

PATIENT AND PARTNER PERCEPTIONS OF THE PATIENT'S CANCER:
IS DISCREPANCY IMPORTANT?

Claire Louise Mitchell

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The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others

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Abstract

Background: Research suggests that illness perceptions influence psychosocial outcomes across a range of chronic illnesses, including cancer. Such research traditionally takes an individualistic perspective, focusing on the patient. However, family members, in particular partners, play a crucial role in chronic illness and should be considered when examining adjustment. Partners also form illness perceptions about their partner's illness, which may differ from the patient's views, and some studies have found that such 'discrepancy' can be associated with negative psychosocial outcomes. However, the research in this area has produced mixed results and many studies neglect partner outcomes. Furthermore, there is little research exploring how perceptions evolve and are negotiated in couples.

Aims: A quantitative study primarily aimed to examine associations between discrepancy in illness perceptions and quality of life in couples facing cancer, addressing limitations in previous research. A qualitative study aimed to develop understanding of how differences or similarities in perceptions develop and are negotiated in couples, and the role of discrepant perceptions within the adjustment process.

Method: Thirteen couples completed questionnaires assessing their illness perceptions and health-related quality of life. This sample size was much smaller than anticipated due to recruitment difficulties and therefore the quantitative aims were not realised. For the qualitative study, six of the couples were interviewed both jointly and individually, with their data being analysed using the Voice-centred Relational Method and Interpretative Phenomenological Analysis.

Results: Case studies highlighted that the evolution of couples' understandings of the cancer was complex and idiosyncratic. Five group level themes were developed: *unique roles and needs; in it together; outside influences; negotiations; and how we are left.* These themes highlighted that couples balanced various complementary and competing perceptions that arose from the influence of numerous factors both within and outside the couple relationship. Balancing these multiple understandings required the use of various negotiation processes and attempts at negotiations varied in their ability to obtain a satisfactory resolution. Discrepancy was experienced both positively and negatively by the couples.

Discussion: The recruitment difficulties that prevented some of the research aims being addressed are discussed. The qualitative findings are discussed in relation to the wider literature and clinical implications highlighted. Overall, the study highlights the importance of including partners in care provision and supports a relationship-centred approach to cancer.

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Abbreviations

APIM: Actor-Partner Interdependence Model

CICS: Couples' Illness Communication Scale

HR-QoL: Health-Related Quality of Life

IPA: Interpretative Phenomenological Analysis

IPQ-R: Illness Perception Questionnaire-Revised

NICE: National Institute for Health and Care Excellence

PSA: Prostate Specific Antigen

QoL: Quality of Life

RAND-36: RAND 36-item health survey (version 1.0)

SRM: Self-regulatory model of illness cognition and behaviour

VRM: Voice-Centred Relational Method

CHAPTER 1: INTRODUCTION

In the UK, the lifetime risk for developing cancer is approximately one in three (Cancer Research UK, 2013a). Advances in early detection and treatment have resulted in more people surviving cancer, generating a greater need for research into cancer survivorship and quality of life (Baker, Denniston, Smith & West, 2005). Definitions of 'cancer survivorship' include family members, friends and caregivers, in order to recognise the profound impact of cancer on loved ones as well as patients (Twombly, 2004). This chapter describes the background to prostate and colorectal cancers, and the impact they can have on the quality of life of patients and their families. It goes on to consider the impact of individuals' beliefs about illness on psychosocial outcomes in chronic illness, particularly cancer, by examining the literature on the self-regulatory model of illness cognition and behaviour (SRM). Recent research applying the SRM to couple adjustment will be examined, which has explored the impact of discrepancy in illness perceptions within couples on psychosocial outcomes. The chapter will also discuss additional systemic perspectives that can provide further insights into couple adjustment to chronic illness and consider potential factors that may influence the development and negotiation of discrepant or shared illness perceptions.

Cancer

The most common cancers in England are breast, prostate, lung and colorectal (Cancer Research UK, 2013a). This thesis explored colorectal and prostate cancers; therefore some background to these cancers is presented.

Colorectal Cancer

Colorectal cancer, commonly known as bowel cancer, originates in the colon or rectum. It is the fourth most common cancer in England, being more common in males than females, with around 40,700 cases diagnosed in the UK in 2010 (Cancer Research UK, 2013b). Incidence of colorectal cancer increases with age, with most cases occurring in people over the age of 60 (Cancer Research UK, 2013b). UK five-year survival rates are around 54% (Coleman et al., 2011).

Around 5% of colorectal cancer cases are accounted for by two genetic syndromes: familial adenomatous polyposis and hereditary non-polyposis colorectal cancer (NICE, 2004). A further 20% of cases are estimated to be accounted for by other hereditary factors (Fearnhead, Wilding & Bodmer, 2002). Lifestyle and

environmental factors, such as smoking, alcohol intake, diet and physical activity, are estimated to account for 54% of cases (Parkin, Boyd & Walker, 2011).

Treatment for colorectal cancer usually involves surgery, which can be accompanied by chemotherapy and/or radiotherapy. However, if the disease is too advanced at diagnosis, curative intervention cannot be attempted (NICE, 2004). Surgical treatment can result in a temporary or permanent stoma, which can generate lifestyle changes and require significant psychological adjustment (Brown & Randle, 2005). Other treatment and disease consequences include bowel, urinary and sexual dysfunction (Denlinger & Barsevick, 2009).

Prostate Cancer

Prostate cancer is the most common cancer in males, constituting around 25% of all male cancers in the UK, with around 41,000 cases diagnosed in 2010 (Cancer Research UK, 2013c). The number of identified cases has increased in recent years due to prostate specific antigen (PSA) testing facilitating earlier diagnosis (NICE, 2002). Incidence rates in men under 50 are very low, but rates increase sharply and continuously with age, reaching an overall peak in men aged 75-79 (Cancer Research UK, 2012). Five-year survival rates in England are around 77% (Office for National Statistics, 2009).

Genetic factors are suggested to underlie about 9% of prostate cancer cases (McLellan & Norman, 1995). Other risk factors include high levels of insulin-like growth factor (Rowlands et al., 2009) and a diet characterised by high intake of animal fats and dairy products (NICE, 2002).

Treatment options for prostate cancer include active monitoring, surgery, radiotherapy and hormone treatment (NICE, 2008). There is no consensus on the optimum treatment approach, therefore patients must be actively involved in deciding which treatment is best for them, depending on their individual values and situation (NICE, 2002). Disease progression and treatments for prostate cancer can be associated with sexual, bowel and urinary dysfunction (Lubeck et al., 1999).

Summary of Colorectal and Prostate Cancer

There are some differences in presentation, risk factors, and treatments between prostate and colorectal cancer; however they share some common factors. For example, sexual, urinary and bowel dysfunction are common treatment effects, therefore, they are likely to require adaptation to similar functional consequences. Both are also likely to involve facing challenges which are common across many cancer diagnoses, discussed below.

Common Challenges Following Cancer

For some, cancer can impact on practical aspects of daily life, such as creating the need for time off work, financial changes and difficulties carrying out usual activities due to treatment side-effects like pain and fatigue, which can lead to changes in roles and responsibilities (Mann & Badr, 2008). Many cancer survivors do not face everyday pragmatic issues; however, the threatened loss and fear of recurrence can afflict many aspects of patients' lives, even after successful treatment and the threat has diminished (Rolland, 1994). For example, Baker et al. (2005) found that the majority of patients diagnosed with commonly occurring cancers remained concerned about recurrence and were fearful of the future one year after diagnosis. These issues also have significant repercussions for the entire family, particularly partners who provide the majority of emotional and practical support (Manne & Badr, 2008). The practical issues and role changes must often be managed together and partners also fear recurrence, possibly more so than patients (Mellon, Kershaw, Northouse & Freeman-Gibb, 2007). During survivorship, negotiating the return to normal life is an important challenge, with patients and partners often having different paces regarding this (Manne & Badr, 2008). For many, the nonmedical challenges are more powerful than the medical challenges (Wolff, 2007).

Therefore, cancer can have a profound effect on many aspects of the lives of patients and their families (Parker, Baile, De Moor, & Cohen, 2003; Rees, O'Boyle, & MacDonagh, 2001). Individuals and families vary in their ability to adjust to the cancer-related stressors, with adjustment commonly assessed using measures of well-being, mood, functioning and quality of life (Sharpe & Curran, 2006).

Quality of Life and Cancer

Quality of life (QoL) is a psychosocial construct describing a person's appraisal of their physical, psychological and social well-being (Brown, Renwick, & Nagler, 1996). It is an important outcome measure as it covers multiple dimensions and is an important indicator of treatment outcome (Raeburn & Rootman, 1996).

Health-Related Quality of Life

QoL affected by a health concern is referred to as health-related quality of life (HR-QoL), which incorporates four principle domains: physical (bodily function, which can be affected by disease or treatment); functional (ability to perform activities); emotional (psychological and mental functioning); and social (maintenance of

relationships) (Cella & Tulsky, 1993). Therefore, HR-QoL represents a combination of the person's subjective experience and emotional evaluation of their health problems.

HR-QoL and Cancer Research

Research has demonstrated that cancer can have a negative impact on the different components of HR-QoL for the patient, including the physical, functional, and social domains (Boini, Briançon, Guillemin, Galan, & Hercberg, 2004; Ramsey et al., 2000). Cancer has also been found to be associated with reduced emotional well-being. For example, prevalence studies of psychological distress in cancer patients have found overall rates of around 35%, with rates varying by cancer site (lung cancer, 43.4%; breast cancer, 32.8%; colon cancer, 31.6%; prostate cancer, 30.5%) (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001).

Although less extensively researched, there is some evidence that cancer can also impact on aspects of HR-QoL of partners and spouses. For example, spouses have been found to suffer from poor emotional well-being, reporting similar levels (Compas et al., 1994) or higher levels (Kornblith, Herr, Ofman, Scher & Holland, 1994) of psychological distress compared to the patient. However, despite the multidimensional nature of HR-QoL, most studies have focussed on psychological distress in spouses and caregivers (Kim & Given, 2008). Consequently, less is known about the impact of cancer on other HR-QoL dimensions for partners.

Therefore, evidence suggests that cancer can be associated with reduced HR-QoL in cancer patients and partners. Achieving a better understanding of variables that predict HR-QoL in patients and partners should make a positive contribution towards identifying strategies for improving their HR-QoL.

Factors predicting quality of life in cancer patients and partners

Unsurprisingly, certain disease characteristics have been found to be associated with HR-QoL for cancer patients. For example, associations have been found between recurrent disease and poorer physical HR-QoL (Parker et al., 2003), less advanced disease and better emotional HR-QoL (Parker et al., 2003) and longer time since diagnosis and better physical and social HR-QoL (Terrell et al., 2004). Disease characteristics have also been found to be associated with HR-QoL in partners, such as more advanced disease being associated with poorer HR-QoL (Kornblith et al., 2001).

Demographic factors have also been found to be associated with HR-QoL. For example, older patients report better emotional HR-QoL than younger patients (Parker

et al., 2003) and women report lower HR-QoL, regardless of whether they are the patient or partner (Hagedoorn, Sanderman, Bolks, Tuinistra, & Coyne, 2008).

Studies have also found that cancer patients' and partners' HR-QoL are interdependent, with significant positive correlations found between patient and carer outcomes (Hodges, Humphris & Macfarlane, 2005; Mellon, Northouse & Weiss, 2006). Some research suggests that the direction of influence of psychological distress is more commonly from the partner to the patient (Segrin et al., 2005; Segrin, Badger & Harrington, 2012), although there is also some evidence for patient well-being predicting partner well-being (Dorros, Card, Segrin & Badger, 2010).

In summary, evidence suggests that cancer can have a negative impact on adjustment for patients and partners, as measured by HR-QoL. However, there has been limited research with partners and dyads, with much research focusing on specific domains of HR-QoL, particularly psychological distress, rather than exploring it as an entire construct. Furthermore, such research tells us little about the important processes involved in adjustment for individuals and families. Knowledge of such processes can help identify factors that are modifiable and can be targeted by interventions (Gray et al., 2011). Various psychological models have been proposed that aim to provide insight into illness adjustment.

Models of Adjustment to Chronic Illness

Coping Theories

Coping theories form the foundation for much of the research exploring adjustment to illness. Lazarus & Folkman's (1984) stress-coping theory emphasises that a person's appraisal of the situation is more important than the objective circumstances. The theory suggests two types of appraisal: primary appraisal, which involves evaluating potential threat to personal well-being, and secondary appraisal, which involves evaluating available coping resources. A situation is perceived as a stress if it is appraised as personally significant and exceeding the person's coping resources. These appraisals influence the types of coping strategies used.

Stress-coping theory has been influential and stimulated a large body of research (Bodenmann, 2005). However, there are several criticisms to the research, including limitations with the coping measures used and the limited clinical benefit it has produced (Somerfield & McCrae, 2000). Furthermore, the theory is criticised for conceptualising coping as an individual process and lacking consideration of social and environmental influences (Revenson, Kayser & Bodenmann, 2005).

Social Cognition Models

Social cognition models are also interested in appraisals and important cognitions, and the roles these play in health behaviours (Conner & Norman, 2005); however they give more attention to social-contextual factors (Sharpe & Curran, 2006). An important social cognition model, which was influential in the design of this thesis, is the self-regulatory model of illness cognition and behaviour (SRM) (Leventhal, Meyer & Nerenz, 1980), also known as the 'common-sense model'.

Leventhal's Self-Regulatory Model

The SRM suggests that people respond to health threats by actively constructing their own mental representation of their illness in order to make sense of and manage the problem. These illness perceptions (or illness representations) consist of beliefs and expectations about the illness based on information from social contacts (e.g. family members, health professionals), cultural knowledge, and personal experience of the illness (e.g. symptomatic information) (Leventhal, Brissette & Leventhal, 2003). Illness perceptions are made up of both cognitive dimensions, comprising the individual's perception of the health threat, and emotional dimensions, encompassing the individual's emotional reaction to the threat (Leventhal et al., 1980). Illness perceptions are highly personal and vary in terms of medical accuracy and coherence (Cameron & Moss-Morris, 2004).

The SRM outlines three stages that individuals undergo when responding to a health threat. Firstly, illness perceptions are formed around a number of dimensions of the illness experience: identity (symptoms and names); timeline (duration and course of illness); consequences (impact of illness on life functions); causes (perceived causes of symptoms); and control (controllability of the illness). In the second stage, these perceptions determine coping efforts, which in turn affect outcomes and adjustment. In the third stage, outcomes are evaluated, which may lead to adjustment of perceptions and coping efforts. Thus, illness perceptions are viewed to have a central role in adaptation to health threats.

Measuring Illness Perceptions

The Illness Perception Questionnaire-Revised (IPQ-R; Moss-Morris et al., 2002) has been devised which measures the five dimensions outlined and has been extended to measure emotional perceptions (affective responses) and illness coherence (overall understanding). This has facilitated the widespread use of the SRM in research examining adaptation to chronic illness.

Illness Perceptions and Chronic Illness

The SRM has received empirical support across various illnesses. Early research focussed on the relationship between illness perceptions and health behaviours, also referred to as 'problem-focussed coping responses' (Sharpe & Curran, 2006). Illness perceptions have been found to predict various health behaviours in a range of chronic illnesses. For example, research has found that attendance at cardiac rehabilitation is more likely among patients who believe their condition is controllable, symptomatic, with severe consequences, and feel they understand the condition (French, Cooper & Weinman, 2006). Treatment control perceptions have been found to be associated with antibiotic use in Cystic Fibrosis (Bucks et al., 2009) and emotional and timeline dimensions predict self-care behaviours in end-stage renal disease (O'Connor, Jardine & Millar, 2008).

The SRM also suggests that coping strategies play a mediating role in the relationship between illness perceptions and outcomes. However, there is a body of research suggesting that coping does not mediate this association in a number of illnesses (Dorrian, Dempster & Adair, 2009; Edgar & Skinner, 2003; Kaptein et al., 2006). Furthermore, numerous studies have found that illness perceptions are stronger correlates of outcomes than coping strategies (Dempster et al., 2011a; Moss-Morris, Petrie & Weinman, 1996; Rozema, Vollink, & Lechner, 2009). Leventhal, Breland, Mora & Leventhal (2010) suggest these findings may be because coping measures evaluate coping styles rather than specific actions, which are the proposed mediators.

Due to the limited success in providing support for the role of coping strategies, research has focussed on the relationship between illness perceptions and outcomes, with many studies finding support for the predictive role of illness perceptions in emotional and physical adjustment across various illnesses (Hagger & Orbell, 2003). Generally, more positive attributions, where the illness is perceived as controllable, having less serious consequences and having a shorter timeline, are suggested to be associated with adaptive outcomes (Sharpe & Curran, 2006). However, some argue that positive attributions are not always beneficial and that illness beliefs must match reality to prevent maladaptive outcomes (Folkman, 1984). For example, research has found that beliefs that the illness is controllable are associated with poorer outcomes in severely ill patients (Christensen, Benotsch, Wiebe & Lawton, 1995; Park, Folkman & Bostrum, 2001), which suggests that unrealistic positive attributions are unlikely to facilitate adjustment (Sharpe & Curran, 2006). Furthermore, Kaptein et al. (2003)

found that different illness perceptions are important for outcomes in different chronic illnesses.

Illness Perceptions and Cancer

Illness perceptions have been found to be related to various domains of HR-QoL in a variety of cancers. In breast cancer patients, Millar, Purushotham, McLatchie, George & Murray (2005) found that a higher number of symptoms attributed to the cancer (identity) and shorter perceived duration of the illness (timeline) was associated with greater distress. Shorter timeline being associated with greater distress is contrary to predictions; however the authors suggest that this could reflect pessimism about survival leading to greater distress.

Another study of breast cancer patients found that greater illness identity and greater perceived negative consequences were associated with poorer physical HR-QoL, whereas less perceived treatment control and more negative emotional perceptions were associated with poorer mental health HR-QoL (Rozema et al., 2009).

In head and neck cancer, Scharloo et al. (2005) found that fewer perceived symptoms were significantly associated with better role and emotional functioning and global HR-QoL. Less belief in a cyclical timeline was associated with better role and cognitive functioning. A less strong emotional response was associated with better emotional and social functioning and less belief in own behaviour as a cause was associated with better social functioning. Another study investigating head and neck cancer patients found that beliefs about a long timeline were associated with lower global HR-QoL (Llewellyn, McGurk & Weinman, 2007).

In oesophageal cancer, beliefs regarding more severe consequences, less coherence and that stress or poor emotional health were causes have been found to be associated with poor emotional health (Dempster et al., 2012). Gould, Brown, & Bramwell (2010) investigated gynaecological cancer patients and found that perceptions of cyclical timeline, more severe consequences, low personal and treatment control and low coherence were associated with greater mood disturbance.

Illness Perceptions in Colorectal and Prostate Cancer

Gray et al. (2011) investigated associations between illness perceptions and HR-QoL in colorectal cancer. This study found that perceptions of a high number of symptoms, cyclical timeline and more negative consequences were associated with poorer HR-QoL, whereas higher personal and treatment control were associated with better HR-QoL. In prostate cancer, beliefs about greater treatment control, greater illness coherence, fewer negative consequences and fewer personality and

behavioural causes have been found to be associated with greater emotional well-being (Traeger et al., 2009).

Summary

Research has demonstrated associations between illness perceptions and various domains of HR-QoL in a variety of cancers, with many of these studies finding a relationship even after controlling for medical and demographic variables. However, the research has demonstrated inconsistent findings regarding the specific illness perceptions associated with HR-QoL. Variations in outcome measures and cancer populations could explain some of the discrepant findings. Nevertheless, across chronic illnesses, certain perceptions have emerged as being most consistently related to HR-QoL outcomes, namely the consequences, timeline and control dimensions, whereby perceptions of more severe consequences and longer timeline are linked to reduced well-being, and higher control appraisals are linked with enhanced well-being (Hagger & Orbell, 2003). Greater coherence has also been found to be associated with greater emotional well-being in cancer patients (Dempster et al., 2012; Traeger et al., 2009) and identity appears important in cancer (Kaptein et al., 2003).

The evidence that illness perceptions are related to outcomes in chronic illness, including cancer, is important because some recent research has demonstrated that perceptions are modifiable through interventions and that these changes can influence behavioural outcomes, such as increased adherence (Broadbent, Ellis, Thomas, Gamble & Petrie, 2009; Petrie, Perry, Broadbent & Weinman, 2011). However, a review of such research suggests that the effect of changes in beliefs on psychological and behavioural outcomes remains unclear and warrants further methodologically sound research (Goulding, Furze, & Birks, 2010).

Critique of the SRM

The SRM emphasises the importance of social factors in the development of illness perceptions, however when this model is operationalized, social factors are often neglected. Research traditionally takes an individualistic perspective, focusing on the patient. However, family members, in particular partners, play a crucial role in chronic illness. They also seek to understand their family member's illness and form illness perceptions that correspond with the SRM dimensions (Weinman, Heijmans & Figueiras, 2003), which may concur with or differ from the patient's perceptions. Therefore partners' appraisals should also be taken into consideration when examining adjustment to chronic illness (Berg & Upchurch, 2007).

Research Integrating Carer Perceptions in the Self-Regulatory Model

Carers' Illness Perceptions and Carer Outcomes

There is some evidence demonstrating that carers' illness perceptions can affect their HR-QoL. For example, in oesophageal cancer, Dempster et al. (2011b) found that family carers who had good illness coherence, perceived less serious consequences, believed the patient has personal control over the illness and believed the cancer was caused by external factors were less likely to experience poor emotional HR-QoL. Carer perceptions have also been found to be associated with carer distress in psychosis (Barrowclough, Lobban, Hatton & Quinn, 2001; Fortune, Smith & Garvey, 2005), stroke (McClenahan & Weinman, 1998; Twiddy, House & Jones, 2012) and Huntington's disease (Kaptein et al., 2007) populations.

Carers' Illness Perceptions and Patient Outcomes

There is also some limited evidence demonstrating that carers' illness perceptions can affect patients' HR-QoL. For example, Dempster et al. (2011a) found that carers perceptions of more severe consequences and less treatment control was associated with higher levels of psychological distress in patients with oesophageal cancer. Karademas and Giannousi (2013) found that partner perceptions of control were associated with anxiety in cancer patients. However, the majority of this research has focused on associations between carers perceptions and behavioural or physical outcomes, such as exercise behaviour in myocardial infarction (Weinman, Petrie, Sharpe & Walker, 2000) and physical functioning in stroke (Molloy et al., 2008). Furthermore, some studies only found associations between carer perceptions and certain domains of HR-QoL of patients (Kaptein et al., 2007).

Patient Illness Perceptions and Carer Outcomes

Few studies have examined the influence of patient perceptions on carer outcomes. One study exploring this in Huntington's disease found that patient perceptions of having control over the illness were associated with higher vitality in their carers; however there were no associations with other domains of HR-QoL (Kaptein et al., 2007). Furthermore, Karademas and Giannousi (2013) found that cancer patients' perceptions of control were not related to partners' emotional well-being. The limited amount of research and variations in findings suggests that this issue would benefit from further research.

Discrepancy in Illness Perceptions and Outcomes

Patients' and partners' HR-QoL may not only be dependent on individual illness perceptions, but may also be influenced by whether those close to them hold similar views. Research suggests that patients and partners can have different beliefs about the illness (Heijmans, de Ridder & Bensing, 1999). Such dissimilarity, divergence or incongruence in illness perceptions is often referred to as discrepancy.

There is a growing body of research into the relationship between discrepancy and outcomes in chronic illness. Some studies have found support for an association between discrepancy and higher patient and carer distress. For example, Kuipers et al. (2007) found that discrepancy in perceptions of consequences was associated with greater psychological distress in patients with psychosis, whereas discrepancy in perceptions of controllability was associated with greater distress in carers. Support for a relationship between discrepancy and patient adjustment has been found in various other conditions, such as rheumatoid arthritis (Sterba et al., 2008), infertility (Benyamini, Gozlan & Kokia, 2009), chronic fatigue syndrome and Addison's disease (Heijmans, et al., 1999). There has been limited research in cancer populations, although discrepancy in couples' perceptions of adjustment to breast cancer has been found to be associated with mood disturbance in the patient (Romero, Lindsay, Dalton, Nelson, & Friedman, 2008) and discrepancy in couples' perceptions of urinary and bowel function in prostate cancer has been found to be associated with poorer HR-QoL for both patients and partners (Mertz et al., 2011). Although these studies provide some support regarding the importance of discrepancy, they did not assess the illness perception domains of the SRM.

Possible explanations for the association between discrepancy and poor HR-QoL outcomes are that incongruence has negative consequences such as increasing conflict (Deal, Wampler, & Halverson, 1992), resulting in incompatible coping and support strategies (Ben-Zur, Gilbar & Lev, 2001) or causing patients to feel that they are either not taken seriously or are being overprotected (Heijmans et al., 1999).

However, there is evidence to suggest that the relationship between discrepancy and outcome is not straightforward. The methods used to investigate discrepancy in previous studies vary in how they have operationalised and analysed discrepancy, which has highlighted the complexity of the relationship.

Some studies have examined the direction of the discrepancy between patients and partners. Partners can hold more pessimistic views and maximise the seriousness of the illness compared to the patient (known as spouse maximisation) or they can hold more positive views and minimise the seriousness (spouse minimisation). Research examining both maximisation and minimisation has produced mixed results.

Studies have found that both maximisation and minimisation can be associated with both positive and negative outcomes depending on the nature of the illness and the illness perception dimension (Benyamini et al., 2009; Heijmans, et al., 1999; Richards et al., 2004). A possible reason for discrepancy not always having negative consequences could be that one person having positive perceptions boosts the mood and motivates better coping strategies in the other (Figueiras & Weinman, 2003).

Some studies have examined the direction of similarity in perceptions. Both the patient and partner could have negative illness perceptions or they could both have positive perceptions. Some research has classified couples as similarly positive, similarly negative, or discrepant, which has demonstrated that similarity is not always beneficial. For example, Figueras and Weinman (2003) studied men recently diagnosed with myocardial infarction and found that similarity in negative perceptions was associated with poorer patient outcomes than similarity in positive perceptions.

Summary and Critique of SRM Research

The relationship between illness perceptions and outcomes is supported by a wealth of studies, across a range of chronic illnesses. However, there is limited research regarding partner perceptions and outcomes, particularly in cancer populations, and many studies only examine one outcome, such as distress, with limited research investigating HR-QoL as a whole.

Research suggests that carer perceptions are associated with both their own and patient outcomes. However, this area has received much less research interest than patients' illness perceptions and outcomes. Furthermore, very few studies have examined associations between patient perceptions and carer outcomes. Therefore further research in this area would be valuable.

Overall, the emerging evidence offers tentative support for the assumption that discrepancy in illness perceptions can affect both partners' adjustment across a range of chronic illnesses; however there have been mixed results concerning whether the direction of the discrepancy or similarity is important. Nevertheless, the general pattern of relationship suggests that minimisation by the partner is associated with worse patient outcomes and maximisation by the partner is associated with worse partner outcomes (Benyamini et al., 2009), although the impact of the direction of discrepancy appears to depend on the illness and illness perception dimension.

The large variations between discrepancy studies in terms of the nature of the illness, outcome measures, carer types, and approaches to discrepancy and analysing the data are likely to have influenced the varied results. These methodological variations also make it difficult to explain the mixed findings, but they do suggest that

further research would be beneficial. A significant limitation in previous research is the tendency to focus on patient outcomes, suggesting a need for further research examining partner outcomes. Previous research highlights that an individual's own illness perceptions are associated with their own outcomes; however, in general, discrepancy studies ignore this and do not control for the individual's own illness perceptions when examining discrepancy. Therefore, discrepancy research that controls for the individual's own perceptions would be beneficial.

The SRM research has proved valuable in providing evidence for the importance of illness perceptions in predicting adjustment as an outcome. However, this research provides little information about the process of adjustment and the role of couples' perceptions in this process. There is limited understanding about how discrepancy evolves in couples, with the vast majority of research into discrepancy investigating this as a predictor of outcome using quantitative methods (Ezer, Rigol Chachamovich & Chachamovich, 2011). There has been little exploration into the factors associated with discrepancy or the processes involved in its development. Such investigations would be valuable for attempting to identify appropriate interventions that could assist couples in minimising and managing discrepancy, which could potentially prevent poor HR-QoL. A conceptual framework that can bring adjustment in the context of relationships to the foreground is systems theory.

Systems Theory

Systems theory, originating from early work by Gregory Bateson (1972), conceptualises families as interdependent, homeostatic systems, where each family member affects other members, with a strong tendency towards reaching and maintaining a balance. It emphasises the reciprocal and recursive nature of relationships, attending to family interactions and relationships not just coexistence of individuals, considering multiple perspectives simultaneously. This reciprocity requires an on-going process of adaptation to respond to demands or stressors that arise from both within and outside the system.

Chronic illness, such as cancer, poses a significant challenge to family systems, necessitating the restructuring of internal processes in order to balance homeostasis and the need to change. Various dimensions of family functioning may influence how families respond to such challenges, such as pre-existing relationship patterns, family background, norms, boundaries, rules, communication styles and roles (Palmer & Glass, 2003). Significantly, family belief systems and shared perceptions are considered integral to family adaptation to illness (Rolland, 2005).

Systems theory also emphasises that families are strongly influenced by the environment with which they interact, which encompasses cultural, community and political factors (Dallos & Stedmon, 2006). Therefore, family adjustment to illness should be considered within families' broader social context.

