete the questionnaire.

Initially, participants were sourced by contacting a range of relevant community groups. Advertising materials (Appendix E4) and PIS (Appendix E3) were distributed and, where possible, a Letter of Introduction (Appendix E2.) was sent seeking permission to personally attend group meetings to present the study to members. Groups approached in this manner are summarised in Table 7.1. Equivalent study materials were also distributed to supportive private Urology clinics and one Oncology clinic.

Advertising for the study was also possible in appropriate magazines and newsletters. These were The Senior Magazine, Ileostomy Association Newsletter, S.A. 50's Lifestyle Magazine, Along the Grapevine Magazine, S.A. Country Woman's Association Magazine, Southern Health News, Research Pulse (Flinders University), the Freemasons Men's Health newsletter and the Ostomy Australia Magazine. Further advertising was undertaken through a television news item (Australian Broadcasting Commission). A number of organisations allowed the study to be promoted on their website (Freemasons Foundation Centre for Men's Health Cancer Council Australia, Adelaide Independent News (InDaily) and Flinders Centre for Innovation in Cancer.

Table 7.1 *Community Groups Approached or Sent Study Materials*

Community Groups
Ileostomy Association
Cancer Care South Australia
Aged care community recreation and meeting centres
Retired Persons Associations
Masonic Lodge
Community libraries
Bowling clubs
Over 50s clubs
Probus clubs
RSL clubs
Senior citizens clubs
Men’s sheds
Royal District Nurses Society
South Australian Urology Nurses Association
Continence Nurses Society
Independent Living Centre
Continence Resource Centre

Posters and study information were distributed to the Ileostomy association, Cancer Care SA, aged care community recreation and meeting centres, retired persons associations, Masonic Lodge, community libraries, bowling clubs, Over 50’s club, Probus clubs, RSL clubs, senior citizens clubs, Men’s Shed Organisation, Royal District Nurses Society, Continence Nurses Society, the South Australian Urology Nurses Association, Independent Living Centre, and the Continence Resource Centre.

Final recruitment involved accessing the database of a public hospital Urology department that had been the source of Phase 1 participants. Among others, this resulted in ten participants (five couples) who had participated in Phase 1 also completing the Phase 2 questionnaire. Given these distribution procedures, it is difficult to specify in every case how many questionnaires were taken by potential participants (e.g. the Ileostomy Association office). What is known is the number provided. However, Table 7.2 provides a quantification of the breakdown of participants sourced for Phase 2.

All participants were provided with a reply-paid envelope in which to return their questionnaire free of charge. Questionnaires and envelopes were coded to enable collation of dyadic responses and to track the sources of participants. To enable privacy of responses which may have been crucial to honest responding, individuals rather than couples were provided with study information and questionnaires.

Table 7.2 *Sources of the Phase 2 Participant Sample*

Source	**Questionnaires supplied**	**Questionnaires returned**	**% return rate**
Ileostomy Association	52	19	36.5
Ostomy Australia Magazine	120	87	72.5
The Senior Magazine	4	2	50.0
ABC News	4	4	100.0
Websites	20	14	70.0
Private Urologists	18	8	44.4
Oncologist	4	4	100.0
Hospital database	500	74	14.8
Phase 1 participants	16	10	62.5
Total	**738**	**222**	**30.0**

7.4 QUESTIONNAIRES

There were two questionnaires: one for the clinical participant and one for partners (Appendix E5 and E6). While similar, the Bladder Cancer Index (BCI) was not included in the latter questionnaire. Subtle word changes were required, phrases such as ‘since your partner’s (or family member’s) illness’ were substituted for ‘since your illness’. The content of the questionnaires is described in the following sections, presented according to the level of RAM the collected data was chosen to represent and is summarised in Table 7.3.

7.4.1 Demographic Information (Including RAM Input)

Clinical participants were asked their gender, age, highest level of education (nil, primary, secondary, trade, tertiary), marital status (single, married/defacto, separated, divorced, widowed), number of years married/defacto, race or ethnic identity, employment (studying, domestic duties, retired, working casual, working part-time, working full-time, self-employed) and number of years with BlCa. The partner or other family provided their gender, age, highest level of education, relationship to the person with BlCa (including caregiving relationship such as other family member or friend), number of years if married/defacto, race or ethnic identity, and employment. Finally, a single question asked clinical participants the nature of their treatment (retained native bladder; surgical intervention - ileal conduit, neo-bladder, and catheterisable pouch).

7.4.2 Input: Orientation toward the Healthcare System

The Psychological Adjustment to Illness Scale (PAIS; Derogatis 1986) was specifically developed for use with both patients and their families (Morrow *et al.* 1978, 1981). It comprises seven central domains (*Healthcare Orientation, Vocational Environment, Domestic Environment, Sex Relations, Extended Family, Social Environment*, and *Psychological Distress*). PAIS is commonly-used in studies of the psychosocial adjustment to

Table 7.3 *Operationalisation of RAM*

RAM	**Phase 1** **Themes**	**Phase 2** **Measurement**
Inputs (environmental stimuli)	**Participant's presentation:** 1) Diagnosis and information 2) Treatment and side effects 3) The nature of care 4) Discomfort	**Demographics:** Age Gender Treatment Disease duration **PAIS:** Healthcare Orientation
Biopsychosocial behavioural responses (control processes)	**Physical reactions (function):** 5) Continence matters **Cognitive reactions (burden):** 6) A life overshadowed 7) Anxiety and shock	**BCI:** Function Burden
Adaptive modes (self-concept, role function, independence modes)	**Psychosocial:** 8) Sexuality and loving 9) Public persona 10) Embarrassment and intrusiveness 11) Life supports 12) Talking it over 13) On-going needs	**PLSS:** Sex and love **PAIS:** Social environment; Domestic environment; Extended family environment
Adaption levels (integrated, compensatory, compromised)	**Adaptive Mechanisms:** 15) Acceptance 16) Having faith 17) Avoidance, denial, distancing	**Mini-MAC:** Cognitive Distress

cancer (Merluzzi & Sanchez, 1997; Northouse *et al.* 2000; Gilbar 2002; Ezer *et al*. 2006; 2011; Manos *et al*. 2009; Sherman *et al.* 2009, 2012) and in studies of kidney disease (Davison & Jhangri 2012), chronic illness (Livneh & Antonak 2005; Berg & Upchurch 2007), diabetes (Willoughby *et al*. 2000), and factor structure and item stability involving organ transplantation (Rodrigue *et al*. 2000). Such studies illustrate the reliability, validity and internal consistency of the PAIS.

For the current study, *Healthcare Orientation* (beliefs and views about healthcare and information) was used as a RAM input to allow the evaluation of encounters with the healthcare system from diagnosis through the dissemination of information, and expressed satisfaction or discomfort about treatment and side effects, and the care provided, required and received. *Healthcare Orientation* comprises eight items to which participants respond using purpose-written 4-point scales for each item that characterise experiences with health care from extremely positive to extremely negative. Higher scores (range 8-32) represent a more positive view of the healthcare system. Table 7.4 summarises *Healthcare Orientation* data for both clinical participants and partners. It should be noted that the internal consistencies (α; Cronbach 1951) failed to achieve the recommended level of 0.70 (Nunnally, 1978). However, item analysis demonstrated that, with the removal of items 1 and 2, α for both BlCa participants and their partners was able to be improved substantially (Table 7.4). Therefore, this 6-item scale was used for all analyses.

7.4.3 Coping Mechanisms: Perceptions of Function and Burden

RAM *Coping Mechanisms* are characterised as physical and cognitive reactions to negative *Input.* In the context of Phase 2, these were operationalised as the functional evaluation of the disease (physical) and perceived psychological burden of the disease (cognitive), assessed using the BCI (Gilbert *et al*. 2007, 2010). This validated instrument, applicable to both men and women, contains 36 items that assess function and burden in three domains (urinary,

Table 7.4 *Summary of PAIS Healthcare Orientation Data*

		Clinical Participants				**Partners**			
Subscale	**Theoretical range**	**Obtained range**	**Mean**	**(SD)**	**α**	**Obtained range**	**Mean**	**(SD)**	**α**
HCO (original 8-item scale)	8 - 32	14 - 32	26.7	(3.7)	.69	15 - 32	27.1	(3.1)	.61
HCO (6-item scale)	6 - 24	12 - 24	20.8	(3.1)	.76	9 - 24	20.9	(2.8)	.72

Note: *HCO = Healthcare Orientation.*

bowel, and sexual health). The BCI has demonstrated both divergent and convergent validity, internal consistency, and test-retest reliability (Gilbert *et al.* 2007, 2010; Shih & Porter 2011), including for the individual health domains. Relative independence across the domains has also been noted (Gilbert *et al.* 2007, 2010).

Responses are sought using both 4- and 5-point Likert scales that quantify the frequency and severity of physical symptoms and degree of distress, respectively, for each domain. Eleven scores have been calculated, all of which is scaled to a 0 to 100 range, with higher scores denoting better function or less perceived psychological burden (Gilbert *et al.* 2007, 2010). For each of urinary, bowel and sexual domains, a function score, burden score and total score may be calculated. Overall function and burden scores have also been calculated (Table 7.5). Internal reliabilities for all scores were very satisfactory.

Table 7.5 *Summary of Bladder Cancer Index (BCI) Scores*

Subscales	**Theoretical range**	**Obtained range**	**Mean**	**(SD)**	**α**
Urinary domain (total)	0 – 100	30 – 100	83.8	(18.2)	.88
Urinary domain (function)	0 – 100	0 – 100	78.2	(27.6)	.82
Urinary domain (burden)	0 – 100	28 – 100	86.2	(17.0)	.85
Bowel domain (total)	0 – 100	22 – 100	81.6	(15.1)	.80
Bowel domain (function)	0 – 100	25 – 100	79.2	(18.8)	.73
Bowel domain (burden)	0 – 100	17 – 100	82.7	(17.5)	.78
Sexual domain (total)	0 – 100	0 – 96	36.5	(24.5)	.90
Sexual domain (function)	0 – 100	0 – 93	23.4	(27.2)	.94
Sexual domain (burden)	0 – 100	0 – 100	54.9	(30.5)	.83
Function (total)	0 – 100	17 – 91	53.1	(15.8)	.79
Bother (total)	0 – 100	32– 100	76.9	(14.9)	.84

7.4.4 Biopsychosocial Behavioural Responses: Family and Social Dynamics

Three domains of the PAIS, as introduced in section 7.4.2, were used to operationalise the *Biopsychosocial Behavioural Responses*, or *Adaptive Modes*, of RAM. *Domestic Environment* assesses difficulties faced by having an illness and how that may relate to relationships with a partner and family, communication, the value placed on the relationships, economic issues or disability (Derogatis 1986; Merluzzi & Martinez Sanchez 1997; Sherman *et al*. 2009, 2012). There are 8 items (range 8-32). *Extended Family* enquires about any interruption to normal extended family relationships, communication and interactions due to illness. Five items provide a range of 5-20. *Social Environment* measures the individual's abilities to socialize and take part in leisure activities alone, with family or in a social setting, assessing interest and abilities (Derogatis 1986; Merluzzi & Martinez Sanchez 1997; Sherman *et al.* 2009, 2012). It comprises 6 items, with scores ranging from 6 to 24. In all cases, higher scores indicate the interpretation of a more positive social and family environment. Table 7.6 summarises these variables. For *Extended Family* as reported by partners, α was slightly lower than optimal (0.69). However, item analyses indicated that it was not possible to improve α by removing an item or items from this scale.

7.4.5 Biopsychosocial Behavioural Responses: Relationship Dynamics

The theme of *Sexuality and Loving* was highlighted by both clinical participants and partners in Phase 1. To operationalise this theme, the 17-item Perceptions of Love and Sex Scale (PLSS; Hendrick & Hendrick 2002) was used. The PLSS does not concentrate on a particular type of relationship, but rather any type of loving relationship, with *sex* referring to any physical affection although it is predominantly used with couples, during life change events such as the illness of a partner (Hendrick & Hendrick 2002; Neto, 2012). Each item is accompanied by five responses: 'strongly disagree' (1), 'disagree' (2), 'neutral' (3), 'agree' (4), 'strongly agree' (5), with items used to create four subscales. *Love Is Most Important* explores whether the emotion of love comes before everything else including sex (range 6-30). *Sex Demonstrates Love* surveys whether romantic love is expressed in a deeper sense through sex (4-20). *Love Comes Before Sex* enquires about whether love ‘drives’ sex rather than sex driving love (4-20). *Sex is Declining* simply asks whether there has been a reduction of sexual activity within the relationship (3-15).

Table 7.7 presents summary data for these four PLSS dimensions. Two observations are relevant. First, *Sex is Declining* demonstrated very poor α coefficients. Second, two subscales both emphasise the importance of love over sex. These subscales were found to correlate at 0.32 ($p < .001$) for clinical participants and 0.42 ($p < 0.001$) for partners. For these reasons, clinical participant data were subjected to a factor analysis to determine whether (1) α coefficients could all achieve a more satisfactory level, and (2) whether the items could be amalgamated more parsimoniously. The results of the factor analysis indicated that only two subscales were supported by the current data. The first (7 items; range 7-35) placed an emphasis on the multidimensional nature of love that goes beyond sex (e.g. ‘my partner and I love each other for many reasons other than sex’). This scale was termed *Love, Friendship, Affection*. The second (6 items; range 6-30) indicated the importance of sex as a physical demonstration of love (e.g. ‘when we have sex, it proves that we love each other’). This scale was termed *Sex Proves our Love*. Table 7.7 also summarises these final variables and indicates that α coefficients for both clinical participants and partners were very satisfactory.

7.4.6 Output: Adaptation to Bladder Cancer

Output(s) for the RAM model were derived from the Mini-Mental Adjustment to Cancer (Mini-MAC) Scale (Watson *et al*. 1994), which is an abridged 29 item version of the Mental Adjustment to Cancer Scale (Greer 1989; Watson *et al*. 1988). It is a reliable tool used for many cancers as it quantifies both cognitive and behavioural responses making this tool

Table 7.6 *Summary of PAIS Scores*

		Clinical Participants				Partners			
Subscales	**Theoretical range**	**Obtained range**	**Mean**	**(SD)**	**α**	**Obtained range**	**Mean**	**(SD)**	**α**
Social Environment	6 – 24	6 – 24	19.4	(5.1)	.93	6 - 24	21.0	(3.9)	.91
Domestic Environment	8 – 32	16 – 32	28.3	(3.5)	.79	19 - 32	29.1	(3.2)	.70
Extended Family Environment	5 – 20	8 – 20	18.3	(2.6)	.76	11 - 20	18.7	(2.0)	.69

Table 7.7 *Summary of PLSS Scores*

		Clinical Participants				**Partners**			
Subscales	**Theoretical range**	**Obtained range**	**Mean**	**(SD)**	**α**	**Obtained range**	**Mean**	**(SD)**	**α**
Love is Most Important	6 – 30	11 – 30	25.1	(3.4)	.75	15 – 30	24.2	(3.6)	.72
Sex Demonstrates Love	4 – 20	4 – 20	10.5	(3.9)	.87	4 – 20	10.5	(3.7)	.84
Love Comes Before Sex	4 – 20	10 – 20	15.4	(2.8)	.73	6 – 20	15.2	(3.3)	.79
Sex is Declining	3 – 15	3 – 15	8.5	(2.9)	.67	3 – 15	8.1	(2.6)	.48
Love, Friendship, Affection	7 – 35	17 – 35	28.3	(4.0)	.76	18 – 35	27.8	(4.1)	.73
Sex Proves our Love	6 – 30	6 – 30	18.0	(4.8)	.81	6 – 30	17.7	(4.6)	.76

a popular psycho-oncology measure of adaptation (Gilbar *et al*. 2005; Watson & Homewood 2008; Johansson *et al.* 2011; Hulbert-Williams *et al.* 2012; Zucca *et al.* 2010, 2012; Cieślak *et al*. 2013).The Mini-MAC comprises five subscales (*Fighting Spirit, Helplessness/Hopelessness, Anxious Preoccupation, Fatalism and Cognitive Avoidance*) of between four and eight items in length. Each item quantifies how applicable a feeling, belief or behaviour has been for respondents using a 4-point scale ('definitely does not apply', 'rarely applies', 'often applies', 'definitely applies').

The data from the current sample (Table 7.8) highlights poor internal consistencies for *Fighting Spirit* and *Fatalism* particularly. However, there are numerous alternative scoring algorithms for the Mini-MAC, including two, three, and four-dimension models (Anagnostopoulos *et al*. 2006, 2010, 2011; Kang *et al*. 2008; Capozzo *et al*. 2009, 2010; Costa-Requena & Gil 2009; Johansson *et al*. 2011; Hulbert-Williams *et al.* 2012; Cieślak *et al.* 2013; Wang *et al.* 2013; Hopman & Rijken 2015). After reviewing a number of these options, including the potential for scales to be derived specifically from the current data, the primary factor reported by Hulbert-Williams *et al.* (2012) was chosen as the sole *Output* for the RAM models to be reported.

Hulbert-Williams *et al.* (2012) describe a four-factor model, all but Factor 1 (*Cognitive Distress*) have relatively few items with substantial loadings (3-5 items). *Cognitive Distress* comprises 12 items (range 12-48), with higher scores indicative of higher distress. The items represent *Helplessness/Hopelessness* (7), *Anxious Preoccupation* (4), and *Fatalism* (1). *Cognitive Distress* has already been found to satisfactorily represent clinical participant outcomes in preliminary analyses of the current data (Heyes *et al*. 2016). Table 7.8 includes summary data for *Cognitive Distress,* indicating satisfactory α coefficients for both clinical participants and partners.

Table 7.8 *Summary of Mini-MAC Scores*

		Clinical Participants				**Partners**			
Subscales	**Theoretical range**	**Obtained range**	**Mean**	**(SD)**	**α**	**Obtained range**	**Mean**	**(SD)**	**α**
Helplessness-Hopelessness	8 – 32	8 – 26	9.9	(3.5)	.84	8 – 24	10.0	(2.8)	.73
Anxious Preoccupation	8 – 32	8 – 29	13.8	(5.0)	.80	8 – 30	15.4	(5.4)	.87
Fighting Spirit	4 – 16	4 – 16	10.8	(3.2)	.58	4 – 16	11.1	(2.4)	.37
Cognitive Avoidance	4 – 16	4 – 16	8.7	(3.6)	.78	4 – 16	8.5	(3.2)	.75
Fatalism	5 – 20	5 – 20	13.1	(3.3)	.52	5 – 20	13.4	(3.3)	.57
Cognitive Distress	12 – 48	12 – 44	16.9	(6.0)	.84	12 – 41	17.7	(5.3)	.82

7.5 DATA HANDLING

The IBM SPSS statistics 22.0 data analysis software package was used in Phase 2. Two files (one for the BlCa participants and another for their partners) were initially created but were merged using corresponding identification numbers to allow for additional dyadic analysis.

7.6 CHAPTER SUMMARY

This chapter has described the design, setting, sample, measures and ethical considerations with documented approvals, to demonstrate the rigour surrounding this single time point cross sectional study. The process of sample recruitment including various locations and means involved, and exhibits the extent of difficulties faced during the 14 months (24th April 2013 to 27th of June 2014) of recruiting sufficient numbers of participants to enable sound statistical analysis. Participants were recruited through community groups, magazines, websites, urology and oncology clinics, and a public hospital urology department database. Chapter 7 also described the Mini-MAC, PAIS, PLSS, and BCI instruments and demographic information utilized in Phase 2. These validated instruments were chosen on the basis of the Phase 1findings from interviews with 20 clinical participants and partners. The instruments were also mapped to the nursing theory of RAM to allow a quantitative model of adaptation to BlCa to potentially be described. Chapter 8 describes the statistical tests used to test RAM, and presents the results of all statistical analyses of the sample data.

CHAPTER 8

QUANTITATIVE RESULTS

8.0 INTRODUCTION

The purpose of this chapter is to describe the statistical analyses and results of Phase 2 of the research program. As described in Chapter 7, the questionnaires were completed by people with BlCa (clinical participants) and their intimate partners, a family member or friend (partners). The methods used to obtain these data were also documented in Chapter 7.

8.1 AIMS

The general aim of Phase 2 was to determine whether the qualitative findings from Phase 1 could be replicated using larger samples and structured questionnaire data. In this Chapter, the characteristics of the two samples will first be described. Second, bivariate associations among variables within each level RAM will be presented for clinical participants and their partners separately where relevant. Third, associations between variables from individuals with BlCa and their respective partners will be compared as repeated measures (dyadic) data. Finally, the degree to which the obtained data accord with RAM will be explored using multivariate Structural Equation Modelling (SEM) techniques (Kline 2016).

8.2 PARTICIPANT CHARACTERISTICS

Data were obtained from 119 people with BlCa and 103 partners. However, there were only 101 sets of couple data available for repeated measures analyses. The 103 partners comprised 98 (95.1%) spouses, 3 children (2.9%) and 2 friends (1.9%). The mean age of the clinical sample was 70.7 years (SD = 9.6; range 38 - 92). They had had BlCa (*Duration of Disease*) for between 1 and 55 years (Mean = 8.2, SD = 8.8). Treatment modalities were ileal conduit (n = 67, 56.3%), neo-bladder (n = 4, 3.4%) and catheterisable pouch (n = 3, 2.5%), while 45

(37.8%) had their native bladder. For analytical purposes, these data were compared in terms of *native bladder* (bladder retained; n = 45, 37.8%) versus bladder removed (n = 74, 62.2%). The majority of the sample were male (n = 88, 73.9%), retired (n = 85, 72.6%), described themselves as Australian, English or Caucasian (n = 97, 85.8%) and were married (n = 103, 86.6%). The length of marital relationships ranged from 3 to 64 years (Mean = 37.6, SD = 15.3). The average level of education reached was *secondary* level (n = 50, 42.4%).

The mean age of partners was 66.8 years (SD = 9.5; range 42 - 88). The majority were female (n = 77, 74.8%), retired (n = 56, 55.4%), described themselves as Australian, English or Caucasian (n = 82, 84.5%) and were married to the person to whom they provide care (n = 98, 97.0%). Relationships or married couples ranged between 3 and 64 years (Mean = 37.4, SD = 14.6). The majority of partners (n= 51, 50.5%) reported achieving *secondary* education.

8.3 ASSOCIATIONS AMONG VARIABLES WITHIN EACH RAM COMPONENT

In the following sub-sections, the associations (or differences, depending on level of measurement) among variables chosen to represent each of the components of RAM are presented. Data for both clinical participants and partners is analysed, as are comparisons between clinical participants and partners.

8.3.1 Inputs (Demographic Information and Healthcare Orientation)

Of the described demographic and disease characteristics, *Age*, *Gender*, *Bladder Outcome* (retained or removed) and *Disease Duration* were proposed as *Inputs* in the RAM model. For both clinical participants and partners, associations among or differences between, these variables are described below. The final *Input* (*Healthcare Orientation*) is also included.

For clinical participants, there was no difference between the ages of males (Mean = 71.5 years, SD = 9.4) and females (Mean = 68.6 years, SD = 9.9; $t_{(116)} = 1.46$, $p = 0.148$). Similarly, there was no difference between the ages of participants who had retained their native bladder (Mean = 71.8 years, SD = 10.9) and those who had had a surgical intervention (Mean = 70.1 years, SD = 8.7; $t_{(116)} = 0.94$, $p = 0.349$). *Age* was positively associated with *Disease Duration* ($r_{(113)} = 0.24$, $p = 0.010$). That is, older clinical participants had had BlCa for a longer time. However, there was no association between *Age* and *Healthcare Orientation* scores ($r_{(114)} = 0.12$, $p = 0.199$).

There was no difference between males (n = 34, 38.6%) and females (n = 11, 35.5%) in terms of whether they had retained their native bladder ($\chi^2_{(1)} = 0.10$, $p = 0.756$) as opposed to having it removed. Neither did males (Mean = 8.7 years, SD = 9.9) or females (Mean = 6.9 years, SD = 4.2; $t_{(111)} = 1.34$, $p = 0.182$) differ in their *Disease Duration* or their *Healthcare Orientation* scores ($t_{(113)} = 0.51$, $p = 0.611$). Males reported a mean score of 20.7 (SD = 3.1) while the female mean score was 21.0 (SD = 3.0).

Clinical participants who had retained their native bladder (Mean = 10.6 years, SD = 10.4) had a significantly longer *Disease Duration* than those who had had a surgical intervention (Mean = 6.8 years, SD = 7.3; $t_{(111)} = 2.12$, $p = 0.038$). Further, those who had retained their native bladder (Mean = 19.7, SD = 3.7) reported a significantly more negative view of the healthcare system than those who had had their bladder removed (Mean = 21.4, SD = 2.4; $t_{(113)} = 2.76$, $p = 0.008$). Finally, a significant negative correlation ($r_{(110)} = -0.27$, $p = 0.004$) indicated that healthcare dissatisfaction was associated with a longer *Disease Duration*.

For partners, there was no difference between the ages of males (Mean = 67.2 years, SD = 10.6) and females (Mean = 66.6 years, SD = 9.2; $t_{(100)} = 0.29$, $p = 0.774$). Similarly, there was no difference between the ages of partners whose clinical participant had retained their bladder (Mean = 69.0 years, SD = 11.8) and those whose bladder was removed (Mean = 65.8 years, SD = 8.2; $t_{(98)} = 1.40$, $p = 0.167$). Partner *Age* was not associated with *Disease Duration* ($r_{(96)} = 0.16$, $p = 0.124$). However, there was a significant positive correlation between partner *Age* and their reported *Healthcare Orientation* scores ($r_{(102)} = 0.31$, $p = 0.002$); older partners were more satisfied with the healthcare system they had experienced.

There was no difference between male (n = 8, 30.8%) and female partners (n = 26, 34.7%) in terms of whether their clinical participant had retained their native bladder ($\chi^2_{(1)} = 0.02$, $p = 0.903$) as opposed to having had their bladder removed. Neither did male partners (Mean = 6.6 years, SD = 4.3) or female partners (Mean = 8.0 years, SD = 8.9; $t_{(95)} = 1.04$, $p = 0.301$) differ in the duration of the disease experienced by their clinical participant. Finally, the *Healthcare Orientation* scores of male partners (Mean = 20.9, SD = 3.2) and female partners (Mean = 20.9, SD = 2.6) did not differ significantly ($t_{(101)} = 0.08$, $p = 0.934$).

For partners, the analysis of *Disease Duration* by treatment modality mirrors that conducted above for clinical participants. However, partners of clinical participants who had retained their native bladder (Mean = 19.9, SD = 3.1) reported a significantly more negative view of the healthcare system than those whose clinical participant had had a surgical intervention (Mean = 21.4, SD = 2.5; $t_{(99)} = 2.60$, $p = 0.011$). Finally, for partners, *Disease Duration* and *Healthcare Orientation* were statistically unrelated ($r_{(97)} = -0.17$, $p = 0.093$).

For relevant data (only *Healthcare Orientation*), scores were also compared within couples (as a dyad). Repeated measures (paired) *t* tests (to check for mean differences) and correlations (to check for correspondence in responding) were conducted. There was no difference between *Healthcare Orientation* scores of clinical participants (Mean = 20.8, SD = 2.9) and their partners (Mean = 20.9, SD = 2.8; $t_{(100)} = 0.35$, $p = 0.729$), with the association between responses being significantly correlated ($r_{(101)} = 0.49$, $p < 0.001$).

8.3.2 Coping Mechanisms (Perceptions of Function and Burden)

These data, from the BCI, were only applicable to clinical participants. Subscale correlations are presented in Table 8.1. While most scores are significantly associated with each other, of

Table 8.1 *Correlations among BCI Scores*

Scores	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
1 Urinary domain (total)										
2 Urinary domain (function)	.87***									
3 Urinary domain (burden)	.92***	.61***								
4 Bowel domain (total)	.37***	.21*	.41***							
5 Bowel domain (function)	.25**	.15	.28**	.77***						
6 Bowel domain (burden)	.38***	.22*	.41***	.89***	.40***					
7 Sexual domain (total)	.20*	.18*	.17	.01	-.05	.07				
8 Sexual domain (function)	.09	.07	.06	-.07	-.15	.03	.89***			
9 Sexual domain (burden)	.28**	.27**	.26**	.10	.08	.09	.82***	.46***		
10 Function (total)	.55***	.57***	.41***	.29**	.27**	.26**	.79***	.80***	.53***	
11 Burden (total)	.74***	.52***	.78***	.59***	.31***	.63***	.57***	.30**	.72***	.58***

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

interest are the relatively modest, albeit significant, associations between *Function* and *Burden* within domains. There was also a lack of significant associations between sexual domain scores and most urinary and bowel domain scores. On the basis of these correlations it was determined that the variables to be used for final testing of RAM would be, on the one hand, domain total scores (i.e. *Urinary Domain, Bowel Domain, Sexual Domain*), and on the other, total scores reflecting a functional evaluation (*Function*) of the disease and a perception of the psychological burden (*Burden*) occasioned by the disease.

8.3.3 Biopsychosocial Behavioural Responses (Family and Social Dynamics)

Correlations among *Family and Social Dynamics* variables are presented in Table 8.2 for both clinical participants and partners. For both samples, *Domestic Environment, Extended Family* and *Social Environment* provided significant positive correlations suggesting that these variables were tapping similar constructs. However, the variables describing couples' sexual relationship (*Love, Friendship, Affection* and *Sex Proves our Love*), were unrelated. Similarly, they were not related to *Domestic Environment, Extended Family* or *Social Environment* beyond a single modest positive association between *Domestic Environment* and *Love, Friendship, Affection* for clinical participants.

Results of within-dyad paired *t* tests and correlations for these variables are shown in Table 8.3. Please note that for the PLSS scales, only partners involved in an intimate relationship with their clinical participant provided responses. All variables demonstrated significant positive associations between members of the dyad. However, there were significant mean differences for *Domestic Environment* and *Social Environment*. In both cases partners reported more positive evaluations than their clinical participants had.

Table 8.2 *Correlations among Biopsychosocial Behavioural Responses*

	Clinical Participants				**Partners**			
Subscales	**1**	**2**	**3**	**4**	**1**	**2**	**3**	**4**
1 Domestic Environment								
2 Extended Family	.69***				.66***			
3 Social Environment	.73***	.66***			.68***	.67***		
4 Love, Friendship, Affection	.19*	.10	.07		-.10	-.13	-.10	
5 Sex Proves our Love	.06	-.10	.02	-.06	-.04	-.08	-.06	-.05

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 8.3 *Score Comparisons between Clinical Participants and Partners for Biopsychosocial Behavioural Responses*

	Clinical Participants		**Partners**			
	Mean	**(SD)**	**Mean**	**(SD)**	***t* (paired)**	***r***
Domestic Environment	28.4	(3.4)	29.2	(3.0)	2.27*	.49***
Extended Family	18.4	(2.5)	18.8	(1.9)	1.37	.43***
Social Environment	19.7	(4.8)	21.2	(3.7)	3.89***	.61***
Love, Friendship, Affection	28.3	(4.1)	27.8	(4.1)	1.12	.41***
Sex Proves our Love	18.1	(4.9)	17.7	(4.6)	0.64	.24*

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

8.3.4 Output (Cognitive Distress)

As documented in Chapter 7, *Output* was operationalised as *Cognitive Distress,* as described by Hulbert-Williams *et al*. (2012). A within-dyad paired *t* test and correlation for this variable are presented in Table 8.4. There was a moderate significant positive correlation between the responses of clinical participants and their partners, but no mean difference in responding.

8.4 ASSOCIATIONS BETWEEN RAM COMPONENTS

This section documents the associations (or differences) between each of the components of RAM using the variables chosen to operationalise each component. Data for both clinical participants and partners is analysed separately. The goal was to determine those elements of the RAM components that may later contribute to the final models to be tested (section 8.5).

8.4.1 Inputs, Coping Mechanisms, Biopsychosocial Behavioural Responses, Output

For clinical participants, analyses between RAM *Inputs* and all other proposed components are presented in Table 8.5. Age was not a key variable, with no significant results evident. Longer disease durations were associated with higher *Cognitive Distress* and a poorer view of the *Social Environment*. *Disease Duration* did not provide any further significant results. *Healthcare Orientation* was more important, being negatively associated with *Cognitive Distress,* and positively related to *Domestic Environment, Extended Family, Social Environment, Love, Friendship, Affection,* total *Urinary Domain* and *Bowel Domain* scores, and overall *Burden*. These results suggest that a more positive view of the healthcare system was associated with a more positive view of BlCa, relationships and psychological wellbeing.

Significant gender effects were noted for *Social Environment* and *Sex Proves our Love*. Females (Mean = 21.0, SD = 3.6) had a more positive view of the *Social Environment* than males (Mean = 18.9, SD = 5.4), while males were more likely to endorse *Sex Proves our Love* (Mean = 18.9, SD = 4.6) than females (Mean = 15.1, SD = 4.2).

Table 8.4 *Score Comparisons between Clinical Participants and Partners for Output*

	Clinical Participants		**Partners**			
	Mean	**(SD)**	**Mean**	**(SD)**	***t* (paired)**	***r***
Cognitive Distress	16.9	(6.2)	17.5	(5.3)	0.85	.39***

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 8.5 *Correlations and t test Results between Inputs and Coping Mechanisms, Biopsychosocial Behavioural Responses and Outputs for Clinical Participants*

	Age	**Disease Duration**	**HCO**	**Gender**	**Bladder removed**
Cognitive Distress	.06	.27**	-.48***	0.02	2.03*
Domestic Environment	.09	.01	.56***	0.46	0.32
Extended Family	.13	-.04	.43***	1.47	2.09*
Social Environment	-.02	-.24**	.51***	2.48*	1.84
Love, Friendship, Affection	.00	.08	.22*	0.24	1.07
Sex Proves our Love	.08	-.05	-.01	3.84***	0.41
Urinary Domain	.11	-.16	.43***	0.61	0.13
Bowel Domain	.02	-.08	.25**	0.24	0.98
Sexual Domain	-.27**	-.12	.03	0.61	0.89
Function	-.27**	-.16	.13	0.31	0.86
Burden	.05	-.17	.40***	1.23	0.76

Notes: $^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$;
HCO = Healthcare Orientation.

Clinical participants with their own bladder differed from those who had had their bladder removed in terms of Cognitive Distress and *Extended Family*. They reported higher *Cognitive Distress* (Mean = 18.3, SD = 6.7 vs. Mean = 16.0, SD = 5.4), and a poorer view of *Extended Family* (Mean = 17.6, SD = 2.9 vs. Mean = 18.7, SD = 2.4).

Analyses for partners are shown in Table 8.6. Partners' *Age* was negatively correlated with *Cognitive Distress,* indicating that lower distress was associated with increasing *Age*. Positive correlations between *Age* and both *Extended Family* and *Social Environment* suggest a more positive view of these *Family and Social Dynamics* variables with increasing *Age*. The length of time that their clinical participant had had BlCa (*Disease Duration*) was unrelated to other RAM components for partners.

Table 8.6 *Correlations and t test Results between Inputs and Biopsychosocial Behavioural Responses and Outputs for Partners*

	Age	**Disease Duration**	**HCO**	**Gender**	**Bladder removed**
Cognitive Distress	-.20*	-.04	-.21*	1.36	1.32
Domestic Environment	.16	-.07	.56***	0.47	1.20
Extended Family	.19*	-.04	.44***	1.06	1.03
Social Environment	.22*	-.06	.45***	0.36	1.99*
Love, Friendship, Affection	.16	.06	.04	0.95	0.27
Sex Proves our Love	.16	.10	.01	0.53	2.75**

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$;
HCO = Healthcare Orientation.

Healthcare Orientation was negatively associated with *Cognitive Distress*, and positively related to *Domestic Environment, Extended Family*, and *Social Environment*. These results mirrored those for clinical participants, with a more positive view of the healthcare system being associated with a more positive view of relationships and psychological wellbeing.

There were no gender differences for any of the RAM components illustrated in Table 8.6. However, partners whose clinical participant had retained their bladder (Mean = 20.2, SD =

4.3) had a significantly poorer view of the *Social Environment* than partners whose clinical participant had had their bladder removed (Mean = 21.7, SD = 3.3). The former (Mean = 19.5, SD = 4.0) were also more likely than the latter (Mean = 16.8, SD = 4.6) to endorse *Sex Proves our Love*. No other significant differences were noted.

8.4.2 Coping Mechanisms, Biopsychosocial Behavioural Responses, Output

Associations between *Cognitive Distress* (*Output*), *Family and Social Dynamics* variables (*Biopsychosocial Behavioural Responses*) and perceptions of *Function* and *Burden* (*Coping Mechanisms*) are shown in Table 8.7 for clinical participants. For *Cognitive Distress*, significant negative correlations were identified for *Urinary* and *Bowel Domain* scores, but not *Sexual Domain*. Higher *Cognitive Distress* was reported by clinical participants who noted greater problems in the *Urinary* and *Bowel Domains*. These findings were replicated for total *Function* and *Burden* scores such that more substantial functional problems and greater perceived *Burden* were both associated with higher *Cognitive Distress.*

There was a consistent pattern of results for *Domestic Environment, Extended Family* and *Social Environment*. Significant positive correlations were obtained across all variables assessing perceptions of *Function* and *Burden*, with greater functional deficits and higher perceived burden being associated with a poorer evaluation of the *Family and Social Dynamic. Extended Family* with *Bowel Domain* was the only exception. Variables concerning love and sex were not related to perceptions of *Function* and *Burden.*

While *Coping Mechanisms* data (*Function* and *Burden*) were only provided by clinical participants, their associations with partner data were nevertheless examined to determine whether they influenced partner cognitions. Results appear in Table 8.8. *Cognitive Distress* was higher among partners whose clinical participant reported higher *Burden,* particularly in the *Urinary Domain*. Higher *Burden* was also associated with poorer perceptions of the

Table 8.7 *Correlations between Coping Mechanisms and Biopsychosocial Behavioural Responses and Outputs for Clinical Participants*

	Urinary Domain	**Bowel Domain**	**Sexual Domain**	**Function**	**Burden**
Cognitive Distress	$-.35^{***}$	$-.35^{***}$	-.18	$-.31^{***}$	$-.42^{***}$
Domestic Environment	$.49^{***}$	$.28^{**}$	$.20^{*}$	$.35^{***}$	$.49^{***}$
Extended Family	$.30^{**}$	.17	$.19^{*}$	$.25^{**}$	$.32^{***}$
Social Environment	$.34^{***}$	$.28^{**}$	$.26^{**}$	$.29^{**}$	$.44^{***}$
Love, Friendship, Affection	.10	.08	-.10	.05	-.04
Sex Proves our Love	.03	-.11	.10	.08	.01

Notes: $^{*}p < 0.05$; $^{**}p < 0.01$; $^{***}p < 0.001$.

Domestic Environment and *Social Environment*. The latter was also evident for the *Urinary Domain*. Partners whose clinical participant reported greater problems with the *Sexual Domain* were more likely to endorse that *Sex Proves our Love*.

8.4.3 Biopsychosocial Behavioural Responses and Output

Table 8.9 presents correlations between *Cognitive Distress* (*Output*) and all *Family and Social Dynamics* variables (*Biopsychosocial Behavioural Responses*). Substantial significant negative associations held for *Domestic Environment, Extended Family* and *Social Environment*, demonstrating that clinical participants were experiencing lower *Cognitive Distress* if they perceived a more positive *Family and Social dynamic*. This pattern did not hold for either *Love, Friendship, Affection* or *Sex Proves our Love* which were not related to *Cognitive Distress*. These results were largely replicated for partners (Table 8.10), although the significant correlations were more modest.