Regarding couples' perceptions of illness, this suggests couples work together to continually co-construct their understanding of illness within the context of their history, such as personal and illness-related experiences, as well as their social environment. Relationship and interpersonal processes are also implicated in the co-construction process. Ways that these factors may influence understandings and adjustment in couples facing cancer are described below.

Illness-Related Experiences

A family's history of illness experiences can influence how they understand and adapt to future illness (Rolland, 1994). For example, they may have developed beliefs about their ability to master illness, expectations about outcomes of illness and preferential ways of managing disease-related practical and affective tasks that they apply to future illness (Rolland, 1987). Personal experience of illness can also lead people to see this as part of 'normal' life and anticipate future illness, therefore experiencing it as less disruptive (Lindsay, 2009).

Personal and Life Experiences

Personal experience of non-illness stressors can also affect how individuals and families appraise and manage illness crises (Rolland, 1994). For example, successful coping with previous stressors could provide a frame for current coping; however, previous failure to cope could reduce confidence in managing current stress. The impact of an illness on individuals and families can also depend on concurrent life experiences, which could make it more difficult to cope (Rolland, 1994). For example, higher levels of co-occurring stressors have been found to be related to higher distress in partners of breast cancer patients (Northouse, Dorris, & Charron-Moore, 1995).

Social Context

Chronic illnesses are understood within a social and cultural context (Clarke & Everest, 2006), which can include friends, medical institutions, religious and cultural beliefs, and mass media influences. For example, interactions with health professionals, such as the way diagnoses are communicated, can have an important influence on families' understanding (Ong, de Haes, Hoos & Lammes, 1995; Rolland, 2005). Furthermore, mass media frequently uses metaphors of war and battle in

reference to cancer, which can reinforce fear reactions (Clarke & Everest, 2006). Religious and cultural beliefs also influence perceptions about caregiving roles, normative illness rituals, and appropriate illness communication (Rolland, 2005).

Relationship and Interpersonal Processes

Relationship qualities

Relationship quality is known to be an important factor in illness adjustment, with research in cancer populations suggesting that being in a higher quality relationship is associated with less distress than being in a dysfunctional relationship (Banthia et al., 2003), which is suggested to be due to the beneficial emotional and practical support provided by close relationships (Manne, 1998). Another important process in chronic illness is relationship awareness, involving perceiving the illness to be a relationship issue rather than an individual issue, which has been found to have adaptive consequences (Rohrbaugh, Mehl, Shoham, Reilly, & Ewy, 2008). High quality relationships may also be characterised by open communication about illness, however this is not necessarily the case (Boehmer & Clark, 2001).

Communication

Systems theory views communication processes as the primary means for achieving optimum family functioning. Open communication, involving authentic self-disclosure of thoughts, feelings and information, has been found to be beneficial for illness adaptation (Goldsmith, Miller & Caughlin, 2008), whereas avoidance of illness communication has been linked to higher distress (Manne et al., 2006). This pattern is suggested to be due to the importance of open communication for coordinating coping, increasing closeness and engaging in sense-making (Goldsmith et al., 2008).

Despite the suggested benefits, open communication about illness can be difficult for couples, with illness often being associated with a closing of communication (Hilton & Koop, 1994). For example, cancer patients and partners have been found to avoid discussing prognosis and negative medical information, possibly due to not wanting to upset one another (Manne, 1998) and wanting to sustain normality (Gray, Fitch, Phillips, Labrecque & Fergus, 2000). Furthermore, various factors can influence couples' communication. For example, couples who do not talk about cancer tend to be older and have been in a relationship longer than couples who share concerns (Hilton & Koop, 1994). Women are also likely to self-disclose more than men; although this gender difference is small (Dindia & Allen, 1992) it can result in imbalanced communication preferences in heterosexual couples.

Moreover, greater amount and frequency of illness-related communication has not always been found to be beneficial (Manne, 1998), with some evidence suggesting that selective disclosure is more valuable for couple adjustment (Hilton & Koop, 1994). Cancer-related talk covers a wide range of issues, with some topics being particularly challenging for many people to discuss and more likely to generate conflict (Goldsmith & Miller, 2013). Furthermore, it can be functional for couples to avoid disclosing certain beliefs at certain times in order to support one another (Rolland, 1994) and avoidance of communication is not always perceived negatively by spouses if it is interpreted as being for positive rather than negative reasons (Caughlin & Afifi, 2004). This suggests that general prescriptions to “talk openly” may not be useful, with a functional balance in communication being more helpful (Goldsmith & Miller, 2013).

Nevertheless, illness-related communication is likely to be an important factor in couples’ understandings, with the potential for avoidance of communication to influence the development of discrepancy due to partners not sharing information and differences in beliefs not being discussed, therefore reducing the potential for them to converge. Communication is also a key element of negotiations.

Negotiations

Negotiation can be defined as a way of getting things done when parties need to deal with each other to accomplish objectives (Strauss, 1978). Negotiations are relevant for when parties perceive there to be disagreement or non-identical preferences, as negotiation is unnecessary in the case of agreement (Evertsson & Nyman, 2009). Therefore, negotiation processes are likely to play a role in couples’ attempts to adjust to cancer-related changes and manage different perceptions that can arise within this process.

Negotiation can be explicit, involving open discussion and problem solving, or implicit, involving tacit agreements or understandings that often hinge on subtle gestures and are reached with minimal discussion (Strauss, 1978). Parties may be aware of implicit negotiations but find these difficult to describe, or they may be so implicit that they occur with little awareness. Implicit agreements are common within families and intimate relationships, often occurring in the context of past explicit negotiations and family rules that impose limits on behaviours (Strauss, 1978).

The negotiation behaviours that people adopt can be influenced by their motivational orientation. Negotiators can have a competitive orientation, characterised by primary concern for personal outcomes and the use of persuasive behaviours, which may be related to higher impasse rates and fewer attempts to negotiate (Thompson, 1990). Alternatively, negotiators can have a cooperative orientation,

characterised by concern for both parties' outcomes and the use of problem-solving behaviours to reach an integrative outcome (Barry & Oliver, 1996). Negotiators in close relationships are more likely to have a cooperative orientation and emphasise protecting the relationship (Fry, Firestone & Williams, 1982).

Negotiation processes may vary depending on factors such as age, gender and subject matter. For example, older adults have been found to be less likely to confront disagreements than younger adults (Folkman, Lazarus, Pimley & Novacek, 1987), which could be due to age affecting individuals' tendency to engage in conflict or reflect cohort differences. Furthermore, women have been found to be more cooperative in negotiations than men (Walters, Stuhlmacher, & Meyer, 1998) and individuals may use different negotiation strategies depending on topic salience (Zietlow & Sillars, 1988).

Summary of Systems Theory

Systems theory is useful for highlighting the importance of family interactions in adjustment, which can readily be applied to couples coping with cancer. Research suggests that the concepts underlying systems theory are important in adjustment, and highlight various factors that could potentially influence the development and negotiation of shared or not shared understandings of cancer in couples.

However, although systems theory is valuable for providing general explanations and an overall understanding of family interactions, some of the concepts are abstract and difficult to operationalize for research purposes. Furthermore, although it highlights the importance of co-constructing understandings and potential processes implicated in this, few studies have directly examined this in couples facing chronic illness, such as cancer; therefore little is known about how partners influence one another in their understanding of the illness, and further research would be valuable to clarify these issues. Potential insights can be gained from qualitative research into couples' adjustment to cancer.

Couples Adjustment Processes in Cancer

Much of the qualitative research into adjustment as a process has interviewed only one participant, typically the patient, and derived information about the roles of family and partners from the data from the one participant (Emslie et al., 2009; Tanner, Galbraith, & Hays, 2011). However, research incorporating both partners is more beneficial for examining couple adjustment, being useful for examining relationship

dynamics, individual needs, and similarities and differences in perceptions (Kendall et al., 2009).

Some qualitative research that has interviewed couples has emphasised the importance of couples' understandings and meaning-making in adjustment. Germino, Fife & Funk (1995) interviewed 50 recently diagnosed breast, lung and colorectal cancer patients and their partners separately about their experiences and concerns since diagnosis. They found that both patients and partners searched for meaning that would decrease the threat of the cancer. The cancer held similar meaning for patients and partners regarding uncertainty for the future in terms of potential recurrence, spread of disease and death. However, differences in meanings were also evident, whereby patients primarily focussed on themselves, such as being anxious about pain and death, whereas partners were equally concerned about themselves and the patient, such as the impact of balancing illness demands with work and daily living on both the patient and themselves. Communication difficulties were common, with many participants avoiding talking about their fears and anxieties to anyone due to the pain and grief produced by these discussions. The authors also combined these findings with quantitative data which suggested that positive meaning-making was associated with better adjustment. They concluded that this combination of findings suggests that meaning is important in adjustment for patients and partners. However, the study provided no detail about the qualitative method used to obtain these results and the findings were described in a brief narrative without clearly explicating themes, making it difficult to tease out the key issues.

Skerrett (1998) also highlighted the pivotal role of meaning in a study of couples' adjustment to breast cancer. Twenty married couples, all 18-31 months post diagnosis, were interviewed jointly and individually about their communication styles, illness and health beliefs, feelings about body image, sexuality, loss and mortality, and their experience with health professionals. Grounded theory analyses identified two broad patterns of adjustment: 'resilient' and 'problematic'. Resilient couples, who felt able to master the challenge of the diagnosis, co-created meaning and viewed the experience as "our problem" with shared beliefs, which directed a mutual coping philosophy. These couples also had the capacity to be sensitive and selective in their communication and use past illness histories positively to co-create meaning. Problematic couples, who were struggling with the challenge of the cancer, lacked a co-constructed meaning or held conflicting beliefs and appeared unable to construct a mutual coping philosophy. The study concluded that co-constructed meaning was critical, providing coherence and directing coping. The use of joint and individual interviews was beneficial in this study, providing opportunities for participants to

express different views in addition to joint understandings, and suggesting that different views could be problematic.

Kayser, Watson and Andrade (2007) similarly found that appraisal of cancer as a “we-stress” facilitated adjustment. This study used the voice-centred relational method to analyse data from 10 joint interviews with couples where the patient had been diagnosed with breast cancer within the last three months. They identified two patterns of relational coping: mutual responsiveness and disengaged avoidance. Mutually responsive couples perceived the cancer as a joint problem and communicated openly and empathically about their stress, which allowed them to coordinate mutually responsive coping strategies and view the experience as personally and relationally beneficial. Couples who used disengaged avoidance viewed the cancer as affecting them individually and avoided discussing the cancer, which prevented them coping together or finding benefits from the experience.

Gardner (2008) investigated relationship processes in 35 couples where one partner was diagnosed with terminal cancer using joint and individual interviews. A combination of the voice-centred relational method and grounded theory analyses identified three key themes: living with uncertainty, search for shared meanings, and illness and death trajectories. An overarching finding was the construction of both individual and shared understandings within couples, which often coincided but sometimes diverged in terms of different individual concerns or a difference between individual concerns and a dyadic sense of hope and solidarity. However, the study did not discuss how divergent understandings influenced couple adjustment and the terminal nature of the cancer in this study resulted in a focus on understandings and meanings constructed around prognosis and death over other areas of adjustment.

Illingworth, Forbat, Hubbard & Kearney (2010) analysed data from joint interviews with 43 patient-carer dyads, mainly comprising patient-partner relationships, using a mixed sample of breast, lung, prostate, colorectal and gynaecological cancers within the first year after diagnosis. Using elements of the voice-centred relational method and thematic analyses, this study emphasised the centrality of relationships in experiencing and understanding the cancer experience at all stages. They illustrated this within four themes: relationships, symptom recognition and diagnosis; relationships role in mediating decision-making; the joint ownership of cancer; and relational balancing beyond treatment. This study highlighted that on-going interaction between couples and their sharing of different interpretations facilitated their cooperative efforts in making sense of the experience. However, this study focussed on the relationship as a source of support and stabilisation and did not describe differences that were a source of stress or conflict.

Summary

Research has highlighted the importance of relationships in couple adjustment, with several studies emphasising benefits of shared understandings and meanings. Studies using both joint and individual interviews have proved helpful for highlighting that couples often experience differences in understanding; however, this has not been explored in depth, with limited consideration of how they evolve and are negotiated. Furthermore, research has often focussed on the initial diagnosis and treatment period. Issues around shared and discrepant understandings may vary along the illness trajectory; therefore, further research exploring post-treatment survivorship would be valuable. More research has been conducted in breast cancer than other cancers and it may be useful to consider these issues across cancer types.

Summary and Rationale for Thesis

Both quantitative and qualitative research suggests that patient and partner perceptions of the patient's cancer play a role in couples' adjustment. The research into the SRM has proved valuable in exploring adjustment as an outcome and providing evidence for the importance of illness perceptions in predicting outcomes. However, this research provides little information about the process of adjustment and the role of couples' perceptions in this process. Qualitative research with couples, typically informed by systemic perspectives, suggests that couple understandings play an important role in adjustment; however, there is little research on how perceptions evolve and are negotiated in couples.

The present research aims to add to the evidence base surrounding illness perceptions and adjustment. Colorectal and prostate cancer populations were chosen because they are two common cancers but they have not been extensively researched in the discrepancy literature. Adjustment to these cancers is also theoretically interesting because they can share similar functional consequences, such as sexual, urinary and bowel dysfunction, with couples being challenged to manage their emotional responses to these changes as well as their uncertainty around recurrence. The current study is also interested in investigating couples' where the patient is in a relatively stable condition, to explore the role of patient and partner perceptions during survivorship, rather than initial diagnosis and treatment stages, which has typically been the focus.

The original aims included addressing limitations in previous quantitative research by examining illness perceptions and partner outcomes as well as patient outcomes and using HR-QoL as an outcome measure, which examines multiple areas

of functioning rather than a specific domain, such as distress. Informed by the research suggesting that communication is important in couples' co-construction of meaning, the study also aimed to quantitatively explore associations between illness-related communication and discrepancy. However, these aims were not realised due to recruitment difficulties.

Therefore, the main aim of the study is to qualitatively explore the development and influence of patient and partner illness perceptions in the process of adjustment, and the role of discrepant perceptions within this process.

Research Questions

Quantitative Study: Dyadic Illness Perceptions and HR-QoL

The original research aims included quantitatively exploring illness perceptions and outcomes in couples. The hypotheses were:

1. Discrepancy in illness perceptions between cancer patients and their partners will be associated with patient and partner HR-QoL.
2. Patient illness perceptions regarding more symptoms attributed to the cancer, more severe consequences, a longer timeline, less personal controllability and a less clear understanding of the cancer will be associated with poorer HR-QoL in both patients and partners.
3. Partner illness perceptions regarding more symptoms attributed to the cancer, more severe consequences, a longer timeline, less personal controllability and a less clear understanding of the cancer will be associated with poorer HR-QoL in both patients and partners.
4. Discrepant illness perceptions will be associated with low illness-related communication.

However, an insufficient sample size resulted in the data from these questions being used descriptively to situate the sample only.

Qualitative Study: Development of Discrepancy in Couples

The main aim of the study is to develop understanding of discrepancy by qualitatively exploring couples' perceptions. The research questions for this aim are:

5. How do shared and discrepant understandings evolve within couples?
6. How do couples respond to and deal with discrepancy?
7. How do couples experience discrepancy?

CHAPTER 2: METHOD

This chapter will begin by detailing the methodological considerations involved in the design of this research. It will then discuss ethical issues and describe the design of the quantitative and qualitative studies separately, providing detail on recruitment issues and explaining how this influenced the methods.

Methodological Considerations

Rationale for Mixed Methods

The original study aims comprised a series of related questions. A combination of both quantitative and qualitative methods was deemed best suited to addressing these aims, as different types of research questions require different methods. Quantitative methods are ideal for providing descriptive information about phenomena and measuring patterns of associations (Creswell, Klassen, Plano Clark & Smith, 2011). Therefore, this approach was suitable for investigating the level of discrepancy within couples and examining associations between discrepant illness perceptions and Health-Related Quality of Life in patients and partners. The research also aimed to understand how discrepant or congruent illness perceptions evolve and are negotiated within couples coping with cancer. Qualitative research was considered appropriate for addressing this aim as it permits identification of previously unknown processes and can help explain how and why phenomena occur (Pasick et al., 2009).

Some researchers argue that quantitative and qualitative methods are incompatible due to being underpinned by different philosophical assumptions (Howe, 1988). However, this view is widely criticised and many researchers advocate a pragmatic approach that sees the research problem as being of primary importance, encouraging the use of “what works” (Morgan, 2007). The two methods are deemed complementary, with each data type regarded as enhancing the other (Plano Clark, 2010). Therefore, a pragmatic approach was adopted, with the methods being a direct response to the demands of the research questions, aiming to produce a thorough understanding of couples’ illness perceptions and adjustment to cancer.

It was therefore decided to survey a cohort of cancer patients and their partners using quantitative questionnaires, to provide data about patterns of associations between discrepant illness perceptions and HR-QoL as well as enabling the identification of couples with discrepant and congruent perceptions to be selected for participating in interviews to investigate how they negotiated their shared or not shared understandings. Thus the two methods were considered to address

complementary aims, with the qualitative analysis aiming to elaborate upon quantitative findings and answer questions that quantitative analyses cannot.

Unfortunately, recruitment issues prevented a sufficient sample being obtained for the quantitative analyses. Therefore, the questionnaire data was only used to provide descriptive information and the procedure for selecting couples for the qualitative study was amended to suit the limited information on levels of discrepancy.

Quantitative Methodology

Selection of survey approach and measures

A postal survey method was considered appropriate to enable the researcher to approach a large sample. However, this method prevented the researcher verifying that patients and partners completed measures separately, without discussing their responses. To offset this, each pair of responses was examined and if identical responses had been provided, it would be assumed that the couple had likely colluded and they would be excluded from analysis. Using postal questionnaires also required that all measures were self-report measures of reasonable length so that they were suitable for participants to complete independently, without being too demanding on their time. All measures were available for use without restrictions.

Illness Perception Questionnaire-Revised (IPQ-R, Moss-Morris et al., 2002). This measure assesses illness perceptions and has proven reliability and validity across illness populations. The items are tailored for the particular illness under investigation, in this case, cancer. The IPQ-R measures the following illness perceptions: identity, timeline (acute-chronic and cyclical), control (personal and treatment), consequences, cause, emotional perceptions and illness coherence. It contains over 80 items, which can be demanding for participants and could reduce response rates. Therefore, to decrease participant burden, the present study focused on the identity, timeline (acute-chronic), consequences, control (personal), and illness coherence subscales (appendix 1). These subscales were chosen because they are the dimensions most consistently related to HR-QoL outcomes in previous research (Dempster et al., 2012; Hagger & Orbell, 2003; Kaptein et al., 2003). The identity subscale uses a yes/no format, asking participants if they have experienced a symptom since their cancer and whether this is related to their cancer. The remaining subscales comprise statements about the cancer and ask participants to rate their level of agreement on a five-point scale ranging from 'strongly disagree' to 'strongly agree'. Mean values were calculated for these scales. Higher timeline scores indicate

stronger beliefs in the chronicity of the cancer, higher consequences scores indicates a perception of more severe consequences of the cancer, higher personal control scores indicate positive beliefs about controllability of the cancer and higher coherence scores represent greater perceived understanding of the cancer. A slightly reworded version was used for the partner's perception of the patient's cancer, following the strategy of Barrowclough et al. (2001) (appendix 2).

RAND 36-Item Health Survey (Version 1.0). (RAND-36, Hays, Sherbourne, & Mazel, 1993). This measure was selected to assess HR-QoL because it is suitable for both patient and general adult populations, allowing direct comparison of patient and partner scores. The RAND-36 is a freely available version of the widely-used Medical Outcomes Study 36-item Short Form Health Survey (SF-36), which requires a license agreement and substantial fee. The two versions have identical items but use a somewhat different scoring procedure. The RAND-36 was selected due to budget constraints. The RAND-36 assesses eight health concepts: 1) Physical functioning; 2) Role limitations due to physical problems; 3) Role limitations due to emotional problems; 4) Energy/fatigue; 5) Emotional well-being; 6) Social functioning; 7) Pain; and 8) General health. This produces eight scale scores and two component summary scores (Physical Health and Mental Health). There is a further unscaled question regarding changes in health over the past year. The scoring process involves recoding the precoded numeric values using a scoring key provided, with item scores ranging from 0 to 100 and higher scores representing better HR-QoL. Items in the same scale are averaged to create scale scores. The component summary scores are presented as T-scores, with a mean of 50 and standard deviation of 10. This measure has demonstrated good reliability when scored using the RAND-36 method (Hays et al., 1993). Appendix 3 contains the RAND-36 items.

Couples' Illness Communication Scale (CICS), Arden-Close, Moss-Morris, Dennison, Bayne, & Gidron, 2010). This brief measure, developed in cancer and Multiple Sclerosis populations, aims to provide insight into patient and partner illness communication. It comprises four questions rated on a 5-point likert scale, ranging from disagree strongly to agree strongly (appendix 4). Two items are reverse scored. The questions cover two domains: how comfortable the individual feels discussing the illness with their partner and their impression of their partner's willingness/reluctance to discuss the illness. Scores range from 4 to 20, with higher scores representing better communication. The CICS has demonstrated good reliability and validity in preliminary investigations (Arden-Close et al., 2010).

Strategies for obtaining a sufficient sample

Recruitment difficulties were anticipated because response rates for postal surveys are often low and requiring responses from both partners was likely to further reduce response rates. A number of solution strategies were implemented to attempt to address this. Cancer registry data was consulted to identify the prevalence of cancer diagnoses in the region, which indicated that there were large populations of prostate and colorectal cancer patients to select potential participants from. Exclusion criteria were kept to a minimum to increase the number of eligible respondents. The aim was to approach a sample of 400 participants, which was much larger than that required for analysis in order to minimise the impact of a low response rate. The study recruited through specialist nurses who were involved with the patients' clinical team and discussions with the nurses in March 2012 suggested that it would be possible to identify 400 potential participants to approach within the timeframe. The nurses agreed to sign the invitation letters, as having a letter signed by a familiar care provider is suggested to make people more receptive to recruitment letters (Voils et al., 2011). Additional strategies were considered, such as an online survey and advertising the study through posters in relevant clinics and support groups. However, these strategies were unable to be implemented due to online survey tools being unable to link data from two individuals completing questionnaires separately, local clinic policies preventing the display of posters and ethical issues about self-selecting participants potentially being unsuitable due to a poor prognosis.

Analysis approaches

Various approaches to the quantitative analysis were considered. Discrepancy in illness perceptions can be measured in various ways, including classifying couples into groups based on their illness perception scores or calculating a difference score. Similarly, a variety of approaches to data analysis can be used, including analysis of variance, paired t-tests and linear regression. The various approaches each have strengths and weakness (see Twiddy, 2008, for a review). Due to considerations about the likely characteristics of the data collected, including a relatively small sample size and possible interdependence between the couples' outcome scores, it was predicted that the Actor-Partner Interdependence Model (APIM), which deals with non-independence of outcome scores and uses the dyad as the unit of analysis (Campbell & Kashy, 2002), would likely be the most suitable analysis approach. This model suggests that a person's independent variable score affects both their own dependent variable score (known as the actor effect), and their partner's dependent variable score (known as the partner effect) (Campbell & Kashy, 2002). Consequently, actor

effects are estimated after controlling for partner effects. Discrepancy scores are then modelled while controlling for actor and partner effects. Three statistical techniques are appropriate for analysing the APIM: ordinary regression analysis, structural equation modelling and multilevel modelling. However, if no interdependence had been found, the data would likely have been analysed using multiple regression, with separate analyses for patients and partners and for each illness perception. A difference score is the most appropriate way to operationalize discrepancy in both the APIM and multiple regression analyses, and therefore this approach was intended.

Qualitative Methodology

Rationale for a qualitative method

Little is known about how couples negotiate their shared and discrepant understanding of illness; therefore qualitative methods were appropriate to the exploratory nature of the study, facilitating in-depth study of experiences and the emergence of unpredicted findings.

Selecting a qualitative method

A number of qualitative methodologies were considered, as described later. Interpretative Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009) was selected based on the following considerations. IPA is an inductive qualitative approach dedicated to examining how people make sense of their experiences (Smith et al., 2009). It typically involves using semi-structured interview data to develop a detailed understanding of how people view, experience, and make meaning of their world, reflecting its phenomenological underpinnings (Willig, 2008). Therefore, this method was considered suitable because cancer is a major life experience and the way couples make sense of this event will depend on their personal experiences, meaning-making, and emotional responses. Furthermore, it could facilitate the exploration of how couples experience holding discrepant beliefs.

IPA is typically concerned with peoples' individual perceptions of experiences; therefore IPA studies normally use one-to-one interviews. However, Palmer, Larkin, de Visser & Fadden (2010) argue that group interviews do not dilute accounts of personal experience and can even elicit more experiential reflection. Furthermore, IPA has been used to analyse data from joint couple interviews (Harris, Pistrang & Barker, 2006) and to explore how couples experience and make meaning of illness (Mann & Dieppe, 2006). Therefore, IPA represented a suitable option for the present study.

IPA adopts a critical realist epistemology which assumes a relationship between a person's words and their beliefs, experience and meanings. However, it also emphasises the researcher's role in making sense of participants' interpretations of their experience. This involves a double hermeneutic (Smith & Osborn, 2003), where the participant is making sense of their experience and the researcher is making sense of the participant's sense-making. This theoretical position was appropriate for developing insight into couples' beliefs and meaning-making, which was assumed to require interpretation from the researcher.

Following preliminary familiarisation with the transcripts, IPA alone appeared limited in its ability to focus on the relational negotiation of discrepancy. Therefore, it was decided to supplement IPA with elements of the voice-centred relational method (VRM) (Gilligan, Spencer, Weinberg & Bertsch, 2003). Many researchers advocate using multiple qualitative methods in order to best address the research questions, providing they have complementary assumptions (Chamberlain, Cain, Sheridan, & Depuis, 2011). IPA and the VRM both adopt a critical realist epistemology and emphasise the active role of the researcher in attempting to make sense of the participant's personal world. The VRM resonates with IPA, containing aspects of phenomenological and hermeneutic assumptions (Mauthner & Doucet, 2003). Furthermore, they are both centrally concerned with meaning-making and some IPA researchers are interested in the use of narrative for understanding experience (Smith et al., 2009). Other researchers have combined elements of the VRM and IPA (Aducci, Baptist, George, Barros & Nelson Goff, 2011).

The VRM is not a set of prescriptive procedures, but an adaptable framework for analysis that can be used for different contexts (Gilligan et al., 2003). It is interested in interpreting narratives to understand meaning-making. It assumes that humans develop in relationship with others and provides a systematic way of attending to multiple voices within accounts of experiences. It can therefore facilitate the examination of relational process, including how people talk about experiences and how they communicate with others during interviews. Other researchers have used this method with dyads (Gardner, 2008; Kayser et al., 2007).

The VRM involves multiple readings of the interview data, focussing on different voices and aspects of a person's expression of their experience (Gilligan et al., 2003). The first two readings are the fundamental aspects of the approach, with subsequent readings being flexible according to the particular research questions. The first reading identifies the plot or story and considers the researcher's responses to the narrative. The second reading concentrates on the voice of the 'I' of the person speaking, which helps to focus attention on and amplify the participants' voices.

Researchers who have used this approach with dyads have also included listening for 'we' voices within the second reading (Kayser et al., 2007). The aim of these readings in the current analysis was to assist in distinguishing between personal meaning-making and joint understandings. Subsequent readings identify aspects of the data that may address the research questions. In the current study, this step was used to focus on relationships and consider how couples described their relationships with each other, their family and their wider social network, to explore relational influences on meaning-making and negotiations.

The analysis approach therefore drew upon aspects of the VRM and Interpretative Phenomenological Analysis (IPA) to address the research questions about how discrepant understandings evolve and are negotiated within couples and the implications of these for lived experience. This process is described later.

Alternative methodological approaches

Grounded theory is compatible with diverse data collection techniques and is suited to the study of social-psychological processes, such as the ways people negotiate and manage social situations (Willig, 2008), therefore potentially representing a suitable option. However, grounded theory aims to generate a theory of a process based on views from large samples, whereas this study was more concerned with providing a detailed account of experiences using a smaller sample.

Discourse analysis is concerned with the use of language in conveying messages within a given context and can shed light on negotiations of social interaction (Starks & Trinidad, 2007). However, discourse analysis questions the ability to access cognitions from participants' speech. This assumption did not fit with the study aims of exploring perceptions.

The interviews

It was decided to interview couples both jointly and individually, because the two approaches can shed light on different aspects of experience and there is a call for more research using a combined approach (Taylor & de Vocht, 2011). The joint interview formed the majority of the data collection process as an aim of the study was to develop insight into joint understandings and meaning-making, which are more likely to be apparent when a couple's experience is described in a shared narrative (Taylor & de Vocht, 2011). Joint interviews provide the opportunity to observe interactions, which was considered valuable for achieving a better understanding of how the couples' influence one another and negotiate understandings. Furthermore, joint interviews can provide a more complete picture of the couple's experiences and

perspectives (Sohier, 1995), with partners being able to provide supplementary information, verify events and modify each other's accounts (Seymour, Dix & Eardley, 1995). However, limitations to joint interviews include the potential for participants to conceal their private thoughts in the company of their partner and present public rehearsed accounts (Morris, 2001; Seymour et al., 1995).