8.5 TESTING RAM USING STRUCTURAL EQUATION MODELLING

The final goal of the quantitative results section is to attempt to *fit* the data to RAM. Structural Equation Modelling (SEM; Kline 2016) was used for this purpose, conducted using the AMOS algorithms available within SPSS (version 22). The models presented were informed by both theory and the bivariate analyses summarised in sections 8.3 and 8.4. A range of goodness-of-fit indices are reported as is the usual recommendation, as each provides a separate qualitative commentary on the model (Hu & Bentler 1999; Hooper *et al*. 2008; Kline 2016). Table 8.11 summarises the indices used. While thresholds for acceptable model-fit are noted, these are considered *rules of thumb* at best.

Models are presented alternately and separately for clinical participants and partners. Within each sample, a scaffolding strategy is used. First, associations that link *Biopsychosocial Behavioural Responses* to *Output* are reported. Second, models of *Coping Mechanisms* to

Table 8.8 *Correlations between Coping Mechanisms and Biopsychosocial Behavioural Responses and Outputs for Partners*

	Urinary Domain	**Bowel Domain**	**Sexual Domain**	**Function**	**Burden**
Cognitive Distress	-.21*	-.19	-.09	-.14	-.26**
Domestic Environment	.19	.08	.14	.15	.20*
Extended Family	.08	.19	.03	.09	.11
Social Environment	.25*	.15	.13	.10	.33***
Love, Friendship, Affection	.03	-.08	-.19	-.10	-.14
Sex Proves our Love	.01	-.07	.21*	.12	.09

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 8.9 *Correlations between Biopsychosocial Behavioural Responses and Outputs for Clinical Participants*

	Domestic Environment	**Extended Family**	**Social Environment**	**Love, Friendship, Affection**	**Sex Proves our Love**
Cognitive Distress	$-.60^{***}$	$-.49^{***}$	$-.56^{***}$	-.05	-.02

Notes. * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 8.10 *Correlations between Biopsychosocial Behavioural Responses and Outputs for Partners*

	Domestic Environment	**Extended Family**	**Social Environment**	**Love, Friendship, Affection**	**Sex Proves our Love**
Cognitive Distress	$-.33^{***}$	$-.35^{***}$	$-.48^{***}$	.14	.07

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Table 8.11 *Goodness of Fit Indices Reported*

Index	**Name**	**Threshold Level**
Absolute Fit Indices		
χ^2	Chi-square	Non-significant (> .05)
χ^2/df	Relative Chi-square	5:1 adequate 2:1 or 3:1 good
RMSEA	Root Mean Square Error of Approximation	< .08 adequate < .05 good < .03 excellent
Incremental Fit Indices		
NFI	Normed-fit Index	> .90 adequate > .95 excellent
TLI	Tucker-Lewis Index	> .90 adequate > .95 excellent
CFI	Comparative Fit Index	> .90 adequate > .95 excellent

Notes: *Cited threshold levels obtained from Hu and Bentler (1999), Hooper et al. (2008) and Kline (2016)*

Biopsychosocial Behavioural Responses to *Output* are presented. Finally, full models acknowledging all RAM levels (*Inputs* to *Coping Mechanisms* to *Biopsychosocial Behavioural Responses* to *Output*) are documented.

All models are displayed diagrammatically. Path coefficients are standardised, with significant paths (⟶) and covariances (⟷) indicated at $p < .05$ (*), $p < .01$(**) and $p < .001$ (***). Non-significant paths (----->) are shown if their inclusion improved overall fit. Otherwise, non-significant paths that were evaluated for inclusion and demonstrated not to contribute to the model have been removed to improve interpretation. For the same reason, error terms attached to both latent and endogenous variables are not shown.

8.5.1 Biopsychosocial Behavioural Responses to Output

To reiterate, the proposed *Output* of RAM is *Cognitive Distress*. The B*iopsychosocial Behavioural Responses* (*Family and Social Dynamics*) comprise *Domestic Environment, Extended Family* and *Social Environment*, and *Love, Friendship, Affection* and, *Sex Proves our Love*. It was proposed to treat these two sets of indicators as latent variables. In the case of *Family and Social Dynamics*, the three measured variables were significantly correlated with each other (Table 8.2) for both clinical participants and partners. Latent variable loadings were .93 (*Domestic Environment*), .80 (*Extended Family*) and .83 (*Social Environment*) for clinical participants and .82, .81 and .83 for partners. However, *Love, Friendship, Affection* and *Sex Proves our Love* were unrelated (Table 8.2). Further, they showed only very occasional associations with variables chosen to represent other levels of RAM (Tables 8.5 to 8.10). The use of these variables would also reduce the available sample size for multivariate analyses as they have only been answered by partners sharing an intimate relationship with their clinical participant. For these reasons, *Love, Friendship, Affection* and *Sex Proves our Love* were not considered further in the application of RAM. Therefore, the *Family and Social Dynamics* latent variable was the only operationalisation of B*iopsychosocial Behavioural Responses*.

Figures 8.1a and 8.1b display the simple relationship between *Family and Social Dynamics* and *Cognitive Distress* for clinical participants and partners, respectively. The figures further demonstrate the robust nature of the *Family and Social Dynamics* latent variable and its strong significant association with *Cognitive Distress*, particularly for clinical participants. Those with a more positive view of their family and social circumstances expressed less distress. Given the modest nature of these early ‘models’, no fit indices were calculated.

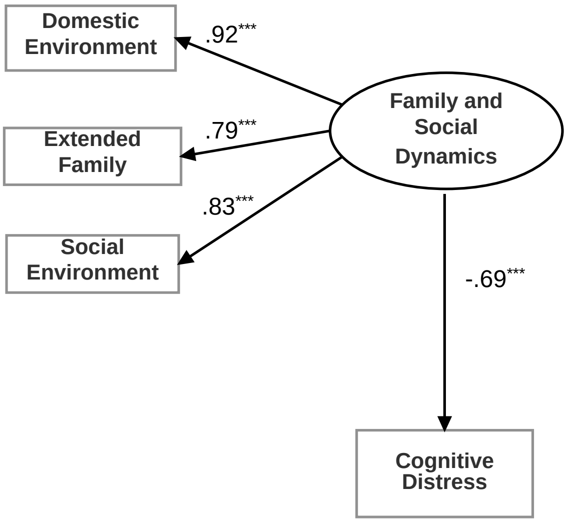


Figure 8.1a *Family and Social Dynamics to Cognitive Distress: Clinical Participants*

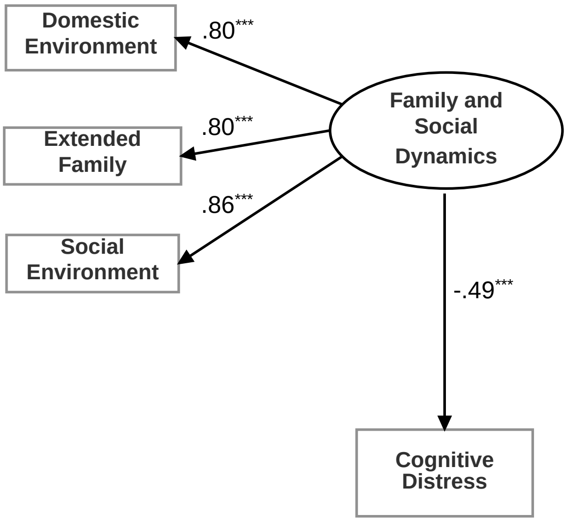


Figure 8.1b *Family and Social Dynamics to Cognitive Distress: Partners*

8.5.2 Coping Mechanisms to Biopsychosocial Behavioural Responses to Output

Step two was to introduce the predictive power of *Coping Mechanisms*. *Function* and *Burden* (globally and for individual domains), and total *Urinary, Bowel* and *Sexual Domain* scores were used in turn to represent *Coping Mechanisms*. Goodness-of-fit indices for clinical participants are presented in Table 8.12. The first four models (Figures 8.2.a to 8.5a) demonstrate the effect of *Function* and *Burden* assessed first with a *Global* measure, and then for each of the *Urinary, Bowel* and *Sexual Domains*. The proposition was that the evaluation of *Function* would predict the psychological evaluation of *Burden*, while both *Function* and *Burden* may impact on *Family and Social Dynamics* and *Cognitive Distress,* respectively.

Table 8.12 *Goodness of Fit Indices for Coping Mechanisms to Output: Clinical Participants*

Scales used	χ^2	**df**	***p***	χ^2**/df**	**TLI**	**NFI**	**CFI**	**RMSEA**
Global Scores	4.02	7	.778	0.57	1.000	.987	1.000	.000
Urinary Domain	7.65	7	.364	1.09	.994	.976	.998	.028
Bowel Domain	11.91	7	.104	1.70	.944	.958	.981	.076
Sexual Domain	4.24	7	.752	0.61	1.000	.984	1.000	.000
All Domains	9.94	10	.446	0.99	1.000	.967	1.000	.000

Notes: *RMSEA is zero and CFI and TLI are one when the* χ^2 *value is less than df.*

The *Urinary Domain* provided very satisfactory goodness-of-fit figures, while the *Bowel Domain* model was adequate. However, the *Global* and *Sexual Domain* indices are problematic. Jöreskog (1993) suggests that χ^2/df figures of less than one indicate ‘overfitting’. That is, the model may include parameters that reflect random error rather than a real effect. Given the differences in fit across models, which differ only subtly in the nature of the *Function* and *Burden* measures used, this seems a plausible interpretation.

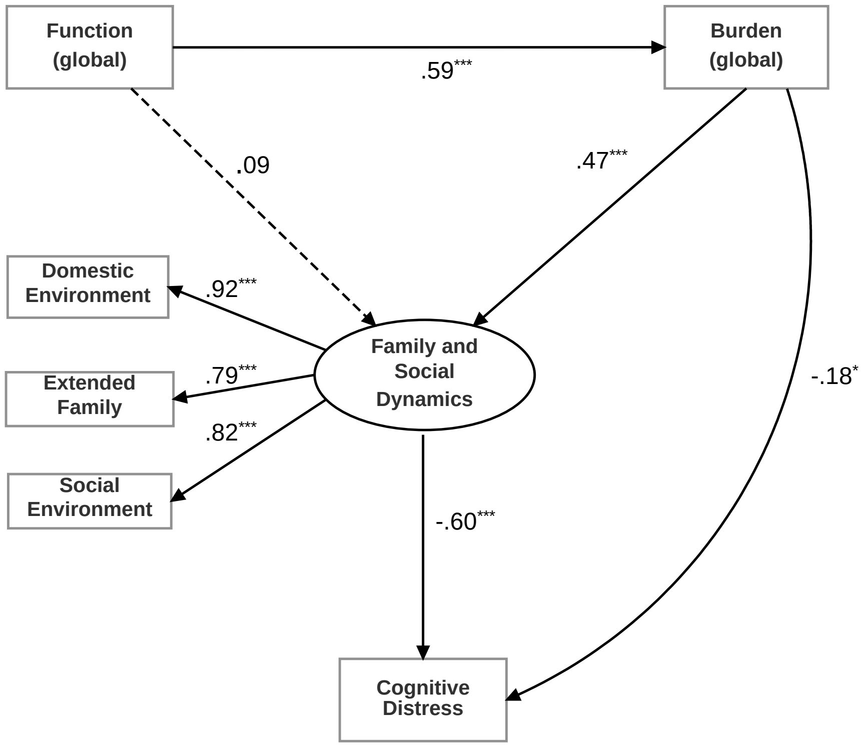


Figure 8.2a *Global Coping Mechanisms to Cognitive Distress: Clinical Participants*

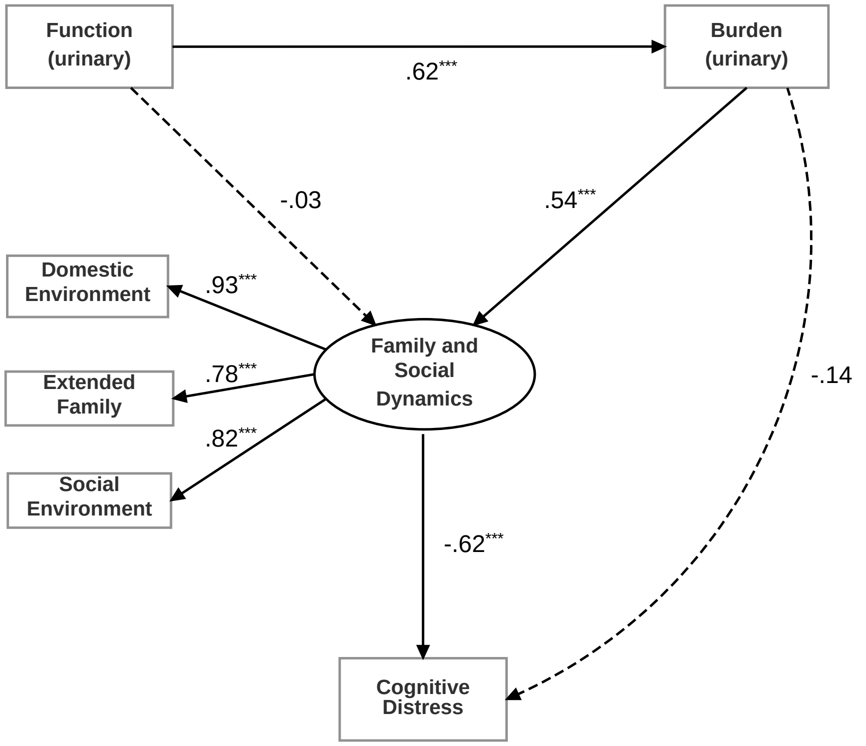


Figure 8.3a *Urinary Coping Mechanisms to Cognitive Distress: Clinical Participants*

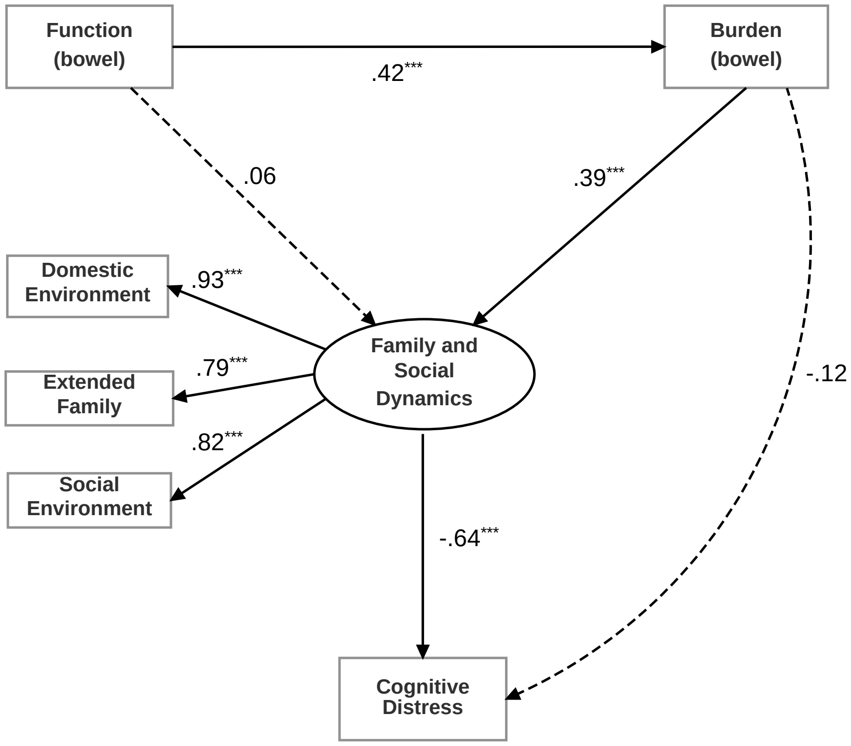


Figure 8.4a *Bowel Coping Mechanisms to Cognitive Distress: Clinical Participants*

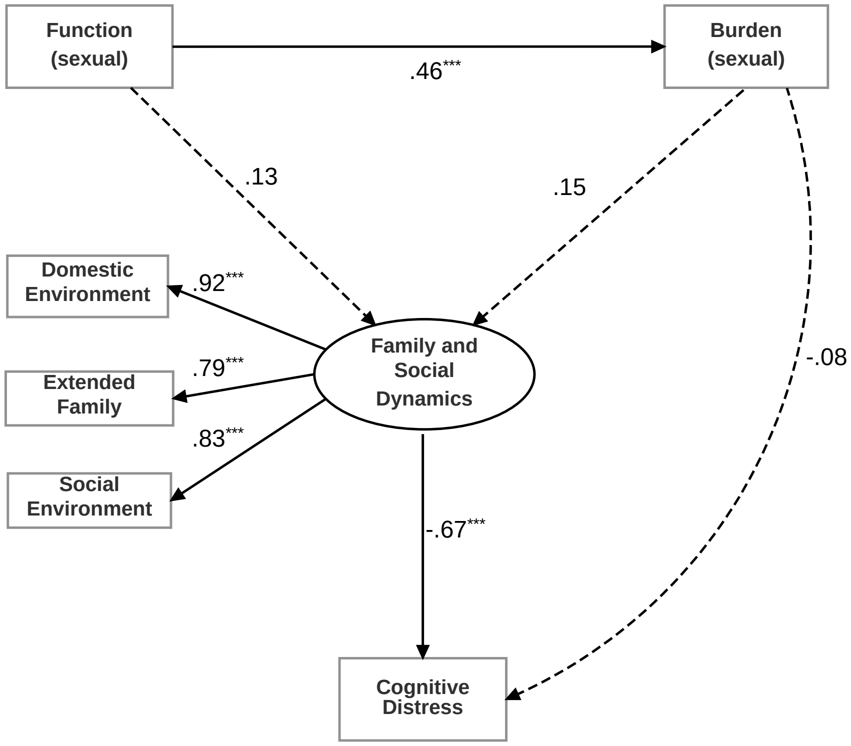


Figure 8.5a *Sexual Coping Mechanisms to Cognitive Distress: Clinical Participants*

Nevertheless, what can be gained from these models is a likely mediation effect of *Function* on *Family and Social Dynamics* through *Burden*. There appears to be no direct effect of *Function* on either *Family and Social Dynamics* or *Cognitive Distress*, while the direct effect of *Burden* on *Cognitive Distress* is equivocal (but extremely modest at best).

The fifth model (Figure 8.6a) demonstrates a different approach with total *Urinary, Bowel* and *Sexual Domain* scores used which combine *Function* and *Burden* evaluations. Again, a χ^2/df index of less than one was noted suggesting caution in the interpretation of this model. However, on face value, all *Domains* demonstrated significant direct effects to *Family and Social Dynamics* (and thus mediated effects to *Cognitive Distress*), while *Bowel Domain* showed a direct effect to *Cognitive Distress*. Note that *Inputs* were not added to this final model option (see section 8.5.3). Predictors of variables for which there are covariances indicated (e.g. between domains in this instance) are not permissible.

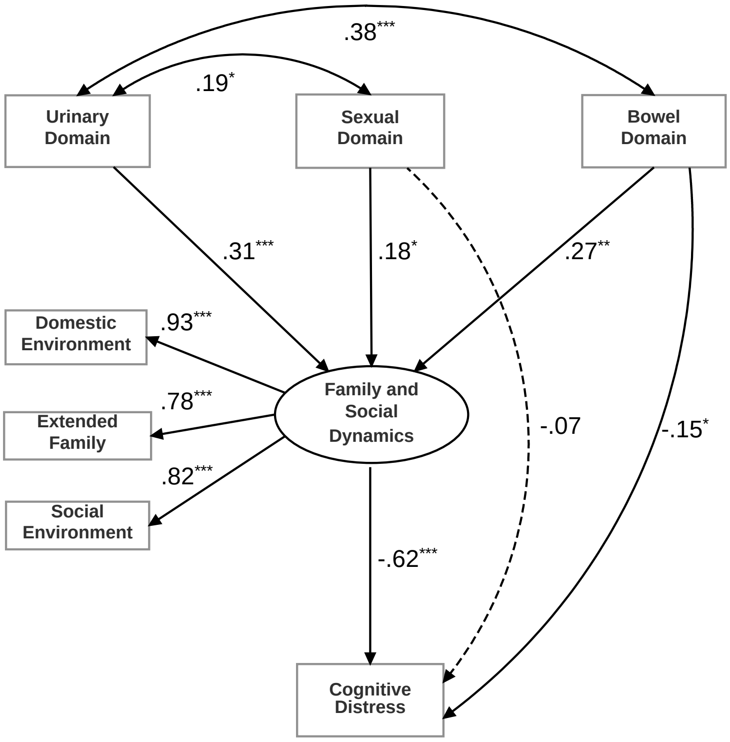


Figure 8.6a *All Domains Coping Mechanisms to Cognitive Distress: Clinical Participants*

These models were then repeated using the data from partners. However, *Function* and *Burden* measures were those of the clinical participants under the premise that their disease evaluations may impact on their partner's interpretation of *Family and Social Dynamics* and/or *Cognitive Distress*. Table 8.13 presents fit indices. In this instance all models produced valid indices, although the models themselves differed from those of clinical participants in that *Function* was not relevant. That is, while the Burden expressed by clinical participants impacted on their partners, *Function* did not.

Table 8.13 *Goodness of Fit Indices for Coping Mechanisms to Output: Partners*

Scales used	χ^2	**df**	***p***	χ^2**/df**	**TLI**	**NFI**	**CFI**	**RMSEA**
Global Burden	9.19	4	.057	2.30	.884	.950	.967	.104
Urinary Burden	9.21	4	.056	2.30	.882	.949	.969	.104
Bowel Burden	5.38	4	.250	1.35	.968	.970	.991	.054
Sexual Burden	8.30	4	.081	2.08	.899	.952	.973	.095
All Domains	12.78	11	.308	1.16	.976	.941	.991	.037

The relevant models are shown in Figures 8.2b to 8.5b. *Global Burden*, *Urinary Burden* and *Bowel Burden* produced essentially the same model. There was a direct effect of *Burden* on *Family and Social Dynamics* (and hence a mediated effect from *Burden to Cognitive Distress*) and a non-significant direct effect from *Burden* to *Cognitive Distress*. The direct effect of *Sexual Burden* on *Family and Social Dynamics* failed to achieve significance. As shown in Table 8.13, goodness-of-fit indices for these models, particularly non-significant χ^2, the χ^2/df ratio, NFI and CFI, are very satisfactory.

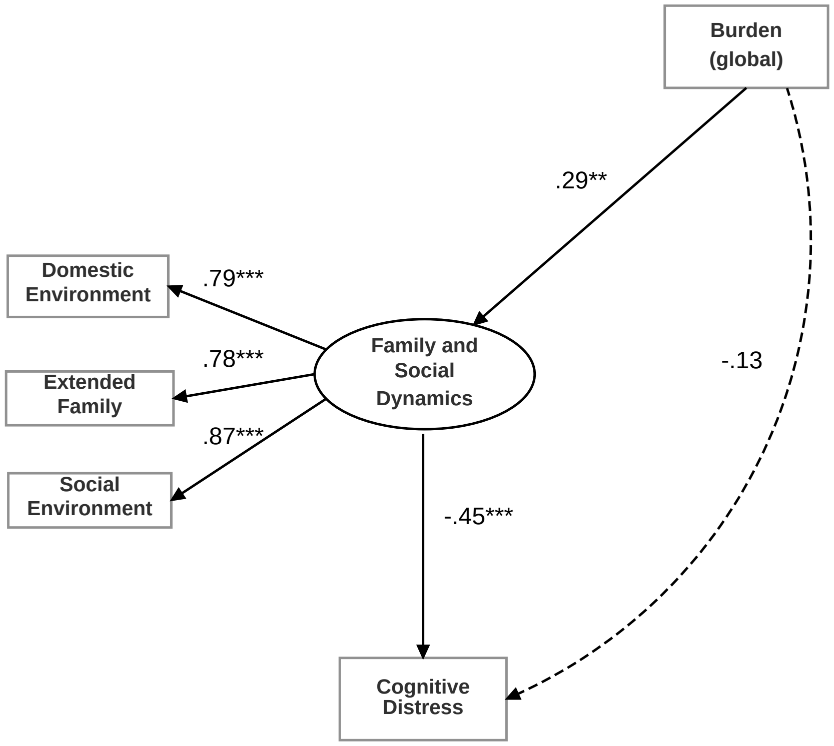


Figure 8.2b *Global Coping Mechanisms to Cognitive Distress: Partners*

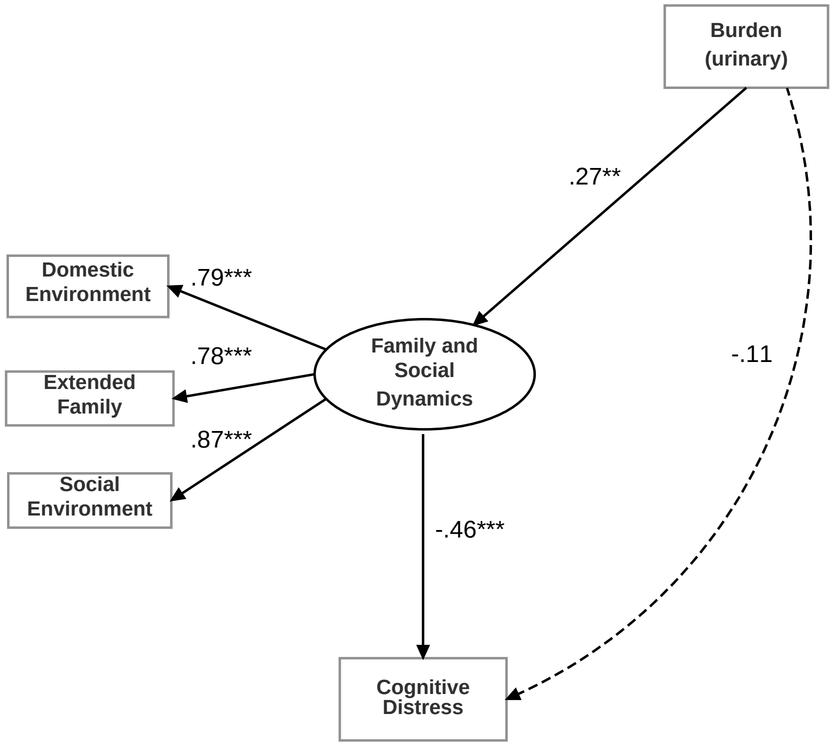


Figure 8.3b *Urinary Coping Mechanisms to Cognitive Distress: Partners*

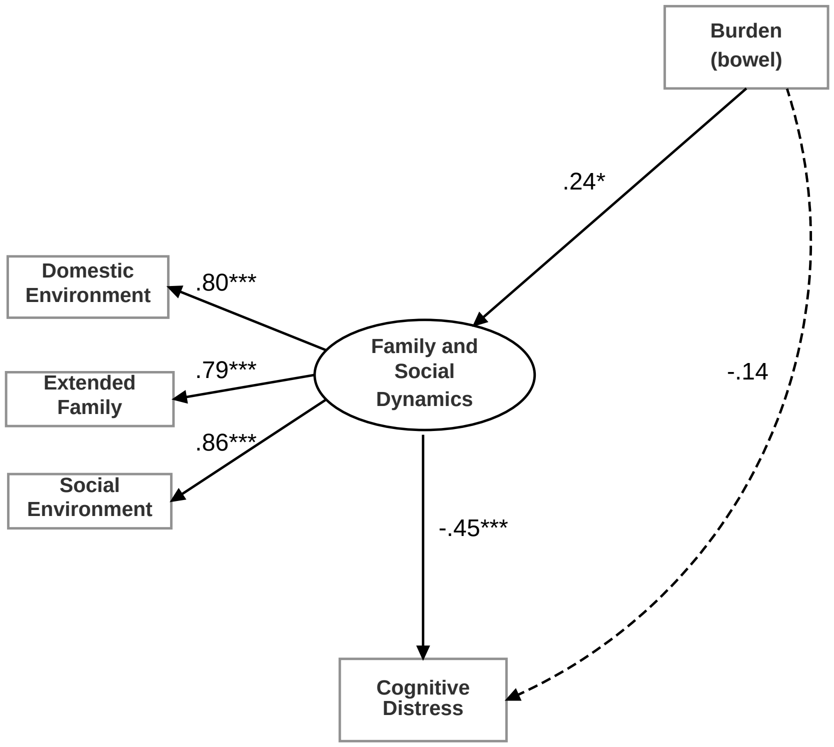


Figure 8.4b *Bowel Coping Mechanisms to Cognitive Distress: Partners*

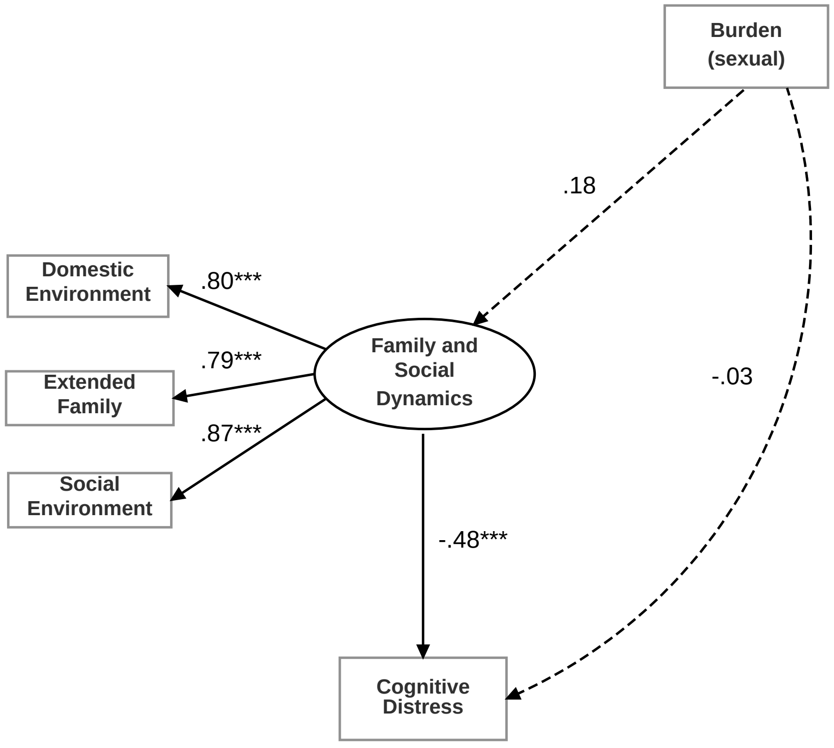


Figure 8.5b *Sexual Coping Mechanisms to Cognitive Distress: Partners*

The final model for partners (Figure 8.6b) included total *Urinary, Bowel* and *Sexual Burden* scores. Note again that unlike for clinical participants, *Function* scores were omitted due to their lack of significance to partners. While indices were almost universally indicative of a good fitting model (Table 8.13), none of the key paths achieved significance beyond the established link between *Family and Social Dynamics* and *Cognitive Distress*, and the covariances between *Urinary Burden* and *Sexual Burden* and *Bowel Burden*, respectively.

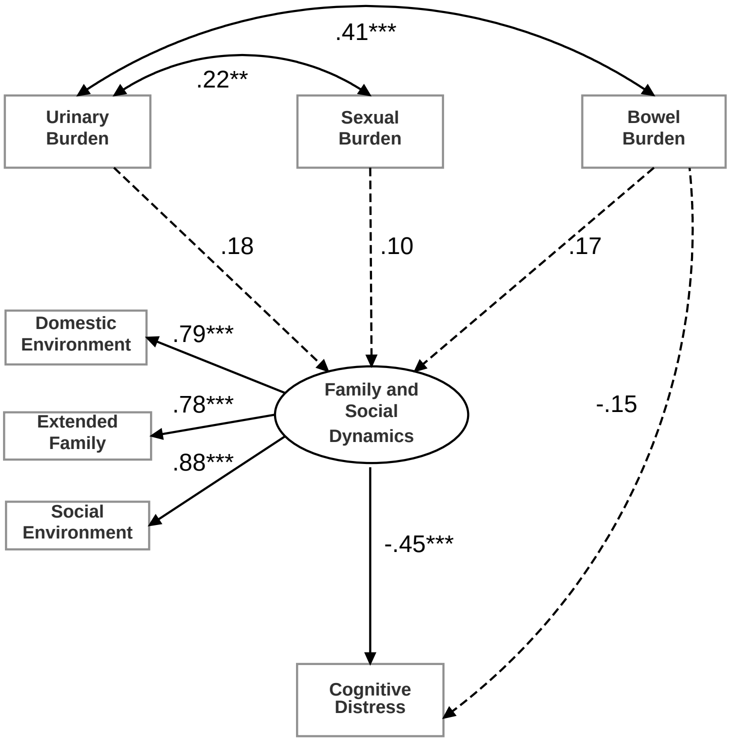


Figure 8.6b *All Domains Coping Mechanisms to Cognitive Distress: Partners*

8.5.3 Inputs to Output: Evaluating all RAM Levels

While the preceding sections provide informative precursor details, of key interest is the testing of models that include representative variables of all four levels of RAM. The *Inputs* for clinical participants found to augment the above models were *Age*, *Health Care Orientation* and *Disease Duration*. Table 8.14 presents goodness-of-fit indices for the final clinical participant models for *Global* scores, and *Urinary, Bowel* and *Sexual Domain* scores, respectively. In all cases valid indices have been produced, with *Sexual Domain* scores providing the best fit, as only NFI fell into the 'adequate' range. Otherwise, this model suggests excellent fit (Figure 8.10a). The *Global* model (Figure 8.7a) is adequate, as is that containing *Bowel Domain* scores (Figure 8.9a). The *Urinary Domain* model (Figure 8.8a) is relatively poor, with a significant χ^2 value, low TLI, relatively low NFI, and high RMSEA.

Table 8.14 *Goodness of Fit Indices for Inputs to Output: Clinical Participants*

Scales used	χ^2	**df**	***p***	χ^2**/df**	**TLI**	**NFI**	**CFI**	**RMSEA**
Global Scores	31.94	22	.078	1.45	.946	.925	.974	.061
Urinary Domain	41.72	22	.007	1.90	.892	.901	.947	.086
Bowel Domain	32.99	22	.062	1.50	.930	.910	.966	.065
Sexual Domain	25.40	22	.278	1.15	.979	.933	.990	.036

Considering these models as a whole, there are a number of significant direct and indirect paths to *Cognitive Distress* indicated that accord with both theory and the themes that emerged in Phase 1 of this research program and are therefore worthy to highlight. First, significant covariances were noted at the *Inputs* level between *Disease Duration* and both *Health Care Orientation* and *Age* (the latter being unsurprising) in all models, while *Age* and *Health Care Orientation* were unrelated. The direct effects to *Cognitive Distress* implied in these models comprise very strong associations for *Family and Social Dynamics* (all models) and *Disease Duration* (all models, although modest).