The shorter individual interviews were used to complement the joint interviews and allow participants to discuss their thoughts, feelings and experiences in a way that was uninhibited by the presence of their partner (Taylor & de Vocht, 2011). This aimed to help highlight any discrepancies between individual and shared accounts and tease out individual experiences from collective ones.

However, combining these two approaches required sensitivity. Requesting separate interviews could imply that secrets exist and will be shared with the researcher, which could provoke anxiety. This is especially pertinent in the context of cancer's history of keeping diagnosis and prognosis information secret from patients (Morris, 2001). Therefore, the information sheet explained the rationale for having both interviews to attempt to alleviate this anxiety. Nevertheless, during the individual interviews it was possible that participants could share private information that they did not wish to be disclosed to the other partner. Therefore, the information sheet made it clear that no information discussed in individual interviews would be shared with the other partner and the individual interviews took place after the joint interview so the researcher was not aware of any private information during the couple interview. After completing the individual interviews, all participants were asked whether they were happy for this information to be used in subsequent reports. They were given the option of requesting parts of their interview to be excluded, to review their information before reports were submitted or for the researcher to use the information without further contact. All participants opted for the information to be used without restrictions. This was recorded on a consent form (appendix 5).

A semi-structured interview schedule (appendix 6) guided the interviews, which was developed with feedback from supervisors and the Qualitative Research Support Group within the Clinical Psychology training programme. The schedule adopted a logical order, following the timeline of the cancer experience. It began by asking about life before diagnosis to ease participants in to sharing their experiences. It then explored their experience of diagnosis, treatment, life after treatment, and expectations for the future. Questions were also asked about their experiences of managing well together and any different views, in order to explore their negotiations. This was followed by individual interviews, which asked participants if there was anything they would like to add and any interesting experiences from the joint interview were

explored further. Broad questions were asked first (e.g. tell me about...?) which were followed up with more specific questions to address any gaps and obtain more detail about perceptions and beliefs about experiences. The schedule was used flexibly, meaning that the researcher was responsive to participants and allowed them to guide the interview. Therefore, not all questions were asked to every couple and questions were not necessarily asked in the order on the schedule. Furthermore, additional questions and prompts not appearing on the schedule were used to enable the interview to flow. The schedule was piloted with a friend with experience of cancer and her partner in order to gain feedback on the questions and for the researcher to practice using the schedule.

Ethical Issues

Approval

Ethical approval was obtained from Leeds East Research Ethics Committee (REC Reference: 12/YH/0272, see appendix 7). The study was also approved by the research and development department of Leeds Teaching Hospitals NHS Trust. The Clinical Trials Research Approval Board (CTRAB) at St James' Hospital provided approval for nursing resources to support recruitment. All consultants working into the clinics provided email consent for their patients to be approached.

Consent

Informed consent was obtained from both patients and partners by providing them with information sheets detailing the study (appendix 8) and asking them to sign a consent form (appendix 9). The information sheet explained that participation was voluntary and would not impact on their treatment. It also explained their right to withdraw and how to do this. Participants approached during clinics were able to ask the nurses or researcher questions about the study. Participants recruited via post were provided with contact details for them to be able to ask questions.

Distress

Although unlikely, it was possible that participants could become distressed through focussing on illness perceptions when completing the questionnaires; therefore, all participants were fully informed about the nature of the research, and the subject area, and were reminded of their right to withdraw at any time.

During the interviews, the researcher asked participants to recount their experiences surrounding diagnosis and treatment of cancer, which could potentially

have caused distress. However, Corbin and Morse (2003) argue that when interviews are conducted sensitively they should cause no more distress than talking to friends and family, and could even be rewarding. Nevertheless, all participants were informed they could stop the interview at any time and were offered a debrief. If participants had shown signs of undue distress, the researcher would have remained with them until this subsided; however, this was not necessary. Participants were also offered a list of helpline numbers and local contacts that they could access for further support.

Confidentiality

Participants were assigned identification numbers which were used on all questionnaires. Information connecting identification numbers with participant details was stored on a password protected computer network. Interviewees were allocated pseudonyms and identifiable information was removed from transcripts. All data, including consent forms, questionnaires, audio recordings and transcripts, were stored securely using a combination of locked cabinets, encrypted memory sticks and password protected computer networks, in accordance with ethical approval. All data will be stored securely for three years after completion.

Quantitative Method

Design

This study used a cross-sectional design, where all patients and partners completed validated measures assessing illness perceptions, illness-related communication and HR-QoL at one time point. This data was intended to be used to examine predictors of patient and partner HR-QoL, after controlling for socio-demographic and biomedical factors, using illness perceptions and discrepancy in illness perceptions as the independent variables. The study also aimed to explore factors associated with discrepancy using couple illness-related communication as the independent variable and discrepancy as the dependent variable.

Participants and setting

The sample included patients with a diagnosis of colorectal or prostate cancer and their partners, recruited from outpatient clinics at St James' Hospital, Leeds.

Inclusion criteria

Specialist nurses screened their clinic and research trials lists to identify patients who met the following inclusion criteria: a) the patient had received a

diagnosis of colorectal or prostate cancer over 6 months ago and within the last three years; b) the patient was in a relatively stable condition, having been or currently being treated with curative intent; c) both patient and their partner were aged 18 years or over; d) both patient and partner were cognitively able to provide informed consent. Nurses did not have access to all information about the patients, therefore participants self-identified if they met the following criteria: a) had a cohabiting partner; b) sufficiently fluent in English to complete measures and interviews.

Recruitment

Information packs were posted or handed to patients when they attended clinics. The packs included an invitation letter endorsed by the nurse (appendix 10) and information sheets for both the patient and their partner. This information included details about how participants could contact the researcher if they wished to participate, including a reply-paid envelope for responding via mail. Both patients and partners were asked to indicate whether they were interested in participating. The researcher also attended several clinics to be available to answer questions from staff and patients and obtain consent to contact suitable patients for follow-up.

Procedure

Couples who responded to the information pack were posted a questionnaire pack containing consent forms, a demographic questionnaire, the relevant measures and two reply-paid envelopes. The demographic questionnaire was designed by the researcher to request personal details of both patient and partner (age, gender, ethnicity, other illnesses), details about the patient's cancer (type, time since diagnosis, treatment details) and details about their relationship (marital status, length of relationship). Patients and partners were asked to complete the questionnaires separately in their own home, expected to take around 30-40 minutes, and return them in the separate envelopes along with the consent forms. The consent forms asked participants to indicate if they were happy to be contacted for interviews and some participants who consented were followed up for the qualitative study (see below).

Recruitment issues

Obtaining ethical and R&D approval delayed the start of recruitment from May 2012 to August 2012. By early October, only 17 patients had been approached and 3 responses received. Meetings with the recruiting nurses identified that they were having difficulties finding time to screen for potential participants due to staffing shortages. Resources were diverted into recruitment efforts.

Further meetings with recruiting nurses were held to review the screening process. This identified that some nurses were choosing not to approach some patients due to a belief that they were potentially not appropriate candidates for reasons other than not meeting the inclusion criteria. This was an understandable attempt to prevent wasted effort of approaching unsuitable or uninterested patients; however, this could have meant that some potentially interested patients were missed. Therefore, the purpose of the study and the inclusion criteria were reiterated with the recruiting staff and it was agreed that all potential participants would be approached. Presentations were also delivered to the relevant clinical teams to promote the research and increase understanding of the value of the project.

Following meetings with nurses from additional clinics, approval was sought from the research and development department to add three further clinics to the list of recruiting sites. The recruitment period was also extended by three months.

Despite these efforts, recruitment of a sufficient sample for the quantitative analysis was unsuccessful; therefore the qualitative phase was made into a stand-alone study, with the quantitative data used to situate the sample but not modelled statistically.

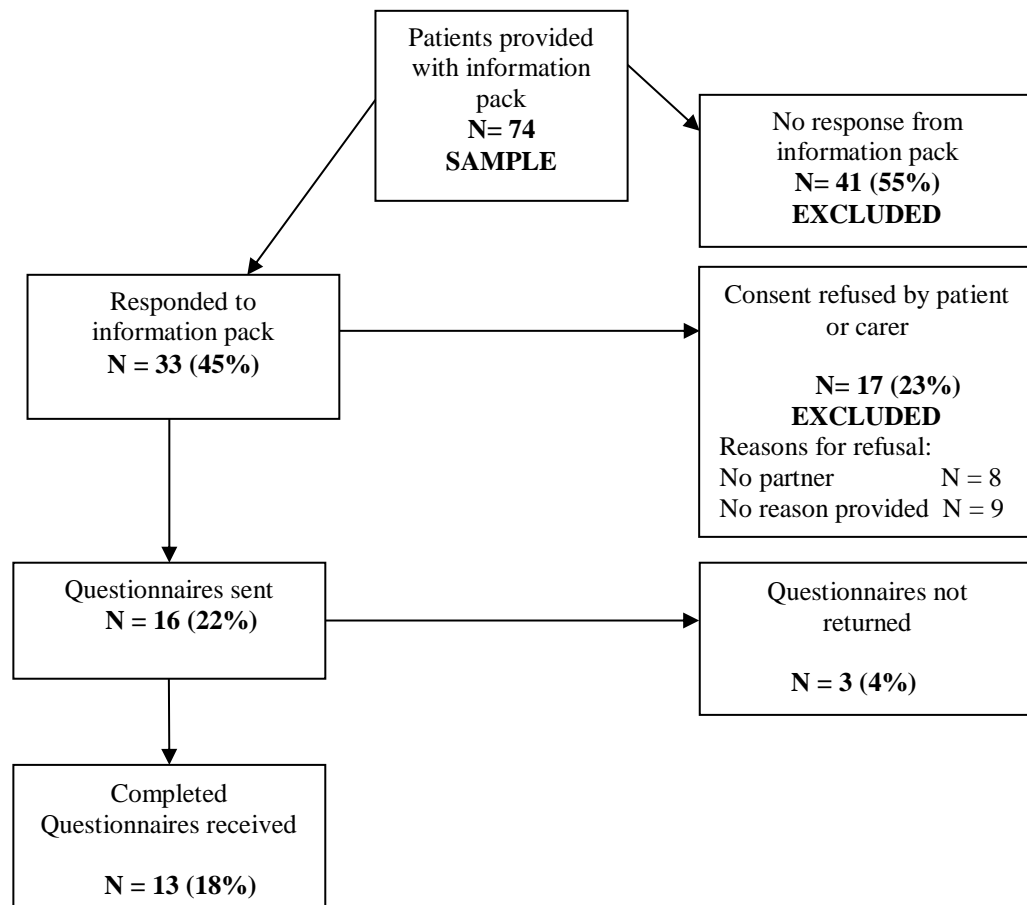


Figure 1: Flow Diagram of Recruitment Process for Quantitative Study

Analysis

The recruitment difficulties meant that the intended analysis was not possible. Therefore, descriptive statistics, including mean scores for illness perceptions, HR-QoL and illness-related communication, will be presented briefly in the results section.

Qualitative Method

Design

The study used a qualitative cross-sectional design. Couples were interviewed at one time point to gather a detailed account of the couples' experience of adjusting to a cancer diagnosis and examine how they have negotiated their shared and not shared understandings of the patient's cancer.

Sample

Couples who consented to interviews when recruited to the quantitative study formed the potential sample for the qualitative study. Recruitment delays meant it was not possible to select couples based on discrepancy scores. Instead, the first eight responding couples were selected, with the remaining five couples' questionnaires being received too late for inclusion. Two couples declined to take part when approached. The final sample comprised three couples adjusting to colorectal cancer and three couples adjusting to prostate cancer. Couples' IPQ-R scores were examined after selection to explore discrepancy levels. Discrepancy was determined using the criteria of Twiddy (2008), whereby couples were classed as discrepant if the difference between patient and partner mean scores on any IPQ-R scale was more than one, or if they reported more than five different symptoms. Consequently, three couples were classed as similar in their perceptions and three couples were discrepant.

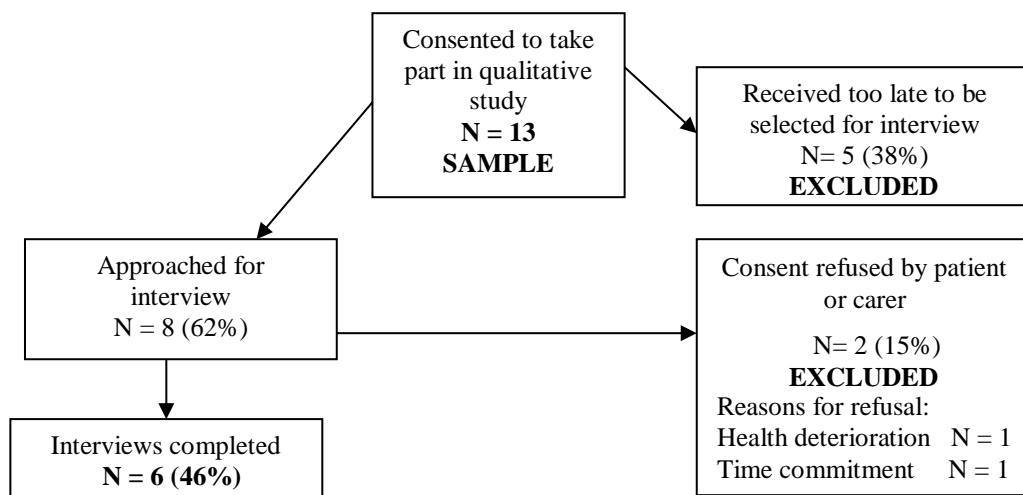


Figure 2: Flow Diagram of Recruitment Process for Qualitative Study

Procedure

The researcher contacted selected couples and asked if they were still willing to participate in interviews. The study was explained again and opportunity to withdraw provided. For consenting couples, a convenient time and place for the interviews was arranged. All interviews took place in the couples' home, although alternative locations were offered so participants could choose for them to occur in a more public place.

Prior to starting the interviews, the researcher explained the purpose and format of the interview and participants were given the opportunity to ask questions. Permission was obtained to record the interviews on a Dictaphone. The semi-structured interviews were then conducted, with the joint interviews lasting between 60-120 minutes, followed by individual interviews lasting between 15-30 minutes.

The recorded interviews were transcribed verbatim, including details of non-verbal communications such as pauses, laughter, crying. The researcher made field notes after the interviews, which included information on non-verbal interactions and researcher reflections. These notes were included in the analysis.

Analysis process

The first interview was transcribed by the researcher, with the remaining five completed by external transcribers and quality checked by the researcher for accuracy and to allow re-familiarisation with the data. Each case was examined in detail, following the VRM and IPA methods described below, before moving on to the next case. Consistent with IPA's idiographic commitment, all cases were examined individually before looking across cases for converging themes (Smith et al., 2009).

Voice-centred relational method

Listening for the plot. In this stage I read through the transcript and field notes in full, attending to what was happening and what stories were being told by the couple. I noted any recurrent images, metaphors, main themes, contradictions and social context. I then split the joint interview data into separate computer files, with one containing all contributions from the patient and one containing all partner contributions. The individual interview data was also added. This helped me examine what stories were told by which person within the couple and I recorded a comparison of the stories. I attended to and recorded my own reactions to the narratives, identifying my thoughts, feelings, connections and disconnections with participants.

'I' poems and 'we' poems. 'I' poems were created by underlining every instance in the transcript of the participant using personal pronouns such as 'I' and 'you' when

referring to themselves, along with key accompanying words. Different colours were used for patients and partners. These phrases were cut and pasted from the electronic transcript into a separate document for each person, with each 'I' statement arranged onto a separate line and stanzas formed based on natural breaks in themes to resemble poems. Phrases were kept in the same order they appeared in the text. I completed the same process for 'we' poems, underlining when couples referred to their relationship or the situation in terms of 'we' and creating 'we' poem documents for each partner. Comparisons were made between the two 'I' poems and between the 'I' poems and 'we' poems. Figure 3 illustrates these poems.

	Simon (patient)	Jane (Partner)
'I' Poems	I accepted that I just accepted it I don't put things to one side I accept whatever's going to happen I'm not one for hiding things in my brain I just accept it	I've got some good friends at work I've been able to handle it I've had some good friends I've had the support I've always been outspoken I think that's been good for me
'We' Poems	We're going to get through this We've like fought it really We can get through this We've never been down We've always been positive	We've had some bad results We've had some good ones We'll get some good ones again We've fought it

Figure 3: Extracts of Poems from Interview with Simon (pt4) and Jane (pr4)

Listening for relational voices. This stage involved reading the transcript for instances of the participants referring to interpersonal relationships and underlining these with different colours for patients and partners.

I then brought this information together to compile a case study for the couple, identifying the shared and discrepant stories and developing initial interpretations of their meaning-making processes. This process also enabled me to isolate sections of the transcript that were relevant to the couple's understandings. The IPA process then focussed on these sections to explore the experience of meaning-making and negotiating discrepant beliefs to identify themes across the couples.

Interpretative Phenomenological Analysis

The first step of IPA, immersing myself in the data and noting reflections, had been completed through the VRM process. I then re-read the sections identified as being relevant to shared and discrepant understandings, making notes in the left-hand margin of the transcript to produce a comprehensive set of exploratory comments on the data. These comments included descriptive, linguistic and conceptual comments. The exploratory comments were then used to identify preliminary emergent themes that captured the essence of the text, which were noted in the right-hand margin. The

themes reflected the participant's words and thoughts as well as my interpretation of their experience. I took particular notice of metaphors, imagery, patterns and contradictions. The individual interview themes were also compared and contrasted with the joint interview data to identify inconsistencies and new information that could potentially reveal aspects of the couple's story that may have been lost in the joint account. I listed the preliminary themes for the couple on a piece of paper to look for connections between them and clustered themes together. I tentatively named the theme clusters and looked for ways they fit together coherently.

This process was repeated for each couple. I was inevitably influenced by themes identified in earlier cases but endeavoured to treat each case on its own terms and allow new themes to emerge. Finally, I explored patterns and connections across the couples to capture shared higher order concepts that represented potential themes for the entire group. This was achieved by writing the names of the theme clusters with a brief description onto index cards and sorting them in to piles to develop group subthemes and master themes. The themes were reviewed and refined by re-reading the coded data extracts to check they fit the data. This led to some themes being revised and relabelled, with some being collapsed together and others being divided into separate themes. Once I was satisfied with the themes, I re-read the entire data set to check the themes worked and identify whether any data fitting the themes had been missed. An example of the development of themes is shown in figure 4.

Original Text	Preliminary emergent theme	Cluster	Group Subtheme	Group Master Theme
Jane: It did frighten me because as I say I've thought I'm going to lose him here, what am I going to do?	Fear of loss and coping alone	Threat of being left behind	Relationship to the cancer	Unique roles and needs
Ruth: Why do I have to carry this thing with me everywhere I go?	Carrying the cancer	Experiencing cancer internally	Relationship to the cancer	Unique roles and needs
Rob: I wrote down and sort of almost analysed it really almost like a business project	Using business skills	Drawing on past skills and knowledge	Personal contributions	Unique roles and needs
Katie: I'm an optimist, [Kevin]'s a bit of a pessimist	Optimism-pessimism difference	Personality differences	Personal contributions	Unique roles and needs

Figure 4: Example of Theme Development

Quality Checks

Numerous guidelines have been developed which aim to help researchers improve the quality of their qualitative research (Henwood & Pidgeon, 1992; Elliott,

Fischer, & Rennie, 1999; Madill, Jordan & Shirley, 2000). This study adopted Elliott et al.'s (1999) guidelines, as these are situated within a phenomenological-hermeneutic tradition. Details of the application of these guidelines are outlined below.

Owning one's perspective. Disclosure of one's personal values, interests and assumptions enables readers to track their influence on the research process and interpretations of the data. I have therefore included a reflexive statement at the end of this chapter, as well as presenting reflections within the analysis and discussion.

Situating the sample. Sufficient participant information should be provided to enable readers to understand the relevant characteristics of the sample in relation to the topic. This study provides demographic information as well as case studies detailing the couples' perceptions of the cancer, highlighting relevant discrepancies.

Grounding in examples. The provision of data extracts renders the analytic and interpretive processes transparent. This study has provided examples of the analysis process and the results section illustrates all themes with participant extracts.

Providing credibility checks. Several types of credibility checks can be used to verify that the analysis is coherent and understandable. In this study, I discussed the analysis with my supervisors at various stages and incorporated their feedback. The results were shared with colleagues who have experience of working with couples with chronic illnesses to gain feedback. The reliability of themes was tested by getting colleagues to apply them to the data. The original analysis was elaborated in accordance with colleagues' feedback.

Coherence. The presentation of findings should be coherent and understandable, illustrating how themes fit together. The themes in this study are presented in a diagram to illustrate their relationship with one other, followed by tables describing the subthemes and narrative descriptions of the themes.

Accomplishing general vs. specific research tasks. Attempts to produce generalizable findings should use appropriately sized samples. Studies aimed at understanding specific experiences should examine the experience comprehensively and systematically. The current study's limitations of extending the findings beyond the participants involved are addressed in the discussion.

Resonating with readers. The presentation of the findings should be perceived by readers to accurately represent the topic or clarify their understanding of it. The results of this study were shared with a friend who indicated that it resonated with her experience of cancer. This report has attempted to be easily understandable, situating the findings within the context of previous literature.

Reflexivity

In the following reflexive statement I reflect on how my experiences, beliefs and perspectives may have influenced the collection and analysis of the data.

I am a 30 year old white British middle-class woman. I have cohabited with my boyfriend for four years. I have never been married and do not have children. I am a Psychologist in Clinical Training, currently undertaking a psycho-oncology placement. My experience of cancer includes my mother and close friend being diagnosed with and surviving cancer when I was in my teens and early twenties.

My personal experiences with cancer influenced my interest in researching the impact of cancer on family members as well as patients. It is also important to acknowledge my experience of holding discrepant understandings about the cancer within my family. I believed that my mother's cancer was easily treatable, which contrasted with her perception that she may not survive and needed to prepare for the possibility of her death. I struggled to understand my mother's response and she was upset that I did not show more concern. My experience of discrepancy being unhelpful could potentially bias my interpretations of others' experience of discrepancy.

My age may have influenced the research process. I am significantly younger than the participants, which could have influenced their interactions with me and my interpretations. Participants may have believed I would not understand some of their experiences due to my age, influencing what they shared, and my similarity in age to many of their children could have generated a desire to protect me from their difficult experiences. Generational differences in cultural values between me and the couples could also have influenced my interpretations. For example, the more individualistic rather than communal values of my generation may have led me to interpret independence within couples more positively than participants. My perceptions of relationships and communication could also be different, having not spent the majority of my life living with a partner like most couples. For example, I may not have recognised some subtle processes accompanying long-term relationships.

Despite the differences, I shared a middle class background with most couples. I noticed myself recognising familiarity in their descriptions of aspects of their lives, such as their family roles, which may have led me to assume we had shared understandings and draw conclusions from my assumptions and not their meanings.

As a Psychologist in Clinical Training, with an integrative theoretical orientation, my interpretations are likely to be influenced by various psychological models including cognitive-behavioural, psychodynamic, and systemic. My psycho-oncology placement involves working with patients and families who have difficulties coping with cancer, potentially leading me to perceive difficulties as more common than is the case.

CHAPTER 3: RESULTS

Quantitative Study

Due to recruitment difficulties resulting in an insufficient sample size for the intended analyses, this section will present demographic information about the sample and brief descriptive statistics of the quantitative data.

Sample

Completed questionnaires were received from 13 couples, comprising 7 prostate cancer patients and 6 colorectal cancer patients and their partners. 11 (84.62%) patients were male. Patients were on average 64.23 years (SD 5.51) and partners were on average 59.15 years (SD 9.18). All participants were White British and in heterosexual relationships, with 11 married and 2 cohabiting couples. The average length of relationship was 29.85 years (SD 14.60). 2 patients and 3 partners had additional serious illnesses.

Time since diagnosis ranged from 9-30 months (mean 18.23, SD 7.21) and time since treatment ranged from 1-24 months (mean 11.38, SD 7.31). 12 patients (92.31%) were treated with surgery; 8 (61.45%) also received radiotherapy and/or chemotherapy and 1 (7.69%) received radiotherapy and hormones only.

Descriptive statistics

The mean and standard deviations (SD) of patients' and partners' illness perceptions for the 13 couples are presented in table 1. The small sample size precluded analyses to determine whether patient and partner scores differed significantly. Overall patient and partner scores showed similarity in the direction of their beliefs, sharing moderately negative perceptions of consequences and positive perceptions of coherence and control.

Table 1: Mean IPQ-R Scores for Patients and Partners

Illness Perception	Patient Mean (SD) n=13	Partner Mean (SD) n=13
Illness Identity	2.54 (2.33)	3.15 (2.44)
Timeline Acute/Chronic	2.56 (0.88)	2.35 (0.41)
Consequences	2.87 (0.87)	2.85 (0.63)
Coherence	3.82 (0.85)	4.06 (0.63)
Personal Control	3.09 (0.92)	2.88 (0.94)

The means and standard deviations of patients' and partners' Health-Related Quality of Life (HR-QoL) scores, as measured by the RAND-36, are presented in table 2 along with normative data from the Medical Outcomes Study baseline sample (Hays et al., 1993) with which to compare the data. The sample had higher HR-QoL scores in all domains compared to the general population, with the exception of health changes over the past year being lower for patients.

Table 2: Mean RAND-36 Scores for Patients and Partners

Scale	Patient Mean (SD) n=13	Partner Mean (SD) n=13	Comparison Mean (SD) MOS Study N=2471
Physical functioning	89.23 (15.12)	88.46 (16.63)	70.61 (27.42)
Role functioning physical	76.92 (37.45)	73.08 (43.85)	52.97 (40.78)
Role functioning emotional	87.18 (28.99)	87.18 (32.03)	65.78 (40.71)
Energy/fatigue	67.31 (20.06)	63.85 (23.99)	52.15 (22.39)
Emotional well-being	79.38 (20.06)	80.62 (14.41)	70.38 (21.97)
Social functioning	87.50 (21.04)	89.42 (16.01)	78.77 (25.43)
Pain	83.27 (24.93)	76.54 (22.56)	70.77 (25.46)
General Health	74.23 (19.77)	73.46 (25.53)	56.99 (21.11)
Health change	43.75 (11.57)	53.13 (31.16)	59.14 (23.12)
Physical Component Summary	52.65 (8.55)	50.93 (10.57)	44.9 (10.9)
Mental Component Summary	51.96 (9.66)	52.83 (9.53)	48.4 (11.8)

The means and standard deviations of patients' and partners' illness-related communication scores, as measured by the CICS, are presented in table 3 along with means published from the development of the scale (Arden-Close et al., 2010) with which to compare the data. Both patients and partners reported good illness-related communication.

Table 3: Mean CICS Scores for Patients and Partners

	Current Sample Mean (SD) n=13	Comparison Mean (SD) n=123 (patients) n=101 (partners)
CICS Patients	17.77 (2.49)	13.84 (3.83)
CICS Partners	16.85 (4.04)	15.53 (3.21)

Summary

Patients and partners did not associate the cancer with many symptoms but perceived it to have moderately negative consequences. They believed they understood the cancer and that the patient had good control over their recovery.

Both patients and partners had good HR-QoL across physical and mental health domains and reported good illness-related communication. The sample had better HR-QoL and illness-related communication than comparison samples.

Qualitative Study

The qualitative analysis will be presented in separate sections. Firstly, brief case studies provide contextual information about the couples, highlighting their discrepant perceptions about the patient's cancer. This aims to place the group analysis themes into context for the reader and highlight the idiosyncrasies of the couples' understandings before highlighting commonalities in their experiences. The group analysis will then be presented, which summarises the main themes regarding the negotiation of shared and discrepant perceptions that are representative of the group.

Conventions used

Participant quotes are used throughout, highlighted in *italics*. Participants' pseudonyms accompany the quotes with a code to indicate whether the person is a patient (pt) or partner (pr) and their couple number. For example, John, the patient from couple 1 is identified by (John, pt1). Data that could identify participants, such as names and places, are altered and placed in square brackets e.g. [consultant]. Some quotes use (...) to indicate that text considered unnecessary for illustrating the theme has been removed. Participant hesitations are indicated by two full stops: ..

Participants

Six couples were interviewed about their experience of cancer. Relevant demographic information is provided in table 4.

Table 4: Participant Information for Qualitative Study

Couple	Pseudonyms	Age	Occupations	Relationship	Cancer Diagnosis	Discrepant (IPQ-R)
1	John	68	Teacher (retired)	Married	Prostate	Yes
	Margaret	61	Teacher (retired)	38 years	12 months	
2	Kevin	59	Management	Married	Prostate	Yes
	Katie	49	Retail	30 years	14 months	
3	Rob	65	IT Manager (retired)	Cohabiting	Prostate	No
	Helen	64	Administrator (retired)	13 years	9 months	
4	Simon	71	Caretaker (retired)	Married	Colorectal	No
	Jane	49	Supervisor	14 years	18 months	
5	Brian	69	Farmer	Married	Colorectal	Yes
	Mary	69	Housewife	48 years	18 months	
6	Ruth	62	Childcare (retired)	Married	Colorectal	No
	Mark	63	Management (retired)	41 years	24 months	

Case Studies

These case studies present the demographic and background information for each couple, including a brief history of the patient's cancer and their questionnaire data. Generally, couples presented shared understandings and did not identify any discrepant perceptions when asked directly. However, through reading the transcripts for the plot, 'I' and 'We' voices, and relational voices, it was possible to detect their most notable shared and discrepant understandings. Therefore, a summary of the overall joint and individual stories and key discrepancies are presented, supported by quotes and excerpts from 'I' and 'we' poems. Impressions formed during and after the interviews, which were recorded in a reflective journal, are also discussed, including reflections on non-verbal communication and interaction styles.