Further, the significant indirect effects (mediated paths) to *Cognitive Distress* were *Function* to *Family* and *Social Dynamics* (*Sexual Domain* only), *Function* to *Burden* to *Family and Social Dynamics* (all models except the *Sexual Domain*), *Age* to *Function* to *Family and*

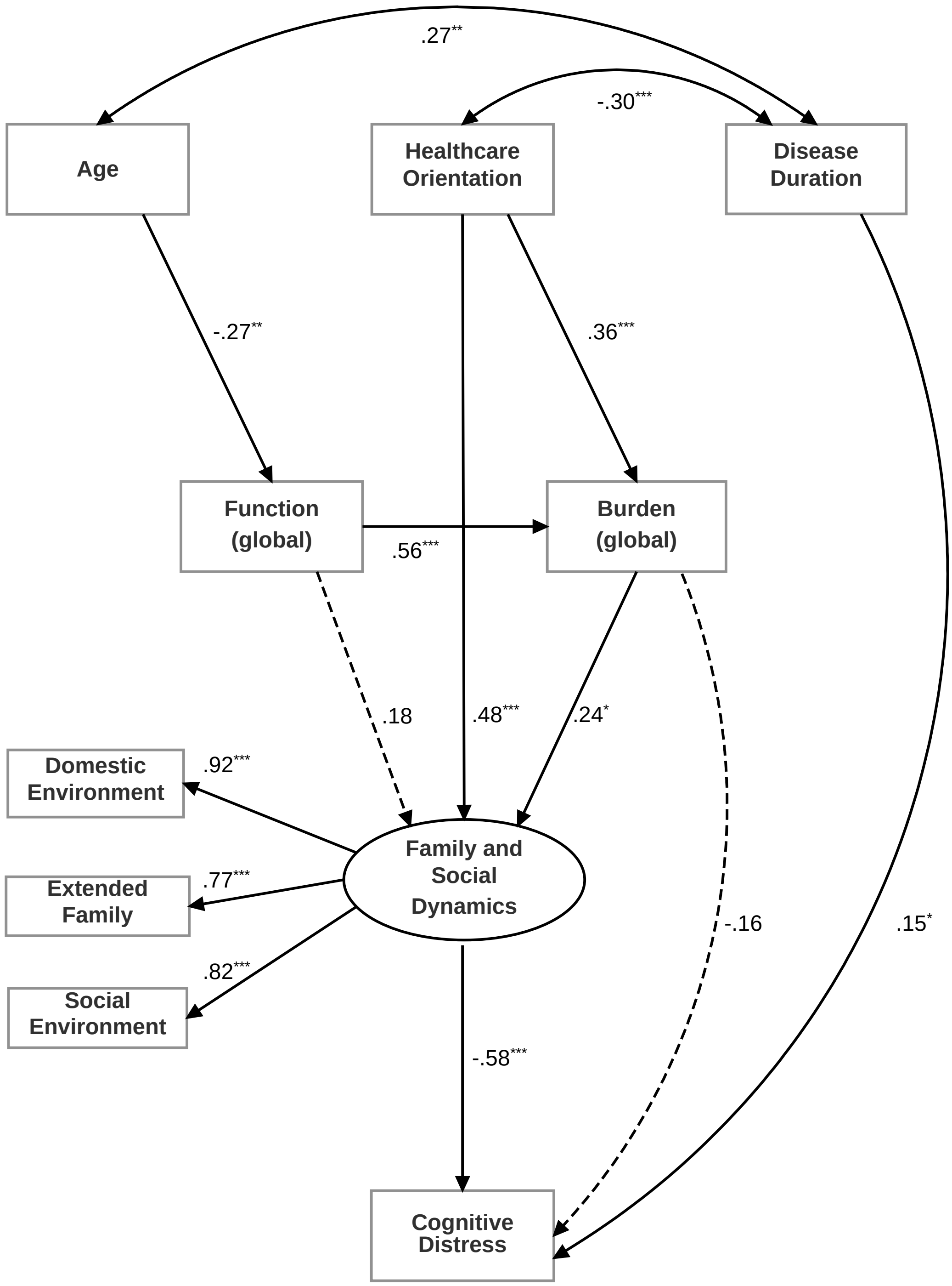


Figure 8.7a *Inputs to Cognitive Distress with Global Coping Mechanisms: Clinical Participants*

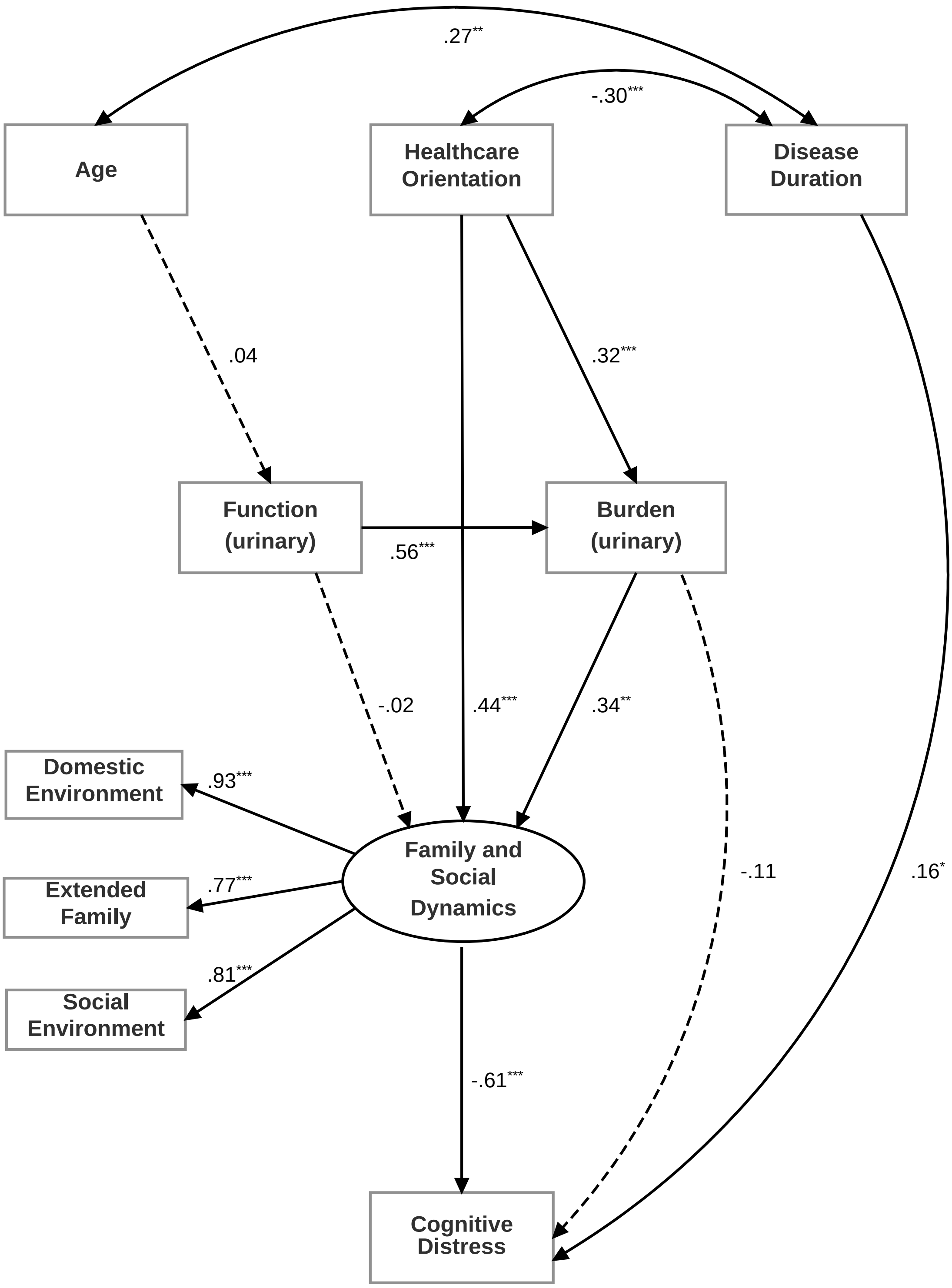


Figure 8.8a *Inputs to Cognitive Distress with Urinary Coping Mechanisms: Clinical Participants*

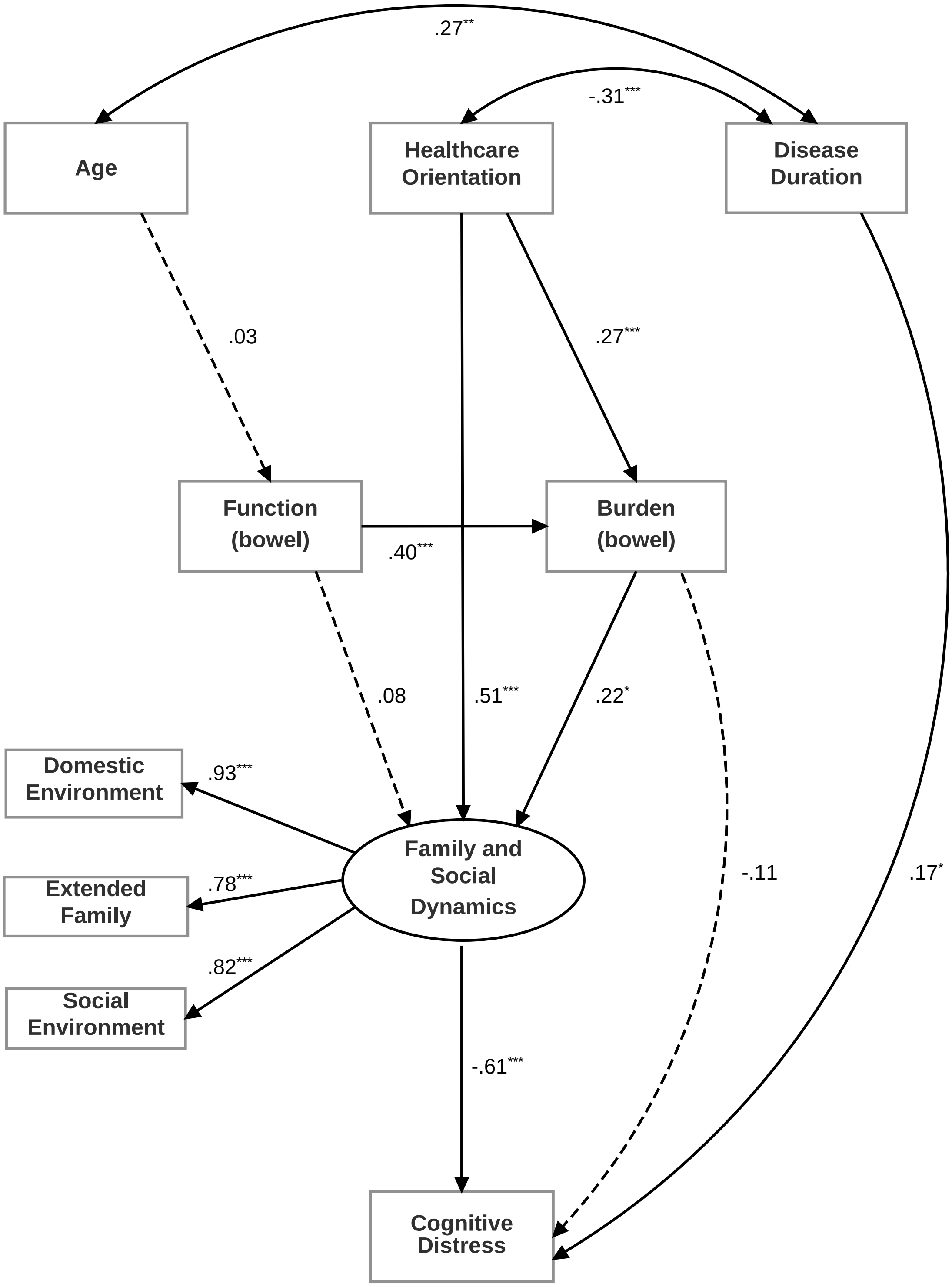


Figure 8.9a *Inputs to Cognitive Distress with Bowel Coping Mechanisms: Clinical Participants*

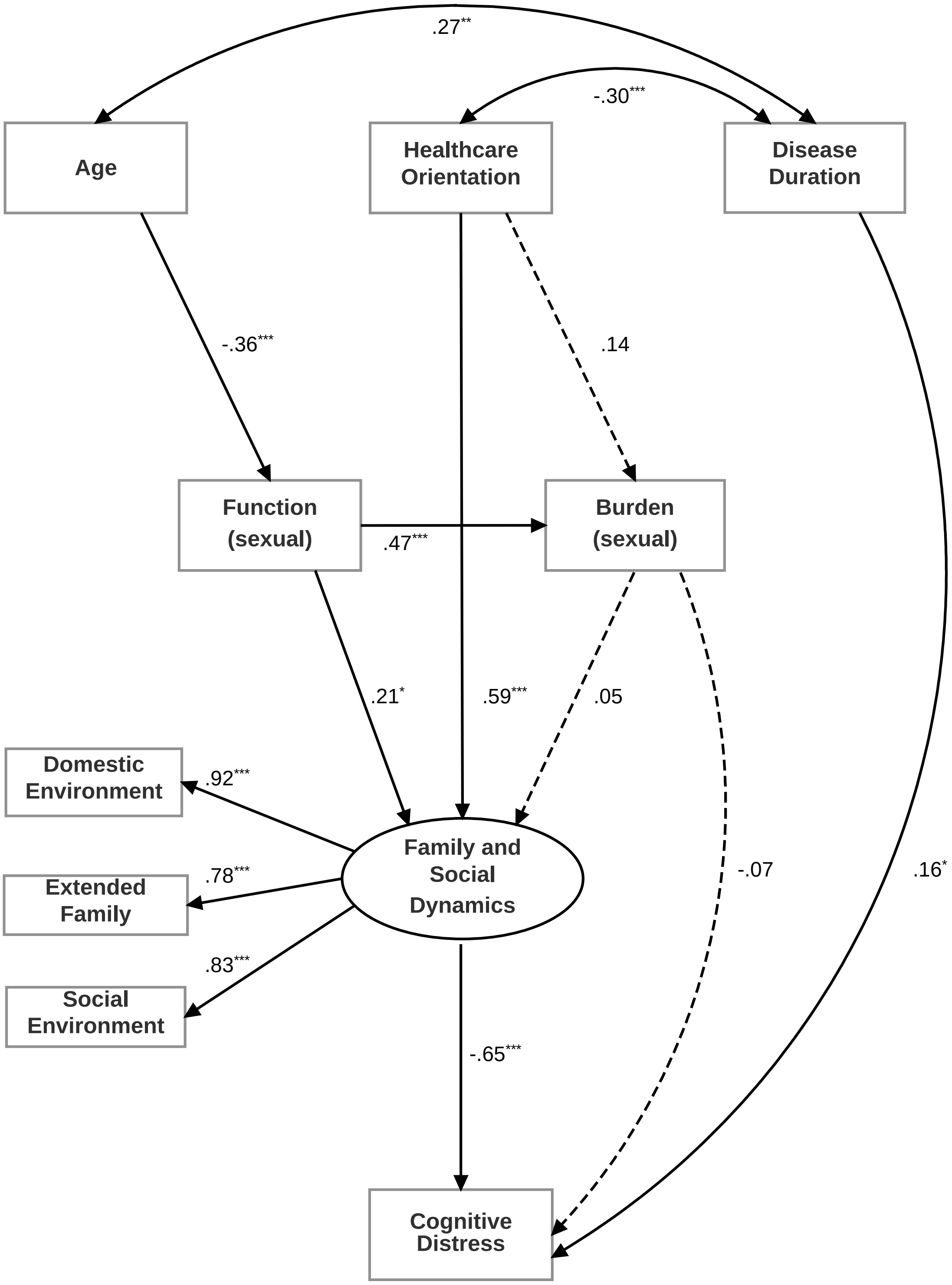


Figure 8.10a *Inputs to Cognitive Distress with Sexual Coping Mechanisms: Clinical Participants*

Social Dynamics (*Sexual Domain* only), *Age* to *Function* to *Burden* to *Family and Social Dynamics* (*Global* model only), *Health Care Orientation* to *Family* and *Social Dynamics* (all models), and *Health Care Orientation* to *Burden* to *Family and Social Dynamics* (all models except the *Sexual Domain*).

In the case of partner data, the contributing *Input* variables were slightly different to those for clinical participants with *Gender*, but not *Disease Duration*, contributing to the final models. Further, as indicated in Section 8.5.2 only *Burden* measures (and not *Function* measures) made a significant contribution to partner models. The goodness-of-fit indices for the equivalent full RAM models for partners are shown in Table 8.15. Again, all indices are valid, and on balance suggest slightly more robust models than those for clinical participants. The model containing *Bowel Burden* scores (Figure 8.9b) was very satisfactory (only NFI fell below the 'excellent' range), while the *Urinary Burden* (Figure 8.8b) and *Sexual Burden* (Figure 8.10b) models produced essentially equivalent indices, falling in the 'adequate' to 'good' range. The *Global* model (Figure 8.7b) is adequate.

Table 8.15 *Goodness of Fit Indices for Inputs to Output: Partners*

Scales used	χ^2	**df**	***p***	χ^2**/df**	**TLI**	**NFI**	**CFI**	**RMSEA**
Global Burden	22.50	17	.166	1.32	.945	.910	.974	.052
Urinary Burden	20.90	17	.231	1.23	.961	.915	.981	.044
Bowel Burden	17.22	17	.440	1.01	.998	.928	.999	.010
Sexual Burden	20.26	17	.261	1.19	.966	.916	.984	.040

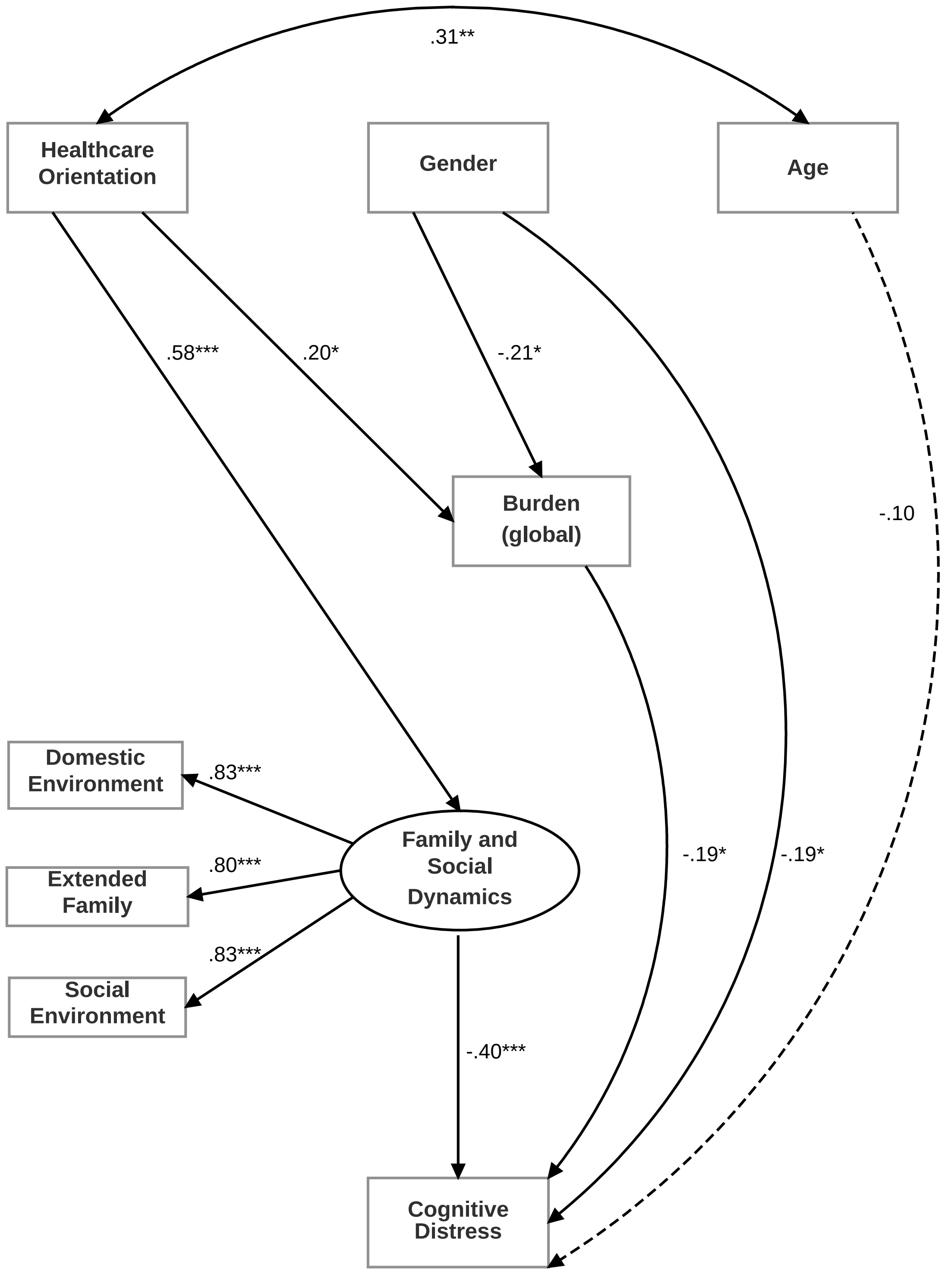


Figure 8.7b *Inputs to Cognitive Distress with Global Coping Mechanisms: Partners*

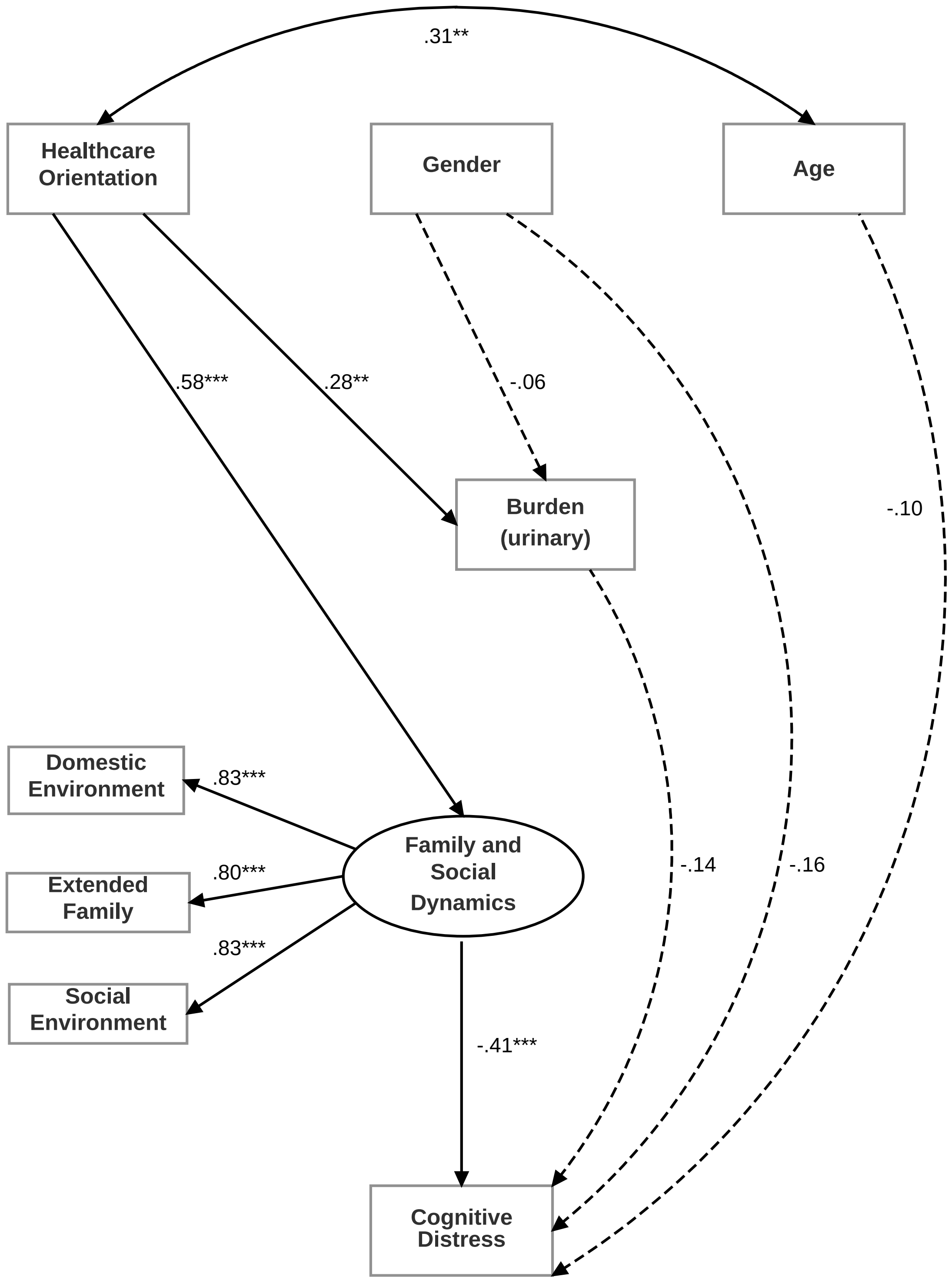


Figure 8.8b *Inputs to Cognitive Distress with Urinary Coping Mechanisms: Partners*

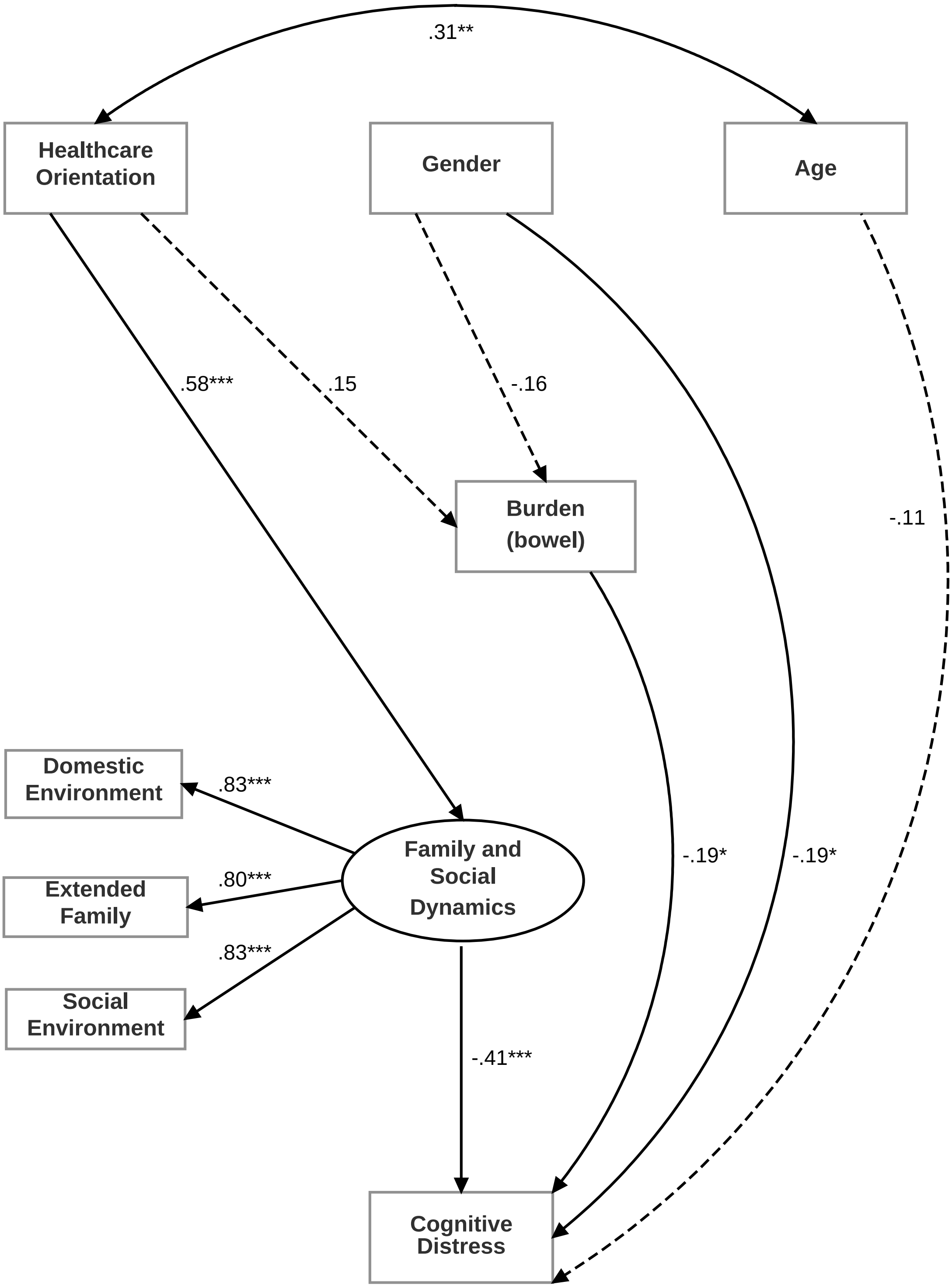


Figure 8.9b *Inputs to Cognitive Distress with Bowel Coping Mechanisms: Partners*

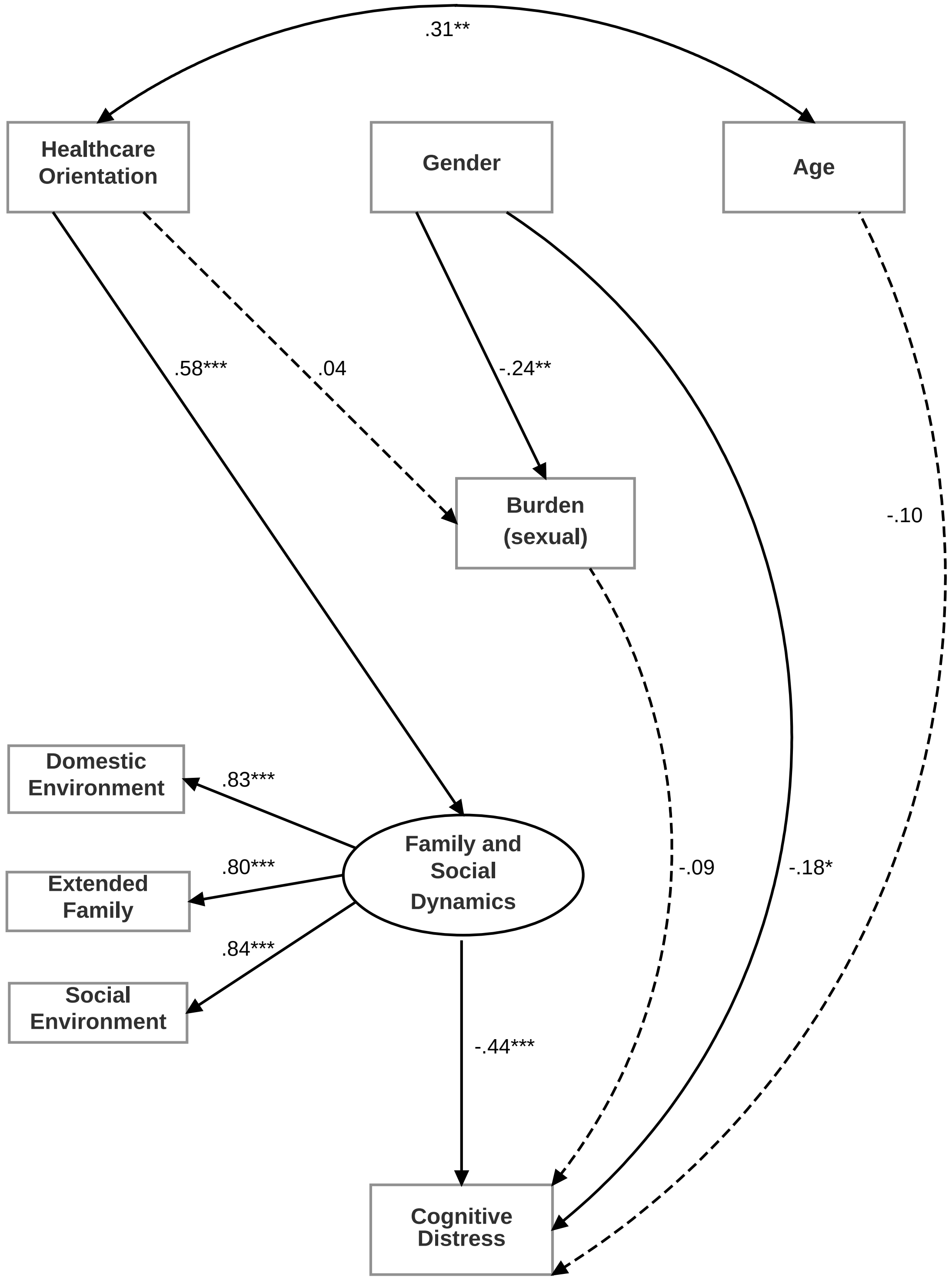


Figure 8.10b *Inputs to Cognitive Distress with Sexual Coping Mechanisms: Partners*

In these models, a single significant covariance was noted at the *Inputs* level, with partner *Age* being positively associated with *Health Care Orientation*. Direct paths to *Cognitive Distress* involved *Family and Social Dynamics* (all models), *Burden* (*Global* and *Bowel Burden* models only) and *Gender* (all models except *Urinary Burden*). Indirect effects (mediated paths to *Cognitive Distress*) comprised *Health Care Orientation* to *Family and Social Dynamics* (all models), *Health Care Orientation* to *Burden* (*Global* model only), and *Gender T*o *Burden* (*Global* model only).

8.6 OVERVIEW OF PHASE 2 RESULTS

Increasingly, research in the health sciences is focused on not only the reason behind patient behaviours but also of the family unit and others supporting the patient (Forthofer 2003; McDowell *et al.* 2010; Smith *et al.* 2012; Nicholls *et al*. 2014; Mohamed *et al.* 2014). The meaningful delivery of healthcare to patients and families relies on such innovative research to determine their needs, allowing a model of care that is appropriate and supportive (Forthofer 2003). Phase 2 of this research program has accomplished this by conducting a questionnaire study to test the relevance of RAM as a framework for adaptation to BlCa.

The results indicated that clinical participants with NMIBlCa had a longer duration with BlCa than did those diagnosed with MIBlCa who subsequently underwent RC. This longer duration was more likely to lead to *Cognitive Distress* and less family and social connections. Clinical participants with NMIBlCa had a more negative view of the *Healthcare System*, and they experienced less satisfaction with treatment. While BlCa surveillance and treatment are administered to save lives, they also lead to a negative view of the *Healthcare System* and the urology clinic as it is there that bad news is dispensed, such as the initial BlCa diagnosis and subsequent re-diagnosis or discovery of more tumours. Tests and procedures, found to be painful and embarrassing, with poorly tolerated side effects, are also conducted at the urology clinic, leading to further negative associations. Perhaps for these reasons, clinical participants with NMIBlCa had higher levels of *Cognitive Distress* and less positive expectations than their extended family. However, older partners were more satisfied with the *Healthcare System,* except for those whose clinical participant had NMIBlCa.

While clinical participants detailed their decreasing physical *Function* in Phases 1 and 2, it was the perception of the *Burden* associated with this diminished *Function,* and not the dysfunction itself, that led to *Cognitive Distress.* However, with the presence of a supportive partner the perception of *Burden* diminishes, and the clinical participant is more likely to adapt to BlCa. The clinical participant is more likely to express *Cognitive Distress* without a supportive partner. Clinical participants' *Cognitive Distress* was correlated most acutely with their urinary and bowel dysfunction. In instances of greater dysfunction, higher levels of perceived *Burden* were experienced, which was also associated with the perception of a decrease in family and social support. However, clinical participants experienced less *Cognitive Distress* when they perceived more family and social supports. Participants who had a more positive view of the healthcare system also had a more optimistic outlook towards BlCa, their relationships with each other, family and friends, and had better psychological wellbeing (less *Cognitive Distress).*

Partners' *Cognitive Distress* increased in line with their clinical participants' perceived *Burden,* particularly urinary dysfunction. Females were more likely to have a positive attitude toward social interactions with family and friends than men, and older partners reported less *Cognitive Distress* and better family relationships and socialisation. However, partners with a clinical participant who had NMIBlCa were more likely to endorse *Sex Proves our Love.* Males were also more likely to endorse *Sex Proves our Love*.

Using SEM, the four levels of RAM for clinical participants included *Healthcare Orientation* and *Disease Duration* as *Inputs, Function* and *Burden* as *Coping Mechanism*s, *Family and Social Dynamics* as *Biopsychosocial Behavioural Responses*, all leading to *Cognitive Distress*. For partners, these levels are represented by *Age* and *Healthcare Orientation (Inputs), Burden* (the only *Coping Mechanism)*, and *Family and Social Dynamics (Biopsychosocial Behavioural Responses*). Again, these were all considered as potential precursors to levels of *Cognitive Distress*.

For clinical participants there were a number of mediated paths from either *Age* or *Healthcare Orientation* through either *Function, Burden,* or both, and *Family and Social Dynamics.* However, only one mediated path moved through all four levels (from age to *Function* to *Burden*, through *Family and Social Dynamics* to *Cognitive Distress*). This was for the Global model only. The only direct path from *Input* to *Output* (*Cognitive Distress*) was *Disease Duration* (all models). This finding indicates that there was a significant impact by the *Healthcare System* on clinical participants, with older *Age* being noteworthy. It is logical that an older person might have had BlCa for longer, with a longer duration also implying more contact with the *Healthcare System* through treatment and surveillance, perhaps leading to a lower tolerance.

For partners, the important mediated paths were from *Healthcare Orientation* to either *Family and Social Dynamics* or *Burden* to *Cognitive Distress.* They also had a number of indirect (mediated) paths from *Inputs* to *Outputs,* but no *Input* variable offered a significant path through all four RAM levels. The only direct path was from *Gender* to *Cognitive Distress* (*Global*, *Sexual* and *Bowel* models), with males expressing higher *Cognitive Distress*. This association had not been evident in bivariate analyses.

In summary, SEM revealed that family and social support was associated with less *Cognitive Distress* and that, for clinical participants, other key factors were at play. These included urinary, sexual and bowel dysfunction, *Burden*, *Disease Duration* and dealings with the *Healthcare System*. Conversely, partners' *Cognitive Distress* was related to gender, the *Healthcare System*, and their clinical participants' *Burden*.

8.7 CHAPTER SUMMARY

Chapter 8 has described the results of the Phase 2 study, conducted using a quantitative design to determine whether Phase 1 findings could be further clarified with a larger sample. In presenting these results, the characteristics of both clinical participants and their partners, in terms of descriptive information and bivariate associations, for all variables operationalised as assessing the four levels of RAM, were described. Additionally, comparisons were made in the responses of clinical participants and partners within the dyad. Most importantly, SEM was used to test whether, and if so how, the chosen variables aligned with RAM for clinical participants, partners, or both. While a range of variables were identified as predictive of *Cognitive Distress,* the effects of *Family and Social Dynamics, Function* and *Burden* (clinical participants), *Burden* (partners), *Healthcare Orientation* and *Disease Duration* (clinical participants) were highlighted as being significant.

The goal of Chapter 9 is to provide a holistic discussion of the research program, including the degree to which Phase 1 findings and Phase 2 results are complementary or contrasting. It also provides a commentary on both the limitations of the research program and the usefulness of the findings as contributing elements to a model of care to be applied with future BlCa patients and their partners.

CHAPTER 9

INTEGRATION, DISCUSSSION AND RECOMMENDATIONS

9.0 INTRODUCTION

This research program used the MMR approach to explore the experiences and QoL of clinical participants and their partners. This chapter provides the opportunity for a final integration of the both phases and overview the results of this program of research. It allows a review of the original research questions posed in Chapter 1, including an evaluation of the degree to which those questions are answered using the MMR approach. The issue of how the findings may inform a model of care for clinical participants and partners in the future is also addressed in terms of clinical implications and the potential for future research, alongside a commentary on limitations and conclusion.

9.1 INTEGRATING THE RESEARCH APPROACHES

Integration of the phases were noted in both Chapters 1 and 3 as being a necessary endpoint to the MMR approach. There are various stages of the research process during which integration of findings may be desirable. In the current study integration occurred at various points of both the *methods* and the *interpretation and reporting levels* (Fetters *et al.* 2013).

The first opportunity for integration was within the *methods level* (multi-stage design), described by Fetters *et al.* (2013) as *merging, embedding, connecting, and building* techniques. In the current study, *merging* was evident through the merging of textual and numerical data (Creswell *et al.* 2004; Fetters *et al.* 2013). Phase 1 themes were matched to RAM in terms of measurable theoretical constructs, with questionnaire instruments selected to enable these constructs to be operationalised (Chapters 5, 6, 7 and 8). These methods are also considered as *embedding* as they involved *connecting* (n = 16 Phase 1 participants in the Phase 2 sample), with *building* attributed to Phase 1 as it contributed to the Phase 2 findings

(Creswell *et al.* 2004; Fetters *et al.* 2013). Another level of integration occurred at the *interpretation and reporting level*. This can take place through 1) *narrative* (*weaving, contiguous,* and *staged approaches*), and 2) *data transformation* (through *joint displays* of both the findings and results together), as noted by Fetters *et al.* (2013). Primarily, the *narrative* approach assisted the integration of themes and concepts. The *contiguous* approach was also used when the findings and results were represented sequentially. Further, the *narrative weaving* approach (Fetters *et al.* 2013) was utilized when presenting the qualitative findings and quantitative results of multivariate analyses (SEM) using the same themes, domains, and levels of RAM. In this way, the questionnaire domains were mapped to equivalent themes from the qualitative findings and in RAM.

At another level, integration occurred through *data transformation* in which the qualitative findings were matched to RAM and operationalised quantitatively (Fetters *et al.* 2013). However, this was more clearly demonstrated through *joint displays* using tables and figures to represent RAM. These perspectives of the qualitative themes and questionnaire domains enabled a greater, more in-depth understanding of the Phase 1 findings, with the results of Phase 2. According to Fetters *et al.* (2013), these methods of integrating a multi-stage MMR approach around thematic or domain significance to enable *merging,* requires higher order inferences than using triangulation alone. The *narrative weaving* links themes and domains that imply a contextual integration.

The *fit* of the integration is reported in terms of *confirmation, expansion,* or *discordance* (Fetters *et al.* 2013). The current study used both *confirmation* and *expansion* as both research phases confirmed the use of RAM as the basis for a viable model of care when tested in Phase 2. However, the divergence of the two phases has allowed greater insight into knowledge concerning the QoL of clinical participants and partners, and provided better understanding of BlCa due to the divergent nature of thematic findings and multivariate analyses (SEM) in using RAM to test an under-studied phenomenon.

9.2 DISCUSSION OF THE RESEARCH QUESTIONS

The following overarching question was posed in Chapter 1 of this research program:

> *How do the experiences of community-dwelling clinical participants with a diagnosis of BlCa, and their partners, affect QoL, and can these experiences inform a model of care?*

To address this research question further, four questions were utilised in both phases of this thesis as a guide to enable an understanding of the experiences of BlCa, the effects on QoL, and needs of clinical participants and their partners. In this chapter, these four questions will be answered using the joint outcomes of both phases of this research.

1. What is already known about the effects of living with BlCa?
2. What are the QoL experiences of clinical participants and partners as they adapt to BlCa?
3. What physical and psychosocial experiences are described by clinical participants diagnosed with BlCa and their partners?
4. What elements of the experiences of clinical participants, and their partners, inform a model of care for BlCa?

9.2.1 What is already known about the effects of living with BlCa?

The first research question sought to determine what is already known about the effects of living with BlCa. A review of the literature (Chapter 2) demonstrated that there is scarce primary research available in a number of areas related to BlCa. Little research has been conducted using qualitative methodologies that might enlighten us as to the experiences of clinical participants or the QoL of their partners, other than those studies arguing for one form of surgery over another. Research involving NMIBlCa is limited despite 70% of bladder cancer diagnoses being NMIBlCa (Kowalkowski *et al.* 2014; Mohamed *et al.* 2016). There are relatively few studies concerning women with BlCa, and supportive roles of partners. Much of the available literature is quantitative, involves MIBlCa, and/or discusses the benefits to QoL afforded by a particular type of surgical diversion, the benefits of certain treatments, or testing of instruments.

The 25 key studies appraised primarily consisted of quantitative studies focusing on MIBlCa. Even though two studies recruited female participants only, 78% of all participants in the 25 studies were men. Only one study included caregivers. Together, these studies discussed QoL over time, with an IC, or Neobladder, or with a BI. Consideration was also given to MIBlCa symptom support and the benefits of conservative treatment to retain the bladder. This gap in knowledge led to an exploration of the personal perception of living with BlCa, and caring for someone with the disease. Unlike the literature reviewed, the current study also included participants with NMIBlCa, women with BlCa, and their partners, and utilised both qualitative and quantitative methodologies in a MMR approach.

While the literature typically states that BlCa occurs in the elderly and the incidence increases with age, the median age (at diagnosis) of the current participants was 52.5 years (age range 32-79 years in Phase 1), and 70.77 years (age range 38-92 years in Phase 2). Therefore, many participants were not elderly. At the time of her interview, Alicia was 41 years old and Gareth 49. The youngest partners at the time of interview were Grace (47), Allen (53), Debbie (54) and Barbara (56 years). The Alicia/Allen and Gareth/Grace dyads were the youngest of the ten couples, and the Phase 2 partners’ age range was 42-88 years.

In response to the first question, numerous studies have sought to inform about aspects of BlCa. However, most of these studies focus on medical aspects of MIBlCa with minimal insight into the lives of individuals with NMIBlCa. Further, participants in other studies were primarily male, with little focus on partners or caregivers, or qualitative methodologies. These observations and gap in knowledge helped to inform the current program of research.

9.2.2 What are the QoL experiences of participants as they adapt to BlCa?

The second research question examined the QoL experienced by clinical participants and partners during their adaptation to BlCa. The literature review (Chapter 2 and Section 9.2.1), discussed the effects of BlCa on the QoL of participants. It was evident that urinary, bowel and sexual dysfunction, incontinence, CIC, skin disorders caused by the stoma pouch attachment, having a stoma, pain, fatigue, leakage, sleep disorder and psychological health greatly affect QoL (Yuh *et al.* 2008; Fitch *et al.* 2010; Cerruto *et al.* 2014, Gomez *et al.* 2014; Fung *et al.* 2016). However, there were no differences in QoL when considering age, gender, and treatment over time except for radiotherapy, chemoradiation, or chemotherapy alone (Singer *et al.* 2013). Nor have differences in QoL been found according to age and time since diagnosis or for participants with a BI or those having undergone RC (Allareddy *et al.* 2006). Phase 2 of the current program demonstrated similar findings, with no associations for *Age*, *Gender* or *Disease Duration* with QoL, or for *Age* with diagnosis (BI or post-RC).

In the current study, QoL was defined (Chapter 1 section 1.3) as an umbrella term comprising four elements. These areas of QoL may differ due to environmental differences or cultural beliefs. QoL has been depicted as including social relationships, personal beliefs, physical wellbeing, psychological status, and independence. However, the four elements of QoL in this study are the experiences of the *Healthcare System*, *Physical Wellbeing, Psychosocial Wellbeing,* and *Adaptation*. Therefore, it could be suggested that all aspects of BlCa discussed in this thesis have the potential to affect QoL adversely, although to varying degrees.

9.2.3 What physical and psychosocial experiences are described?

The third research question sought to expand the limited knowledge base noted previously (Section 9.2.1) by asking both clinical participants and their partners about their physical and psychosocial experiences of BlCa. *Physical Responses* were associated with the process of going through BlCa treatment and surveillance, including cystoscopy, TURBT, intravesical chemotherapy, or BCG, radiotherapy and RC, the discomfort of these procedures and their subsequent side effects (e.g. urinary, sexual and bowel dysfunction). On-going needs related to post-treatment care and any deterioration of physical function requiring support. In Phase 2, these issues associated with urinary, bowel and sexual function and burden were noted again. More specifically, SEM found that participants struggled to adapt to the burden of such dysfunction, more so than the lack of physical function. For partners, the physical function cannot be measured even though partners assist with incontinence and stoma care. However, partners were affected by the perceived burden felt by their clinical participant.

Psychosocial responses are those located in the *Cognitive* and *Emotional Reactions* of Phase 1 that were mapped to RAM and operationalised as the *Biopsychosocial Behavioural Responses* in Phase 2. They included dealing with the anxiety associated with having BlCa and feeling confronted by their mortality as a reaction to diagnosis. According to the results of SEM, domestic partner, family, and social activities featured most prominently in the *Biopsychosocial Behavioural Responses* of participants. Conversely, sexuality, love, friendship, and affection were important supportive elements, with the potential to enable the clinical participants’ adaptation, rather than lead to cognitive distress. In addition, the role that participants play in their daily life within their family, employment, and community contexts was expressed as defining the clinical participant. These may be positive with the appropriate support, whereas a lack of support may have a negative effect on the clinical participant. For example, clinical participants are then less able to enjoy everyday activities such as participating in relationships with family and friends, sports, socialising or other recreational activities, and employment that may lead to financial difficulties. There are issues with depression and of self-image due to a changed body. These culminate in reduced confidence and lack of ability to take part in these physical and cognitive daily activities.

The loving relationships demonstrated the overwhelming support offered by partners, and the importance of communication and patience for couples to manage the required changes to their normal pattern of life. This was particularly so when faced with a changed body, UFU, incontinence and sexual dysfunction. Female partners noted a positive change in their clinical participant since his diagnosis, being more able to discuss health and difficulties, and making more timely visits to his physician when unwell. Partners also depended on family and social supports, friendship, love, affection, and sexual relationships. However, for female partners love and affection were more important than mourning the loss of sexual function.

9.2.4 What elements of these experiences inform a model of care for BlCa?

The final research question sought to identify elements of the experiences of clinical participants and their partners that could inform a model of care for BlCa. When Phase 2 operationalised the findings from Phase 1, the four levels of RAM were used to map all the outcomes to an appropriate framework for the promotion of adaptation. These analyses tested links between both phases and RAM for use as a framework for a model of care relevant to clinical participants and partners. To achieve this, community dwelling clinical participants and partners completed a questionnaire (Chapter 7). The results (Chapter 8) highlighted the association between Phase 1 findings (Chapters 4 and 5) and RAM (Chapter 6). While numerous elements of RAM and Phase 1 findings were used to test their relevance, statistical analysis and SEM revealed that some of these components did not have a good *fit.* Based on SEM, the four levels of RAM were deemed relevant for use in a model. Depicted were the key elements of *Healthcare Orientation, Disease Duration, Age, Physical Function* (urinary, bowel and sexual function, and burden of clinical participants), perceived *Burden* (partners), *Family* and *Social Dynamics,* and *Cognitive Distress*.

Rather than regarding the results of the questionnaire as an end-statement, they were viewed as a guide providing evidence of support for a model of care reflecting all four levels of RAM tested. For clinical participants, SEM highlighted these levels as 1) *Inputs* (RAM's: *Environmental Stimuli*) of *Age, Healthcare Orientation,* and *Disease Duration*. Level 2) *Coping Mechanisms* (RAM's: *Control Processes*) were represented as the urinary, bowel and sexual *Function* and perceived *Burden*. At level 3) *Biopsychosocial Behavioural Responses* (RAM's: *Adaptive Modes*) were represented by the social and family elements of life (named *Family* and *Social Dynamics*). This element comprised the clinical participants and partners' Domestic *Environment, Extended Family* relationships and their *Social Environment*. Level 4) *Output* (RAM's: *Adaptation Levels*) was identified as *Cognitive Distress*.

Similarly, for partners important Level 1) *Inputs* were *Healthcare Orientation, Gender,* and *Age*. Level 2) *Coping Mechanisms* were the perceived *Burden* only of the clinical participant, as the partners could not experience the actual physical functioning of their clinical participant. This *Burden* included in the partners' SEM was the global scale, including all of urinary, bowel and sexual perceived *Burden*. Levels 3 and 4 the *Biopsychosocial Behavioural Responses* and *Output* were identical to those of the clinical participants. The ways in which the results of the questionnaire study align with the four levels of RAM are further depicted in an outline of a model of care. Using the contemporary nomenclature, RAM provide a roadmap through the care required for clinical participants and partners (see Section 9.3).

It is worth noting the difficulties that clinical participants and partners faced with the healthcare system. Phase 1 highlighted that 30% of clinical participants were not told of their BlCa diagnosis. Instead, other terms (polyp, tumour, and carcinoma) were used. Clinical participants did not understand the meaning of these terms though a couple of partners suspected that the diagnosis was not good, with one partner fearful of how her husband would react when he realised his diagnosis. Finally discovering their actual diagnosis sometime later was devastating for participants and almost caused one man to drive off the road thinking he was dying anyway (that was 20 years ago).

Patients would prefer urologists to name the disease and severity of it. If the patient has cancer, the word ‘cancer’ must be used, as patients are familiar with that term, and often do not understand carcinoma, tumour, or polyp as used by physicians (Thorne *et al.* 2010). After any procedure, the urologist needs to sit with the patient to explain his/her diagnosis (Thorne *et al*. 2010; Brown *et al.* 2011). If more BlCa is found later that needs to be explained again, along with the new treatment plan (Schaepe 2011). This telling and re-telling of the patient’s BlCa diagnosis is required to ensure its severity is understood (Jacobsen *et al.* 2013), and enable patients to become involved in their own treatment decision making.

Another cause for concern noted in Phase 1 was that clinical participants had an anxious one month wait following the arrival of their appointment card for their next surveillance cystoscopy, often becoming anxious and concerned about the results. However, other participants were quick to telephone the clinic to make an appointment when their card had not arrived, and were disappointed at this occurrence given that they were due for surveillance. To that end, some partners became appointment secretaries as they felt the need to be responsible for following up on appointments, fearing that they might ‘fall through the cracks’. Other options for this process require investigation. For example, patients could be given their next appointment before they are discharged from each clinic treatment to ensure the patient already has the card. Alternatively, the card could be posted to the patient a week to 10 days prior, or text message reminders could be used.

While participants appreciated comprehensive care, there were also complaints about many other aspects of the healthcare system. Such as having a different urologist each time to perform their cystoscopy, lack of information or explanation, painful procedures, appointment times that led to long waiting times in clinics, and the expectations of care from partners but lack of inclusion of partners in care. The autocratic, rushed delivery of healthcare was clearly not meeting the participants' needs as many aspects of care were not attended to, information was not forthcoming, and other multidisciplinary team members were not consulted for their assistance and knowledge in dealing with the array of symptoms caused by BlCa. Participants in both phases were not informed that sexual dysfunction was a possible side effect and became anxious and frustrated when it occurred. Additionally, the ongoing regular nature of surveillance and treatment, with associated discomfort, humiliation, embarrassment, and intrusiveness seemed to dominate participants lives.

The current research and literature review (Chapter 2) have confirmed that information is helpful to participants' understanding of the disease process and requirements for specific treatment protocols. Images of the anatomy depicting the progress of BlCa would be helpful and give the couples a better understanding of their disease. Patients will only be well informed about their progress if their treatment protocol has been explained satisfactorily. Such explanations must be given using simple terms with pamphlets featuring relevant diagrams and pictures (Jacobsen *et al.* 2013). An online interactive site containing short informational videos, might be appropriate for patients and this information could be more easily updated. Information in these forms at the time of diagnosis and along the BlCa trajectory, particularly when the patients' situation changes, are key features required of the healthcare system and included in the model of care (Table 9.1) developed from this study.

Information about risk factors and smoking cessation, including support programs at the hospital, clinic, in the community, or by telephone, may assist patients and partners to cease smoking. Further, both separate and combined support programs for patients and partners might equip them with more constructive coping strategies to facilitate adaptation and develop the necessary skills for dealing with their own, and their partners' distress during the BlCa journey. In addition, counselling should be similarly recommended.

Understanding the important roles played by partners will enable healthcare professionals to be more encouraging of partners' involvement in care and make partners feel included rather than 'on the outside'. Having communication with partners might remind healthcare professionals to keep partners informed even when unforeseen events occur rather than have them discover this information later. Similarly, an ongoing relationship with, and knowledge of their circumstances (e.g. if the partner works or children are involved), the couple may remind healthcare professionals to check when would be an ideal time for partners to collect the patient after treatment rather than have them leave work early only to sit waiting. After an RC, their partner should be ready for the patient to be discharged and have had sufficient training, despite any arrangements for home visits by the stoma nurse. Incorporating these factors into a model of care to use in urology clinics, particularly at diagnosis and early follow-up, may assist couples with information and supportive care.

9.3 STUDY LIMITATIONS

At this point, it is worth noting some limitations of this program of research. In Phase 1, participants were all recruited from the same source. Participants from another type of institution, from the community or from private practices may have had different experiences of BlCa. Another limitation was the requirement to speak English. Again, people from a non-English speaking background may have viewed their BlCa experiences differently from participants from English speaking cultures. Further, in this research, dyads were mostly limited to heterosexual couples. The views of families rather than married couples may change the picture of the experiences of BlCa from those described in this research. More, or less support for either the clinical participant or partner, may have been represented. The insights into BlCa may have been different from the perspectives of the lesbian, bisexual, gay, transgender, or intersex groups who may have had less support or acceptance of their relationships within the community, or even possibly from the healthcare system. This could have added to the sense of not fitting in to *social norms* due to their BlCa. Similarly, expectations and requirements for people with disabilities and their carers, who may be professional carers' not family members, could also be different.

Within the questionnaire utilised in Phase 2, information on *Employment* was sought. In hindsight, there could have been the additional choice of *Unemployed* as a number of respondents noted that they were unemployed due to their BlCa. Clinical participants were asked: *How long have you had bladder cancer for?* There could have been an additional question for participants who had undergone a surgical cystectomy, asking how long it had been since that surgery, providing two dates, the date of diagnosis and the date of surgery. It is possible to be diagnosed with BlCa, undergo treatment and then for the BlCa to progress into muscle invasive disease, at which point the treatment would be a cystectomy. Participants' hand-written messages on their questionnaires reflected that the time limit for the questions was not suitable for all situations. For example, someone who had a cystectomy 10 years ago would have very different responses from someone who had a cystectomy a month ago, or who had intravesical treatment in the last six weeks. Additionally, some clinical participants post-cystectomy considered themselves *cured* as the bladder and other nearby organs were removed and they required only annual surveillance. These participants completed their questionnaire as if they were cured and therefore, not necessarily from the perspective of a person *with* BlCa. Their partners completed their questionnaires similarly.

Sexual dysfunction was an issue of concern to clinical participants that was discussed in Phase 1. However, the quantitative research phase did not verify these findings, which may have been due to the instruments used. While the sexual functioning and burden questions in the BCI are specific to BlCa, the core questions used from the PLSS, are more general. Further, as noted above, the members of a small number of dyads were not in a sexual relationship. For either or both of these reasons, the sexual component of the quantitative research did not provide results in line with those reported in Phase 1 or the literature. Some participants were also reluctant to answer questions about sexuality. This reluctance was related to their age, as they had lost interest in sex or lost the physical capacity for sex with age. Some participants had lost their partner and had no interest in a new relationship. In addition, co-morbidities, and pain associated with sexual intercourse resulted in disinterest. In such cases, questions concerning sexuality were not answered.

Finally, there are general limitations to any cross-sectional study. For example, a prospective study would not require participants to rely on their memory about feelings and symptoms, and might explain the relevance of adaptive behaviour as it occurs rather than having to rely on the accurate retrieval of information. More complex statistical data analyses in Phase 2 would have been possible with a larger sample. However, sample recruitment was difficult and lengthy due to multiple healthcare needs, side effects, and progression of the disease.

9.4 A MODEL OF CARE FOR CLINICAL PARTICIPANTS AND PARTNERS

The concerns raised by participants (Section 9.2.4) need to be addressed, particularly the lack of communication from healthcare providers. This lack of meaningful communication is the reason behind participants not having a clear understanding of their diagnosis, and receiving inadequate information about BlCa, treatment, side effects or prognosis. While partners in Phase 1 complained of feeling on the outside and excluded, to some extent it would appear that clinical participants in both phases (judging from the hand-written notes on returned questionnaires) were treated similarly. There seemed to be a commitment to treating the clinical participant rather than the couple. In doing so, the supportive care person (partner) in the clinical participant’s life was alienated. Additionally, there were no recommendations or referrals to other multidisciplinary team (MDT) members despite participants feeling the need and asking for some form of counselling, support, and connections with others experiencing BlCa. Key recommendation arising from this research program is that these clinical implications be incorporated into a model of care for use in urology clinics. This model considers the concerns and suggestions of participants and aligns them with RAM.

The proposed nursing management of adaptation to BlCa is a nurse-led model of care for use by urologic-oncology nurses (U/O nurse) and RNs, and could involve stoma and wound-ostomy nurses. The model also suggests using the skills of radiology staff to assist urologists with diagnosis and treatment options. Other relevant MDT members include social workers, occupational therapists, physiotherapists, psychologists, and community nurses. This six-step model (Table 9.1) is for use with all clinical patients regardless of gender, age or type of BlCa, from newly diagnosed to *survivors*. The model may be linear for some patients but for others it may not. Clinical patients and partners may be represented differently within the framework and may not necessarily be at the same stage. This is another reason why treating individual members of a couple is important. However, there is also a need for rapid diagnosis of BlCa using a model that incorporates a same-day, nurse-led haematuria clinic, to help speed up the process from first experiencing haematuria and undergoing a cystoscopy, to diagnosis. This type of ‘one stop clinic’ used in Melbourne, Perth and overseas, reduces the time patients spend visiting various doctors before finally seeing a urologist (Ooi *et al*. 2011; Sapre *et al*. 2015). These same-day clinics streamline the care and diagnosis of BlCa by using appropriate measures to collect all the required data to ensure up to date patient information. Additionally, this system safeguards the patients’ future care by making sure that they do not become lost to the system for surveillance, as mentioned by participants in Phase 1 and as has been experienced by other urology clinics (Ooi *et al*. 2011; Sapre *et al.* 2015).

This is another reason why patients should be given their next surveillance cystoscopy appointment before they leave the hospital. This type of appointment booking system would make it easier to see when and how many staff will be required in clinics, and keep managers informed of busy and quieter times, which applies to not only the urology clinic but also radiology and theatre. Given that many urological issues are more prevalent with age, the baby boomer cohort will place a huge strain on the urology system requiring more staff and better use of available resources. A more efficient system is also more amenable to auditing and research. Furthermore, streamlining rapid diagnosis of BlCa within a couple of weeks of visible haematuria can have a 5% improvement in survival rates (Ooi *et al*. 2011).

The following sections articulate each step of the proposed model of care, with the six-step model being the framework for care delivery for patients and partners from post-BlCa diagnosis through surveillance to survivorship and death. While the six-step model is the framework for creating appropriate care pathways, these can differ depending on the type of BlCa diagnosed, escalation from NMIBlCa to MIBlCa, and types of treatment recommended.

9.4.1 Step 1: Assess Inputs Level

First, it is necessary to mention the *Inputs* level that is the environmental stimuli or triggers to behavioural changes that gauge the amount of stress, anxiety, and dominance over the QoL that BlCa has on the patient (clinical participant) and partner, paying particular attention to those elements that are most prominent in their minds. These *Inputs* may be given different priorities over time by patients. Therefore, urology-oncology nurses and the MDT need to be aware not only of how environmental stimuli might enable adaptation, but also the measures that might facilitate adaptation in the presence of these changing priorities, including the resources required. In particular, key elements include issues around diagnosis, disease duration, information provision, type of treatment, side effects, and incontinence.

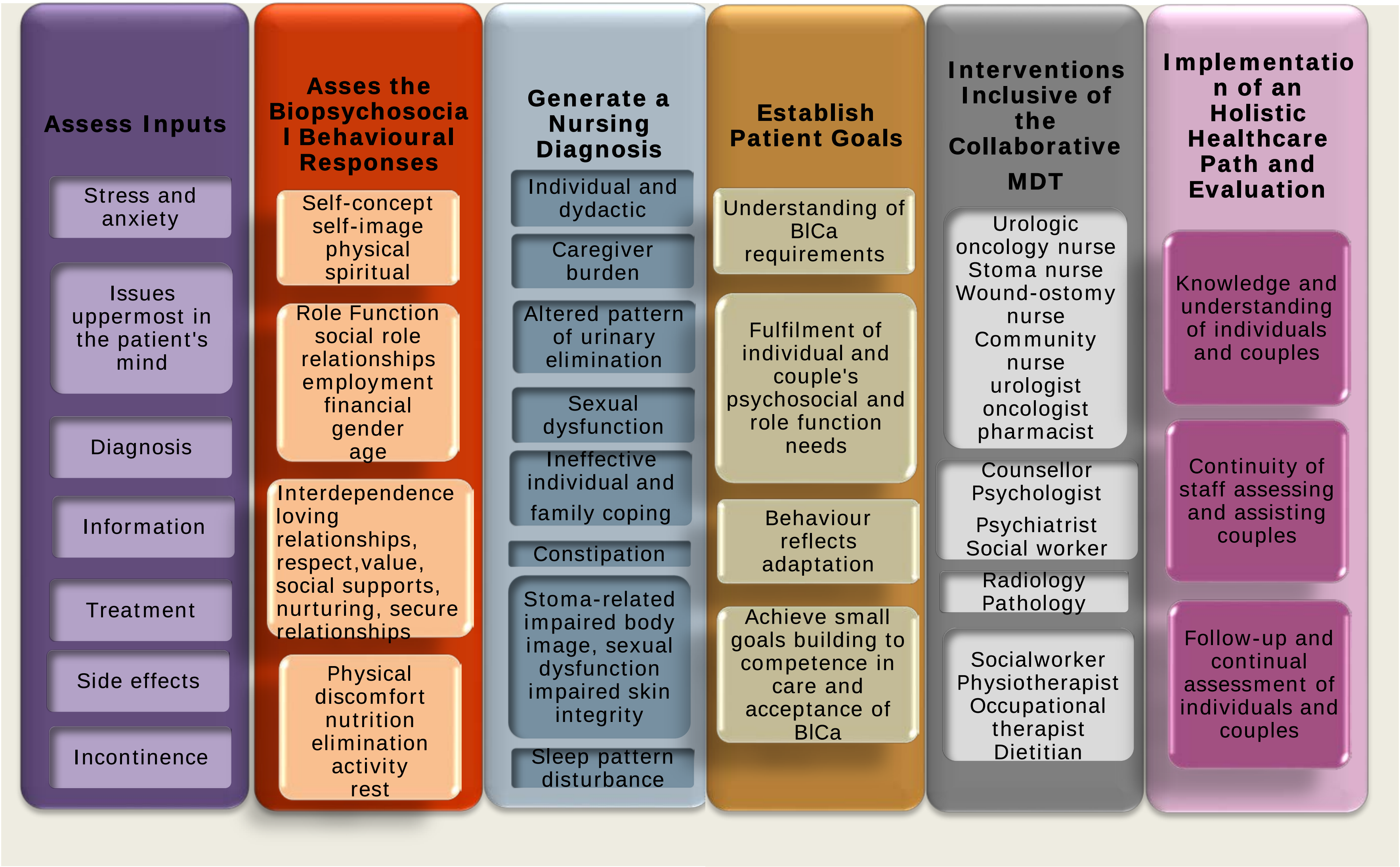
At diagnosis, patients and partners do not take in this additional information, particularly if it is delivered using medical jargon (Thorne *et al.* 2010; Brown *et al*. 2011; Jacobsen *et al.* 2013). Patients cannot process this immediately and in fact may take some time before they are ready to hear and understand it. However, they cannot be released from the clinic after their diagnosis knowing nothing and without adequate support. After the urologist has given the patient their BlCa diagnosis, there needs to be time for reflection before the couple leave. For example, having a casual chat with a U/O nurse afterwards would help to assess how much the patient has taken in and how much they would like to know. If the patient has any questions at that point they need to be answered and the patient given reading material, online support, community support, and the contact number for the U/O nurse.

For patients who are not ready to hear this information, the nurse needs to give the patients the same take-home information and emphasise that they can contact the U/O nurse should they have concerns. In addition, at the patient’s next appointment there needs to be another opportunity for a similar discussion with the U/O nurse to check their understanding and enable couples to ask questions in an unrushed environment. Follow-up with the patient should take place within three days after the cystoscopy, to reassure and check the patient understands his/her next appointment and any other information required. Even if the patient and/or partner appear to have understood the information, it should not be presumed. Hence, another U/O nurse chat soon after their next appointment would be recommended.

9.4.2 Step 2: Assess Biopsychosocial Behavioural Responses

Assessment of behaviour is shown in *Biopsychosocial Behavioural Responses* to the physiological changes brought about by BlCa. This includes self-concept, self-image, the interdependence with partners and family, and maintenance of their functional roles.

Table 9.1 *Six-Step Model of Care for Clinical Participants and Partner Using RAM*



Assess Inputs	Asses the Biopsychosocial Behavioural Responses	Generate a Nursing Diagnosis	Establish Patient Goals	Interventions Inclusive of the Collaborative MDT	Implementation of an Holistic Healthcare Path and Evaluation
Stress and anxiety	Self-concept self-image physical spiritual	Individual and dydactic	Understanding of BlCa requirements	Urologic oncology nurse Stoma nurse Wound-ostomy nurse Community nurse urologist oncologist pharmacist	Knowledge and understanding of individuals and couples
Issues uppermost in the patient's mind	Role Function social role relationships employment financial gender age	Caregiver burden	Fulfilment of individual and couple's psychosocial and role function needs	Counsellor Psychologist Psychiatrist Social worker	Continuity of staff assessing and assisting couples
Diagnosis	Interdependence loving relationships, respect,value, social supports, nurturing, secure relationships	Altered pattern of urinary elimination	Behaviour reflects adaptation	Radiology Pathology	Follow-up and continual assessment of individuals and couples
Information	Physical discomfort nutrition elimination activity rest	Sexual dysfunction	Achieve small goals building to competence in care and acceptance of BlCa	Socialworker Physiotherapist Occupational therapist Dietitian	
Treatment		Ineffective individual and family coping			
Side effects		Constipation			
Incontinence		Stoma-related impaired body image, sexual dysfunction impaired skin integrity			
		Sleep pattern disturbance			

That is, how is the patient behaving in terms of his/her changed physical body and function and the burden that those changes trigger? Is the patient adapting to the new self-image? Can the patient embrace personal and social relationships and support? Can the patient give and receive love? Is the patient able to fulfil normal roles in society, as a parent, partner, or family member, relating to employment, gender, age, and developmental stage?

9.4.3 Step 3: Generating a Nursing Diagnosis and Plan of Care

The nursing diagnosis of patients and partners will be complex. The nurse must generate nursing diagnoses appropriate for each member of the dyad and address the criteria applicable to help each patient and partner to adapt and meet their individual goals. Examples of appropriate nursing diagnoses might be ineffective coping, anxiety, knowledge deficit, risk of sexual dysfunction, or caregiver burden. The use of a psychological tool to assess cognition and emotional stages that may include the stages of loss and grieving may be appropriate guides to the patient and partner’s mental and psychological health. Therefore, referral to a psychologist on a six-monthly basis may be appropriate for newly diagnosed patients and partners, with yearly psychological testing for the first five years. As evident within the current study, cognitive distress diminished with longer disease duration and older age. Further, perceptions of family and social supports also improved over time and with age.

9.4.4 Step 4: Inclusion and Collaboration

To assist this process of caring for the patient and partner collaboration within a MDT is necessary. These collaborators could include a wound-ostomy nurse, stoma nurse, community nurses, urologist, physiotherapist, occupational therapist, nutritionist or dietitian, pharmacist, psychologist, social worker, counsellor, radiographers and radiologists. The U/O nurse would make referrals to the appropriate discipline for each couple and individual members of the dyad. The nursing role is also to inform couples how they might access the services and information available. In addition, community services and home visits may be required for more frail patients, along with transportation to clinics or MDT appointments.

9.4.5 Step 5: Establishing Patient Goals

Patient goals are concerned with supporting a continuous move toward adaptation (Clarke *et al.* 2011). Adaptation has been described (Chapters 5 and 6) as resulting from the management of health threats, improved self-awareness, and personal social status (Fife 2005). It is relevant to both the '*physical and social environment*' (Lazarus & Folkman 1984, p.182). Socially, adaptation refers to happiness with life, in terms of relationships with family and friends, social and emotional being, and the ability to continue social roles such as employment. Physically, adaptation refers to mastery of the specific personal adversity (e.g. BlCa). In the current context, this may include the functional limitations imposed by BlCa, side effects of treatment and surveillance. Patients and their partners may be considered to have *adapted* by displaying positive behaviours, along with appropriate cognitions and affective reactions, at the *Biopsychosocial Behavioural Responses* level of RAM.

Rather than adaptation being achieved as a single goal, patients and their partners may initially require a series of smaller, more attainable goals. Such mini-goals should be guided by the patients' and partners' physical and psychosocial capabilities and preferences. In a urologic-oncology model of care, some goal-oriented interventions may be relevant to both members of the dyad, whereas others may require separate appointments with different types of MDT members. Intervention(s) might include information sessions and counselling support. Repeat evaluation of the interplay between the *Inputs* that stimulate behavioural responses, *Biopsychosocial Behavioural Responses* and *Outputs* of both patients and partners may be required to facilitate ongoing participation in care.

9.4.6 Step 6: Implementation of an Holistic Healthcare Path

Specifically designed holistic healthcare paths for individual patients and partners would enable referral to appropriate MDT members, and continual assessment and follow-up of patients and partners. Consistent, individualised care with knowledge of the patient/dyad by healthcare staff would include ideally, continuity of staff assisting and assessing the patient and partner.

All patients would be telephoned within three days of their procedure to check on their welfare and requirements. Text message, email, or telephone calls to remind patients of their next appointment would be initiated three days prior to remind the patient to attend. The addition of a telephone counselling service run by the urology-oncology nurse could answer patients' questions to relieve the anxiety couples face initially, particularly after relatively short consultation times with urologists (Sherman *et al.* 2009, 2012). An on-line resource for patients and partners could provide the much-needed information and resources requested.

9.5 RECOMMENDATIONS FOR FUTURE RESEARCH

The key potential for future research to arise from the current program is the evaluation of the proposed role of the dedicated urology-oncology nurse. To reiterate, this role involves the management of a nurse-led, haematuria clinic for diagnosis of BlCa, and patient follow-up, and clinics for intravesical therapy and surveillance (Appendix Tables G1 and G2). These clinics would be guided by the six-step model of care (Table 9.1).

Once the six-step model is in place at a trial site, prospective observations and data could be collected using a MMR approach to explore the (new) experiences of patients with BlCa and their partners in relation to the diagnosis, treatment and management of BlCa, including the impact of informational requirements and support on QoL. The views of medical staff (urologists, oncologists, radiologists, and nurses) should also be sought. Initially, such data would replicate the current research program, but be expected to demonstrate a greater level of satisfaction, QoL, and ultimately, adaptation to BlCa after the implementation of the model. This model of care could operate in a urology clinic environment for three to five years to reflect the prolonged nature of surveillance and treatment experienced by patients, as many (e.g. those who undergo RC), might only be seen in the clinic annually.

Two groups of research participants would be involved. Those commencing under the proposed model of care upon diagnosis in the haematuria clinic (Appendix Table G1) would be the first to appreciate fully the greater attention to detail provided by this approach to care. Their level of adaptation to BlCa, informational requirements and support needs would be evaluated, with follow-up of these patients helping to determine the effects of rapid diagnosis on QoL. Further, at the point at which the model of care is introduced, there will be patients and their partners already in the system (post-diagnosis). However, these participants should also be followed over time to determine if this alternate form of intervention nevertheless improves their experiences of care, leading to greater satisfaction with the healthcare system overall, and improves their ability to adapt to BlCa.

The purpose of interviewing urologists, oncologists, radiologists, and nurses is to seek their experiences of running the model of care to gain their professional views on the validity of the model, ease of implementation, perceived benefits, and any noted limitations. It is anticipated that there will be fewer patients lost to surveillance with this model. Patients, partners, and medical staff should have better communication, information, understanding of the system and requirements for adaptation, with less confusion and angst.

Another variation on this research plan is to conduct a randomised controlled trial in which only half of the patients receive the new model of care, with the other half of the patients receiving usual care. Data collection could still proceed according to the protocol described above, but the benefit would be the availability of a built-in control group against which the outcomes of the new model of care could be compared. Such a trial may pose ethical issues as patients being treated in the same clinic could be receiving different type of care.

9.6 STUDY CONCLUSION

This research has used a MMR approach to explore an understudied topic. The use of pragmatism afforded an appreciation of clinical participants and partners as individuals, and as a dyad. In doing so, additional information relevant to urologic-oncology practitioners has been presented. This has included an appreciation of the QoL of participants, and an understanding of the couple’s needs, their outcomes after treatments, including sensitive family, social, spiritual, and community needs, and the required collaborations of a supportive MDT.

The discovery of the vital role the healthcare system plays in the lives of participants is relevant as BlCa is a chronic disease for most patients, one that will see the patient and partner returning regularly to the healthcare facility and interacting with healthcare professionals. This study has realised some of the undesirable encounters experienced by clinical participants and partners as they interacted with the *Healthcare Environment.* The most pertinent of these was the desire to name the disease ‘cancer’, which is the word that patients understand. There was a great lack of information and support both at the time of diagnosis and on return for further treatment. Participants want the urologist to sit with them after their TURBT to explain what happened during the procedure and articulate the care plan. There are simple strategies that could be used to address this information need, leading to a fuller understanding of the disease and treatment protocols. Other statements about the medical model alluded to the clinical participant not being listened to, their questions not answered, and being told, rather than asked about which treatment they would receive. Some had doubts about their treatment regimen, particularly the effects on sexual dysfunction.

Participants are requesting support and to meet others with BlCa who are at the same stage or further along the BlCa trajectory than themselves. They want a glimpse of what is in store in their future, and how other couples deal with side effects and the very personal issues related to BlCa. Participants also asked why there is no counselling offered to them given the depressive nature of the disease and the severity of the side effects. They questioned the lack of public awareness and fund raising for BlCa, and asked why there is no information about BlCa, risk factors and symptoms in the media, as they had never heard of BlCa, until their diagnosis. A key request from partners is for recognition of their role in the relationship and the love, care and support they offer around the clock.

In this thesis, qualitative findings have been triangulated through the quantitative mapping of findings and results to RAM. Further, this research has utilised all four levels of RAM and not just focused on one or two aspects of the model as previous studies have done. It has highlighted the difficulties faced by clinical participants, the key role of partners, and identified a model of care appropriate for use in the urology clinic with patients and partners.

This final thesis chapter has explained the integration of this MMR approach and the opportunities that allowed these integrations to occur. It has highlighted how the findings and results have mapped to the research questions first posed in Chapter 1. This has included what was known about BlCa, the QoL, physical and psychosocial experiences and the elements that informed a model of care. The six-step model developed from this research was depicted, with an explanation of each step. Future research proposed to test the model and implement the urologic-oncology nurse role.

This thesis sought to add an original contribution to knowledge on the topic of BlCa and its effects on the lives of patients and partners. It has done so in terms of further describing the firsthand experiences of living with BlCa, and in drawing attention to the importance of the

Healthcare Environment. It has highlighted the importance of urinary, bowel and sexual function and burden, noting their role in adaptation, and has distinguished that clinical participants found the psychological perception of burden to be more troublesome than self-reported loss of function. Further, the significance of social and family support in negating the cognitive distress of clinical participants was emphasised. From the models tested, this appeared to be the strongest and most positive adaptive mechanism. Importantly, the research has shown the benefits of partner support and its assistance for clinical participants' acceptance of, and adaptation to, their BlCa. Finally, these observations have been assimilated into a proposed holistic model of care that, if implemented, should result in a more satisfying journey, and better QoL for patients with BlCa and their partners.