Couple 1: John and Margaret

Background

John and Margaret are retired teachers in their sixties and have been married for 40 years. They live in a clean, tidy house with many family photographs on display. They have children and grandchildren living nearby for whom they regularly babysit. They have many independent interests.

John was diagnosed with prostate cancer a year prior to interview. He was treated with surgery and radiotherapy, having his last radiotherapy treatment 2 months previously. John recovered quickly from surgery and experienced minimal side-effects from the radiotherapy. Prior to diagnosis, John had little personal experience of illness and was very fit and active.

Margaret was diagnosed with polycystic kidney disease (PKD) 15 years ago and has been treated with dialysis and a kidney transplant. Her current transplant is failing and she is awaiting another. Her treatments have restricted her activities and John has provided carer support to Margaret. Margaret's illness is caused by a genetic mutation and her children have a high chance of developing PKD, which she found "*really upsetting*". This heritability was an important concern for her.

Impressions and interactions

John and Margaret sat at opposite ends of their sofa and used more 'I' talk than 'we' talk, which reflected their independent characters. Initially Margaret did not seem engaged in the interview until John requested her input, and it appeared that Margaret was taking a backseat when she typically took the lead. During the interview,

they became more talkative, often talking over one another. They talked to each other frequently, checking details and sharing recollections, often laughing together.

John and Margaret's story

John and Margaret were very shocked by the cancer diagnosis. It challenged their strongly held ideas about their identities and roles within the relationship and they initially found it difficult to adjust to these role changes. As Margaret described:

“I was always the creaky gate and [John] was always the big healthy one (...) and suddenly roles were reversed”

They also experienced difficulties in deciding on treatment and managing home care after surgery. However, they were confident in their ability to cope, which they attributed to their positive outlook and experience of coping with Margaret's illness.

*“We have been quite independent
We didn't go down any specific routes
We are quite positive
We've learned to cope with [Margaret's illness]”* (John, we poem).

They described being “*mutually supportive*” with each other's illnesses. Margaret's PKD appeared to have required more support and joint coping than John's cancer. They made frequent comparisons between the illnesses, suggesting that the previous illness experience played a key role in how they made sense of the cancer.

The couple described family as the most important thing in their lives, with protecting the children from the impact of the cancer being vital. They felt they had successfully minimised the impact of the cancer on themselves and their family.

Questionnaires

Table 5: Couple 1 Questionnaire Data

Measure	Scale	Patient Score	Partner Score
IPQ-R	Illness Identity	3	6
	Timeline Acute/Chronic	2	2.67
	Consequences	2.5	2.67
	Coherence	3.2	3.8
	Personal Control	3.83	2.5
RAND-36	Physical Component Summary	59.0	24.4
	Mental Component Summary	50.5	58.0
CICS		20	20

Margaret had lower physical HR-QoL than John, which was lower than general population and current sample norms and was likely related to her PKD. They both reported high levels of illness-related communication. Although the IPQ-R scores suggested that their only difference in perceptions concerned John perceiving greater control than Margaret, the interviews highlighted further discrepancies.

John's story

John struggled to comprehend how a fit, healthy man like himself could develop cancer. He worried about recurrence and contemplated how he could cope if this occurred. He also searched for positive meaning in the experience and actively took steps to gain control, such as making lifestyle changes, finding that feeling in control helped him cope with anxiety: *"I'm in control, there is no big worry for me"*.

John wanted to recover from the cancer quickly and regain normality, choosing not to have hormone treatment due to wanting treatment to end as soon as possible.

John reported few consequences of the cancer and appeared to focus on physical outcomes, rather than emotional ones. He often used the personal pronoun 'you' when discussing his emotional responses, which I interpreted as reflecting difficulty in expressing his feelings. His story appeared to represent a conflict between his distress and his desire to stay positive.

*I was very anxious
You are feeling a bit sorry for yourself
I'm not saying I was negative but
You try to be as positive as possible ('I' poem)*

Margaret's story

Margaret was experienced at coping with illness. She described her illness as uncontrollable, stating *"you just have to live with it, you can't do anything"*. Consequently, she appeared to have found it adaptive to relinquish control of her illness to the medical professionals and focus her coping on regulating her emotions, such as by focusing on the positive. She also described holding back from coping until she had suitable opportunities to act, demonstrating restraint coping. These perceptions and coping strategies were reflected in her approach to John's cancer. For example, she focused on positive treatment outcomes and did not consider the possibility of recurrence. She reported that, in contrast to John, she would have accepted all available treatments, corresponding with her treatment experience. She shared John's desire to return to normality; however, she was more concerned about safety and did not want his recovery efforts to jeopardise his health.

Margaret believed the cancer had an important impact on John's emotional state, causing him worry and uncertainty, leading to weight loss. She attributed his worry to his brother's death from cancer and the potential genetic aspect of the disease, which fits with her experience of a heritable illness.

Margaret's own illness appeared to act as a lens through which she interpreted John's cancer and she seemed to struggle to understand when John responded differently to her expectations from her experience.

*I just know from my personal experience
I'm sure [John] might be the same
I think being able to talk things through is so important
I'm just thinking from my own personal circumstances ('I' poem)*

Key discrepancies

John and Margaret held numerous different perceptions about the cancer. John was more worried about recurrence than Margaret and attempted to gain control to manage his anxiety. In contrast, Margaret preferred to accept the situation, stay positive and relinquish control. Their different approaches were described as longstanding but also appeared shaped by their prior illness experience. Margaret often encouraged John to adopt more positive perspectives and restraint coping strategies, which appeared to have become their joint coping approach over time. Margaret seemed more satisfied with this strategy, with John making more concessions to accommodate this approach.

John prioritised returning to normality whereas Margaret emphasised his physical recovery, which corresponded with their different views on continuing treatment. They readily agreed that John's views would take priority in deciding treatments, due to it being his body.

John perceived mainly physical consequences from the cancer, whereas Margaret highlighted John's emotional outcomes. John did not share Margaret's attribution of his anxiety to his brother's death. He focused on the differences between him and his brother, which seemed to decrease his anxiety. Their discussion around this seemed to generate mild tension and this issue did not appear resolved.

Their differences in views were openly acknowledged and discussed. They frequently seemed empathic and understanding of each other's perspectives despite holding different views. Margaret showed some irritation about their differences in emotional response and coping style. In response to this, John appeared to try to hide the full extent of his concerns, although his anxiety was sometimes evident.

Summary

John and Margaret seemed like an independent couple coping with two different illnesses by primarily managing them separately but supporting the other when needed. They held various different views about John's cancer, which mainly appeared to be influenced by Margaret interpreting John's illness in reference to her own, whilst John's views reflected attempts to reduce his anxiety and regain normality. Overall, their differences appeared well managed through open communication and willingness to make concessions. Some differences seemed difficult to resolve when individual beliefs were fundamental aspects of the person's understanding and coping.

Couple 2: Kevin and Katie

Background

Kevin is a professional man in his late fifties. Katie is a retail manager in her late forties. They have been married for 30 years and have one daughter together. Kevin has been married previously, with children and grandchildren from his previous marriage. Kevin described himself as a workaholic with few interests outside work. Katie is also committed to her work and studies in her spare time. They described being very busy and having little time together, although both enjoyed shared holidays.

Kevin was diagnosed with prostate cancer 14 months prior to interview. He was treated with surgery and will have radiotherapy if his PSA level increases. Complications with his surgery resulted in an extended hospital stay and blood transfusions. Neither Kevin nor Katie had personal experience of illness; however Katie's sister died from Leukaemia ten years earlier.

Impressions and interactions

It was difficult to arrange the interview with Kevin and Katie due to their busy work schedules and it took place late one evening in their sociable open plan living space. Their daughter was sometimes present and they spoke openly in front of her. Both Kevin and Katie were talkative throughout, describing experiences in detail. Kevin's manner of speaking was calm and quiet whereas Katie was lively and animated. At times, Katie attempted to guide the conversation and prevent Kevin from providing too much detail about topics that she considered irrelevant, which I interpreted as reflecting her dominance in the relationship.

Kevin and Katie's story

Kevin and Katie found the diagnosis “*a bit of a shock*” but perceived illness as “*one of those things*”, expecting “*something's got to go wrong at some point*”. These views appeared to help them quickly accept the diagnosis and activate coping.

They both found decision-making challenging and relied on expert advice to choose their treatment option.

“With [consultant]’s advice (...) he would choose to have the radical prostatectomy so we decided to go that way” (Kevin)

Furthermore, despite Kevin’s complications, they were certain they had received the best treatment possible, perceiving their care as “*marvellous*”, which appeared to reflect their trust in the experts.

They described the cancer as generating “*an outline of change*” in their lives. This seemed to reflect a sense that core aspects of their lives remained intact but some peripheral adaptations had been required. For example, the prostatectomy altered their sex life but they had easily made adjustments, viewing this as “*a small price to pay*”. Conversely, they felt they had successfully prevented the cancer from negatively affecting their relationship and experienced their couple identity as intact.

*We got through it
We're still very lovey dovey
We just have a bit of a laugh
We've coped quite well (Katie, 'we' poem)*

They described themselves as “*complete opposites*” with Kevin the “*shy worrier*” and Katie being “*outgoing*” and “*bubbly*”, corresponding with my experience.

Questionnaires

Table 6: Couple 2 Questionnaire Data

Measure	Scale	Patient Score	Partner Score
IPQ-R	Illness Identity	0	0
	Timeline Acute/Chronic	3.17	3
	Consequences	2.67	2
	Coherence	2.67	2
	Personal Control	2.83	1.33
RAND-36	Physical Component Summary	58.8	61.2
	Mental Component Summary	58.2	57.6
CICS		19	20

On the IPQ-R, Kevin expressed greater perceived control than Katie. They both reported above average physical and mental HR-QoL and their CICS scores suggested high levels of illness-related communication.

Kevin's Story

Kevin perceived himself as a strong, healthy man whose role was to provide for and protect his family. He initially viewed the cancer as very serious and a threat to this role. Therefore, he took great efforts to stay healthy and prevent treatment having a negative impact, particularly on his work life, in order to be able to continue to protect and provide for his family. He worried about future potentialities and felt the cancer should make them more cautious and plan more effectively for the future, in case Katie had to cope without him. Continued survival was his main concern. He perceived other consequences, such as their altered sex life, as comparatively unimportant.

Over time, Kevin came to view the cancer as less serious, following feedback from medical professionals. Nevertheless, he remained concerned about recurrence, which he attributed to cancer cells being discovered at the margins. He also viewed his PSA level increase as being significant, based on his knowledge of statistics, despite reassurance from medical professionals that they were unconcerned.

He strived to protect others from his worries by not discussing them and presenting an outward appearance of normality; however this appeared to mask an internal sense of change and on-going concerns.

I worry

I don't tend to mention things much to [Katie]

I don't say things about it to her

I just try and be as normal as I can ('I' poem)

Katie's Story

Katie's experience was one of continued normality, stating "*to me nothing has changed*", consequently perceiving the cancer as not particularly challenging. She described Kevin's portrayals of normalcy and her "*outward view*" of him appearing well as influencing these perceptions. She believed that the cancer had been successfully removed and was unlikely to recur, therefore perceiving that the experience need not make them more careful, as this could result in missed experiences. Rather than plan for events that may not occur, Katie preferred to defer coping and use acceptance and positive reinterpretation coping strategies. However, she also instigated many of the couple's active coping efforts, such as asking questions from medical professionals, taking advantage of her more outgoing nature.

Despite Kevin's assurances to the contrary, Katie perceived their altered sex life as having more of an impact on Kevin than her. Societal views of sex being more important for men than women appeared to influence Katie's perceptions on this.

Katie's experience with her sister's Leukaemia and subsequent death was influential on her perceptions, leading her to believe that these experiences are uncontrollable and random but that hope and optimism can keep you going.

*I'm an optimist
I was saying you'll be fine
I always had the faith
I'm quite optimistic ('I' poem)*

She also saw prostate cancer as a 'good cancer' in comparison to Leukaemia.

Key discrepancies from interview

Initially Kevin viewed the cancer as more serious than Katie, although their views became more similar over time. Kevin was more worried about recurrence, which made him feel the need to attempt to gain control, be more cautious and plan for the future. In contrast, Katie perceived recurrence as unlikely and felt the cancer was uncontrollable, therefore they should defer coping until they knew they had something to deal with. She preferred to accept the situation and remain positive rather than worry. Katie appeared to view Kevin's perceptions and responses as overreactions.

Their different perceptions about the importance of reduced sex appeared to generate some tension. Kevin appeared somewhat confused by Katie continuing to believe this was an issue for him when he had assured her that it was not. The influence of societal stereotypes appeared to override Kevin's assertions for Katie.

The couple were open about their differences, easily contradicting one another with lively discussions often containing humour and laughter. They readily accepted their differences and often attempted to find a middle ground. They described their differences as beneficial, enabling them to "*bounce off each other*"; however, Katie sometimes found them frustrating. The differences did not always appear helpful, sometimes making it difficult for them to appreciate each other's experience. Kevin reported hiding the full extent of his feelings, which seemed to be influenced by Katie's lack of understanding as well as his desire to protect her.

Summary

Kevin and Katie seemed like an independent couple, dealing with cancer at a time in their lives when work was a priority. Katie appeared to have been protected

from the impact of the cancer by Kevin, helping her view it as easily manageable. Her experience with her sister's cancer also seemed to help her accept the cancer and perceive it as less serious. Kevin is older than Katie and views his role as protecting her and his family, causing him anxiety about the possibility of not being around to look after his younger wife. They openly discussed and saw benefits in their differences; however, some caused frustration and disharmony.

Couple 3: Rob and Helen

Background

Rob and Helen are in their mid-sixties and are both retired. They have been in a relationship for 13 years, cohabiting for 10 years. They have both been married before, with children and grandchildren from previous relationships. They are both very active, with many shared and individual interests, and met through a mutual hobby.

Rob was diagnosed with prostate cancer 9 months prior to interview. He was treated with surgery and will have radiotherapy if his PSA level increases. Prior to diagnosis, Rob had little personal experience of illness. His brothers have also been diagnosed with prostate cancer, with one diagnosed 15 years previously and the other diagnosed after Rob. Rob has since considered the possibility of a genetic link.

Impressions and interactions

The interview took place at the table in the couple's dining room, which was minimally decorated with few personal effects displayed. Rob and Helen showed consideration for one other throughout, endeavouring not to talk over one another, which gave a sense of formality to the interview. They both provided limited spontaneous detail, requiring some prompting. Rob seemed uncomfortable talking about his cancer and was more relaxed and chatty when discussing other topics. Helen seemed surprised when questions were directed at her, appearing unfamiliar with people considering her experience of the cancer.

Rob and Helen's story

Rob and Helen described the cancer diagnosis as having a very minimal impact on their lives, with few emotional and physical consequences. They felt it "*never seemed to be that big frightening thing*", which appeared influenced by the matter-of-fact and confident responses of the professionals leaving them reassured. The only physical challenge was recovery from surgery, which they described as quick

and straightforward. They appeared to have been confident in their ability to cope throughout, influenced by their belief that they had dealt with worse in the past.

“that was probably far more distressing and hard and certainly hard on the relationship than, than going through cancer treatment anyway” (Helen)

The couple appeared to have similar preferred coping strategies, both actively taking steps to deal with the cancer and seeking social support. They were open in discussing the experience between themselves and with family, without any attempts to hold back difficult information. Rob felt less proficient at being open than Helen but they were both satisfied with the communication and described frequent discussions.

*We’re very open
We’ve never sort of restricted conversation
We face up to our problems
We discuss it as best we can (Rob, ‘we’ poem)*

Overall, they did not perceive the cancer as a big challenge, viewing it as having had a positive impact, enabling them to appreciate their lives more.

“overall it’s been beneficial really (...) and all I had to go through was a quick operation!” (Rob)

Questionnaires

Table 7: Couple 3 Questionnaire Data

Measure	Scale	Patient Score	Partner Score
IPQ-R	Illness Identity	0	0
	Timeline Acute/Chronic	2.5	2.67
	Consequences	1.67	2.67
	Coherence	5	4
	Personal Control	4.17	4.5
RAND-36	Physical Component Summary	58.7	54.1
	Mental Component Summary	57.6	53.4
CICS		17	16

Rob and Helen reported above average HR-QoL. Their illness communication was lower than the sample average, potentially reflecting Rob’s discomfort discussing the cancer. They reported similar views on the IPQ-R, matching the interview data.

Rob’s story

Rob perceived himself as having a very positive attitude, which he had sustained throughout the cancer experience. He also appeared to have used his

statistical and analytical skills acquired during his employment to help him cope, by using them to support his information seeking and decision-making efforts.

Rob felt fit and healthy throughout his cancer journey, making it hard for him to acknowledge that he had been ill. He fluctuated between describing himself as cancer free or surviving with cancer in remission, appearing to reflect a difficulty in integrating the cancer into his identity.

*I've never been anything other than fine
I'm great, never been otherwise
I can see I've got cancer
I've had cancer really or have cancer
I had it removed ('I' poem)*

Helen's story

Helen appeared not to have strong views about the cancer. She described finding it difficult to form opinions due to lacking the relevant knowledge, therefore placing her trust in the professionals. She also saw Rob's interpretations as more important than her own, readily agreeing with his views. She appeared content to take a backseat and be there to provide support if needed, although she occasionally felt dismissed by people outside their relationship.

*I wasn't err actively involved in it
I did feel it was [Rob's] decision
I wasn't shut out from it
I wouldn't have err opposed
I would always let [Rob] take the lead ('I' poem)*

Key discrepancies from interview

During the interview I did not identify any obvious discrepancies between Rob and Helen's views. Rob primarily took the lead and his views appeared to be prioritised. Helen willingly contributed to discussions and supplemented Rob's descriptions with further information, but predominantly agreed with Rob. However, a few discrepancies were identified through closer examination of their interview data. These mainly concerned different interpretations of some of their cancer-related experiences. For example, Rob viewed the purpose of the exercise group he attended as mainly a source of peer support whereas Helen viewed it as for improving fitness. Rob also perceived his ability to have surgery as due to being fit for his age, whereas Helen perceived this as a typical treatment option for his age. They also had different understandings of Rob's experience of coping well. Rob perceived this as a consistent

personal trait whereas Helen attributed it to co-occurring positive events. These different views did not seem to cause difficulties for the couple, with them describing it as helpful to have some differences to “*bind us together*”. They appeared to willingly accept the other person’s views without attempting to judge or change them.

Summary

Rob and Helen began their relationship in the later stages of their lives and were accustomed to coping with their own individual stressors. Accordingly, the cancer appeared to have been appraised as largely Rob’s stressor, with Helen’s role being a source of support in the background, which seemed to suit both parties well. They presented similar views on the cancer, with the discrepancies identified seeming relatively unimportant and easily negotiated through acceptance and appreciation.

Couple 4: Simon and Jane

Background

Simon is in his early seventies and Jane is in her late forties. They have been married for 13 years. They have both been married before, with children and grandchildren from previous marriages. Jane’s 12 year old granddaughter lives with them permanently. They have very close, supportive families. Simon is retired and has had various careers, most recently taking a large pay cut to become a caretaker to improve his quality of life. Jane previously worked in care and is now a supervisor at a school. She has a busy lifestyle, balancing full time work, household tasks and caring for her granddaughter. They both enjoy regular holidays.

Simon was diagnosed with colorectal cancer and liver metastases 18 months previously. He was treated with chemotherapy, radiotherapy and surgery. His last treatment, a liver resection, was 5 months prior to interview. Simon had life-threatening complications following his initial surgery and was unconscious for two weeks. He has a temporary stoma, which he hopes will be reversed.

Impressions and interactions

The age difference between Simon and Jane was noticeable and they introduced this into conversation several times. They were very talkative and this was the longest interview conducted. They bounced off each other, stimulating each other to add further information, and I sometimes found it difficult to interrupt to ask further questions. Simon was jovial and humorous throughout, appearing uncomfortable during discussions about difficulties and quickly diverting conversation back to more

positive topics. Jane appeared more comfortable articulating her negative emotional reactions, although she was also very positive. Simon and Jane were very expressive about their feelings for one another and used a lot of ‘we’ talk.

Simon and Jane’s story

Simon and Jane described having a special relationship with an extremely close bond and depth of feeling for each other that they had not experienced in past relationships. Maintaining this special relationship and caring for each other was highly important to them, and the diagnosis represented a great threat to this. The risk of their bond being broken by the cancer and Simon’s life-threatening complications brought them closer together, making them appreciate each other more.

Despite the complications, they felt their medical experience was “*fantastic*” and were very grateful of the medical professionals, appearing to reflect their relief and gratitude over Simon’s survival.

Simon and Jane appeared to have appraised the cancer as a joint stressor, which they ‘fought’ together.

*We’ve just got on with it haven’t we?
 We’ve just accepted it and got on with it
 We says right we’re going to get through this
 We’ve like fought it really (Simon, ‘we’ poem)*

They also believed that having a positive attitude “*goes a long long way to repairing things*”. Adopting a ‘fighting spirit’ and ‘positive attitude’ towards cancer are popular societal messages, which the couple appeared to place a lot of faith in.

Questionnaires

Table 8: Couple 4 Questionnaire Data

Measure	Scale	Patient Score	Partner Score
IPQ-R	Illness Identity	1	1
	Timeline Acute/Chronic	1.33	1.5
	Consequences	1	1.33
	Coherence	5	4.8
	Personal Control	5	4
RAND-36	Physical Component Summary	58.6	58.9
	Mental Component Summary	62.0	59.8
CICS		20	20

On the IPQ-R, Simon and Jane reported similar perceptions. This similarity generally corresponded with the interview data; however, some discrepancies were

evident and some perceptions appeared to have become more similar over time. They both reported good HR-QoL and illness-related communication.

Simon's story

Despite his initial shock, Simon quickly accepted the diagnosis, perceiving the cancer as manageable and remaining optimistic throughout. He retained his sense of himself as a funny, cheerful man, appearing to find humour a helpful coping strategy.

*I'm still as daft as ever
I've got a good sense of humour
I kept telling him jokes
I mean that's me ('I' poem)*

Simon's aims were to recover as quickly as possible and not be a burden to Jane, wanting to resume his role as the strong, protective man of the house.

Simon perceived himself to have experienced minimal suffering from the cancer, appearing to lack awareness of some of his difficulties due being unconscious during the complications, despite being subsequently informed of their life-threatening nature. He felt the stoma was the only difficult consequence for him, due to having experienced some public accidents which caused him embarrassment and made him reluctant to socialize. It also prevented him wanting to engage in sexual relations with Jane until after his reversal, due to believing she would find the appearance repellant.

Jane's story

Jane initially perceived the cancer as very serious. She was surprised by her level of distress and it took her some time to come to terms with it. She gave the impression of initially feeling overwhelmed by the situation, particularly when her father died during Simon's treatment.

*I thought I would be strong
I lost quite a bit of weight
I was just sort of sat there
I think it upset me more thinking about you because dad passed away
I just think everything were getting muddled ('I' poem)*

She coped with her distress by taking things in stages, seeking social support and expressing her emotions.

Jane was very frightened by witnessing how poorly Simon became with the surgical complications and having to make decisions about his care independently.

The life-threatening nature of his complications appeared to increase her desire to protect and take care of him during recovery.

Key discrepancies from interview

Jane initially perceived the cancer as more serious than Simon; however their views became more similar over time through Simon using his positivity to reassure Jane, helping her view it as less threatening. However, she continued to hold more negative perceptions of the consequences of the cancer, and believed that Simon's more positive perceptions reflected the fact that he had not "*got it into his head how poorly he really has been*".

Jane did not share Simon's embarrassment about the stoma, seeing his views as "*old-fashioned*". For her it was "*no big deal*" and something she was familiar with from her previous care work. Nevertheless, she respected his decisions to wait until after the reversal to resume previous levels of socializing and sexual relations.

Jane saw her role as being to take care of Simon during recovery, whereas he saw this as being a burden. However, they understood each other's underlying desire to protect the other and attempted to respect both approaches.

Simon and Jane had some different individual coping strategies. Jane sought social support and expressed her emotions whereas Simon engaged in acceptance and focussing on the positive, and did not seek support outside their relationship. Simon did not feel the need to "*deal with it in stages*" like Jane but adopted this strategy to accommodate her needs, despite it not benefiting him personally.

Simon seemed eager to emphasise the benefits of his positivity to help others learn from his approach, possibly masking underlying concerns and over-exaggerating differences between him and Jane, who more willingly expressed difficulties.

Simon and Jane were sensitive and empathic towards each other, readily prioritising the other's needs. They felt able to tell what the other was thinking without communicating verbally, frequently appearing successful at this. However, they sometimes made inaccurate assumptions about the other's thoughts and feelings.

Summary

Simon and Jane seemed like a very close couple who provided a lot of support to one another. They had some frightening experiences during the cancer treatment, which threatened their close relationship, making them seek even closer proximity to one another. Generally, they appeared to have shared understandings of the cancer and a joint approach to 'fighting' the illness. They were empathic and respectful of each other's differences, often finding them beneficial for helping one another.

Couple 5: Brian and Mary

Background

Brian and Mary are in their late sixties and have been married for nearly 50 years. They live in a large homely farmhouse and have children and grandchildren nearby. Brian is a farmer who is gradually handing over responsibility of the farm to his sons. Mary is a housewife and also helps on the farm. Farming is an important part of their lives and they described farming responsibilities as taking priority over other interests. They primarily have independent interests, with Brian enjoying his agriculture and Mary enjoying various active pursuits.

Brian was diagnosed with colorectal cancer 18 months prior to interview. He was treated with chemotherapy, radiotherapy and surgery. His last treatment was 12 months previously. He reported no side-effects from radiotherapy or chemotherapy; however his bowel repair did not heal properly causing leakage and requiring further surgery. Mary provided a lot of care during his hospital stays and recovery. Brian now has a permanent stoma. They reported no history of personal illnesses.

Impressions and interactions

Brian and Mary sat on separate settees and primarily directed their responses at me, having few conversations between themselves. They appeared comfortable describing medical encounters and their closeness and shared experiences during treatment were apparent; however, they appeared uncomfortable when asked about thoughts and feelings, often finding it hard to answer such questions. This seemed to reflect their joint stoical approach of enduring difficulties without complaint, which had possibly developed in response to having to withstand the hardships of farming life. In the joint interview Mary often thought carefully before answering questions, appearing to be deciding what to say and how to word it, whereas in her individual interview she spoke more freely with more emotional content and expressed various discrepancies from the joint story. This appeared to reflect an attempt to maintain the status quo around Brian, whilst privately desiring change.

Brian and Mary's story

Brian and Mary were disappointed with some of their medical experiences. Brian's initial symptoms were misdiagnosed, delaying treatment. They also believed that his hospital care contributed to his complications and were unhappy that follow up care did not identify the problems, despite them expressing concerns. They sought advice from their Urologist friend, reporting "*we don't know what we'd have done if we*

hadn't had him", suggesting a lack of confidence in their ability to cope. Despite their difficult experiences, they retained their trust and confidence in the professionals.

Brian's stoma was viewed as their most difficult challenge due to it generating substantial lifestyle changes, including altering sleeping arrangements and limiting socialising. They both believed the cancer experience had been more challenging for Mary than Brian. She provided extensive care to Brian and struggled with not knowing how he was feeling, in part influenced by his difficulties communicating. Limited communication was described as a consistent feature of their relationship.

The couple's joint approach to coping was characterised by resigned acceptance and 'getting on with it' without talking about it, which they felt had been effective and resulted in shared views despite not discussing things in depth.

*We've both coped very well
 We've accepted things for what they are
 We've had shared views
 We haven't discussed them greatly
 We do quite well .. accepting things (Brian, 'we' poem)*

They also both described taking "*the easy way out*" for some of their difficulties, appearing to avoid confronting issues due to not wanting to make things more difficult.

Questionnaires

Table 9: Couple 5 Questionnaire Data

Measure	Scale	Patient Score	Partner Score
IPQ-R	Illness Identity	6	6
	Timeline Acute/Chronic	3.67	2.5
	Consequences	4	3
	Coherence	4	4.6
	Personal Control	2.17	3.33
RAND-36	Physical Component Summary	35.0	56.9
	Mental Component Summary	61.1	57.2
CICS		18	16

On the IPQ-R, Brian had more negative perceptions of control and timeline than Mary, which was also evident during interview. Brian had lower physical HR-QoL scores than Mary. Mary reported lower satisfaction with their illness communication, with a lower score than the sample average, which matched her interview data.

Brian's story

Brian believed the cancer would have a long-term impact, with continued lifestyle changes due to his stoma and on-going fears of recurrence.

“I’ve obviously still got doubts in my mind that this cancer won’t go away or it’ll reoccur or whatever it is and I’ll die a long time before [Mary] does”

He felt he was improving rapidly with his stoma management but believed this would always be difficult for him. Nevertheless, he reported being optimistic and felt that *“things are very positive”*.

Brian described *“going along with”* medical professionals’ advice and being dependent on Mary for support, giving the impression he lacked personal control. He was grateful for Mary’s support, yet did not communicate this to her.

*I feel more dependent and grateful for her presence than I did
I appreciate it more
I’m not quite sure I’ve said that
I don’t know how I’d manage without her
I don’t say it of course (‘I’ poem)*

After initial increased closeness, Brian was satisfied with resuming their previous levels of closeness and independence, due to wanting a return to normality.