APPENDICES

APPENDIX A

BLADDER CANCER

A1. ***Staging of primary tumours in bladder cancer***

TX: Primary tumour cannot be assessed

Ta: Non-invasive papillary carcinoma Tis: Carcinoma in situ

T1: Tumour invades lamina propria

T2: Tumour invades muscularis propria

T2a: Invades superficial muscularis propria (Inner half)

T2b: Invades deep muscularis propria (outer half)

T3: Tumour invades perivesical tissue/fat

T3a: Invades perivesical tissue/fat microscopically

T3b: Invades perivesical tissue fat macroscopically (extravisical mass)

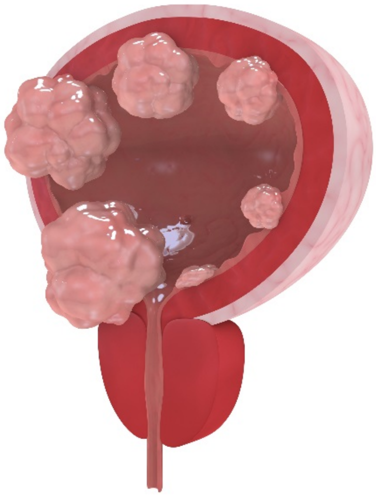
T4: Tumour invades prostate, uterus, vagina, pelvic wall, or abdominal wall

T4a: Invades adjacent organs (uterus, ovaries, prostate stoma)

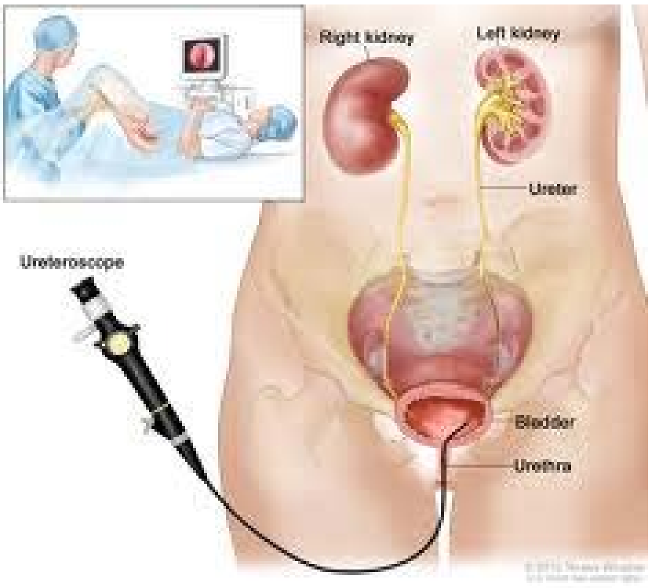
T4b: Invades pelvic wall and/or abdominal wall

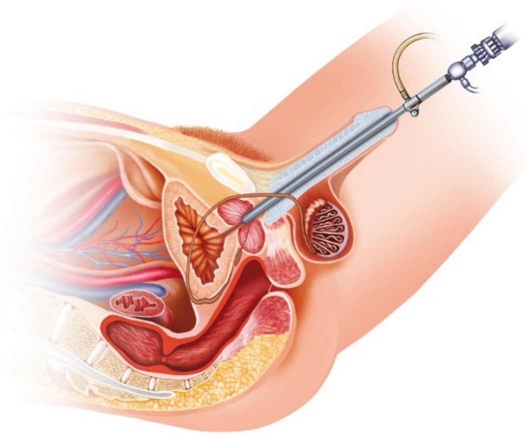
(Hall *et al.* 2014)

A2. ***Bladder Cancer Tumour Staging (Dreamtime_xl_10332957)***



A3. *Cystoscopy* (Winslow 2010)





A3. *Cystoscopy* *(Dreamstime_xl_28569244)*

APPENDIX B

LITERATURE REVIEW

B1. ***Database Search Strategy - Ovid-Medline***

#	Searches	Results	Annotations
1	Urinary bladder neoplasms/ or (bladder* adj3 (cancer* or neoplas* or tumour* or tumor* or carcinoma* or malignan*)).tw,kw.	58857	Bladder cancer search
2	Px.fs. or Adaptation, Psychological/ or Anxiety/ or Depression/ or Perception/ or Fear/ or Self concept/ or Personal satisfaction/ or "Attitude to death"/ or Comprehension/ or Confusion/ or Depressive disorder/ or Emotions/ or Mental disorders/ or Mental health/ or Resilience, psychological/ or Attitude to health/ or Patient satisfaction/ or Body image/ or Stress, Psychological/ or Sexual Dysfunctions, Psychological/ or Sexuality/ or Sexual behavior/ or Affective symptoms/ or Expressed emotion/	1281616	
3	(psycholog* or psychosocial* or psycho-social* or mental* or emotion* or resilien* or anxiet* or anxious or depression or depressive or fear* or distress* or self concept* or self image or self confiden* or body image* or satisfaction or attitud* or perception* or belief* or perceived or comprehension* or sexual*).tw,kw.	1536014	
4	2 or 3	2144700	Psychological aspects – combined MeSH and textwords
5	Patient participation/ or Patient preference/ or Autonomy/ or Life style/ or Social support/ or Interpersonal relations/ or Decision making/ or Life change events/ or Family/ or Caregivers/ or "Cost of illness"/ or Social adjustment/ or Social participation/ or Consumer participation/ or Family health/ or Spouses/ or "Attitude of health personnel"/ or Sick role/ or Stigma/ or Professional-Patient Relations/	520779	
6	((patient* adj2 (preference* or choice* or decision* or autonomy or participation)) or Life style or lifestyle or Social support or Interpersonal* or inter-personal* or relationships or Family or spous* or carer* or Caregiver* or burden or Social adjustment or (Social* adj2 participat*) or Sick role or Stigma*).tw,kw.	1197823	
7	5 or 6	1547192	Social aspects – combined MeSH and textwords
8	Quality of life/ or Urinary incontinence/ or Urination disorders/ or Sexual Dysfunction, Physiological/ or Erectile dysfunction/ or Pain/ or Coitus/ or Libido/ or "Activities of Daily Living"/ or Adaptation, physiological/ or "Recovery of function"/ or Fatigue/	467701	
9	("quality of life" or QoL or HRQoL or HQoL or unmet need* or dysfunction* or pain* or "activities of daily living" or ADL or recovery or fatigue or physical activit*).tw,kw.	1472866	
10	8 or 9	1687384	Physical aspects – combined MeSH and textwords
11	1 and (4 or 7 or 10)	5853	Bladder cancer AND combined aspects search

12	interviews as topic/ or focus groups/ or narration/ or self report/ or qualitative research/ or "Surveys and questionnaires"/	431542	
13	((semi-structured or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide? or group*) adj3 (discussion* or questionnaire*)).tw,kw.	32276	
14	(Interview* or focus group* or diary or diaries or transcrib* or verbatim or field not* or memo? or memoing).tw,kw.	348702	
15	(audiotap* or audio-tap* or audio record* or audiorecord* or tape record* or taperecord* or video*).tw,kw.	101262	
16	((context* or semantic or content) adj2 analys*).tw,kw.	20871	
17	(narrat* or qualitative* or ethnograph* or fieldwork or field work or field research* or informant* or phenomenolog* or hermeneutic* or grounded or interpretive* or participant observ* or background observ* or reflective* or reflection* or textual* or open-ended or theme? or thematic* or triangulat*).tw,kw.	376161	
18	(((personal* or patient* or participant* or lived) adj2 (experience or experiences or perception* or perceptive or perspective*)) or patient reported outcome* or PROM or PROMs or PROs).tw,kw.	78571	
19	or/12-18	1108618	Methods/approaches search
20	11 and 19	447	Topic and methods search combined
21	limit 20 to English language	402	

B1. ***Database Search Strategy (continued) - CINAHL (EBSCOHOST)***

#	Query	Limiters/Expanders	Results
S1	(MH "Bladder Neoplasms")	Search modes - Boolean/Phrase	1,722
S2	TI ((bladder* N3 (cancer* or neoplas* or tumour* or tumor* or carcinoma* or malignan*))) OR AB ((bladder* N3 (cancer* or neoplas* or tumour* or tumor* or carcinoma* or malignan*)))	Search modes - Boolean/Phrase	1,416
S3	S1 OR S2	Search modes - Boolean/Phrase	2,136
S4	MW psychosocial factors	Search modes - Boolean/Phrase	204,257
S5	(MH "Adaptation, Psychological")	Search modes - Boolean/Phrase	14,381
S6	(MH "Coping")	Search modes - Boolean/Phrase	19,539
S7	(MH "Anxiety") OR (MH "Anticipatory Anxiety")	Search modes - Boolean/Phrase	17,790
S8	(MH "Depression") OR (MH "Depression, Reactive")	Search modes - Boolean/Phrase	48,019
S9	(MH "Perception") OR (MH "Self Concept")	Search modes - Boolean/Phrase	28,287
S10	(MH "Fear")	Search modes - Boolean/Phrase	5,808
S11	(MH "Personal Satisfaction")	Search modes - Boolean/Phrase	4,504
S12	(MH "Attitude to Death") OR (MH "Attitude to Illness")	Search modes - Boolean/Phrase	11,581
S13	(MH "Confusion")	Search modes - Boolean/Phrase	1,263
S14	(MH "Emotions") OR (MH "Suffering")	Search modes - Boolean/Phrase	12,089
S15	(MH "Mental Health") OR (MH "Positive Psychology") OR (MH "Psychological Well-Being")	Search modes - Boolean/Phrase	22,158
S16	(MH "Mental Disorders")	Search modes - Boolean/Phrase	29,439
S17	(MH "Hardiness")	Search modes - Boolean/Phrase	3,886
S18	(MH "Patient Satisfaction")	Search modes - Boolean/Phrase	27,678
S19	(MH "Body Image") OR (MH "Personal Appearance")	Search modes - Boolean/Phrase	6,376

S20	(MH "Stress") OR (MH "Stress, Psychological")	Search modes - Boolean/Phrase	26,804
S21	(MH "Sexual Dysfunction, Male") OR (MH "Sexual Dysfunction, Female") OR (MH "Psychosexual Disorders")	Search modes - Boolean/Phrase	2,488
S22	(MH "Sexuality") OR (MH "Attitude to Sexuality")	Search modes - Boolean/Phrase	17,290
S23	(MH "Affective Symptoms")	Search modes - Boolean/Phrase	1,188
S24	TI ((psycholog* or psychosocial* or “psycho-social*” or mental* or emotion* or resilien* or anxiet* or anxious or depression or depressive or fear* or distress* or “self concept*” or “self image” or “self confiden*” or “body image*” or satisfaction or attitud* or perception* or belief* or perceived or comprehension* or sexual*)) OR AB ((psycholog* or psychosocial* or “psycho-social*” or mental* or emotion* or resilien* or anxiet* or anxious or depression or depressive or fear* or distress* or “self concept*” or “self image” or “self confiden*” or “body image*” or satisfaction or attitud* or perception* or belief* or perceived or comprehension* or sexual*))	Search modes - Boolean/Phrase	371,470
S25	S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24	Search modes - Boolean/Phrase	559,894
S26	(MH "Consumer Participation")	Search modes - Boolean/Phrase	10,892
S27	(MH "Autonomy") OR (MH "Patient Autonomy")	Search modes - Boolean/Phrase	8,884
S28	(MH "Life Style Changes") OR (MH "Life Style")	Search modes - Boolean/Phrase	19,093
S29	(MH "Support, Psychosocial")	Search modes - Boolean/Phrase	39,834
S30	(MH "Interpersonal Relations")	Search modes - Boolean/Phrase	20,577
S31	(MH "Decision Making") OR (MH "Decision Making, Patient")	Search modes - Boolean/Phrase	32,525
S32	(MH "Life Change Events") OR (MH "Role Change") OR (MH "Life Experiences")	Search modes - Boolean/Phrase	16,858
S33	(MH "Family") OR (MH "Family Relations") OR (MH "Family Functioning") OR (MH "Family Coping") OR (MH "Spouses") OR (MH "Patient-Family Relations")	Search modes - Boolean/Phrase	39,816

S34	(MH "Caregivers")	Search modes - Boolean/Phrase	18,569
S35	(MH "Attitude of Health Personnel")	Search modes - Boolean/Phrase	20,567
S36	(MH "Sick Role")	Search modes - Boolean/Phrase	928
S37	(MH "Stigma")	Search modes - Boolean/Phrase	7,001
S38	(MH "Professional-Patient Relations")	Search modes - Boolean/Phrase	19,524
S39	TI (((patient* N2 (preference* or choice* or decision* or autonomy or participation)) or “Life style” or lifestyle or “Social support” or Interpersonal* or “inter-personal*” or relationships or Family or spous* or carer* or Caregiver* or burden or “Social adjustment” or (Social* N2 participat*) or “Sick role” or Stigma*)) OR AB (((patient* N2 (preference* or choice* or decision* or autonomy or participation)) or “Life style” or lifestyle or “Social support” or Interpersonal* or “inter-personal*” or relationships or Family or spous* or carer* or Caregiver* or burden or “Social adjustment” or (Social* N2 participat*) or “Sick role” or Stigma*))	Search modes - Boolean/Phrase	275,933
S40	S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39	Search modes - Boolean/Phrase	412,754
S41	(MH "Quality of Life") OR (MH "Life Purpose")	Search modes - Boolean/Phrase	48,150
S42	(MH "Urinary Incontinence")	Search modes - Boolean/Phrase	5,793
S43	(MH "Urination Disorders")	Search modes - Boolean/Phrase	897
S44	(MH "Impotence")	Search modes - Boolean/Phrase	2,570
S45	(MH "Pain") OR (MH "Chronic Pain")	Search modes - Boolean/Phrase	47,601
S46	(MH "Activities of Daily Living")	Search modes - Boolean/Phrase	18,111
S47	(MH "Adaptation, Physiological")	Search modes - Boolean/Phrase	3,618
S48	(MH "Functional Status")	Search modes - Boolean/Phrase	14,314
S49	(MH "Fatigue")	Search modes - Boolean/Phrase	8,812

S50	TI (("quality of life" or QoL or HRQoL or HQoL or “unmet need*” or dysfunction* or pain* or "activities of daily living" or ADL or recovery or fatigue or “physical activit*” or “physically active”)) OR AB (("quality of life" or QoL or HRQoL or HQoL or “unmet need*” or dysfunction* or pain* or "activities of daily living" or ADL or recovery or fatigue or “physical activit*” or “physically active”))	Search modes - Boolean/Phrase	242,265
S51	S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50	Search modes - Boolean/Phrase	302,694
S52	S25 OR S40 OR S51	Search modes - Boolean/Phrase	958,074
S53	S3 AND S52	Search modes - Boolean/Phrase	417
S54	S3 AND S52	Limiters - Published Date: 20110101-20161231; English Language Search modes - Boolean/Phrase	131

B1. ***Database search strategy (continued) - PsycINFO***

#	Searches	Results
1	exp Bladder/ and exp Neoplasms/	55
2	(bladder* adj3 (cancer* or neoplas* or tumour* or tumor* or carcinoma* or malignan*)).tw,id.	159
3	1 or 2	164
4	exp Adaptation/ or exp Adjustment/ or exp Major Depression/ or exp Emotional Adjustment/ or exp Well Being/ or exp Coping Behavior/	230361
5	exp ANXIETY/	58664
6	exp REACTIVE DEPRESSION/ or exp "DEPRESSION (EMOTION)"/	23126
7	exp SELF-PERCEPTION/ or exp PERCEPTION/	297598
8	exp FEAR/	17677
9	exp Self-Concept/	64298
10	exp Self-Esteem/	22656
11	SATISFACTION/ or CONSUMER SATISFACTION/ or CLIENT SATISFACTION/ or LIFE SATISFACTION/	26204
12	Death Attitudes/ or Death Anxiety/ or Preferences/	19905
13	Decision Making/ or MENTAL CONFUSION/ or Emotional Trauma/	74757
14	NEGATIVE EMOTIONS/ or EMOTIONS/ or POSITIVE EMOTIONS/	37241
15	Mental Health/	48900
16	Mental Disorders/	72816
17	exp "RESILIENCE (PSYCHOLOGICAL)"/	8945
18	Body Image/	8963
19	PSYCHOLOGICAL STRESS/ or STRESS/	56811
20	Sexual Function Disturbances/ or Psychosexual Behavior/ or Erectile Dysfunction/	28399
21	SEXUALITY/	13132
22	expressed emotion/	1361
23	(psycholog* or psychosocial* or psycho-social* or mental* or emotion* or resilien* or anxiet* or anxious or depression or depressive or fear* or distress* or self concept* or self image or self confiden* or body image* or satisfaction or attitud* or perception* or belief* or perceived or comprehension* or sexual*).tw,id.	1877841
24	PARTICIPATION/	6799
25	autonomy/	6247
26	"Quality of Life"/ or Lifestyle/	40454

27	Social Support/	30039
28	Interpersonal Interaction/ or Interpersonal Relationships/ or Interpersonal Communication/	56593
29	Life Changes/	3344
30	FAMILY RELATIONS/ or FAMILY/ or FAMILY MEMBERS/	82967
31	spouses/ or husbands/ or wives/ or significant others/	15923
32	Caregivers/	22253
33	Financial Strain/	2294
34	Social Adjustment/	9196
35	stigma/	8284
36	((patient* adj2 (preference* or choice* or decision* or autonomy or participation)) or Life style or lifestyle or Social support or Interpersonal* or inter-personal* or relationships or Family or spous* or carer* or Caregiver* or burden or Social adjustment or (Social* adj2 participat*) or Sick role or Stigma*).tw,id.	635444
37	Urinary Incontinence/	1842
38	Urinary Function Disorders/	499
39	PAIN/	21194
40	"Sexual Intercourse (Human)"/	2559
41	LIBIDO/	623
42	Daily Activities/ or "Activities of Daily Living"/ or Physical Activity/ or Activity Level/	28422
43	"Recovery (Disorders)"/	10361
44	FATIGUE/	7244
45	("quality of life" or QoL or HRQoL or HQoL or "unmet need*" or dysfunction* or pain* or "activities of daily living" or ADL or recovery or fatigue or physical activit*).tw,id.	296431
46	or/4-45	2519884
47	3 and 46	94
48	limit 47 to English language	88

B1. ***Database search strategy (continued) - Informit (Health subsets only)***

((psycholog* OR psychosocial* OR "psycho-social"* OR mental* OR emotion* OR resilien* OR anxiet* OR anxious OR depression OR depressive OR fear* OR distress* OR "self concept"* OR "self image" OR "self confiden"* OR "body image"* OR satisfaction OR attitud* OR perception* OR belief* OR perceived OR comprehension* OR sexual*) OR (((preference* OR choice* OR decision* OR autonomy OR participation) % patient*)) OR ("Life style" OR lifestyle OR "Social support" OR Interpersonal* OR "inter-personal"* OR relationships OR Family OR spous* OR carer* OR Caregiver* OR burden OR "Social adjustment") OR ((Social* %2 participat*) OR "Sick role" OR Stigma*) OR ("quality of life" OR QoL OR HRQoL OR HQoL OR "unmet need"* OR dysfunction* OR pain* OR "activities of daily living" OR ADL OR recovery OR fatigue OR "physical activit"*)) AND (((cancer* OR neoplas* OR tumour* OR tumor* OR carcinoma* OR malignan*) %3 bladder*))

Table B2. ***Summary Table of Included Quantitative and Mixed Methods Studies***

Author (S) /Year /Location	Purpose	Methodology/ Instruments	Sample	Major Results	Recommendations
D′Agostino, D, Racioppi, M, Pugliese, D, Ragonese, M, Di Gianfrancesco, L, Filianoti, A, Palermo, G, Belgrano, E, Siracusano, S, Niero, M, Imbimbo, C, Iafrate, M, Artibani, W, Cerruto, MA, Talamini, R & Bassi, P . 2016 Italy.	To evaluate the differences in the patients after radical cystectomy and ileal orthotopic neobladder at different follow-up times, 1)12-18 months, 2) 19-36 months, 3) 37-72 months, and 4) > 72 months.	Multicentre cross-sectional study using validated questionnaires EORTC QLQ-C30, IOB-PRO and EORTC QLQ-BlM30, which were completed at an interview with the participant at various intervals post-surgery. The questionnaires identified QoL issues relevant to radical cystectomy and ileal neobladder.	N = 171 patients who had undergone radical cystectomy and orthotopic neobladder. Mean age 66 years. Males 91.2%.	Physical function improved long term. Cognition remained stable. Independence of daily activities significantly increased long term which may be due to experience and adaptation. Good global QoL long term. Perception of body image increases over time but over 5 years it starts to decrease possibly due to relevance in older age. Social related aspects peaked at 72 months and then decrease possibly due to increased urinary symptoms, increased age and decrease in ability to manage the neobladder with age. Fatigue and sleep disorders affected all patients gaining in intensity long term. Sex life was better at short and medium term follow-up but decreased long term with more problems over time possibly due to the decrease in socioemotional, body image issues, aging and comorbidities. Difficulties managing and emptying the neobladder increased over time particularly at night which negatively affected QoL.	Pre-surgery education of the positive and negative aspects of a neobladder should be explained to patients. Their active participation in treatment decision making may be a key to more improved QoL at follow-up.

Li, M-Y, Yang, Y-L, Liu, L & Wang, L. 2016 China	To asses QoL and the effects of social support, hope and resilience in Chinese BlCa patients post-surgery.	Cross-sectional Questionnaire Demographics FACT-BL Perceived Social Support Scale, Adult Hope Scale, Resilience Scale.	N=188 Post-surgical treatment Mean age 63.76 Males 80.9%	QoL in patients >75 years is significantly lower. Higher education leads to higher QoL. Social support, hope and resilience have a significant effect on QoL in Chinese BlCa patients.	Positive social and psychological resources to support QoL. Targeted positive psychological interventions to support QoL. Pay attention to less educated patients.

Liu, C, Ren, H, Li, J, Li, X, Dai, Y, Liu, L, Li, M, He, Q & Li, X. 2016 China	To assess QoL of BlCa patients and factors that affect QoL after ileal conduit.	Cross-sectional questionnaire survey. Stomal Self-management Scale, Social Support Revalued Scale, WHOQOL-BREF.	N=188 Post ileal conduit (1 month -2 years). Male 80.9% > 60 years (66%)	Overall QoL was good but sexual satisfaction was poor. Changes to urination patterns. Males > 60 years had worse QoL than females and < 60 years. Employed patients (22%) had better QoL. Better social support and stomal self-management improved QoL.	Nursing care to promote social and family supports, and stomal self-management for improved physical and psychological health and QoL particularly in older patients, men, and patients who are not employed or who are from low socioeconomic groups.

Schmidt S, Frances, A, Garin, JAL, Juanpere, N, Trull, JL, Bonfill, X, Marinez-Zapata, MJ, Suarez-Varela, MM, de la Cruz, J, Emparanza, JI, Sanchez, M-J & Zamora, J. 2015 Spain	To describe the evolution and HRQoL of non-muscle invasive bladder cancer (NMIBlCa) cancer over time and identify clinical treatment related to HRQoL adaptation in the first year of managing bladder cancer.	Observational multicentre prospective cohort study from diagnosis of biopsy to follow up at 6 and 12 months. Interviews of socio-demographic characteristics and questionnaires. Health Survey Short Form-36 version 2 and Bladder Cancer Index. Responses were compared with population norms.	N=244 consecutive patients with NMIBlCa undergoing TURBT in 7 Spanish hospitals. Mean age 70 years. Males 84%. 144 had TURBT only, 82 had combined intravesical TURBT + BCG or chemotherapy.	Patient’s had low mental scores and urinary, bowel and sexual problems. At 12 months using TURBT only or + mitomycin C improved urinary and bowel symptoms, but sexual declined. TURBT with BCG had small bowel and urinary improvement and sexual stability. Mental health was below normal at diagnosis and 6 month follow-up, improved with TURBT + mitomycin C. Urinary issues improved from diagnosis to 12 months, bowel was stable, sexual function decreased, sexual bother remained stable. Significant differences seen by gender, age education, tumour grade and comorbidities.	Clinicians should be aware of deteriorating mental health from time of diagnosis. Urinary symptoms may improve with TURBT with or without BCG or mitomycin C. Bowel and sexual domains may improve with combined TURBT with BCG and mitomycin C.

Imbimbo C, Mirone, V, Siracusano, S, Niero, M, Cerruto, MA, Lonardi, C. 2015 Italy	To assess HRQoL in patients with Ileal Orthotopic Neobladder to identify clinical pathologic predictors of HRQoL.	Prospective multicentre observational study. EORTC generic QLQ-C30, BlCa specific QLQ-BLM30 and IONB-PRO.	N = 174 Ileal Orthotopic Neobladder patients from 5 urology centres. Median age 66 years Males 91.4% Median follow-up 37months.	Being > 65 years, with urinary incontinence, influences HRQoL and predict worse body image and urinary symptoms. Urinary continence was indicative of worse body image but also better functioning in emotions, fatigue and relationships. Peripheral vascular disease and > 36 months follow-up were indicative of better QoL.	When counselling patients pre and post IONB age, urinary incontinence and co-morbidities should be taken into account as well as follow-up time in relation to HRQoL. Age is not a contraindication though counselling is advised.

Bartsch G, Daneshmand, S, Skinner, EC, Syan, S, Skinner, DG & Penson, DF 2014 USA	To investigate the urinary function of female patients with a neobladder and assess HRQoL and long-term outcomes	Single centre cohort study. Questionnaires contained the Bladder Cancer Index (urinary domain only) and un-validated items querying the need for intermittent catheterization, problems and preferences.	N=56 Female patients with a neobladder. Median age 61.4 years	Higher educated patients had worse urinary function and bother. Those with organ confined BlCa had better urinary function and bother. 16 reported leakage every day, 19 during sleep. 35 depended on CIC to empty the neobladder. 25 to empty the neobladder daily. 3 used CIC 1-2 daily, 4 used it 3-4 times a day, and 6 used it 4 times a day. 33 preferred to use CIC than have leakage. Patient prefer to use CIC than have leakage. CIC did not bother anyone.	Extensive preoperative information on the expectations of the neobladder and CIC may elevate higher expectations of well educated women. The high rate of CIC is the highest recorded in the literature without clear explanation of this urinary retention. Stress incontinence may cause leakage.

Benner C, Greenberg, M, Shepard, N, Meng, MV & Rabow, MW. 2014 USA	To characterize the history of symptoms over time in BlCa patients. undergoing cystectomy	Prospective cohort study - baseline pre cystectomy, with a follow-up at 2, 4 and 6 months, as were family caregivers. Measures-pain, fatigue, depression, anxiety, HRQoL, spiritual well-being. Using the BPI Cancer Fatigue Scale, HADS, Functional Assessment of Chronic Illness Therapy-Spirituality (FACIT-SP-12), FACT-G, and Patient Satisfaction Questionnaire III and an exit interview. Caregivers used the Zarit Burden Inventory and FAMCARE survey.	N = 33 patients with muscle invasive bladder cancer (MIBlCa). Patients and family caregivers. Mean age 65 in 2004, 68.3 in 2011-12. Males 22 in 2004, 19 in 2011-12. Neobladder 14 in 2004, 7 in 2011-12. Ileal conduit 9 in 2004, 15 in 2011-12. N=19 caregivers, 3 left as their partner died.	Post cystectomy pain remains high for 6 months. Depression increased slightly after surgery. No improvements in mood, fatigue, HRQoL or spiritual well-being at 6 months. Improvements seen in post-traumatic growth up to 2 months, then falling back to baseline. No change over time with depression, anxiety, QoL, spirituality, well-being or satisfaction. Family caregivers reported no burden nor satisfaction changes over time with the peak burden being 2 months post cystectomy. In exit interviews patients reported being satisfied with treatment.	Post cystectomy pain requires more aggressive assessment and treatment.

Fung C, Pandya, C, Guancial, E, Noyes, K, Sahasrabudhe, DM, Messing, EM & Mohile, SG. 2014 USA	To compare HRQoL in patients before and after their BlCa diagnosis.	Cross sectional study questionnaire pre and post diagnosis. Assessed differences in physical and mental scores. Measures by PCS and MCS scores of SF-36 version 1 or VR-12. PCS-physical function, role-physical, bodily pain, general health. MCS-vitality, social function, role-emotional, mental health.	N=620 pre diagnosis patients aged > 65 years from the SEER-MHOS database. Pre-diagnosis males 80.6%. Post-diagnosis N= 856, of these 179 completed both pre and post questionnaires. Mean age at diagnosis 76.4 years. Males 77.2%.	Significant difference in physical and mental scores pre and post diagnosis for first 5 years. Most had NMIBlCa pre-diagnosis 77.4%, post-diagnosis 88%. MCS scores differed at any interval. 4 or more comorbidities and 1 or more ADL deficits were more likely to have low physical scores. Worse HRQoL in urinary and sexual domains was seen in bladder reconstruction. Ileal conduit patients had a worse body image, travel and activity levels and were more self-conscious. Continent diversion resulted in urinary symptoms and catheter complaints. Neobladder night time leakage had a negative HRQoL impact.	Age, comorbidities and function require addressing in decision making as they can lead to differences in HRQoL as can patient's acceptance and tolerance of MIBlCa. Interventions are required to improve HRQoL particularly in older patients. Maintenance of HRQoL for patients with MIBlCa could include exercise program or pre-treatment geriatric assessment.

Gomez A, Barbera, S, Lombrana, M, Izquierdo, L & Banos, C. 2014 Spain	To assess HRQoL in patients 6 months post cystectomy and construction of a Bricker-type incontinent urostomy.	Data collected via telephone interview survey using the Stoma quality of life Stoma-QOL instrument 6 months post-surgery. 11 functional patterns evaluated over 20 items.	N=37 patients post-cystectomy with incontinent urinary diversion. Mean age 72 years. Males 80%.	35 participants scored 64-73 (mean 68.54) indicating good HRQoL 6 months post-surgery. 2 participant's scored 30 and 48 indicating moderate HRQoL. No scores indicated a poor QoL. Wound ostomy care nurses should begin education before ostomy surgery and post-operative education as soon as feasible. Participants rated	Nursing care should include ongoing stoma evaluation, include partners or caregivers in teaching and counselling and at least 1 pouch change supervised by the nurse. Encourage discussion on doubts, fears, difficulties, transition to ostomy care to community and social support.

Goosens-Laan, CA, Kil, PJM, Bosch, JLHR & De Vries, J. 2014 Netherlands	To measure QoL, health status and sexual function in patients diagnosed with BlCa who underwent RC and examine the differences between health status and QoL outcome.	Prospective case control study. Questionnaires at pre-diagnosis, 3, 6, and 12 months post-cystectomy. WHOLQOL-BREF, STAI-Trait Anxiety Inventory, RAND medical outcomes Study Short Form-12, Functional Assessment of Cancer Therapy-Bladder Cancer FACT-BL, International Index of Erectile Function IIEF, demographics.	N = 476 consecutive patients with haematuria of unknown cause pre diagnosis at 6 academic large teaching departments of urology. Post diagnosis N=18 RC patients mean age 62.3 years, males 77.8%. Neobladder 5 males, ileal conduit 9 males, 4 female. N=20 case controls, mean age 64.9 years, males 85%.	BlCa patients had the same QoL as Controls but lower physical and sexual function pre-diagnosis. RC patients had better QoL and health status pre-diagnosis than post cystectomy which did not return to baseline after 1 year. Patients 3-12 months post RC had worse physical, psychological, social relationships, environmental and sexual activity scores. Physical function, role limitations, energy, and fatigue were lower for RC patients. RC mental scale was higher pre diagnosis than Controls but similar or lower post-RC. In all IIEF fields RC patients scored worse than Controls at pre-diagnosis, 3, 6, and 12 months post-RC. FACT-BL showed 1 year scores were the same as 3 month post RC scores. Physical, emotional and social domains remained stable over time but functional well-being decreased.	Expand this research with a larger sample and include comorbidities and smoking history.

Kowalkowski MA, Chandrashekar, A, Amiel, GE, Lerner, SP, Wittmann, DA, Latini, DM & Goltz, HH. 2014 USA	To evaluate the impact of sexual dysfunction of survivors of non-muscle invasive bladder cancer (NMIBlCa) and describe psychosocial characteristic of patients reporting differing sexual function.	Mixed methods. Study 1 - cross-sectional survey using European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Bladder Cancer Superficial-24, Illness Intrusiveness Rating Scale, Brief Symptoms Index - 18. Study 2 - Qualitative interviews for 48-120 minutes. Constant comparative and thematic analysis.	Study 1 N=117, veterans from a tumour registry and patients from an academic urology clinic. Mean age 64.6 years, males 72.6%. Study 2 N=26 recruited from the same VA registry and urology clinic and from a bladder survivorship website. Mean age 69.1 years. Males 84%.	Study 1-NMIBlCa treatment was linked to relationship and sexual issues. ED 60%, vaginal dryness 62.5%, worry re contaminating partner with treatment agent 23.2%. Talking to their partner about sexual issues was useful, only 1/5 reported all concerns. The importance of communication was stressed. Study 2- 50% of participants reported sexual dysfunction, 2/3 had a negative impact on relationships, perceived loss of intimacy and divorce, over 1/3 were concerned about contamination their partner or spreading NMIBlCa and so were sexually inactive.	Pre- treatment talks and information on sexual side effects and need for communication and are required. Information about contaminating partners with the treatment agent may stop couples from avoiding sex. Sex therapy may increase their repertoire. Communication about fears and concerns regarding sexual abilities, desires and dysfunction may assist couples. Social worker may assist in grieving.

Rouanne, M, Legrand, G, Neuzillet, Y, Ghoneim, T, Cour, F, Letang, N, Yonneau, L, Hervé, J-M, Botto, H & Lebret, T. 2014 France	To define HRQoL among long-term disease free female survivors who underwent radical cystectomy and orthotopic neobladder reconstruction. Specifically, daytime and night-time urinary incontinence and hyper-continence.	Three validated questionnaires-the medical outcomes study short form 12 SF-12, the urinary symptoms profile and the Contilife to evaluate general HRQoL, voiding and urinary incontinence. Participants had a personal interview with a male interviewer to gather data on HRQoL and continence status e.g. Urine leakage, pad usage, need to self-catheterize.	N=31 women who had had an orthotopic neobladder reconstruction. Mean age 64.8 years. Mean post-operative follow up 68 months.	After cystectomy there were 9 complications -ileal bladder fistula, severe sepsis, small bowel obstructions, pyelonephritis, abdominal hernias, and vaginal fistulas. Day and night continence was 74 and 71%. 74% used 1 pad a day 80% used 1 at night. Day time stress urinary incontinence (SUI) was 10-27%. 8 had daytime leaks. 29% had nocturnal leakage. 25% depended on self-intermittent catheterization (SIC). 29% had hyper-continence. HRQoL was lower in women who needed SIC. 18 were sexually active due to nerve sparing surgery. Being > 65 years was associated with post-operative daytime SUI. 24 women had good-excellent health, 25 were a little/not embarrassed socially or in relationships, 22 felt good about themselves. Being aged < 60 at surgery predicted continence.	It is suggested that orthotopic neobladder is safe for women and preserves physical and mental wellbeing and maintains HRQoL. Women should be informed using meaningful data when making treatment choices.

Tejido-Sanchez A, García-González, L, Jiménez-Alcaide, E, Arrébola-Pajares, A, Medina-Polo, J, Villacampa-Aubá, F & Díaz-González, R. 2014 Spain	To determine variable that might affect quality of life in patients treated by radical cystectomy with ileal conduit	Questionnaires study EQ-5D-3L assessed QoL and evaluated mobility, personal care, daily activities, pain/ discomfort, anxiety/ depression and the health condition. Included were tumour characteristics, adjuvant therapy, comorbidities and socio-economics	N=59 Mean age 69 years. Males 84.7% Mean time since cystectomy 43 months.	61% of complications were associated with the stoma. There were 86 complications under 8 variables. Particularly retraction, stenosis and prolapse affected 25-30% of patients. Lower QoL was associated with chemotherapy and stoma complications. These limited personal care, pain/ discomfort, anxiety and QoL. Females were more limited in daily activities and general QoL, had adjuvant chemotherapy, and anxiety /depression.	The QoL is mainly affected by stoma complications which affect personal care and mood disorders and are associated with pain and discomfort which decrease QoL. Having adjuvant chemotherapy, and being female affects mood, daily activities and limits QoL.

Singer S, Ziegler, C, Schwalenberg, T, Hinz, A, Götze, H & Schulte, T. 2013 Germany	To answer three questions which comparing how patients with BlCa vary from the general population in QoL, if patients with RC differ in QoL from those who had conservative treatment, and if patients with a neobladder have better QoL than those with other diversion types?	Cross sectional study. EORTC QLQ-C30 questionnaire measured QoL	N = 823 patients with either MIBlCa or NMIBlCa. Plus, a control of N= 2037 community sample for comparison. Mean age 67 years. Males 71%.	Patients with any type of BlCa had worse functioning and more problems than those in the community. Radiotherapy caused more pain, dyspnoea, constipation, appetite loss and less social functioning. Chemotherapy caused more dyspnoea. Cystectomy patients had more fatigue, appetite loss and lower role functioning. Males 70 years or older with a conduit had more sleep and emotional problems	Patients should be informed prior to any treatment that QoL could be affected and to what degree so they do not have overly optimistic expectations they find disappointing or depressing. Adding radiotherapy to the treatment should be carefully considered as it has the most negative effect on QoL. Patients >70 years may have less problems with a continent diversion than a conduit

Tal R, Cohen, MM, Yossepowitch, O, Golan, S, Regev, S, Zertzer, S & Baniel, J. 2012 Israel	To identify predictors of self-stoma care and the impact on QoL after urostomy formation in patients with an ileal conduit.	Prospective questionnaire study. Telephone interviews using a non-validated questionnaire specific to the study questions including demographic data, stoma care patient education data and QoL parameters	N=65 patients who had undergone an ileal conduit post RC. Mean age 71.9 years. Males 80%. Mean follow up 30 months.	Female gender predicted self stomal care. Perceived quality of pre and post-surgery education was higher in those who self-managed their stoma. Believing that their questions were answered before surgery, good stomal bag training and greater stomal care skills at discharge and 1 month after were predictors of long-term self-care. Stomal self-care was related to higher QoL and psychological impact which were also correlated with perceived quality of pre and post-operative education. Only 52% cared for their stoma due to physical limitations, and psychological issues (body image, repulsion, denial, avoidance). Others who cared for the stoma were spouse 64%, sibling10%, stoma nurse 16%other assistant 10%.	Results regarding education may suggest that post-operative education has a greater effect on skills levels, and subsequently ability to self-care, which improves QoL and psychological functioning. Earlier post-operative education for a longer period may assist this.

Takenaka A, Hara, I, Soga, H, Sakai, I, Terakawa, T, Muramaki, M, Miyake, H, Tanaka, K & Fujisawa, M. 2011 Japan	To compare post-operative QoL on long-term follow-up with age-matched normative values in a control population	Comparing scores with Age matched normative values. Questionnaires for general health and urinary function via SF-36 and ICSmaleSF, sexual function by the International Index of Erectile Function IIEF-5. Satisfaction with urinary and sexual function by using a visual analogue scale (VAS).	N=86 patients with an orthotopic neobladder followed up for 5 years or more. 3 did not have BlCa. Median age 62 years Males 78. Mean follow-up was 89 months.	Role-physical and role-emotional functioning were significantly lower and bodily pain was better than age matched population. The need for clean intermittent catheterization (CIC) and day time incontinence resulted in worse scores and affected QoL. 88% of patients lost sexual function five years post-surgery. VAS urinary function satisfaction was 5.63, sexual function was 0.98. Global QoL is generally good though role physical and role emotional may decline over time. Those needing CIC or who had day time incontinence had lower scores.	Pre sexual function and female sexual function were not examined. Surgeons did not believe that patients had the opportunity to be sexually active prior to neobladder and expected better urinary function that what appeared to be the case

Thulin H, Kreicbergs, U, Wijkström, H, Steineck, G & Henningsohn, L. 2010 Sweden	To investigate nocturnal urinary disturbances and QoL in patients who have undergone radical cystectomy (RC)with a urinary diversion	Questionnaire designed through qualitative interviews with men and women post RC. Validated face to face. QoL variables used a visual digital scale. The questionnaire was tested in a pilot study.	N= 452 patients from urological centres. 190 had a urostomy, 82 continent reservoirs and 180 had a neobladder. Mean age urostomy- 70.1, reservoir - 66, neobladder 64.3 years. Males N=348.	Neobladder patients had increased risk of nocturnal urinary leakage and evacuation frequency which affected sleep and QoL. These patients reported negative effects on sleep, frequent emptying, pad use, anxiety. Leakage is defined as moderate to high volume at least once a week. Neobladder patients need to evacuate more at night than in the day and may set an alarm to wake regularly to empty the neobladder to avoid leakage. This reduced QoL affects physical health and energy levels.	Pre-surgery counselling on the nocturnal leakage issues associated with a neobladder may prompt some patients to opt for a different diversion if sleep disturbances are seen as severe. Knowing these side effects beforehand may make them more tolerable. Patients with a neobladder should be screened for sleep disorders.

Hashine K, Miura, N, Numata, K, Shirato, A, Sumiyoshi, Y & Kataoka, M. 2008 Japan	To assess QoL of BlCa patients following bladder preservation therapy (BPT) for muscle invasive bladder cancer (MIBlCa).	Cross-sectional Questionnaire study. International prostate symptoms score IPSS, the SF-36 for general HRQoL, and the Expanded Prostate Cancer Index Composite EPIC questionnaires were used. The EPIC contains questions on bladder, bowel and sexual bother. (Sexual function and bother were used for men)	N=33 patients treated with BPT which includes intra-arterial chemotherapy combined with radiotherapy. Mean age 70 years. Males 28. N=128 patients treated with TURBT for superficial BlCa as a control group. Mean age 71 years. Males 100.	QoL scores for BPT were lower than control. Role physical and role emotional in BPT decreased at 70-80 years. In physical and role function age was the main factor in lower scores. Body pain was found in BPT patients. EPIC showed that urinary function and bother were the same in each group. Irritative symptoms were worse in BPT patients. Bowel function and bother were worse in BPT patients than control. Bowel function depended on type of treatments presumably radiotherapy.	Control group had NMIBlCa using patients who had MIBlCa and underwent RC as the control in future. No baseline QoL so no knowledge of the extent of improvement or decline. No standard protocols for BPT exist these outcomes of acceptable QoL suggest the need for these protocols.

Yuh B, Butt, Z, Fazili, A, Piacente, P, Tan, W, Wilding, G, Mohler, J & Guru, K *et al.* 2008 USA	To determine the effects of robot-assisted radical cystectomy (RARC) on QoL after surgery.	Prospective study. Baseline was 3 weeks prior to surgery, then 1, 3 and 6 months post RARC using FACT-BL. Measuring well-being (WB), physical well-being (PWB), social/ family (SWB), emotional (EWB), functional (FWB) and additional concerns (AC) from the FACT-G. AC relates to body image, urinary, bowel, ostomy problems and erectile dysfunction.	N= 34 participants post RARC. Mean age 65 years. Males 88%.	Significant decrease in PWB at 3 months improving at 6 months to baseline. An expected decline due to debilitating effects of surgery. SWB was constant as most patients had stable supports. EWB was higher than baseline due to the quick recovery. FWB decreased after RARC but attained baseline levels by 6 months post RARC. AC scores improved over time and were higher than baseline by 6 months post RARC. FACT-BL and FACT-G cumulative scores show that other score which decrease at 1 month, improving to better than baseline at 6 months. Initial decline is matched with PWB and FWB for a short period before increasing.	QoL returns to or better than baseline scores by 6 months post RARC. This improvement could allow for adjuvant chemotherapy earlier.

van der Aa MNM, Steyerberg, EW, Sen, EF, Zwarthoff, EC, Kirkels, WJ, van der Kwast, TH & Essink-Bot, M-L. 2008 Netherlands	To compare non muscle invasive bladder cancer patients perceived burden of flexible cystoscopy using cysto-urethroscopic surveillance (CUS), with surveillance microsatellite analysis (MA) in voided urine.	RCT in 10 centres comparing CUS with MA completed a questionnaire 1 week post CUS (each time) for discomfort and pain at 4 time points, preparation for CUS, introduction of scope, undergoing CUS, during hours after CUS. Compared to experiences of MA at the clinic and waiting for results (each time). Physical symptoms, medical usage and general function in the next week post CUS or MA. CUS patients received results after the procedure, MA participants received results 2 weeks later.	Total N=201 participants N=108 patients who had 24 months of 3 CUS and microsatellite analysis (MA) 3 monthly. N= 93 who had MA and CUS at 3, 12, and 24 months or if MA showed positive results. Mean age CUS 68.3, MA 68.2 years. Males CUS 73%, MS 77%.	Insertion of the scope resulted in discomfort 39%, pain in 35%. Micturition was painful and more frequent in the week post CUS 30%, than post MA 12%. Fever with CUS 1% or MA 2%, haematuria CUS 7% or MA 6% were similar. Urge and frequency CUS 34%, MA 25%. Medication or antibiotic use in CUS 3%:10% MA 5%:10%. Impact of daily life CUS 19%, MA 12%. Overall burden was higher in CUS. Dissatisfaction with clinic reception, waiting time and explanations CUS 2%:7%:4%, MA 8%:8%:12%. Older patients had less pain and discomfort post CUS not related to number of times. Waiting time for MA results was burdensome in 19%. There was no explanation for the high level of painful micturition post MA.	Further need of less invasive forms of surveillance but as accurate at detecting BlCa recurrence.

Allareddy V, Kennedy, J, West, MM & Konety, BR. 2006 USA	To examine QoL in long-term BlCa survivors and compare QoL differences between patients who had a radical cystectomy (RC) and those with a bladder intact (BI) including type of urinary diversion that may influence QoL among RC survivors.	Cross sectional questionnaire study. Functional assessment of cancer therapy FACT-BL, and demographic details.	N=259 long-term survivors of BlCa minimum time from diagnosis 45 months. They had RC 82 (mean age 73.4 years, males74.4%), or other therapy with a BI 177 (mean age 73.2, males 78.5%). Of the RC sample, 62 had an immediate cystectomy (IC), and 20 had a RC following other treatments (CFOT). The RC sample had 56 with a conduit and 26 had a continent cutaneous diversion or neobladder.	Patients QoL overall scores were high with high emotional well-being scores. No difference between BI and RC groups or between IC and CFOT. There was no difference in QoL between diversion types. The BI group had worse QoL with lower additional concerns and FACT-BL scores in the > 80 years group there were no other age differences. No differences were seen between the RC and BI groups using FACT-BL meaning that QoL may be equal in these groups. Sexual dysfunction was higher in RC including lack of interest. Few complained of body image issues with no difference between RC and BI.	These long-term survivors may have psychologically adapted to body image and not be affected. More positive emotions around surviving may be present regardless of body image. There is a suggestion that the sample were emotionally stable. Repeated treatment and surveillance in BI patients may have caused their lower QoL scores.

Yoshimura K, Utsunomiya, N, Ichioka, K, Matsui, Y, Terai, A & Arai, Y. 2005 Japan	To assess general health related quality of life (GHRQoL) in patients with superficial BlCa (NMIBlCa), who underwent trans-urethral resection (TUR)	Prospective longitudinal study A questionnaire was completed 1 week before each TUR. Medical Outcomes Study Short-Form-36. At the 1st TUR 93 patients completed the questionnaire, at the 2nd TUR 34 answered, at the 3rd TUR 17, and at the 4th TUR 34 patients responded. Age and gender matched to Japanese norms.	N=133 participants with superficial BlCa undergoing transurethral resection (TUR).	General Health was the most affected and thought to be ‘bad’. Mental health scores for the 1st TUR were severely affected but returned after repeated TURs. Social function and Role Emotion were the worst at the 2nd TUR. 2nd and 3rd TUR Role Physical scores were lower than Japanese norms. There was more Body pain in patients with failed treatment. Physical and social function, role physical and role emotional related to employment status were worse at the 2nd TUR but returned to normal afterwards. Post TUR effects of lower urinary tract symptoms, vesical irritation and dysuria may affect GHRQoL.	Four or more TURs may indicate less problems due to adaptation to the symptoms.

Notes:- *ADL- Activities of Daily Living; BlCa- Bladder Cancer; CC- Case Control; CIC- Clean Intermittent Catheterization; ED- Erectile Dysfunction; EORTC- European Organization for Research and Treatment of Cancer; FACT-G- Functional Assessment of Cancer Therapy-General; HADS- Hospital Anxiety and Depression Scale; HRQoL- Health Related Quality of Life; IC-Ileal Conduit; IONB- Ileal Orthotopic Neobladder; MIBlCa- Muscle Invasive Bladder Cancer; NMIBlCa- Non-Muscle Invasive Bladder Cancer; PRO- Patient reported outcomes; QoL- Quality of Life; RC- Radical Cystectomy; SIC-Self Intermittent Catheterization; SUI- Stress Urinary Incontinence*

Table B2. ***Summary Table (continued) of Included Qualitative Studies***

Author (s) /Year /Location	*Purpose*	*Methodology*	*Participants*	*Major Findings*	*Recommendations*
Mohamed NE, Chaoprang, HP, Hudson, S, Revenson, TA, Lee, CT, Quale, DZ, Zarcadoolas, C, Hall, SJ & Diefenbach, MA. *2014* *USA*	*To examine unmet informational and supportive care needs of BlCa patients with muscle invasive bladder cancer (MIBlCa) along the illness trajectory.*	*Qualitative audio recorded interviews. Face to face interviews with 9 participants and via telephone for 21. Interviews lasted from 1-2 hours. Notes were made at the interview and medical records were viewed to confirm diagnosis, treatment, recurrence or metastasis. The focus was on informational and supportive care needs at diagnosis, post-operatively, and at survivorship 6-72 months post surgery. Content analysis was used.*	*N=30 patients treated with cystectomy for MIBlCa. Recruited from the urology department at Mount Sinai and BCAN website.* *Median age 70 years.* *Males 73.33%*	*At diagnosis unmet information need on urinary diversion options, side effects, self-care, recovery, medical insurance. Unmet psychological needs included depression, worry about body image and sexual function. Post-operative unmet needs included pain, bowel dysfunction, support for stomal appliances, catheters, incontinence. At survivorship unmet needs included depression, body image, sexual dysfunction, adjustment to changes in daily living.*	*Information on CDs, in pamphlets, or websites, but clear advice from a doctor is preferable. Counselling for psychological or emotional distress and use of a screening tool. Follow-up call from the medical team may uncover the need for further referrals. A longer period of stoma self-care training of partners or caregivers in post-operative care is required.*

Cerruto MA, D’Elia, C, Cacciamani, G, De Marchi, D, Siracusano, S, Iafrate, M, Niero, M, Lonardi, C, Bassi, P, Belgrano, E, Imbimbo, C et al. 2014 Italy	To examine the changes in expectations and needs involved in human adaptation and behaviour in patients with ileal conduit after radical cystectomy.	Grounded Theory, multicentre cross-sectional study. Interviews focused on the time before surgery, after surgery and time compared to today at the last follow-up. Follow-up mean 7 years, profiles at 3, 5, 7 and >7 years. Content analysis used.	N= 30 participants purposive sampling used from 3 urology academic centres. Mean age 76.43 years. Males 17.	Two profiles found- Positive-in older patients with longer follow-up, less complications, good ostomy management, resume normal daily activities without restrictions personally and socially = good QoL. Negative-Ostomy means worse QoL. Stoma is difficult to manage, problems existing with a stoma, partial resumption of daily activities.	Innovative strategies for follow-up are required such as qualitative interviews. Patients require adaptation to their urinary diversion and see it as a new phase of life rather than a deterioration of life.

Fitch MI, Miller, D, Sharir, S & McAndrews, A. 2010 Canada	To gain an understanding of participants' experience post radical cystectomy, focusing on QoL, in particular intimacy, sexuality, body image, and sense of femininity / masculinity.	Descriptive qualitative approach. Interviews and focus groups. Interviews for 60 minutes, 12-36 months post radical cystectomy. Content and thematic analysis. Post-analysis participants invited to a focus groups, with men and women separately.	N = 22 participants who had an Ileal conduit (5 males, 4 females), Neobladder (9 males, 4 females). 1 Neobladder convert to Ileal conduit. 12-36 months post-surgery. Recruited from 2 institutions. Males 13, mean age 68.4 years. Females 9, mean age 73.1 years. 2 focus groups-N=6 (5 males).	Lack of knowledge about BlCa. Feeling shock & fear at the diagnosis. Desire for open communication and information. Importance of support from family and friends. Initial recovery period. Dealing with incontinence. Adjusting to changes in body image and function. Alteration in sexual relationships. Changes in life perspectives. Focus group recommended more BlCa awareness information for the public, more post-operative information, suggested information as posters, booklets, awareness campaigns, patient education packages.	Suggest a tool to explain different reconstruction options to assist decision making for surgery to meet individual's needs and lifestyle. Nursing education concerning patient's needs, family support, teaching on incontinence and handling leakages.

Table B3. ***Critical Review Questions for Qualitative Studies***

	Title and abstract
1	Is the title of the research paper concise, clear, and congruent with the text?
2	Were the aims and/or objectives stated?
3	Did the abstract contain sufficient information about the stages of the research process (aim, research approach, participants, data collection, data analysis, and findings)?
	Identify the phenomenon/phenomena of interest
1	Is the phenomenon focused on human experiences within a natural setting?
2	Is the phenomenon relevant to nursing, midwifery, and/or health?
	Structuring the study
1	Is it clear that the selected participants are living the phenomenon of interest?
2	How is published literature used in the study?
3	Does the question identify the context (participant/group/place) of the method to be followed?
4	Is the theoretical framework clearly stated?
5	Does the theoretical framework fit the research question?
6	Is the method of data collection and analysis clearly specified?
7	Does the qualitative method of data collection chosen fit the research question (e.g. grounded theory, ethnography)?
8	Are the limitations of the study stated?
	Research question and design
1	Was the research question determined by the need for the study? Is it clear how that determination was made?
2	Are the data collection strategies appropriate for the research question?
3	Do the data collection strategies reflect the purpose and theoretical framework of the study (in-depth interviews, focus groups)?
4	Can the data analysis strategy be identified and logically followed?
	Participants
1	How were the participants and setting selected (sampling strategy)?
2	Was confidentiality of the participants measured?
3	Was the anonymity of participants assured?
4	Were ethical issues identified in the study?
5	Were the ethical issues addressed?

Data analyses	
1	How were the data analysed?
2	Is the analysis technique congruent with the research question?
3	Is there evidence that the researcher’s interpretation captured the participants; meaning?
4	Did the researcher say how the criteria for judging the scientific rigour of the study were maintained in terms of credibility, auditability, fittingness, and confirmability?
Describing the findings	
1	Does the researcher demonstrate to the reader the method (audit trail) by which the data were analysed?
2	Does the researcher indicate how the findings are related to theory?
3	Is there a link between the findings to existing theory or literature, or is a new theory generated?
Researcher’s perspective	
1	Are the biases of the researcher reported (researcher/participant expectations, researcher biases and power imbalance)?
2	Are the limitations of the study acknowledged?
3	Are recommendations suggested for further research?
4	Are implications for healthcare mentioned?

Table B3. ***Critical Review (continued) Questions for Quantitative Studies***

	Title and abstract
1	Is the title of the research paper concise, clear, and congruent with the text?
2	Were the aims and/or objectives stated?
3	Did the abstract contain sufficient information about the stages of the research process (aim, hypothesis, research approach, sample, instruments, and results)?
	Structuring the study
1	Is the motivation for the study demonstrated through the literature?
2	Is the literature cited current, relevant, and comprehensive? Are the references recent?
3	Are the stated limitations and gaps in the reviewed literature appropriate and convincing?
4	How was the investigation carried out?
5	Is the hypothesis stated?
6	Which hypothesis is stated: the scientific hypothesis or the null hypothesis?
7	Does the hypothesis indicate that the researcher is interested in testing for differences between groups or in testing for relationships?
	Sample
1	Is the sample described?
2	Is the sample size large enough to prevent an extreme score from affecting the summary statistics used?
3	Was sample size determined?
4	Was the sample size appropriate for the analyses used?
	Data collection
1	How were the data collected (questionnaire or other data collection tools)?
2	Who collected the data?
3	Are the data adequately described?
4	What is the origin of the measurement instruments?
5	Are the instruments adequately described?
6	How were the data collection instruments validated?
7	How was the reliability of the measurement instruments assessed?
8	Were ethical issues discussed?
	Data analyses
1	Are descriptive or interferential statistics reported?
2	What tests were used to analyse the data: parametric or non-parametric?
3	Were the descriptive statistics/inferential statistics appropriate to the level of measurement for each variable?
4	Were the appropriate tests used to analyse the data?
5	What is the level of measurement chosen for the independent and dependent variables?

6 Were the statistics appropriate for the research question and design?
7 Are there appropriate summary statistics for each major variable?
8 Were the statistics primarily descriptive, correlational, or inferential?
9 Is there clear identification of the outcome for each statistical analysis?
10 Is the meaning of each outcome explained?

Results

1 Were the results expected?
2 Is there enough information present to judge the results?
3 Are the results clearly and completely stated
4 Describe the researcher’s report of the results.
5 Identify any limitations or gaps in the study.
6 Were suggestions for further research made?
7 Did the researcher mention the implications of the study for healthcare?
8 Was there sufficient information in the report to permit replication of the study?

Table B3. ***Critical Review (continued) Questions for Mixed Methods Studies***

Study evaluative overview	
Bibliographic Details	Author, title, source (publisher and place of publication), year?
Purpose	What are the aims of this paper? If the paper is part of a wider study, what are its aims?
Key Findings	What are the key findings?
Evaluative Summary	What are the strengths and weaknesses of the study and theory, policy and practice implications?
Study and context (setting, sample and outcome measurement)	
The Study	What type of study is this? What was the intervention? What was the comparison intervention? Is there sufficient detail given of the nature of the intervention and the comparison intervention? What is the relationship of the study to the area of the topic review?
Context: (1) Setting	Within what geographical and care setting is the study carried out? What is the rationale for choosing this setting? Is the setting appropriate and/or sufficiently specific for examination of the research question? Is sufficient detail given about the setting? Over what time period is the study conducted?
Context II: Sample	What was the source population? What were the inclusion criteria? What were the exclusion criteria? How was the sample (events, persons, times and settings) selected? (For example, theoretically informed, purposive, convenience, chosen to explore contrasts) Is the sample (informants, settings, and events) appropriate to the aims of the study? If there was more than one group of subjects, how many groups were there, and how many people were in each group? Is the achieved sample size sufficient for the study aims and to warrant the conclusions drawn? What are the key characteristics of the sample (events, persons, times and settings)?
Context III: Outcome Measurement	What outcome criteria were used in the study? Whose perspectives are addressed (professional, service, user, carer)? Is there sufficient breadth (e.g. contrast of two or more perspective) and depth (e.g. insight into a single perspective)?

Ethics	
Ethics	Was Ethical Committee approval obtained? Was informed consent obtained from participants of the study? How have ethical issues been adequately addressed?
Group comparability	
Comparable Groups	If there was more than one group was analysed, were the groups comparable before the intervention? In what respects were they comparable and in what were they not? How were important confounding variables controlled (e.g. matching, randomisation, or in the analysis stage)? Was this control adequate to justify the author's conclusions? Were there other important confounding variables controlled for in the study design or analyses and what were they? Did the authors take these into account in interpretation of the findings?
Qualitative data collection and analysis	
Data Collection Methods	What data collection methods were used in the study? (Provide insight into: data collected appropriateness and availability for independent analysis). Is the process of fieldwork adequately described? (For example, account of how the data were elicited; type and range of questions; interview guide; length and timing of observation work; note taking).
Data Analysis	How were the data analysed? How adequate is the description of the data analysis? (For example, to allow reproduction; steps taken to guard against selectivity) Is adequate evidence provided to support the analysis? (For example, includes original / raw data extracts; evidence of iterative analysis; representative evidence presented; efforts to establish validity - searching for negative evidence, use of multiple sources, data triangulation); reliability / consistency (over researchers, time and settings; checking back with informants over interpretation) Are the findings interpreted in the context of other studies and theory?
Researcher’s Potential Bias	What was the researcher's role? (e.g. interviewer, participant observer) Are the researcher’s own position, assumptions, and possible biases outlined? (Indicate how these could affect the study, in particular, the analysis and interpretation of the data)

Policy and practice implications	
Implications	To what setting are the study findings generalisable? (For example, is the setting typical or representative of care settings and in what respects? If the setting is atypical, will this present a stronger or weaker test of the hypothesis?) To what population are the study's findings generalisable? Is the conclusion justified given the conduct of the study (For example, sampling procedure; measures of outcome used and results achieved?) What are the implications for policy? What are the implications for service practice?
Other comments	
Other comments	What was the total number of references used in the study? Are there any other noteworthy features of the study? List other study references

Table B4. ***Critical Appraisal of the Included Quantitative Studies***

Study	Title/ abstract	Structure of study	Sample	Data collection	Data analysis	Results	Total for 40 questions
D’Agostino 2016	3/3	6/7	3/4	8/8	10/10	7/8	92%
Li 2016	3/3	2/7	3/4	8/8	10/10	8/8	85%
Lui 2016	3/3	4/7	3/4	8/8	10/10	6/8	85%
Imbimbo 2015	3/3	4/7	3/4	8/8	10/10	7/8	87%
Schmidt 2015	3/3	4/7	3/4	7/8	10/10	7/8	85%
Bartsch 2014	3/3	4/7	2/4	7/8	10/10	6/8	80%
Brenner 2014	3/3	2/7	1/4	8/8	6/10	8/8	70%
Fung 2014	3/3	4/7	3/4	5/8	10/10	8/8	82%
Gomez 2014	3/3	3/7	1/4	6/8	4/10	6/8	47%
Goossens-Laan 2014	3/3	4/7	2/4	7/8	10/10	7/8	82%
Rouanne 2014	3/3	4/7	2/4	7/8	10/10	6/8	80%
Tejido-Sanchez 2014	3/3	6/7	2/4	7/8	10/10	6/8	85%
Singer 2013	3/3	4/7	3/4	8/8	10/10	7/8	87%
Tal 2012	3/3	5/7	2/4	5/8	9/10	8/8	80%
Takenka 2011	2/3	4/7	2/4	7/8	8/10	7/8	75%
Thulin 2010	3/3	3/7	3/4	8/8	8/10	6/8	77%
Hashine 2008	3/3	4/7	2/4	8/8	10/10	7/8	85%
Van der Aa 2008	3/3	4/7	2/4	7/8	9/10	7/8	80%
Yuh 2008	3/3	4/7	2/4	8/8	10/10	8/8	87%
Allareddy 2006	3/3	6/7	3/4	8/8	10 /10	6/8	90%
Yoshimura 2005	3/3	4/7	3/4	7/8	10/10	5/8	80%
	100%	58%	57%	86%	86%	85%	

Table B4. ***Critical Review Summary of the Included Qualitative Studies***

Study		Title/ abstract	Phenomena of interest	Structure of study	Question /design	Participants	Data analysis	Describe Findings	Researcher's perspective	Total for 33 questions
Cerruto	2014	3/3	2/2	7/8	4/4	1/5	0/4	2/3	1/4	61%
Mohamed	2014	3/3	2/2	8/8	4/4	1/5	3/4	3/3	3/4	82%
Fitch	2010	3/3	2/2	7/8	4/4	3/5	4/4	2/3	2/4	82%
		100%	100%	92%	100%	33%	58%	78%	50%	

Table B4. ***Critical Review Summary of the Included Mixed Methods Study***

Study	Study over view	Study and context	Ethics	Group comparability	Qualitative data	Policy and practice	Other comments	Total for 51 questions
Kowalkowski 2014	3/4	20/21	2/3	6/6	8/8	6/6	3/3	94%
	75%	95%	67%	100%	100%	100%	100%	

B5. ***Supplementary literature: QoL Between RC Surgical Diversions***

Relevant research on the impact of BlCa can often be divided according to the patient groups, with a strong tendency to study either MIBlCa or NMIBlCa in patients. Among studies of MIBlCa, it is most common to report the quantitative outcomes of retrospective studies that measure outcomes of RC. Such studies mainly focus on comparing alternative surgical diversions to address the question of which type of surgery might afford a better QoL for the patient. However, in these studies (Appendix B5), there is commonly no conclusive evidence that one type of surgical diversion offers better QoL due to the lack of validated instruments and the use of various methods used to judge the benefits and limitations of each diversion in relation to QoL (Cerruto *et al.* 2016).

A number of authors have also reviewed the existing literature using systematic review, non-systematic review, literature review, and critical review of the literature in relation to QoL in patients treated for BlCa. Some of these reviews also compare one type of surgery with another, typically a continent diversion (orthotopic neobladder) is compared with incontinent diversions (ileal conduit). However, these literature reviews (Appendix B6) have found similar outcomes in that no definitive outcomes regarding better QoL can be agreed upon (Ali *et al.* 2015). A particularly well-known literature review focusing on QoL in BlCa participants with either NMIBlCa or MIBlCa was conducted by Botteman *et al.* (2003). The 35 articles located highlighted that in relation to MIBlCa participants had a reduction in urinary and sexual function with no significant differences found between types of diversion, but that each type of diversion had its own specific symptoms that affect QoL. Sexual dysfunction was a side effect in all types of surgical diversions including links to the psychological and physical aspects of surgery (Botteman *et al.* 2003). Other literature reviews predominantly emphasise the effects of MIBlCa on QoL (appendix B6), in respect to preserving the bladder using radiotherapy (Feuerstein & Goenka 2015), sexual function

(Modh *et al.* 2014), using multimodal therapy (Keegan *et al.* 2012), and chemotherapy for MIBlCa (Meeks *et al.* 2012), and the effects of age and gender (Shariat *et al.* (2009).

Other studies have interpreted QoL with a focused on RC only, and have noted the urinary and sexual dysfunction and reduction in sexual activity, urinary leakage, effects on cultural differences, depression, skin irritation, decline in social activities, sleep disturbances, adaptation to and management of the urinary diversion, bowel dysfunction, body image, and psychological issues generally (Månsson *et al.* 2007; Richbourg *et al.* 2007; Gemmill *et al.* 2010; Hedgepeth *et al.* 2010; Thulin *et al.* 2010). Investigations of the typically older patient have focused on their ability to handle an ileal conduit (Saika *et al.* 2007; Sogni *et al.* 2008) and bone loss caused by chronic metabolic acidosis post-RC that places participants at increased risk of bone fracture (Gupta *et al.* 2014). MIBlCa post-surgical adverse events (e.g. deep vein thrombosis, pulmonary embolus, puncture, decubitus ulcers, sepsis, and death), and readmissions to hospital have been reported (Kim *et al.* 2012; Skolarus *et al.* 2014).

Datta *et al.* (2009) studied married participants and found that they were more likely to report better overall health and therefore fewer comorbidities, better survival rates (both men and women), and better finances than non-married participants. Married men were more likely to seek treatment, which also results in better survival rates than non-married men. This was also true for women, although married men in the later stages of BlCa fare better than do married women (Datta *et al.* 2009). These rates may indicate that the support of a partner increases the chances of survival through emotional and social supports regardless of the treatment regimen, type of hospital, or other health issues and that the beneficial effect is more linked to social nuances than medical intervention (Datta *et al.* 2009). Given the demands of treatment and surveillance for NMIBlCa, the outcomes may also allude to better assistance with transportation to frequent urology clinic appointments, compliance with treatment protocols, and assistance with side effects in the presence of a partner (Datta *et al.* 2009).

Despite the majority (70%) of BlCa cases comprising of NMIBlCa, few studies have highlighted the QoL experienced by these patients (Hevér *et al.* 2015; Mohamed *et al.* 2016). The primary and secondary sources already mentioned above, while important and informative, do not specifically highlight the QoL outcomes for patients with either MIBlCa or NMIBlCa. Some compare types of surgery, or treatment prescriptions or focus on a particular issue without considering the overall QoL of the patient with BlCa. Therefore, a literature review specifically highlighting the QoL outcomes of patients with either MIBlCa or NMIBlCa was undertaken to inform this program of research (Chapter 2).

B6. ***Studies Comparing Types of Surgical Diversion and QoL***

Author (s)	**Year**	**Comparisons**	**Main conclusion**
Cerruto *et al.*	2016	Orthotopic Neobladder vs Ileal Conduit	HR-QoL advantage of ileal ONB compared to Ileal Conduit.
Gacci *et al.*	2013	Ureterostomy vs Neobladder	HRQOL with Ureterostomy worse than Ileal Neobladder (Females).
Vakalopoulos *et al.*	2011	Orthotopic Neobladder vs Ileal Conduit	Equal effects on quality of life.
Hedgepeth *et al.*	2010	Orthotopic Neobladder vs Ileal Conduit	No difference in body image of ileal conduit and neobladder.
Large *et al.*	2010	Neobladder vs Indiana Pouch	These two diversions have similar HRQoL (Females).
Severin *et al.*	2010	Incontinent vs Continent Diversion	No clear differences.
Autorino *et al.*	2009	Orthotopic Neobladder vs Ileal Conduit	No significant difference was found in scale scores.
Frich *et al.*	2009	Bricker conduit vs Studer neobladder vs Hemi-Kock neobladder	No associated difference in QoL outcome between these three diversions.
Hedgepeth *et al.*	2009	Orthotopic Neobladder vs Ileal Conduit	No difference in body image between ileal conduit and neobladder
Lee	2009	Orthotopic Neobladder vs Ileal Conduit	No major QOL benefits.
Phillips *et al.*	2009	Orthotopic Neobladder vs Ileal Conduit	Better QoL and a more active life-style among neobladder patients
Harano *et al.*	2007	Orthotopic Neobladder vs Ileal Conduit	QOL and frequency of complications were similar.
Saika *et al.*	2007	Orthotopic Neobladder vs Ileal Conduit vs ureterocutaneostomy	No significant differences among urinary diversion in QoL.
Kikuchi *et al.*	2006	Orthotopic Neobladder vs Ileal Conduit vs Continent Reservoir	Type of urinary diversion does not seem to be linked with QoL.
Gray & Beitz	2005	Orthotopic Neobladder vs Heterotopic	No evidence to determine if QoL outcomes differ in women.

Ramirez *et al.*	2005	Continent Diversion vs Ileal Conduit	Ten HRQOL domains identified as important for both diversions
Mansson *et al.*	2004	Continent cutaneous diversion vs orthotopic bladder substitution.	Few factors differed between the two groups and may indicate a difference between neutral 3rd party administration vs surgeons.
Dutta *et al.*	2002	Orthotopic Neobladder vs Ileal Conduit	Orthotopic neobladder has slight QoL advantages in younger patients
Hara *et al.*	2002	Orthotopic Neobladder vs Ileal Conduit	No QoL difference between these groups.
Mansson *et al.*	2002	Orthotopic Neobladder vs Ileal Conduit	No advantage in QoL between different types of diversion. (Males)
Miyake *et al.*	2002	Orthotopic Neobladder vs Colon Neobladder	No significant differences were observed in the QOL between the groups.
Conde *et al.*	2001	Orthotopic Neobladder vs Ileal Conduit	Health-related QoL is higher after orthotopic neobladder.
Hobrisch *et al.*	2001	Orthotopic Neobladder vs Ileal Conduit	QoL is preserved better in orthotopic neobladder
Fujisawa *et al.*	2000	Orthotopic Neobladder vs Ileal Conduit	No significant differences were observed.
Hardt *et al.*	2000	Continent diversion vs incontinent diversion	Both kinds of diversions satisfy the patients in general.
Hobrisch *et al.*	2000	Orthotopic Neobladder vs Ileal Conduit	QoL is preserved to a higher degree after orthotopic neobladder
McGuire *et al.*	2000	Ileal Conduit vs Indiana Pouch	Ileal conduits patients have significantly decreased mental health QoL.

Notes*: HRQoL - Health related quality of life; ONB - Orthotopic neobladder; QoL - Quality of life.*

B7. ***A Summary of Literature Reviews Comparing QoL in Types of Surgical Diversion***

Author (s)	Year	Overall Topic	Conclusion comparing types of diversion
Mohamed *et al.*	2016	Pursuing quality in bladder cancer QoL research	
Ali *et al.*	2015	HRQoL after cystectomy comparing orthotopic neobladder and ileal conduit diversions.	Orthotopic neobladder may have better QoL outcomes than ileal conduit particularly in younger fitter patients.
Feuerstein & Goenka	2015	QoL outcomes of bladder preservation with radiotherapy	
Feuerstein *et al.*	2015	QoL and symptom assessment in RCTs of bladder cancer	
Modh *et al.*	2014	Sexual dysfunction after cystectomy and urinary diversion	
Perlis *et al.*	2014	Conceptual global HRQoL in bladder cancer	
Keegan *et al.*	2012	Multimodal therapies for MIBlCa	
Meeks *et al.*	2012	Neoadjuvant and adjuvant chemotherapy for MIBlCa	
Mohamed *et al.*	2012	MIBlCa from diagnosis to survivorship	
Shih & Porter	2011	HRQoL after cystectomy and urinary diversion for BlCa	There is no convincing evidence that any method of urinary diversion offers better HRQOL outcomes.
Shariat *et al.*	2009	Effects of age and gender on BlCa	
Somani *et al.*	2009	QoL and body image for BlCa after radical cystectomy and urinary diversion	Overall good QoL irrespective of the type of UD, with no significant differences among the different diversion types.
Wright & Porter	2007	QoL assessment in patients with bladder cancer	There is no convincing evidence that superior HRQOL is achieved with a particular type of urinary diversion

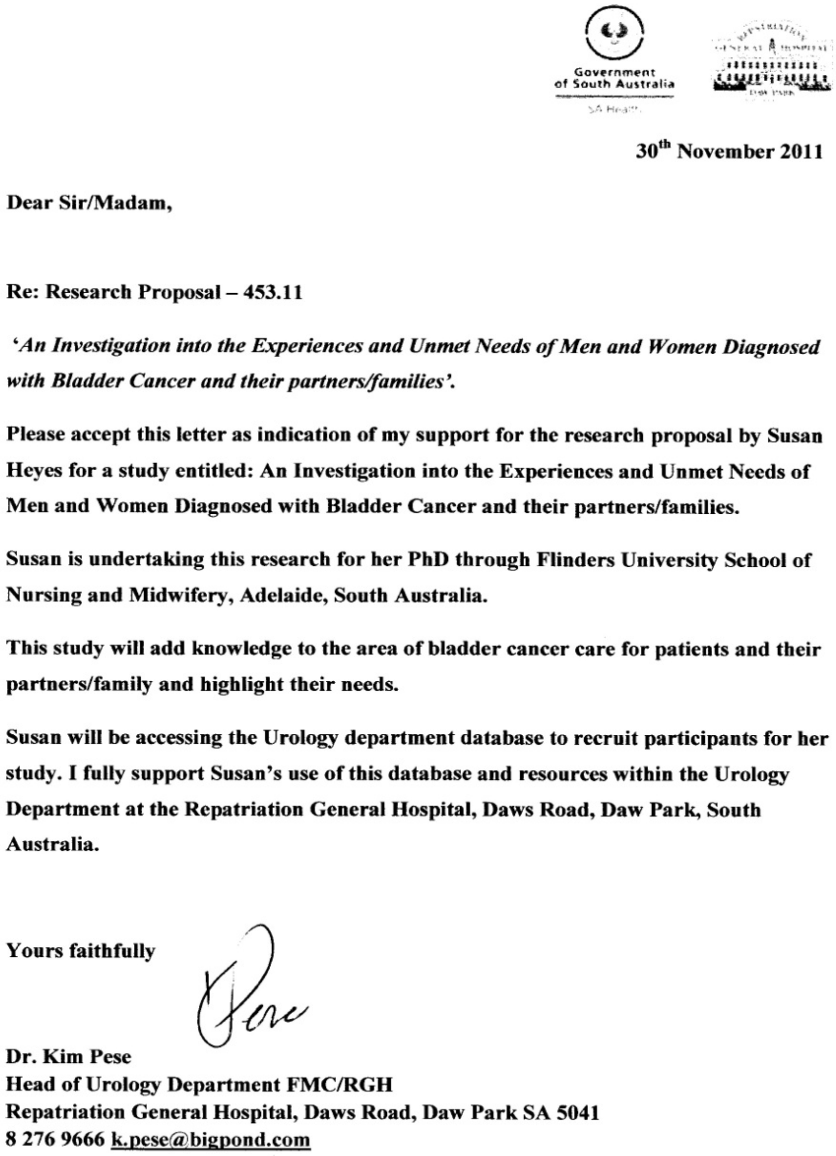
Gerharz *et al.*	2005a	QoL after cystectomy and urinary diversion	Existing studies are unable to prove that continent reconstruction after radical cystectomy is superior to conduit diversion.
Gerharz *et al.*	2005b	QoL in patients with bladder cancer	There are no significant advantages shown that QoL is superior for continent urinary reconstruction over a conduit.
Gray & Beitz	2005	Counselling patients undergoing urinary diversion to determine if the type of diversion influences QoL	HRQOL in urinary diversion vs orthotopic neobladder leans slightly towards continent diversions, particularly in younger patients.
Porter *et al.*	2005	QoL issues in BlCa patients following cystectomy and urinary diversion	Unique factors associated with a specific type of diversion may impact HRQOL in ways that make one superior to another.
Porter & Penson	2005	HRQoL after radical cystectomy and urinary diversion for BlCa	Literature is insufficient to conclude that one form of urinary diversion is superior to another based on HRQOL outcomes.
Botteman *et al.*	2003	QoL aspects of bladder cancer	

Notes: *HRQoL – Health-related quality of life; ONB - Orthotopic neobladder; QoL - Quality of life; RCT - Randomised controlled trial; MIBlCa - Muscle invasive bladder cancer; UD - Urinary diversion.*

APPENDIX C

PHASE 1 ETHICS DOCUMENTATION

C1. *Letter of Endorsement from the Head of Departments-Medical*



Government
of South Australia
SA Health

30th November 2011

Dear Sir/Madam,

Re: Research Proposal – 453.11

'An Investigation into the Experiences and Unmet Needs of Men and Women Diagnosed with Bladder Cancer and their partners/families'.

Please accept this letter as indication of my support for the research proposal by Susan Heyes for a study entitled: An Investigation into the Experiences and Unmet Needs of Men and Women Diagnosed with Bladder Cancer and their partners/families.

Susan is undertaking this research for her PhD through Flinders University School of Nursing and Midwifery, Adelaide, South Australia.

This study will add knowledge to the area of bladder cancer care for patients and their partners/family and highlight their needs.

Susan will be accessing the Urology department database to recruit participants for her study. I fully support Susan's use of this database and resources within the Urology Department at the Repatriation General Hospital, Daws Road, Daw Park, South Australia.

Yours faithfully

Dr. Kim Pese
Head of Urology Department FMC/RGH
Repatriation General Hospital, Daws Road, Daw Park SA 5041
8 276 9666 k.pese@bigpond.com

C2. *Letter of Endorsement from the Head of Departments-Nursing*

REPATRIATION
GENERAL HOSPITAL
DAW PARK

**Repatriation
General Hospital**

Daws Road,
Daw Park SA 5041

Tel 08 8276 9666
Fax 08 8277 9401

ABN 14227133 467

www.rgh.sa.gov.au

1 November 2011

The Chairman Research & Ethics Committee
Flinders Medical Centre
3 Flinders Drive
BEDFORD PARK SA 5042

Dear Chairman

Re: Research Proposal - **An Investigation into the Experiences and Unmet Needs of Men and Women Diagnosed with Bladder Cancer and their partners/families.**

Please accept this letter as indication of my support for the research proposal by Susan Heyes for a study entitled: An Investigation into the Experiences and Unmet Needs of Men and Women Diagnosed with Bladder Cancer and their partners/families.

Susan is undertaking this research for her PhD through Flinders University School of Nursing and Midwifery, Adelaide, South Australia.

Outcomes of this study will be of interest to the development of nursing practice.

Yours faithfully

Lesley Jeffers
Director of Nursing & Patient Services

Government
of South Australia
SA Health

Government
of South Australia

C3. *Bladder Cancer Database RN's Letter*

Department of Urology

Telephone: 8275 1121

11th October 2011

Ms Susan Heyes
PhD Candidate

School of Nursing and Midwifery

Flinders University

Dear Susan,

Re: Your proposed study 'An Investigation into the Experiences and Unmet needs of Men and Women Diagnosed with Bladder Cancer and their partners/families'.

The RGH Bladder Cancer Outcomes Database is primarily used for tracking patients to ensure that there is no loss to follow-up and to allow the progress of individuals to be monitored.

My role as data manager is to make sure that patients attending RGH with a diagnosis of bladder cancer are entered into the database and their progress updated from sources such as medical records and OACIS in order to facilitate clinical care.

If your proposed study is approved by the Southern Adelaide Clinical Human Research Ethics Committee, I would be able to provide a list of possible participants to you. There would be no reason for this to be noted in the database as their participation in your study would have no bearing on their clinical management.

I cannot see any reason for your proposed study to impact on either the function of the database or the clinical care of any participant.

With kind regards
Yours sincerely

Data Manager
Bladder Cancer Outcomes Database

C4. *Indemnity/Participant Compensation*

Dear Susan,

Thank you for the information on the Study: An Investigation of the Experiences and Unmet Needs of men and Women Diagnosed with Bladder Cancer.

I advise that the indemnity and insurance being provided by Flinders University is acceptable.

Kind Regards

John Markic

Manager, Insurance Services

Finance & Administration

SA Health

Government of South Australia

Tel: 08 8425 2450

Fax: 08 8425 2471

Mobile: 0401 120 335

E-mail: john.markic@health.sa.gov.au

Web site: www.health.sa.gov.au

Hi Susan

To clarify our issue on the Ethics Application 453.11

‘I confirm that the University’s general and liability protections will indemnify the Flinders University research participants’.

Please present this email and John Markic’s email on 1 November 2011 as confirmation of your insurance requirements.

Kind Regards

Steve Semmler

Insurance Officer
Flinders University
Ph: (08)8201 2618
Email: steve.semmler@flinders.edu.au

C5. *Ethics Approval Phase 1*

Dear Susan

Your ethics application has been approved by the Southern Adelaide Clinical Human Research Ethics Committee.

Please retain the attached PDF for your records.

Please feel welcome to contact research.ethics@health.sa.gov.au with any enquiries you may have on this matter and we will be happy to assist.

Kind Regards,

Monika Malik

Administrative Services Officer
Southern Adelaide Clinical Human Research Ethics Committee
SA Local Health Network
Room 2A221 - Inside Human Resources
Flinders Medical Centre, Bedford Park SA 5042

Tel: 08 8204 6453
Fax: 08 8204 4586
Email: research.ethics@health.sa.gov.au
Website: http://www.flinders.sa.gov.au/research/pages/ethics/6590/

C6. *Letter of Introduction*

Professor Jan Paterson
Professor of Nursing
(Health Care for the Older Person)
School of Nursing & Midwifery
21st November 2011
Faculty of Health Sciences
GPO Box 2100 Adelaide SA 5001
Telephone +61 8 +61 8 8201 3266
Facsimile +61 8 +61 8 8276 1602
jan.paterson@flinders.edu.au
www.flinders.edu.au

Dear Sir/Madam,

This letter is to introduce Ms Susan Heyes, who is a PhD student in the School of Nursing & Midwifery at Flinders University. Susan will produce her student card, which carries a photograph, as proof of her identity. Susan is undertaking research, which will lead to the production of a PhD thesis and other publications. This study will explore the experiences of men and women with bladder cancer from diagnosis through to various treatment phases, and identify unmet health care needs of both the patient with bladder cancer, and their partner/family member.

Susan would be most grateful if you and your partner would volunteer to assist in this project, by granting interviews, which covers certain aspects of bladder cancer. You and your partner/family member will be interviewed separately. The interviews would take one hour each of both yours and your partner/family member's time. At a later date, you will be asked to read the transcripts of your interviews to check they are valid. Be assured that any information provided will be treated in the strictest confidence and you, your partner and none of the other participants will be individually identifiable in the resulting thesis, report or publications. You are of course, entirely free to discontinue your participation at any time or to decline to answer particular questions or ask for your transcript to be amended. If you do not want your information used, and wish to opt out from being contacted again about this study, please telephone Susan on 0408892948 or email daws0049@flinders.edu.au. Should you wish to opt out; the care you receive at the Repat will not be influenced in any way.

Since Susan intends to make tape recordings of the interviews, she will seek your consent to record the interviews and to use the recording of your transcripts in preparing her thesis, report or other publications, on condition that your names or identities are not revealed. It may be necessary to make the recordings available to secretarial assistants for transcription, in which case you may be assured that the confidentiality of the material is respected and maintained.