Mary’s story

Mary perceived the cancer as a short-term, acute episode that had been dealt with and would not impact on Brian’s life expectancy. Consequently she believed that they should be moving on from the experience, but felt Brian was not improving as quickly as expected. She believed the continued restrictions on their social life were unnecessary and hoped things would improve.

Mary felt the cancer had initially brought her and Brian closer and hoped that it would signify a *“lovely new beginning”* for their relationship; however, she felt this hope had not been realised. She wanted them to talk more, particularly about their feelings for one another, but felt ill-equipped to change this. She chose not to try to instigate more communication because *“it can land you in something worse rather than better”*.

*I would like to talk
I can’t
I don’t know how to do it
I’ve probably not got any tact at all
I’m just in with two feet
I probably take the easy way out by not saying anything (‘I’ poem)*

Key discrepancies from interview

During the joint interview Brian and Mary mostly presented similar views and were quick to agree with one another; however, their individual interviews suggested that these agreements masked underlying differences.

Brian perceived the cancer as having more negative and longer-term consequences than Mary. Mary was disappointed that it was continuing to impact on their lives in ways she perceived unnecessary. Despite his more negative perceptions, Brian was described as more positive than Mary. However, when Brian was poorly Mary took over the positive role, counteracting his more negative outlook, suggesting they were sometimes able to use differences to their advantage.

Mary initially believed the cancer signalled the potential for a fresh start to their relationship, hoping they would become closer and talk more. However, after initial increased intimacy, Brian was satisfied with re-establishing their previous levels of closeness and communication. Mary interpreted this as *“a bit of a man thing”* of disliking being dependent on others, whereas Brian reported appreciating her support but wanting a return to normality. He did not want to talk about the cancer, believing this would make him feel worse by making him *“dwell on it”*.

Mary reported being *“fed up”* and became visibly upset when discussing their differences in views and communication preferences. She tried to empathise and understand Brian’s differences but reported feeling unsuccessful at this. She hid her feelings and concerns from Brian to protect him and the relationship, leaving Brian unaware of many of their differences.

Summary

Brian and Mary seemed like a stoical couple who had faced numerous challenges during their cancer experience. Despite limited communication, they had shared understandings about their medical experiences; however, they had important discrepant understandings about the meaning of the cancer for their relationship and its continued impact on their lives. The discrepancies caused disappointment for Mary and she was dissatisfied with their communication levels. The couple appeared reluctant to address their disagreements for fear of making things worse.

Couple 6: Ruth and Mark

Background

Ruth and Mark are in their early sixties. They have been married for 40 years and have children and grandchildren. They are both retired, with Ruth having worked in childcare and Mark in management. They described being independent with

separate interests during their working lives, becoming closer with more shared activities since retirement.

Ruth was diagnosed with colorectal cancer 2 years prior to interview. She was treated with surgery and did not require a stoma. Ruth previously had a hysterectomy and Mark had a motorcycle accident in his teens, suffering significant injuries and requiring him to learn to walk again. Ruth's brother-in-law died from prostate cancer the same year Ruth was diagnosed.

Impressions and interactions

Ruth and Mark sat close together holding hands during the interview, portraying their closeness. They were both very talkative and jointly contributed to discussions, with Mark providing much of the descriptive content and Ruth providing more emotional content. They were complimentary about one another, often describing each other's strengths and explaining how these had helped them cope, highlighting their appreciation of one another. When discussing previous difficulties, they seemed surprised to realise how much they had overcome together, giving the impression of being a positive couple who did not dwell on past difficulties.

Ruth and Mark's story

The diagnosis was a big shock to Ruth and Mark because Ruth had no symptoms and felt "*the healthiest I've ever felt*". The cancer was only diagnosed due to Ruth's participation in the NHS bowel cancer screening programme.

Ruth's surgery was uncomplicated and they were both relieved that she did not require a stoma. They both greatly trusted medical professionals, explaining "*we do as we're told*" and consulting them for support over any concerns.

The couple described few on-going challenges from the cancer experience. Ruth's recovery from surgery generated temporary role changes, with Mark taking on household chores which he had previously never done. Mark enjoyed adopting a caring role and Ruth greatly appreciated his care. Their lives had gradually returned to normal with Ruth slowly rebuilding her fitness and progressively taking over chores again. They felt the only lasting impact was being required to consider Ruth's needs for prompt toilet access when going out.

They described themselves as "*chalk and cheese*"; however, they also believed they had shared values about the importance of family, travel, and a comfortable home life. They described having had worse experiences to cope with in the past, which they had worked through together in the same manner as they had coped with the cancer.

*We surround ourselves with family
 We've got the same resolve
 We're of the same mind within reason
 We managed it together basically
 We've worked together (Mark, 'we' poem)*

Both Ruth and Mark had found positive meaning in the cancer experience, perceiving it as making them “*more mellow*” and improving their relationship.

Questionnaires

Table 10: Couple 6 Questionnaire Data

Measure	Scale	Patient Score	Partner Score
IPQ-R	Illness Identity	5	5
	Timeline Acute/Chronic	2.33	2.17
	Consequences	3.33	3.33
	Coherence	2.6	2.8
	Personal Control	2	2
RAND-36	Physical Component Summary	45.1	54.2
	Mental Component Summary	57.6	59.2
CICS		15	17

Ruth and Mark reported similar perceptions on the IPQ-R. Ruth had lower physical HR-QoL scores than Mark and reported less satisfaction with their illness-related communication, which was lower than the sample average. This appeared to represent her uncertainty over whether Mark found it difficult to talk about his feelings about the cancer.

Ruth's story

Ruth initially perceived the cancer as very serious, causing her “*panic and turmoil*”. At first, she sought information to gain control but found that this increased her concerns. Her brother-in-law's death coinciding with her treatment also raised her anxiety. She originally tried to keep the diagnosis and her distress private from friends and family to not worry them, but she found this unhelpful and subsequently shared it with them, using them for emotional support throughout the cancer experience.

*I just cracked up
 I need to talk to them
 I need to talk to my sister
 I did crying over the phone trying to tell them ('I' poem)*

However, Ruth found some of her friends' reactions unhelpful, with some expressing common societal perceptions that bowel cancer is not as “*romantic*” as breast cancer.

Generally Ruth felt that she had recovered well but she remained frightened of recurrence and experienced traumatic memories of her hospital experiences and seeing the tumour during the colonoscopy. She did not feel able to continue talking to others about these memories due to their perceptions that *"it's done and you're ok"*, suggesting to her that she should not continue to feel distressed.

Mark's story

Mark *"wasn't at all concerned"*, automatically accepting the diagnosis and feeling confident that the treatment would successfully remove the cancer, with recurrence being unlikely due to early diagnosis. He attributed his optimism to the medical professionals' explanations and confidence.

Mark perceived the cancer as Ruth's illness and therefore did not consider its impact on him, reporting *"I don't have a view on it"* and *"I didn't feel anything"*. He also described feeling he had little control over the cancer and therefore providing support and remaining strong was all he could do. This could suggest that his lack of concern and emotional expression was aimed at being strong for Ruth.

*I just supported you
I was just here for [Ruth]
I'm here for her
I just felt it's something I've got to manage
I couldn't do anything could I? ('I' poem)*

Furthermore, he described becoming less selfish and more considerate of Ruth since the diagnosis, potentially reflecting an emotional response to the cancer that he had not identified it as such.

Mark believed that Ruth had recovered physically and emotionally from the cancer experience and felt pleased that he had been able to support her with this.

Key discrepancies from interview

Ruth initially perceived the cancer as more serious and more likely to recur than Mark, finding it harder to accept the diagnosis. Ruth's more negative views caused her to experience strong emotional reactions that she had to express, requiring emotional support from family and friends to cope. She therefore struggled to understand Mark's lack of demonstrable emotions and wondered what this might signify, possibly being concerned about his feelings for her. In contrast, Mark sometimes found Ruth's anxiety and distress frustrating, due to not appreciating her need to express these feelings. They both tried to empathise with and accommodate

the other's preferences, and mainly seemed successful at this, although not entirely. They used a lot of humour during their discussions about their differences, which appeared to help them raise these difficult topics.

A particularly stark contrast in their views was around the impact of the cancer on Ruth. Ruth found the experience incredibly disturbing and continued to experience residual trauma, explaining *"it's a traumatic experience and I suppose the trauma is still there"*. However, Mark appeared unaware of this and believed the opposite, stating *"she came away and there was no, if you like, trauma"*. Ruth had not shared the full extent of her continued trauma due to wanting to show her appreciation of his support by demonstrating that she had recovered. She also perceived an expectation for her to move on from the experience because other people appeared to have done so, and appeared to have tried to present such an impression despite not entirely feeling this was the case. The discrepancy between her continued distress and the perception from others that she should move on had caused her to be concerned that her distress was unreasonable and disproportionate.

Summary

Ruth and Mark seemed to view the cancer as Ruth's stressor, with Mark's role being to support and remain strong for her, minimising his own emotions. Ruth greatly appreciated Mark's support and attempted to show her appreciation by demonstrating how helpful it had been for her recovery. However, her attempts to refrain from expressing her distress were difficult for her and she was not always successful at this. Their difference in emotional expression generated some misunderstandings and frustrations. Nevertheless, they were able to discuss their differences and presented as a united couple who worked together to cope with the cancer.

Summary of case studies

All couples had some discrepant perceptions alongside their shared understandings. However, no specific cancer-related topics consistently generated discrepancy. Some of the more common discrepancies included: patients being more concerned about recurrence than partners; one person perceiving the cancer as having more serious consequences; and members of the couple having different preferred coping strategies. Furthermore, discrepancies appeared to vary in how important they were to the couple. Discrepancies in interpretations of medical experiences appeared relatively unimportant and easily negotiated, whereas discrepancy in beliefs that were fundamental aspects of the individuals' meaning-making and coping appeared to cause more difficulties.

Negotiating Shared and Discrepant Understandings

Two of the case studies will now be illustrated in more depth to draw out more clearly the discrepancies between individual accounts, individual accounts as part of a co-constructed narrative and the perceived co-constructed accounts. By broadening the analysis from the 'I' and 'We' poems to include the context from which they were constructed, this aims to describe how understandings that appeared to be constructed and shared at a couple level and those that appeared to represent individual level understandings manifest during the interviews and how discrepancies in the accounts were negotiated.

Couple 5: Brian and Mary

Brian and Mary demonstrated that some of their understandings were shared and constructed together through collaborating during their storytelling, whereby they would extend each other's ideas, answer questions that furthered their joint story, and confirm each other's accounts, such as through statements of agreement. For example, they demonstrated a shared construction of the belief that Brian's hospital care had contributed to his complications following surgery and experienced a shared disappointment with their medical experiences.

Joint interview

Mary *He was sat in that chair for 4 hours*

Brian *For 4 hours while they found a bed, which .. we're fairly sure it didn't do any good*

Mary *You know that's .. that's fairly devastating when you go the next day and you find.. everything's sort of gone well and something like that's happened, and it shouldn't happen.*

(...)

Brian *We blame, rightly or wrongly, that 4 hours sitting in the chair, didn't help that at all*

Mary *Mmm*

Similarly, they described co-constructed accounts of their retained confidence and trust in professionals despite the complications.

Joint interview

Mary *We're grumbling to you about the bits and pieces but really you thought you were in the best place .. for things that have happened, you know really.*

Brian *Yes (...) And as I say some of [the medical professionals] were lovely, absolutely perfect and you know, everything was ..*

Mary *Very good.*

Brian *Wonderful.*

These jointly constructed accounts appeared to tap into their shared meanings and perceptions of their experiences; however, sometimes the couple's shared understandings were not necessarily the meanings the individuals carried on their own. For example, the couple described a shared understanding that they had accepted the cancer and its consequences and that they got on with things without discussing them in detail. Both Brian and Mary referred to this in their joint interview and this understanding was present in both of their 'We' and 'I' poems during their joint account; however, Mary was less outspoken about this during the joint interview and in her individual interview she suggested she felt differently, describing a sense of not having accepted their situation completely and desiring some change and further discussions.

Joint interview

Brian *I think the positive side is that we've accepted things, we haven't discussed them greatly which is exactly right. Accepted things for what they are. I think that's one thing that we do quite well is accepting things as they are*

Mary *Yes*

Brian *If you can't change it, accept it and move on, as it were.*

(...)

Mary *I think we have accepted things ...*

Mary's individual interview

I would like to talk (...) there are certain things about his illness and this blinking stoma, you know, like change your .. a bit more often, this sort of thing (...) I think it could get better

This appeared to represent the couple's sense of who they are as a unit and their joint coping approach differing from Mary's individual identity and preferences. There appeared to be some tension between whether Mary wanted to act in accordance with the couple approach or her individual preferences, although during the joint account she concurred with the couple story. Mary may have deferred to Brian's preference to support him and she suggested that she feared making things worse by attempting to exert her individual preference on Brian.

The couple also presented a joint account of Brian's stoma representing their most difficult challenge, although they felt that they had learned to manage this well as a couple. In the joint interview, Brian's individual account was consistent with the co-constructed account, describing himself as coping well and feeling more confident

managing the stoma. However, in Brian's individual interview, he expressed less confidence in his stoma management and reported more difficulties. Mary also expressed satisfaction with their stoma management in the joint interview; however in her individual interview she reported having some personal concerns for herself.

Joint interview

Mary I think you're managing it much, much better, the whole thing

Brian That's true, I'm certainly confident in managing .. a day's activities better than I did (...) I mean we've been away in the caravan since the operation and coped with that (...)

Mary We can cope with these things can't we?

Brian's individual interview

I'm not even confident, comfortably to go and see my own daughter and stay with her for few days (...) it's not ideal (...) I don't feel confident in my mind to go away.

Mary's individual interview

there are times when I've been embarrassed that he hasn't sorted himself out, hygienically

Therefore, in the joint interview the couple's individual accounts appeared to attempt to fit with their dominant joint story of managing well, which provided them with a sense of confidence and solidarity. However, individually they were able to express some personal concerns that did not fit the shared story.

At times, Brian and Mary expressed direct contradictions between their individual beliefs during the joint interview. For example, they expressed different beliefs about the impact of the cancer on Brian's life expectancy. This appeared to generate some tension and during the joint interview Brian appeared to try to minimize the difference in their views; however, during the individual interview he returned to expressing his personal concerns.

Joint interview

Brian I don't think that having this cancer, certainly it hasn't done anything to improve my long term, longevity prospects

(...)

Mary Well you seem to think that er because this has happened, you're, you said that you don't think you'll live as long as you thought you would. But I don't think, I don't see the, I don't see that, I can't see that at all. I don't see why the rational thinking in that at all but ..

Brian No, you're absolutely right there. I did say that and to some extent I still think it but I think I think it less than I did 6 months ago.

Brian's individual interview

I've obviously still got doubts in my mind that .. this cancer won't go away or it'll reoccur or whatever it is and I'll die a long time before Mary does

This suggests that Brian and Mary were both consciously aware of their difference in perceptions of the cancer and discussed this openly; however the tension between their individual beliefs appeared to generate a desire to minimize the difference when together and express concerns privately.

Some individual discrepant understandings were only shared in the individual interviews and the couple did not appear to be aware of their different perceptions. For example, Brian described feeling dependent on Mary and being grateful for her support. However, Mary was unaware of his feelings regarding this and believed that he was not grateful for her support.

Brian's individual interview

I feel more dependent and grateful for her presence than I did before. The presence is no different and no less supportive or more supportive, I don't think. But I think I appreciate it more, whether I've said that or not I'm not quite sure, probably not

Mary's individual interview

he's .. not said unkind things, but not been appreciative at all

Some of their similar understandings were only described in the individual interviews and not acknowledged in the joint interview. For example, they both perceived themselves as taking the easy way out and avoiding some of their challenging experiences. This did not appear to fit with their shared account of acceptance and getting on with things and seemed to represent individual perceptions that concurred without overt negotiation, but were not emphasized in their shared account.

Brian's individual interview

My first reaction is the easy way out, no we'll stay at home

Mary's individual interview

I probably take the easy way out by not saying anything

Couple 5 summary

Important shared understandings for this couple appeared to emphasize acceptance and hope, which seemed to be an attempt to support one another to cope. Individual perceptions that did not fit this shared narrative generated some tension,

which led to these discrepant understandings being minimized or avoided in the joint context in order to focus on the shared story.

Couple 6: Ruth and Mark

Ruth and Mark also demonstrated their jointly constructed views through collaborating and agreeing during their storytelling and demonstrating consistency between their 'We' poems and 'I' poems. For example, they described a shared belief that the cancer had positive meaning for their relationship.

Joint interview

Ruth So here we are, mellowed.

Mark Oh I think so. I'm more mellow (...) I've matured a lot. A bit more patient.

They also appeared to be continuing to construct and negotiate new shared understandings within the interview through discussing their experiences together. For example, they initially described having not had many challenges to cope with in the past; however, through reviewing their past experiences together they spontaneously changed their understanding and considered themselves to have coped with many challenges.

Joint interview

Ruth We've been through a bit haven't we?

Mark Yes

They also provided a jointly constructed account of looking forward rather than dwelling on the past. However, this joint account appeared to represent a shared meaning that worked for them as a couple but did not work for Ruth on an individual level. During the joint interview they both described this shared approach, which appeared to reflect their longstanding way of managing effectively together in the past. However, Ruth presented a different account in her individual interview, describing herself as ruminating on the past and finding it difficult to move forward.

Joint interview

Ruth We look forward (...) We always have plans and things to look forward to. There's always something to look forward to, all the time. Isn't there?

Mark Yes, great

Ruth's individual interview

I just turn it over in my mind. Sometimes I think you just need to .. talk about the whole thing and what you can remember or something to get it out of your head. Or can you, I don't know. It's still there.

Some of their individual differences were openly discussed in the joint interview. For example, they were both aware of their differences in emotional reactions and were accepting of these differences, framing the two approaches as complementary and beneficial for their coping.

Joint interview

Mark I've never felt any anxiety or fears or anything so I'd like to think that's bounced off on [Ruth] by having this .. I know it's like Steve Wright's Sunday love songs .. I think I've been a rock!

Ruth: Yeh (...) I'm glad that .. there's no good both of us being anxious (...) I just think it's been good that we've both worked together

Ruth and Mark's individual accounts during their joint interview were often consistent with their accounts during their individual interview. The same themes emerged in their 'I' poems in both contexts, although some understandings that were divergent from the joint story or the other person's story appeared to be downplayed in the joint interview, such as by moving on to another topic that was more consistent. They would then expand on their different perspective in their individual interview. For example, Ruth hinted at her desire to continue discussing her experience in the joint interview but moved on quickly to another topic. She then discussed this in much more depth in her individual interview.

Joint interview

Ruth I thought I can't say that to anybody (...) I will say .. I do come and say things, I don't keep everything in and I'll just say, it's like when I was in such .. and doing the day that such and such happened or whatever. But as I say, everything was handled properly and it's all healing properly and we look forward to things.

Ruth's individual interview

you almost sort of wish someone sort of just said, how are you .. like you're doing now and what are you thinking about?.. I don't know because ... yeh I say it all in my mind and to begin with you're talking to your sisters or whoever or [Mark] and then you think, I can't say all that again because they've heard all that, they don't want to hear me going on about that. You should have forgotten about that by now. (...) I've talked to [Mark] about everything that's sort of happened and everything, it's just that I wouldn't, I know he would sit and he

would listen, if I kept going on, over and over but I'm sure he'd probably be thinking ..it's done and you're ok. So as I say, I just turn it over in my mind.

Mark shared his belief that the experience had not been traumatic for Ruth in the joint interview. Ruth did not contradict this at the time and focussed on the more positive experience of Mark's care for her during recovery. However, in her individual interview she described continued trauma, which Mark appeared to be unaware of.

Joint interview

Mark So she came away and there was no if you like, trauma or anxiety and it was just that will to mend and .. take the rest. So she took to her bed, does as I told (...) It was all relaxed, take your time .. I .. fed and nursed you didn't I? as best I could

Ruth Yeh

Mark and .. Just so the recovery process was successful, that's my view of it, wasn't it?

Ruth Because the other thing was not being disrespectful but [Mark] was never one to do the housework and cook or anything like that, were you?

Mark No

Ruth You've just not been in and I have. It's just the age we're from probably and I've been quite happy to do that, I don't mind. So actually, he did absolutely fantastically well because as I say, he cooked and cleaned and did washing.

Ruth's individual interview

It's a traumatic experience and I suppose the trauma is still there (...) I don't think there's a day goes by without something either triggering it or whatever, that I think about it.

Couple 6 summary

Important jointly constructed understandings for this couple appeared to focus on looking forward, which worked at a relationship level for the couple. However, they also held concurrent individual understandings that did not entirely correspond with the shared story. They expressed many of their individual understandings in the joint context but did not focus on those that did not fit their joint story. They viewed some of their differences as beneficial and were happy for these understandings to coexist without attempts to minimise them. However, some differences were not shared fully, with the individual restricting personal concerns to their individual interview.

Summary of negotiating understandings

The couples described various co-constructed narratives that they shared at a couple level, which appeared to represent shared meanings that they had constructed through sharing and collaborating information to reach a mutually agreeable shared story. Often, these shared narratives were consistent with the personal accounts of the individual members of the couple; however, sometimes the individuals described discrepant personal perceptions alongside the shared understandings. When individual perceptions that differed from the shared story were discussed in joint narratives, these sometimes generated tension and were minimised by the individual to be more consistent with the co-constructed understanding, but were later expanded on during individual interviews. Some differences between individual understandings were openly discussed in detail. The couples differed in their approach to managing these conscious differences, with one couple attempting to minimise the difference and the other couple framing them as beneficial and being content for them to coexist openly. Some differences between individual accounts were only shared in the individual interviews and often the other partner seemed unaware of the different views. This appeared to represent individuals sharing their personal concerns individually in order to be able to focus on their shared understandings that promoted solidarity and united coping in the joint context.

Group Analysis

Participants' experiences of negotiating shared and discrepant perceptions are now presented. Figure 5 provides a summary of the themes and tables describe the subthemes, accompanied by a narrative description containing supporting quotes.

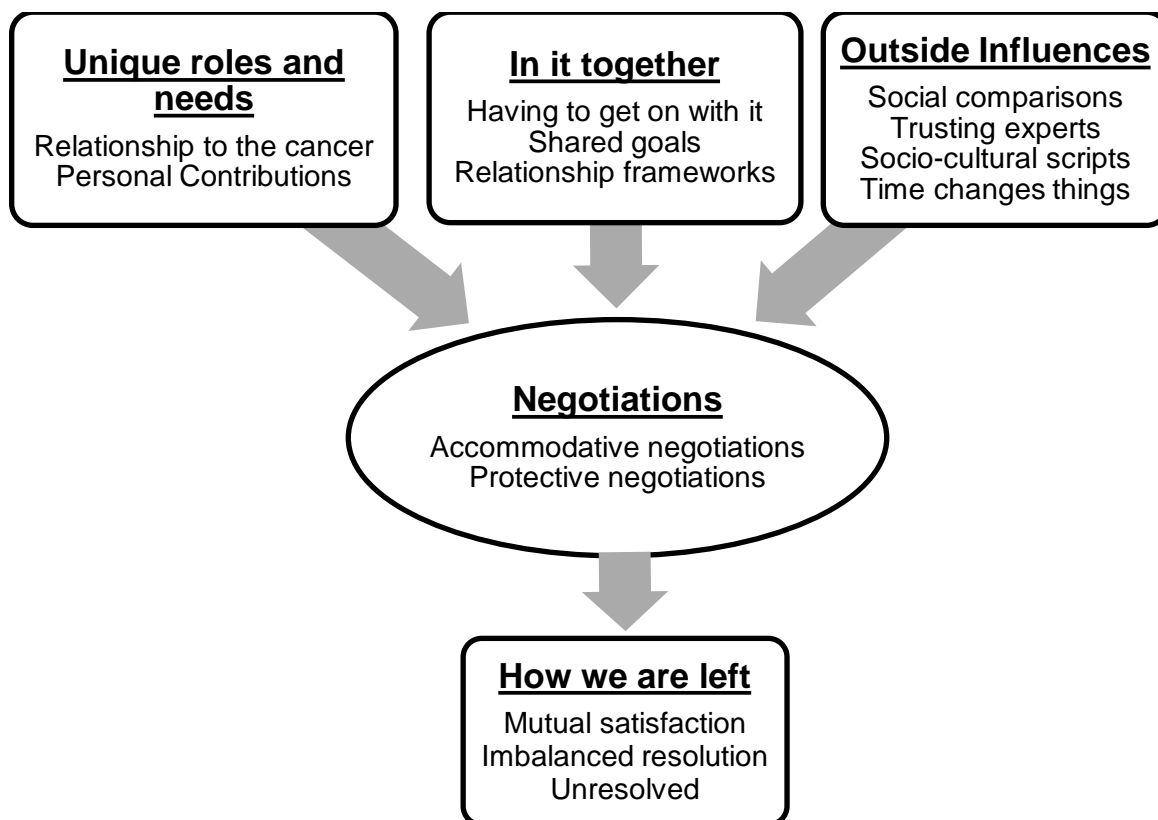


Figure 5: Themes in Relationship to One Another

Theme 1: Unique Roles and Needs

This theme portrays differences in experiences, needs and contributions of patients and partners. Although all patients and partners experienced the diagnosis as unexpected and shocking, they had unique roles and needs in response to this shared experience. These factors appear to promote the development of discrepancy.

Table 11: Unique Roles and Needs Subthemes

Subtheme	Description
Relationships to the cancer	Patients and partners were positioned in different relationships to the cancer, influencing different needs and understandings
Personal contributions	The members of the couple had different experiences and characteristics that they contributed to the understanding of the experience

Relationship to the Cancer: "I've got this thing" vs "You haven't got it"

Patients experienced the cancer and the associated symptoms inside themselves, whereas partners viewed these experiences from the outside, representing a more distant relationship to the cancer. This could make it easier for partners to view the cancer as transient. For example, one partner described easily accepting the medical view that the cancer was removed, whereas the patient felt that the cancer continued to be inside her.

"my mind told me when it was explained to me, we'll cut this out and there's nothing else anywhere, which they've proven medically (...) As soon as they told me that, I thought, settled down completely .. rightly or wrongly" (Mark, pr6)

"why do I have to carry this thing with me wherever I go, and that's all I thought about (...) I've got this thing, why does it have to go everywhere with me!" (Ruth, pt6)

Many partners described not fully appreciating the patient's experience from their more distant relationship. This appeared to be influenced by patients not sharing their inner experiences fully with their partners. For example, one well partner described feeling that it had not really hit home that the patient had cancer because outwardly he appeared normal. The patient however was always aware that he has cancer but did not communicate the full extent of this to his partner.

"I don't see you as having, I never seen you as having cancer (...) I suppose it's the outward view isn't it? (...) if you were having treatment and you're feeling physically ill then I suppose then you would associate it more" (Katie, pr2)

"it's always on my mind but I can't be telling people that" (Kevin, pt2)

One patient described how he thought it was difficult for his partner to cope with being on the outside of experiences. His partner agreed that she found it hard to appreciate how things were for him.

"I would think it's more difficult to cope when you're not the patient (...). When you're stood at the side, as [Mary] is, there must be an element of .. doubt as to whether (...) what she's seeing is what is actually there (...) Or is it me just putting on a brave face" (Brian, pt5)

"I was daft enough, I hadn't realised that he must have been feeling quite edgy about going [for his colonoscopy] (...) I probably don't appreciate what he goes through thinking that it might not be (...) a long life as it were" (Mary, pr5)

Both patients and partners attempted to protect the other person from the difficult aspects of their relationship to the cancer, such as patients feeling a burden and partners' difficulties in providing care, which created challenges in understanding one another's perspectives. This often became apparent in individual interviews, where participants would share difficulties associated with their relationship to the cancer not shared in the joint interviews. For example, Mary (pr5) only described the difficulty of providing care in her individual interview.

"the tiredness of by the end of the 6 weeks, you know, being there in the afternoons and the evenings (...) there was no sort of real break (...) so it was very tiring actually being there all the time" (Mary, pr5)

Similarly, Ruth (pt6) only disclosed the traumatic nature of her experience as a patient when Mark (pr6) was not present, leaving Mark unaware of the trauma.

"I suppose the trauma is still there ... [Mark and other family members] don't want to hear me going on about that" (Ruth, pt6)

Some patients excluded partners from experiences to protect them, whilst partners often wanted to be involved in experiences to understand better.

"I says you don't need to be down there sitting because you can be sat there 2 hours, I'm perfectly alright" (Simon, pt4)

"I want to be there then and I need to know" (Jane, pr4)

Being a patient often influenced a desire to recover as quickly as possible, whereas partners were often protective of the patient and did not want them to overdo things and cause harm.

"I was told off because I was trying to go too quickly wasn't I?" (John, pt1)
"oh it was ridiculous. I would say (...) don't do that, you don't want to do any damage" (Margaret, pr1)

The different relationships to the cancer influenced how involved partners felt in the cancer experience.

"I think a lot of people dismiss you as just, you know, you're just, you haven't got it" (Helen, pr3)

Many couples described the diagnosis representing a threat of loss and separation, but they experienced different relationships to the loss in terms of being left alone or leaving someone behind.