Susan will be contacting you within approximately two weeks of you receiving this letter. Any enquires you may have concerning this project should be directed to me at the address given above or by telephone on 82013266 by fax on 82011602 or by email at jan.paterson@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely

J. B. Paterson

inspiring
achievement

Professor Jan Paterson, PSM, RN, PhD, FCN

School of Nursing & Midwifery

ABN 65 542 596 200, CRICOS No. 00114A

C7. *Participant Information (clinical participants)*

Project Title: *'An Investigation of the Experiences and Unmet Needs of men and Women Diagnosed with Bladder Cancer'*

Lay Title*: Exploring the Needs of People with Bladder Cancer*.

This research is being conducted by Susan Heyes, a PhD student at Flinders University School of Nursing and Midwifery.

Your information has been chosen from the patient database in the Urology department at the Repat. You are invited to participate in this research project but you do not have to be involved, whether you wish to or not is entirely up to you. Whether you take part or not, your medical care and the services provided to you at the Repat will not be affected in any way.

This research study aims to investigate people's experiences of bladder cancer and their partner/family member/carers experiences. I understand that this topic is very personal and may be difficult for you to discuss. You have the right to refuse to answer questions if you find them too uncomfortable. The information that you provide will be of great value in establishing future improvements to resources, services and care, of people with bladder cancer and their partners/family carers.

This study will require you to have a one-on-one interview with the researcher about your bladder cancer. Interviews will be conducted at a time and place that is convenient to you, and will take one hour. The interview will be audio recorded so that the researcher can transcribe your words exactly. You will be asked to sign a written consent form before the interview begins. You will remain completely anonymous and will be given a false name to be known by in this study. All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Your information will be combined with that of many other people during the analysis phase of the study, so you will remain unidentifiable. Records and data about your participation in this study may be used for study purposes or further analyses in the future. All such records and your right to them will be protected in accordance with Australian law. Information relating to this study will be kept on a password protected computer, hard copies will be stored in a locked filing cupboard in a security pass locked room accessible only by the researcher for security and to maintain confidentiality. All files and data from this study will be locked in storage for 15 years. The outcomes of this study will be published in conference papers, international peer reviewed journal articles or other venues as appropriate.

Your participation in this study is voluntary and without remuneration. You have the right to withdraw from the study at any time without giving a reason. If you decide not to participate in this study, or if you withdraw from the study, you may do so freely, without affecting the standard of care or treatment you will receive. In the very unlikely event that you suffer an injury as a result of participating in this study, hospital care and treatment will be provided by the public health service at no cost to you and/or a counsellor will be made available to you. If you suffer injury as a result of participation in this study, compensation might be paid without litigation. However, such compensation is not automatic and you may have to take legal action to determine whether you should be paid.

The Southern Adelaide Clinical Human Research Ethics Committee has reviewed this study. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Officer on 8204 6453 or email research.ethics@health.sa.gov.au

You can contact Susan via email on daws0049@flinders.edu.au or on 0408892948 for further details or to arrange an interview time.

Thank you.

C8. *Participant Information (partner)*

Project Title: *‘An Investigation of the Experiences and Unmet Needs of men and Women Diagnosed with Bladder Cancer’*
Lay Title*: Exploring the Needs of People with Bladder Cancer*.

This research is being conducted by Susan Heyes, a PhD student at Flinders University School of Nursing and Midwifery.

Your partner’s information has been chosen from the patient database in the Urology department at the Repat. You are invited to participate in this research project but you do not have to be involved, whether you wish to or not is entirely up to you. Whether you take part or not, your partner’s medical care and the services provided to her/him at the Repat will not be affected in any way.

This research study aims to investigate people’s experiences of bladder cancer and their partner/family member/carers experiences. I understand that this topic is very personal and may be difficult for you to discuss. You have the right to refuse to answer questions if you find them too uncomfortable. The information that you provide will be of great value in establishing future improvements to resources, services and care, of people with bladder cancer and their partners/family carers.

This study will require you to have a one-on-one interview with the researcher about your partner’s/family member’s bladder cancer. Interviews will be conducted at a time and place that is convenient to you, and will take one hour. The interview will be audio recorded so that the researcher can transcribe you words exactly. You will be asked to sign a written consent form before the interview begins. You will remain completely anonymous and will be given a false name to be known by in this study. All records containing personal information will remain confidential and no information which could lead to your identification will be released, except as required by law. Your information will be combined with that of many other people during the analysis phase of the study, so you will remain unidentifiable. Records and data about your participation in this study may be used for study purposes or further analyses in the future. All such records and your right to them will be protected in accordance with Australian law. Information relating to this study will be kept on a password-protected computer; hard copies will be stored in a locked filing cupboard in a security pass locked room accessible only by the researcher for security and to maintain confidentiality. All files and data from this study will be locked in storage for 15 years. The outcomes of this study will be published in conference papers, International peer reviewed journal articles or other venues as appropriate.

Your participation in this study is voluntary and without remuneration. You have the right to withdraw from the study at any time without giving a reason. If you decide not to participate in this study, or if you withdraw from the study, you may do so freely, without affecting the standard of care or treatment your partner will receive. In the very unlikely event that you suffer an injury as a result of participating in this study, hospital care and treatment will be provided by the public health service at no cost to you and/or a counsellor will be made available to you. If you suffer injury as a result of participation in this study, compensation might be paid without litigation. However, such compensation is not automatic and you may have to take legal action to determine whether you should be paid.

The Southern Adelaide Clinical Human Research Ethics Committee has reviewed this study. If you wish to discuss the study with someone not directly involved, in particular in relation to policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Executive Officer on 8204 6453 or email research.ethics@health.sa.gov.au

You can contact Susan via email on daws0049@flinders.edu.au or on 0408892948 for further details or to arrange an interview time.

Thank you.

C9. *Consent to participation in research-clinical participant*

I, ...
(First or given names) (Last name)

request and give consent to my involvement in the research project (Short title): *Exploring the Needs of People with Bladder Cancer*. I have been provided with a 'Patient Information Sheet' about this study, which I have read and understand. I realise that this study may require me to answer some specific questions about myself and my bladder cancer. I have volunteered to have a one-on-one interview with the researcher. In order to protect my identity and provide confidentiality the researcher will de-identify all data and use another name for me in her written reports and publications.

- I have understood and am satisfied with the explanations given to me and hereby give consent to participate in the study above.
- I understand that I will have a one hour interview with the researcher
- The interview will be audio recorded for future transcription of my words
- I understand that the result of this study may be published, but my identity will be kept confidential at all times.
- I understand that I may withdraw my consent at any stage without reprisal.
- A representative for the Hospital Research and Ethics Committee may need to access my medical records for information related to this study for the purpose of auditing.
- I grant access to my medical records.
- I declare that I am over the age of 18 years.

Signature of Research Participant: ______________________Date:_____/2012

Signature of witness: _________________________________Date:_____/2012

Printed name of witness: ____

I, Susan Heyes have described to______________________________________

the research project and nature and effects of procedure(s) involved. In my opinion, he/she understands the explanation and has freely given his/her consent.

Signature: ________________________________Date:_____/2012

If you have any questions contact Susan on daws0049@flinders.edu.au or 0408892948.

Thank you for your time.

C10. *Consent to participation in research-partner*

I, ……………………………………………………………………………………………………
(First or given names) (Last name)

request and give consent to my involvement in the research project (Short title): *Exploring the Needs of People with Bladder Cancer*. I have been provided with a 'Patient Information Sheet' about this study, which I have read and understand. I realise that this study may require me to answer some specific questions about my partner's/family member's bladder cancer. I have volunteered to have a one-on-one interview with the researcher. I understand that the interview will take approximately one hour and will be audio taped so that the researcher can transcribe my words exactly. In order to protect my identity and provide confidentiality the researcher will de-identify all data and use another name for me in her written reports and publications.

- I have understood and am satisfied with the explanations given to me and hereby give consent to participate in the study above.
- I understand that I will have a one hour interview with the researcher
- The interview will be audio recorded for future transcription of my words
- I understand that the result of this study may be published, but my identity will be kept confidential at all times.
- I understand that I may withdraw my consent at any stage without reprisal.
- A representative for the Hospital Research and Ethics Committee may need to access my medical records for information related to this study for the purpose of auditing.
- I grant access to my medical records.
- I declare that I am over the age of 18 years.

Signature of Research Participant: _______________________Date:_____/2011

Signature of witness: __________________________________Date:_____/2011

Printed name of witness: ____

I, Susan Heyes have described to______________________________________

the research project and nature and effects of procedure(s) involved. In my opinion he/she understands the explanation and has freely given his/her consent.
Signature: ___________________________________Date:_____/2011

If you have any questions contact Susan on daws0049@flinders.edu.au or 0408892948.

Thank you for your time.

C11. ***Semi-structured open-ended interview guide (Clinical participant)***

Introduction

- Introduction to participant
- Explain process of the interview and participants rights
- Make participant aware of tape recorder
- Allow participant time to read and sign consent form
- Answer any questions before commencing interview

Demographics

- Name..MRN.......................
- Address...
  ....
- Telephone..DOB..........................
- Nationality..
- Language spoken at home...
- Occupation...
- Highest education level...
- Trade..
- Living conditions (alone, partner, children)...
- Other health conditions..
- Medication..
- ....

Pre-diagnosis

- How long have you had BlCa?
- Can you tell me about the first signs and symptoms that you had or what made you go to see your doctor?
- What did you know about BlCa and its risk factors?

Diagnosis

- Can you describe what happened and how it felt when you were diagnosed with BlCa?
- What exactly was your diagnosis?

- What were your immediate thoughts and concerns?
- What type of tests did you have as part of the diagnosis process?
- Who did you discuss your BlCa with?

Ongoing treatments and tests

- Please tell me about the tests and ongoing treatment that you have had or are having.
- How did you cope with the tests and treatment?
- Who did you have to support you at home?
- What needs did you have during the tests and treatment and how were those needs met?
- Were there any needs you were unable to have met?
- What types of external support services do you use or need?
- How has your BlCa affected your social and work life?
- What affect has BlCa had on your intimate relationships and sexuality?
- How do you manage to cope with your BlCa?
- What symptoms are you living with now?
- What would you say is the worst part of having BlCa?
- How would you describe your journey with BlCa so far?
- What advice would you give to someone else who asked you about BlCa?
- If you could, what would you change about the things you have been through and the decisions you have made in regard to your BlCa?
- Can you describe your experiences with medical staff and services?
- Do you have any questions for me?

End interview, thank participant for their time and sharing their unique experiences. Ask participant how they feel post interview, is assistance required?

C12. ***Semi-structured open-ended interview guide (Partners)***

Introduction

- Introduction to participant
- Explain process of the interview and participants rights
- Make participant aware of tape recorder
- Allow participant time to read and sign consent form
- Answer any questions before commencing interview

C12. ***Semi-structured open-ended interview guide (Partner)***

Demographics

- Name...MRN............................

- Address...
  ....

- Telephone..DOB...............................

- Nationality..

- Language spoken at home..

- Occupation...

- Highest education level..

- Trade...

- Living conditions (alone, partner, children)...
- Other health conditions...
- ....

Pre-diagnosis

- How long has your partner/family member had BlCa?
- Can you tell me about the first signs and symptoms that your partner/family member had or what made him/her go to see his/her doctor?
- What did you know about BlCa and its risk factors?

Diagnosis

- Can you describe what happened and how it felt when he/she was diagnosed with BlCa?
- What exactly was his/her diagnosis?
- What were your immediate thoughts and concerns?

- What type of tests did he/she have as part of the diagnosis process?
- Who did you discuss his/her diagnosis of BlCa with?
- How long have you been together as a couple?
- OR How long have you been caring for your family member?

Ongoing treatments and tests

- Please tell me about the tests and ongoing treatment that he/she has had or is having.
- How did he/she cope with the tests and treatment?
- Were you his/her only support or support at home?
- What needs did he/she have during the tests and treatment and how were those needs met?
- Were there any needs he/she did not have met?
- What types of external support services does he/she use or need?
- How has his/her BlCa affected your social and his/her work life?
- What affect has BlCa had on your intimate relationships and sexuality?
- How do you manage to cope with his/her BlCa?
- What symptoms are he/she living with now?
- What would you say has been the worst part of his/her BlCa diagnosis?
- How would you describe your journey together with BlCa so far?
- What advice would you give to someone else who asked you about BlCa?
- If you could, what would you change about the things he/she has been through and the decisions he/she/you have made concerning his/her BlCa?
- Can you describe your experiences with medical staff and services?
- What needs have you had during this process and how have they been met?
- How has your partner/family members’ BlCa affected life at home/your relationship/relationships with other family members and friends?
- Do you have any questions for me?

-End interview, thank participant’s partner for their time and sharing their unique experiences. Ask how they feel post interview, is assistance required?

APPENDIX D

PARTICIPANT INFORMATION AND ANALYSIS OF FINDINGS

Table D1. ***Patients on the Hospital Database Diagnosed with BlCa.***

547 BlCa patients		Age range	Average
Females	118 (22%)	15-88	69.32 years
Males	429 (78%)	24-98	71.17 years

Note: *Age at first admission*

Table D2. ***Age and Gender Distribution of Hospital Patients Diagnosed with BlCa***

Age range	Female	%	Male	%	Total Age range	% of Age range
10-19	**1**	*1%*	**-**	-	**1**	*0.2%*
20-29	**-**	-	**1**	*0.2%*	**1**	*0.2%*
30-39	**2**	*2%*	**6**	*1%*	**8**	*1.5%*
40-49	**4**	*3%*	**16**	*3.8%*	**20**	*4%*
50-59	**12**	*10%*	**41**	*9%*	**53**	*10%*
60-69	**30**	*26%*	**106**	*25%*	**136**	*25%*
70-79	**50**	*42%*	**149**	*35%*	**199**	*36%*
80-89	**19**	*16%*	**98**	*23%*	**117**	*21%*
90+	**-**	-	**12**	*3%*	**12**	*2.1%*
Totals	**118**	*100%*	**429**	*100%*	**547**	*100%*

D3. *Thematic Analysis - Open Codes*

Diagnosis	How they were told of diagnosis	Delay in diagnosis	No-One Ever Said Cancer	Shock, Surprise
Preparing For the Worst	Death & Dying	Risk Factors	Confidence	Faith, Hope & Trust
Feelings & Emotions	Symptoms	Relief	Disappointment Anger	Worry, Fear
Pain & Incapacity	Denial	Continence	Flow & Urgency	Being Wary
Treatments	Side Effects	Time	Embarrassment	Surveillance
Searching For Answers	Acceptance	Urgency to Treat	Leakage	Knowledge
Partner/Family Support	Advice & Information	Information Given, Sought, Shared	Coping Mechanisms	Talking about it
Quality Of Life	Domination of Life	Partner Relationship	Comfort & Supports	Effects on Social, & Work life
Sexuality	Body Image	Needs	Interference	Caring Continuity

D4. *Further Refined themes*

Diagnosis, how they were told, delays in diagnosis, information given, no-one ever said cancer

Feelings & emotions, embarrassment, relief, disappointment, anger, worry, fear shock, & surprise

Caring, continuity of care. Comfort, supports (partner/family), caring

Continence, leakage, flow & urgency, being constantly wary

Confidence, faith, hope & trust

Coping mechanisms & adaption, acceptance, denial

Treatments side effects, symptoms, surveillance, time, urgency to treat. Pain & incapacity

Knowledge, explained, searching for answer; risk factors. Information/advice sought and shared

Preparing for the /worst, death & dying, domination of life

Needs. Communication. Worry, fear shock, and surprise

Sexuality, body image & partner relationships, interference. Effects on masculinity

Effects on social life, work life

D5. ***Four Core Themes and sub-themes***

Physical Responses	**Cognitive Reactions**	**Emotional Reactions**	**Survival Techniques**
Treatment and side effects	Diagnosis and information	Embarrassment and intrusiveness	Acceptance
Continence	A life overshadowed	Anxiety and shock	Having faith
Discomfort	Public persona	Life supports	Avoidance denial and distancing
On-going needs	Being macho	Sexuality and loving relationships	
	Talking it over	The nature of care	

APPENDIX E

PHASE 2 ETHICS DOCUMENTATION

E1. *Phase 2 Ethics Approval*

FINAL APPROVAL NOTICE

Dear Susan,

The Chair of the Social and Behavioural Research Ethics Committee (SBREC) at Flinders University considered your response to conditional approval out of session and your project has now been granted final ethics approval. Your ethics final approval notice can be found below.

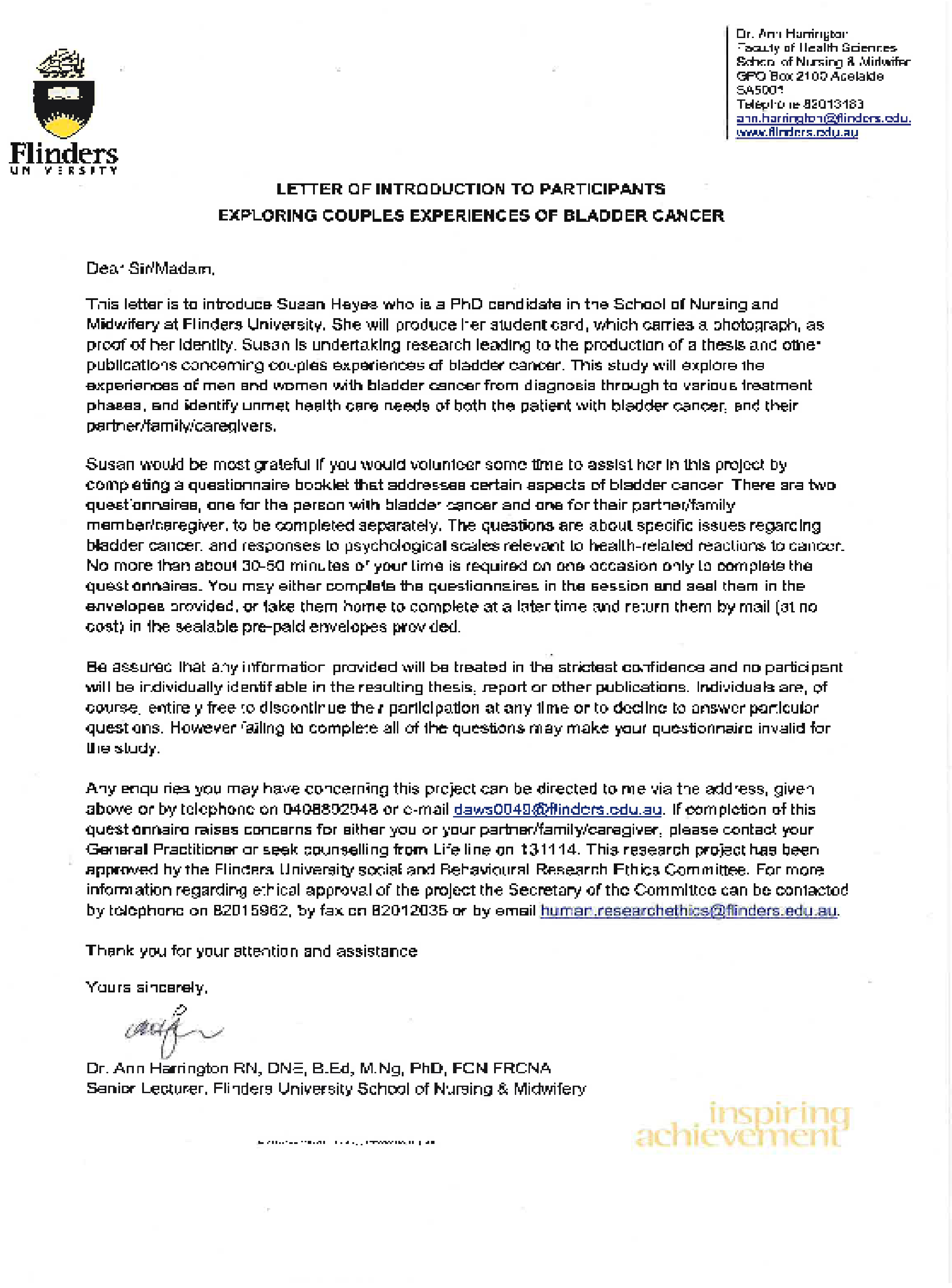
Project No.:	**5956**		
Project Title:	An investigation into the Experiences and Health Related Quality of Life of Men and Women Diagnosed with Bladder Cancer and their Partner, Family / Caregiver		
Principal Researcher:	Ms. Susan Heyes		
Email:	daws0049@flinders.edu.au		
Address:	School of Nursing and Midwifery		
Approval Date:	**7 March 2013**	Ethics Approval Expiry Date:	**21 March 2017**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

Andrea Fiegert
Executive Officer
Social and Behavioural Research Ethics Committee

c.c. A/Prof Malcolm Bond

E2. *Letter of Introduction to Participants*



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LETTER OF INTRODUCTION TO PARTICIPANTS

EXPLORING COUPLES EXPERIENCES OF BLADDER CANCER

Dear Sir/Madam,

This letter is to introduce Susan Hayes who is a PhD candidate in the School of Nursing and Midwifery at Flinders University. She will produce her student card, which carries a photograph, as proof of her identity. Susan is undertaking research leading to the production of a thesis and other publications concerning couples experiences of bladder cancer. This study will explore the experiences of men and women with bladder cancer from diagnosis through to various treatment phases, and identify unmet health care needs of both the patient with bladder cancer, and their partner/family/caregivers.

Susan would be most grateful if you would volunteer some time to assist her in this project by completing a questionnaire booklet that addresses certain aspects of bladder cancer. There are two questionnaires, one for the person with bladder cancer and one for their partner/family member/caregiver, to be completed separately. The questions are about specific issues regarding bladder cancer, and responses to psychological scales relevant to health-related reactions to cancer. No more than about 30-60 minutes of your time is required on one occasion only to complete the questionnaires. You may either complete the questionnaires in the session and seal them in the envelopes provided, or take them home to complete at a later time and return them by mail (at no cost) in the sealable pre-paid envelopes provided.

Be assured that any information provided will be treated in the strictest confidence and no participant will be individually identifiable in the resulting thesis, report or other publications. Individuals are, of course, entirely free to discontinue their participation at any time or to decline to answer particular questions. However failing to complete all of the questions may make your questionnaire invalid for the study.

Any enquiries you may have concerning this project can be directed to me via the address, given above or by telephone on 0408802048 or e-mail daws0049@flinders.edu.au. If completion of this questionnaire raises concerns for either you or your partner/family/caregiver, please contact your General Practitioner or seek counselling from Life line on 131114. This research project has been approved by the Flinders University social and Behavioural Research Ethics Committee. For more information regarding ethical approval of the project the Secretary of the Committee can be contacted by telephone on 82015962, by fax on 82012035 or by email human.researchethics@flinders.edu.au.

Thank you for your attention and assistance

Yours sincerely,

Dr. Ann Harrington RN, DNE, B.Ed, M.Ng, PhD, FCN FRCNA
Senior Lecturer, Flinders University School of Nursing & Midwifery

inspiring
achievement

E2. *Letter of Introduction to Chairperson/Head/Group Leaders*

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LETTER OF INTRODUCTION TO

CHAIRPERSON/HEAD/GROUP LEADERS

EXPLORING COUPLES EXPERIENCES OF BLADDER CANCER

Dear Sir/Madam,

This letter is to introduce Susan Heyes who is a PhD candidate in the School of Nursing and Midwifery at Flinders University. She is undertaking research leading to the production of a thesis concerning couples experiences of bladder cancer. Susan will produce her student card, which carries a photograph, as proof of her identity. This study will explore the experiences of men and women with bladder cancer from diagnosis through to various treatment phases, and identify unmet health care needs of both the participant with bladder cancer, and their partner/family/caregivers.

Susan would be most grateful if you would allow her to describe her study to your group/club members and offer them the opportunity to participate in her research. Health information relating to bladder cancer is sought as well as responses to psychological scales relevant to health-related quality of life for people with bladder cancer and their partners/family/caregivers. No more than about 30-50 minutes of each participant's time is required to complete the questionnaires. Participants with bladder cancer must have a partner/family member or caregiver who is also willing to participate. Participants may either complete the questionnaire when they see Susan (and seal it in the envelope provided), or complete the questionnaires at a later time and return them by mail in the pre-paid envelopes provided (at no cost).

Be assured that any information provided will be treated in the strictest confidence and no participant will be individually identifiable in the resulting thesis, report or other publications. Individuals are, of course, entirely free to discontinue their participation at any time or to decline to answer particular questions. However failing to complete all of the questions may make their questionnaire invalid for the study.

Any enquiries you may have concerning this project can be directed to me via the address, telephone number or e-mail given above. This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee. The Executive Officer of this Committee can be contacted on 82013116 or by e-mail (human.researchethics@flinders.edu.au). If completion of this questionnaire raises concerns for any of your members, please advise them to contact their General Practitioner or seek counselling through Life line on 131114.

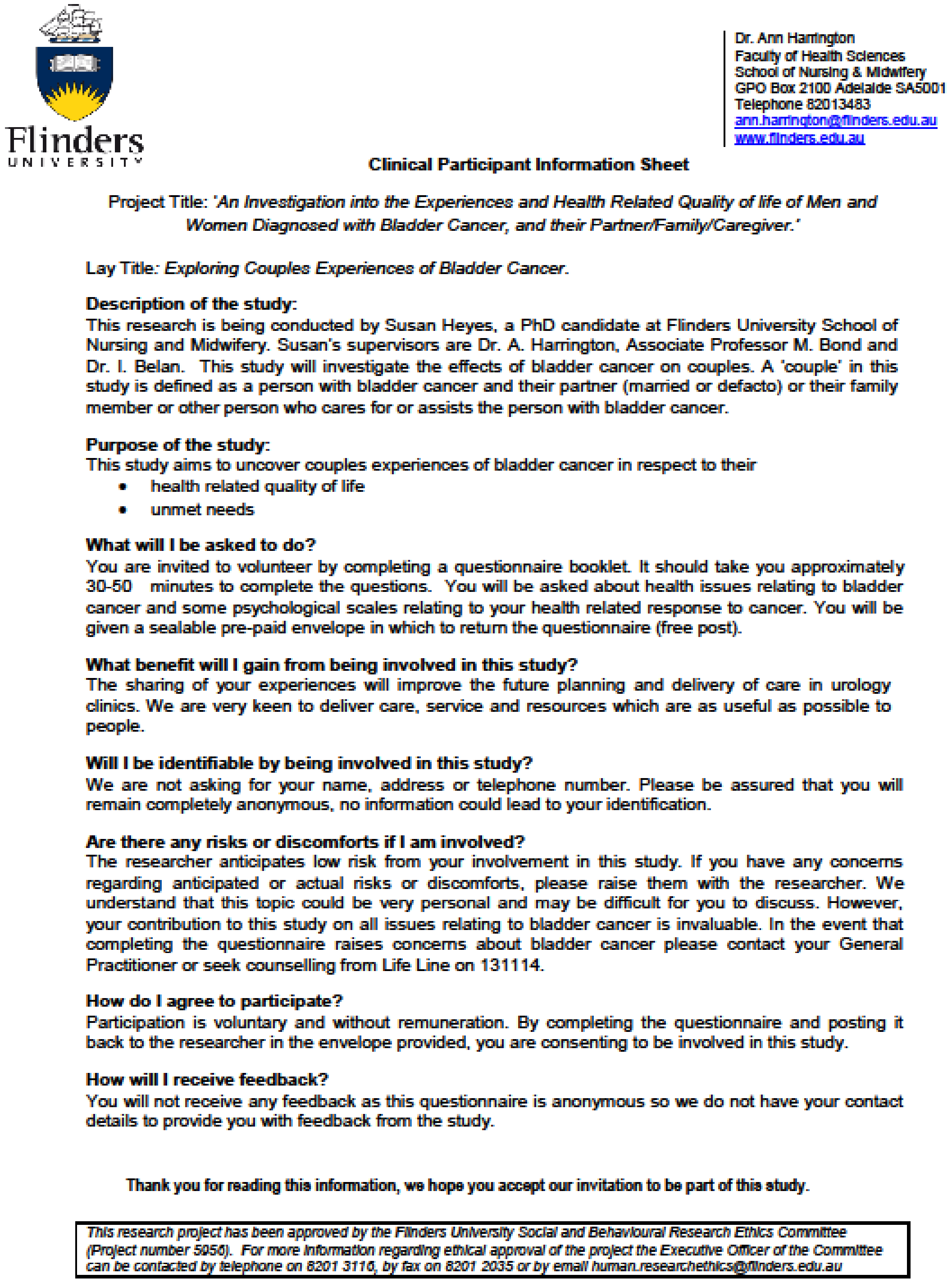
Thank You for your attention and assistance

Yours sincerely,

Dr. Ann Harrington RN, DNE, B.Ed, M.Ng, PhD, FCN FRCNA
Senior Lecturer, Flinders University School of Nursing & Midwifery

inspiring

E3. *Clinical Participant's Information Sheet*



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Clinical Participant Information Sheet

Project Title: '*An Investigation into the Experiences and Health Related Quality of life of Men and Women Diagnosed with Bladder Cancer, and their Partner/Family/Caregiver.*'

Lay Title: *Exploring Couples Experiences of Bladder Cancer.*

Description of the study:
This research is being conducted by Susan Heyes, a PhD candidate at Flinders University School of Nursing and Midwifery. Susan's supervisors are Dr. A. Harrington, Associate Professor M. Bond and Dr. I. Belan. This study will investigate the effects of bladder cancer on couples. A 'couple' in this study is defined as a person with bladder cancer and their partner (married or defacto) or their family member or other person who cares for or assists the person with bladder cancer.

Purpose of the study:
This study aims to uncover couples experiences of bladder cancer in respect to their

- health related quality of life
- unmet needs

What will I be asked to do?
You are invited to volunteer by completing a questionnaire booklet. It should take you approximately 30-50 minutes to complete the questions. You will be asked about health issues relating to bladder cancer and some psychological scales relating to your health related response to cancer. You will be given a sealable pre-paid envelope in which to return the questionnaire (free post).

What benefit will I gain from being involved in this study?
The sharing of your experiences will improve the future planning and delivery of care in urology clinics. We are very keen to deliver care, service and resources which are as useful as possible to people.

Will I be identifiable by being involved in this study?
We are not asking for your name, address or telephone number. Please be assured that you will remain completely anonymous, no information could lead to your identification.

Are there any risks or discomforts if I am involved?
The researcher anticipates low risk from your involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher. We understand that this topic could be very personal and may be difficult for you to discuss. However, your contribution to this study on all issues relating to bladder cancer is invaluable. In the event that completing the questionnaire raises concerns about bladder cancer please contact your General Practitioner or seek counselling from Life Line on 131114.

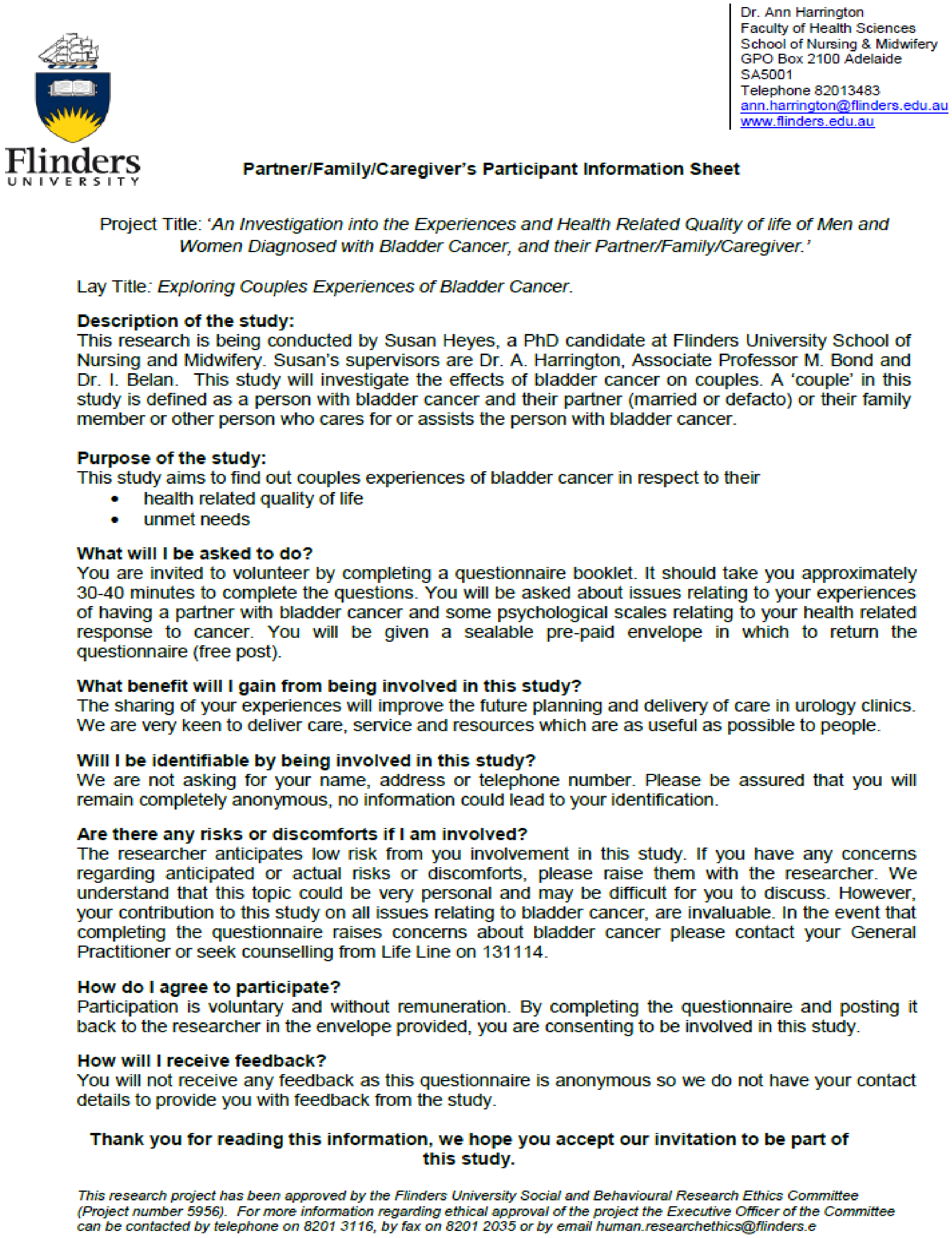
How do I agree to participate?
Participation is voluntary and without remuneration. By completing the questionnaire and posting it back to the researcher in the envelope provided, you are consenting to be involved in this study.

How will I receive feedback?
You will not receive any feedback as this questionnaire is anonymous so we do not have your contact details to provide you with feedback from the study.

Thank you for reading this information, we hope you accept our invitation to be part of this study.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 5056). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

E3. *Partner's Participant Information Sheet*



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Partner/Family/Caregiver's Participant Information Sheet

Project Title: '*An Investigation into the Experiences and Health Related Quality of life of Men and Women Diagnosed with Bladder Cancer, and their Partner/Family/Caregiver.'*

Lay Title*: Exploring Couples Experiences of Bladder Cancer.*

Description of the study:
This research is being conducted by Susan Heyes, a PhD candidate at Flinders University School of Nursing and Midwifery. Susan's supervisors are Dr. A. Harrington, Associate Professor M. Bond and Dr. I. Belan. This study will investigate the effects of bladder cancer on couples. A 'couple' in this study is defined as a person with bladder cancer and their partner (married or defacto) or their family member or other person who cares for or assists the person with bladder cancer.

Purpose of the study:
This study aims to find out couples experiences of bladder cancer in respect to their

- health related quality of life
- unmet needs

What will I be asked to do?
You are invited to volunteer by completing a questionnaire booklet. It should take you approximately 30-40 minutes to complete the questions. You will be asked about issues relating to your experiences of having a partner with bladder cancer and some psychological scales relating to your health related response to cancer. You will be given a sealable pre-paid envelope in which to return the questionnaire (free post).

What benefit will I gain from being involved in this study?
The sharing of your experiences will improve the future planning and delivery of care in urology clinics. We are very keen to deliver care, service and resources which are as useful as possible to people.

Will I be identifiable by being involved in this study?
We are not asking for your name, address or telephone number. Please be assured that you will remain completely anonymous, no information could lead to your identification.

Are there any risks or discomforts if I am involved?
The researcher anticipates low risk from you involvement in this study. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher. We understand that this topic could be very personal and may be difficult for you to discuss. However, your contribution to this study on all issues relating to bladder cancer, are invaluable. In the event that completing the questionnaire raises concerns about bladder cancer please contact your General Practitioner or seek counselling from Life Line on 131114.

How do I agree to participate?
Participation is voluntary and without remuneration. By completing the questionnaire and posting it back to the researcher in the envelope provided, you are consenting to be involved in this study.

How will I receive feedback?
You will not receive any feedback as this questionnaire is anonymous so we do not have your contact details to provide you with feedback from the study.

Thank you for reading this information, we hope you accept our invitation to be part of this study.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 5956). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.e

E4. *Recruitment poster*

School of Nursing & Midwifery

COUPLES & FAMILIES NEEDED FOR RESEARCH INTO BLADDER CANCER

We are looking for volunteers to take part in a study on bladder cancer. This study will explore the effects on quality of life that bladder cancer has on couples. Therefore, to take part in this study you need to either be diagnosed with bladder cancer or be the partner/family member/caregiver of someone with bladder cancer.

As participants in this study you and your partner/family/caregiver will be asked to complete a questionnaire each, on one occasion only. Completing the questionnaire should take approximately 30-50 minutes. We are not asking for your names, addresses, telephone numbers or any other personal details, so completing the questionnaires is completely anonymous and confidential. You will be provided with sealable, pre-paid envelopes in which to return your completed questionnaires. You are both free to withdraw from the study at any time.

For more information about this study or to volunteer for this study contact Susan Heyes on 0408892948 or susan.heyes@flinders.edu.au

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number 5956). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

E5. *Questionnaire for the Clinical Participant*

Study ID ☐☐☐

FLINDERS UNIVERSITY

FACULTY OF HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

COUPLES' EXPERIENCES OF BLADDER CANCER

TO BE COMPLETED BY A PERSON WITH BLADDER CANCER

INSTRUCTIONS

This questionnaire is concerned with the effects that your illness may have had on you.

Most questions can be answered by placing a tick mark (✓) in the appropriate box.

Please try to answer all questions and not skip any. If none of the answers to a question match your experience exactly, please choose the answer that is closest to your experience.

Some questions assume that you are married or have a steady partner you are close to. If there is a person you are close to who is not your spouse, please answer questions that use the word "spouse", assuming the question to mean "partner".

When questions ask about job performance, please answer in terms of any employment you may have. Otherwise, please answer in terms of your normal day-to-day activities (e.g., study, daily tasks around the house, etc.).

This section is about your urinary habits.
Please consider **ONLY THE PAST 4 WEEKS**

1. Which of the following do you have? *(Tick one)*

( ) Own (native) bladder
( ) Ileal conduit/ostomy
( ) Neo-bladder
( ) Continent urinary diversion/catheterizable pouch (such as an Indiana, Koch, Miami, Maintz or UCLA pouch)
( ) Other: Please specify

2. Over the past 4 weeks, how often did you typically feel the need to empty your bladder, neo-bladder, pouch of external appliance (bag) during the day? *(Tick one)*

( ) More frequently than once an hour
( ) Once an hour
( ) Once every 2 hours
( ) Once every 3-5 hours
( ) Only once or twice a day

3. Over the past 4 weeks how often have you leaked urine while awake and doing your normal activities? *(Tick one)*

( ) Every day
( ) About once a week
( ) Less than once a week
( ) Not at all

4. Over the past 4 weeks how often have you leaked urine while sleeping? *(Tick one)*

( ) Every day
( ) About once a week
( ) Less than once a week
( ) Not at all

5. Over the past 4 weeks which of the following best describes your urinary leakage when you are awake? *(Tick one*)

( ) No control whatsoever
( ) Frequent dribbling
( ) Occasional dribbling
( ) Total control

6. **Over the past 4 weeks** which of the following best describes your urinary leakage when you are asleep? *(Tick one)*

( ) No control whatsoever
( ) Frequent dribbling
( ) Occasional dribbling
( ) Total control

7. How big a problem if any, has each of the following been for you **during the past 4 weeks?** *(Tick one on each line)*

		No problem	**Very small problem**	**Small problem**	**Moderate problem**	**Big problem**
a.	Urinary leakage causing skin irritation	( )	( )	( )	( )	( )
b.	Urine leakage causing body odour	( )	( )	( )	( )	( )
c.	Blood in the urine	( )	( )	( )	( )	( )
d.	Pain related to urination, stoma or catheterization	( )	( )	( )	( )	( )

8. How big of a bother, if any, has your bladder, stoma, neo-bladder or catheterizable pouch been for you **during the past 4 weeks?** *(Tick one)*

( ) No bother
( ) Very small bother
( ) Small bother
( ) Moderate bother
( ) Big bother

9. Over the past 4 weeks, how much have difficulties with your bladder, stoma, neo-bladder or catheterizable pouch limited your activities. *(Tick one on each line)*

		Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
a.	Social activities with friends	( )	( )	( )	( )	( )
b.	Exercise	( )	( )	( )	( )	( )
c.	Sleep	( )	( )	( )	( )	( )

The next section is about your bowel habits and abdominal pain.
Please consider **ONLY THE PAST 4 WEEKS**.

1. How often have you had rectal urgency (felt like I had to pass stool, but did not) **during the past 4 weeks?** *(Tick one)*

( ) More than once a day
( ) About once a day
( ) More than once a week
( ) About once a week
( ) Rarely or never

2. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) **during the past 4 weeks?** *(Tick one)*

( ) Never
( ) Rarely
( ) About half the time
( ) Usually
( ) Always

3. How often have your bowel movements been painful **during the past 4 weeks?** *(Tick one)*

( ) Never
( ) Rarely
( ) About half the time
( ) Usually
( ) Always

4. How many bowel movements have you had on a typical day **during the past 4 weeks?** *(Tick one)*

( ) One or less
( ) Two
( ) Three
( ) Four or more

5. How big a problem, if any, has each of the following been for you **during the past 4 weeks?** *(Tick one on each line)*

		No problem	**Very small problem**	**Small problem**	**Moderate problem**	**Big problem**
a.	Urgency to have a bowel movement	( )	( )	( )	( )	( )
b.	Increased frequency of bowel movements	( )	( )	( )	( )	( )
c.	Bloody stools	( )	( )	( )	( )	( )
d.	Rectal/Abdominal/ Pelvic pain	( )	( )	( )	( )	( )
e.	Constipation	( )	( )	( )	( )	( )

6. Overall, how big a problem have your bowel habits been for you **during the past 4 weeks?** *(Tick one)*

( ) Big problem
( ) Moderate problem
( ) Small problem
( ) Very small problem

The next section is about your sexual function and satisfaction.
Please consider **ONLY THE PAST 4 WEEKS**.

1. How would you rate each of the following **during the past 4 weeks?** *(Tick one per line)*

		Very Poor	**Poor**	**Fair**	**Good**	**Very Good**
a	Your level of sexual desire?	( )	( )	( )	( )	( )
b	Your ability to reach orgasm (climax)?	( )	( )	( )	( )	( )
c	Your level of sensation in the genital area?	( )	( )	( )	( )	( )
d	Your ability to be sexually aroused?	( )	( )	( )	( )	( )
e	Your ability to have intercourse?	( )	( )	( )	( )	( )

2. **Over the past 4 weeks**, how often did you have any sexual activity? *(Tick one)*

( ) Not at all
( ) Less than once a week
( ) About once a week
( ) More than once a week

3. Over the past 4 weeks, how often have you had pain related to intercourse? *(Tick one)*

( ) Never
( ) Seldom
( ) Not often
( ) Often
( ) Very often

4. How big a problem, if any, has each of the following been for you **during the past 4 weeks?** *(Tick one on each line)*

	No Problem	**Very Small Problem**	**Small Problem**	**Moderate Problem**	**Big Problem**
a. Your level of sexual desire	( )	( )	( )	( )	( )
b. Your ability to have intercourse	( )	( )	( )	( )	( )
c. Your ability to reach orgasm.	( )	( )	( )	( )	( )

5. Overall, how would you rate your ability to function sexually **during the past 4 weeks?** (*Tick one)*

( ) Very Poor
( ) Poor
( ) Fair
( ) Good
( ) Very good

6. Overall, how big a problem has your sexual function or lack of sexual function been for you **during the past 4 weeks?** *(Tick one)*

( ) No problem
( ) Very small problem
( ) Small problem
( ) Moderate problem
( ) Big problem

For this section, please indicate how much each of the following statements has applied to you **during the past 4 weeks**.

		Definitely does not apply	**Rarely applies**	**Often applies**	**Definitely applies**
1.	At the moment I take one day at a time	( )	( )	( )	( )
2.	I see my illness as a challenge	( )	( )	( )	( )
3.	I’ve put myself in the hands of God	( )	( )	( )	( )
4.	I feel like giving up	( )	( )	( )	( )
5.	I feel very angry about what has happened to me	( )	( )	( )	( )
6.	I feel completely at a loss about what to do	( )	( )	( )	( )
7.	It is a devastating feeling	( )	( )	( )	( )
8.	I count my blessings	( )	( )	( )	( )
9.	I worry about the cancer returning or getting worse	( )	( )	( )	( )
10.	I try to fight the illness	( )	( )	( )	( )
11.	I distract myself when thoughts about my illness come into my head	( )	( )	( )	( )
12.	I can’t handle it	( )	( )	( )	( )
13.	I am apprehensive	( )	( )	( )	( )
14.	I am not very hopeful about the future	( )	( )	( )	( )
15.	I feel there is nothing I can do to help myself	( )	( )	( )	( )
16.	I think it is the end of the world	( )	( )	( )	( )
17.	Not thinking about it helps me cope	( )	( )	( )	( )

		Definitely does not apply	Rarely applies	Often applies	Definitely applies
18.	I am very optimistic	( )	( )	( )	( )
19.	I've had a good life. What's left is a bonus	( )	( )	( )	( )
20.	I feel that life is hopeless	( )	( )	( )	( )
21.	I can't cope	( )	( )	( )	( )
22.	I am upset about having cancer	( )	( )	( )	( )
23.	I am determined to beat this disease	( )	( )	( )	( )
24.	Since my cancer diagnosis, I now realise how precious life is and I'm making the most of it	( )	( )	( )	( )
25.	I have difficulty in believing that this is happening to me	( )	( )	( )	( )
26.	I make a positive effort not to think about my illness	( )	( )	( )	( )
27.	I deliberately push all thoughts of cancer out of my mind	( )	( )	( )	( )
28.	I suffer great anxiety about it	( )	( )	( )	( )
29.	I am a little frightened	( )	( )	( )	( )

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question.

1. Which of the following statements best describes your usual attitude about taking care of your health?

( ) I am very concerned and pay close attention to my personal health.

( ) Most of the time I pay attention to my health care needs.

( ) Usually, I try to take care of health matters but sometimes I just don't get around to it.

( ) Health care is something that I just don't worry too much about.

2. Your present illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction?

( ) I do things pretty much the way I always have done them and I don't worry or take any special considerations for my illness.

( ) I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.

( ) I do a pretty good job taking care of my present illness.

( ) I pay close attention to all the needs of my present illness and do everything I can to take care of myself.

3. In general, how do you feel about the quality of medical care available today and the doctors who provide it?

( ) Medical care has never been better, and the doctors who give it are doing an excellent job.

( ) The quality of medical care available is very good, but there are some areas that could stand improvement.

( ) Medical care and doctors are just not of the same quality they once were.

( ) I don't have much faith in doctors and medical care today.

4. During your present illness you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?

( ) I am very unhappy with the treatment I have received and don't think the staff has done all they could have for me.

( ) I have not been impressed with the treatment I have received, but I think it is probably the best they can do.

( ) The treatment has been pretty good on the whole, although there have been a few problems.

( ) The treatment and the treatment staff have been excellent.

5. When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please tick the statement below which comes closest to describing your feelings?

( ) I am sure that I am going to overcome the illness and its problems quickly and get back to being my old self.
( ) My illness has caused some problems for me, but I feel I will overcome them fairly soon, and get back to the way I was before.
( ) My illness has really been a great strain, both physically and mentally, but I am trying very hard to overcome it, and I feel sure that I will be back to my old self one of these days.
( ) I feel worn out and very weak from the illness, and there are times when I don't know if I am really ever going to be able to overcome it.

6. Being ill can be a confusing experience, and some patients and the people close to them feel that they do not receive enough information and details from their doctors and the medical staff about their illness. Please select a statement below which best describes your feelings about this matter.

( ) The doctor and the medical staff have told me very little about my illness even though I have asked more than once.
( ) I do have some information about my illness but I feel I would like to know more.
( ) I have a pretty fair understanding about my illness and feel that If I want to know more I can always get the information.
( ) I have been given a very complete picture of my illness, and my doctor and the medical staff have given me all the details I wish to have.

7. In an illness such as yours, people have different ideas about the treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your treatment.

( ) I believe the doctors and medical staff are quite able to direct my treatment and feel it is the best treatment I could receive.

( ) I have trust in the doctor's direction of my treatment however; sometimes I have doubts about it.

( ) I don't like certain parts of my treatment which are very unpleasant, but the doctors tell me I should go through it anyway.

( ) In many ways I think the treatment is worse than the illness, and I am not sure it is worth going through it.

8. In an illness such as yours, patients and the people closest to them are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about your treatment.

( ) I have been told almost nothing about my treatment and feel left out about it.

( ) I have some information about my treatment, but not as much as I would like to have.

( ) My information concerning treatment is pretty complete, but there are one or two things I still want to know.

( ) I feel my information concerning treatment is very complete and up-to–date.

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question.

1. Has your illness interfered with your ability to do your job (or other activities)?
   - ( ) No problems with my job
   - ( ) Some problems, but only minor ones
   - ( ) Some serious problems
   - ( ) Illness has totally prevented me from doing my job
2. How well do you physically perform your job (or other activities) now?
   - ( ) Poorly
   - ( ) Not too well
   - ( ) Adequately
   - ( ) Very well
3. During the past 30 days, have you lost any time at work (or other activities) due to your illness?
   - ( ) 3 days or less
   - ( ) 1 week
   - ( ) 2 weeks
   - ( ) More than 2 weeks
4. Is your job (or other activities) as important to you now as it was before your illness?
   - ( ) Little or no importance to me now
   - ( ) A lot less important
   - ( ) Slightly less important
   - ( ) Equal or greater importance than before
5. Have you had to change your goals concerning your job (or other activities) as a result of your illness?
   - ( ) My goals are unchanged
   - ( ) There has been a slight change in my goals
   - ( ) My goals have changed quite a bit
   - ( ) I have changed my goals completely
6. Have you noticed any increase in problems with your co-workers (or other acquaintances, neighbours) since your illness?
   - ( ) A great increase in problems
   - ( ) A moderate increase in problems
   - ( ) A slight increase in problems
   - ( ) None

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question.

1. How would you describe your relationship with your husband or wife (partner, if not married) since your illness?
   - ( ) Good
   - ( ) Fair
   - ( ) Poor
   - ( ) Very poor

2. How would you describe your general relationships with the other people you live with (e.g., children, parents, aunts, etc.)?
   - ( ) Very Poor
   - ( ) Poor
   - ( ) Fair
   - ( ) Good

3. How much has your illness interfered with your work and duties around the house?
   - ( ) Not at all
   - ( ) Slight problems, but easily overcome
   - ( ) Moderate problems, not all of which can be overcome
   - ( ) Severe difficulties with household duties

4. In those areas where you illness has cause problems with your household work, how has the family shifted duties to help you out?
   - ( ) The family has not been able to help out at all
   - ( ) The family has tried to help but many things are left undone
   - ( ) The family has done well except for a few minor things
   - ( ) No problem

5. Has your illness resulted in a decrease in communication between you and members of your family?
   - ( ) No decrease in communication
   - ( ) A slight decrease in communication
   - ( ) Communication has decreased, and I feel somewhat withdrawn from them
   - ( ) Communication has decreased a lot, and I feel very alone.

6. Some people with an illness like yours feel they need help from other people (friends, neighbours, family, etc.) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?
   - ( ) I really need help but seldom is anyone around to help
   - ( ) I get some help, but I don't count on it all the time
   - ( ) I don't get all the help I need all of the time, but most of the time help is there when I need it
   - ( ) I don't feel I need such help, or the help I need is available from my family or friends

7. Have you experienced any personal physical disability since your illness was diagnosed?
   - ( ) No physical illness
   - ( ) Slight physical illness
   - ( ) Moderate physical illness
   - ( ) Severe physical illness

8. An illness such as yours can sometimes cause a drain on the family's finances; are you having any difficulties meeting the financial demands of your illness?
   - ( ) Severe financial hardship
   - ( ) Moderate financial problems
   - ( ) A slight financial drain
   - ( ) No money problems

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question.

1. Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your illness?
   - ( ) Contact is the same or greater since illness
   - ( ) Contact is slightly less
   - ( ) Contact is markedly less
   - ( ) No contact since illness

2. Have you remained as interested in getting together with theses members of your family since your illness?
   - ( ) Little or no interest in getting together with them
   - ( ) Interest is a lot less than before
   - ( ) Interest is slightly less
   - ( ) Interest is the same or greater since illness

3. Sometimes, when people are ill, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?
   - ( ) I need no help, or they give me all the help I need
   - ( ) Their help is enough, except for some minor things
   - ( ) They give me some help but not enough
   - ( ) They give me little or no help even though I need a great deal.

4. Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your illness reduced such socializing?
   - ( ) Socializing with them has been pretty much eliminated
   - ( ) Socializing with them has been reduced significantly
   - ( ) Socializing with them has been reduced somewhat
   - ( ) Little or no socializing, or slight or no effect of illness

5. In general, how have you been getting along with these members of your family recently?
   - ( ) Good
   - ( ) Fair
   - ( ) Poor
   - ( ) Very poor

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question.

1. Are you still as interested in your leisure time activities and hobbies as you were prior to your illness?

( ) Same level of interest as previously
( ) Slightly less interest than before
( ) Significantly less interest than before
( ) Little or no interest remaining

2. How about actual participation? Are you still actively involved in doing those activities?

( ) Little or no participation at present
( ) Participation reduced significantly
( ) Participation reduced slightly
( ) Participation remains unchanged

3. Are you still interested in leisure time activities with your family (i.e., playing cards & games, taking trips, going swimming, etc.) as you were prior to your illness?

( ) Same level of interest as previously
( ) Slightly less interest than before
( ) Significantly less interest than before
( ) Little or no interest remaining

4. Do you still participate in those activities to the same degree you once did?

( ) Little or no participation at present
( ) Participation reduced significantly
( ) Participation reduced slightly
( ) Participation remains unchanged

5. Have you maintained your interest in social activities since your illness (e.g., social clubs, church groups, going to the movies, etc.)?

( ) Same level of interest as previously
( ) Slightly less interest than before
( ) Significantly less interest than before
( ) Little or no interest remaining

6. How about participation? Do you still go out with your friends and do those things?

( ) Little or no participation at present
( ) Participation reduced significantly
( ) Participation reduced slightly
( ) Participation remains unchanged

The following section is about **your current views** on love and sex.
Please tick the **one response** for **each item** that best applies to you.

	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
1. For us, sex is secondary to the friendship aspects of our relationship	( )	( )	( )	( )	( )
2. For my partner and me, sex is not necessary but it can make our love stronger	( )	( )	( )	( )	( )
3. My partner and I love each other for many reasons other than sex	( )	( )	( )	( )	( )
4. We don’t always have time for sex, but it is important to show love in other ways	( )	( )	( )	( )	( )
5. For my partner and me, communication is more important than physical affection	( )	( )	( )	( )	( )
6. For us, the physical aspect is a small part of the whole of our relationship	( )	( )	( )	( )	( )
7. Sex shows our love for each other	( )	( )	( )	( )	( )
8. For my partner and me, love and sex cannot be separated	( )	( )	( )	( )	( )
9. When we have sex, it proves that we love each other	( )	( )	( )	( )	( )
10. Words tell us we love each other, but sex shows us we love each other	( )	( )	( )	( )	( )

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
11. My partner and I wouldn’t have had sex if we didn’t love each other	( )	( )	( )	( )	( )
12. We had to love each other before we could really enjoy being sexual with each other	( )	( )	( )	( )	( )
13. For my partner and me, sex came first, followed by love	( )	( )	( )	( )	( )
14. For my partner and me, love came first, followed by sex	( )	( )	( )	( )	( )
15. My partner and I are drifting apart, and sex is declining	( )	( )	( )	( )	( )
16. We love each other and are comfortable together, but the excitement of being ‘in love’ has decreased	( )	( )	( )	( )	( )
17. We were sexual at the beginning of our relationship, but now we are abstinent	( )	( )	( )	( )	( )

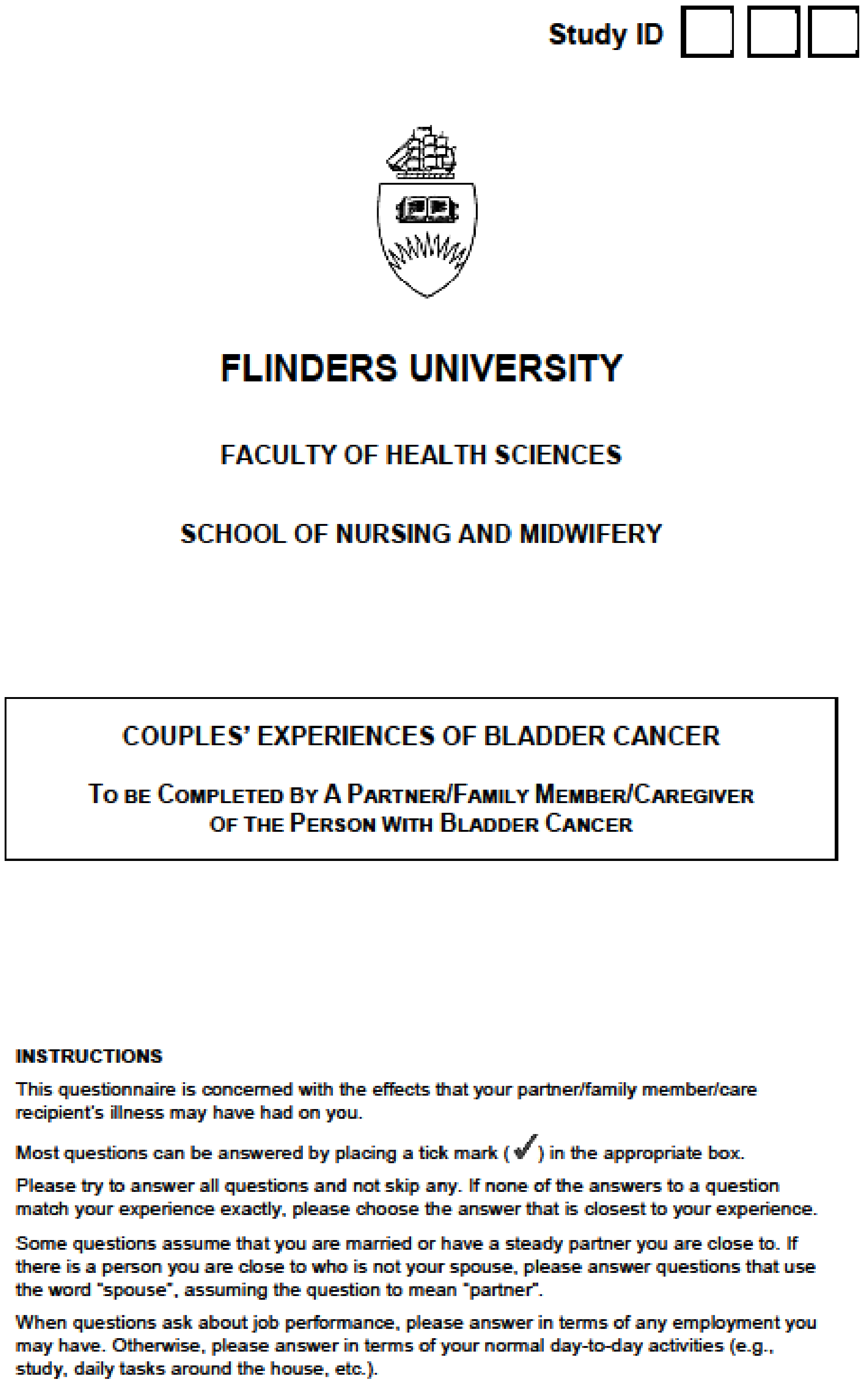
Finally, I would like to ask you a few general questions about **yourself**.
Please tick the relevant box in each case.

1. What is your gender? ( ) Male ( ) Female
2. What is your current age? (In years) __________________
3. What is the highest level of education you have completed?
    - ( ) No formal education
    - ( ) Primary school
    - ( ) Secondary school
    - ( ) Trade qualification
    - ( ) Tertiary degree (or equivalent)
4. What is your marital status?
    - ( ) Single
    - ( ) Married / or Defacto relationship (for __________ years)
    - ( ) Separated, divorced
    - ( ) Widowed
5. What is your race or ethnic identity? ____________________________
6. Are you currently employed?
    - ( ) Studying
    - ( ) Domestic duties
    - ( ) Retired
    - ( ) Working casual
    - ( ) Working part-time
    - ( ) Working full-time
    - ( ) Self-employed
7. How long have you had bladder cancer for? _______________________years.

We appreciate the time you have taken to fill in this form. Please check again to make sure you have completed all the items. If you have any questions about the form, please write them on the back page. Please return the form as soon as you have completed it.

Thank you.

E6. *Questionnaire for the Partner*



Study ID ☐ ☐ ☐

FLINDERS UNIVERSITY

FACULTY OF HEALTH SCIENCES

SCHOOL OF NURSING AND MIDWIFERY

COUPLES' EXPERIENCES OF BLADDER CANCER

TO BE COMPLETED BY A PARTNER/FAMILY MEMBER/CAREGIVER
OF THE PERSON WITH BLADDER CANCER

INSTRUCTIONS

This questionnaire is concerned with the effects that your partner/family member/care recipient's illness may have had on you.

Most questions can be answered by placing a tick mark (✓) in the appropriate box.

Please try to answer all questions and not skip any. If none of the answers to a question match your experience exactly, please choose the answer that is closest to your experience.

Some questions assume that you are married or have a steady partner you are close to. If there is a person you are close to who is not your spouse, please answer questions that use the word "spouse", assuming the question to mean "partner".

When questions ask about job performance, please answer in terms of any employment you may have. Otherwise, please answer in terms of your normal day-to-day activities (e.g., study, daily tasks around the house, etc.).

For this section, please indicate have much each of the following statements has applied to you **during the past 4 weeks**.

		Definitely does not apply	**Rarely applies**	**Often applies**	**Definitely applies**
1.	At the moment I take one day at a time	( )	( )	( )	( )
2.	I see my partner’s illness as a challenge	( )	( )	( )	( )
3.	I’ve put myself in the hands of God	( )	( )	( )	( )
4.	I feel like giving up	( )	( )	( )	( )
5.	I feel very angry about what has happened to my partner	( )	( )	( )	( )
6.	I feel completely at a loss about what to do	( )	( )	( )	( )
7.	It is a devastating feeling	( )	( )	( )	( )
8.	I count my blessings	( )	( )	( )	( )
9.	I worry about the cancer returning or getting worse	( )	( )	( )	( )
10.	I try to fight the illness	( )	( )	( )	( )
11.	I distract myself when thoughts about my partner’s illness come into my head	( )	( )	( )	( )
12.	I can’t handle it	( )	( )	( )	( )
13.	I am apprehensive	( )	( )	( )	( )
14.	I am not very hopeful about the future	( )	( )	( )	( )
15.	I feel there is nothing I can do to help myself	( )	( )	( )	( )
16.	I think it is the end of the world	( )	( )	( )	( )
17.	Not thinking about it helps me cope	( )	( )	( )	( )

		Definitely does not apply	Rarely applies	Often applies	Definitely applies
18.	I am very optimistic	( )	( )	( )	( )
19.	He/she has had a good life. What's left is a bonus	( )	( )	( )	( )
20.	I feel that life is hopeless	( )	( )	( )	( )
21.	I can't cope	( )	( )	( )	( )
22.	I am upset about my partner having cancer	( )	( )	( )	( )
23.	I am determined to help him/her beat this disease	( )	( )	( )	( )
24.	Since my partner's cancer diagnosis, I now realise how precious life is and I'm making the most of it	( )	( )	( )	( )
25.	I have difficulty in believing that this is happening to me	( )	( )	( )	( )
26.	I make a positive effort not to think about my partner's illness	( )	( )	( )	( )
27.	I deliberately push all thoughts of cancer out of my mind	( )	( )	( )	( )
28.	I suffer great anxiety about it	( )	( )	( )	( )
29.	I am a little frightened	( )	( )	( )	( )

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question.

1. Which of the following statements best describes your usual attitude about taking care of your health?

( ) I am very concerned and pay close attention to my personal health.
( ) Most of the time I pay attention to my health care needs.
( ) Usually, I try to take care of health matters but sometimes I just don’t get around to it.
( ) Health care is something that I just don’t worry too much about.

2. Your partner’s illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction?

( ) I do things pretty much the way I always have done them and I don’t worry or take any special considerations for my partner’s illness.
( ) I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.
( ) I do a pretty good job taking care of my partner’s illness.
( ) I pay close attention to all the needs of my partner’s present illness and do everything I can to take care of him/her.

3. In general, how do you feel about the quality of medical care available today and the doctors who provide it?

( ) Medical care has never been better, and the doctors who give it are doing an excellent job.
( ) The quality of medical care available is very good, but there are some areas that could stand improvement.
( ) Medical care and doctors are just not of the same quality they once were.
( ) I don’t have much faith in doctors and medical care today.

4. During your partner’s present illness they have received treatment from both doctors and medical staff. How do you feel about them and the treatment your partner has received from them?

( ) I am very unhappy with the treatment he/she has received and don’t think the staff has done all they could have for my partner.
( ) I have not been impressed with the treatment he/she has received, but I think it is probably the best they can do.
( ) The treatment has been pretty good on the whole, although there have been a few problems.
( ) The treatment and the treatment staff have been excellent.

5. When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please tick the statement below which comes closest to describing your feelings?

( ) I am sure that my partner is going to overcome the illness and its problems quickly and get back to being his/her old self.

( ) My partner’s illness has caused some problems for me, but I feel he/she will overcome them fairly soon, and get back to the way he/she was before.

( ) My partner’s illness has really been a great strain, both physically and mentally, but he/she is trying very hard to overcome it, and I feel sure that my partner will be back to his/her old self one of these days.

( ) My partner feel worn out and very weak from the illness, and there are times when I don’t know if he/she is really ever going to be able to overcome it.

6. Being ill can be a confusing experience, and some patients and the people close to them feel that they do not receive enough information and details from their doctors and the medical staff about their illness. Please select a statement below which best describes your feelings about this matter.

( ) The doctor and the medical staff have told me very little about my partner’s illness even though I have asked more than once.

( ) I do have some information about my partner’s illness but I feel I would like more.

( ) I have a pretty fair understanding about my partner’s illness and feel that If I want to know more I can always get the information.

( ) I have been given a very complete picture of my partner’s illness, and the doctor and the medical staff have given me all the details I wish to have.

7. In an illness such as yours, people have different ideas about the treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your partner’s treatment.

( ) I believe the doctors and medical staff are quite able to direct my partner’s treatment and feel it is the best treatment he/she could receive.

( ) I have trust in the doctor’s direction of my partner’s treatment however; sometimes I have doubts about it.

( ) I don’t like certain parts of his/her treatment which are very unpleasant, but the doctors say he/she should go through it anyway.

( ) In many ways, I think the treatment is worse than the illness, and I am not sure it is worth going through it.

8. In an illness such as your partner’s, patients and the people closest to them are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about their treatment.

( ) I have been told almost nothing about my partner’s treatment and feel left out about it.

( ) I have some information about my partner’s treatment, but not as much as I would like to have.

( ) My information concerning their treatment is pretty complete, but there are one or two things I still want to know.

( ) I feel my information concerning treatment is very complete and up-to–date.

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question.

1. Has your partner's illness interfered with your ability to do your job (or other activities)?
    ( ) No problems with my job
    ( ) Some problems, but only minor ones
    ( ) Some serious problems
    ( ) Illness has totally prevented me from doing my job

2. How well do you physically perform your job (or other activities) now?
    ( ) Poorly
    ( ) Not too well
    ( ) Adequately
    ( ) Very well

3. During the past 30 days, have you lost any time at work (or other activities) due to your partner's illness?
    ( ) 3 days or less
    ( ) 1 week
    ( ) 2 weeks
    ( ) More than 2 weeks

4. Is your job (or other activities) as important to you as it was before your partner's illness?
    ( ) Little or no importance to me now
    ( ) A lot less important
    ( ) Slightly less important
    ( ) Equal or greater importance than before

5. Have you had to change your goals concerning your job (or other activities) as a result of your partner's illness?
    ( ) My goals are unchanged
    ( ) There has been a slight change in my goals
    ( ) My goals have changed quite a bit
    ( ) I have changed my goals completely

6. Have you noticed any increase in problems with your co-workers (or other acquaintances, neighbours) since your partner's illness?
    ( ) A great increase in problems
    ( ) A moderate increase in problems
    ( ) A slight increase in problems
    ( ) None

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question

1. How would you describe your relationship with your husband or wife (partner, if not married) since his/her illness?
   - ( ) Good
   - ( ) Fair
   - ( ) Poor
   - ( ) Very poor

2. How would you describe your general relationships with the other people you live with (e.g., children, parents, aunts, etc.)?
   - ( ) Very Poor
   - ( ) Poor
   - ( ) Fair
   - ( ) Good

3. How much has your partner's illness interfered with your work and duties around the house?
   - ( ) Not at all
   - ( ) Slight problems, but easily overcome
   - ( ) Moderate problems, not all of which can be overcome
   - ( ) Severe difficulties with household duties

4. In those areas where your partner's illness has cause problems with your household work, how has the family shifted duties to help you out?
   - ( ) The family has not been able to help out at all
   - ( ) The family has tried to help but many things are left undone
   - ( ) The family has done well except for a few minor things
   - ( ) No problem

5. Has your partner's illness resulted in a decrease in communication between you and members of your family?

   ( ) No decrease in communication

   ( ) A slight decrease in communication

   ( ) Communication has decreased, and I feel somewhat withdrawn from them

   ( ) Communication has decreased a lot, and I feel very alone.

6. Some people with a partner who is ill like yours feel they need help from other people (friends, neighbours, family, etc.) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?

   ( ) I really need help but seldom is anyone around to help

   ( ) I get some help, but I don't count on it all the time

   ( ) I don't get all the help I need all of the time, but most of the time help is there when I need it

   ( ) I don't feel I need such help, or the help I need is available from my family or friends

7. Have you experienced any personal physical illness since your partner's illness was diagnosed?

   ( ) No physical illness

   ( ) Slight physical illness

   ( ) Moderate physical illness

   ( ) Severe physical illness

8. An illness such as your partners can sometimes cause a drain on the family's finances; are you having any difficulties meeting the financial demands of your illness?

   ( ) Severe financial hardship

   ( ) Moderate financial problems

   ( ) A slight financial drain

   ( ) No money problems

Please answer the following questions with respect to the **past 30 days**.
Tick **one response** per question.

1. Are you still as interested in your leisure time activities and hobbies as you were prior to your partner's illness?
   - ( ) Same level of interest as previously
   - ( ) Slightly less interest than before
   - ( ) Significantly less interest than before
   - ( ) Little or no interest remaining

2. How about actual participation? Are you still actively involved in doing those activities?
   - ( ) Little or no participation at present
   - ( ) Participation reduced significantly
   - ( ) Participation reduced slightly
   - ( ) Participation remains unchanged

3. Are you still interested in leisure time activities with your family (i.e., playing cards & games, taking trips, going swimming, etc.) as you were prior to your partner's illness?
   - ( ) Same level of interest as previously
   - ( ) Slightly less interest than before
   - ( ) Significantly less interest than before
   - ( ) Little or no interest remaining

4. Do you still participate in those activities to the same degree you once did?
   - ( ) Little or no participation at present
   - ( ) Participation reduced significantly
   - ( ) Participation reduced slightly
   - ( ) Participation remains unchanged

5. Have you maintained your interest in social activities since your partner's illness (e.g., social clubs, church groups, going to the movies, etc.)?
   - ( ) Same level of interest as previously
   - ( ) Slightly less interest than before
   - ( ) Significantly less interest than before
   - ( ) Little or no interest remaining

6. How about participation? Do you still go out with your friends and do those things?
   - ( ) Little or no participation at present
   - ( ) Participation reduced significantly
   - ( ) Participation reduced slightly
   - ( ) Participation remains unchanged

The following section is about **your current views** on love and sex.

Please tick the **one response** for **each item** that best applies to you.

	Strongly disagree	**Disagree**	**Neutral**	**Agree**	**Strongly agree**
1. For us, sex is secondary to the friendship aspects of our relationship	( )	( )	( )	( )	( )
2. For my partner and me, sex is not necessary but it can make our love stronger	( )	( )	( )	( )	( )
3. My partner and I love each other for many reasons other than sex	( )	( )	( )	( )	( )
4. We don’t always have time for sex, but it is important to show love in other ways	( )	( )	( )	( )	( )
5. For my partner and me, communication is more important than physical affection	( )	( )	( )	( )	( )
6. For us, the physical aspect is a small part of the whole of our relationship	( )	( )	( )	( )	( )
7. Sex shows our love for each other	( )	( )	( )	( )	( )
8. For my partner and me, love and sex cannot be separated	( )	( )	( )	( )	( )
9. When we have sex, it proves that we love each other	( )	( )	( )	( )	( )
10. Words tell us we love each other, but sex shows us we love each other	( )	( )	( )	( )	( )

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
11. My partner and I wouldn't have had sex if we didn't love each other	( )	( )	( )	( )	( )
12. We had to love each other before we could really enjoy being sexual with each other	( )	( )	( )	( )	( )
13. For my partner and me, sex came first, followed by love	( )	( )	( )	( )	( )
14. For my partner and me, love came first, followed by sex	( )	( )	( )	( )	( )
15. My partner and I are drifting apart, and sex is declining	( )	( )	( )	( )	( )
16. We love each other and are comfortable together, but the excitement of being 'in love' has decreased	( )	( )	( )	( )	( )
17. We were sexual at the beginning of our relationship, but now we are abstinent	( )	( )	( )	( )	( )

Finally, I would like to ask you a few general questions about **yourself**.
Please tick the relevant box in each case.

1. What is your gender? ( ) Male ( ) Female

2. What is your current age? (in years) ___________________

3. What is the highest level of education you have completed?

   ( ) No formal education

   ( ) Primary school

   ( ) Secondary school

   ( ) Trade qualification

   ( ) Tertiary degree (or equivalent)

4. What is your relationship to the person with bladder cancer?

   ( ) Married / or Defacto relationship (for __________ years)

   ( ) Family member (please state relationship) _________________________

   ( ) Informal caregiver, (non-family member)

   ( ) Professional, paid caregiver

5. What is your race or ethnic identity? _____________________________

6. Are you currently employed?

   ( ) Studying

   ( ) Domestic duties

   ( ) Retired

   ( ) Working casual

   ( ) Working part-time

   ( ) Working full-time

   ( ) Self-employed

We appreciate the time you have taken to fill in this form. Please check again to make sure you have completed all the items. If you have any questions about the form, please write them on the back page. Please return the form as soon as you have completed it.

Thank you.

APPENDIX F

COPYRIGHT PERMISSIONS

F1. *Permission to use the mini-MAC*

28/11/2012

Dear Susan
Many thanks for your enquiry. Your research is very interesting and I wish you success.
I have not worked at The Royal Marsden Hospital since 1995 and no longer have copies of the MAC and Mini-MAC scales.
I suggest you contact:
Dr Maggie Watson
Psychological Medicine
Royal Marsden NHS Trust
Downs Road
Sutton
Surrey
SM2 5PT
United Kingdom.

Best wishes
Dr Steven Greer
Consultant Psychiatrist

Candis Shattell
Medical Secretary
St Raphael's Hospice
Tel: 02083354575

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APPENDIX G

MODELS OF CARE

Table G1 *Initial Diagnosis Model – Nurse-led Haematuria Clinic*

Nurse-led, Same-day Haematuria clinic	**Test Results**	**Medical Imaging**	**Flexible Cystoscopy**	**Bladder Cancer Diagnosis**	**Urology - Oncology Nurse Follow-up**
Urine sample test, blood test, past medical history, HR, BP, Sp02, ECG, weight, smoking history, family history	Positive results Cytology - Yes History - Yes	Radiologist and urologist view imaging Positive - Yes	Take the patient to theatre and prepare for cystoscopy. Give patient take-home information and antibiotics.	Cystoscopy positive - Yes Urologist to explain the BlCa diagnosis to the patient	Telephone patient within 3 days. Book appointments.Refer to online supports. Enquire about understanding of BlCa. Ask about needs and supports. Answer all questions. Book U/O nurse chat before next cystoscopy to check level of understanding. Send required information**.**
	Positive results signify the patient is at risk of having BlCa and requires further tests	Urologist to explain the results and same-day cystoscopy to patient. Urologist to seek patient's consent		U/O nurse chat with the couple in a quiet space. Explain the diagnosis and give take-home information, contact details for U/O nurse and other supports. Encourage involvement of partners**.**	
Test results Cytology History -Negative Refer back to GP	Same day medical imaging CT	Imaging negative Refer back to GP. Follow-up in 6-12 mths.	Cystoscopy - negative Refer back to GP. Follow-up in 6-12 months		

Table G2 *Ongoing Treatment Pathways and Future Care*

Positive Flexible Cystoscopy	**TURBT with Anaesthetic**	**Surveillance Cystoscopy**	**Intravesical Therapy Chemotherapy or BCG**	**Radical Cystectomy**	**Future Care**
After urologist has given the patient their BlCa diagnosis and the couple have had a chat with the U/O nurse, plans for a TURBT need to be made.	U/O nurse check on patients undergoing procedures plus chemotherapy if included.	Arrange a U/O nurse chat prior to patient's next cystoscopy.	During the procedure ensure patient is aware of what the treatment is including side-effects. Answer questions and provide information required.	When the diagnosis is MIBlCa, an RC is planned and explained by urologist.	Gradually space out U/O nurse chat to 2/ years or as required. Make referals to MDT as required. Check if continence nurse or counselling are needed. Refer couple for counselling if failing to adapt to BlCa. Work through goals and strategies with couple. Couple to complete psychological assessments.
After expaining the procedure send the patient to the same-day, pre- anaesthetic check-up. Make TURBT appoinement.	Post-TURBT ensure patient has take-home information and antibiotics. Make next surveillance appointment. Check partner knows when to pick patient up. U/O nurse phones patient within 3 days.	Answer any questions, make referals, provide information.	Post-treatment make next treatment appointment. Telephone the patient within 3 days to check how they are.	U/O nurse chat with the couple to check their understanding of RC. Refer to stoma nurse and pre-anaesthetic check. Make appointment times. Give take home information re-RC and post-surgery side effects.	
		Take patient to theatre for cystoscopy. Check that patient has antibiotics and follow-up appointment.			

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A final word

Je n'ai fait celle-ci plus longue que parce que je n'ai pas eu le loisir de la faire plus courte.

I have made this longer than usual because I have not had time to make it shorter

(Blaise Pascal 'Lettres Provinciales', 1657)