“it did frighten me because as I say I’ve thought I’m going to lose him here what am I going to do?” (Jane, pr4)

“I’ve obviously still got doubts in my mind that this cancer won’t go away or it’ll reoccur and I’ll die a long time before Mary does so (...) I’m working on it at the moment to make sure that that pension is (...) appropriately arranged so that it carries on for her” (Brian, pt5)

Personal Contributions: “We are a bit different in that respect”

Most couples described differences in their personal characteristics, which they experienced as influential in the way they perceived and responded to the cancer. Personality can be defined as “characteristic patterns of thoughts, feelings, and behaviour over time and across situations” (Connor-Smith & Flachsbart, 2007). Many couples identified that they differed from each other in terms of their characteristic ways of interpreting and responding to situations. For example, it was common for one member of the couple to be considered to have a more optimistic personality, characterised by consistent confidence that things will turn out well, than the other partner who was considered more pessimistic and prone to doubt and worry.

“I would say his glass is always half empty and mine is always nearly full and it’s the same glass (laughs)” (Margaret, pr1)

Other personality differences, such as extraversion and temperament, also appeared influential. For example, Katie (pr2) was described as more extraverted and therefore would take the lead in finding out information from the medical professionals.

“I’m quite a bubbly outgoing person who can get up and talk to anybody (...) you’re quite, a more shy worrier who tends to keep himself to himself (...) I’m a firm believer in, in just because the doctors and consultants and nurses, you can’t just take their word (...) there’s part of you that should question, and I did question and my answers were, were answered” (Katie, pr2)

Couple 4 described their personality differences as affecting how they dealt with disagreements, with Jane being more heated during arguments and Simon remaining calmer and trying to avoid arguments.

“We don’t argue at all but [Jane] is, you know I’m the placid one and [Jane], sometimes” (Simon, pt4)
“I’m fiery” (Jane, pr4)

Participants’ life experiences influenced their perceptions of the cancer. Many couples had been together since early adulthood and had a great deal of shared or similar experiences. However, many participants applied lessons learnt from shared experiences to the current context in different ways.

For example, couples’ shared experiences with illness, either in themselves or relatives, influenced their expectations about the cancer experience and the coping strategies used in different ways. Couple 1 had shared experiences of the partner having an inherited illness and the patient’s brother dying of cancer; however, they related these experiences differently to their current situation. Margaret viewed the experiences of John and his brother as likely to be similar, influenced by her personal experience of a genetically inherited disorder, and was therefore concerned about history repeating itself. John perceived his brother’s experience as different to his own, being likely to have been more advanced when identified, enabling him to minimise the concern that he may have a similar outcome.

“I think when there’s been other members of your family who have had the dreaded cancer (...) even though you know it’s not the same cancer that your brother had its still that same disease that if you don’t do something about it might turn into that” (Margaret, pr1)
“no because when he died he did complain about some back problem and side problem (...) he was in a lot of pain and I think he had indicators” (John, pt1)

In couple 2, Katie’s (partner) sister died of Leukemia aged 30. Although the couple were together at this time and went through this experience together, Katie was closer to this experience than Kevin (patient) and it appeared to have had more of an impact on her views. Katie learnt from this experience that cancer can affect anybody and nobody is protected. In contrast, Kevin still held the belief that he was invincible and was shocked that someone as healthy as him could get cancer.

“I think that was the first real illness that our family’s ever had because people like us don’t get cancer (...) because we’re normal people and we’re clouded by this safety net and obviously when that happened we realised well we do don’t we .. It’s just life isn’t it? It just teaches you life’s very short and we never know what’s going to happen” (Katie, pr2)

Most of the couples came from similar backgrounds, with similar upbringings. Nevertheless, some couples described learning different ways of perceiving and coping with stressors from their family of origin. For example, Kevin and Katie's families were described as having very different approaches to family illness in the past, which was reflected in how they had responded to the cancer, with Kevin expressing more emotion and concern than Katie expressed:

*"[Kevin's sister had] just lost her husband, she was in despair wasn't she, she was, she couldn't tolerate anything ... she was very upset (...)
it did take a toll on my mum and dad but (...) they don't wear their feelings on their sleeve do they? (...) they've always acted with dignity"* (Katie, pr2)

Patients and partners also often had unique experiences that influenced their understandings. Two couples had a large age gap between the partners, which they described as influencing different views. For example, Jane is younger than Simon by over twenty years and she described how this appeared to influence their difference in views about having a sexual relationship whilst Simon has a temporary stoma.

"I do miss [sex] (...) but I think, I'm a lot younger than [Simon] and I look at it as (...) he's old fashioned (...) I'm hoping things change when he's had his stoma reversed" (Jane, pr4)

Many participants used their work experience or specific skills and knowledge derived from their past experiences to help them make sense of and cope with the cancer. Most couples had engaged in different careers and had different skills to apply to the experience, resulting in different ways of conceptualising and responding to it. For example, Kevin used his background in statistics from his occupational role when trying to make sense of information about his PSA levels. His partner, Katie, viewed this information differently based on the medical professionals' reassurance and perceived Kevin to be overreacting.

"you're trying to get somebody who understands maths and figures to take that (...) very deliberate reading that says it's 50% higher and say well no it's just something and nothing so" (Kevin, pt2)

"Oh god, he's dying (sarcastic tone) .. he thought he were dead and buried" (Katie, pr2)

Theme 2: In it Together

This theme captures the experience of couples having shared experiences that provided them with a sense of working together. Most couples had shared values and skills that they used to make sense of the experience and help them cope. These factors appear to unite the couple into shared understandings or ways of responding.

Table 12: In it Together Subthemes

Subtheme	Description
Having to get on with it	Both members of the couple being affected and having to manage changes
Shared goals	Shared priorities and desired outcomes
Relationship frameworks	Relationship histories and qualities that frame the current experience

Having to “get on with it”

All couples referred to how the cancer had brought about changes for them as a couple and described that they had a shared sense of having to get on with it together. This theme was prominent in couple ‘we’ poems.

“There’s some things, an outline of change but everything we can deal with can’t we? And we understand and we just get on with it really” (Kevin, pt2)

“we always thought it’s part of our life and get on with it” (Helen, pr3)

Shared Goals and Values: “We’ve got the same resolve”

In response to the threat and shock, many couples had shared views on their priorities that both partners were motivated to work at preserving, being most concerned about the impact of the cancer on these areas.

For example, in couple 1, their children were their most important priority and they jointly worked towards protecting the children throughout the cancer journey.

“the most difficult thing was really telling (...) my three children, that was by far the most difficult, we found that both (...) family has been probably by far the most important factor in our marriage, hasn’t it?” (John, pt1)

Some couples prioritised each other and their relationship.

“if I know [Simons]’s OK that makes me OK” (Jane, pr4)

“I’m not important really it’s [Jane] who’s important. I can manage, I can sort things out, I can accept whatever but I need to know she’s alright” (Simon, pt4)

Some couples also gained lots of satisfaction from their shared activities in their lives and felt it was a priority to restore their functioning in these areas. For example:

“We like us holidays (...) going for a meal and holidays, that’s about it (...) It hasn’t stopped us going out, it hasn’t stopped us going on holiday so I wouldn’t say it’s affected us whatsoever” (Simon, pt4)

Many couples had a shared sense of the outcomes they were hoping for at the end of the cancer journey. For many couples, this was a desire to return to normality.

“you know we’re getting back to normality, it was the normality wasn’t it? More than anything else” (Jane, pr4)

Some couples hoped for improved outcomes from the cancer. For example, Couple 6 shared the desire for the experience to result in a greater appreciation of one another and improve their relationship, which they felt had been achieved, describing themselves as being less selfish and more mellow with one another.

However, not all couples had shared priorities and desired outcomes. For example, Mary (pr5) prioritised their relationship whereas Brian (pt5) prioritised his work-related activities. Mary also hoped that the experience would bring renewed closeness whilst Brian desired a return to their normal relationship. Brian was not aware of the difference in desired outcomes because Mary felt unable to discuss this with him. This prevented them developing a shared understanding and coping approach. The difference appeared more detrimental for Mary than Brian.

“I suppose I’m disappointed (...) after a lot of years of marriage, it sort of gets a bit stale and, we came very close when he was in hospital, and I think oh this is a lovely new beginning and it will be better, well not that it was bad before, or anything like that (...) but that added sort of oomph to your marriage again and I feel as though we’ve gone a step back rather than a step forward” (Mary, pr5)

Relationship Frameworks: “This time has been no different”

Relationship histories and qualities helped couples jointly cope with the experience. Many couples had experience of coping with difficulties in the past and framed the cancer experience within the wider story of their lives together. Previous successful coping appeared to give couples confidence in coping with the current adversities and feel safe that disagreements and difficulties would not be detrimental to their relationship.

For example, couple 3 described going through a difficult time when they got together due to negative reactions from their children over the relationship. They felt that if they could overcome that experience without it having a detrimental impact on their relationship, they could manage the cancer together:

“yeah that was probably far more distressing and hard and certainly hard on the relationship than going through cancer treatment anyway” (Helen, pr3)

Couple 6 described a difficult period when Mark lost his job, which they coped with together, and they felt that the cancer experience was not as difficult to manage.

“That was a very black hole for me. So, again between us .. worked through it gradually (...) [the cancer experience] wasn't any black hole like I had when I lost my job (...) I just felt that it's something we've got to manage” (Mark, pr6)

Having the ability to communicate within their relationship helped couples develop a shared understanding and work together to cope. For example, couple 6 described being able to talk about their disagreements and did not assume the other would automatically understand their view without them openly expressing it.

“But we don't (...) argue argue and fall out. Yes we have our disagreements but we tend to resolve them by talking and discussing” (Ruth, pt6)

“you might think that the other understands but unless you say it .. so we've been able to talk about it (...) and it's helped. It really has, there's no ..no substitute for it really” (Mark, pr6)

Couples who described their relationship as lacking in-depth communication appeared to have less awareness of their discrepancies, which could generate dissatisfaction. For example, couple 5 explained that they did not talk openly about their experiences and feelings, yet perceived themselves to have similar views anyway. However, it was evident from their individual interviews that they held different views of which the other was unaware, which caused Mary (pr5) some distress.

Theme 3: Outside Influences

This theme portrays the role of factors outside the couple that influenced their understandings of the cancer. These factors influenced changing perspectives, which could serve to promote either discrepancy or shared understandings.

Table 13: Outside Influences Subthemes

Subtheme	Description
Social comparison	Comparing perceptions and experiences with those of family, friends and peers
Trusting experts	Trusting expert knowledge, advice and reassurance
Applying socio-cultural scripts	Using socio-cultural messages to make sense of experiences
Time changes things	Time affording people different perspectives on the experiences

Social Comparison

Couples' compared their perceptions with those of others in their social network and some would change their understandings in response to differing perceptions from others. For example, reactions that appeared to contradict their understandings could cause doubt about the sense they had made of the experience:

“something else that's a bit of a shock is when you do tell friends, is their reaction, because how shocked they are because you've just come to terms with it (...) and then you see their reaction and you think oh maybe it's worse than I thought” (Margaret, pr1)

Social comparisons with the experience of peers often gave couples a different perspective on their situation and could generate re-evaluations of their own progress.

“I was getting quite worried (...) then you start talking to [peers] (...) and you feel in some ways (...) at the side of someone, lucky” (Kevin, pt2)

“you look at others and think ohh yeah I'm doing quite well or I'm not doing so well really relative to others” (Rob, pt3)

Trusting Experts

Medical experts, including GPs, consultants and nurses, had an important influence on participants' perceptions. Their trust in the experts, gratitude for their care and the reassurance received helped couples make sense of their experiences.

Couples often trusted the advice of experts and used this to finalise decisions. For example, John (pt1) could not decide whether to have hormone treatment. Mary (pr1) reported that she would have the treatment but John was reluctant. He sought expert advice to resolve this, trusting expert reassurance to follow his instincts.

"I remember saying to [Consultant] (...) the hormone I said I'm not sure whether I want it. He said 'what's your gut feeling?' and I said not to do it and he said 'that's your decision' (...) that was so helpful (John, pt1)

The gratitude participants felt for their care often united their views on their experiences. Couples often chose to focus on the positive experiences and ignore less positive ones out of gratitude to the professionals, resulting in shared perceptions. For example, in couple 4, complications during Simon's operation resulted in *"life-threatening"* complications. However, the couple downplayed this and only spoke positively about their care, appearing to reflect gratitude over Simon's survival.

"the team they've got down there is unbelievable (...) absolutely remarkable, cannot fault it at all" (Jane, pr4)

"I can't thank any of them enough (...) absolutely fantastic" (Simon, pt4)

Many couples felt differently about the cancer following professional reassurance, often providing them with a shared sense of comfort and hope.

"we went to see [consultant] after the operation and he more or less said the operation was excellent it was superb, it was totally successful (...) that was very reassuring to know that you more or less were clear" (John, pt1)

Applying Socio-Cultural Scripts

Couples often used societal and cultural messages to make sense of their experiences. For example, societal ideas about gender helped couples explain their different reactions to the cancer. Common gender scripts influencing understandings and responses were ideas that men and women differ in their desire to communicate and that men do not like admitting weaknesses.

"we're not erm not exempt from the usual problems that men and women have discussing I mean (...) men are not as open as women in discussing things and so I suppose that's always been (...) problematic" (Rob, pt3)

"it's a man thing probably, but you don't like saying...I wasn't well or anything like this" (John, pt1)

Despite knowing each other well, some couples still relied on gender scripts to understand the other person's experience, sometimes resulting in misinterpretations.

“obviously for a man, obviously that’s slightly different the act of sex can be more important” (Katie, pr2)

“It is but it isn’t, it’s not, it’s not, it isn’t, in the whole circle of things now, it’s, it’s not that important, it is important but” (Kevin pt2)

The importance of positivity in coping with cancer is a widely known and strong societal message. This was evident as having an influence of all of the couples, with many describing a sense of being required to adopt this view.

“You have to dwell on the positive” (Margaret, pr1)

“I’m stressing positive thinking (...) it’s a long long way towards getting better definitely” (Simon, pt4)

Cultural messages about appropriate behaviours also influenced people’s responses. For example, messages about the undesirability of discussing sexual functioning with others outside of the relationship had influenced some couples.

“I haven’t obviously discussed [sexual changes] outside our own personal relationship, because it’s not something you do really” (Rob, pt3)

Time Changes Things

Perceptions changed over time as couples gained new perspectives on their experiences. Looking back on experiences helped people to see things in a different light, either seeing things more positively or realising the extent of the hardship.

“I think it’s easy to be positive in hindsight” (Margaret, pr1)

“At the time it wasn’t [difficult] (...) looking back on it, it was horrible but at the time it wasn’t” (Mary, pr5)

Looking into the future, couples could also see their perceptions changing.

“at the moment I’m kind of dealing with it alright and then looking into the future I suppose if (...) they said look we were going to have to have radiotherapy now, I think that would bring an amount of worry again” (Kevin, pt2)

Couples also identified that over time they had changed their views about how they have responded to the cancer. For example, during treatment Brian (pt5) did not

think it was necessary for Mary (pr5) to attend radiotherapy appointments but looking back he thinks it could have been beneficial.

“With hindsight, it’s nice to have support in a way but on the other hand if it’s not necessary” (Brian, pt5)

Theme 4: Negotiations

The multitude of influences on couples’ perceptions resulted in couples experiencing various discrepant and shared understandings. Shared responses and needs co-occurred alongside different experiences and needs, which could sometimes contradict one another. Most couples adopted a variety of negotiation strategies in order to manage holding these shared and discrepant understandings, which have been summarised in the following subthemes.

Table 14: Negotiations Subthemes

Subtheme	Description
Accommodative negotiations	Direct approaches towards discrepancies that aimed to help the couple adjust to differences and obtain agreement. Strategies included empathising and understanding, humour, compromise, and prioritising views.
Protective negotiations	Indirect approaches towards discrepancies that aimed to protect the couple or their relationship from their impact. Strategies included topic management, hiding feelings and mind reading.

Accommodative Negotiations

Many couples took direct approaches to dealing with discrepancy by making active attempts to accommodate their differences using various strategies. Attempting to *empathise and understand* the other person’s views was a common strategy. This helped couples to continue to hold different views without this generating hostility or distress. For example, couple 1 experienced different views about continuing treatment. The partner described attempting to empathise with the patient’s view, despite holding a different view herself, which helped her to accept his viewpoint.

“there was an awful lot of visits to the hospital and I could well understand, cos I wasn’t going on those 20 days, but I could understand somebody saying I’ve had enough, I don’t need to do it, I’m happy with my treatment” (Margaret, pr1)

When approaching discrepancies, many couples used *humour* which appeared to reduce emotional tension and conflict around the differences, allowing them to be discussed in a non-threatening way. For example:

“as long as he agrees with me it’ll be fine (laughter)” (Margaret, pr1)

“you worry and I don’t” (Katie, pr2)

“Aye you let me worry” (Kevin, pt2)

“I let you worry” (laughter) (Katie, pr2)

Most couples described both partners making concessions in order to reach a mutually acceptable *compromise* over their views. Sometimes the compromise would involve partners being willing to accept the other’s view as a possibility without fully committing to holding the view themselves. For example, in couple 1 the partner attributed the patient’s weight loss down to stress whereas the patient attributed it to loss of appetite caused by his treatments. Both of them attempted to consider the other’s view and accepted the alternate perception as a possibility.

John I lost a lot of weight at the time, I lost was it 2 and half stone?
Margaret Mmmm. That’s just, I think that’s just stress and anxiety ...
John well maybe stress I mean you don’t feel like stressed (...) probably stress but er I’m er ... also you didn’t feel like eating as much
Margaret I suppose you lose your appetite

Some compromises involved the couple integrating both viewpoints into their understanding. For example, in couple 3 the patient and partner had different views about the purpose of the patient’s exercise group and through discussion compromised to agree that both interpretations were likely.

Helen I think the idea of the group was to encourage (...) a more active and therefore healthy lifestyle
Rob Yes they said that that was the one thing that men would do really because men are not like women, they won’t just come together for a chat, they don’t do that but they’ll come together for circuit training and then have a chat (...)
Helen I think the idea was to encourage the, the activity side wasn’t it?
Rob (...) it fulfilled both roles really as they try to get you more physically active and it was a way of bringing you together anyway
Helen Yes

Some compromises involved partners attempting to behave differently to accommodate the other person’s preferences for coping. For example, in couple 2:

"I'm too blasé about things (...) he knows he worries too much so we try and come to some kind of compromise (...) I can see things maybe worry him and I'm just shrugging it off and really I should turn round and say right let's talk about this, what is really worrying you" (Katie, pr2)

When attempting to address discrepancy, it was common for couples to *prioritise* a certain viewpoint over others. This was sometimes the expert view, the patient's view due to it being their body or the view of the person who was more dominant in the relationship. For example, couple 2 differed in their views about the seriousness of the patient's PSA level increasing. In the end they focussed on the expert view to resolve the discrepancy. In couple 3 the partner did not have strong views about treatment but prioritised the patient's views as he was the one receiving it.

"I did feel it was [Rob]'s decision (...) I think you have to be err happy in your own mind that you've, your decision is the right one for you and it, that certainly seemed to be the case" (Helen, pr3)

In couple 4, the partner was often in charge of taking action in the relationship and when the partners disagreed about the need for the patient to visit the doctors, the spouse's view took priority over the patient.

"I rung the doctor without him knowing and I made an appointment and I rung him up and I said 'you've got appointment at so and so time', 'I aren't going', I went 'yeah you are'" (Jane, pr4)

Protective Negotiations

Some negotiations protected the couples from any potentially negative impact of the discrepancies by enabling them to not directly address the differences. This was achieved through various methods.

Couples sometimes used *topic management* strategies to avoid talking about issues that generated conflict or upset for one or both of members of the couple. This could involve immediately moving on to a different topic, closing down areas of discussion (e.g. *"next question"*, Simon, pt4) and brushing away the issues (e.g. *"but yeah we're as I say we're fine"*, Simon, pt4).

When couples felt differently about the cancer, such as one partner being more worried or frightened about negative outcomes, it was common for the more concerned partner to *hide their feelings* from the other to protect the other person.

“[Katie] knows I worry but I don’t say things about it to her, you know, I just try and (...) be as normal as we can” (Kevin, pt2)

“I kept thinking that’s it, I’m going to die, that’s all I kept thinking. And I thought, I can’t say that to anybody.” (Ruth, pt6)

(...)

“Well she never said that to me” (Mark, pr6)

Some couples engaged in *mind reading*, where they attempted to predict what the other person was thinking without discussing the issue. Sometimes the assumption was that the other person shared their view, which could be accurate or inaccurate. Inaccurate prediction prevented differences being acknowledged. On other occasions it was assumed that the other person felt differently so the person did not raise the issue to avoid having this confirmed and potentially causing problems.

“if I kept going on, over and over (...) I’m sure he’d probably be thinking, it’s done and you’re ok. So (...) I just turn it over in my mind” (Ruth, pt6)

Theme 5: How we are left

The couples experienced the outcomes of their negotiations in various ways. As most couples engaged in various negotiation strategies for different topics, they could also experience multiple outcomes.

Table 15: How We Are Left Subthemes

Subtheme	Description
Mutual satisfaction	Agreed understanding and approach that satisfies both parties
Imbalanced resolution	Agreed understanding that does not fully satisfy both parties
Unresolved	Failure to arrive at a shared understanding

Mutual Satisfaction: Benefiting and Complementing

Some couples described having different views initially and subsequently developing a similar view and a united approach to coping. Often this was a balanced agreement that both partners were happy with. For example, in couple 4 Jane (partner) had a more negative view of the diagnosis initially and was very distressed by it. By talking it through with each other the couple came to a joint understanding of the cancer as not life threatening and something they could cope with.

Many couples resolved the discrepancy by accepting the differences. For example, in couple 1 the partners disagreed on views about treatment but accepted these different views and did not try to convince the other to change.

“that’s just probably what I would have done but I wasn’t going for it (...) I’m not necessarily saying that I wanted [John] to go for it, but had I been him I probably would have gone for it because that’s just me” (Margaret, pr1)

Accepting the differences often involved the partners celebrating their differences and perceiving them as complementary and beneficial.

“It’s like any relationship, I think if you had 2 people who were the same, what a depressing place if we’re both pessimistic and worriers, I don’t think we’d do anything would we, so I think the balance, we’ve got a balance” (Katie, pr2)

“I know if I’m positive then [Jane]’s going to be reassured and it’s going to be better for her. I don’t do it for that but I know it does reassure her” (Simon, pt4)

Imbalanced Resolution: Feeling divided

Sometimes an agreement was reached but this was unbalanced, with one member of the couple making more concessions than the other and leaving the couple with a sense of division. For example, John (pt1) was a lot more worried about the future than Margaret (pr1) but the couple implicitly agreed on a joint ‘get on with it’ and ‘worry about it later’ approach. It was evident in John’s ‘I’ poems and individual interview that this joint approach was not easy for him to adopt, leaving him feeling conflicted. Margaret was aware of John’s continued worries and was frustrated by this.

Similarly, in couple 5 the joint approach was implicitly agreed as not talking about their experiences to avoid dwelling on difficulties but Mary (partner) reported that she was dissatisfied with this mutual approach and was left feeling unhappy.

“I’ve been a bit fed up with him occasionally” (Mary, pr5)

The differences could also be openly discussed and accepted, yet the members of the couple could still not be fully satisfied with the presence of differences. For example, some couples openly reported differences in worrying, although the partners expressed not being fully content with this:

“it gets a bit frustrating sometimes” (Katie, pr2)

“in effect it got on my nerves a little bit” (Mark, pr6)

Unresolved: Continued uncertainty

Some discrepancies remained unresolved within the couples. This was interpreted from the topics frequently recurring, with inconsistencies and ambiguities present in the participants' descriptions and appearing to represent a continued search for resolution. For example, couple 1 repeatedly discussed their different views about the impact of the patient's brother's cancer on their perceptions of the cancer. John's views on this were inconsistent, with him sometimes expressing a different view to Margaret and at other times adopting a similar view, which appeared to represent an attempt to integrate Margaret's view into his understanding. However, this appeared to be an ongoing process that had not yet been resolved.

Similarly, couple 5 fluctuated between describing the cancer as having had very little impact on their lives to describing it as having generated many lifestyle changes. Both partners fluctuated between the two viewpoints, appearing to represent and attempt to integrate the understandings.

Reflections on analysis

When analysing the transcripts I was aware of feeling uncomfortable when making interpretations that deviated too far from participants' descriptions and words. I also did not want to make negative interpretations of experiences and observations due to my gratitude towards my participants for giving me their valuable time. These processes may have made me overly cautious in my interpretations and produced a more descriptive account. This is a common experience in novice IPA researchers, which Smith (2004) suggests is acceptable, advocating that inexperienced researchers should aim for 'good enough' analysis, rather than attempting to produce an incredibly interpretative one.

CHAPTER 4: DISCUSSION

The overall aim of the current study was to develop understanding of the role of couples' perceptions in adjustment to cancer. This chapter will briefly discuss the problems with the quantitative study that prevented some of the research aims being addressed. It will then discuss the qualitative analysis that addressed the main aims of the study, with a critical evaluation of the qualitative methodology. It will also consider suggestions for future research and clinical implications, before presenting some final reflections.

Quantitative Study

The main aim of the quantitative study was to examine associations between discrepancy in illness perceptions and adjustment outcomes in couples facing cancer. Whilst investigating this question, the aim was to also examine associations between individual illness perceptions and adjustment for both partners, as well as explore associations between discrepancy and illness-related communication. However, it was not possible to address these aims due the recruitment problems outlined in chapter two. Therefore, this data was only used to situate the sample.

Limitations and Lessons Learnt

Despite discussions with recruiting staff at planning stages suggesting an adequate sample was possible, as well as various strategies being implemented to improve recruitment, efforts failed to produce a sufficient sample. A major limitation was the reliance on the voluntary efforts of nursing staff to identify suitable candidates, owing to ethical restrictions preventing the researcher accessing participant information prior to consent. Therefore nurses were responsible for approaching the vast majority of participants via post or within clinic, which they undertook on top of other responsibilities and could not be prioritised. The researcher was not able to contact participants personally and establish rapport, which has been found to increase the likelihood of participation (Preloran, Browner & Lieber, 2001).

Staffing shortages amongst the recruiting nurses and nurses believing that patients were not appropriate candidates, combined with a conflict between researcher availability and clinic schedules, resulted in only 74 information packs being distributed rather than the anticipated 400. Other researchers have been impeded in their recruitment efforts by similar obstacles (Shue, 2011). Furthermore, a low response rate was achieved from those approached, with only 13 completed questionnaires

returned, representing an 18% response rate. Low response rates have been found in similar studies recruiting patient-carer dyads, such as Dempster et al. (2011a) who obtained a 17% response rate for completed questionnaires from couples in an oesophageal cancer sample. This is potentially due to reliance on postal recruitment efforts and requiring both the patient and carer to consent.

It is possible that approaching more participants face-to-face during clinics could have improved recruitment. Such recruitment requires sufficient researcher presence at clinics to not miss potential participants, having flexibility to work around clinic schedules and good collaboration between clinic staff and researchers (Shue, 2011). Due to this project being unfunded doctorate research that was completed alongside other work commitments it was not possible to increase presence and flexibility around clinics. Increased collaboration with staff was attempted and this improved recruitment somewhat, but not sufficiently to achieve an adequate sample.

The benefit of having someone involved with the patients' clinical team sign the recruitment letter was discussed with the specialist nurses who advised that they would be most appropriately placed to do this. They identified that due to multiple consultants working in to the clinics, it would significantly increase the demands on their time if they were required to identify and obtain signatures from the consultants. Recruitment may have been improved if the letters were signed by the consultants, who are potentially more recognisable and influential members of team.

The information sheets included in the initial pack were very detailed in order to comprehensively explain the research and cover all ethical issues. It could have been better to send out a briefer information sheet in the initial pack to spark interest before sending the detailed version with the questionnaire pack and consent forms, as this has been found to improve recruitment efforts (Voils et al., 2011).

The questionnaires and interviews may have been considered time-consuming by participants and dissuaded participation. Cancer patients are regularly approached to take part in research and many potential participants were likely to have been recruited to other trials that provide direct therapeutic benefits. This may have caused reluctance to add further time commitments to their care without personal benefit.

Future research

The small sample prevented the intended associations being examined; therefore, there is still a call for more research into discrepancy and adjustment that explores both patient and partner outcomes and controls for interdependence between couples' outcome scores, such as by using the Actor-Partner Interdependence Model.

Qualitative Study

The aim of the qualitative study was to develop understanding of how perceptions evolve and are negotiated in couples and the role of discrepant perceptions in the adjustment process. The research questions were:

- How do shared and discrepant understandings evolve within couples?
- How do couples respond to and deal with discrepancy?
- How do couples experience discrepancy?

The interrelated themes derived from the analysis suggest that the development of understandings within couples involves balancing various complementary and competing perceptions that arise from the influence of numerous factors both within and outside the couple relationship. Balancing these multiple understandings requires the use of various negotiation processes and attempts at negotiations can vary in their ability to obtain a satisfactory resolution.

Five themes were developed: *unique roles and needs*, which described the individual experiences that influenced patients' and partners' personal understandings; *in it together*, which described the shared experiences that shaped couples' understandings; *outside influences*, which describes the influence of external factors on the understandings of individuals and couples; *negotiations*, which encompasses the strategies used by couples to manage the co-occurring understandings; and *how we are left*, which reflects the outcomes of the negotiation processes. These themes will be discussed in the context of the research questions and in relation to the wider literature.

How do shared and discrepant understandings evolve within couples?

The case studies of the couples highlighted that the evolution of their understandings of the cancer was complex and idiosyncratic, being framed within the context of their individual and shared life histories. Discrepant perceptions developed in many areas. Some of these corresponded with the illness perceptions suggested by Leventhal's self-regulatory model (SRM) (Leventhal et al., 1980), such as beliefs about the chronicity, controllability and impact of the cancer. The different perceptions appeared to influence the adoption of different coping responses, which is also predicted by the SRM. However, discrepant understandings were also identified in other areas, such as the meaning of the cancer for the couples and their interpretations of cancer-related experiences. This aligns with systems theories that suggest that people need to make meaning of all their experiences (Cheung, 1997)

and will make subjective interpretations of experiences and behaviours (Marley, Rasheed & Rasheed, 2011).

The multitude of influences on the couples' understandings were summarised in the interrelated themes '*unique roles and needs*', '*in it together*' and '*outside influences*'. These themes highlight that the cancer affects each member of the couple on an individual and couple level, with patients and partners developing beliefs and understandings of their personal stressors and the other person's experience, as well as the impact of the cancer on them as a couple. In attempting to make sense of this complexity, patients and partners drew on various personal and couple factors as well as information from external sources. These results support components of the theoretical models introduced in chapter one. For example, the SRM proposes that perceptions are developed from information from social contacts and personal illness experiences. Systems theory also suggests that family understandings are reciprocally constructed within personal and social contexts. However, such frameworks have not fully depicted the detail about how couples' develop understandings of illness or how the factors influence couples. This study allowed for the intricacy of the experience to be revealed in more depth, as discussed below.

Unique roles and needs

Research directly comparing roles and needs of patients and their partners or carers is rare (Soothill et al., 2003). Most previous studies have explored their experiences separately, or have focussed on the joint experiences without highlighting differences. However, Germino et al. (1995) described somewhat different concerns between patients and partners during the cancer experience. Difference was also highlighted in the present study, which suggested that patients and partners experienced the cancer through different lenses and this influenced their understandings and views of the experience. An important difference in perspective was the distance between the individual and the cancer. Patients had a closer relationship to the cancer, experiencing it internally, whereas partners had a more distant relationship, experiencing the cancer from an external perspective. This appeared to represent members of the couple having somewhat different stressors to appraise. These differences influenced their perceptions of the permanency and corporeality of the cancer, as well as their perceptions of the nature of the threat the cancer represented. This corresponds with stress-coping theory (Lazarus & Folkman, 1984) which posits that appraisal of stressors involves evaluating personal threat. Furthermore, a lack of communication about the differences in experience, due to the desire to protect one another, gave rise to difficulties in fully appreciating the other

person's perspective. This corresponds with previous research suggesting that couples avoid communicating about aspects of the cancer experience to protect one another (Manne, 1998; Gray et al., 2000).

Unique personal contributions that each member of the couple brought to the experience, such as their personality, skills and lessons learnt from prior experiences, were also influential in the development of understandings and promoting difference. Previous literature based on clinical experience has suggested that understandings of illness within families are likely to be influenced by personal experiences (Rolland, 1994). Furthermore, Yorgason et al. (2010) found that couples who were managing multiple-chronic illness applied life's lessons to understanding and managing them. The life lessons in their study appeared to reflect characteristic ways of responding and longstanding coping philosophies learnt from past experiences, which correspond to the present study's findings of the influence of personality and prior experiences. However, the current study also emphasised specific skills and knowledge contributed by participants as influential and found that these lessons were important in the development of different perceptions, whereas Yorgason et al. (2010) found that lifelong lessons influenced similarity in perceptions.

In it together

All couples in the current study described a sense of jointly having to 'get on with it', which appeared to represent the cancer being understood as a shared issue to which both members of the couple were attempting to adjust. Most couples also described shared goals and priorities that they were both motivated to work towards achieving and drew on past relationship histories and qualities, such as coping experience and communication skills, to help them adjust. The couples with mutual goals and positive relational frameworks appeared to have more shared understandings and joint approaches to coping, whereas couples who did not agree on goals and whose relational histories were characterised by difficulties coping and communicating appeared to have more discrepant perceptions.

These findings are consistent with previous research which has highlighted that relationship awareness, involving perceiving illness as a relationship issue and joint problem, can have adaptive consequences (Kayser et al., 2007; Rohrbaugh et al., 2008; Skerrett, 1998). Despite a number of researchers documenting that a relational orientation to illness is beneficial, they emphasise different features of this orientation as being important for conferring benefits, such as self-disclosure, compatible coping strategies or joint problem solving (Fergus, 2011). The current findings emphasise agreement on tasks and goals and positive relational bonds as being important, which

corresponds with literature on the core qualities of beneficial helping relationships (Bordin, 1979). These features have primarily been considered in terms of formal therapeutic relationships, however it is likely that informal helping relationships share similar qualities (Pistrang & Barker, 2005). Furthermore, the current study found that prior relationship qualities appeared important, particularly communication skills, which supports findings that adjustment efforts and 'we-ness' are linked to positive pre-cancer marital adjustment (Fergus, 2011) and that communication is important for adjustment, in part due to it facilitating in sense-making (Goldsmith et al., 2008).

Outside influences

Participants also described the influence of factors outside their personal and couple experiences that influenced their understandings. Sometimes this appeared to represent participants actively seeking information from external sources to manage their uncertainty and help them make sense. Other times, participants appeared to have developed relatively firm beliefs which were subsequently challenged by external factors, causing them to re-evaluate their understandings.

Comparison to peers who were undergoing similar circumstances was common, which corresponds with previous literature applying social comparison theory (Festinger, 1954) to health threats. This theory suggests that when individuals are uncertain about their beliefs or abilities, they compare them to others to evaluate their appropriateness. Social comparison activities in individuals undergoing health threats have been described by Taylor and Lobel (1989), who suggest that patients engage in downward evaluation with people less fortunate to feel better about own situation and improve self-esteem, and engage in upward contacts with more fortunate others to learn ways to improve and obtain hope and motivation. This pattern was observed in the current study for both patients and partners; however, it also highlighted the influence of comparisons on specific illness perceptions, such as understandings about severity and perceptions of progress. In addition to comparison with peers, the current study also recognised the influence of comparison with others who had not experienced similar circumstances, such as friends and relatives, which is not typically considered in social comparison research regarding illness.

Most patients show high levels of trust in their medical professionals (Hall et al., 2002), which is suggested to be due to the vulnerability created by illness requiring trust that the professional will care for the patients interests (Hall, Dugan, Zheng, & Mishra, 2001). This was reflected in the current sample, for partners as well as patients, whereby all couples described their trust and gratitude towards professionals, even those who experienced complications and difficult healthcare encounters. This

resilient trust appeared important in shaping perceptions and increasing shared understandings, due to both partners having confidence in the professionals' perceptions and readily accepting their views. However, not all patients trust the professionals involved in their care. Older patients have been found to trust their physicians more than younger patients (Bachinger, Kolk, & Smets, 2009), which could potentially be a generational effect or reflect more frequent contact with healthcare professionals (Hall et al., 2001). Furthermore, communication styles and interpersonal skills of professionals have been found to be related to trust (Hall et al., 2002). Therefore, the high levels of trust in the current sample could be related to their age and the fact that they were recruited from the same hospital and received care from the same professionals, who may be proficient at developing trust. Furthermore, all the couples attended all information-receiving hospital appointments together, which may not be the case for all couples and could influence the impact of professionals' perceptions.

Dominant social and cultural messages also shaped couples' understandings in this study, which is consistent with systemic social constructionist ideas (Marley et al., 2011). Stereotypes about masculinity and femininity are deeply ingrained in western cultures and these were commonly used by participants to make sense of differences in responses to the illness by the men and women in this study. This appeared to lead to discrepancy in understandings when members of the couple had personal experiences that contradicted societal messages about gender. Societal messages about the reliance on positive thinking and 'fighting spirit' were also prominent in couples' understandings. These ideas appeared to provide a shared focus for couples in this sample, however they can also inhibit people openly discussing their feelings and minimise the seriousness of the illness (Brennan, 2004), which could have resulted in couples presenting a shared understanding that masked their true feelings.

Participants also reflected on the changes in their perceptions over time. Research into memory has found that people's reconstructions of the past are influenced by their current beliefs and views (Wilson & Ross, 2003). In particular, people have the tendency to perceive improvement over time by being critical of their past performances, which can help individuals to feel good about their present situation (Wilson & Ross, 2000). Therefore, the couples in this study may have reflected on their changing perceptions to be able to see themselves as improving and boost their confidence.

Although external factors appeared to have an important influence on the couples, most appeared to primarily manage the cancer within the couple relationship,

with relatively limited external influences. This is possibly due to the types of cancer studied, which are related to changes in sexual and bodily functioning that people may be reluctant to discuss outside their relationships and may generate social stigma. Furthermore, the age of sample may influence their limited social networks, due to older adults being found to have fewer, more intense relationships and predominantly interacting with their spouse, children and grandchildren (Carstensen, 1991). Therefore, the influence of external factors may be different in cancers that experience fewer stigmas and affect younger patients.

In summary, these interrelated themes highlight that the evolution of shared and discrepant understandings is complex, being constantly revised in response to the various influences on understandings. The uniqueness of the individual experiences of patients and partners appeared to promote the development of discrepant perceptions, whilst the shared aspects of the cancer and relational experiences appeared to promote shared understandings. External influences varied in their impact on understandings, variably promoting discrepancy or shared understandings within and across couples. This complex process of developing understandings required couples to engage in various strategies to attempt to balance the multiple, changing perceptions.

How do couples respond to and deal with discrepancy?

All couples engaged in multiple strategies in their attempts to deal with their discrepancies, however, some had a wider repertoire than others. The strategies used appeared to have different functions, with some being attempts to accommodate the difference in views, whilst others served to protect the couple or their relationship from the impact of the discrepancies.

Accommodative negotiations were characterised by couples acknowledging their differences and making active attempts to adjust to the discrepant views. In these negotiations partners typically had a good understanding of each other's perspectives, which appeared to help in their negotiations. Strategies were then used to either reach agreement or accept the differences.

Empathy is considered a crucial component of healthy couple relationships (Busby & Gardner, 2008). In this study, empathy appeared to help bridge differences in views within couples, by enabling them to understand the challenges each other were facing and respect the differences in their perceptions. Often this appeared to help couples compromise over their differences and develop a shared understanding, which corresponds with the suggestion that empathy is important for the co-

construction of meaning (McLeod, 1999). Similarly, empathy is suggested to be essential for successful helping relationships, both formal and informal, due to facilitating clarification of understandings (Rogers, 1957). Therefore, empathy is likely to be important for couples attempting to help each other adjust to and understand the cancer experience.

Humour appeared helpful for raising difficult discussions about differences and breaking the ice when tension started to build during these discussions. This seemed to reflect couples looking at the bigger picture and not allowing the differences to detract from their overall satisfactory relationship. Seymour-Smith & Wetherell (2006) similarly found that humour can be used to 'smooth over' troubled interactions and reinforce co-constructed accounts of illness in couples.

It was common for couples to prioritise a particular viewpoint over others in an attempt to resolve their different views. Prioritising the patient typically occurred for difference in opinions about treatment, due to it being the patient's body that would receive this and experience the effects. O'Rourke and Germino (2000) similarly found that wives of prostate cancer patients reported treatment decisions being the man's responsibility due to him having to live with the consequences. The expert view was often prioritised for making sense of medical experiences and treatment options, which appeared to reflect the trust placed in professionals and beliefs that expert knowledge was most likely to be accurate. The dominant person in the relationship was often prioritised for determining joint coping responses, such as seeking medical advice or adopting restraint coping strategies, appearing to reflect longstanding relationship patterns of that person taking the lead.

Protective negotiations were characterised by couples attempting to avoid and not directly address their differences. In these negotiations, couples had less awareness and understanding of their differences in perceptions and avoided sharing potential differences to prevent negative consequences. Expressing disagreements about cancer-related topics is challenging for couples (Goldsmith & Miller, 2013) and avoiding communication around difficult topics to protect one another is common (Manne, 1998).

Topic management was a common protective negotiation strategy. This appeared helpful when both members of the couple viewed it as effective for focussing on a shared outlook, such as staying positive or preserving normality; however, it appeared unhelpful when viewed by one member of the couple as being for negative reasons, such as not caring about their views or feelings. This corresponds with research that suggests that topic avoidance does not have a negative impact on

relationships if it is perceived as having praiseworthy rather than blameworthy motives (Caughlin & Afifi, 2004).

Hiding feelings was also used as a protective negotiation strategy. A central assumption of psychodynamic psychotherapy is that inhibiting emotions can lead to psychological distress, suggesting that this strategy would be unhelpful for individuals. Furthermore, suppressing emotion can prevent others from having information about and attending to one's needs (Clark & Finkel, 2004) and can lead to lower levels of rapport and affiliation in relationships (Butler et al., 2003). However, in some circumstances, suppression can be adaptive, fulfilling important social functions, such as preventing escalation of negative emotions, including aggression and anxiety, thereby benefiting social partners and their relationship (Butler et al., 2003). Therefore, hiding feelings can be detrimental but sometimes the benefits outweigh the costs (Butler & Gross, 2004); however, if used chronically and inflexibly, hiding feelings is likely to interfere with adjustment (Gross & Levenson, 1997). Most couples in the current study suppressed their emotions flexibly to benefit their partner and their relationship; however couples who used this strategy more habitually appeared to be more dissatisfied with their differences.

Many couples engaged in mind reading, whereby they attempted to predict what the other person was thinking or feeling, which could be accurate or inaccurate. This is an important strategy in relationships as partners are not able to have perfect information about the other person's views, even if attempts are made to communicate these, therefore some conjecture is necessary. Perceived similarity has been found to often be accurate because partners usually have similar views; therefore it is reasonable to use personal views to infer one's partner's views (Kenny & Acitelli, 2001). However, people in long-term committed relationships are often over-confident in their ability to predict their partner's thoughts, which can be problematic, causing people to base important decisions on erroneous beliefs and cause disharmony due to not providing appropriate support to each other (Swann & Gill, 1997). Nevertheless, inaccuracies can also be benign and confidence in the ability to mind-read may generate comfort due to enabling partners to feel that they know what to expect of each other (Swann & Gill, 1997).

As discussed, many of the negotiation strategies could be expected to have both positive and negative consequences. Fittingly, the current study found that the two types of strategies, accommodative and protective, did not necessarily correspond with certain outcomes. Often accommodative negotiations would result in the development of a shared understanding and approach with which both members of the couple were satisfied. This resembles Corbin and Strauss' (1984) concept of

'collaborative working', where couples work together harmoniously in a mutually satisfactory manner to achieve agreed tasks, which they suggest is helpful for couples managing chronic illness. However, sometimes accommodative negotiations could produce a shared approach that one member of the couple was less satisfied with, and sometimes the actively addressed differences could remain unresolved. These imbalanced and unresolved outcomes could have resulted from specific communication processes that were not observed during the interview preventing a satisfactory outcome or could be due to the inflexibility of members of the couple in modifying their personal views. For example, one couple openly discussed and attempted to empathise with each other about their different views on an issue but they did not appear to have achieved a resolution. It is possible that their communication around the issue during interview was not representative of their typical discussions, preventing less helpful strategies being identified. Furthermore, it is possible that the fundamental nature of the beliefs made this issue more difficult to resolve, despite using strategies that were usually successful.

Similarly, although avoidance of discussions around conflict areas is suggested to prevent resolution (Christensen & Shenk, 1991), in the current study topics that were not directly addressed could still appear resolved, with couples seeming to have been able to resolve differences implicitly. For example, some couples appeared to have implicitly agreed on a joint coping approach that fit within their relationship framework, despite underlying differences not being actively negotiated. Nevertheless, the resolutions of protective negotiations typically appeared imbalanced, with one member of the couple making more concessions than the other, and could also often leave discrepancies unresolved.

The distinction between the two types of negotiation identified could be understood in terms of coping literature. A common distinction used to describe coping strategies is approach versus avoidance (Skinner, Edge, Altman, & Sherwood, 2003). Approach coping involves instrumental action directed toward the threat, which shares similarity with accommodative negotiation strategies, whereas avoidance coping involves orienting attention away from the threat, comparable to protective negotiations. Both types of approaches can be adaptive and are considered complementary, with most people adopting both types (Skinner et al., 2003). For example, approach coping can be helpful when it is possible to exert control over the situation, but may not be helpful in circumstances when there are limited opportunities for control. In the current context, this could explain why some accommodative strategies were not helpful for resolving differences in rigidly held beliefs that both partners were unwilling to relinquish. Similarly, avoidance coping can be helpful for

conserving resources during stressful circumstances; however it can be unhelpful when instrumental action is necessary. In the current study, this could explain why protective strategies were adaptive in some circumstances, such as avoiding conflict during a vulnerable time, whereas they sometimes appeared maladaptive due to preventing important topics being satisfactorily resolved.

Although most couples adopted both types of negotiations, some couples differed in their negotiation preferences, with one partner predominantly preferring protective strategies whilst the other desired more accommodative strategies, which appeared to generate some resentment and dissatisfaction. This resembled the demand-withdraw pattern of communication often found in couples, characterised by one partner pressuring the other to talk while the other partner withdraws, which has been found to be associated with higher distress and lower relationship satisfaction in couples coping with cancer (Manne et al., 2006). These differences in communication preferences can predate the cancer, as described by one couple in the current sample. It is likely that concordance in communication preferences is important (Baider, 2008), with satisfaction depending on whether the pattern of engagement or avoidance fits with the members of the couple's preferred patterns of relating (Sillars, Canary, & Tafoya, 2004).

Overall, the results highlighted that negotiation was complex. Many different strategies were used both within and across couples, which varied by topic and goals of the negotiations, representing an on-going process of trying to negotiate a workable balance. Despite the different strategies not necessarily corresponding with certain outcomes, generally couples appeared more satisfied when discrepancies were actively addressed, even if a shared understanding was not achieved, as the strategies enabled both partners to develop awareness of their differences, helping them to respect each other's views and adapt to the discrepancy. Nevertheless, protecting each other and the relationship was important at times; therefore less direct attempts were also beneficial on some occasions. This supports suggestions that selective communication is valuable for adjustment (Hilton & Koop, 1994). The current case studies suggest that the selective use of appropriate strategies was idiosyncratic to the particular couple. Topics that were appraised as particularly salient by the couple appeared to benefit from more shared understandings and joint coping, which could require accommodative negotiations to resolve discrepancies, whereas for less salient topics that did not require a joint approach, protective negotiations appeared satisfactory and helped prevent potential conflict. This suggests that couples' appraisals were important for selecting strategies for coping with discrepancy, which supports stress-coping theory (Lazarus & Folkman, 1984).

How do couples experience discrepancy?

Despite all couples experiencing some discrepancy, the questionnaire data suggested that all couples had good mental health HR-QoL. Only half of the couples had one member who experienced lower physical HR-QoL than average, which appeared related to the reduced functioning generated by their personal illness. This could suggest that couples do not experience discrepancy as detrimental for adjustment, which potentially contradicts previous research that has suggested that discrepancy is associated with poor adjustment, particularly emotional distress (Benyamini et al., 2009; Heijmans, et al., 1999; Romero et al., 2009). However, the interview data suggested that some participants experienced difficulties that were not picked up by the questionnaires, such as continued traumatic memories and unhappiness over lifestyle changes. Therefore, the quantitative measures may not have been sensitive to the relevant concerns for the couples.

Researchers have hypothesised potential reasons for discrepancy having a negative influence on adjustment, such as generating conflict, incompatible coping strategies or feelings of being dismissed or overprotected (Ben-Zur et al., 1992; Deal et al., 1992; Heijmans et al., 1999). Other researchers have also suggested that discrepancy may not always have negative consequences, potentially due to differences enabling partners to boost one another's mood and motivate better coping strategies (Figueiras & Weinman, 2003). However, the previous quantitative research has not provided testimony of participants that could examine the validity of these proposals. The current study provides some insights into the experience of discrepancy in couples that can illuminate its influence on couples' adjustment.

When asked directly, most couples were unable to report any discrepancy in their views or beliefs. This could suggest that the differences identified within this study are not experienced as important or not registered at a conscious level. Alternatively, it may be that couples were reluctant to disclose their differences. However, it was possible to identify discrepancies from the couples' narratives of their experiences and the differences appeared to play an important role in adjustment.

Some couples described experiencing their differences as beneficial and complementary. Discrepancy was often perceived as enabling partners to reassure one another, encourage each other to adopt different strategies for coping or assist each other in thinking differently about the situation. Many referred to feeling that such differences helped to achieve a complementary balance, particularly in terms of expression of anxiety, which they described as a positive outcome. Systems theories highlight that couples often express complementary strategies (ones that 'fit together') for managing difficulties such as anxiety and conflict, whereby couples regulate each

other's behaviour to maintain stability; however, this has been found to predict marital discord (Skowron, 2000) rather than be beneficial. It is possible that stability was perceived to be beneficial for the participants in the current study as it maintained their usual patterns of interacting, which was familiar and comfortable, but actually may have been sustaining problematic ways of relating, such as avoiding discussing feelings. However, it is also likely that some differences can be helpful within couples. Pistrang & Barker (2005) suggest that partners can help each other make sense of problems and explore different ways to think about them, usually drawing from their personal life knowledge and general lay theories, which can sometimes help each other to see problems in a different light. Therefore, discrepant perceptions can be seen as helpful for contributing to couples' joint exploration of the meaning of the cancer and sense-making of the experience.

Nevertheless, it was also common for couples to project a sense of feeling divided by some of their differences. This appeared to typically occur when attempts to accommodate the differences had led to an explicit or implicit agreement on ways of responding which did not fully satisfy one or both partners, leaving them feeling frustrated and less connected to the other person due to their negative feelings about the joint approach. Feelings of division were particularly apparent in those couples who had difficulty communicating their dissatisfaction about the differences, which could be explained by the literature highlighting the importance of open communication for intimacy and relationship satisfaction (Emmers-Sommer, 2004; Manne & Badr, 2008). This could therefore reflect a consistent difficulty with communicating in their relationship resulting in them feeling divided, rather than specifically discrepancy, although the majority of these couples described open communication and connectedness in some areas, suggesting this did not simply reflect general relationship factors.

Some couples also appeared to experience continued uncertainty due to their unresolved discrepancies. Uncertainty is common in cancer patients and families due to the lack of clear answers about disease process and prognosis. In the current study, different understandings between partners appeared to generate doubt about personal perceptions and lead to a continued search for a united meaning. This uncertainty was most apparent in relation to discrepancies in beliefs that were integral to the individuals' meaning and adjustment. Previous research has highlighted that living with uncertainty is a difficult challenge for couples and having shared understandings has been suggested to help couples cope (Gardner, 2008). The current findings add to this, suggesting that not shared understandings prevented the development of certainty and confidence in beliefs, which could potentially influence adjustment.

These unresolved differences could also potentially hinder adjustment due to continued conflict.

In summary, discrepancy appeared to be experienced both positively and negatively by the couples in this study. This corresponds with previous research that has found discrepancy to be associated with both positive and negative adjustment outcomes (Benyamini et al., 2009; Heijmans, et al., 1999; Richards et al., 2004). The current study provides some insight into the effects that could influence positive adjustment, such as helping with meaning-making, coping efforts and providing reassurance. Similarly, potentially negative effects identified include causing couples to feel less connected with one another and generating continued uncertainty.

What does this research add to existing theoretical literature?

Individualistic models of coping, such as the self-regulatory model (SRM) (Leventhal et al., 1980), predominate within the literature on adjustment to illness. Individuals are portrayed as appraising and coping with stressors relatively independently. Although the SRM recognises that social contexts influence individual appraisals, by contributing to the formation of underlying prototypes and schemata that are used for comparison with personal experience and assisting in assigning meaning to the illness experience, these processes are less well explored in the SRM (Leventhal et al., 2010) and it does not consider shared appraisals and joint coping when people confront illness together. The current study highlighted that the cancer was appraised and coped with at both the individual and couple level, which contrasts with the individualistic focus of the SRM and its limited consideration of the more interpersonal understandings and coping.

The current findings regarding the interpersonal and negotiated understandings are more consistent with existing systemic theories that consider social processes more explicitly than individualistic models. For example, the finding that couples continually constructed their understandings by drawing on and being influenced by various individual, couple and wider socio-cultural factors fits with Bronfenbrenner's (1986) Ecological Systems theory. This is a holistic framework highlighting the importance of considering human development within the context of the individual's reciprocal interactions with an ever-broadening range of social and environmental contexts, from close interpersonal interactions to broader cultural influences. The theory suggests that exposure to and interaction with the environment can change perceptions and understandings, with the ecological systems surrounding individuals providing both external stressors that challenge adaptation as well as sources of growth that facilitate adaptation, through access to increased options and social

knowledge. Therefore, in the current study, the multitude of influences on couple understandings, which could be both supportive and challenging for the development of understandings, is consistent with Bronfenbrenner's theory. This highlights the value of developing understanding of the environmental contexts that may be contributing to couples' understandings of illness.

A further framework that helps to understand families dealing with chronic illness is the Family Systems Illness Model developed by Rolland (1987, 1994, 2005). This model highlights the fit between the psychosocial demands of an illness over time and family and individual development, multigenerational legacies of coping, and belief systems. It aims to provide a psychosocial map that can help couples and families tackle the difficulties and uncertainties of illness such as cancer by providing information on predictable strains associated with adjusting to the illness and identifying optimal coping processes. Some key elements of Rolland's model that are consistent with the current findings include the importance of beliefs and multigenerational legacies in guiding the construction of meanings about illness and the value of understanding the fit of health beliefs within the family and with the wider systems to assist in developing a workable accommodation of these values. This corresponds with the current findings that relationship frameworks and histories of coping appeared important for couple understandings and adjustment. The current study also highlighted that couples were challenged with finding ways to accommodate different understandings between themselves and with wider systems, and extends this argument by providing insight into ways this can be successfully negotiated, such as through empathy, humour, compromise, prioritising and appreciating the benefits of difference. Furthermore, the current study highlights that experiencing discrepant understandings is a predictable strain that couples are likely to have to negotiate and helping couples to view this as normal could be beneficial.

Dyadic coping frameworks place emphasis on couples' attempts to cope with shared stressors as an interpersonal unit rather than as separate individuals and has been applied to the context of chronic illness. There is an array of overlapping conceptual approaches and terms used to characterise coping as an interpersonal process, including dyadic, interpersonal, relationship-focussed, communal and collaborative coping (Revenson et al., 2005; Berg et al., 2008). Within chronic illness, the conceptualisation of communal or collaborative coping has emerged as particularly beneficial, which is characterised by appraising the illness in relationship terms, viewing it as 'our' issue, and taking a joint 'we'-based approach to coping, such as pooling resources and joint problem solving (Berg et al., 2008; Rohrbaugh et al., 2008). Numerous studies provide support for a positive association between

communal coping and adjustment in chronic illness (Berg & Upchurch, 2007; Bodenmann, Meuwly, & Kayser, 2011). For example, Berg et al. (2008) found that collaborative coping was associated with more positive mood in couples coping with prostate cancer.

The current study also found that couples perceived themselves as 'in it together' suggesting a collaborative approach to coping with the cancer, which appeared to be beneficial for couples in uniting their understandings and facilitating adjustment. However, the current study highlights that members of the couple also had individual perceptions and needs that appeared to require more individual coping alongside the dyadic appraisal and coping. The collaborative coping literature tends to focus on the collective needs at the expense of the individual and does not consider the negotiation of these multiple, co-existing appraisals.

One dyadic coping approach which does highlight that couples faced with a shared stressor cope both individually and collectively is the Systemic-Transactional Model (STM) (Bodenmann, 1997, 2005). This model suggests that interdependence between spousal well-being and communal concerns and goals within couples stimulate dyadic coping, usually in addition to individual coping efforts. This corresponds with the current findings that shared goals and experiences united couples into shared understandings and ways of coping, alongside their individual needs and coping. Bodenmann (2005) also highlights the importance of partners being able to communicate their personal stresses to each other, which also emerged as influential in the current study, with difficulties communicating openly appearing to prevent partners understanding the other's experience.

Although the current findings appear consistent with the STM, Bodenmann (2005) suggests that couples engage in dyadic coping after individual coping efforts have been unsuccessful, whereas in the current study the individual and joint understandings and coping appeared to be co-occurring rather than sequential, which highlights the importance of negotiating a balance between individual and couple appraisals and coping which is not considered within the STM.

Therefore, the current study appears to highlight the importance of considering both individual and systemic understandings concurrently, whereas existing theories tend to privilege one over the other. Consideration of these multiple understandings suggests that helping couples to find ways to accommodate these co-occurring perceptions could be valuable.

Methodological critique

The vast majority of research into discrepant understandings has investigated this quantitatively, which has provided some evidence for discrepancy as a predictor of adjustment outcomes. This study complements such research by shedding light on the processes involved in discrepancy and their role in the adjustment process.

Sampling and recruitment

The couples who were interviewed were selected from the sample derived through the quantitative data collection process, which achieved a low response rate and the limitations leading to this have been discussed. Consequently, the qualitative sample only represents a small minority of couples invited to participate and it is important to consider why these couples agreed and others did not. Couples were informed of the nature of the study and the joint and individual interviewing procedures in the initial information pack. Couples who had very different perceptions that were a source of difficulty for the couple and couples who did not openly discuss the cancer may not have responded. Therefore, the couples who took part may represent those who have more shared understandings or have negotiated their differences well and are willing to openly discuss the cancer together. However, the interview data suggests that the couples did experience discrepancy in understandings and some difficulties in communication were described. Furthermore, despite the potential that the sample is biased towards those couples who communicate and manage difference well, this can still provide useful insights that could potentially help couples who are having difficulty negotiating their differences.

The homogeneity of the sample may also have been an issue. Smith et al. (2009) recommend that a reasonably homogenous sample should be used within IPA, which ensures that participants are discussing similar experiences from similar perspectives. Accordingly, the participants in the current sample shared similar characteristics, such as being diagnosed with cancer or in a relationship with someone with cancer, White British ethnicity and residing in northern England; therefore the findings may provide insights relevant to couples who share these characteristics. However, participants in the sample also differed to some extent. For example, the time since diagnosis varied from nine months to two years, therefore the couples may have been at different stages within the adjustment process. Most patients were male, however, one female patient took part; although her accounts were consistent with those of other couples, the shortage of data from female patients may have masked gender differences. Some couples were married whilst some cohabited and the length of relationship varied from 13 to 48 years, potentially influencing their relationship

processes. Furthermore, patients' ages ranged from 59 to 71 and partners' ages ranged from 49 to 69, meaning that participants were at somewhat different life stages and potentially dealing with different life issues. These factors increased the heterogeneity of the group, potentially leading to couples having somewhat different perspectives on the shared experience of developing understandings of the cancer. Nevertheless, the existence of common themes across the group could potentially suggest that the findings may provide some insights relevant across couples dealing with different cancers at different stages, within different couple relationships. However, the small sample size limits the potential for generalising from the experience of the participants in this study to other couples.

Interviews

A strength of the study was the inclusion of partners in both joint and individual interviews, which is suggested to be the gold standard for couple research (Seymour et al., 1995). This was of particular benefit in the current study as it provided the opportunity to observe interactions between partners and explore their joint understandings, as well as providing opportunities for differences to emerge in the individual interviews. This process appeared to provide multiple perspectives on the couples' experiences that would not have been obtained through one type of interview alone. However, this combination of interviews required sensitivity. When obtaining consent for conducting both types of interviews at the start, many participants commented that they did not have any secrets, suggesting that this was a concern for them. Consequently, I took the time to explain that the purpose of the individual interviews was to enable them to discuss their personal experiences and ensured that both partners were comfortable with this before continuing. Nevertheless, the closeness of the individual interviews to the joint interview appeared to generate discomfort in those participants who did express different views during the individual interview and could potentially have prevented other participants from presenting contradictory views. A possible solution could have been to conduct the individual interviews on a different day when the joint interview was not so fresh in their minds; however, this could also have the disadvantage of participants' perceptions having changed following discussions between the couple after the joint interview.

The information shared by participants in the interviews may also have been influenced by social desirability. Couples may have been reluctant to experience or discuss disagreements in front of the researcher and therefore presented more similar views which were not representative of their perceptions and interactions when alone. Furthermore, a number of couples described hoping that their information would be

used to benefit others, which may have led them to focus on positive aspects, therefore not describing more contentious issues.

The information derived from interviews will be influenced by the style of the interviewer. I attempted to create a conversational space of rapport and mutual understanding through empathy and transparency. This appeared to help participants be open about their experiences and share very personal information; however, it is possible that this style was less neutral and objective than other interviewers. My interview style was passive, standing by and supporting participants to tell their story. Therefore, I felt that I did not use as many prompts as I could have, which resulted in some areas not being explored in as much depth as possible.

The use of interviews relied on participants' retrospective recall of their experiences that happened months before. This could have been an issue in the current study as participants may have attributed their current perceptions and beliefs to their past experience when their perceptions at the time actually differed, which could have prevented the researcher being aware of perceptions evolving over time.

However, overall, the combined interviews represented a good option for eliciting participants' accounts and providing rich, multi-perspective data. Furthermore, several participants commented on the value and enjoyableness of the interview, indicating that they had found it helpful to reflect on their experiences.

Data analysis

As an inexperienced researcher, the guidelines from the voice-centred relational method (VRM) and Interpretative Phenomenological Analysis (IPA) were helpful for providing a structure for the analysis. A limitation of the VRM is that it is extremely time-consuming, with each transcript needing to be read multiple times, and this was also combined with IPA in the current study. However, an advantage of this process was that it facilitated complete immersion in the data, enabling me to hear the many stories being told and enabling a detailed, focussed analysis. The 'I' and 'we' poems were very powerful and beneficial for amplifying the individual and shared perceptions. Nonetheless, a more experienced researcher may have identified more complex, interpretative themes through this process.

The data produced from this analysis was diverse and complex, with many overlaps and interactions, which were difficult to represent within the written report. My attempts to find order may have led me to focus on certain areas over others. Another researcher could have approached the data differently, focussing on different themes and developing them differently. I have attempted to address biases in my data collection and interpretations through the inclusion of reflexivity sections throughout,

demonstrating transparency in the process of developing themes, and supporting themes with quotes representing both patient and partner voices. Therefore, the current analysis represents only one way of interpreting and presenting the data, with the diagrammatic and narrative representations signifying a tentative approach to understanding the process of negotiating understandings and managing discrepancies.

Additional quality checks

As discussed in chapter two, numerous quality checks were implemented in accordance with guidelines by Elliott et al. (1999). These will not be reiterated here, however, it is recognised that alternative checks could have been used. For example, respondent validation, involving returning to participants to obtain feedback on the analysis, is considered helpful for ensuring validity and was considered for this study; however, this process is not consistent with IPA, due to the interpretative element potentially producing more abstract understanding that may differ greatly from participants' understandings (Smith et al., 2009).

Future research

The current study explored the development and negotiation of understandings of colorectal and prostate cancers in a sample of White British heterosexual couples, contributing to understandings of these processes in such samples. This raises questions of the applicability of these findings across other samples, suggesting a need for further research within different cancer types, dyads and cultures. Such research could highlight similarities and differences with the processes identified in the current study. For example, different cancer types share common challenges, such as managing uncertainty, which may influence similarities in processes; however, cancers also have unique issues, such as being more prevalent in younger patients where understandings may be more family-based than couple-based and influenced by wider social networks. Similarly, understandings between patients and extended family members, such as siblings, children and grandchildren, may be less interdependent than between partners. Furthermore, there are likely to be important differences in processes within other cultures. For example, Asian cultures value multigenerational interdependence, adopt hierarchical relations and decision-making, and prefer more subtle, indirect communication over the open expression of emotions valued amongst Western cultures (Nilchaikovit, Hill & Holland, 1993). Therefore, research in other cultures would be particularly interesting.

Only one female patient was included in this study and, despite displaying commonalities with other couples, some important gender differences may have been masked and warrant further exploration.

Longitudinal research directly exploring the evolution of understandings over time may also enhance understanding and provide insight into whether negotiations vary over the course of adjustment. For example, protective negotiations may play a more important role during early stages when couples are experiencing acute stress. Furthermore, the analysis of recordings of dyads discussing divergent topics together could provide a more detailed picture of negotiation processes.

Clinical implications

Despite the Department of Health (2011) recommending that cancer services should pay more attention to supporting the needs of relatives and involving them in care, such recommendations have not yet been effectively implemented in practice, with cancer care remaining predominantly patient-centred. The current findings highlight the importance of including family, particularly partners, in care provision due to the role of relationships in understanding and adjusting to cancer. A more relationship-centred approach is warranted, placing couples and families at the centre of care. Although such an approach has important ethical implications requiring careful negotiation of informed consent from patients to include family members, professionals should aim to include couples in joint consultations wherever possible.

The findings have implications for professionals working with couples adjusting to cancer, identifying key areas that should be addressed in assessments and interventions. It is important for professionals to consider and assess the separate needs of each person in the couple as well as their joint and relationship needs. This could be achieved by providing both partners with the opportunity to discuss their thoughts and concerns about the cancer separately and together. Obtaining a history of couples' premorbid marital functioning and observations of how they interact and negotiate difficulties together could provide valuable information about their needs for guidance and assistance in joint coping and managing conflict.

Interventions could help couples to understand that differences in views are normal and understandable considering their different experiences and perspectives. Helping couples to understand and respect their differences, rather than attempting to have united views on all aspects, may prove beneficial. Professionals could support both members of the couple to take each other's perspective and understand how their respective beliefs and coping affect each other to generate greater mutual understanding. Discussions of the merits of their differences could help couples to find

things to appreciate within one another and view their relationship as a resource for coping. Supporting couples to identify and develop shared tasks and goals of adjustment may also prove beneficial. Such interventions could help couples develop a relational orientation to the illness, which has been found to be beneficial for adjustment (Rohrbaugh et al., 2008; Skerrett, 1998).

Although some discrepancy within couples is to be expected and can have benefits, couples with very divergent views that interfere with their ability to develop shared goals and have a detrimental impact on their relationship may benefit from tailored interventions to address their discrepant perceptions and improve their communication skills. Research suggests that illness perceptions can be changed with cognitive behavioural and educational interventions (Goulding et al., 2010) and communication skills training has been found to be an effective component of couple therapy (Snyder, Castellani, & Whisman, 2006), suggesting that such interventions may prove successful.

The finding that both patients and partners use peers to evaluate their understandings could suggest that support groups for couples could be of benefit. Cancer support groups typically focus on either the patient or the partner separately, primarily the patient, and these have been found to enhance adjustment (Bottomley, 1997). Groups directly aimed at couples could enable couples to discuss their experiences of adjusting together, providing them with opportunities to compare their experience with others.

Conclusion

This study has provided insight into the role of couples' perceptions in adjustment to cancer. Although recruitment difficulties prevented some of the research aims being addressed, the qualitative study has furthered understanding of the development and negotiation of understandings within couples and the role of discrepant perceptions in the adjustment process. The majority of research into discrepancy in perceptions has adopted a quantitative approach and has presented a mixed picture about the impact of discrepancy. This study allowed for the intricacy of the experience of discrepancy in couples to be revealed in more depth.

The study highlighted that the development of shared and discrepant understandings is complex and extends beyond the perceptions considered within the SRM. Cancer affected both members of the couple on an individual and couple level, requiring patients and partners to make sense of their personal stressors, the other person's experience, and the impact of the cancer on them as a couple. In attempting to make sense of this complexity, patients and partners drew on and were influenced

by various personal and couple factors as well as information from external sources, which served to promote either shared or discrepant understandings. Managing the various complementary and competing perceptions that arose was an on-going process of attempting to develop a workable balance. Generally, actively addressing discrepancy appeared more beneficial for couples, even if a shared understanding was not achieved, enabling couples to develop awareness of their differences, respect each other's views and accommodate their differences. Nevertheless, less direct negotiation attempts were also beneficial on some occasions, enabling couples to protect each other and their relationship during a vulnerable period. Discrepancy had positive and negative effects on couple adjustment. Positive effects included helping with meaning-making, coping efforts and providing reassurance. Negative effects included causing couples to feel less connected with one another and generating continued uncertainty.

Therefore, this analysis has emphasised that the impact of cancer extends beyond the patient and has demonstrated the importance of couple relationships in understanding and adjusting to the disease. This suggests that models of care should adopt a relationship-centred approach to cancer, supporting family members as well as patients, with interventions aimed at strengthening interpersonal relationships.

Closing reflections

Being faced with the recruitment challenges in this study has been a valuable learning experience, making me more aware of common pitfalls and providing me with insights into potential ways to minimise these in future research. I think it is important for researchers to share their experiences of such challenges to help other investigators; however research papers often present a simple portrayal of their recruitment and miss out the important lessons learnt.

During my professional role in clinical health psychology, in particular psycho-oncology, I have been surprised by the lack of inclusion of family members within the support services provided. Undertaking this research has reinforced to me the importance of adopting a relationship-centred approach to chronic illness and has fostered my commitment to supporting the development of models of care that support patients and families.

My personal views on discrepancy have shifted over the course of this research, from seeing discrepancy as generally unhelpful from my previous personal experience to understanding how natural and unavoidable differences are and perceiving it as important to respect these differences rather than strive for completely shared understandings. I learnt a great deal from my participants about how to

successfully negotiate holding different views, but appreciate that it is a delicate balance that is difficult to get right all the time.

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APPENDICES

Appendix 1: Illness Perception Questionnaire (IPQ-R) Patient Version

YOUR VIEWS ABOUT YOUR CANCER

Listed below are a number of symptoms that you may or may not have experienced since your cancer. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your cancer, and whether you believe that these symptoms are related to your cancer.

	I have experienced this symptoms <i>since my cancer</i>			This symptom is <i>related to my cancer</i>	
	Yes	No	-----	Yes	No
Pain	Yes	No	-----	Yes	No
Sore throat	Yes	No	-----	Yes	No
Nausea	Yes	No	-----	Yes	No
Breathlessness	Yes	No	-----	Yes	No
Weight loss	Yes	No	-----	Yes	No
Fatigue	Yes	No	-----	Yes	No
Stiff joints	Yes	No	-----	Yes	No
Sore eyes	Yes	No	-----	Yes	No
Wheeziness	Yes	No	-----	Yes	No
Headaches	Yes	No	-----	Yes	No
Upset stomach	Yes	No	-----	Yes	No
Sleep difficulties	Yes	No	-----	Yes	No
Dizziness	Yes	No	-----	Yes	No
Loss of strength	Yes	No	-----	Yes	No

We are interested in your own personal views of how you now see your current cancer.

Please indicate how much you agree or disagree with the following statements about your cancer by ticking the appropriate box.

	Views about your cancer	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP1	My cancer will last a short time					

	Views about your cancer	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP2	My cancer is likely to be permanent rather than temporary					
IP3	My cancer will last for a long time					
IP4	This time will pass quickly					
IP5	I expect to have this cancer for the rest of my life					
IP6	My cancer is a serious condition					
IP7	My cancer has major consequences on my life					
IP8	My cancer does not have much effect on my life					
IP9	My cancer strongly affects the way others see me					
IP10	My cancer has serious financial consequences					
IP11	My cancer causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my cancer gets better or worse					
IP14	The course of my cancer depends on me					
IP15	Nothing I do will affect my cancer					
IP16	I have the power to influence my cancer					
IP17	My actions will have no effect on the outcome of my cancer					
IP18	My cancer will improve in time					
IP24	The symptoms of my condition are puzzling to me					
IP25	My cancer is a mystery to me					
IP26	I don't understand my cancer					
IP27	My cancer doesn't make any sense to me					
IP28	I have a clear picture or understanding of my condition					

Appendix 2: Illness Perception Questionnaire (IPQ-R) Partner Version

YOUR VIEWS ABOUT YOUR PARTNER'S CANCER

Listed below are a number of symptoms that your partner may or may not have experienced since their cancer. Please indicate by circling *Yes* or *No*, whether your partner has experienced any of these symptoms since their cancer, and whether you believe that these symptoms are related to their cancer.

	My partner has experienced this symptoms <i>since their cancer</i>			This symptom is <i>related to their cancer</i>	
	Yes	No	-----	Yes	No
Pain	Yes	No	-----	Yes	No
Sore throat	Yes	No	-----	Yes	No
Nausea	Yes	No	-----	Yes	No
Breathlessness	Yes	No	-----	Yes	No
Weight loss	Yes	No	-----	Yes	No
Fatigue	Yes	No	-----	Yes	No
Stiff joints	Yes	No	-----	Yes	No
Sore eyes	Yes	No	-----	Yes	No
Wheeziness	Yes	No	-----	Yes	No
Headaches	Yes	No	-----	Yes	No
Upset stomach	Yes	No	-----	Yes	No
Sleep difficulties	Yes	No	-----	Yes	No
Dizziness	Yes	No	-----	Yes	No
Loss of strength	Yes	No	-----	Yes	No

We are interested in your own personal views of how you now see your partner's cancer.

Please indicate how much you agree or disagree with the following statements about your partner's cancer by ticking the appropriate box.

	Views about your partner's cancer	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP1	Their cancer will last a short time					

	Views about your partner's cancer	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
IP2	Their cancer is likely to be permanent rather than temporary					
IP3	Their cancer will last for a long time					
IP4	This time will pass quickly					
IP5	I expect them to have this cancer for the rest of their life					
IP6	Their cancer is a serious condition					
IP7	Their cancer has major consequences on my life					
IP8	Their cancer does not have much effect on my life					
IP9	Their cancer strongly affects the way others see me					
IP10	Their cancer has serious financial consequences					
IP11	Their cancer causes difficulties for those who are close to them					
IP12	There is a lot they can do to control their symptoms					
IP13	What they do can determine whether their cancer gets better or worse					
IP14	The course of their cancer depends on them					
IP15	Nothing they do will affect their cancer					
IP16	They have the power to influence their cancer					
IP17	Their actions will have no effect on the outcome of their cancer					
IP18	Their cancer will improve in time					
IP24	The symptoms of their condition are puzzling to me					
IP25	Their cancer is a mystery to me					
IP26	I don't understand their cancer					
IP27	Their cancer doesn't make any sense to me					
IP28	I have a clear picture or understanding of their condition					

Appendix 3: RAND 36-Item Health Survey 1.0

1. In general, would you say your health is:

Excellent	Very Good	Good	Fair	Poor
1	2	3	4	5

2. Compared to one year ago, how would you rate your health in general now?

Much better now than one year ago	Somewhat better now than one year ago	About the same	Somewhat worse now than one year ago	Much worse now than one year ago
1	2	3	4	5

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much? (**Circle One Number on Each Line**)

	Yes, Limited a Lot	Yes, Limited a Little	No, Not limited at All
3. Vigorous activities , such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4. Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5. Lifting or carrying groceries	1	2	3
6. Climbing several flights of stairs	1	2	3
7. Climbing one flight of stairs	1	2	3
8. Bending, kneeling, or stooping	1	2	3
9. Walking more than a mile	1	2	3
10. Walking several blocks	1	2	3
11. Walking one block	1	2	3
12. Bathing or dressing yourself	1	2	3

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**? (**Circle One Number on Each Line**)

	Yes	No
13. Cut down the amount of time you spent on work or other activities	1	2
14. Accomplished less than you would like	1	2
15. Were limited in the kind of work or other activities	1	2
16. Had difficulty performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)? **(Circle One Number on Each Line)**

	Yes	No
17. Cut down the amount of time you spent on work or other activities	1	2
18. Accomplished less than you would like	1	2
19. Didn't do work or other activities as carefully as usual	1	2

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?
(Circle One Number)

Not at all	Slightly	Moderately	Quite a bit	Extremely
1	2	3	4	5

21. How much **bodily** pain have you had during the **past 4 weeks**? **(Circle One Number)**

None	Very mild	Mild	Moderate	Severe	Very Severe
1	2	3	4	5	6

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)? **(Circle One Number)**

Not at all	A little bit	Moderately	Quite a bit	Extremely
1	2	3	4	5

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the **past 4 weeks**... **(Circle One Number on Each Line)**

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6

32. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)? **(Circle One Number)**

All of the time 1	Most of the time 2	Some of the time 3	A little of the time 4	None of the time 5
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How TRUE or FALSE is each of the following statements for you. **(Circle One Number on Each Line)**

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5

Appendix 4: Couples' Illness Communication Scale

Patient version

The following questions ask about your relationship with your partner. Each question should be answered on the scale shown below.

1	2	3	4	5
Disagree Strongly	Disagree	Undecided	Agree	Agree strongly

- (1) It is hard for me to express feelings about my illness to my partner. _____
- (2) I feel comfortable discussing issues related to my illness with my partner. _____
- (3) My partner is reluctant to talk about my illness. _____
- (4) My partner is willing to share his/her feelings about my illness with me. _____

Partner version

The following questions ask about your relationship with your partner. Each question should be answered on the scale shown below.

1	2	3	4	5
Disagree Strongly	Disagree	Undecided	Agree	Agree strongly

- (5) It is hard for me to express feelings about his/her illness to my partner. _____
- (6) I feel comfortable discussing issues related to his/her illness with my partner. _____
- (7) My partner is reluctant to talk about his/her illness. _____
- (8) My partner is willing to share his/her feelings about his/her illness with me. _____

Appendix 5: Individual Interview Consent Form

There are parts of my interview that I do not wish to be used in the thesis.
I have made these parts known to the researcher.

I would like to review my data before the thesis is submitted

I agree to the researcher using my data without contacting me again

Participant Name

Date

Signature

Researcher

Date

Signature

Appendix 6: Interview Schedule

Tell me a bit about life before [patients] diagnosis?

- Working history, social life, relationship
- General health/other illness experiences
- Pre-diagnosis, can you think of any difficulties you have had to manage as a couple?
How did you cope?

Talk me through what happened at diagnosis?

- What led you to seek medical advice? What signs/symptoms have you experienced?
- What are your beliefs about how you came to get cancer?
- How did you find the doctors way of telling you? Who attended the appointment?
- What did you think about the diagnosis? What did it mean to you? How did you feel?
How did you react?
- How well do you feel you understand the diagnosis?
- What impact did the diagnosis have?

What treatment has [patient] received?

- Where? How? Who attended appointments?
- How was the treatment for you [both]? What are your views on the treatment?
- Has [patient] experienced any side-effects?
- What do you believe about your ability to influence the course of the cancer? What will help control it? What might make it worse or cause recurrence?

Tell me about life after treatment/diagnosis so far?

- How has cancer affected your life? What are the consequences? Examples.
- How has cancer affected your relationship?
- How has it affected you emotionally?
- What difficulties have you faced? What has been most difficult for each of you?
- What has helped/hasn't helped?
- Who do you talk to? Who do you keep it from and why?

Tell me about something you feel you have managed well together regarding the cancer?

- How did you manage this? How did things turn out?

Tell me about something you think you have had different views about regarding the cancer?

- What happened? What effect did the different views have for you?
- Have your views changed? How? How did things turn out?

What are your views about the future? How has cancer changed your views of the future?

- How do you expect the cancer to progress?

Is there anything else that I haven't asked that you wished I had?

Example probes for all above questions:

- Can you tell me more about that?
- Can you give me an example of that?
- What did you think about that?
- What did you feel about that?
- What did that mean for you?

Individual Interview Questions

Is there anything that we discussed that you would like to say more about?

Is there anything related to the cancer that you feel shouldn't be talked about together? Why?

What would be the consequences if discussed?

Appendix 7: Ethical Approval Letter



Health Research Authority

NRES Committee Yorkshire & The Humber - Leeds East
Yorkshire and Humber REC Office
First Floor, Millside
Mill Pond Lane
Meanwood
Leeds
LS6 4RA

Telephone: 0113 3050108
Facsimile:

22 June 2012

Miss Claire Mitchell
Psychologist in Clinical Training
The Leeds Teaching Hospitals NHS Trust

Dear Miss Mitchell

Full title of study: Patient and partner perceptions of the patient's cancer and their association with quality of life: Is discrepancy important?
REC reference number: 12/YH/0272
Protocol number: n/a
EudraCT number:

Thank you for your letter of 21 June 2012. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 12 June 2012. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Letter of invitation to participant	1.1	01 June 2012

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

Appendix 8: Patient Information Sheet¹

Patient and partner perceptions of the patient's cancer and their association with quality of life

I would like to invite you to take part in a research study. Before you decide if you would like to participate, it is important for you to understand why the research is being carried out and what taking part will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please feel free to ask me if you would like any further information, or anything is not clear.

What is the purpose of the study?

I am studying the personal views of patients with a diagnosis of colorectal or prostate cancer and their partners regarding how they see the patient's cancer. I am interested in finding out whether what you and your partner think about your cancer is associated with your quality of life. I am also interested in finding out more about how your views about the cancer have come about.

Who is involved in running the study?

My name is Claire Mitchell and I am a Psychologist in Clinical Training. I am carrying out this research under supervision of Professor Allan House, Dr. Maureen Twiddy and Dr. Laura Ashley from The University of Leeds.

Why have I been chosen to take part?

You have been invited to take part because you have been diagnosed with colorectal or prostate cancer within the last three years. You may also have a partner who lives with you and who may be willing to participate. Due to the nature of the study, it will not be possible to include people without a partner who is willing to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. You will also be asked for permission to contact your partner so that they can be given information about the study and asked to provide their own informed consent. If you or your partner decide not to take part, or decide to withdraw at any time, it will not affect your care in any way. You are both free to withdraw at any time without giving a reason.

What does taking part involve?

If you and your partner are willing to take part in the study, you will both be asked to complete three questionnaires. These will ask you for your views about your cancer, about your overall physical and emotional health, and about your illness-related communication with your partner. The questionnaires will be posted to you to complete at home. With them will be a reply-paid envelope so you can post them back to me. They should take no more than 40 minutes to complete.

Most participants will only be required to complete the questionnaires. However, I would also like to interview some patients and their partners. If you are willing to take part in this, I would arrange to interview you and your partner somewhere convenient for you, most likely your own home. The interview will focus on your experience of receiving a diagnosis of cancer, including how both you and your partner feel about your cancer and how it has affected both your lives. The interviews would last about 90 minutes, which will include an hour joint interview with you and your partner together and two fifteen minutes individual interviews with you and your partner separately. I would like to interview you both together to understand your joint

¹ Partners received an information sheet with the same content but slightly different wording

experience of adjusting to the cancer, however I recognise that people's experiences are not identical to their partners and I would like to make sure that I capture your individual perspectives, which can be easier in separate interviews. I would need to tape record these interviews so that I can use what I learn from our discussion in my research.

Are there any risks in taking part?

There are no risks involved in taking part in this study. Your involvement in the study would be no more than completing three sets of questionnaires or completing the questionnaires and taking part in an interview. You have the right to omit or refuse to answer any question that is asked of you. Before deciding to take part in the interview, you may wish to consider how you and your partner feel about discussing your experience of your cancer. If you believe you would find the discussion distressing you may prefer to only complete the questionnaires, or not take part in the research. If you decide to take part in the study, you are still free to withdraw at any time.

Are there any benefits in taking part?

The study will not be of direct benefit to you but we hope that the knowledge gained will help us to develop better ways to improve quality of life in people with cancer and their partners.

What if I am unhappy or there is a problem?

If you are unhappy with the way you are treated by the researcher and wish to complain the normal National Health Service complaints mechanism will be available to you.

Will my participation be kept confidential?

If you decide to participate in the study, all the information collected about you will be kept strictly confidential. It will be coded with an anonymous ID number so that it cannot be identified and will be stored securely using locked filing cabinets and password protected computers. Your personal details and the information linking the ID number to your identity will be kept separate from the questionnaire and interview information. All information will be destroyed after a period of three years.

The interviews will be audio-taped and what is discussed will be typed up so that I can analyse it. You can have a typed copy of what was discussed, and you can also ask for sections of the interview not to be used. Your names and any information which could be used to identify you or your partner will not be included. Some quotes from your interview may be used in the final report and any associated publications but you will not be identifiable in any way. No information disclosed in individual interviews will be shared with the other partner.

If I learned that you or someone you know had been harmed or was in serious danger of being harmed, I would need to inform the appropriate agencies.

What will happen to the results of the study?

We expect to publish the results of this research in scientific journals, and I will be using the results to obtain a degree (Doctorate in Clinical Psychology) at the University of Leeds. You will not be identified in any report or publication. At the end of the study you will be sent a summary of the findings and given details of any report that is to be published as a result of this study.

If you have any questions about the study, please contact:

Claire Mitchell, Clinical Psychology Training Programme, Leeds Institute of Health Sciences,
The University of Leeds, Room G.04, Charles Thackrah Building, 101 Clarendon Road,
Leeds, LS2 9LJ. Telephone: 07599 081 193. Email: umclmi@leeds.ac.uk.

Thank you for taking the time to read this information sheet.

Please keep this sheet in a safe place. You may need it to contact me.

Appendix 9: Consent Form²

Patient identification number:

PATIENT CONSENT FORM

Title of Project: Patient and partner perceptions of the patient's cancer and their association with quality of life

Name of Researcher: Claire Mitchell

(Please tick the boxes)

YES NO

I have read the Patient Information Sheet

I have received enough information about the study

I understand that I am free to withdraw from the study at any time, without having to give a reason, and without it affecting my medical care

I agree to my partner being approached to request their participation in the study.

I agree to take part in the **questionnaire study**.

I agree to being **interviewed** jointly with my partner as well as individually and for these interviews to be audio-recorded.

I agree to anonymous quotes from my interview being used in the thesis and any associated publications.

Name of Patient

Date

Signature

Researcher

Date

Signature

² Partners completed a consent form with the same content but slightly different wording

Appendix 10: Invitation Letter

(Headed paper)

Date:

Dear

Re: Research Project

You have been sent this information pack by (insert name of recruiting nurse)

I am interested in finding out more about what patients and their partners think about the causes and effect of their cancer, and I would very much like to hear your views. I am therefore writing to give you some information about the research project and to invite you and your partner to take part in the study.

Enclosed with this letter are some information sheets which I would be obliged if you could take the time to read through. When you have read the information sheets, I would be grateful if you and your partner would let me know whether or not you are interested in finding out more about this project. To do this, please complete the tear off slip at the bottom of this letter and return to me in the freepost envelope provided. Alternatively, you can contact me on the telephone number or email address provided below. I have not been provided with any of your details so can you please include your address/contact details in order for me to be able to send you further information.

Thank you for your time.

Yours sincerely

Claire Mitchell (MSc)
Psychologist in Clinical Training
Tel: 07599 081 193
Email: umclmi@leeds.ac.uk

Research

Are you both interested in taking part in the above project? Yes No

Patient name: _____ Partner name: _____

Patient signature: _____ Partner signature: _____

Please provide your contact details below:

Address:

Contact Telephone Number: