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HEALTH BASELINE COMPARISONS AND QUALITY OF LIFE IN PEOPLE WITH CANCER

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Abstract:
Health Baseline Comparisons and Quality of Life in People with Cancer

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This programme of research involved the development of a new health psychology concept: health baseline comparisons (HBCs). This is defined as the comparative baselines used to assess subjective health status. The following broad research questions were tested: Which HBCs are adopted by individuals with cancer?; What are the implications of different HBCs for quality of life (QoL) and other types of well-being?; How stable are HBCs throughout a course of treatment?

A mixed-methodology approach was adopted to address the research questions. Five studies were conducted, all but the initial pilot study involving a clinical sample of people with cancer. A questionnaire to measure the use of different HBCs was developed and pilot tested, before being used to examine HBCs in people with breast and prostate cancer. On further refining the HBC construct, the questionnaire was re-validated and used to explore HBCs in women undergoing chemotherapy for breast cancer. The extent to which HBCs predicted QoL and psychological well-being was also examined in these studies. The stability of HBCs was sought from the same women two-months post-chemotherapy, focusing on associations with QoL and emotional well-being.

The cross-sectional and longitudinal findings obtained in the first four studies were supplemented by a series of semi-structured interviews with a purposive sample of women from the longitudinal study. Interview transcripts were analysed via interpretative phenomenological analysis.

Five categories of health baselines emerged from this programme of research: social; social comparison; biological; illness-specific; and turning to others. Some evidence was found that HBCs can change over time or be affected by illness and its treatment. Some HBCs, particularly social comparison and illness-specific baselines, were found to be significant predictors of QoL and psychological well-being, but the variance accounted for in these outcomes was generally small.

Although the HBC questionnaire had acceptable internal consistency and reflected the experiences of people during cancer treatment and in the survivorship period, evidence was also found that the type and pattern of HBCs are subject to individual differences. This indicates that assessment of the construct also requires a qualitative and personalised component. The implications of the findings for the development of interventions are discussed and ideas for future research explored.

Preface

Health is among the top five priority areas for many people, as is the health of significant others (Bowling, 1995). Good health is a pre-requisite for engagement in other life priorities, including relationships and activities of daily living. Rarely a day goes by without health issues appearing in the news or on the front page of popular magazines. Health is not just an individual priority, but a national priority.

Healthcare has primarily been informed by the biomedical model, but the value in obtaining subjective evaluations of health status is widely acknowledged. Little is known, however, about how subjective health status is formed. Whilst there is a wealth of insight into the predictors of health behaviours (i.e. the Health Belief Model; Rosenstock, 1974) and ways of coping with threats to health (i.e. the Protection Motivation Theory; Rogers, 1975), there is a paucity of literature that examines the cognitive processes involved in health evaluations.

In an effort to explore the ways in which people evaluate their health, the concept of 'health baseline comparisons' (HBCs) (i.e. comparative points of reference) has been introduced. It is argued that HBCs play a key role in the cognitive process involved in evaluating personal health status. In exploring this line of enquiry, the concept of HBCs has been applied to cancer in this thesis. The rationale for this is that in order to understand how people evaluate their health, it is important to understand how they react to illness. It is also important to understand how health baselines might change when confronted with chronic illness and the side-effects of treatment.

In an effort to find evidence in support of health baseline comparisons, five studies have been conducted, which are presented within this thesis. Firstly, Chapter 1 presents a review of the literature, introduces the concept of health baseline comparisons (HBCs) and discusses its development by a review of the relevant literature. Chapter 2 (Study 1) examines the utility of the health baseline comparison concept through the development and pilot testing of a questionnaire designed to measure HBCs – the Health Baseline Comparison Questionnaire (HBCQ). This was subsequently utilised to examine the existence and salience of health baselines in people with breast and prostate cancer (Chapter 3; Study 2a and 2b). Chapter 4 (Study 3) describes further modification and revalidation of the instrument, based on greater insight into the HBC construct obtained by quantitative data and qualitative feedback from participants. Chapter 5 and 6 (Study 4a and 4b) present longitudinal data that examines the stability of health baselines, as well as their salience and impact on quality of life during chemotherapy and two-months post-chemotherapy, in a sample of women with breast cancer. The final study is presented in Chapter 7 (Study 5). This utilises interpretative phenomenological analysis to examine five case studies that describe the experiences of a sample of women who took part in the longitudinal component of this research. To conclude, Chapter 8 provides a discussion of the findings of these studies and their potential application in various healthcare domains. The chapter concludes by discussing several issues emerging from this programme of research, as well as highlighting directions for further research.

Publications and Contributions to Knowledge

The following articles, conference presentations, and invited talks were derived from skills and knowledge gained during research for this thesis.

Refereed Articles in Academic Journals:

- **Davies, N.J. (2009)** Cancer survivorship: Living with or beyond cancer. Cancer Nursing Practice, Volume 8, Number 7, pp. 29-34.

- **Davies, N.J. (2009)** Measuring health-related quality of life in cancer patients, Nursing Standard, Volume 23, No. 30, pp. 42-49.

- **Davies, N.J., Kinman, G., Thomas, R.J., Bailey, T.A. (2009)** Health Baseline Comparison Theory: Predicting Quality of Life in Breast and Prostate Cancer. Health Psychology Update, Volume 17, Issue 3, pp. 3-12.

- **Davies, N.J. (2008)** Questionnaire design in health research. Health Psychology Update, Volume 16, Issue 4, pp. 62-64.

- **Davies, N.J., Kinman, G., Thomas, R.J., and Bailey, T.A. (2008)** Information satisfaction in breast and prostate cancer patients: Implications for quality of life. Psycho-Oncology, published online at http://www3.interscience.wiley.com/cgi-bin/abstract/117871474/ABSTRACT.

- **Davies, N.J. (2008)** Prostate cancer. Nursing Standard, 19-25;22(28):59.

Commissioned Systematic Reviews:

- **Davies, N.J. and Batehup, L. (2010)** Self-management support for cancer survivors: Guidance for developing interventions. An Update of the evidence. Macmillan Cancer Support, NCSI.

- **Davies N.J. and Batehup L. (2009)** Cancer Follow-Up: Towards a Personalised Approach to Aftercare Services. National Cancer Survivorship Initiative, Macmillan Cancer Support, November 2009.

- **Davies, N.J. (2009)** A Structured Review of Outcome Measures for a Cancer Self-Management Programme: Patient, Service, and Commissioner Outcomes – Macmillan Cancer Support, April 2009.

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- Davies, N.J., Kinman, G., Thomas, R.J., Bailey, T.A. (2007) Health baseline comparison theory: Quality of life in breast and prostate cancer. Division of Health Psychology Annual Conference, University of Nottingham, September 2007.

- Davies, N.J., Kinman, G., Thomas, R.J., Bailey, T.A. (2007) Health baseline comparison theory: Quality of life in breast and prostate cancer. PsyPAG Conference, London, July 2007.

- Workshop on self-management support for cancer survivors (2010), Cancer Network Development Programme, Heathrow, March 2010.

- Seminar on Quality of Life (2008), University of Bedfordshire, April 2008.

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Chapter 1

Introducing Health Baseline Comparison Theory: Potential Utility within Psycho-Oncology

The first chapter of this thesis introduces Health Baseline Comparison (HBC) theory and the literature within the field of health psychology that influenced its development. The potential role of HBC theory in the quality of life and subjective health status of individuals experiencing chronic illness is examined, with specific focus placed on its role within the field of psycho-oncology. Before introducing this new theory, a critique of Social Cognition Models (SCMs) will be presented. A number of gaps are identified within these models which, it is argued, HBC theory has the potential to fill. A review of the psycho-oncology literature will follow, focusing on breast and prostate cancer epidemiology and adjustment via quality of life (QoL) outcomes.

Traditional and contemporary methods that have been utilised to assess adjustment to cancer via QoL outcomes will be reviewed. The potential for relationships between HBC theory, subjective health status and QoL outcomes will be discussed, with a specific focus placed on the validity of HBC theory in explaining individual experiences of adjustment to cancer and its treatment. The development of a pilot questionnaire designed to measure HBCs will be outlined, but the value of combining quantitative with qualitative approaches and the need for longitudinal data will be emphasised. Finally, the aims and objectives of this programme of research are presented, followed by an outline of subsequent chapters.

1.1.   Subjective Health Status

Subjective health refers to self-assessed health status based on the evaluation of personally relevant health-related information, as opposed to evaluations made by others or based on clinical tests. The way in which people evaluate their health status and the factors that influence these evaluations underlie the majority of theories and concepts within health psychology. However, little is known about the underlying processes involved in forming subjective health (Baron-Epel and Kaplan, 2001). This programme of research is anticipated to increase knowledge of this process by investigating subjective health during illness, since those factors that influence health status evaluations are likely to be more salient when health is challenged via illness, or threats of illness. Indeed, self-regulation theory (Leventhal, Brissette, and Leventhal, 2003), defined as *'those processes, internal and/or transactional, that enable an individual to guide his/her goal-directed activities over time and across changing circumstances'* (Karoly, 1993, pp.23–52), assumes that given a health crisis or general change in health status quo, an individual will be motivated to solve this problem in order to re-establish a state of normality.

Support for self-regulation theory has been demonstrated in the field of psycho-oncology. For example, research has demonstrated that men with prostate cancer sometimes self-regulate by using complementary and alternative therapy in attempts to maintain or improve health (Porter and Diefenbach, 2009). In contrast, threat representations that include genetic predisposition as causing illness are sometimes seen as uncontrollable, activating a belief that there are no active coping procedures that will reduce the health threat (Nelkin and Lindee, 1996; Shiloh, Rashuk-Rosenthal, and Benyamini, 2002), subsequently limiting self-regulatory efforts. Of particular relevance to the current programme of research is the concept that effective health self-regulation is dependent on precise and valid personal health status evaluations (Graser, 2005).

The importance of accurate evaluations of personal health status is also highlighted in literature on subjective health status. Research findings indicate that subjective evaluations of health status are consistent predictors of objective health status. From early to more recent research, self-reported health status has been found to predict mortality (Grant, Piotrowski, and Chappell, 1995; Idler and Asngl, 1990; Millunpalo, Vuori, Oja, Pasanen, Urponen, 1997; Pijls, Feskens, and Kromout, 1993; Romelsjo, Kaplan, Cohen, Allebeck, and Andreasson, 1992; Wolinsky and Johnson, 1992); disability (Idler and Kasl, 1995); illness (Ferraro, Farmer, and Wybraniec, 1997; Shadbolt, 1997); and hospitalisation (Romelsjo et al., 1992). Furthermore, this association remains even after controlling for other major predictors of health status such as demographic factors (i.e. age, gender, and socio-economic status), objective measures of health (i.e. diagnosed major illness, laboratory measures of disease, and mental health), and social support (Grant, et al., 1995; Pijls et al., 1993; Schoenfeld, Malmrose, Blazer, Gold, and Seeman, 1994). The extensive and ever-growing evidence for the utility of measuring perceived health provides support for research that aims to gain further insight into the influences behind how people achieve their perceived health status.

Kelly and Ratner (2005) examined responses to the commonly utilised single-item measure of self-reported health: 'In general how would you rate your health?' Responses were either: Excellent, very good, good, fair or poor. The study aimed to assess how participants established a self-reported health rating, something which had in the past prompted some theorising but very little systematic research (Appels, Bosma, Brabauskas, Gostautas, and Sturmans, 1996; VanderZee, Buunk, and Sanderman, 1995). Kelly and Ratner found that one of the main influences on health status evaluations was social comparisons.

Social comparison theory was first developed by Festinger in 1954. It s described thus: *"There exists in the human organism, a drive to evaluate his opinions and abilities"* (p. 117). Festinger argued that people tend to make comparisons with similar others, but have a tendency to engage in 'upward comparisons' (i.e. comparisons with people who are viewed as being superior to them on a particular comparative dimension). In 1981, Wills expanded social comparison theory by introducing the concept of 'downward comparisons,' where people compare themselves to people they view as being inferior

on a particular comparative dimension. Kelly and Ratner's research on subjective health status demonstrated that health status evaluations are frequently the result of different types of social comparison. They claim that these comparisons vary in terms of type (i.e. with whom), direction (i.e. upward or downward), and magnitude (i.e. comparison made with one person or many people).

Whilst Kelly and Ratner (2005) have provided some insight into how people establish a perceived health status, their sole focus on social comparisons leaves little room for other influencing factors. There is no doubt that social comparisons are influential in human judgment-making and self-evaluations (Festinger, 1954; Mussweiler, 2003a; Suls et al., 2002), but there is evidence that other influences are important in forming self-evaluations of health status, such as self-efficacy (Bandura, 1997) and self-concept (Greve, 2000). Indeed, Kelly and Ratner (2005, p. 4) acknowledge that *"something other than social comparison is important in the determination of one's response"* [to the self-reported health question]. Although they highlight the influence of perceived 'poor health behaviour' (i.e. smoking, lack of exercise) on subjective health status, the nature of these potential determinants is not examined.

The importance of subjective health is also recognised outside of the discipline of health psychology and within government policy pertaining to patient-reported outcome measures (PROMs). PROMs are questionnaires that provide a means of eliciting health-related information from the patient perspective. The new Standard NHS Contract for Acute Services, introduced in April 2008, includes a requirement to report from April 2009 on PROMs for patients undergoing primary unilateral hip or knee replacements, groin hernia surgery or varicose vein surgery. Furthermore, the Department of Health (DH, 2009a) has highlighted PROMs as being especially useful in monitoring long-term health conditions.[1] Not only can subjective measures of health and well-being be used to predict treatment outcomes, but they can also help assess the efficacy of different treatment and service models.

1.2.   Social Cognition Models

Self-reported health status has frequently been explored via social cognition models (SCMs), which argue that behaviour is a function of a person's perceived reality (Fiske and Taylor, 1991). In this instance, that health behaviour is driven by a person's perceived health status.

The Health Belief Model (HBM; Rosenstock, 1966) is the oldest of the SCMs and the foundation of other models that are frequently applied in healthcare settings, such as Protection Motivation Theory (PMT; Rogers, 1975). The HBM model emphasises two aspects of an individual's response to threat of illness: a) perceptions of illness threat

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[1]The DH commissioned the PROMs Group of the University of Oxford (including the author of this thesis) to review the evidence for PROMs in predicting outcomes for asthma, chronic obstructive pulmonary disease, diabetes, epilepsy, heart failure, stroke, and cancer.

and b) evaluation of behaviours to counteract the threat. Thus, the model stipulates that health behaviours can be predicted from the way an individual appraises the risk of illness. Threat perceptions are thought to be dependent on beliefs of perceived susceptibility to the illness and perceived severity of the consequences of the illness. The HBM has been applied in a number of areas, including illness-protective health behaviours such as exercise (Wallace, 2002), adherence to self-management (Gillibrand and Stevenson, 2006), and mammography (Paraska, 2006).

The HBM has demonstrated particularly strong utility in predicting attendance at breast-screening. One study demonstrated that women with a genetic mutation linked with breast cancer made changes to their lifestyle based on their perceived susceptibility to breast cancer being high (Spector, 2007). Another study demonstrated that threat perceptions are predictive of testicular self-examination in undergraduate students (McClenahan, Shevlin, Adamson, Bennett, and O'Neill, 2007). In contrast, a systematic review by Yarbrough and Braden (2001) concluded that the application of the HBM was inconsistent and that at best it explained 47% of the observed variance in breast-screening behaviour when socio-economic status was included. Without socio-economic status, the predictive power was low, ranging from 15-27%.

Protection Motivation Theory (PMT) overlaps the HBM with the constructs of perceived susceptibility and severity, but adds a dimension of fear-arousal that is purported to enhance appraisal of threat (Rogers, 1975). The appraisal of susceptibility and severity is assumed to be a linear process, which is then followed by coping appraisal, involving response efficacy (i.e. the potential effectiveness of the coping behaviour) and self-efficacy (i.e. the belief that one has the ability to carry out the coping behaviour successfully). The outcome of these appraisals can result in adaptive action in the form of protection motivation, or maladaptive action in the form of denial or avoidance of the health threat (i.e. evasion of breast screening through fear of being told one has cancer).

Support for the PMT has been demonstrated in parental safety behaviours (Beirens, Brug, Dekker, den Hertog, and Raat, 2008), adherence to physical rehabilitation (Grindley, Zizzi, and Nasypany, 2008), and sun protective behaviour (Prentice-Dunn, Mcmath, and Cramer, 2009; Azzarello, Dessureault, and Jacobsen, 2006). However, research has also demonstrated the relationship between threat appraisal and coping appraisal to be much more complex than the PMT proposes. In particular, it has been argued that the outcome of these appraisals depends on which stage of the decision-making process an individual is at (Seydel et al., 1990). For example, women who had received information about breast screening were more likely to be influenced by response efficacy and self-efficacy, whilst women who had not received such information tended to be more influenced by perceived susceptibility and self-efficacy (Seydel et al., 1990). Furthermore, as argued by Vernon et al. (1990), inducing benefits and gains via informing women of the efficacy of breast-screening in detecting cancer can work just as effectively as invoking fear. Indeed, as demonstrated with the HBM model, fear can sometimes be counteractive in the adoption of health behaviours

(Sheeran and Abraham, 2003). People may be over-exposed to fear-related imagery, resulting in habituation and resistance to the health message.

Evidence has demonstrated the utility of the HBM and PMT in a number of areas within the field of health psychology, yet there is equally an extensive array of research refuting their utility. Indeed, it was an identified weakness within these models that led to this current programme of research. It is argued that both models fail to acknowledge individual differences in the reference points that people utilise when appraising health status and health threats. This weakness will be discussed in more detail, following an outline of the literature pertaining to one of the most frequently assessed outcomes of subjective health status – quality of life.

1.3. Outcomes of Subjective Health Status: Quality of Life

When examining the implications of self-reported health status and subsequent health behaviours, a key issue is whether subjective health predicts adjustment to illness, specifically in terms of quality of life and well-being outcomes. Quality of life (QoL), though widely examined within the literature, is ill-defined and poorly conceptualised. As far back as 384-322BC, Aristotle contemplated the meaning of QoL: *"Both the multitude and person of refinement . . . conceive "the good life" or "doing well" to be the same thing as "being happy." But what constitutes being happy is a matter of dispute . . . some say one thing and some another, indeed very often the same man says different things at different times: when he falls sick he thinks health is happiness, when he is poor, wealth."* Yet, despite being contemplated for centuries, there remains a lack of consensus surrounding QoL. Farquhar (1995) carried out a review of the range of definitions of QoL within the health discipline and found three categories of QoL: global definitions (i.e. QoL referred to in general terms, e.g. life satisfaction); component definitions (i.e. QoL divided into dimensions, e.g. health, psychological well-being, social well-being); focused definitions (i.e. where the emphasis is on one or two of the possible component definitions). Component definitions include health-related QoL (HRQoL) and, like general QoL, are subject to considerable variation.

The most common conceptualisation for HRQoL is that which has been proposed by the World Health Organisation (WHO) Constitution: "*the perception by individuals of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*" (WHO, 1993). WHO also clarify that "*It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationships to salient features of the environment.*" Further definitions of HRQoL that highlight the variation within the concept can be seen in Table 1.1.

Table 1.1: Definitions of HRQoL

Author	Definition
Cella and Tulsky (1993)	*"Patient's appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be possible or ideal"*
Gotay et al. (1992)	*"a state of well-being which is a composite of two components: the ability to perform everyday activities which reflect physical, psychological and social well-being, and patient satisfaction with levels of functioning and the control of disease and/or treatment related symptoms"*
Testa and Simonson (1996)	*"The physical, psychological, and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations, and perceptions"*
Schipper (1990)	*"a pragmatic, day to day, functional representation of a patient's physical, psychological, and social response to a disease and its treatment"*

Despite the inconsistency in how HRQoL is conceptualised, there is consensus that it is a multidimensional concept. These dimensions have been outlined by Fitzpatrick, Davey, Buxton, and Jones (1998): physical function; symptoms; global judgments of health (i.e. perceived health status); psychological well-being; social well-being; cognitive functioning; role activities (e.g. employment, household management); personal constructs (e.g. life satisfaction, spirituality); and, satisfaction with care.

1.3.1. Measuring Quality of Life

Methods for measuring HRQoL usually involve one or a combination of three systems (Table 1.2). The method used depends on whether the concept is assessed subjectively, objectively, or via external conditions.

Table 1.2: Measurement of HRQoL (Schalock, 2004, p. 207)

System Level	Measurement Focus	Measurement Strategy
Microsystem	Subjective nature of HRQoL (i.e. personal appraisals)	• Satisfaction surveys • Happiness measures • Perceived health
Mesosystem	Objective nature of HRQoL (i.e. functional assessments)	• Rating scales of levels of functioning • Observation • Medical tests • Role status (i.e. education, employment)
Macrosystem	External conditions (i.e. social indicators)	• Standard of living • Employment rates • Mortality rates • Life expectancy

Traditionally, assessing health outcomes has been approached via the mesosystem, such as using objective data from laboratory or clinical tests (Higginson and Carr, 2001). Such measures provide valuable information on the disease, but exclude the individual and their social context. Thus, the primary methodology within health psychology is quantitative in nature, which is typically a scientific or positivist approach to research. However, there has been a noticeable increase in the use of qualitative approaches, which are more interpretive or constructivist in nature.

One of the key differences between quantitative and qualitative approaches to measuring subjective health status and QoL is in levels of internal validity (i.e. the validity of causal inferences) and external validity (i.e. the validity of generalising inferences to real-life situations). Quantitative methods generally have high levels of internal validity, meaning that strong conclusions and often causal inferences can be made (McGrath and Johnson, 2003). This is achieved by using precise measures and controlling variables via experimental conditions; thus, alternative explanations for results are controlled or excluded. However, increased internal validity can come at the cost of reduced application to real-life situations (i.e. reduced external validity). In contrast, qualitative data is usually analysed within the context of real-life, sometimes at the cost of precision and control of research variables. The benefits of this approach, however, are that examining phenomena in context enhances the identification of meanings, processes, and relationships that might be fundamental in understanding the concept being explored.

Despite these fundamental differences between approaches, more recently there has been recognition in the merits of combining the two approaches via a mixed methodology (Yardley and Bishop, 2008). It could even be argued that it is not only advantageous, but morally appropriate for researchers to take a mixed methods

approach in order to gain a comprehensive understanding of the human experience (Yardley and Bishop, 2008). More specifically, Yardley and Bishop (2008) have argued that if differences in the theoretical underpinnings of quantitative and qualitative approaches are considered throughout the design of research, these contrasting methods can complement rather than hinder one another. For example, interpretative research can be useful in testing the validity of a concept as well as providing meaning to data gained from quantitative research.

Furthermore, as highlighted at the 2008 International Society for Quality of Life Research (ISOQOL) conference, there needs to be greater recognition of mixed methodology for questionnaire design (Fayers, 2008). Breadth of coverage is essential since omitting an important item is tantamount to omitting part of the construct being measured (Fayers, 2008). On the other hand, a mixed methods approach to research ensures that the correct concept is being measured (i.e. qualitative) and that this concept is being measured effectively (i.e. quantitative). Additionally, a mixed methods approach complements the national service frameworks (NSFs), which are now in place across a number of NHS services and require a greater effort to listen to the 'expert patient' (DH, 2009b).

In terms of quantitative methods of measuring health outcomes, another distinction comes in the form of cross-sectional versus longitudinal design. Cross-sectional measures are taken at one-point in time whilst longitudinal measures are taken across different points in time. Thus, whilst cross-sectional data might help establish the existence or use of a particular concept as well as relationships between concepts fairly easily, longitudinal data can provide insight into the stability or flexibility of a concept over time as well as the temporal sequencing of phenomena under investigation. The strongest types of longitudinal study are panel studies, whereby the same individual provides data at two or more points in time (Polit and Beck, 2005). The strength of this design is in the amount of information provided in terms of patterns in change and reasons for change. The ease of the cross-sectional approach and the brevity of the longitudinal approach are the obvious advantages of these designs. The greatest disadvantage of cross-sectional design is possible cohort effects, whilst longitudinal studies can be prone to drop-out, practice effects, and response shift (i.e. a change in the conceptualisation of HRQoL over the course of a disease trajectory; Schwartz and Sprangers, 1999).

Taking into account the recent recognition of the benefits of combining research approaches and methodologies that are distinct, a mixed methodology approach will be adopted in this programme of research. It is anticipated that the proceeding discussion on gaps within the literature and the subsequent introduction of a new theory will benefit from such an approach. It is anticipated that qualitative data will facilitate theory development and understanding, whilst quantitative data will enhance the statistical basis for which the theory evolves. In turn, adopting both cross-sectional and longitudinal quantitative designs at various stages of the research process is likely to provide a broader range of data pertaining to subjective health status and the temporal sequencing of subjective health status evaluations.

1.4.   Gaps in Research: Cognitive Processes Influencing Subjective Health

There is extensive research into the behavioural and QoL outcomes of subjective health status (1.2.; 1.3.). However, fundamental gaps within this research have been identified. In particular, little research has examined the cognitions and processes that influence subjective health status. This programme of research is based on the belief that further insight is required into this issue in order to enhance the understanding of health-related quality of life.

Although the social cognitive models introduced earlier in this chapter (1.2.) consider other influencing factors besides perceived susceptibility and severity (e.g. individual differences in demographics), they fail to acknowledge individual differences in the reference points that people utilise when appraising health status and health threats. For example, not only does the HBM not acknowledge the role of past behaviour in influencing cognitive evaluations of threat appraisal, it also fails to consider the cognitive processes involved in subjective health status that might precede an evaluation of perceived illness susceptibility and severity. Without this process of health status evaluation, it is argued that an individual may feel there is no need to consider potential threats to health unless a medical problem arises. Even then, actual behaviour change or action to carry out protective behaviours may not be implemented until the individual has updated their perceived health status to include the new information.

Failure to acknowledge the reference points that people utilise when appraising health status is also evident within tools used to measure self-reported health status. In particular, self-report measures have been criticised for failing to acknowledge a phenomenon known as 'response shift.' Response shift has been described as a change in internal standards, values and the conceptualisation of life quality over the course of the health or disease trajectory (Schwartz and Sprangers, 1999). The working definition of response shift refers to a change in the meaning of one's self-evaluation of a target construct as being the result of: (a) a change in the respondent's internal standards of measurement; b) a change in the respondent's values; or (c) a redefinition of the target construct (i.e. reconceptualisation). Schwartz and Sprangers apply response shift to how people estimate their health status and QoL using questionnaires. The concept of response shift suggests that changes in questionnaire outcomes may not necessarily reflect the outcome of a particular variable or intervention, but more so a shift in the respondent's beliefs about the concept that is being measured. At present, it could be argued that much of the literature on subjective health status and QoL outcomes is ambiguous in that it is based on self-reported measures that do not account for changes in personal beliefs and standards.

In summary, current health models and methods of assessing subjective health outcomes that purport to explain the relationship between cognition and behaviour overlook a potentially important factor; they fail to account for other influences involved in perceived health status. It is proposed that before perceived health status is formed,

it is necessary for a cognitive process of health status evaluation to occur. More specifically, a baseline or benchmark is sought as a comparison point for evaluating one's current health status. The SCMs or QoL literature reviewed above fail to acknowledge this cognitive process that is proposed to precede subjective evaluations of health status.

This programme of research aims to provide new insight into the identified health models and health outcomes in two ways: 1) the development of a theory that has the potential to enhance insight into subjective evaluations of health status: Health Baseline Comparison Theory; and 2) the design of a questionnaire to measure the baselines adopted to evaluate health status: the Health Baseline Comparison Questionnaire. It is anticipated that the theory will provide further insight into the factors that influence perceived health status and, accordingly, subjective health outcomes, whilst the questionnaire could offer insight into the most influential comparative baselines that predict personal health status and how these factors might change during the course of chronic illness.

1.5.   Introducing Health Baseline Comparison Theory

The influences involved in the formation of subjective health status inspired this programme of research. Based on the identified gaps within the literature and the conjecture that changes in standards or reference points (i.e. health baselines) might influence subjective health status, a new theory has been devised: Health Baseline Comparison Theory.

The term 'health baseline comparison' refers to the baseline or comparison point which is used by people to evaluate their current health status. This theory purports that whether people perceive themselves to be more or less 'healthy' depends on the standard of comparison. Based on a review of the literature, a number of potential baseline influences could be identified. Indeed, the literature suggests that there are a range of influences on subjective health status, which tend to be biological or social in nature.

1.5.1. Biological Baselines

Possibly the most frequent method of evaluating personal health status is via biological influences, whether they be symptoms or changes in appearance or physical functioning. For example, the majority of breast cancer clinical assessments are first preceded by the self-discovery of a lump or the presentation of symptoms (Morris, Wheatley, and Ingram, 2008). Nevertheless, worthy of note is the fact that biological influences on subjective health status are not necessarily the most effective method of detecting health problems. For example, confusion surrounding the symptoms of a cancerous lump, in particular the misconception that cancerous lumps are always

painful, has been found to cause delays in seeking medical assistance (Arndt, Stürmer, Stegmaier, Ziegler, Becker, and Brenner, 2003; Burgess et al., 2001; Facione, Miaskowski, Dodd and Paul, 2002; Lam, Tsuchiya, Chan, Chan, Or, and Fielding, 2009). Similarly, the slow-growing and progressive nature of some diseases means that they can frequently be asymptomatic during the early stages, as is often the case with prostate cancer (Chodak, 2006). Detection of prostate cancer is further complicated by the fact that many men over the age of 50 years will experience symptoms independently associated with both prostate cancer and ageing: difficulty passing urine, urgency in passing urine, 'dribbling,' and passing urine more often, especially at night. However, these symptoms are often the result of benign prostatic hyperplasia (also known as an enlarged prostate) (Macmillan Cancer Support, 2007). Similar misattributions may also occur with neuromuscular or musculoskeletal diseases such as arthritis and myasthenia gravis (serious muscle weakness), whereby bone stiffness and changes in physical ability can be mistaken for natural ageing (Vincent et al., 2003).

Biological influences on subjective perceptions of health status can be extremely anxiety-provoking for a number of reasons. Firstly, symptoms or physiological changes often require medical investigation. Secondly, the waiting time between test results and follow-up appointments can be a time of great stress. For example, levels of anxiety are initially high in women who find breast lumps (Vaidyanathan et al., 2002), but can be exacerbated by the proceeding medical investigations and waiting times (Poole et al., 1999).

Moreover, the initial symptoms of prostate cancer can be physically and psychologically uncomfortable for men and can also interfere with work and social activities due to a need for sudden and drastic lifestyle changes. It is often such symptoms that alert the GP to refer their patient to an Urologist for further investigations, these most routinely being digital rectal examinations (DRE), prostate specific antigen (PSA) testing (a blood test for prostate specific antigen, which is often raised in prostate cancer), trans-rectal ultrasound biopsy (TRUS; an ultrasound examination of the prostate using a probe inserted into the rectum), and needle biopsy (Donovan, Frankel and Faulkner, 1999; Martin et al., 2006). As with breast cancer, the biological implications of the diagnostic process can be extremely anxiety-provoking, before obtaining the test as well as while waiting for test results (Burford, Kirby and Austoker, 2008; Chamberlain, Melia and Moss, 1997; Roth et al., 1998).

The literature supports the hypothesis that biological or physiological factors such as symptoms or a change in appearance might act as biological baselines (or reference points) that alert an individual to a change in health status. In turn, this could impact QoL in a number of ways, including health anxiety and the subsequent distress of some of the invasive medical procedures that follow seeking medical advice.

1.5.2. Social Baselines

Social comparison theory (Festinger, 1954), briefly defined and discussed in 1.1., was originally developed within the field of social psychology, but has subsequently been utilised in health psychology to examine the impact of evaluating one's health and well-being relative to others. The use of social comparisons has been widely reported by people whose health is under threat (Gibbons and Gerrard, 1991; Wood, Taylor, and Lichtman, 1985; Wood, 1989). A tendency to utilise social comparisons under such circumstances is likely to be associated with the assumptions behind Crisis Theory (Moos and Schaefer, 1984). This suggests that people in crisis are particularly susceptible to external influences. In threatened populations, social comparisons may be utilised for a number of reasons, such as to evaluate the nature and impact of the disease, to learn about treatments, and to evaluate how well they are coping compared to others.

There is some evidence that downward social comparisons are more likely to be utilised by threatened populations (Collins, 1996; Wills, 1981). In a healthcare environment, comparing oneself to a patient who is not doing as well is likely to provide a contrast that signifies one is doing better. For example, people with cancer have been found to rate themselves as superior to other people with cancer on coping skills (Jenkins and Pergament, 1988; Wood et al., 1985) and physical dimensions (VanderZee, Buunk, DeRuiter, Tempelaar, VanSonderen, and Sanderman, 1996). This in turn can facilitate better adjustment (Jenkins and Pergament, 1988; VanderZee et al., 1996), which supports the common assumption that downward social comparisons are self-enhancing (Wills, 1981).

An explanation for this tendency towards downward social comparisons might be partially explained by Taylor's (1983) argument that after a stressful or traumatic event, intense emotions need to be reduced before active problem-solving can take place. Downward comparisons resulting in feelings of superiority might be the most effective way of promptly reducing intense negative emotions. In contrast, upward comparisons have been found to be a useful information-seeking aid, and thus might be adopted later, during the problem-solving phase of coping (Bennenbroek, Buunk, van der Zee, and Grol, 2002). Another possible explanation is offered by Prospect Theory (Kahneman and Tversky, 1979), which introduces the concept of loss-aversion. This is an apparently common phenomenon experienced by human beings, whereby they are more influenced by loss than gain. This has been supported by a number of studies whereby influencing factors in health status evaluations have been demonstrated to change according to age and illness, particularly in terms of maintaining a gain-framed comparator (Kaplan and Baron-Epel, 2003).

Rather than rely on the traditional assumptions that upward comparisons are necessarily negative and downward comparisons are positive, more recent research has demonstrated that both types of comparison can be positive or negative (Buunk, Collins, Taylor, Van Yperen, and Dakof, 1990; Major, Testa, and Blysma, 1991). Buunk et al. (1990) found that 82% of participants with cancer reported making

downward comparisons that made them feel good, whilst 59% made such comparisons but felt bad. In terms of upward comparisons, 78% reported making upward comparisons that had positive outcomes, whilst 40% made upward comparisons that made them feel bad. The proportion of participants feeling good after an upward or downward comparison is relatively similar, leading to much theorising regarding the determinants of whether a social comparison outcome will be positive or negative/adaptive or maladaptive. However, it is worth distinguishing between 'comparison' and 'identification.' The outcome of social comparisons used for finding difference (i.e. comparison) as opposed to similarity (i.e. identification) could influence the interpretation of the findings within this study. Indeed, the selective accessibility model suggests that assimilative responses (i.e. identification) are observed when stimuli are perceived to be similar to a target and that contrastive responses (i.e. comparisons) are observed when stimuli are perceived to be different from a target (Mussweiler, 2003a; Mussweiler, 2003b).

The literature supports the hypothesis that social factors such as other people's health might act as social baselines (or reference points) when evaluating one's own health status. This is especially likely when health has already been compromised by illness and the individual is seeking information from other people with the same illness. In turn, this could impact QoL in a number of ways, including raising fears about potential declines in future health.

It could be argued that these biological and social influences of subjective health status can be categorised as being either intrinsic (i.e. drawing on physiological cues) or extrinsic (i.e. drawing on social comparison cues). Given the research discussed above, it appears that relying on both of these methods to appraise health status can offer advantages and disadvantages. For example, biological cues are more personalised and based on objective changes in health that can be further investigated by medical professionals. On the other hand, possibly because they are so personalised as well as being outside an individuals 'normal' state, relying on biological cues may provoke anxiety (Gram and Slenker, 1992; Lauver and Ho, 1993; MacFarlane and Sony, 1992). Similarly, the literature suggests that relying on social comparison cues may alleviate an individual's health anxiety by providing hope if the comparators are doing particularly well. Nevertheless, the comparator is likely to be fundamentally different in terms of personal circumstances and thus such comparisons can be misguided or even result in greater anxiety if the comparator is doing well (Buunk et al.,1990).

1.6.   The Health Baseline Comparison Questionnaire

HBC theory was first explored through an MSc research project conducted with people living with Rheumatoid Arthritis (RA), 50% of whom had moderate RA, 35% severe and 15% mild (Davies and Kinman, 2006[2]). This exploratory study aimed to answer the

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[2] A paper based on this study is published in Health Psychology Update.

following questions: do people with chronic illness use health baselines when evaluating personal health status?; what type of baselines, or reference points, might people with a chronic illness adopt in forming a subjective health status?; and, are these baselines associated with outcomes relating to adjustment to chronic illness?

In order to answer these questions, it was necessary to construct a questionnaire that would elicit the HBCs adopted by these participants. An exploratory 13-item Health Baseline Comparison Questionnaire (HBCQ) was designed to measure perceived health status and HBCs. The design was guided by the literature discussed above pertaining to biological (intrinsic) and social influences (extrinsic) on subjective health status. Respondents were asked to what extent they agreed with a number of intrinsic and extrinsic health baselines. Intrinsic baseline items included statements such as: 'I am as healthy as personal circumstances permit,' whereas extrinsic baseline items included statements such as: 'I am less healthy than most people I know.'

The sample comprised 16 individuals from an RA internet support group. The HBCQ was thus administered to the participants, along with the COPE Scale (Carver, 1997) to measure the use of particular coping styles and the Arthritis Impact Measurement Scale (AIMS; Meenan, 1982) to measure objective health status and psychosocial adjustment to RA, including anxiety and depression. Not only did this preliminary exploration of HBC theory demonstrate the existence of HBCs in the evaluation of health status among people with RA, but it also revealed significant relationships between HBCs and adjustment outcomes.

Descriptive statistics revealed a high level of agreement with the utilisation of each HBC represented within the questionnaire. Agreement was above 66% on all of the intrinsic baselines and below 50% on all but one of the extrinsic baselines. Therefore, the findings of this study suggested that, although people with a chronic illness undoubtedly draw on extrinsic baselines to determine their health status they may be more likely to utilise intrinsic or personalised baselines.

Significant correlations were found between specific types of HBC and well-being, most notably the more participants relied on social comparison health baselines to evaluate their health status, the greater their levels of depression. The findings also revealed that people who tended to utilise extrinsic health baselines were more likely to rely on maladaptive coping strategies than those who utilised more intrinsic baselines.

Some support for a role for HBCs in psychological adjustment to chronic illness was found, thus justifying further examination of the construct.

1.7.   Further Development of Health Baseline Comparison Theory

The findings of this exploratory research with RA are promising, but the design had limitations and the sample size was small. There is evidently a need to build upon the findings of this earlier study. The current programme of research aims to utilise

quantitative and qualitative methodology to build on the earlier study to gain further insight into the nature and outcomes of the health baselines that are adopted by people with chronic illness when evaluating personal health status. The research will utilise samples of people with breast and prostate cancer, the two most common cancers among women and men, respectively.

The use of such samples to explore HBC theory is based on a number of factors. Firstly, the already cited extensive literature examining comparative processes utilised by people with cancer (1.5.1.; 1.5.2.). Secondly, research on the predictors of psychological well-being of people with cancer is limited (Macmillan Cancer Support, 2008) and testing HBC theory in this context would offer benefits on a wider research scale. Furthermore, cancer is a common chronic disease with known relationships to adjustment difficulties, quality of life, and well-being. Cancer is a potentially life-threatening illness which leaves little time for adjustment; thus, the role of HBCs in outcomes may be more fundamental due to a necessary continual process of adjustment.

Further development of the HBC construct reported in this thesis comprises a mixed methods approach (quantitative and qualitative) within a longitudinal design. The development and refinement of a psychometrically valid questionnaire will be reported that is informed by the study of different samples of people with cancer and the views of healthcare professionals. Relationships between specific baselines assessed by this questionnaire and adjustment to cancer and QoL will be examined. A longitudinal design is utilised that elicits qualitative as well as quantitative data to examine how these identified baselines might change through time and whether these changes are related to changes in quality of life and other outcomes.

It is envisaged that HBC theory will be relevant to chronic illness in general. Nonetheless, this research programme examines the utility of HBC theory within the context of breast and prostate cancer. The next section will focus on the epidemiology of breast and prostate cancer, and the literature pertaining to adjustment, quality of life, and well-being in people with cancer.

1.8.   Cancer

Cancer, in simple terms, is a disorder of cellular growth and occurs when normal cells within the tissues and organs of the body divide and grow uncontrollably, causing a tumour to form. It arises from one single cell progressing from a pre-cancerous lesion to a malignant tumour. This progression from pre-cancerous lesion to cancer results from the interaction between genetic factors and one of three external agents: 1) physical carcinogens (i.e. ultraviolet and ionising radiation); 2) chemical carcinogens (i.e. asbestos, tobacco, arsenic); 3) biological carcinogens (i.e. infections from viruses, bacteria or parasites) (WHO, 2009). Benign tumours remain localised, whereas malignant tumours have the ability to metastasise and spread to other parts of the body. This can cause secondary cancers and mortality through disruption of organ

functions. Since there are over two hundred different cell types within the body, there are over two hundred different cancers (Cancer Research UK, 2008).

In England, 242,200 new cases of malignant cancer (excluding non-melanoma skin cancer) were registered in 2006, 121,600 of which were in males and 120,600 in females; ONS, 2008a). The four most common cancers accounted for over half of all new cases: breast, lung, colorectal and prostate cancer (ONS, 2008a).

Whilst cancer incidence is on the increase, so are prevalence rates. In England, the 3-year average mortality rates for cancer (ages under 75) fell by 18.2% from 1993-2007 (ONS, 2008a). Earlier detection and more effective treatments have led to an increase in survival. Recently published figures on the prevalence of cancer in England illustrate that there were about 1.6 million cancer survivors in 2004, and that 10% of people aged 65 or above are cancer survivors (Maddams Moller and Devane, 2008). The number of cancer survivors is increasing by 3.2% each year, leading to a standardised definition of 'survivorship' being developed; thus, cancer survivors are people *'living with or beyond cancer'* (Macmillan Cancer Support, 2008). The historical assumption of cancer being terminal is no longer applicable as cancer becomes a chronic illness as opposed to a life-threatening disease.

Such advancements in diagnosis and treatment are indeed a magnificent feat for medical science. However, it is important to recognise that this has also resulted in an increase in the number of people living with the often long-term physical and psychological consequences of cancer and its treatment. Quality of life outcomes are thus becoming just as important as 'hard' outcomes such as mortality (Rosenbaum, Fobair and Spiegel, 2006), as has been supported by an increase in evidence showing QoL to be more predictive of cancer survival than measures of performance status (Coates, Porzsolt, and Osoba, 1997; Montazeri et al., 2003; Eton et al., 2003).

1.8.1. Breast Cancer

Breast cancer is the most common cancer in the UK and by far the most common cancer in women; one in nine women will develop breast cancer at some point in their lives (ONS, 2008b). Breast cancer can occur in men but is rare, affecting approximately 290 men annually in the UK (ONS, 2008b). In England, breast cancer accounted for one in three newly diagnosed cases of cancer among women in 2006 (ONS, 2008b). Four in five new cases are diagnosed in women aged 50 and over, peaking in the 55 to 64 year age group. Hereditary breast cancer affects much younger women and an awareness of breast cancer in the family can lead to genetic testing and mastectomy (removal of the breast) as a form of prevention. Hereditary breast cancer is rare, occurring in 5-10% of breast cancer cases (Macmillan Cancer Support, 2008). The most common hereditary breast cancer genes are BRCA1 and BRCA2. By examining the DNA pattern of affected family member's BRCA1 and BRCA2 genes, comparisons can be drawn to normative data on these genes. A change or mutation in

the DNA pattern of one of the genes confirms that the cancer is likely to be caused by a faulty gene.

Earlier detection and improved treatment has resulted in rising survival rates. Five-year survival was 81% between 2000-2004 in England (ONS, 2008b). Since both the incidence and prevalence of breast cancer is high, many women are living with the impact of cancer and its treatment. Indeed, an estimated 550,000 women are alive in the UK having received a diagnosis of breast cancer (Maddams, Moller, and Devane, 2008).

1.8.2. *Prostate Cancer*

Prostate cancer is the most common cancer in men in the UK (excluding non-malignant melanoma), accounting for nearly a quarter (24%) of all new male cancer diagnoses (ONS, 2008b). In England, prostate cancer accounted for one in four newly diagnosed cases of cancer among men in 2006 (ONS, 2008b). The lifetime risk of being diagnosed with prostate cancer is currently 1 in 14 for men in the UK.

There has been a considerable rise in prostate cancer over the last 20 years, primarily due to earlier detection via PSA testing. Prostate cancer is strongly related to both age and genetics. Three-quarters of prostate cancer cases occur in men over the age of 65 and thus this is expected to rise due to increasing life-expectancy (Quinn and Babb, 2002). In terms of genetics, it has been estimated that 5–10% of all prostate cancer cases and 30–40% of early onset cases (men diagnosed <55 years) are hereditary (Bratt, 2002).

The five-year survival rate for those diagnosed with prostate cancer was 76% between 2000 and 2005 (ONS, 2008b). Only one in twenty-five men (4%) will die from the disease, thus quality of life implications are a primary concern for these men.

1.8.3. Cancer Outcomes: Adjustment and Quality of Life

Although there have been tremendous advancements in the detection and treatment of cancer, it still remains a potentially life-threatening disease. Inevitably, being diagnosed with cancer is a stressful experience and requires a high level of emotional and social readjustment (Holmes and Rahe, 1967). Whilst many people adjust well to a cancer diagnosis, prevalence rates of 25-30% for psychological distress are consistently reported (Deragotis et al., 1983; Farber, Weinerman, and Kuypers, 1984; Stefanek, Derogatis, and Shaw, 1987; Zabora et al., 2001). Indeed, the first three months of a cancer diagnosis are thought to be the most distressing, evoking an 'existential plight' whereby an individual desperately seeks to make sense of their current circumstances (O'Connor et al., 1990; Lee et al., 2008).

The initial distress of a cancer diagnosis often reduces over time. Indeed, Shontz (1975) describes a sequence of reactions often experienced following diagnosis of chronic illness: Shock (stunned or bewildered; behaving in an automatic fashion; sense of detachment from situation); Encounter (disorganised thinking and feelings of being overwhelmed; loss; grief; helplessness; despair); Retreat (avoidance strategies, e.g. denial); Adjustment (accept reality). A common feeling reported by people with cancer is fear (Bruera and Kim, 2003; Mehnert, Herschbach, Berg, Henrich, and Koch, 2006). Fear created by the illness is not merely a fear for oneself, but can also include a fear for the well-being of children and other family members. Often, the greatest fear evoked by a cancer diagnosis is the possibility of death; an individual is suddenly faced with their mortality (Spiegel, 1995). Kubler-Ross (1970), who spent much of her career working with people who had cancer, suggested a number of stages that people confronted by their mortality might face: denial; anger; bargaining (i.e. seeking a way out of the situation); depression; acceptance. It has been argued that there is little support for the stages approach to dealing with impending death and that everyone will deal with such a situation differently (Corr, 1993). Nevertheless, the existence of the stages of grief outlined by Kubler-Ross (1970) has been supported in studies with individuals who have cancer (Wilson and Fletcher, 2002), most frequently in terms of the stages of denial (Carver et al., 1993; Cooper and Faragher, 1993; Heim et al., 1997) and acceptance (Berckman and Austin, 1993; Carver et al., 1993).

Uncertainty, defined as *"the inability to determine the meaning of illness-related events . . . a cognitive state created when the individual cannot adequately structure or categorize an illness because of insufficient cues"* (Mishel, 1988, p. 25), is a frequently reported reaction to a cancer diagnosis (Brashers, 2001; Penrod, 2007). Uncertainty in people with cancer has been found to manifest itself in three ways: because of limited or lack of information; concerning treatment choices; and related to everyday life and coping with the disease (Shaha, Cox, Talman, and Kelly, 2008). This uncertainty has been found to be associated with impaired QoL (Gaudine, Sturge-Jacobs, and Kennedy, 2003; Klemm, Miller, and Fernsler, 2000; Wallace, 2003; Clark, Bokhour, Inui, Silliman, and Talcott, 2003), especially characterised by enhanced levels of anxiety and depression (Houldin and Lewis, 2006). Feelings of uncertainty and fear of recurrence have been reported as being long-term implications of a cancer diagnosis (Nelson, 1996; Wonghongkul, Moore, Musil, Schneider, and Deimling, 2000).

Despite the grief, uncertainty, and trauma of a cancer diagnosis, research demonstrates that many people adjust well (Kornblith et al., 2003). There are many hypotheses for why some people with cancer adjust better than others, a common hypothesis being that optimism and 'hardiness' play a role. Indeed, optimism has been associated with lower levels of distress in people with cancer (Carver et al., 1993). Psychological 'hardiness' (Maddi et al., 2009), a proposed component of optimism (Kobasa, 1979), is also thought to be involved in resistance to stressors such as illness. Hardiness is made up of three components, which are thought to be the key to successful coping when under stress: challenge; control; commitment. In this sense, the individual with cancer who adjusts more successfully is likely to perceive the cancer as a challenge as opposed to a threat, thus gaining control of their emotional reactions

and developing a commitment to confront the challenge of diagnosis and treatment. The commitment component of hardiness has been proposed to enhance a person's ability to seek knowledge and support from others when coping with stress (Antonovsky, 1979; Kobasa, 1979). Evidence exists in the way of social support being a potential buffer against disease progression (Turner-Cobb et al., 2000), as well as being positively associated with better psychological well-being (Rodrigue, Behen, and Tumlin, 1994; Stanton and Snider, 1993) and better psychosocial adjustment (Heim et al., 1997).

Both optimism and social support have been explored in terms of coping. It has been theorised that when confronted with a threatening situation, such as a cancer diagnosis, people will first engage in a primary appraisal (i.e. assess the threat) and then a secondary appraisal (i.e. an assessment of potential coping responses) (Lazarus and Folkman, 1984). This process is similar to the social cognitive models critiqued in 1.2. Support for this theory can be found in the estimate that at least 50% of the variance in emotional adjustment to cancer can be explained by coping responses (Glanz and Lerman, 1992). A review of 58 studies assessing coping with cancer identified two general clusters of coping responses commonly found among people with cancer: those that contribute to positive psychological adjustment and those that contribute to negative psychological adjustment (van't Spijker et al., 1997). The cluster of coping responses associated with positive adjustment included confrontation, fighting spirit, and optimism (Ferrero et al., 1994; Grassi et al., 1993; Schnoll, Mackinnon, Stolbach, and Lorman, 1995). Those associated with negative adjustment included passive acceptance, avoidance (Friedman et al., 1991), denial, feelings of loss of control, and fatalism (Ferrero et al., 1994; Grassi et al., 1993). Nevertheless, of note are similar studies that offer contradictory findings, especially in terms of evidence that denial and avoidance can be associated with better emotional adjustment to cancer (Ferrero et al. 1994; Filipp et al., 1990; Heim et al., 1997).

Expanding on the role of optimism in adjustment to cancer, much research has found 'benefit-finding' to be a common experience in this group (Andrykowski, Brady and Hunt, 1993; Cordova et al., 2001). When confronted with their mortality, people sometimes re-evaluate or change their goals and priorities, thus developing a greater appreciation of life (Antoni et al., 2001; Parkes, 1971; Tedeschi and Calhoun, 1995). On the other hand, of particular relevance to the current research programme, there is some evidence that pre-illness optimism can result in less accuracy when evaluating personal health status, whilst evaluations made by pessimists have been demonstrated to predict mortality (Benyamini and Leventhal, 1996). This confirms the hypothesis that pessimists hold more accurate views of themselves and others than optimists do (Taylor and Brown, 1994).

As has been demonstrated, a diagnosis of cancer can produce a vast array of physical and psychological challenges. Furthermore, although advances have been made in treatment options, the treatment experience can also be physically and psychologically demanding.

1.8.4. Cancer Treatment

"Simple truth: to defeat cancer you have to destroy a part of yourself. Radiation destroys tissue. Chemotherapy does all sorts of damage to organs and tissue. Whatever way you attack the cancer, you can't kill it without sacrificing some part of yourself, just as no commander can expect to attack the enemy without taking losses."
(Korda, 1996, p. 57).

Following detection and diagnosis of cancer is the choice of treatment, with the appropriate type of treatment depending on the size and spread of the cancer as well as the age and general health of the patient. A range of treatments are available for breast and prostate cancer, including surgery, radiotherapy, chemotherapy, hormone therapy, and simply 'active surveillance' (also known as 'watchful waiting'). Treatment can be adjuvant (provided alongside the primary treatment to assist treatment efficacy) or neo-adjuvant (treatment provided prior to surgery to reduce the size of the tumour). In order to provide insight into the QoL implications of cancer treatment (which is of relevance to the current research programme), these different treatment modalities are briefly discussed in relation to breast and prostate cancer.

a) Active Surveillance

Both low-risk early breast and prostate cancer can be monitored via active surveillance, which is the option of choice if the tumour might not metastasise or may be slow in progression. By monitoring the tumour, more intensive treatment and subsequent adverse side-effects are avoided, thus prolonging QoL. This is most often the case with prostate cancer, whereby men are more likely to die with the disease than from the disease (Burford, Kirby, and Austoker, 2008; Sakr, Grignon, and Haas, 1996). Interestingly, one study demonstrated that out of 457 men allocated to watchful waiting, 74% remained free from treatment at 2-years, 63% at 3-years, and 49% at 5-years, supporting the efficacy of this treatment option (Meng, Elkin, Harlan, Mehta, Lubeck, and Carrol, 2003).

Active surveillance is also an option for men with high risk tumours, providing a number of decision-making implications at an already stressful time. Indeed, research has demonstrated that men with prostate cancer experience a great deal of uncertainty surrounding the potential dangers of watchful waiting, leading to negative affect (Wallace, 2003). Whilst active surveillance might stave off the many adverse side-effects of radical treatment, it has been recognised that the fear and anxiety of cancer spread still remains with the patient (Bailey et al., 2009; Knight, Latini, Cowan, and Carroll, 2006), in some cases contributing to the rejection of this treatment option (Holmboe and Concato, 2000).

b) Surgery

Surgery is used to control local disease, with the standard treatment for localised breast cancer being a lumpectomy (the removal of the tumour and some surrounding

tissue) to prevent the tumour becoming invasive (Fentiman, 2001). This procedure is known as breast conserving treatment, with there being an increasing trend towards more conservative surgery due to QoL implications (White, 2000), particularly in terms of sexual problems, loss of femininity and lowered body image (Fobair, Stewart, Chang, D'Onofrio, Banks, and Bloom, 2006; Hopwood, Lee, Shenton, Baildam, Brain, Lalloo, Evans, and Howell, 2000; White, 2000). Nevertheless, in certain cases removal of the whole breast is necessary (mastectomy). This is most likely in cases where the breast lump is large in proportion to the rest of the breast tissue, there are several areas of cancer cells in different parts of the breast, the lump is just behind the nipple, or there are further pre-cancerous cells within the breast (Macmillan Cancer Support, 2008). Under such circumstances, breast reconstruction is often a viable option, although research does demonstrate that reconstruction does not necessarily equate with improvements in appearance-related QoL (Harcourt, Rumsey, Ambler, Cawthorn, Reid, Maddox, Kenealy, Rainsbury, and Umpleby, 2003).

For prostate cancer, prostatectomy (major surgery to remove the entire prostate via the abdomen) is used for intermediate and high risk tumours. The number of prostatectomies or cystectomies (removal of bladder and prostate) more than doubled from 1997-2007 due to increasing incidence of prostate cancer (Allberry and DH, 2009). A significant reduction in overall mortality and prostate-specific mortality at 12 years has been found for men less than 65 years of age receiving prostatectomy rather than active surveillance (Bill-Axelson et al., 2008). Furthermore, measures of anxiety, depression, and overall mental health have been found to be significantly better in men receiving prostatectomy as opposed to radiotherapy (Korfage et al., 2006). However, erectile dysfunction and urinary incontinence are common side-effects of prostatectomy (Haab, Yamaguchi, and Leach, 1996; Litwin et al., 2001; Potosky et al., 2004) and post-treatment side-effects have been reported to be higher than in men receiving radiotherapy (Korfage et al., 2006).

c) Radiotherapy

Radiotherapy (the controlled administration of ionising radiation to destroy cancer cells) is usually used to control local disease. In breast cancer, adjuvant radiotherapy is established in the multidisciplinary treatment of the disease and is recommended for all patients after breast conserving surgery and in selected groups of patients after mastectomy.

In addition to destroying malignant tissue, radiation also affects normal tissue; this can cause a number of short and long-term side-effects, some of which can occur up to ten years post-treatment (NICE, 2002). The severity of the side-effects is site-, dose-, and tissue volume- dependent, with side-effects usually beginning after the first treatment and increasing in severity with additional treatments. Some symptoms are so severe that patients terminate treatment (Frytak and Moerter, 1981). Over 70% of women with breast cancer receiving radiotherapy will experience nausea, vomiting, appetite loss, and weight loss (Welch, 1980). Disabling arm problems and bone necrosis (i.e. bone death) are also common side-effects of breast cancer radiotherapy (NICE, 2002).

Conversely, radiotherapy can assist with pain control in women with metastatic cancer and thus facilitate palliative care (NICE, 2002).

External beam radiotherapy is the most frequently administered treatment in the UK for men with localised prostate cancer (NICE, 2008). As with prostatectomy, erectile dysfunction and urinary incontinence are common side-effects, but are more likely with surgery compared to radiotherapy (Potosky et al., 2004). Brachytherapy (the insertion of radioactive implants into the prostate gland) has been approved by NICE (2005) as a primary treatment or as a booster dose alongside external beam radiotherapy (NICE, 2006). Brachytherapy may maintain better sexual function than either external radiotherapy or surgery but can cause more urinary problems (Frank et al., 2007; Tsui et al., 2005) and more bowel toxicity (Frank et al., 2007).

d) *Chemotherapy*

Chemotherapy is the use of 'cytotoxic drugs' (i.e. chemicals that are toxic to cells, thus preventing their reproduction and growth) to treat cancer. There are over fifty different drugs that can be used as single agents or in a variety of different combinations. Factors such as the extent of the disease, the patients' general health, and the function of their liver and kidneys are taken into consideration prior to chemotherapy. For this reason a number of tests are required before the start of the treatment, such as blood tests, x-rays or scans (Macmillan Cancer Support, 2007). Chemotherapy can be given in the form of oral tablets, or as a liquid injected into a vein in the arm using a device known as an intravenous cannula. Alternatively, it can be injected into a larger vein in the front of the chest via an apparatus called a central line.

Chemotherapy is often administered in combinations, Cyclophosphamide, Methotrexate, and Fluorouracil (CMF) being a common combination for breast cancer. Adverse effects associated with this treatment include nausea, vomiting, constipation, anaemia, mucositis (pain and inflammation to the lining of the digestive tract), stomatitis (inflammation of the mouth), and alopecia (hair loss) (Nuzzo, Morabito, De Maio, et al., 2008; Poole, Earl, Hiller, Dunn, Bathers, Grieve, Spooner, Agrawal, Fernando, Brunt, O'Reilly, Crawford, Rea, Simmonds, Mansi, Stanley, Harvey, McAdam, Foster, Leonard, Twelves, 2006). Alopecia is consistently rated as being one of the most distressing side-effect of chemotherapy (Boehmke and Dickerson, 2005; Browall, Gaston-Johansson, and Danielson, 2006; Lemieux, Maunsell, and Provencher, 2008), to the extent of being described by women with breast cancer as being more difficult than losing a breast (Browall, Gaston-Johansson, and Danielson, 2006; Freedman, 1994). Alopecia has been associated with a loss of privacy because it signals to others that the individual has cancer (Freedman, 1994; Luoma and Hakamies-Blomqvist, 2004). It is also a visible reminder to the patient of the disease and the severity of the disease (Rosman, 2004; Richer and Ezer, 2002; Williams, Wood, and Cunningham-Warburton, 1999). Hair loss has been found to negatively impact social interactions, especially in terms of continuing or returning to work (Luoma and Hakamies-Blomqvist, 2004; Maunsell, Brisson, Dubois, Lauzier, and Fraser, 1999).

The impact of alopecia further extends to negative body image (Fobair, Stewart, Chang, D'Onofrio, Banks, and Bloom, 2006).

When administered to people with prostate cancer, chemotherapy is mainly used to treat advanced disease that is no longer responsive to hormonal therapy, in order to shrink and control the cancer for symptom relief and prolonged QoL (NHS Evidence, 2007). The most common cytotoxic drugs for prostate cancer are Docetaxel (Taxotere) and Mitoxantrone (Novantrone). Docetaxel is the most widely used in the UK and has been recommended by NICE for the treatment of metastatic hormone-resistant prostate cancer (NICE, 2006). Indeed, clinical trials of Docetaxel have provided evidence of significant improvement in overall survival (Dahut et al., 2004; Petrylak et al., 2004; Tannock et al., 2004). Commonly reported side-effects of Docetaxel include gastrointestinal toxicity, nausea, vomiting, musculoskeletal symptoms, cracking or discoloured nails, sensory neuropathy (loss of sensation), infection, fluid retention, weight gain, and fatigue (Tannock, 2004). Cancer-related fatigue is the most frequently reported side-effect of chemotherapy, causing interference in activities of daily living, as well as having the most negative impact on QoL (Cella, 1998; Portenoy and Miaskowski, 1998; Richardson, 1995; Vogelzang et al., 1997). It has been estimated that as many as 60-90% of individuals with cancer experience fatigue (Portenoy and Miaskowski, 1998; Richardson, 1995; Vogelzang et al., 1997; Winningham et al., 1994) and those patients undergoing chemotherapy are particularly prone to fatigue, which can persist for over a year post-adjuvant treatment (Irvine et al., 1994). Cancer-related fatigue has been found to be associated with depression and anxiety (Schwartz et al., 2000), although distinguishing between fatigue and psychological morbidity has proven difficult due to overlapping symptoms.

Chemotherapy has been described as an 'assault' on the body (Cleeland, 2008). Since chemotherapy reduces the body's ability to fight infection, people with cancer can need urgent treatment for haemorrhages, thrombosis (blood clot inside a blood vessel), renal impairment, liver problems, heart problems, and multi-organ failure. Patients receiving chemotherapy have reported an accumulation of psychological distress as the treatment progresses, and which remained heightened up to three months post-chemotherapy (Buick et al., 2000).

e) Hormone Therapy

For intermediate and high risk disease, neo-adjuvant and/or adjuvant hormone therapy is an additional option. Many breast tumours are 'oestrogen sensitive,' meaning the hormone oestrogen (produced by the ovaries) helps them to grow. The widely publicised Tamoxifen, an anti-oestrogen agent that block's the tumour's ability to use oestrogen, has been the most frequently used hormonal therapy in women with breast cancer. However, adverse side-effects are reported in 63% of patients, resulting in discontinuation by 23% of these women (Demissie, Silliman, and Lash, 2001). Aromatase inhibitors (AIs), which reduce the amount of oestrogen in the body, have been found to be less toxic than Tamoxifen (Bonneterre, Thurlimann, and Roberstson, 2000; Ellis, Coop, and Singh, 2003; Mouridsen, Gershanovich, and Sun, 2001;

Nabholtz, Buzdar, and Pollak, 2000). The most frequently used AIs are Letrozole and Anastrozole and although they are generally well-tolerated, approximately half of those treated with these AIs experience some adverse side-effects, including nausea, hot flashes, joint pain, abdominal discomfort, appetite loss, and headaches (Buzdar, Douma, and Davidson, 2001; Gershanovich, Chaudri, and Campos, 1998; Koberle and Thurlimann, 2001; Thomas, Godward, Makris, Bloomfield, Moody, and Williams, 2004).

Androgen Deprivation Therapy (ADT) has been used to treat prostate cancer since the 1940s. Neo-adjuvant hormone therapy is recommended for men with locally advanced prostate cancer as it can shrink tumours prior to radiotherapy. The addition of this hormone treatment to radiotherapy has proved successful in terms of improved overall survival. However, both the prostate cancer and ADT can have significant detriment on bone quality, resulting in an increased risk of osteoporosis and fractures (Alibhai, Gogov, and Allibha, 2006; Shahinian, Kuo, Freeman, and Goodwin, 2005). ADT has also been implicated in cognitive decline, with a recent review reporting that between 47% and 69% of men receiving ADT declined in at least one cognitive area (Nelson, Lee, Gamboa, and Roth, 2008). Further adverse side-effects reported in patients receiving hormone therapy include hot flushes (Prezioso et al., 2004; Klotz, 2003; Soloway, 2002), sexual problems (Denham et al., 2005), diarrhoea, nausea, abnormal liver function (Denham et al., 2005), asthenia (physical weakness), dyspnoea (shortness of breath) on exertion, depression (Klotz, 2003), and lower overall QoL (Dacal, Sereika, and Greenspan, 2006). Adverse events appear to increase with the duration of hormone therapy, especially in terms of frequency of hot flushes (Gleave, 2001).

As demonstrated via the literature, treatment is a psychologically and physically stressful time for people with cancer. Indeed, treatment can often result in rapid declines in health status. This stress is often exacerbated by changes in biology and disruption to social circumstances, two factors identified as being involved in the proposed HBC theory. Thus, treatment and post-treatment experiences are likely to be an apt time to measure changes in the influences behind subjective health status (i.e. HBCs) and any subsequent QoL implications. The cancer trajectory, from diagnosis to post-treatment is a time when health status is in continual flux, and thus capturing personal health status evaluations during this vital period could provide significant insight into HBC theory and its potential value within the field of psycho-oncology.

1.9. Programme of Research

The literature reviewed in this chapter demonstrates a need for further insight into the factors that influence subjective health status in people with chronic illness. Based on preliminary research, it is proposed that health baseline comparison theory has the potential to provide such insight. This thesis examines the utility of HBC theory for people with cancer. As demonstrated, cancer is a chronic disease that can be an emotionally and physically demanding experience from the initial detection of a lump or presentation of symptoms, to the later stages of either palliative care or survivorship.

Adjustment via quality of life outcomes is thus of significant importance for people living with or beyond this disease (1.8.3.). Subjective health status as well as those health baselines involved in health status evaluations are likely to play an influential role in health and well-being outcomes throughout the cancer trajectory.

This programme of research adopts a cancer-specific approach to the examination of health baseline comparisons, whilst also exploring their role in multidimensional quality of life outcomes. The overall objective is to systematically investigate the type and nature of HBCs adopted by individuals with cancer, as well as any implications resulting from these HBCs throughout the cancer experience. As the only previous research on HBCs is exploratory, the research questions adopted are fairly broad:

- ➢ Which health baseline comparisons are adopted by individuals with cancer?

- ➢ What are the multidimensional QoL outcomes of different health baseline comparisons?

- ➢ How stable are health baseline comparisons throughout cancer treatment?

In order to answer these questions, five studies will be conducted to further develop and refine the concept of HBCs and to investigate the existence and nature of HBCs adopted by individuals with cancer in a longitudinal context. These studies are organised into the following chapters:

- ○ *Chapter 2 (Study 1):* In Study 1, the utility of HBC theory was tested via the development and pilot testing of a questionnaire designed to measure HBCs – the Health Baseline Comparison Questionnaire (HBCQ, v1). The HBCQ (v1) was tested with an opportunity sample (some with chronic illness and some without) to assess the reliability and validity of the questionnaire, leading to modifications (v2).

- ○ *Chapter 3 (Study 2a and 2b):* In Study 2, the existence and salience of HBCs in 214 people with breast and prostate cancer were examined, whilst also assessing the structure of the HBCQ (v2) through principal components factor analysis. Input from oncology professionals facilitated the use of HBCQ factors to explore associations with QoL and whether the factors could predict QoL. Thematic content analysis was conducted with qualitative data obtained in study 2a, the aim being to gain phenomenological insight into the HBC concept whilst also establishing whether the factors contained in the HBCQ (v2) adequately captured the HBC construct.

- ○ *Chapter 4 (Study 3):* The modified HBCQ (v3) resulting from studies 2a and 2b was administered to a sample of 54 breast cancer volunteers from a cancer

support group in Bedfordshire. The HBCQ was again modified based on qualitative responses.

- ○ *Chapter 5 (Study 4a):* The HBCQ (v3) was administered to women with breast cancer (n = 45) receiving chemotherapy, together with a QoL and emotional well-being questionnaire. Data was obtained during two phases (reported in Chapters 5 and 6). The aims of this study were to determine whether HBCs fluctuate or remain stable throughout chemotherapy for breast cancer and to identify any relationships between the flexibility or stability of HBCs and QoL. This chapter presents data from the first data collection period, at least one month into chemotherapy.

- ○ *Chapter 6 (Study 4b):* Data presented in study 4a was compared with post-chemotherapy data from the same women with breast cancer (n = 35) who completed questionnaires during chemotherapy. Differences between the two data collection points were explored, as were relationships between changes in HBC variables and changes in QoL and well-being outcomes.

- ○ *Chapter 7 (Study 5):* Study 5 comprises the interpretative phenomenological analysis of semi-structured interviews with five purposively selected women from the longitudinal stage of this research (4a,b). The aim was to gain insight into the subjective HBC experiences among women with breast cancer as well as to identify any emerging connections between the flexibility or stability of HBCs and overall well-being.

- ○ *Chapter 8 (Discussion):* The final chapter provides a summary of the five studies comprising this programme of research, followed by a discussion of the findings. The value and potential utility of these findings are discussed with reference to the literature, highlighting the strengths and weaknesses of the research. Future directions for this research are explored, with an emphasis on potential HBC interventions.

Chapter 2

Study 1: Testing the Utility of HBC Theory - The Development and Pilot Testing of the Health Baseline Comparison Questionnaire (HBCQ)

In Chapter 1, research pertaining to subjective health status and quality of life was discussed, with particular emphasis on the importance of measuring the impact of subjective health status on health and well-being outcomes (1.1.). Social cognition models of health and illness were critiqued in terms of the identification of perceived gaps within these models, leading to the introduction of a new theory: Health Baseline Comparison Theory (1.5.). Literature supporting the conceptualisation of health baseline comparisons (HBCs) was presented and the theory was presented as a cognitive process that is not currently encapsulated within either the social cognition models or the literature on subjective health status. The potential utility of HBCs within the field of psycho-oncology was discussed, drawing on previous research findings from QoL literature on breast and prostate cancer (1.7.). The aims and objectives of the research programme reported in this thesis were presented (1.9).

This chapter reports a study that examines HBC theory via the development and refinement of a questionnaire designed to measure health baselines: the Health Baseline Comparison Questionnaire (HBCQ). Before describing the development of the HBCQ, a brief account of the need for this questionnaire will be provided as will some of the key considerations involved in questionnaire design and development.

2.1.   Is a Health Baseline Comparison Questionnaire Necessary?

The nature of HBC theory was demonstrated in Chapter 1 (1.4.), as was the potential utility of HBCs in explaining self-reported health outcomes. It was argued that HBCs may be particularly important in terms of QoL outcomes in people with cancer (1.7.). It is therefore vital to develop a valid questionnaire to assess the range of health baselines most commonly utilised, together with the baselines that are the strongest predictors of adaptation. A review of health status measures has shown that although perceived health status is frequently measured by questionnaires, the influences by which these perceptions are formed (i.e. HBCs) are not. Subsequently, information was sought on the design and development of high quality data collection tools. A frequently utilised four-phase process for questionnaire design was identified (Apolone and Mosconi, 2005):

Phase I: A preliminary phase of planning and piloting a conceptual model, including the identification of items from literature searches and discussions with experts and a sample of the population of interest.
Phase II: Preliminary psychometric evaluation and assessment of measurement properties.

Phase III: Clinical validation and comparison with established questionnaires or traditional indicators.
Phase IV: Utilisation of the questionnaire on a broader scale.

These phases will be adhered to throughout the different iterations of the questionnaire. The current chapter outlines the planning and piloting of the HBCQ. Later chapters provide information on the testing of the psychometric properties of different versions of the questionnaire throughout its development, as well as demonstrate the clinical application of the instrument within an oncology setting. Phase IV is outside the scope of this programme of research, but will be considered for future research. At the forefront of each stage of questionnaire development will be the primary aim of eliciting data on different health baselines and their impact on quality of life.

In terms of testing the psychometric properties of an instrument, much research has been conducted into selection criteria for assessing the quality of patient-reported health instruments (Streiner and Norman, 1995; McDowell and Newell, 1996; Fitzpatrick et al., 1998). These criteria are summarised in Table 2.1.

Table 2.1: Questionnaire Selection Criteria

Questionnaire Properties	Description	Criteria for Acceptability
Reliability		
Test-Retest Reliability	Stability over time; assessed by administering the instrument on two different occasions and examining the correlation between test and re-test scores.	Test re-test reliability correlations for summary scores 0.70.
Internal Consistency	The extent to which items within a scale measure the same construct; assessed by Cronbach's alpha's and item-total correlations.	Cronbach's alphas for summary scores ≥0.70. Item-total correlations ≥ 0.20
Validity		
Content Validity	The extent to which the content of a scale represents the concept it is purported to cover; assessed qualitatively during questionnaire development via patient input, expert opinion and literature review.	Qualitative evidence from pilot testing with patients. Patients, experts and literature involved incorporated into questionnaire development.
Construct Validity	Evidence that the scale is correlated, in the expected direction, with other measures of the same or similar constructs.	High correlations between the scale and relevant constructs.
	The ability of the scale to differentiate known-groups; assessed by comparing scores for sub-groups who are expected to differ on the construct being measured (e.g. a clinical and control group).	Statistically significant differences between known groups.
Responsiveness	Ability to detect significant change over time; assessed by comparing scores pre- and post-intervention.	Statistically significant pre- and post-treatment.
Precision	Ability to measure accurately across the full spectrum of a construct.	Floor/ceiling effects for summary scores <15%.
Operational Characteristics		
Acceptability	Respondents' willingness to complete the questionnaire.	Low levels of incomplete data or non-response.
Feasibility	The time, energy, financial resources, or other resources required of respondents or administrators.	Reasonable time and resources to collect and analyse the data.

As can be seen in Table 2.1, both psychometric properties (i.e. reliability, validity) and operational characteristics (i.e. acceptability, feasibility) are important considerations in the selection and development of self-completion health questionnaires. Such factors have been incorporated into the aims and objectives of different stages of this programme of research. Since this chapter outlines the development of the HBCQ, content validity, acceptability, and feasibility will be assessed.

2.1.2. The Exploratory HBCQ

As outlined in 1.6., the utility of HBC theory was first examined through research conducted with people living with Rheumatoid Arthritis (RA) (Davies and Kinman, 2006). This research involved an exploratory 13-item HBCQ designed to measure HBCs and perceived health status in people with RA. The design was guided by the literature discussed in Chapter 1 pertaining to biological and social influences in subjective assessments of health status (1.5.). Respondents were asked to what extent they agreed with a number of biological (intrinsic) and social (extrinsic) health baselines. Examples of the intrinsic baseline items included: 'I am not as healthy as I used to be'; 'Some people judge their health according to past health'; 'I am as healthy as personal circumstances permit.' Examples of the extrinsic baseline items included: 'I am as healthy as anyone I know'; 'I am less healthy than most people I know'; 'Some people judge their health according to media representations.' This preliminary exploration of HBC theory demonstrated that people with a chronic illness endorsed many of these baselines, suggesting that they utilise them. Furthermore, some baselines had significant relationships with adjustment to RA, as assessed via the Arthritis Impact Measurement Scale (Davies and Kinman, 2006).

The response format for the exploratory HBCQ was a five-point Likert scale of 'strongly agree' to 'strongly disagree.' This response format was utilised for a number of reasons. The Likert scale is the most popular within psychology as closed questions with pre-coded response formats are simple to complete and analyse (Jaeschke et al., 1990), thus enhancing acceptability and feasibility. Furthermore, Likert scale data can be categorised in a way that derives comparable data across respondents. A disadvantage is that this type of response format poses potential inconsistency in response option interpretation across respondents. For example, the perceived difference between 'agree' and 'strongly agree' might vary across respondents. However, this method is widely used within the field of health psychology and thus accepted as a valuable data collection method.

Although the study yielded useful findings, greater insight into the type of baselines that people draw on when evaluating their health status was not achieved. Open-ended questions have been recommended for developing theory and subsequent questionnaires (Bowling, 2005). For this reason, subsequent development phases of the questionnaire will include a qualitative component. In the pilot study, insight was gained into the type of baselines people with RA might adopt and how these may be related to adjustment. However, it is also useful to explore HBCs in people who are

healthy as well as those who have a chronic illness. For this reason, although the overall aim of this programme of research is to explore HBCs in people with cancer, Study 1 will briefly explore HBCs in a cross-section of people with and without a chronic illness in order to capture the influences that people draw on when evaluating their health. The preliminary stages of instrument development were conducted outside of the oncology setting for ethical reasons.

2.2. Aims and Objectives

The primary aim of Study 1 of this research programme was to develop a user-friendly, self-report measure that can reliably assess HBCs. This will be achieved by:

> ➢ Examining the health baselines/reference points adopted by people when evaluating their health status.
> ➢ Examining the use of intrinsic (i.e. related to the self) and extrinsic (related to the external world) HBCs.
> ➢ Modifying and pilot testing the preliminary HBCQ.
> ➢ Examining whether people with and without a chronic illness adopt different health baselines.
> ➢ Gaining feedback from respondents on the acceptability of the questionnaire by asking them to comment on the ease and timing of questionnaire completion, as well as on any health baselines that they might draw upon that are not included in the questionnaire.

These aims were met by seeking a convenience sample of staff and students from Cranfield University at Silsoe, some with a chronic illness and some without, who were willing to complete the HBCQ and provide feedback on its content and structure.

2.3. Method

2.3.1. Ethical Approval

Ethical approval was granted by Cranfield University at Silsoe ethics committee (appendix Ai).

2.3.2. Sample

A convenience sample of 26 staff and students from Cranfield University at Silsoe was divided into groups according to whether or not they had a chronic illness. A 'chronic illness' was described as being a long-term persistent medical condition such as asthma, diabetes, or arthritis. A chronic illness as opposed to cancer was selected for ethical reasons in the very initial stages of HBCQ development.

2.3.3. The HBCQ (v1)

The demographic variables requested in the questionnaire included age (i.e. < 20; 21-30; 31-40; 51-60; 61 >), gender (i.e. male; female), marital status (i.e. single; long-term relationship; married; divorced; widowed), and educational level (i.e. no qualifications; GCSE/A-Level; undergraduate; postgraduate). Participants were also asked the questions *'Do you have a persistent and enduring illness or medical condition, such as asthma, diabetes, arthritis, etc'* (i.e. yes; no; *if yes, please state what this medical condition is and the duration of the illness*).

The pilot HBCQ was a 21-item self-administered questionnaire (appendix Ci). The first 18 questions were multiple choice questions designed to assess the health baselines people adopt when evaluating their health status (Table 2.2). Responses were scored on a five-point Likert scale of 'strongly agree' to 'strongly disagree.' It is proposed that the first column illustrates intrinsic (i.e. biological) health baselines whilst the second illustrates extrinsic (i.e. social comparisons) health baselines. Items were scored from 0-4, with lower scores representing stronger agreement with the use of a specific HBC. A total HBC score could be calculated by adding responses to all items. Alternatively, intrinsic and extrinsic HBC scores could be calculated by dividing the items accordingly.

Following on from these multiple choice questions, an open-ended question was included to gain insight into potential health baselines that had not already been identified:

> ➢ What other factors, if any, do you take into consideration when evaluating your health?

Participants were then asked to individually rate their: 1) health and 2) HRQoL, on a scale of 1-7, with 1 representing very poor perceived health or QoL and 7 excellent perceived health or QoL. These two items were drawn from the EORTC QLQ-C30 cancer-specific QoL questionnaire (Aaronson et al., 1991).

Table 2.2: HBCQ (v1) Multiple Choice Items

Intrinsic HBCs (Baselines relating to Self)	Extrinsic HBCs (Baselines relating to External World)
When evaluating my health, I take into consideration my past health.	When evaluating my health, I take into consideration what is portrayed in the media as being healthy or unhealthy.
When evaluating my health, I take into consideration my age.	When evaluating my health, I take into consideration the health of people who appear healthier than myself.
When evaluating my health, I take into consideration personal circumstances in my life.	When evaluating my health, I take into consideration the health of people I know.
When evaluating my health, I do not take into consideration other people's health.	When evaluating my health, I take into consideration the health of people who appear less healthy than myself.
When evaluating my health, I take into consideration my previous personal experiences with illness.	When evaluating my health, I take into consideration the health of people who do not have the same medical condition.
When evaluating my health, I take into consideration my mood at that particular point in time.	When evaluating my health, I take into consideration the health of people who are dissimilar to myself.
When evaluating my health, I take into consideration my long-term mood status.	I have more trust in my family's ability to evaluate my health than my own ability.
When evaluating my health, I take into consideration the health of people with the same medical condition as myself.	I have more trust in my friends' ability to evaluate my health than my own ability.
When evaluating my health, I take into consideration the health of people who are similar to myself.	I have more trust in my doctor's ability to evaluate my health than my own ability.

2.3.4. Feedback Questionnaire

The feedback questionnaire, designed to assess the acceptability of the HBCQ (appendix Di), consisted of two multiple choice items:

- ➤ Approximately how long did it take you to complete this questionnaire?
  (i.e. <5 minutes to > 20 minutes)
- ➤ How would you rate the ease with which you were able to complete this questionnaire?
  (i.e. very easy; easy; unsure; difficult; very difficult).

These were followed by two open-ended questions:

- ➤ What did you find particularly easy about the questionnaire? Please consider both structure and content.
- ➤ What did you find particularly difficult about the questionnaire? Please consider both structure and content.

2.3.5. Procedure

Participants were obtained via a notice being placed on the Cranfield University at Silsoe intranet. Interested individuals emailed the researcher, who then provided the questionnaire in a sealed envelope along with a consent form and participant information sheet reminding participants of confidentiality (appendix Bi). Completed questionnaires were returned in sealed envelopes to the researcher's mailbox in order to maintain participant confidentiality.

2.3.6. Methods of Analysis

All quantitative results were analysed via the SPSS 13.0 for Windows Statistical Package. Specifically, the descriptive statistics of each HBC item were identified for each of the cohorts. This was followed by an analysis of correlations between HBCs and perceived health and QoL, and then independent samples t-tests to identify any differences between cohorts. All qualitative results were analysed via thematic content analysis (Boyatzis, 1998) in order to identify themes indicating previously unacknowledged HBCs, as well as trends in the feedback obtained on the HBCQ.

2.4. Results

2.4.1. Participant Demographics

Participant demographics are presented in Table 2.3. Participants (n = 26) were 62% female with the majority being 30 years old or more. All participants were staff and students of Cranfield University at Silsoe and therefore many of them had a postgraduate background (65%). Of these participants, 46% categorised themselves as having common medical conditions of a chronic nature such as asthma, arthritis or diabetes, whilst 54% categorised themselves as having no chronic illness.

Table 2.3: Participant Demographics

Gender	Number of Participants
Male	10
Female	16
Age in Years	**Participants (%)**
20 or Under	8
21-30	30
31-40	27
41-50	23
51-60	11
Marital Status	**Participants (%)**
Single	31
Married	38
Long-Term Relationship	27
Divorced	4

2.4.2. Descriptive Data

The HBCQ (v1) achieved a Cronbach's alpha of 0.63 for the intrinsic items and 0.74 for the extrinsic items, demonstrating a low to adequate degree of internal consistency. The intrinsic subscale achieved an adequate Cronbach's alpha of 0.75 when one item was excluded: *'When evaluating my health, I do not take into consideration other people's health.'*

In people with a chronic illness, percentage of agreement (i.e. total of 'agree' and 'strongly agree' responses) for various HBCs ranged from 0% for turning to friends and family to 100% for past illness. This was 7% and 78%, respectively, for those with no chronic illness.

In people with no chronic illness, percentage of agreement for various HBCs ranged from 7% for turning to friends and family to 100% for past health. This was 0% and 92%, respectively, for those with a chronic illness.

On a scale of 1-7, with higher scores representing higher perceived health, the mean rating for perceived health was 5.50 (SD = 1.24) for those with a chronic illness and 4.93 (SD = 1.33) for those without.

On a scale of 1-7, with higher scores representing higher perceived QoL, the mean rating for perceived QoL was 5.50 (SD = 1.45) for those with a chronic illness and 4.71 (SD = 1.27) for those without.

Table 2.4 illustrates the mean agreement with HBCQ items, in descending order, for both groups.

Table 2.4: Agreement with HBCQ Items, in Descending Mean Order of Strength of Agreement (n=26)

Chronic Illness	Mean (SD)	% agree/ strongly agree	% disagree/ strongly disagree	No Chronic Illness	Mean (SD)	% agree/ strongly agree	% disagree/ strongly disagree
Past health	.67 (0.65)	92	8	Past health	.86 (0.36)	100	0
Past illness	.67 (0.49)	100	0	Past illness	1.29 (1.20)	78	22
Age	.92 (0.90)	80	20	Personal circumstances	1.43 (1.16)	71	29
Personal circumstances	1.00 (0.60)	84	16	Media	1.50 (1.09)	71	29
Similar people	1.00 (0.74)	92	8	Age	1.57 (0.94)	71	29
Same illness	1.17 (1.03)	75	25	Similar people	1.64 (0.93)	64	36
Healthier people	1.58 (1.17)	58	32	Same illness	1.71 (0.91)	43	57
People I know	1.58 (1.08)	66	34	Present mood	1.71 (0.83)	50	50
Unhealthier people	1.75 (1.14)	58	42	Long-term mood	1.79 (1.05)	50	50
Media	1.83 (1.12)	58	42	Healthier people	1.86 (0.95)	50	50
Long-term mood	1.92 (1.00)	33	67	Unhealthier people	2.07 (0.92)	36	64
Present mood	1.92 (1.17)	41	59	People I know	2.07 (1.14)	50	50
Trust Doctors	2.00 (1.35)	42	58	Not the same illness	2.07 (0.83)	27	73
Not the same illness	2.25 (0.97)	33	67	Trust Doctors	2.21 (1.25)	36	64
Dissimilar People	2.42 (0.90)	25	75	Don't consider others health	2.50 (1.09)	29	71
Don't consider others health	2.83 (0.72)	8	92	Dissimilar People	2.57 (0.85)	21	79
Trust friends	3.25 (0.62)	0	100	Trust family	2.93 (0.83)	7	93
Trust family	3.33 (0.49)	0	100	Trust friends	3.14 (0.77)	7	93

2.4.3. Tests of Difference

Independent samples t-tests revealed no significant difference between individual HBCs or between intrinsic and extrinsic HBCs. No significant differences were revealed for perceived health and QoL in people with and without a chronic illness.

The mean difference between intrinsic and extrinsic HBCs in those with a chronic condition was 7.92 and the 95% confidence interval (CI) for estimated population mean difference between 4.05 and 11.78. The effect size was 1.78. A paired samples t-test demonstrated the difference to be significant; those with a chronic illness were more likely to endorse intrinsic HBCs than extrinsic ones ($t = 4.51$, $df = 11$, $p < .001$).

The mean difference between intrinsic and extrinsic HBCs in those with no chronic condition was 5.93 and the 95% CI for estimated population mean difference between 1.74 and 10.12. The effect size was 1.26. A paired samples t-test demonstrated the difference to be significant; those with no chronic illness were also more likely to endorse intrinsic HBCs than extrinsic ones ($t = 3.06$, $df = 13$, $p < .01$).

2.4.4. Relationships between HBCs and Perceived Health and QoL

Pearson's (r) product moment correlations were used to examine relationships between individual HBCs and perceived health/QoL and intrinsic and extrinsic HBCs and perceived health/QoL.

Chronic Illness Group: No correlations were found between HBCs and perceived health. However, the HBC item *'When evaluating my health, I do not take into consideration other people's health'* significantly correlated with perceived QoL ($r = 0.61$, $n = 12$, $p < 0.05$, one-tailed). The more they take into consideration other people's health when evaluating their own, the better their perceived QoL.

No Chronic Illness Group: The HBC item *'When evaluating my health, I do not take into consideration other people's health'* significantly correlated with perceived health ($r = 0.61$, $n = 14$, $p < 0.05$, one-tailed). The more they take into consideration other people's health when evaluating their own, the lower their perceived health. Four HBC items significantly correlated with perceived QoL: *'When evaluating my health, I take into consideration the health of people who appear healthier than myself'* ($r = -0.55$, $n = 14$, $p < 0.05$, one-tailed); *'When evaluating my health, I take into consideration the health of people who are similar to myself' myself'* ($r = -0.55$, $n = 14$, $p < 0.05$, one-tailed); *'When evaluating my health, I do not take into consideration other people's health'* ($r = -0.61$, $n = 14$, $p < 0.05$, one-tailed); and *'I have more trust in my doctor's ability to evaluate my health than my own ability'* ($r = -0.58$, $n = 14$, $p < 0.05$, one-tailed). In those without a chronic illness, the less they take into consideration their doctors opinion above their own, the greater their perceived QoL. Similarly, the less they take into consideration the health of people who appear healthier than themselves, the better their perceived QoL. In contrast to

the chronic illness group, the less they take into consideration other people's health when evaluating their own, the better their perceived QoL.

As can be seen in Table 2.4, those with a chronic illness and those without expressed similar levels of agreement with the various HBCs presented to them. In particular, past health and past illness were the most frequently endorsed in both groups, whilst turning to friends and family were the least frequently endorsed in both groups. Interestingly, whilst agreement with using the media in making health status evaluations was in the top five for those with no chronic illness, media appeared to be much less salient for those with a chronic illness. In contradiction to this, those without a chronic illness were more likely to claim that they don't take into consideration others health when evaluating their own (29% compared to 8% of those with a chronic illness).

2.4.5. HBCQ Qualitative Findings

Responses to the open-ended question pertaining to other factors considered in health evaluations were organised into categories or 'themes' (Table 2.5) as part of thematic content analysis. Five themes emerged, 89% of which were new HBCs and 11% of which were HBCs already encapsulated in the HBCQ. The new HBCs were distributed between four of the emerging themes and included, in order of popularity (i.e. percentage of data pertaining to each theme):

- Lifestyle Factors (e.g. diet, exercise, smoking, alcohol consumption, etc.)
- Symptomatic Indicators (e.g. pain, illness duration, medication, etc.)
- Appearance Indicators (e.g. complexion, hair condition, weight, etc.)
- Physical Ability/Fitness (e.g. exercise level, strength, stamina, etc.)

Table 2.5: What other factors, if any, do you take into consideration when evaluating your health?

Lifestyle Factors (27%)	Appearance Indicators (22%)	Physical Ability/Fitness (16%)	Symptomatic Indicators (24%)	Established in HBCQ (v1) (11%)
"Commitment pressures (e.g. work commitments)" (Chronic Illness)	"I am slightly overweight" (Chronic Illness)	"Loss of mobility relative to previous periods" (Chronic Illness)	"Repeated periods of pain" (Chronic Illness)	"My health compared to my wife's (she has Chrohn's Disease)" (Chronic Illness)
"I am slightly overweight" (Chronic Illness)	"Healthy weight" (Chronic Illness)	"I am fit and active" (Chronic Illness)	"Free from colds/flu" (Chronic Illness)	"Feedback from family about how I seem, compared to other times, when well or ill" (Chronic Illness)
"Healthy weight" (Chronic Illness)	"Good teeth/hair" (Chronic Illness)	"Fitness" (Chronic Illness)	"Frequency and severity of illness episodes" (Chronic Illness)	I take on board what the media say about what to eat, exercise, etc." (Chronic Illness)
"Blood pressure and cholesterol" (Chronic Illness)	"I take health indicators such as weight, blood pressure, social factors (drinking, smoking) and emotional well-being into account" (Chronic Illness)	"Performance in sport is my main benchmark. Regular training sessions allow me to have a reference point for comparison" (No Chronic Illness)	"Pain levels" (Chronic Illness)	"I listen to my husband" (Chronic Illness)

Table 2.5 continued: What other factors, if any, do you take into consideration when evaluating your health?

Lifestyle Factors (27%)	Appearance Indicators (22%)	Physical Ability/Fitness (16%)	Symptomatic Indicators (24%)	Established in HBCQ (v1) (11%)
"I take health indicators such as weight, blood pressure, social factors (drinking, smoking) and emotional well-being into account" (Chronic Illness)	"Weight" (Chronic Illness)	"How I feel when undertaking strenuous activity, e.g. lifting heavy objects, running, etc." (No Chronic Illness)	"How long it takes me to recover from being ill" (No Chronic Illness)	
"Weight" (Chronic Illness)	"Skin on face is (looks) clear and smooth" (No Chronic Illness)	"I take note of my own body and feelings to evaluate my health" (Chronic Illness)	"Type of illness/bug I've got" (No Chronic Illness)	
Lifestyle at that time; How I've been eating, sleeping, etc." (No Chronic Illness)	"How I feel (symptoms) or look (tired)" (No Chronic Illness)		"How I feel (symptoms) or look (tired)" (No Chronic Illness)	
"Stress levels" (No Chronic Illness)	"Weight" (No Chronic Illness)		"Amount of medication used" (Chronic Illness)	
"Social situation compared to expectations" (No Chronic Illness)			"Whether I'm a sickly person in general" (No Chronic Illness)	
"Weight" (No Chronic Illness)				

The potential utility of the HBCQ in detecting level of agreement with a variety of HBCs has been explored. Furthermore, greater insight into HBCs has been gained from the qualitative items, specifically in terms of a need for additional HBC items to be included in the questionnaire. Further evaluation of the HBCQ can be gained from the following analysis of questionnaire feedback.

2.4.6. Questionnaire Feedback

As can be seen in Tables 2.6 and 2.7, the HBCQ appeared to be acceptable in terms of timing and ease of completion.

Table 2.6: Time Taken to Complete the Pilot HBCQ (v1)

Timing	No. of Participants	%
Under 5 minutes	2	8
5-10 minutes	11	42
10-15 minutes	7	27
15-20 minutes	6	23
Total	26	100

Table 2.7: Ease of HBCQ (v1) Completion

Ease	No. of Participants	%
Very Easy	1	4
Easy	20	77
Don't Know	3	11
Difficult	2	8
Very Difficult	0	0
Total	26	100

Timing of completion ranged from 5 to 20 minutes, with 42% of participants taking 5-10 minutes and 27% taking 10-15 minutes. Table 2.6 shows that 81% of participants found the questionnaire 'easy' or 'very easy' to complete.

Responses to the open-ended feedback questions pertaining to the particularly easy or difficult aspects of the questionnaire were analysed via thematic content analysis to identify common themes (Tables 2.8 and 2.9).

Table 2.8: What was particularly easy about the questionnaire?

Comprehension (37%)	Ease (21%)	Response Options (21%)	Length (7%)	Other (14%)
"Very self-explanatory questionnaire" (No Chronic Illness)	"Well set out, easy enough" (No Chronic Illness)	"Tick boxes easy" (Chronic Illness)	"It's fairly short, which is good" (No Chronic Illness)	"It's interesting to think about your own health in different terms than normal. Therefore some thought is necessary for some questions" (Chronic Illness)
"Questions easy enough to understand" (Chronic Illness)	"All quite easy" (No Chronic Illness)	"Tick boxes are easy format" (Chronic Illness)		"I like that I was able to personalise it to my specific conditions" (Chronic Illness)
"Simple questions" (No Chronic Illness)	"Most questions easy" (Chronic Illness)	"Tick boxes followed by longer answers, led to deeper thought" (Chronic Illness)		
"It's generally clear what is meant by each question" No Chronic Illness)				
"Questions followed a coherent structure" Chronic Illness)				

Table 2.9: What was particularly difficult about the questionnaire?

Comprehension (12%)	Repetition (38%)	Response Options (38%)	Other (12%)
"Some of the questions had to be re-read to understand exactly what you were after, but generally ok" (No Chronic Illness)	"Found the early part more difficult with the same wording (almost) for each question" (Chronic Illness)	"The 'don't know' option didn't seem fitting" (No Chronic Illness)	"I never evaluate my health so first questions are a bit strange to me, I just feel when I'm ill or not" (No Chronic Illness)
	Repetition, e.g. When evaluating my health . . . (No Chronic Illness)	"The 'don't know' option" (No Chronic Illness)	
	"I dislike repetition and hence some of the questions irritated me somewhat, but on the other hand, they are probably useful in capturing the real thoughts of people rather than what they think that they think" (No Chronic Illness)	"The use of 'Don't Know.' Surely this means they don't quite understand the question or just can't be bothered to think about it?!" (No Chronic Illness)	

As can be seen in Table 2.8, comments about the easy aspects of the questionnaire pertained mainly to comprehension and response format. The comments provide further support for the high majority of those rating the questionnaire as 'easy' or 'very easy' (81%). In general, the questionnaire was reported as being *"self-explanatory"* and *"easy enough."* For the 8% of participants who rated the questionnaire as being 'difficult,' the primary reasons were repetition and response options (Table 2.9).

2.5. Discussion

The primary aim of Study 1 of this research programme was to develop a user-friendly measure that can assess HBCs and to examine relationships between intrinsic and extrinsic HBCs and perceived health and health-related QoL. This was achieved by pilot testing the HBCQ with people who do and do not have a chronic condition in order to examine any differences. The HBCs utilised by these groups, as well as any between-group differences that might facilitate later distribution with people with cancer, were examined. Feedback was also sought on further refinement of the HBCQ. The outcomes of these aims follow.

2.5.1. HBCs in People with and without a Chronic Illness

Levels of agreement with the use of various HBCs were identified for those with and without a chronic condition. The HBCs that were most frequently endorsed were those relating to past health and past illness; people with no chronic illness unanimously agreed with the former statement, whilst people with a chronic illness unanimously agreed with the latter. Besides the items pertaining to turning to friends and family, all other HBCs had a reasonable level of agreement, suggesting that these baselines are widely used by respondents who have a chronic illness and those who do not. The focus on past health in those without a chronic illness and on past illness in those who do indicates the possibility of a transition in HBCs; the focus becoming more illness-oriented once health homeostasis is challenged by an illness.

The main difference between the two groups appeared to be in terms of the implications of taking into consideration other people's health status when evaluating one's own. Specifically, this correlated with positive outcomes (i.e. better perceived QoL) in those with a chronic illness and negative outcomes (i.e. lower perceived QoL) in those without. A possible explanation is that taking into consideration others health provides coping tools for those with a chronic illness (Taylor et al., 1983). Another explanation is the already cited self-enhancing potential of downward comparisons (Wills, 1981). It would have been useful to know if those with a chronic illness were taking into consideration the perceived superior or inferior aspects of other people's health when evaluating their own.

In relation to turning to others (such as friends and family) when evaluating health status, the mean level of agreement was higher in those with no chronic illness. Similarly, the use of the media was in the top five HBCs endorsed by people with no chronic illness, but this was not the case for those with a chronic illness. This indicates a greater focus on extrinsic HBCs for those with no chronic illness, which might be partially explained by the fact that people with a chronic illness may be more compelled to become more intrinsically-focused (i.e. more in tune with their own health as opposed to making comparisons with others). It could be argued that the use of intrinsic HBCs when evaluating health status evolve as a way of adjusting to illness. In contrast, people without a chronic illness and any subsequent intrinsic monitoring system (i.e. symptoms) are more likely to require and seek out extrinsic health evaluation methods, such as turning to others or making social comparisons. Indeed, extrinsic HBCs were found to negatively correlate with perceived HRQoL in those with a chronic illness, but not in those without. Although the direction of causation cannot be identified, this suggests that the use of extrinsic HBCs may have a different impact on people with and without a chronic illness.

In terms of perceived health and perceived HRQoL, the mean score was higher in those with a chronic illness; they rated their health status and HRQoL more favourably than did those without a chronic illness. This supports the concept of adjustment to illness, as well as highlighting the possible mechanism of benefit-finding (Andrykowski, Brady and Hunt, 1993; Cordova et al., 2001) and positive reinterpretation (Antoni et al., 2001; Parkes, 1971; Tedeschi and Calhoun, 1995), as cited in the literature (1.8.3.). Another possible reason for this might be in the greater use of extrinsic HBCs by those without a chronic illness than by those with a chronic illness, although this difference was not statistically significant. Further investigation would be needed in order to determine if extrinsic HBCs are more likely to result in lower perceived health and QoL.

The HBCQ provided some valuable information in highlighting the type of HBCs that people with and without a chronic illness report they use when evaluating their health status. As discussed above, differences between these two groups have also been identifiable via HBCQ responses. Nevertheless, an examination of the acceptability of the questionnaire remains fundamental to its overall utility. In collating feedback on the HBCQ as well as analysing HBCQ item responses, potential modifications were identified.

2.5.2. HBCQ Modifications

Identified questionnaire modifications and explanations for these modifications are described.

> The term 'evaluating' will be replaced with 'thinking about' and the term 'my health' with 'how healthy I am' (i.e. items to start with 'When *thinking about how healthy I am . . .*' rather than 'When *evaluating my health.*').

Based on feedback obtained, some simplifications to the language used in the questionnaire seemed warranted. Since the term 'evaluation' is not commonly used among the general population, even if it is a well-known term among academics and researchers, it was anticipated that changing this term might facilitate ease of questionnaire completion. Furthermore, *'how healthy I am'* seemed to more adequately capture efforts to evaluate health than merely thinking about 'my health;' thinking about aspects of health is not necessarily accompanied by evaluations of how healthy or unhealthy one is.

> The term *'portrayed'* in question 2 will be changed to *'see' (i.e. '*When thinking about my health, I take into consideration what and who *I see* in the media' rather than 'When thinking about my health, I take into consideration what is *portrayed* in the media.'

This amendment enhances the first person and subjective nature of the questionnaire, making it more personal to the user.

> The response option of 'don't know' will be replaced with 'unsure.'

One participant aptly commented on the use of the 'don't know' response as: *"Surely this means they don't quite understand the question or just can't be bothered to think about it?!"* (P10). It was therefore decided that 'unsure' would be a more appropriate response option.

> In the demographic items, it was identified that the item pertaining to whether the participant has a persistent and enduring illness or medical condition did not allow for more than one illness.

Clearly, individuals can suffer from more than one chronic illness and the existing wording failed to capture this possibility.

> Ethnicity categories identified by the Race Equality Scheme will be included with demographic items: White (British, Irish, Other), Black (African, Caribbean, Other), Mixed (White and Black Caribbean, White and Black African, White and Asian, Other), and Chinese or Other Ethnicity).

On the basis of this study, it was considered that cultural factors might be a powerful influence on HBCs and subjective health status.

➤ Rather than asking participants to select all qualifications obtained, they will be asked to indicate their 'Highest Educational Level.'

This will be clearer to participants, but will also increase questionnaire feasibility in that responses will be more categorical and thus quicker to score.

➤ Seven new items, identified from a content analysis of qualitative data, will be added to the questionnaire. These additional items, some of which are worded to be cancer-specific in preparation for Study 2, are as follows: When thinking about how healthy I am, I take into consideration:

- my lifestyle (e.g. diet, exercise, smoking, alcohol consumption, etc.)
- my appearance (e.g. complexion, hair condition, weight, etc.)
- what I *can* do (e.g. hobbies, physical and social activities, etc.)
- my physical fitness (e.g. exercise level, strength, stamina, etc.)
- the symptoms I expect to experience from this type of cancer
- the side-effects of my cancer treatment (e.g. tiredness, nausea, etc.)
- the treatment I am undergoing (e.g. radiotherapy, medication, etc.)

Responses highlighting the requirement of these additional items have been illustrated in Table 2.5.

2.5.3. Study Limitations

A limitation of this study is the small sample size. Furthermore, since this research was conducted with a convenience sample of university staff and students, they were generally highly educated and their feedback may not be generalisable. Indeed, whilst exploring HBCs in people with a chronic illness helped refine the HBC construct and questionnaire for use with people experiencing cancer, there are a number of obvious differences between the chronic conditions represented in this study and cancer. For example, despite increased survivorship, cancer remains a life-threatening illness for many; findings from those with a long-term condition might not be comparable to those who are diagnosed with a condition associated with risk of mortality. This will need to be considered throughout further refinement of the HBC construct and the questionnaire.

2.6.   Conclusions

This chapter has outlined the preliminary development and pilot testing of a questionnaire designed to measure the health baseline comparisons adopted when evaluating personal health status. Content validity was strengthened by the input provided by participants with and without a chronic illness. Acceptability was demonstrated by a 100% response rate and the high majority of participants reporting the questionnaire to be quick and easy to complete. Any feedback was carefully considered and noted in the modifications made to the questionnaire format in order that this tool is robust enough to assist with the exploration of HBCs and their impact on subjective health and quality of life outcomes.

The preliminary stages of instrument development were conducted outside of the oncology setting for ethical reasons. Now that the tool has demonstrated a reasonable level of validity and respondent acceptability, the next stage of refining the questionnaire prior to administration within the clinical environment will be to seek advice from oncology professionals and people with cancer. The HBCQ will then be ready for the next stage of this programme of research, whereby relationships between HBCs and QoL will be examined in individuals with breast and prostate cancer.

The next chapter outlines further development of the HBCQ (v2) and presents data from Study 2, which utilises the HBCQ with breast and prostate cancer in an effort to identify HBCs adopted by people with cancer and any relationships with QoL outcomes.

Chapter 3

Study 2a and 2b: Health Baseline Comparisons and Quality of Life in People with Breast and Prostate Cancer

3.1.   Introduction

In Chapter 2, the development and pilot testing of the first draft of the research measurement tool (HBCQ v1) was outlined, and data was collected on the type of HBCs adopted by people with and without a chronic condition. Some evidence was provided that participants endorse a range of HBCs when evaluating their personal health status, providing preliminary support for the HBC concept.

Some differences were found in the extent to which participants endorsed intrinsic and extrinsic HBCs (1.5.). Intrinsic HBCs were significantly more likely to be endorsed by participants, regardless of the existence of a chronic condition (2.4.3.). Nevertheless, extrinsic HBCs were also important in health status evaluations, as indicated by moderate levels of endorsement by both groups. Evidence has been provided, therefore, that further research into the HBC concept should include both types of baseline, not only to establish those that are most commonly utilised, but also to assess those most associated with well-being.

Thematic content analysis of qualitative responses obtained from Study 1 suggest that four additional HBCs should be added to the questionnaire, namely: lifestyle factors (e.g. diet, exercise, smoking, alcohol consumption); appearance indicators (e.g. weight, complexion, hair condition); physical ability/fitness (e.g. exercise level, strength, stamina); and symptoms (e.g. pain, tiredness, nausea). The measure was also refined in response to participants' feedback. It is anticipated that the modified HBCQ (v2) will facilitate the exploration of HBCs in conditions that are generally of a more serious nature than those previously tested. The HBC construct will be examined further in samples of people with breast and prostate cancer, and the measure will continue to be refined in this clinical context.

This chapter outlines the aims and objectives of studies 2a and 2b of the research programme. The main aim of these studies is to examine the structure of the HBCQ (v2) in a clinical setting in order to refine the HBC construct, as well as to explore any potential interactions between HBCs and quality of life (QoL). The endorsement of HBCs will be tested, followed by a principal components factor analysis of the HBCQ (v2) in order to establish the structure of the measure. An examination of the statistical validity of HBCs in

terms of associations or predictive validity will be examined with QoL in a sample of people with breast and prostate cancer.

In order to obtain complementary and richer data on HBCs, qualitative accounts of HBCs will be explored via thematic content analysis. This is a research technique where *"careful reading and re-reading of the data"* (Rice and Ezzy, 1999, p. 258) facilitates the identification of 'themes' emerging from narratives that are based on a particular phenomenon (Daly, Kellehear, and Gliksman, 1997). A process of 'coding' is adopted, whereby important terms, phrases or descriptions within the data are recognised and then organised into themes (Boyatzis, 1998). These themes have been described by Boyatzis (1998) as being *"a pattern in the information that at minimum describes and organises the possible observations and at maximum interprets aspects of the phenomenon."*

The advantages of thematic content analysis are vast. Indeed, it has been argued that thematic content analysis forms the foundation of other qualitative methods such as discourse analysis or grounded theory (Braun and Clarke, 2006). The method is flexible and relatively easy to adopt. Furthermore, the findings are presented in a way that is accessible to the general population and those without a research background. Importantly, thematic content analysis provides an opportunity to summarise large amounts of data in a meaningful way. The method has also been praised for generating unanticipated insights (Braun and Clarke, 2006), a factor important in theory development and thus an important tool for this programme of research.

Adopting a mixed-methodology approach in order to achieve richer insight into the HBC concept and its potential role in QoL outcomes, this chapter describes two studies:

Study 2a: Are HBCs associated with or predictive of QoL in people with breast and prostate cancer?
Study 2b: Subjective insights into the HBCs adopted for health status evaluations.

As illustrated in Chapter 1, there are many intervening variables involved in the health and QoL of people with breast and prostate cancer. Demographic variables such as age, educational status, and gender might be important predictors of perceived health status and health-related QoL (Gallicchio, Hoffman, and Helzlsouer, 2007; Wenzel et al, 1999). Indeed, a number of studies provide evidence that the influencing factors in health status evaluations change according to age and illness (Kaplan and Baron-Epel, 2003). Furthermore, the identification of cancer symptoms or treatment side-effects can be complicated by natural changes in health resulting from the ageing process (Macmillan Cancer Support, 2008). Co-morbidities have been found to correlate with various dimensions of QoL in women with breast cancer (Davies et al., 2008; Smith et al., 2010). Clearly, therefore, these demographic and illness-related factors should be controlled for when examining the role of HBCs in QoL outcomes. In particular, as the two cancer types

included in the current sample (i.e. breast and prostate) are gender specific, differences between the two groups will be explored as part of the overall aims and objectives, as described descried next.

3.2. Aims and Objectives

Study 2a aimed to examine the structure of the HBC concept by testing the HBCQ (v2) alongside QoL outcomes in a sample of people with breast and prostate cancer. More specifically, the aims of the study were to:

➢ Explore the structure of the HBCQ (v2) through the use of factor analysis.
➢ Test for HBC and QoL differences by cancer type.
➢ Examine any relationships between HBCs and QoL in this sample.
➢ Assess the validity of HBCs in predicting QoL.

Study 2b aimed to obtain more in-depth qualitative information about health baselines utilised when evaluating health status and to systematically identify any themes pertaining to health status evaluation methods. A secondary aim was to provide data for the further development of the measuring tool via the identification of any HBCs not yet assessed by the HBCQ (v2).

3.3. Method

3.3.1. Ethical Approval

Ethical approval was granted by Cranfield University at Silsoe (appendix Aii) and Bedford Hospital R&D provided Trust approval (appendix Aiii).

3.3.2. Sample

People with breast cancer and prostate cancer (n = 214) were recruited randomly from the Primrose Oncology Unit of Bedford Hospital during regular clinic visits. Other than having breast or prostate cancer and attending clinics at the Unit, there were no inclusion or exclusion criteria for participants.

3.3.3. Questionnaires

a) Demographics

The demographic variables requested included: age (i.e. < 20; 21-30; 31-40; 51-60; 61 >); gender; and highest educational level (i.e. no qualifications; GCSE/A-Level; undergraduate; postgraduate). Participants were also asked to indicate 'cancer type' (i.e. breast; prostate) and 'current treatment' (i.e. radiotherapy; chemotherapy; hormone therapy; surgery; watch and wait; other). In order to control for any co-morbidities, participants were asked *'Do you have any other persistent and enduring illness/es or medical condition/s?'* (i.e. yes; no; '*if so, please state what these are*').

b) The HBCQ (v2)

The HBCQ (v2) was a 23-item self-administered questionnaire (appendix Cii) based on the Study 1 (Chapter 2) pilot, as well as qualitative data and feedback from people with cancer and oncology clinicians.

The first 22-items were multiple choice questions designed to assess the intrinsic and extrinsic health baselines people agree with adopting when evaluating their health status (Table 3.1). Responses were on a 5-point Likert scale ranging from 0 = 'strongly disagree' to 4 = 'strongly agree.' A higher score represented greater endorsement of a particular HBC. Participants were also provided with space to share qualitative insight into the baselines they use when evaluating their health status.

Table 3.1: HBCQ (v2) Multiple Choice Items

Intrinsic HBCs (Baselines relating to the Self)	Extrinsic HBCs (Baselines relating to the External World)
When thinking about how healthy I am, I take into consideration my lifestyle (e.g. diet, exercise, smoking, alcohol consumption, etc.)	When thinking about how healthy I am, I take into consideration the health of people I know (e.g. friends, family, etc.)
When thinking about how healthy I am, I take into consideration my appearance (e.g. skin colour, hair condition, weight, etc.)	When thinking about how healthy I am, I take into consideration what I see in the media (e.g. health advice/warnings, diet fads, celebrity etc.)
When thinking about how healthy I am, I take into consideration what I *can* do (e.g. hobbies, physical and social activities, etc.)	When thinking about how healthy I am, I take into consideration the health of people who appear healthier than myself.

Table 3.1 Continued: HBCQ (v2) Multiple Choice Items

Intrinsic HBCs (Baselines relating to the Self)	Extrinsic HBCs (Baselines relating to the External World)
When thinking about how healthy I am, I take into consideration my physical fitness (e.g. exercise level, strength, stamina, etc.)	When thinking about how healthy I am, I take into consideration the health of people who appear less healthy than myself.
When thinking about how healthy I am, I take into consideration my past health/ill health.	When thinking about how healthy I am, I take into consideration the health of people without cancer.
When thinking about how healthy I am, I take into consideration my age.	When thinking about how healthy I am, I take into consideration the health of people who are dissimilar to myself.
When thinking about how healthy I am, I take into consideration the health of people with the same type of cancer.	I have more trust in my friend's and family's ability to make decisions about my health than my own ability.
When thinking about how healthy I am, I take into consideration the symptoms I expect to experience from this type of cancer.	I have more trust in my doctor's ability to evaluate my health than my own ability.
When thinking about how healthy I am, I take into consideration the type of treatment I am undergoing (e.g. radiotherapy, medication, etc.)	
When thinking about how healthy I am, I take into consideration the side-effects of my cancer treatment (e.g. tiredness, nausea, etc.)	
When thinking about how healthy I am, I take into consideration how many times I am required to visit the hospital.	
When thinking about how healthy I am, I take into consideration the health of people who are similar to myself.	
When thinking about how healthy I am, I do not take into consideration other people's health.	
When thinking about how healthy I am, I take into consideration how I feel at that particular time (e.g. present mood, stress experienced, etc.)	

c) Quality of Life

The 27-item Functional Assessment of Cancer Therapy – General (FACT-G; Fairclough and Cella, 1996) is a disease-specific instrument addressing the QoL concerns of people diagnosed with cancer (appendix Ei). The domains included in the questionnaire include: physical well-being (PWB, e.g. I have lack of energy); social and family well-being (SWB, e.g. I feel close to my friends); emotional well-being (EWB, e.g. I am satisfied with how I am coping with my illness); and functional well-being (FWB, e.g. I am able to work). Responses were provided on a 4-point Likert scale of 'not at all' to 'very much,' with higher scores representing better well-being on each of the four dimensions. Generic QoL was also calculated by summing the subscale scores, with higher scores representing better QoL.

3.3.4. Procedure

A covering letter, participant information sheet (appendix Bii), and consent form were attached to stamped self-addressed envelopes containing the HBCQ (v2) and FACT-G. The envelopes were identifiable by the words BREAST CANCER (in pink) and PROSTATE CANCER (in blue) being placed at the top of the covering letter in larger bold font. This was to ensure easy identification of the correct questionnaire for both the participants and the researcher.

The covering letter invited individuals to participate in the study and briefly outlined its aims. It was explained that the purpose of questionnaire completion was to increase knowledge of QoL issues experienced by individuals with cancer, and that the eventual aim is to enhance the care of people with cancer.

These questionnaires were situated on reception at the Primrose Oncology Unit, with a box for respondents to place their envelopes after questionnaire completion. The receptionist made attendees to the clinic aware of the questionnaires on their arrival, suggesting that patients could complete the questionnaires while they were waiting. Questionnaires were also further distributed by Consultants if people expressed interest. A record of the number of people invited to participate and the number who accepted or refused was recorded in order to establish the initial target sample. The number of questionnaires taken by clinic attendees and the number returned also facilitated response rate estimates.

3.3.5. Methods of Analysis

A mixed methodology approach was utilised in the analysis and interpretation of study findings. A Principal Components Factor Analysis of the structure and psychometric properties of the HBCQ (v2) was conducted, followed by an examination of the descriptive data for individual HBC items. Independent Sample t-tests were conducted to identify any differences by gender or cancer type, followed by Pearson's correlations to determine associations between the resulting HBC subscales and QoL. Hierarchical multiple regressions were conducted in order to identify potential HBC factors that were predictors of QoL.

All qualitative data was examined via thematic content analysis and the extracting of patterned themes within the narrative. To ensure reliability, a proportion of the data (15%) was analysed by another health psychology researcher[3]. Cohen's Kappa was used to establish levels of concordance.

3.4. Results

3.4.1. Participant Demographics

There were 102 women with breast cancer[4] and 112 men with prostate cancer (total n = 214), offering a response rate of 93%. The majority of participants with breast cancer did not have any co-morbidity (66%) whilst just over one-third of people with prostate cancer did (53%). Participant demographics were examined separately for people with breast and prostate cancer since crosstabulations revealed a highly significant ($p < .001$) association between cancer type with age and treatment. Crosstabulations also revealed highly significant ($p < .001$) associations between gender and age, education, and treatment. Participant demographics by gender can be seen in the bar charts below (Figures 3.1 – 3.4).

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[3] Holds a Masters in Health Psychology and is currently completing a PhD within the field. Areas of expertise include interpretative phenomenological analysis and thus the categorisation and analysis of qualitative data.

[4] Men with breast cancer were not included in this research.
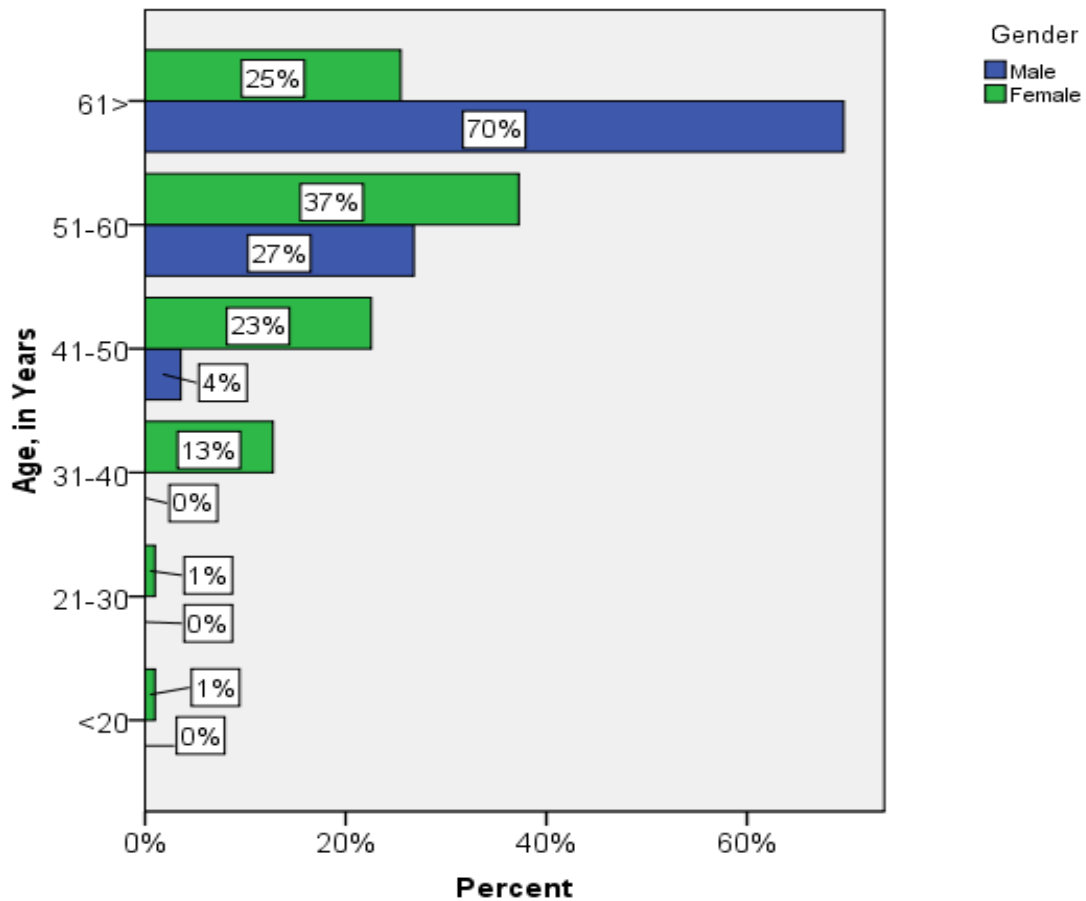
Figure 3.1: Age of Particpants (n=214)

Figure 3.1 illustrates the age distribution of participants. The majority (70%) of participants with prostate cancer were 61-years of age or over whereas age was more widely distributed in participants with breast cancer, ranging from 20 years or under (1%) to 61-years or above (26%).
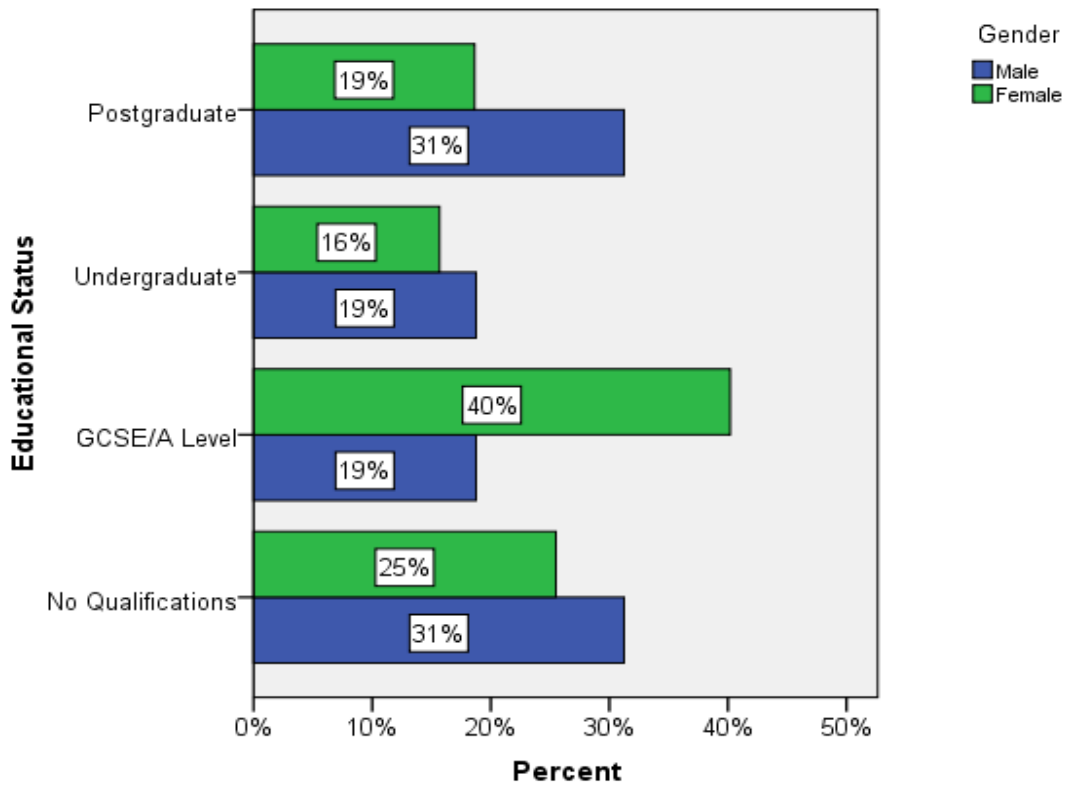
Figure 3.2: Educational Status of Participants

As illustrated in Figure 3.2, 56% of women and 38% of men were educated to at least undergraduate level. More than one third (31%) of men and one-quarter of women (25%) indicated no educational qualifications.
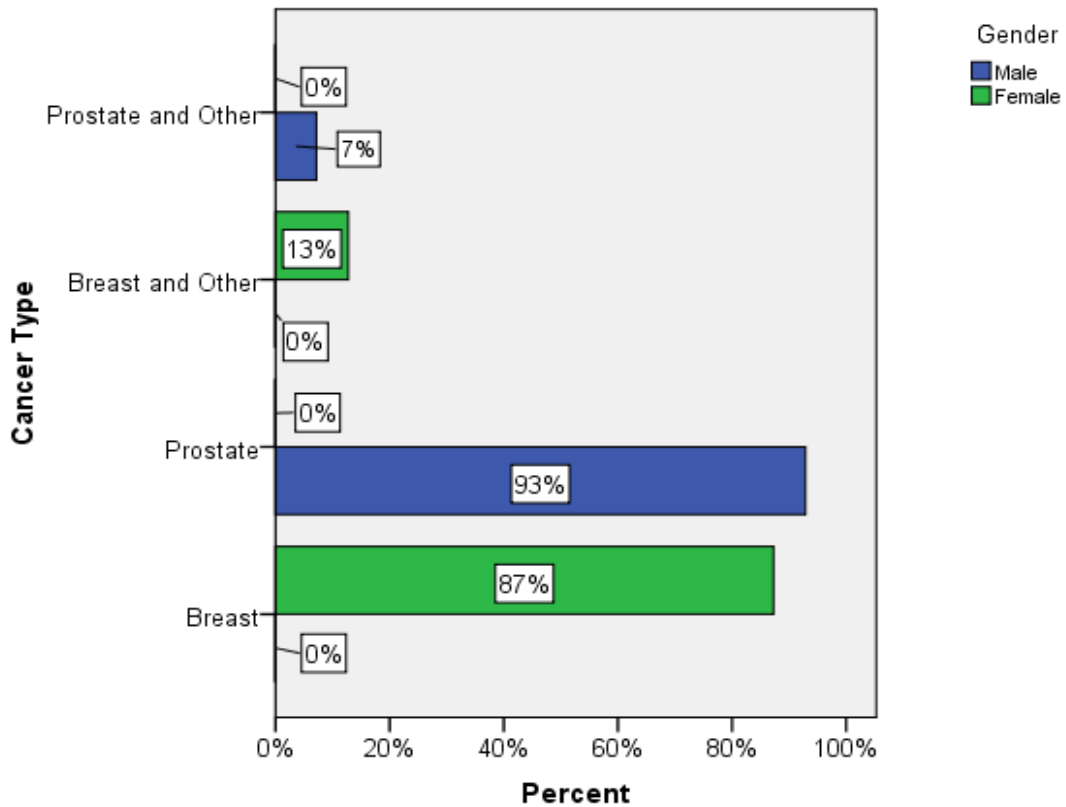
Figure 3.3: Cancer Type

Figure 3.3 illustrates the cancer type experienced by participants. A small proportion of people with breast and prostate cancer were also experiencing secondary cancers (7% for prostate cancer and 13% for breast cancer).
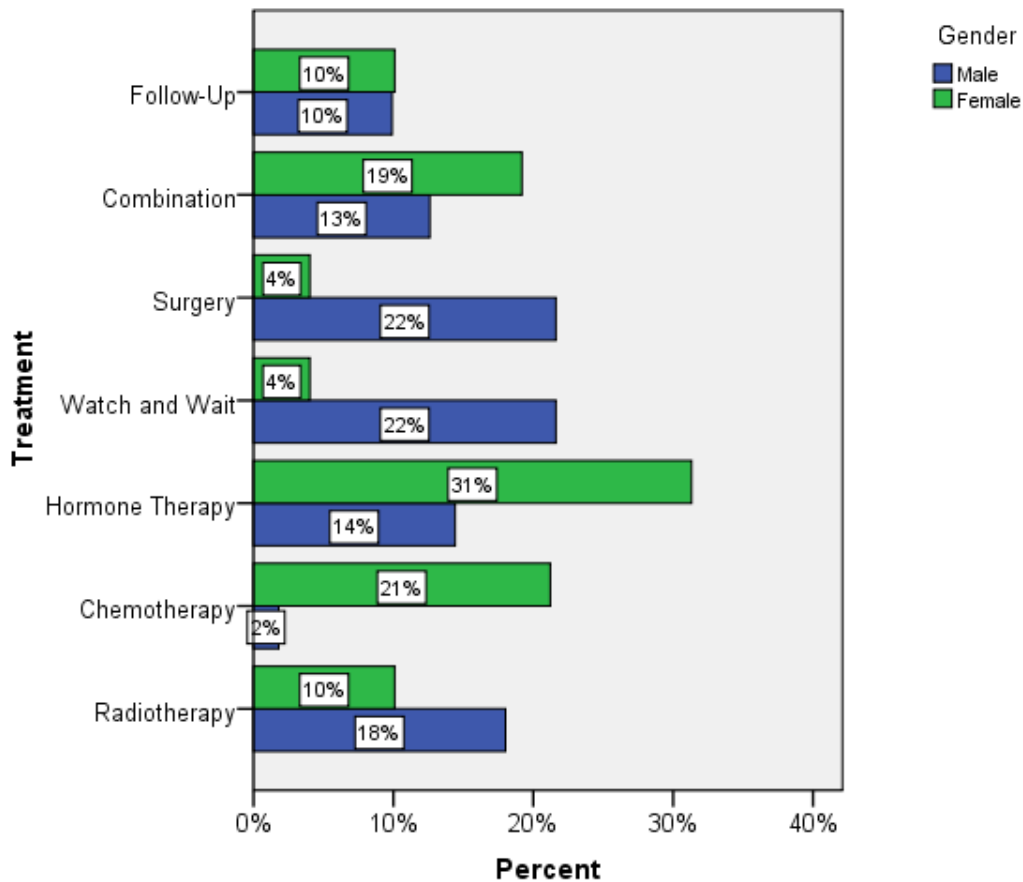
Figure 3.4: Treatment Status of Participants

Figure 3.4 illustrates the treatment received by participants. Treatment pathways were extremely diverse. Most participants with breast cancer were undergoing hormone therapy (31%) or chemotherapy (21%) whilst most participants with prostate cancer were under active surveillance (watch and wait) (22%) or had undergone surgery (22%).

3.4.2. *Factor Analysis of the HBCQ (v2)*

An exploratory principal components factor analysis was utilised in order to examine the structure of the HBCQ (v2). This provided information on whether any items within the HBCQ (v2) were highly correlated and thus likely to be measuring the same psychological construct. This informed the categorisation of HBCQ (v2) items into 'factors' (i.e. subscales), leading to data reduction and potentially a more efficient way of testing HBCQ (v2) variables against the research outcomes. This technique also allowed for informal inferences to made, such as via multiple regression analyses, a statistical technique adopted later to infer the predictive validity of HBCs in QoL outcomes.

The analysis produced a five-factor solution explaining 62% of the variance. Scree plots were examined and factors with eigenvalues greater than 1, indicating that identified factors explain sufficient variance for them to be valid, were accepted (Kaiser, 1960). The Kaiser-Meyer-Olkin (KMO) test of sampling adequacy was utilised in order to test the amount of variance within the data that could be explained by factors. A KMO of 0.5 is poor, .06 is acceptable, and a value closer to one is better. Any HBCQ items with a KMO of <0.5 suggests that this item should be removed prior to the analysis of outcome data obtained from the HBCQ. Of the original 22 items in the HBCQ, 19 loaded highly (0.50+) onto these factors. Loadings ranged from 0.52 to 0.91. Subscales were named according to the different types of health baselines the items encompassed:

Factor 1 – *Social Comparison Baselines*
Factor 2 – *Biological Baselines*
Factor 3 – *Illness-Specific Baselines*
Factor 4 – *Turning to Others*
Factor 5 – *No Comparisons*

The scale means, eigenvalues, Cronbach's alpha, and the amount of variance explained are illustrated in Table 3.2. To summarise:

- Social comparison baselines explained the highest proportion of variance (43%) and comprised eight items (Cronbach's alpha = 0.89).
- Biological baselines explained 7% of variance and comprised five items (Cronbach's alpha = 0.75).
- Illness-specific baselines explained 6% of variance and comprised three items (Cronbach's alpha = 0.74).
- Turning to others explained 3% of variance and comprised two items (Cronbach's alpha = 0.50).
- No comparisons consisted of one item.

The Cronbach's alpha of the identified HBC factors was acceptable for three of the factors: social comparison baselines (α = 0.89); biological baselines (α = 0.75); and illness-specific baselines (α = 0.74). The Cronbach's alpha of the turning to others factor was weak (α = 0.50), whilst the no comparison factor was one-item and thus did not require a test of internal consistency. Bartlett's test of sphericity demonstrated significance of the proportion of variance within the HBCQ items being explained by these factors (p = 0.001), accounting for as much as 0.90 of the variance.

Factor 1 (Social Comparison Baselines) remained as calculated in the factor analysis, with all items loading above 0.5.

Factor 2 (Biological Baselines) lost the variable 'mood' since this variable only loaded 0.47 on this factor.

Factor 3 (Illness-Specific Baselines) lost the variable 'hospital visits' since this variable, although loading at 0.62, was reducing the factor alpha from 0.75 to 0.02.

Factor 4 (Turning to Others) lost the variable 'age' since it only loaded 0.43 and did not theoretically complement the other variables within this factor.

Factor 5 (No Comparisons) remained as calculated in the factor analysis.

Since the five factors explain 62% of variance and, as they provide more in depth information on the categories of HBC that are utilised by people when evaluating their health status, they will replace the previous dichotic categorisation of HBCs into intrinsic and extrinsic. Whilst initially useful, intrinsic versus extrinsic baselines provide less detail about the underlying structure of the measure. Indicating the importance of intrinsic and extrinsic baselines, however, the five factors generally reflect these two categories: biological baselines, illness-specific baselines, and no comparisons might be classified as intrinsic (i.e. personalised), and social comparison baselines and turning to others classified as extrinsic (i.e. external influences).

Table 3.2: Factor Loadings for Items in Health Baseline Comparison Subscales (n=214)

Item stem	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5

1. Social Comparisons (Scale mean = 14.68, SD = 6.54: Eigenvalue = 7.06; alpha = 0.89; % variance = 42.7)
When thinking about how healthy I am, I take into consideration:

Item stem	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
People I know	**0.59**	0.39	0.09	0.20	0.00
The media	**0.52**	0.20	0.24	0.36	0.04
People who appear healthier than me	**0.86**	0.12	0.03	0.16	0.05
People who appear less healthy	**0.79**	0.05	0.17	0.07	0.10
People with the same cancer	**0.61**	0.24	0.31	0.06	0.13
People without cancer	**0.86**	0.03	0.01	0.03	0.02
People who are similar to me	**0.68**	0.01	0.45	0.06	0.18
People who are dissimilar to me	**0.75**	0.17	0.26	0.00	0.03

2. Biological Baselines (Scale mean = 16.70. SD = 2.56; Eigenvalue 2.13; alpha = 0.75; % variance = 6.61)
When thinking about how healthy I am, I take into consideration:

Item stem	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
My lifestyle	0.06	**0.69**	0.05	0.02	0.01
My appearance	0.05	**0.69**	0.04	0.05	0.01
The things I can do	0.04	**0.61**	0.18	0.11	0.08
My level of fitness	0.00	**0.59**	0.04	0.08	0.04
My past health	0.09	**0.56**	0.17	0.11	0.24

Table 3.2 continued: Factor Loadings for Items in Health Baseline Comparison Subscales (n=214)

Item stem	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
3. *Illness Specific Baselines (Scale mean = 9.03, SD = 2.34; Eigenvalue = 1.97; alpha = 0.74; % variance = 5.5)*					
When thinking about how healthy I am, I take into consideration:					
The symptoms I expect from cancer	0.31	0.34	**0.61**	0.01	0.02
The treatment I am undergoing	0.42	0.21	**0.72**	0.14	0.16
Any treatment side-effects	0.65	0.13	**0.79**	0.01	0.04
4. *Turn to Others (Scale mean = 4.72, SD = 1.95; Eigenvalue = 1.43; alpha = 0.50; % variance = 3.8)*					
When thinking about how healthy I am:					
I trust my family's opinions	0.19	0.37	0.17	**0.59**	0.26
I trust the doctor's opinion	0.08	0.08	0.14	**0.85**	0.20
5. *No Comparisons (Eigenvalue = 1.30)*					
When thinking about how healthy I am:					
I don't consider other people's health	0.26	0.06	0.10	0.84	**0.91**

3.4.3. HBC Descriptive Data

Table 3.3 presents the descriptive statistics for all HBCs encompassed in the HBCQ (v2) subscales. These are displayed in descending order of mean strength of agreement with each item. Percentage of agreement for various HBCs ranged from 10% for 'my mood at the time' to 95% for 'my lifestyle,' 'the things I can do,' and 'my appearance.' Agreement was calculated by adding the proportion of the sample that agreed or strongly agreed with each statement whilst disagreement was calculated by those who disagreed or strongly disagreed. The proportion of the sample that was unsure is also provided for each item.

These descriptive statistics provided support for the removal of 'mood' from the biological baselines subscale that was suggested by the preceding principal components factor analysis, since this variable had the lowest mean score of all of the items. The removal of 'hospital visits' from the illness-specific baselines subscale was also supported, since it had the third lowest mean score of all of the items. In terms of the exclusion of 'age' from the 'turning to others' subscale, this variable was omitted on the basis of factor analysis. However, 'age' as a HBC will be re-visited in further development of HBC theory and the HBCQ, since the descriptive statistics do suggest that it may be an important health baseline. Indeed, 'age' had the sixth highest mean level of agreement of all items.

Table 3.3: Agreement with HBCQ (v2) Items, in Descending Mean Order of Strength of Agreement (_n_ = 214)

HBC _When thinking about how healthy I am, I take into consideration:_	Mean (SD)	% agree/ strongly agree	% disagree/ strongly disagree	% Unsure
My lifestyle	3.45 (0.75)	95	3	2
The things I can do	3.42 (0.67)	95	2	3
My level of fitness	3.39 (0.71)	93	2	5
My appearance	3.35 (0.65)	95	2	3
The treatment I am undergoing	3.15 (0.90)	81	7	22
My age	3.10 (0.82)	88	8	4
Any treatment side-effects	3.09 (0.96)	79	9	22
My past health	3.09 (0.83)	86	7	7
My friends/family opinion more than my own	3.04 (1.13)	83	13	4
The symptoms I expect from cancer	2.79 (1.03)	71	14	15
The media	2.53 (1.01)	59	18	23
People who are dissimilar to me	2.16 (1.00)	40	29	31
People who appear healthier than me	1.98 (1.14)	38	43	19
I don't consider other people's health	1.88 (1.25)	39	48	13
People who appear less health than me	1.86 (1.16)	33	46	21
People without cancer	1.85 (1.19)	36	47	17
My doctor's opinion more than my own	1.69 (1.26)	29	48	19
People who are similar to me	1.53 (1.12)	23	57	20
People I know	1.49 (1.01)	19	62	19
The number of times I visit the hospital	1.40 (1.17)	23	23	20
People with the same cancer	1.27 (1.12)	18	34	16
My mood at the time	1.09 (0.92)	10	77	13

As can be seen in Table 3.3, half of the HBCs elicited over 50% endorsement, indicated by a response of agree or strongly agree. Of those HBCs eliciting fewer than 50% endorsement, only three in this latter group elicited over 50% disagreement (i.e. 'my mood at the time'; 'people I know'; 'people who are similar to me'). The five most frequently endorsed health baselines were as follows: 'My lifestyle'; 'The things I can do'; 'My level of fitness'; 'My appearance'; and 'The treatment I am undergoing'. These are primarily biological baselines, as well as illness-specific baselines.

The five least frequently endorsed health baselines were as follows: 'People who are similar to me'; 'People I know'; 'The number of times I visit the hospital'; 'People with the same type of cancer'; 'My mood at the time.' These represent a mixture of social comparison baselines (i.e. 'people who are similar to me'; 'people I know') and illness-specific baselines (i.e. 'the number of times I visit the hospital'; 'people with the same cancer').

3.4.4. Internal Consistency of Outcome Measures

The reliability of the three measures utilised in this study was examined. In the present sample, the Cronbach's alpha of the identified HBC factors were acceptable for all factors except for one that was 0.50 (i.e. Turning to Others). The FACT-G was 0.62, with individual subscales being: 0.65 for emotional well-being; 0.83 for physical well-being; 0.83 for social well-being; 0.87 for functional well-being. Thus, the reliability of data obtained from the HBCQ (v2) and FACT-G was adequate to high.

3.4.5. Tests of Difference between Breast and Prostate Cancer

Since participants were experiencing two different kinds of cancer that were gender-specific, independent samples t-tests were carried out on the five HBC factors and the QoL outcome variables in order to examine any significant differences. This was necessary to increase the validity of subsequent statistical analyses in terms of whether the sample could be aggregated or whether separate analysis was required.

a) Differences in HBCs

No significant difference was found between breast and prostate cancer for social comparison baselines, biological baselines, turning to others, or no comparisons. However, women with breast cancer endorsed illness-specific HBCs more than men with prostate cancer. The mean difference was -0.80 and the 95% confidence intervals (CI) for the estimated population mean difference between -1.43 and -0.17. An independent samples t-test showed that the difference between conditions was significant ($t = -2.49$, $df = 208$, $p < .01$).

b) Differences in QoL

No significant difference was found between breast and prostate cancer for social or functional well-being. However, men with prostate cancer had significantly better physical well-being, emotional well-being, and overall QoL than women with breast cancer:

Physical Well-Being: The mean difference was 2.19 and the 95% CI for the estimated population mean difference between 0.81 (female) and 3.57 (male). An independent samples t-test showed that the difference between conditions was significant ($t = 3.13$, *df* $= 199.46$, $p < .01$).

Emotional Well-Being: The mean difference was 1.64 and the 95% CI for the estimated population mean difference between 0.45 (female) and 2.83 (male). An independent samples t-test showed that the difference between conditions was significant ($t = 2.72$, *df* $= 194.26$, $p < .01$).

Overall QoL: The mean difference was 15.22 and the 95% CI for the estimated population mean difference between 9.58 and 20.87. An independent samples t-test showed that the difference between conditions was significant ($t = 5.31$, *df* $= 212$, $p < .001$).

3.4.6. Relationships between Health Baselines and Quality of Life

Pearson's (r) product moment correlations were used to examine relationships between HBC factors and overall QoL and its dimensions. Analyses were conducted for each cancer type due to the significant differences observed in some of the HBC and QoL variables, as well as for the purpose of examining the extent to which relationships between HBCs and QoL are moderated by disease. Any significant relationships are described below and a correlation matrix is presented in Table 3.4.

a) Social Comparison Baselines and QoL

Breast: Social comparison baselines in the breast cancer cohort were not significantly correlated with any of the QoL dimensions.

Prostate: Social comparison baselines in the evaluation of health status were not significantly correlated with physical, functional, or social well-being in men with prostate cancer. However, they were positively associated with emotional well-being ($r = 0.22$, $p < 0.05$) and overall QoL ($r = 0.16$, $p < 0.05$). Greater endorsement of social comparison baselines was significantly associated with better emotional well-being and overall QoL in men with prostate cancer.

b) *Biological Baselines and QoL*

Breast: biological baselines were not significantly correlated with physical, emotional, or social well-being, or overall QoL in women with breast cancer. However, a significant positive relationship was found with functional well-being ($r = 0.21$, $p < 0.05$). Greater endorsement of biological baselines was significantly associated with better functional well-being in women with breast cancer.

Prostate: Biological baselines in the prostate cancer cohort were not significantly correlated with any of the QoL dimensions.

c) *Illness-Specific Baselines and QoL*

Breast: Illness-specific baselines were not significantly correlated with physical, social, or functional well-being in women with breast cancer, nor with overall QoL. However, they were negatively correlated with emotional well-being ($r = -0.20$, $p < 0.05$). Greater endorsement of illness-specific baselines was significantly associated with lower emotional well-being in women with breast cancer.

Prostate: Illness-specific baselines were not significantly correlated with functional or social well-being in men with prostate cancer. However, they were negatively correlated with physical well-being ($r = -0.26$, $p < 0.01$) and overall QoL ($r = -0.19$, $p < 0.05$). Greater endorsement of illness-specific baselines when evaluating health status was associated with lower physical well-being and lower overall QoL in men with prostate cancer.

d) *Turning to Others*

Breast: Turning to others when evaluating personal health status was not significantly correlated with any of the QoL dimensions in women with breast cancer.

Prostate: Turning to others when evaluating personal health status was not significantly correlated with any of the QoL dimensions in men with prostate cancer.

e) No Comparison

Breast: No comparisons when evaluating personal health status was not significantly correlated with any of the QoL dimensions in women with breast cancer.

Prostate: No comparisons when evaluating personal health status was not significantly correlated with any of the QoL dimensions in men with prostate cancer.

Table 3.4: Correlations between HBCs and QoL in people with Breast Cancer (n = 102) and Prostate Cancer (n = 112)

Variable	1	2	3	4	5	6	7	8	9	10
1. Social Comparison Baselines	.00									
	.00									
2. Biological Baselines	-.20*	.00								
	-.22*	.00								
3. Illness-Specific Baselines	-.31**	.33**	.00							
	-.46**	.34**	.00							
4. Turning to Others	.18	.17	-.12	.00						
	.31**	.10	-.24*	.00						
5. No Comparisons	.37**	.03	-.21*	.26**	.00					
	.32**	-.13	-.11	.05	.00					
6. Physical Well-Being	-.01	-.04	-.06	-.03	.03	.00				
	.02	-.07	**-.26**	.10	-.08	.00				
7. Social Well-Being	.05	-.04	-.09	-.14	-.04	.16	.00			
	.04	.05	.05	-.13	-.14	.18	.00			
8. Emotional Well-Being	.12	-.02	**-.20***	.11	.10	.47**	.20*	.00		
	.22*	-.04	-.15	-.02	-.11	.35**	.33**	.00		
9. Functional Well-Being	.03	**.21***	-.00	-.01	.09	.54**	.41**	.52**	.00	
	.13	.04	-.06	.12	-.10	.41**	.46**	.38**	.00	
10. Overall QoL	.08	-.04	-.26	-.03	.06	.71**	.58**	.73*	.80**	.00
	.15	-.01	**-.19***	.09	-.08	.71**	.63**	.53**	.78**	.00

*One-tailed correlations: *p < .05; **p < .01; ***p < .001*

3.4.7. Predicting Quality of Life from Health Baseline Comparisons

On establishing a number of significant correlations between HBCs and multidimensional QoL, five hierarchical regression analyses were conducted in order to determine the HBCs that were the most significant predictors of overall QoL and its individual well-being dimensions. In Step 1 of each regression analysis, age and educational status were entered in order to control for possible effects, as research has found that such demographic factors might be important predictors of QoL (Wenzel et al, 1999). In Step 2, cancer type was entered, based on significant differences presented in 3.4.5., as well as differences in the pattern and strength of the relationships described in 3.4.6. In Step 3, treatment type was entered, as the literature demonstrates the implications treatment poses for QoL (1.8.4.). In Step 4, co-morbidities were entered in order to control for any potentially confounding effects of other illness experience. The five HBC factors were entered in Step 5. Details of the regressions are shown in Table 3.5.

a)   Predictors of Overall QoL

Age and educational status entered in Step 1 were both significant predictors, together accounting for 10% of the variance in estimates of overall QoL. Cancer type, entered in Step 2, explained a further 3% of the variance whilst treatment type, entered in Step 3, was not a significant predictor of overall QoL. Co-morbidities, entered in Step 4, were a significant predictor, explaining a further 4% of incremental variance. The HBC factors entered in Step 5 together explained a total of 5% of the variance. Examination of the betas indicated that only one HBC factor was a significant predictor of this outcome, namely: illness-specific baselines. The final model explained 22% of the variance in overall QoL.

b) Predictors of Physical Well-Being

Age and educational status entered in Step 1 accounted for 6% of the variance in estimates of physical well-being, with only age being a significant predictor.   Cancer type, entered in Step 2 explained a further 2% of incremental variance, but this was not significant. Treatment type, entered in Step 3, failed to account for any variance. Co-morbidities, entered in Step 4, explained a further 3% of incremental variance. The HBC factors entered in Step 5 explained 4% of the variance. Examination of the betas indicated that only one HBC factor was a significant predictor of this outcome, namely: illness-specific baselines. The final model explained 15% of the variance in physical well-being.

c) Predictors of Social Well-Being

No variables within the model were significant predictors of social well-being.

d) Predictors of Emotional Well-Being

Age and educational status, entered in Step 1, accounted for 5% of the variance in estimates of emotional well-being, with only age being a significant predictor. Cancer type, treatment type and co-morbidities entered in Steps 2, 3 and 4 failed to account for any variance. The HBC factors entered in Step 5 together explained 6% of the variance. Examination of the betas indicated that only one HBC factor was a significant predictor of this outcome: illness-specific baselines. The final model explained 11% of the variance in emotional well-being.

e) Predictors of Functional Well-Being

Age and educational status entered in Step 1 accounted for 4% of the variance in estimates of functional well-being, with only educational status being significant. Cancer type entered in Step 2 and treatment type entered in Step 3 both failed to account for any variance. Co-morbidities, entered in Step 4, explained a further 4% of incremental variance. The HBC factors entered in Step 5 together explained 3% of the variance. Examination of the betas indicated that only one HBC factor was a significant predictor of this outcome: biological baselines; however, this was only marginally significant ($p < 0.05$). The final model explained 11% of the variance in functional well-being.

Table 3.5: Hierarchical Regression Analysis of Predictors of QoL Outcomes (n = 214)

Predictor	QoL			Physical Well-Being			Social Well-Being		
	Beta	F	R^2 (change)	Beta	F	R^2 (change)	Beta	F	R^2 (change)
Step 1									
Age	.27**	11.25***	(.10)	.23***	5.94**	(.06)	-.01	.00	(.00)
Education	.23**			.09			.03		
Step 2									
Cancer	.18**	9.94***	(.03)	.04	4.06**	(.00)	.05	.29	(.00)
Step 3									
Treatment	-.06	7.66***	(.00)	-.13	3.89**	(.02)	.03	.23	(.00)
Step 4									
Co-morbidities	.21**	8.10***	(.04)	.19**	4.70***	(.03)	.15*	1.12	(.00)
Step 5									
Social Comparisons	.07	5.43***	(.05)	-.04	3.23***	(.04)	.11	1.32	(.00)
Biological Baselines	.04			.01			.07		
Illness-Specific Baselines	-.21**			-.21**			-.06		
Turning to Others	.06			.01			-.18*		
No Comparisons	.00			-.04			-.07		
Total R^2			**.22**			**.15**			**.00**

* *p*<.05, ***p*<.01, ****p*<.001

Table 3.5 continued: Hierarchical Regression Analysis of Predictors of QoL Outcomes (n = 214)

Predictor	Emotional Well-Being			Functional Well-Being		
	Beta	F	R^2 (change)	Beta	F	R^2 (change)
Step 1						
Age	.17*	5.10**	(.05)	.13	3.79*	(.04)
Education	.11			.17*		
Step 2						
Cancer	.09	3.81**	(.00)	.04	2.71*	(.00)
Step 3						
Treatment	-.12	3.51**	(.00)	-.00	2.03	(.00)
Step 4						
Co-morbidities	.10	3.01**	(.00)	.21**	3.26**	(.04)
Step 5						
Social Comparisons	.10	2.89**	(.06)	.11	2.26*	(.03)
Biological Baselines	.07			.16*		
Illness-Specific Baselines	-.18*			-.06		
Turning to Others	-.03			-.03		
No Comparisons	.07			.00		
Total R^2			.11			.11

* *p<.05, **p<.01, ***p<.001*

3.4.8. Summary of Quantitative Findings

Before discussing the qualitative data, a summary of the main quantitative findings are presented. An exploratory principal components factor analysis produced a five-factor solution explaining 62% of the variance: Social comparison baselines; biological baselines; illness-specific baselines; turning to others; and no comparisons. Of these baselines, social comparison baselines were significantly correlated with well-being outcomes in men with prostate cancer, biological baselines were significantly correlated with well-being outcomes in women with breast cancer, and illness-specific baseline were significantly correlated with well-being outcomes in both cohorts. Controlling for gender (and thus cancer type), illness-specific baselines were a significant predictor of overall QoL, physical well-being, and emotional well-being. Biological baselines were a significant predictor of functional well-being.

3.4.9. Thematic Content Analysis of Qualitative Data

In order to provide evidence of the existing five HBC factors as well as to identify any additional HBCs, qualitative responses were analysed via thematic content analysis (Figure 3.5). Responses were assigned to one of the five categories already identified via the principal components factor analysis: social comparison baselines, biological baselines, illness-specific baselines, turning to others, or no comparisons. Responses that could not be assigned to one of these categories were assigned to a sixth category of 'other baselines.'

Figure 3.5: Thematic Content Analysis Process (Braun and Clarke, 2006).

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┌─────────────────────────────────┐
│   Become familiar with the data,│
│   reading and re-reading as much│
│         as necessary.           │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│     Highlight interesting data. │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│   Categorise interesting data into│
│    themes, defining and naming  │
│           the themes.           │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│     Review themes, assessing    │
│   whether they are consistent   │
│    with qualitative extracts.   │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│   Select vivid extracts from the│
│  analysis of data in relation to the│
│        research question.       │
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```
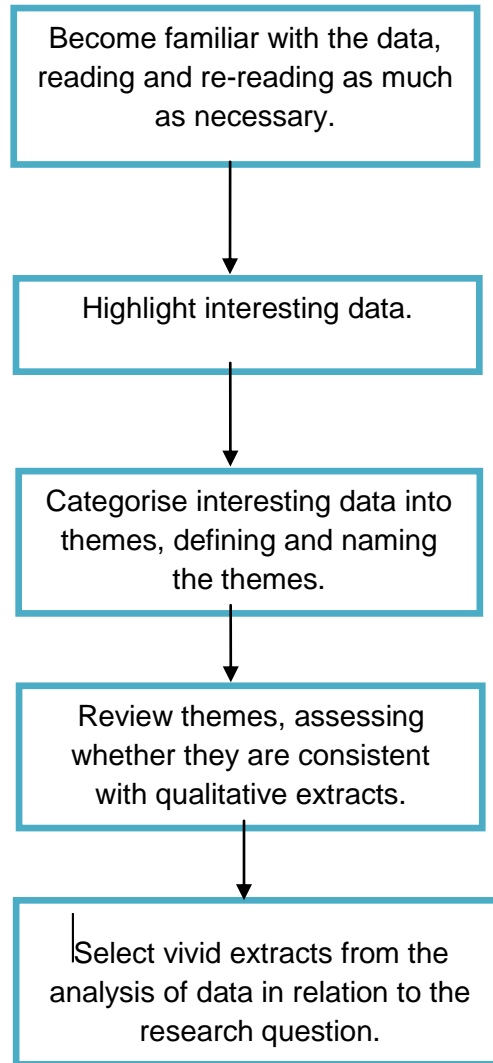
A total of 67% of participants provided qualitative data regarding the baselines they use when evaluating their health status. The distribution of participant responses to the five HBC categories and the 'other baselines' category can be seen in Figure 3.6; other baselines were further analysed for themes, as can be seen in Figure 3.7. Quotes have been presented in both Figure 3.6 and 3.7, providing examples of the type of baselines referred to by participants. To ensure reliability, a proportion of the data (15%) was analysed by another health psychology researcher. An acceptable level of concordance was achieved ($K = 0.70$).

Figure 3.6: Baselines used to Evaluate Health Status (n=180); quotations represent examples of health baselines described by participants.

Health Baselines for Evaluating Health Status

4% (n = 8) of participants described social comparison baselines

"There is always someone who is in a worse state of health than myself" (P162).

32% (n = 57) of participants described biological baselines

"The condition of my hair and nails and the colours of the whites of my eyes" (P111).

17% (n = 31) of participants described illness-specific baselines

"How well I was prior to diagnosis" (P181).

5% (n = 9) of participants described turning to others

"Family opinions" (P76).

1% (n = 2) of participants described no comparisons

"How well my friends are does not affect my feelings about my own overall health" (P181).

41% (n = 73) of participants described other baselines

"Whether I am able to work" (P124).

As can be seen in Figure 3.6, 59% of the HBCs utilised by participants when evaluating their health status had already been identified via previous research stages and reviews of the literature. Illustrative responses for each baseline have been provided and are described in more detail below.

a) Social Comparison Baselines

Social comparison baselines made up 4% of responses, with comparisons generally being guided by age (e.g. *"I am aware of being more mobile than many people of the 82 year old group"*), the influence of friends and family (e.g. *"My friends health does factor in too"*), or a motivation to compare oneself to someone perceived as having inferior health (e.g. downward comparisons: *"There is always someone who is in a worse state of health than myself"*). Although there was little qualitative data pertaining to social comparison HBCs, indicated by the fact that only eight participants highlighted this type of comparison, the descriptive data illustrated in Table 3.3 does indicate a moderate level endorsement. Indeed, the factor analysis indicated social comparison baselines as explaining the highest proportion of variance (Table 3.2).

b) Biological Baselines

Biological baselines made up 32% of responses in total, accounting for the largest percentage of the five HBC factors. Interestingly, whilst biological HBCs explained a small amount of variance in functional well-being in the multiple regression analysis, they accounted for the most qualitative responses out of the five HBC factors. Frequent references were made to physical ability (e.g. *"I evaluate my ability to function with little or no impediments"*), lifestyle choices (e.g. *"I am actually healthier now, working out and strict diet"*), appearance (e.g. *"The condition of my hair and nails and the colours of the whites of my eyes"*), and biological changes over time (e.g. *"sometimes comparison to how I have been/what I did in the past"*).

c) Illness-Specific Baselines

Illness-specific baselines made up 17% of responses, accounting for the second largest percentage of the five HBC factors. Whilst illness-specific baselines were one of the two HBC categories that explained a significant proportion of variance in QoL outcomes in the multiple regression analysis, they also accounted for the second highest percentage of qualitative responses. This highlights their importance in the HBC construct. Responses indicated a number of illness-specific considerations when evaluating health status, including: tumour growth and treatment (e.g. *"Last year, when I was on chemo, I was a bit limited as to what I could do, this year I feel a great deal better although my cancer is in a growth phase, and I am actually less healthy"*); environmental factors such as being at the hospital (e.g. *"if at the hospital the goal posts move to measure myself against others with my disease or having the same treatment"*); and any co-morbidities (e.g. *"Apart from breast cancer I also consider my diabetes (I take lots of pills, not insulin) and my angina"*).

d) Turning to Others

The baseline of turning to others when evaluating health status made up 5% of responses. Responses ranged from using other people's opinions (i.e. *"Family opinions"*) to total reliance on someone else judging one's health status (e.g. *"What my wife thinks"*).

e) No Comparisons

The percentage of participants claiming to not take into consideration other people when evaluating personal health status was 1% (e.g. *"My views of my own health depend on how I feel, what I can do, how I live my life without reference to what other people can or cannot do"*), providing support for the moderate to high endorsement of individual HBCs and, in particular, social comparison HBCs.

f) Other Baselines

Participants made reference to a number of 'other baselines' (41%), which were categorised into seven themes, in descending order of highest percentage: Relationships; Employment; Activities of Daily Living; Mood; Religion; Environmental; and Holistic.

Relationships: The use of relationships as a HBC when evaluating health status accounted for 28% of 'other' HBC responses and was primarily focused on functional ability relating to relationships (e.g. *"My ability to support my friends and family"; "Ability to socialise"*) and coping (e.g. *"The fact that I have a great support system helps me deal with every day issues and activities of daily living"*).

Employment: The use of employment as a HBC when evaluating health status accounted for 23% of 'other' HBC responses and ranged from ability to work (e.g. *"Whether I am able to work"*) to occupational stress (e.g. *"The stress I have with my job plays a very important part in how I feel, and it's usually lousy!"*) to financial implications (e.g. *"My financial position"*).

Activities of Daily Living: The use of activities of daily living as a HBC when evaluating health status accounted for 18% of 'other' HBC responses and was again primarily focused on ability (e.g. "*My ability to get things done – run errands, cook, shop*") and coping (e.g. *"How I cope with everyday life like shopping, gardening and outings"*).

Mood: The use of mood as a HBC when evaluating health status accounted for 13% of 'other' HBC responses and was indicative of the optimism/pessimism dyad (e.g. "*Level of enthusiasm to wake up and actually accomplish something each day"; "The fact that I wake up each day hoping for a better day"*) as well as general daily levels of stress (e.g. *"stress"*). The stress encompassed within the emerging category of mood was unrelated to any specific context, distinguishing it from the work-induced stress encompassed in the employment category.

Religion: The use of religion as a HBC when evaluating health status accounted for 8% of 'other' HBC responses and encapsulated both the notion of faith (e.g. _"Religious faith"_) and religious unity (e.g. _"Spiritual and emotional connectedness to others"_).

Environmental: The use of environment as a HBC when evaluating health status accounted for 5% of 'other' HBC responses (e.g. _"External environmental factors"; "Environmental"_).

Holistic: The use of holistic factors when evaluating health status accounted for 5% of 'other' HBC responses and indicated that some people incorporate a number of factors into their evaluations rather than relying on health status evaluations that are more one-dimensional. Examples of this holistic approach are: _"My life's situations . . . stress level; workload; time of year (allergy season/flu season); what is happening in and around me"; "Quality of life – joy, ability to function normally at work or at play."_

Figure 3.7: 'Other' Baselines used to Evaluate Health Status (n=73); quotations represent examples of other health baselines described by participants.

'Other' Health Baselines for Evaluating Health

28% of participants described relationships

"My home/family relationships and conditions." (P130).

23% of participants described employment

"The stress I have with my job plays a very important part in how I feel, and it's usually lousy!" (P8).

18% of participants described activities of daily living

"My ability to get things done – run errands, cook, shop" (P192)

13% of participants described mood

"My general outlook on life; My mood" (P170).

8% of participants described religion

"Spiritual and emotional connectedness to others" (P69).

5% of participants described environmental factors

"Environment factors" (P160).

5% of participants described Holistic factors

"My life's situations . . . stress level; workload; time of year (allergy season/flu season); what is happening in and around me" (P118).

As can be seen from Figure 3.7, a vast array of 'social' factors was important in the health status evaluations carried out by the participants within this study. From ability to maintain employment, to the strength of relationships, to feelings of relaxation, social factors were important contributors to feelings of health and well-being.

3.4.10. Additional Qualitative Findings: HBC Direction

Categorisation of qualitative responses highlighted a pattern in the direction of HBCs utilised when evaluating health status, whereby HBCs were either 'positively' or 'negatively' directed. 'Positively-directed HBCs' refer to evaluating abilities and gains and 'negatively-directed HBCs' refers to evaluating inabilities and losses. Specific examples are presented in Table 3.6.

Table 3.6: Positively and Negatively Directed HBCs

HBC Direction	Example
Positively-Directed Biological Baseline	*"Physical ability to perform activities that I Find fun."* (P146, Breast Cancer).
Negatively-Directed Biological Baseline	*"Deterioration in strength, abilities, etc."* (P46, Prostate Cancer).
Positively-Directed Illness-Specific Baseline	*"I consider the problems I don't have – diabetes, serious arthritis, heart attack, etc."* (P174, Breast Cancer).
Negatively-Directed Illness-Specific Baseline	*"Apart from breast cancer I also consider my diabetes (I take lots of pills not insulin) and my angina (I take pills)."* (P156, Breast Cancer).

The issue of HBC direction will be revisited in subsequent studies once the HBCQ has been refined to elicit such aspects of the HBC concept.

3.5. Discussion

Study 2a and Study 2b had several aims: firstly, Study 2a aimed to examine the structure of the HBC measure via factor analysis; to test for relationships between HBCs and general and multi-dimensional QoL in people with breast and prostate cancer; and to explore HBC theory as a predictor of general and multi-dimensional QoL outcomes. Additionally, Study 2b aimed to provide qualitative support and further insight into the HBCs utilised when evaluating personal health status. Each of these aims will be discussed separately, commencing with the structural analysis of the HBCQ.

3.5.1. HBCQ Refinement

An exploratory principal components factor analysis of the HBCQ produced a five factor solution, explaining 62% of variance in health baselines. The five factors were: social comparison baselines; biological baselines; illness-specific baselines; turning to others; no comparisons. Internal consistency was acceptable for all but one of the five factors, this being turning to others. Nevertheless, evidence was provided that turning to others when evaluating health status might be frequent; this is suggested by 83% of participants indicating that they turned to friends and family. This suggests that this item should be retained in the next version of the HBCQ.

Social comparison baselines and biological baselines, the inclusion of both being supported by research cited in Chapter 1 (Buunk et al., 1990), explained the highest proportion of variance in health baselines. Indeed, the qualitative data indicates that biological baselines were also the most frequently cited of the five factors, followed by illness-specific baselines. The no comparison factor consisted of one-item pertaining to not making any comparisons with others when evaluating health status. This item failed to predict QoL outcomes, and received only a relatively small level of endorsement (39%). Furthermore, no comparisons only accounted for 1% of qualitative responses.

The five HBC factors were used in this study to test their predictive value in explaining QoL in people with breast and prostate cancer. However, the no comparisons factor will be excluded from subsequent stages of the research programme, since it appears to be a weak factor. Indeed, it could be argued that making no comparisons is indirectly measured via the amount of endorsement (if any) provided to individual HBCs.

Although the no comparison category has been removed from the HBC measure, it might be a fruitful area for future investigation. As well as utilising different types of HBCs, it is clear that some people evidently engage in HBCs less frequently than others. It would be interesting, therefore, to explore this issue further. Such research might examine the protective or detrimental impact of using less (or no) comparisons when evaluating health status. It would also be interesting to examine the personality traits of those who are less likely to engage in such comparisons. For example, it might be that these people have a tendency to be isolated from others or prefer one's own company. Indeed, is there a difference between the HBCs adopted by introverts versus extroverts, and if so, are there any implications of such differences? Further directions for investigation into the HBC concept in general will be explored in Chapter 4.

3.5.2. HBC and QoL Differences by Cancer Type

Since the literature has highlighted QoL differences by gender and cancer type (Gallicchio, Hoffman, and Helzlsouer, 2007; Kaplan and Baron-Epel, 2003), independent sample t-tests were carried out on the five HBCs and the QoL outcome variables in order to establish any differences between those participants with breast cancer and those with prostate cancer.

Women with breast cancer endorsed illness-specific HBCs significantly more strongly than men with prostate cancer. In terms of QoL outcomes, men with prostate cancer had significantly better physical well-being, emotional well-being, and overall QoL than women with breast cancer. It is possible that the variation in illness-specific baseline endorsement between cohorts (which was an important factor in predicting well-being) provides an explanation for the subsequent significant QoL differences. For example, is it possible that greater endorsement of illness-specific baselines is related to the lower perceived QoL in the breast cancer cohort?

The identified HBC and QoL differences between groups were considerable, and thus correlations between variables were examined by cancer type in order to investigate the proposed potential relationship between these significantly different variables.

3.5.3. Relationships between Variables

Neither turning to others, nor no comparisons, was significantly associated with multidimensional QoL. However, significant associations were identified between social comparison baselines, biological baselines, and illness-specific baselines and QoL outcomes.

In terms of social comparison baselines, whilst no associations with QoL were identified in the breast cancer cohort, these baselines were related to emotional well-being and overall QoL in the prostate cancer cohort. Greater endorsement of social comparison baselines was significantly associated with better emotional well-being and overall QoL in men with prostate cancer. These findings, along with the literature cited in Chapter 1, support the theory that social factors such as other people's health might act as social comparison baselines (or reference points) when evaluating one's own health status (Festinger, 1954; Kelly and Ratner, 2005). In turn, this could impact QoL in a number of ways, the data in this study highlighting implications for emotional well-being and overall QoL. If using social comparison baselines when evaluating health status is related to better emotional well-being and overall QoL in men with prostate cancer, as is suggested here and within previous research on downward comparisons (VanderZee et al., 1996), greater insight into this relationship is warranted.

The data obtained within this study might provide support for the theory that downward comparisons offer self-enhancing benefits (Wills, 1981) or, alternatively, of a gender difference in the QoL implications of social comparisons. For example, whilst men might benefit from social comparisons as a HBC, is it possible that women remain indifferent to such methods of health status evaluation? Similarly, is it possible that type and direction (i.e. upward or downward) of social comparison HBCs differ by gender? For example, it is worth distinguishing between 'comparison' and 'identification.' The outcome of social comparisons used for finding difference (i.e. comparison) as opposed to similarity (i.e. identification) could influence the interpretation of the findings within this study. As discussed in Chapter 1, the selective accessibility model (Mussweiler, 2003a; Mussweiler, 2003b) suggests that

assimilative responses (i.e. identification) are observed when stimuli are perceived to be similar to a target and that contrastive responses (i.e. comparisons) are observed when stimuli are perceived to be different from a target.

Research findings highlight important differences in the outcomes of upwards and downwards social comparisons (Wills, 1981; Bennenbroek, Buunk, van der Zee, and Grol, 2002). The HBCQ was not designed to identify the direction of these social comparison baselines (i.e. upward or downward), which might have provided some further insight into how these findings relate to the literature. Nevertheless, the findings of this study might offer scope for further insight into this aspect of cancer-related QoL.

In terms of biological baselines, no significant associations with QoL were identified in the prostate cancer cohort but were present in the breast cancer cohort. Greater endorsement of biological baselines was significantly associated with better functional well-being in women with breast cancer. Such an association might be expected, since both biological baselines and functional well-being are physiological in nature and thus biological baselines are, arguably, a key intrinsic indicator of functionality. Indeed, these findings along with the literature cited in Chapter 1 support the theory that biological or physiological factors such as symptoms or a change in appearance might act as biological baselines (or reference points) that alert an individual to a change in health status (Buunk et al., 1990); and that this in turn could impact QoL (Vincent, Clover, and Buckley, 2003).

Although the causal direction between biological baselines and functional well-being cannot be inferred, it is likely that changes in function trigger biological baselines, as supported by this study and research cited in Chapter 1 (Vincent, Clover, and Buckley, 2003). An opportunity to take action that might prevent further decline is also provided by outcomes resulting from biological baselines. This study might have benefitted from the addition of an objective measure of functional well-being alongside this self-report data, by providing insight into how adaptive such baselines are. Biological baselines are fundamentally 'listening to one's own body,' and thus it would be interesting to examine how effective people are at doing this, as well as the risks associated with an over-reliance on this type of baseline (i.e. hypervigilance, hypochondria). Of particular interest would be an examination of how people with a chronic illness might adjust these biological baselines in line with changes expected of a chronic or progressive condition, and subsequently how this might facilitate adjustment to illness (Davies and Kinman, 2006).

In terms of illness-specific baselines, greater endorsement of these baselines in health status evaluations were related to lower emotional well-being in women with breast cancer, and lower physical well-being and overall QoL in men with prostate cancer. This suggests that illness-specific baselines might lead to over-emphasis on illness as opposed to health. It is plausible that the use of illness-specific baselines results in the development of a strong illness identity, which has been associated with higher levels of psychological distress in individuals with allergies, as well as other illness groups (Knibb and Horton, 2008). Interestingly, illness-specific

baselines made a significantly stronger contribution to QoL outcomes than any other HBCs. This issue will now be discussed.

3.5.4. Predicting Multidimensional QoL from HBCs

Multiple regression analyses highlighted the factors within the HBC construct that were the strongest predictors of QoL. Over all, HBCs explained a very modest proportion of variance, with illness-specific baselines being a significant predictor and biological baselines being a marginally significant predictor. The remaining three HBC factors (i.e. social comparison baselines, turning to others, no comparisons) did not significantly predict QoL or its dimensions in this study.

Since illness-specific baselines were the strongest predictor of QoL out of all HBC factors, it was interesting to find that treatment type (an illness-specific variable) did not predict QoL or its dimensions. One possibility is that people with cancer evaluate their health according to biological illness markers (i.e. symptoms) as opposed to procedural illness markers (i.e. treatment factors). It might be that the cancer itself is more likely to inform health baseline judgements than are procedural issues such as treatment type. Indeed, hospital visits was one of the lowest endorsed HBCQ items, and was excluded due to the low weighting demonstrating via the factor analysis.

Since greater endorsement of illness-specific baselines was found to correlate with lower emotional well-being in women with breast cancer and lower physical well-being in men with prostate cancer, there is need to investigate the role of this HBC in QoL outcomes in more depth. It would also be potentially useful to compare the predictive validity of this baseline in people with and without a chronic illness in order to establish key illness-specific baselines that might facilitate adjustment to cancer and its treatment. Furthermore, examining the importance of individual illness-specific baselines between different illness groups might prove effective in establishing condition-specific HBCs.

In terms of demographic factors, age and educational status were predictive of all QoL outcomes except for social well-being. This was expected due to known relationships within the literature (Wenzel et al, 1999). In fact, age and educational status were expected to explain a greater percentage of the variance in QoL outcomes than they did. This is likely to be explained by the diversity in participant demographics, making it difficult to elicit any strong relationships between the data. This is discussed further in the research limitations (3.5.6.).

Cancer type (i.e. breast or prostate) was predictive of overall QoL, but interestingly, was not predictive of any of the individual QoL dimensions. In this study, cancer type was clearly predictive of overall QoL but not to an extent that it distinguished between the dimensions of QoL. This highlights the potential of combining QoL data-sets from different cancer groups in order to enhance knowledge of cancer; although greater research is needed into this. Furthermore, it was necessary to control for cancer type within this study due to significant HBC and QoL differences identified via independent samples t-tests.

3.5.5. Qualitative Insight into HBCs

The qualitative data provided support for four of the identified HBC factors: social comparison baselines; biological baselines; illness-specific baselines; and turning to others. The one–item factor pertaining to no comparisons was deemed weak in terms of both the percentage of qualitative evidence supporting its endorsement (1%), combined with the factor demonstrating no statistically significant contribution to QoL outcomes.

The qualitative data also provided evidence of HBCs that were not assessed via the HBCQ (v2). Indeed, 41% of qualitative responses were categorised as 'other' baselines, which in turn were themed as: relationships; employment; activities of daily living; mood; religion; environmental; and holistic. These baselines will require further exploration before being integrated into the HBCQ for future stages of this programme of research.

Of these other baselines, the primary theme that emerged was that of a 'social' context. This was noticeably distinct from social comparison baselines in that the latter involved comparisons with other people whilst the former was contextual in nature, referring primarily to work, relationships, and social situations pertaining to activities of daily living. Even factors not explicitly social in nature, such as stress and physical ability, were socially contextualised in the 'other baselines' (i.e. stress at work; physical ability to socialise, etc.).

A further important emergence from the qualitative responses discussed in this chapter was that reported HBCs were clearly distinguishable in terms of their direction (i.e. positive or negative). In study 2a the potential value of being able to identify such directions when interpreting correlations between social comparison baselines and emotional well-being were discussed, with particular reference to research within the literature distinguishing between upward and downward social comparisons (Wills, 1981; Bennenbroek, Buunk, van der Zee, and Grol, 2002). As a result of these combined observations, modifications to the direction of HBCQ items will need consideration in order that this distinction can be explored more thoroughly in future stages of this programme of research. For example, it might be interesting to examine the extent to which these HBCs form categories and also whether positively or negatively directed HBCs are more or less predictive of well-being outcomes.

3.5.6. Research Limitations

The amount of variance in overall QoL and its dimensions that could be explained by HBCs was limited. In retrospect, this was likely to be the consequence of the demographic and treatment-related diversity within the chosen cohorts. There were many factors, not merely related to gender or disease-type, which prevented inferences being made from the data collected. In fact, the diversity of group members in terms of demographics, treatment type, and illness stage rendered it difficult for even disease or gender differences to be accurately identified. For example, the men were significantly older than the women and, within groups, people

were at various stages of active treatment or follow-up. Whilst this study successfully met the required aims in terms of theory and questionnaire development for the general population of people with cancer, it also highlighted the need to have more stringent inclusion and exclusion criteria in subsequent studies. A more rigorous approach will be necessary for gaining focused, reliable, and practical HBC data.

A further limitation of this study was the inability to identify the direction of HBCs (i.e. whether people's baselines were positively or negatively focused, upward or downward, e.g. consideration of negative treatment side-effects versus positive treatment outcomes, etc.). Direction is often assessed in social comparison research (i.e. upward or downward) and research distinguishing between comparative difference and comparative identification (Mussweiler, 2003a; Mussweiler, 2003b), and such a distinction within this study might have facilitated the interpretation of data and any inferences made from the data. This will need to be considered in further refinement of the HBCQ.

Inconsistencies between the demographic data collected within this study and national norms are also worthy of note. A high proportion of patients reported being in the postgraduate category of educational status, which is not consistent with national norms nor well-known adverse relationships between cancer and lower socioeconomic status (ONS, 2005). The term 'postgraduate' might have been misunderstood by the participants in this study, which is another area of consideration when refining the HBCQ.

3.6.   Conclusions

Studies 2a and 2b of this programme of research examined the type of baselines people with cancer are more or less likely to endorse, whilst also providing guidance on the further development of this theory. Significant relationships were demonstrated between some HBCs and multidimensional QoL in people with breast and prostate cancer, primarily in terms of social comparison baselines, biological baselines, and illness-specific baselines. A modest significant contribution of both illness-specific and biological HBCs was also demonstrated in predictive models of QoL outcomes in people with breast and prostate cancer. Specifically, illness-specific baselines were predictive of emotional and physical well-being, as well as overall QoL.

The use of thematic content analysis for complementary HBC data, as well as the provision of more in depth examination of health baselines facilitated the development of HBC theory via the identification of new baselines. This demonstrates the importance of eliciting the patient experience qualitatively as well as quantitatively.

Since the limitations of this study design reflect a need to refine the population of interest, future research stages will focus on one disease only: breast cancer. The breast cancer cohort reported significantly worse QoL than people with prostate

cancer, which it is argued will ultimately provide greater opportunity for exploring HBC and QoL interactions. They also provided significantly greater endorsement for illness-specific baselines, the baselines that explained the most variance in QoL outcomes.

The population of interest also requires refinement in terms of treatment type, with cancer treatments varying in terms of QoL implications. As described in Chapter 1, chemotherapy for breast cancer is the most invasive treatment in terms of side-effects (Cleeland, 2008). Thus, women receiving chemotherapy for breast cancer are likely to experience a number of changes in their health status and QoL. With this in mind, further stages of this programme of research have been designed around women with breast cancer undergoing chemotherapy. Based on findings from this study, as well as information within the literature, this group are likely to provide an opportunity for greater insight into HBCs throughout changes in health status bought about by both illness and treatment.

Before conducting research with the discussed sample of interest, the next chapter outlines the modification of the HBCQ (v2) and presents results from a small pilot study with women experiencing breast cancer. The aim of the next chapter is to provide greater psychometric and operational strength to the HBCQ (v3) before it is implemented in a longitudinal study designed to assess HBCs and QoL across the treatment trajectory.

Chapter 4

Study 3: Further Development of the HBCQ for use with Women Receiving Chemotherapy for Breast Cancer

4.1. Introduction

Study 2a and 2b were described in chapter 3. In Study 2a, relationships between HBCs and QoL outcomes were tested in people with breast and prostate cancer. Significant relationships were found between some HBCs, primarily social comparison baselines, biological baselines, and illness-specific baselines, and multidimensional QoL. Illness-specific and biological baselines HBCs were also found to make a modest significant contribution in predictive models of QoL outcomes in people with breast and prostate cancer. Specifically, illness-specific baselines predicted emotional and physical well-being, as well as overall QoL. In Study 2b, qualitative data pertaining to baselines utilised in health status evaluations by people with breast and prostate cancer were analysed, providing support for the HBC factors and demonstrating the importance of eliciting the patient experience qualitatively as well as quantitatively.

Both of these studies highlighted the potential benefits of focusing on one type of cancer when further exploring the HBC concept. This was due to difficulties in distinguishing between gender and cancer differences where cancer type is gender-specific. The breast cancer cohort in Study 2a reported significantly worse QoL than people with prostate cancer, and were found to endorse illness-specific baselines more strongly, the baselines that explained the most variance in QoL outcomes. It is therefore argued that focusing future studies on people with breast cancer will provide greater opportunity for exploring interactions between HBCs and QoL both quantitatively and qualitatively.

As well as obtaining support for the existing HBC factors, a number of additional factors emerged from Study 2b as participants' provided details of the baselines they use when evaluating their health status. Forty-one percent of qualitative responses referred to HBCs not included in the HBCQ (v2), indicating a requirement to further refine the questionnaire prior to subsequent exploration of the HBC concept.

This chapter discusses modifications made to the HBCQ (v2) on the basis of Studies 2a and 2b presenting the rationale for these modifications. Data is presented from a pilot study of the modified HBCQ (v3). This study was conducted with a sample of women attending a local breast cancer support group, the aim being to test the questionnaire with women experiencing breast cancer prior to utilising it longitudinally with women undergoing chemotherapy for breast cancer.

4.1.1. HBCQ Modifications based on Study 2a and 2b

g) Lost and Retained Items

In Study 2a, a principal components factor analysis of the HBCQ (v2) produced a five factor solution, explaining 62% of variance in HBCQ outcomes. The five factors were: Social Comparison Baselines; Biological Baselines; Illness-Specific Baselines; Turning to Others; No Comparisons. Based on the factor analysis, three items were removed from the HBCQ as they reduced the questionnaire's psychometric properties. The 'mood' item was removed from Factor 2 (Biological Baselines) since this variable only loaded 0.47 on this factor. The 'hospital visits' item was removed from Factor 3 (Illness-Specific Baselines) since this variable, although loading at 0.62, was reducing the factor alpha from an acceptable 0.75 to 0.02. The 'age' item was removed from Factor 4 (Turning to Others) as it only loaded 0.43 on this factor and was not consistent with other items within this factor.

Thematic content analysis (Study 2b) of qualitative descriptions of HBCs provided evidence that two of the items that the principal components analysis suggested should be eliminated were, in fact, important aspects of patients' health status evaluations: age and mood (Table 4.1).

Table 4.1: 'Age' and 'Mood' as HBCs

AGE	MOOD
"General concern about ongoing health failings as one ages" (P81, Prostate Cancer).	*"The joy with which I take any given task"* (P7, Prostate Cancer).
"What I can and cannot do physically and mentally, considering my age" (P96, Prostate Cancer).	*"Ability to smile"* (P11, Prostate Cancer). *"My overall psychological, emotional and spiritual health"* (P181, Breast Cancer).
"I consider my age when thinking about how healthy I am" (P106, Breast Cancer).	*"The fact that I wake up each day hoping for a better day"* (P182, Breast Cancer).
"In early menopause (age 36)" (P157, Breast Cancer).	

As illustrated in Table 4.1, qualitative data obtained in Study 2b suggests that as age and mood contribute to health status evaluations, they should remain in future HBC research. Mood baselines encompass a wide range of affective phenomena, such as positive and negative affect, stress, and other emotional factors; indeed, they comprised 13% of the baselines described via qualitative data (3.4.9). Despite not loading with the other items identified via the factor analysis, age was the sixth most highly endorsed HBC (3.4.3.). Moreover, the literature provides strong evidence of

associations between positive and negative affect and health outcomes (Hu and Gruber, 2008), as well as relationships between age and actual health status (Ubel et al., 2005). Support for measuring mood as a HBC can also be found in the literature on optimism and pessimism, with optimists reporting better perceived health and QoL (de Moor et al., 2006), as well as better adjustment to illness (Yardley and Dibb, 2007).

h) Additional Items

On the basis of thematic content analysis of respondents' comments on HBCs, evidence was provided that participants drew on other types of baseline not yet included in the HBCQ (v2). Whilst 59% of qualitative data could be categorised into the existing five factors identified via the principal components factor analysis (32% biological baselines; 17% illness-specific baselines; 5% turning to others; 4% social comparison baselines; and 1% no comparisons), 41% could not. These 'other baselines' emerging from the qualitative data were categorised into seven themes, presented in descending order of strength of endorsement: Relationships (28%); Employment (23%); Activities of Daily Living (18%); Mood (13%); Religion (8%); Environmental (5%); and Holistic (5%). Of these additional baselines, the primary theme that emerged was the importance of a 'social' context. This can be distinguished from social comparison baselines in that they involve direct comparisons with other people, whereas the additional data emphasises the role of context, referring to work, relationships, and social situations or activities of daily living. Even factors not explicitly social in nature, such as stress and physical ability, tended to be socially contextualised in the 'other baselines' (i.e. stress at work; physical ability to socialise, etc.).

The most frequently endorsed of these 'other' baselines, these being ability to work, socialise, enjoy life, and cope within the social context (as encapsulated in the above categorised themes of relationships, employment, activities of daily living, and mood) were used to develop eight items for a 'social baselines' subscale of the HBCQ (V3) (Table 4.2). As well as being pilot tested within this study, these items were also informally discussed with oncology staff, who also presented the items to a small cohort of patients to confirm acceptability.

i) Item Direction

A limitation with the HBCQ (v2) emerged when interpreting quantitative responses. Some of the items were ambiguous to interpret as whilst they demonstrated agreement or disagreement with the use of specific health baselines, they failed to reveal the direction of use. For example, it could be argued that agreeing with the following statements does not indicate whether the respondent thinks about, for example, the fact that they *do* smoke or the fact that they *don't* smoke, or in terms of the second example, whether they think about the *good* or *bad* health of the people they know:

> ➤ 'When thinking about how healthy I am, I take into consideration my lifestyle (e.g. diet, exercise, smoking, alcohol consumption, etc.).'

> ➤ 'When thinking about how healthy I am, I take into consideration the health of people I know (e.g. friends, family, etc.).'

This distinction is similar to that of upward and downward social comparisons, as discussed in 1.7.1. The social comparison literature suggests that upward and downward comparisons produce different outcomes in terms of either self-enhancement (downward comparisons) (Wills, 1981) or feelings of inferiority (upward comparison) (Festinger, 1954). Thus, it might be expected that upward HBCs leave a person feeling inferior in terms of health, whilst downward HBCs are self-enhancing and motivate positive perceptions of health status. Alternatively, findings from this research might provide evidence to support the hypothesis that both upward and downward comparisons can have positive and negative outcomes (Buunk et al., 1990).

Future HBCQ items were thus designed to explore this issue by dividing each item into two directions (positively and negatively directed), for example:

> ➤ 'When thinking about how healthy I am, I consider my <u>healthy</u> lifestyle choices (e.g. that I eat plenty of fruit and exercise regularly, etc.).'
> ➤ 'When thinking about how healthy I am, I consider my <u>unhealthy</u> lifestyle choices (e.g. that I eat too little fruit and don't exercise enough, etc.).'

> ➤ 'When thinking about how healthy I am, I consider the <u>good health</u> of people I know.'
> ➤ 'When thinking about how healthy I am, I consider the <u>ill health</u> of people I know.'

This approach can be supported further by qualitative data presented in Chapter 3. For example, the following qualitative explanation provided greater insight than simply knowing that this participant carries out social comparison baselines when evaluating their health status: *"I am aware of being more mobile than many people of the 82 year old group."* Without being aware that this participant is making a specific social comparison that demonstrates him to be 'more' as opposed to 'less' mobile than a comparator, interpretation of this HBC is, arguably, less useful.

j) Response Options

The response format of the FACT QoL questionnaire that was utilised in Study 2a was found to provide more explicit information on the experiences of respondents than the original response format of the HBCQ (v2). The FACT utilises a four-point Likert scale ranging from 'not at all' to 'very much,' in comparison to the HBCQ (v2) that utilised a five-point Likert scale ranging from 'strongly agree' to 'strongly disagree,' thus measuring factual experiences rather than level of agreement. Clearly, even strong

levels of agreement or disagreement with a particular HBC does not indicate that a participant actually uses that HBC or, if he or she actually uses it, the frequency of use. Upon reflection, it was decided that the validity of the questionnaire might be enhanced by amending the response options to reflect the extent to which respondents actually use each HBC: 'not at all,' 'a little,' 'quite a bit,' and 'very much,' rather than strength of endorsement. A further reason to change the response format of the HBC scale was the fact that the oncologists who distributed the questionnaires provided feedback indicating that patients found the FACT to be more user-friendly and easier to complete. All of these observations provided support for the modification of HBCQ response options in efforts to enhance data collection.

k) *Invoking a Health Status Evaluation 'Mindset'*

When discussing the questionnaire with other health psychology researchers, it was recognised that there is evidence that health evaluation methods are not necessarily within conscious awareness; such evaluations are likely to be more salient when health is challenged, as suggested by self-regulation theory (Leventhal, Brissette, and Leventhal, 2003). Moreover, the literature suggests that given a health crisis or general change in health status quo, an individual will be motivated to solve this problem in order to re-establish a state of normality (Moos and Schaefer, 1984).

If the need to evaluate health is not within conscious awareness at the time of questionnaire completion, it may be difficult for respondents to put themselves into a health evaluation 'mindset' in order to identify the health baselines they utilise during those times. Ideally, the respondents need to interact with the questionnaire on a more personal level in order to achieve this mindset. Indeed, questionnaire saliency has been found to be an important factor in engaging respondents and increasing completion rates (McColl et al., 2001).

With this in mind, it was anticipated that the validity of the questionnaire might be further enhanced by the inclusion of a short statement aimed at making more salient the cognitive processes that take place during health status evaluations, as follows:

"Often, we are not aware of how much we think about our health, even when confronted by substantial health difficulties. Before completing this questionnaire, please spend a few moments focusing on your current state of health."

As far as can be ascertained, this strategy of invoking a particular mindset prior to questionnaire completion is not common practice. Although inducing the required 'mindset' in respondents has been strongly advocated (McColl et al., 2001), as far as can be established, invoking a contextual mindset (i.e. prompting respondents to enter a 'health evaluation mindset') has not been attempted by others.

I) Questionnaire Presentation

Based on best practice (McColl et al., 2001), the HBCQ (v3) was designed to be more visually appealing than previous versions. A systematic review of factors found to enhance questionnaire response rates suggests that response rates were significantly higher for questionnaires that used coloured ink and were designed to engage the interest of participants (McColl et al., 2001; Edwards, et al., 2002). The HBCQ was further refined based on these recommendations.

4.1.2. Pilot Testing the HBCQ (v3)

As mentioned earlier in this chapter, there are sound reasons for further examination of the HBC concept to be tested on a sample of women undergoing chemotherapy for breast cancer. This study seeks to pilot test the modified HBCQ prior to application within the clinical environment, as outlined in the following aims and objectives.

4.2. Aims and Objectives

The aims of Study 3 were:

> - To pilot test the HBCQ (v3) in women with breast cancer.
> - To obtain focused feedback on the items and the format of the HBCQ (v3).
> - To establish the usefulness of distinguishing positively directly from negatively directed HBCs by establishing any significant differences in endorsement of these two distinct styles of health status evaluation.

These aims were achieved via input from a sample of women attending a local breast cancer support group, who were willing to complete the HBCQ (v3) and provide feedback on the content, structure, and ease of the questionnaire.

4.3. Method

4.3.1. Ethical Approval

Ethical approval was granted by Cranfield University at Silsoe ethics committee (appendix Aiv).

4.3.2. Sample

Women with breast cancer (n = 54) were sought from a local cancer support group. Additional selection criteria were not necessary since the aim of this study was purely to test and gain feedback on the modified questionnaire to facilitate further research into the HBC concept.

4.3.3. Questionnaires

d) Demographics

The demographic variables requested included: age (i.e. < 20; 21-30; 31-40; 51-60; 61 >); ethnicity (i.e. White; Black; Asian; Chinese; Mixed; Other); marital status (i.e. single; long-term relationship; married; divorced; widowed); and highest educational level (i.e. no qualifications; GCSE/A-Level; undergraduate; postgraduate). Participants were also asked to indicate which treatment they had received (i.e. radiotherapy; chemotherapy; hormone therapy; surgery; watch and wait; other), as well as any existing co-morbidities.

e) The HBCQ (v3)

The HBCQ (v3) (appendix Ciii) was a 38-item self-administered questionnaire, presented in a coloured-ink A5 booklet. Participants were introduced to the questions with the following statement: *"Often, we are not aware of how much we think about our health, even when confronted by substantial health difficulties. Before completing this questionnaire, please spend a few moments focusing on your current state of health."*

The questionnaire comprised five subscales: Social Baselines (8-items); Biological Baselines (9-items); Illness-Specific Baselines (7-items); Social Comparison Baselines (8-items); Turning to Others (6-items). Each item was rated on a four-point Likert scale ranging from 'not at all' to 'very much.' Items were totalled for each subscale, with higher scores representing more frequent use of a type of baseline. Items and subscales are present in Table 4.2.

Since the questionnaire was refined based on Study 2, the modified subscales were shown to a small cohort of people with cancer who took part in Study 2 in order to gain feedback. Participants indicated that they understood the rationale for these changes and were satisfied with the new version of the scale.

Table 4.2: HBCQ (v3) Items per Subscale

Biological Baselines	Illness-Specific Baselines	Social Comparison Baselines	Social Baselines	Turning to Others
When thinking about how healthy I am, I consider:	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*
My healthy lifestyle choices (e.g. fruit in diet, regular exercise, moderate alcohol consumption, etc.)	The signs and symptoms I might expect from breast cancer	The healthy people I see in the media (e.g. celebrities, real-life stories, etc.)	The enjoyment and relaxation in my life	The positive opinions of people close to me (e.g. friends, family, etc.).
My unhealthy lifestyle choices (e.g. fat in diet, no exercise, high alcohol consumption, etc.)	Any positive aspects of having cancer (e.g. appreciation of life, increased closeness to friends/ family, etc.)	The unhealthy people I see in the media (e.g. celebrities, real-life stories, etc.)	The stress in my life	The negative opinions of people close to me (e.g. friends, family, etc.).
Signs of good health in my appearance (e.g. healthy weight, clear complexion, etc.)	Any side-effects of treatment (e.g. tiredness, nausea, etc.)	People who appear healthier than me	How well I am coping at that time	The positive feedback from my doctor.
Signs of ill health in my appearance (e.g. overweight/ underweight, pale complexion, hair condition, etc.)	Any benefits of treatment (e.g. destroying cancer cells, etc.)	People who appear less healthy than me	Any difficulties coping at that time	The negative feedback from my doctor.

Table 4.2 continued: HBCQ (v3) Items per Subscale

Biological Baselines	Illness-Specific Baselines	Social Comparison Baselines	Social Baselines	Turning to Others
When thinking about how healthy I am, I consider:	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*
The things I can do (e.g. exercise, hobbies, etc.)	People with breast cancer who seem to be doing well	People who appear similar to me (e.g. same age, gender, social class, etc.)	My ability to socialise (e.g. with friends and family)	My own positive health judgements.
The things I cannot do (e.g. exercise, hobbies,, etc.)	People with breast cancer who seem to not be doing so well	People who appear dissimilar to me in (e.g. different age, gender, social class, etc.)	My difficulties socialising (e.g. with friends and family)	My own negative health.
My past good health	My health before developing cancer	Colleagues who appear healthier than me	My ability to function well at work	
My past ill health		Colleagues who appear less healthy than me	My difficulties functioning at work	
The natural ageing process				

f) The Feedback Questionnaire

The feedback questionnaire (appendix Dii), designed to assess the acceptability and validity of the HBCQ (v3), consisted of four multiple choice items that measured the following: a) time taken to complete the HBCQ (i.e. <5 minutes to >20 minutes); b) ease of completion (i.e. very easy; easy; unsure; difficult; very difficult); c) usefulness of the 'health evaluation mindset' introduction (i.e. very useful; useful; unsure; useless; very useless); and d) satisfaction with the booklet format (i.e. very satisfied; satisfied; unsure; unsatisfied; very unsatisfied). Space was provided for respondents to expand on their answers to each item, as well as to provide any additional comments.

4.3.4. Procedure

A local cancer support group in Bedfordshire was contacted via email explaining the aims of the research and highlighting the benefits of input from group members. On agreeing to take part in the study, participant packs were forwarded to the group. The packs included a covering letter, a participant information sheet (appendix Biii) and consent forms, the HBCQ (v3), the feedback questionnaire, and a stamped addressed envelope to return consent forms and completed questionnaires.

4.3.5. Methods of Analysis

A mixed methodology approach was utilised in the analysis and interpretation of study findings. The internal consistency of the HBCQ (v3) was analysed via Cronbach's alpha, followed by an examination of the descriptive data for individual HBC items. Paired samples t-tests were conducted to identify any differences between positively and negatively directed HBCs.

All qualitative data was examined via thematic content analysis and the extracting of patterned themes within the narrative. To ensure reliability, a proportion of the data (15%) was analysed by another health psychology researcher[5]. Cohen's Kappa was used to establish levels of concordance.

4.4.   Results

4.4.1. Participant Demographics

Table 4.3 provides demographic information for the sample. As can be seen, half of the participants (n = 54) were aged 51-60 years. Thirty-seven percent of participants were educated to undergraduate level and 32% to GCSE/A-level. The majority (65%)

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[5] Holds a Masters in Health Psychology and is currently completing a PhD within the field. Areas of expertise include interpretative phenomenological analysis and thus the categorisation and analysis of qualitative data.

were married and of white ethnicity (94%). Fifty-four percent of participants had co-morbidities. Treatment pathways were varied, the most common being chemotherapy (36%), hormone therapy (19%), and surgery (17%).

Table 4.3: Participant Demographics

Demographic	Percentage
Age, in years:	
o 51-60	50%
o 61>	24%
o 41-50	15%
o 31-40	7%
o 21-30	4%
Ethnicity:	
o White	94%
o Mixed Race	4%
o Black	2%
Marital Status:	
o Married	65%
o Divorced	11%
o Long-Term Relationship	9%
o Single	8%
o Widowed	7%
Highest Educational Level:	
o Undergraduate	37%
o GCSE/A-Level	32%
o Postgraduate	18%
o No Qualifications	13%
Treatment:	
o Chemotherapy	36%
o Hormone Therapy	19%
o Surgery	17%
o Chemotherapy, Radiotherapy, Surgery	8%
o Chemotherapy and Radiotherapy	6%
o Hormone Therapy and Surgery	6%
o Radiotherapy	4%
o Chemotherapy and Hormone Therapy	2%
o Chemotherapy and Surgery	2%
o Radiotherapy and Surgery	2%
o Clinical Trial	2%
Co-morbidities	54%

4.4.2. Health Baseline Descriptive Data

Table 4.4 provides details of each HBC in descending mean order. The proportion of respondents who endorsed each item at least partially is also provided. As can be seen, the five most frequently utilised HBCs in this pilot study were each from one of the five proposed HBC factors: prefer own judgment as opposed to others (Turning to Others); ability to do things (Biological Baselines); healthy lifestyle choices (Biological Baselines); life enjoyment (Social Baselines); healthy appearance (Biological Baselines); and treatment side-effects (Illness-Specific Baselines). This suggests that each factor has some degree of salience to respondents. Four of them were positively directed and one (i.e. treatment side-effects) negatively directed.

The HBCs that had the lowest level of endorsement in this pilot study were all related to social comparison baselines: people perceived as less healthy; colleagues perceived as less healthy; media images perceived as less healthy; media images perceived as more healthy; and dissimilar people. Four of these were negatively-directed and one (i.e. healthy media) positively-directed.

Table 4.4: Utilisation of HBCs, in Descending Mean Order of Frequency of Utilisation

HBC	Mean (SD)	% A Little/Quite a Bit/Very Much	% Not at All	HBC	Mean (SD)	% A Little/Quite a Bit/Very Much	% Not at All
Own judgment as opposed to others	2.30 (0.84)	94	6	Working ability	1.50 (1.13)	72	28
				People with cancer who appear to be doing well	1.48 (0.97)	83	17
Ability to do things	2.20 (0.83)	94	6				
Healthy lifestyle choices	2.17 (0.77)	78	22	People with cancer who appear to not being doing well	1.37 (0.90)	81	19
Life enjoyment	2.15 (0.71)	98	2				
Healthy appearance	2.02 (0.81)	96	4	Work difficulties	1.37 (1.10)	70	30
Treatment side-effects	1.93 (0.99)	91	9	Past illness	1.33 (0.95)	81	19
Unhealthy appearance	1.93 (0.87)	94	6	Social difficulties	1.28 (1.01)	76	24
Unhealthy lifestyle choices	1.83 (0.91)	94	6	Similar people	1.17 (0.94)	76	24
Cancer symptoms	1.83 (1.97)	89	11	Healthier people	1.00 (0.91)	68	32
Coping ability	1.81 0.89)	93	7	Close other's opinion	0.94 (0.81)	68	32
Disability	1.76 (1.10)	81	19	Healthier colleagues	0.93 (0.87)	65	35
Stress	1.72 (0.92)	93	7	People who appear less healthy	0.77 (0.75)	63	37
Treatment benefits	1.72 (0.92)	89	11	Colleagues who appear less healthy	0.72 (0.69)	59	41
Doctor's opinion	1.70 (0.84)	96	4				
Team (self and doctor)	1.65 (0.96)	89	11	Unhealthy media images	0.57 (0.63)	50	50
Coping difficulties	1.65 (0.91)	93	7	Healthy media images	0.50 (0.67)	41	59
Social abilities	1.64 (1.02)	85	15	Dissimilar people	0.48 (0.67)	41	59
Cancer benefits	1.61 (1.04)	81	19				
Health before cancer	1.54 (1.15)	76	24				
Past health	1.52 (0.99)	83	17				
Ageing	1.50 (0.86)	87	13				

4.4.3. Psychometric Properties of the HBCQ (v3)

The Cronbach's alpha of the HBCQ (v3) subscales was calculated in order to test their internal consistency. As can be seen in Table 4.5, all subscales except for turning to others either equalled or exceeded the alpha's of the HBCQ (v2). The social baselines subscale was a new addition to version 3 of the questionnaire.

Table 4.5: Internal Consistency of the HBCQ (v2) and HBCQ (v3)

Subscales	HBCQ (v2)	HBCQ (v3)
Social comparison baselines	0.89	0.89
Biological baselines	0.75	0.78
Illness-specific baselines	0.74	0.76
Turning to others	0.50	0.34
Social baselines		0.84

A more detailed account of the psychometric properties of the revised HBCQ is shown in Table 4.6, below.

Table 4.6: Cronbach's Alpha, Variance, Mean, and Standard Deviation of HBCQ (v3) Subscales

Subscale	α	Variance	Mean	SD
Social Comparison Baselines (8-items)	0.89	20.54	5.88	4.53
Social Baselines (8-items)	0.84	28.88	13.06	5.37
Biological Baselines (9-items)	0.78	23.97	16.26	4.90
Illness-Specific Baselines (7-items)	0.76	19.80	11.48	4.45
Turning to Others (6-items)	0.34	3.94	6.59	1.99

Overall, with the exception of the turning to others subscale, all other subscales exceeded the accepted alpha of 0.70, demonstrating fair to good internal consistency. The turning to others subscale was a low 0.34, which could not be improved by the removal of any items.

4.4.4. Tests of Difference

Since the descriptive data pointed to a greater use of positively directed HBCs, a paired samples t-test was conducted to examine if this observation was significant. The mean difference between negatively and positively directed HBCs was 3.09 and the 95% CI for estimated population mean difference between -5.67 and .512. The effect size was 0.37. A paired samples t-test demonstrated the difference to be significant, confirming that positively directed HBCs were more likely to be endorsed than those that were negatively directed HBCs ($t = 2.40$, $df = 53$, $p < .05$).

4.4.5. Participant Feedback

A summary of the feedback from participants is shown in Figure 4.1. As can be seen, time taken to complete the HBCQ (v3) ranged from under 5 minutes to 20 minutes, the mean completion time being 5-10 minutes (43%). The majority of respondents (84%) found the questionnaire easy to complete (54% easy; 30% very easy), whilst 13% were unsure and only 3% found it difficult (Figure 4.2). The majority (65%) found the health evaluation mindset instructions at the front of the HBCQ (v3) useful (37% useful; 28% very useful), whilst 30% were unsure. Only three participants (6%) found the prompt useless (Figure 4.3). Figure 4.4 illustrates that the booklet format gained mainly positive feedback, with 48% and 37% of respondents being satisfied or very satisfied with it, respectively; 13% were unsure and only one participant (2%) was unsatisfied with the booklet format. Qualitative feedback pertaining to the ease of the questionnaire, as well as comments on the health evaluation mindset technique and the booklet format can be seen in Table 4.6.
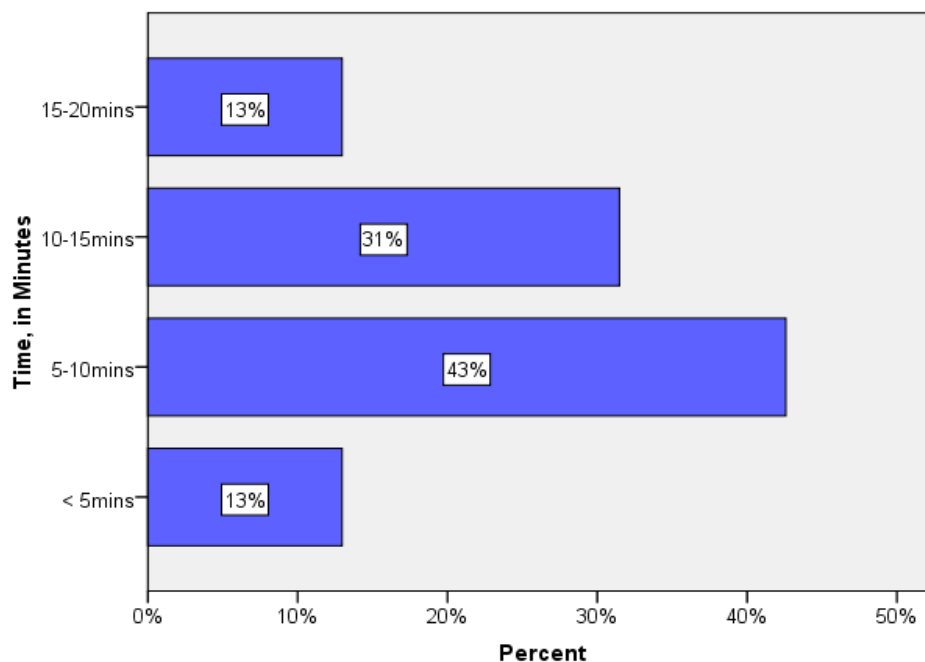
Figure 4.1: HBCQ (v3) Completion Time (n=54)
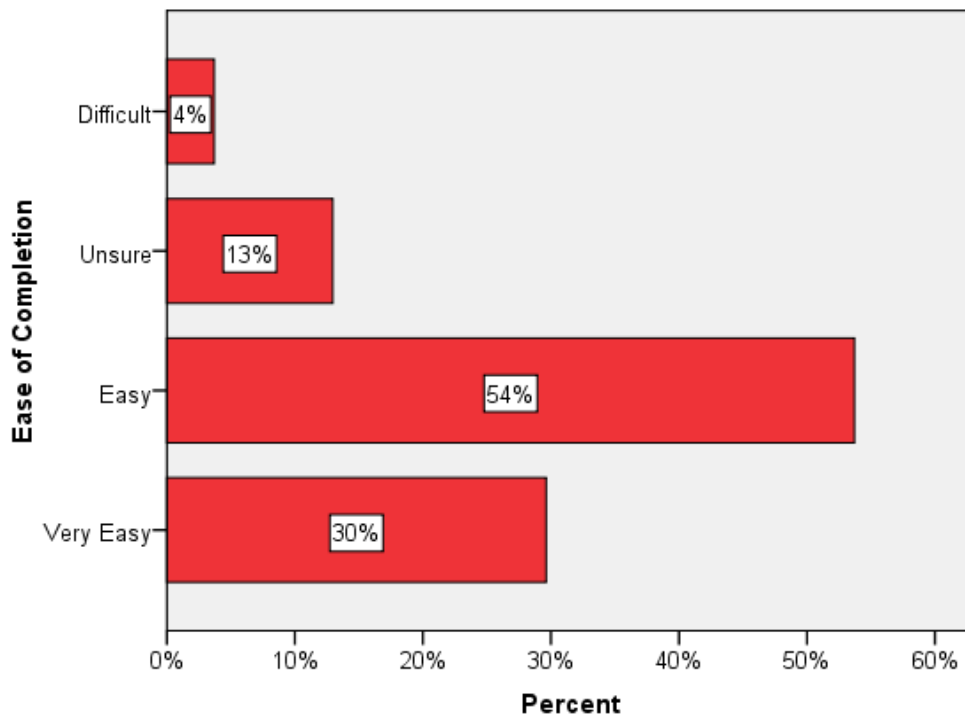
Figure 4.2: Ease of the HBCQ (v3) (n=54)
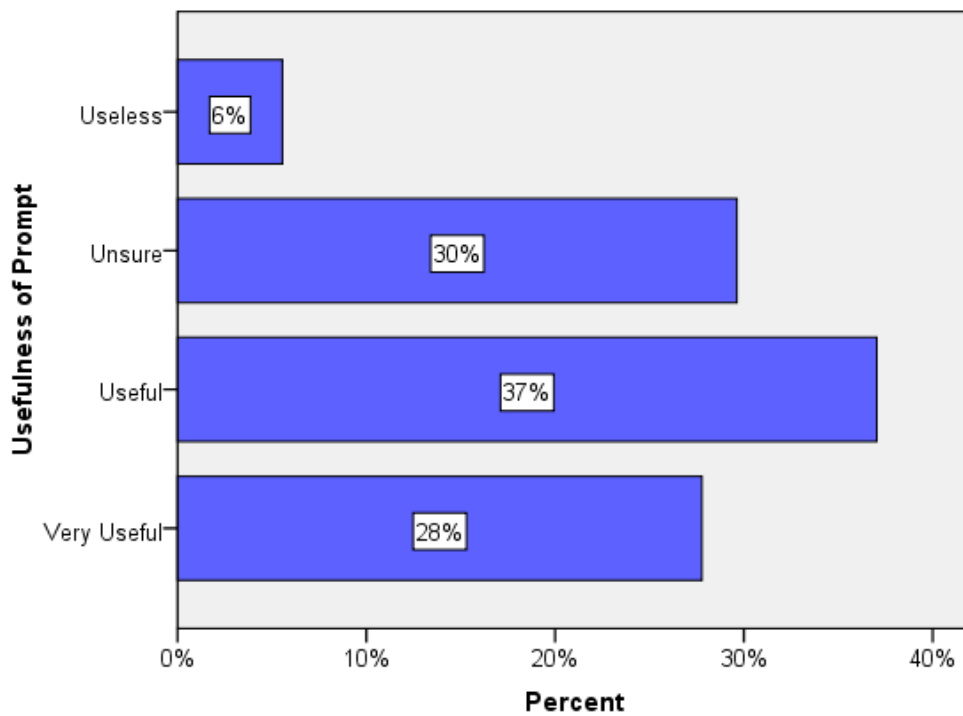
Figure 4.3: Usefulness of the 'Health Evaluation Mindset' Prompt (n=54)
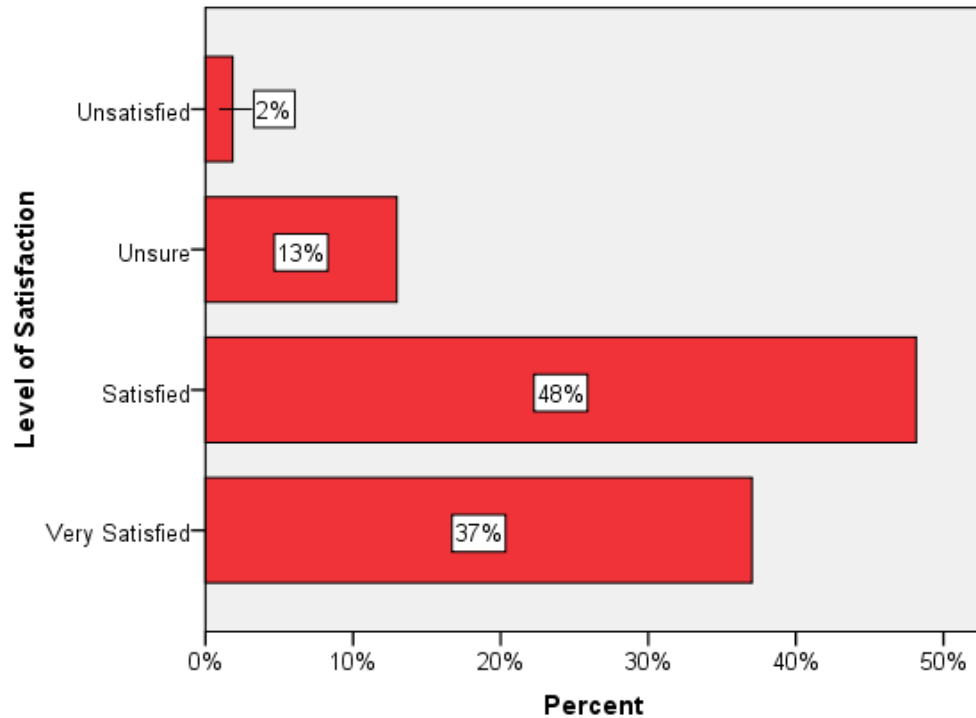
Figure 4.4: Satisfaction with Booklet Format' (n=54)

As can be seen in Table 4.7, 41% of participants provided qualitative feedback on the HBCQ (v3), with responses being categorised into three themes: Ease; Health Evaluation Mindset; and Booklet. Within these themes, 74% of the feedback pertaining to questionnaire ease was positive as opposed to negative; 67% of the feedback pertaining to the health evaluation mindset technique was positive as opposed to negative, and 100% of the feedback pertaining to the booklet format was positive.

- o Positive feedback regarding the ease of completing the HBCQ (v3) included that the questions were easy to understand and the rating scale was quick to use; negative feedback included item repetition and difficulty categorising responses to fit response options.

- o Positive feedback regarding the health evaluation mindset technique at the beginning of the HBCQ (v3) included that it was 'somewhat useful' and it set the tone for the questions to follow; negative feedback included it having no purpose and it being too wordy.

- o Positive feedback regarding the booklet format of the HBCQ (v3) included that it looked good and made completion easy. No negative feedback was received.

Table 4.7: Positive (✓) and Negative (✖) Qualitative Feedback

Ease			
✓	✖	✓	✖
Rating each item from Not at all to Very Much made it pretty simple to answer the questions (P4).	I had a hard time deciding on "quite a bit" and "very much." There isn't much difference between the two in my mind (P6).	Rating scale clear for responses (P36).	
Most choices were given and easy to select (P5).	I had to keep referring back to the question at the top of each page (P42).	The questions were easy to understand (P39).	
The choices offered are limited. This makes choosing easy (P6).	I don't spend a great deal of time thinking about how healthy I am—because I am very satisfied with how I am now. Hence, many of the choices seemed rather confusing (P27).	The questions were easily understood and the rating system was not difficult (P50).	
The questions were clear and seemed targeted (P15).	It's a very subjective and subtle area to contemplate and the questions did not allow me to communicate the essence of how I view my personal health in relationship to my cancer diagnoses and treatment (P34).	There were only a few questions that required thought. Most were quickly done (P49).	
It was a snap (P19).	Sometimes there was no answer that fit correctly (P53).	I found this very easy to fill in (P47).	
The questions were very straight forward yet probing (P26).		Easily layed out and understandable (P52).	
EASY – well laid out and the questions succinct and to the point (P28).		There was nothing about this that was too difficult (P53).	

Table 4.7 continued: Positive (✓) and Negative (✗) Qualitative Feedback

Health Evaluation Mindset		Booklet	
✓	✗	✓	✗
I found the paragraph useful as it did set the tone for the questions that follow (P6).	I just think the opening statement too wordy, health, healthy, a bit much, Personally I would remove the first sentence (P37).	Looked good - when I did one of these surveys at the Dr. office it was photocopied (P3).	
It provided thoughtful direction (P15).	I did not see the need for this at the front (P47).	I liked the format – it made filling it out easy (P6).	
I think the statement is somewhat useful (P27).		I liked the categorisation and structure of questions (P7).	
I found that it was just the right amount of information, to sit for a moment and consider what I was going to say (P28).		I thought that the structure and content were both well thought out and meaningful (P52).	
		Convenient to fill in (P49).	
		Clear; Use of two colours helps, as does t font and size of print (P42).	
		Easy to use (P43).	
		It seems to be well put together (P11).	
		Looked good (P3).	
		The booklet was laid out nicely (P27).	

4.5. Discussion

The aim of Study 3 was to pilot test the HBCQ (v3) in women with breast cancer, to obtain focused feedback on the items and the format of the HBCQ (v3), and to assess the potential usefulness of distinguishing HBCs according to whether they are positively or negatively directed. This was achieved via input from a sample of women attending a local breast cancer support group, who were willing to complete the HBCQ (v3) and provide feedback on the content, structure, and ease of the questionnaire.

4.5.1. Statistical Findings

The internal consistency of the HBCQ (v3) was good. All subscales with the exception of turning to others had an acceptable Cronbach's alpha. Moreover, all subscales, again with the exception of turning to others, either equalled or exceeded the alpha of the HBCQ (v2). Taken in isolation, this suggests that the turning to others subscale should be dropped from the questionnaire. Nonetheless, analysis of the descriptive data of the HBCQ (v3) strongly suggested that turning to others is a strongly endorsed HBC; 96% and 68% of the women in this study reported that they turn to their doctor or close others, respectively, when evaluating their health status. This subscale will thus be retained in this programme of research.

Examination of the variance, mean, and standard deviation highlighted the prominence of social comparison, social, and biological baselines. The latter might be expected based on the literature discussed in Chapter 1 (1.5.1.), whereby biological signs and symptoms are often the motivating factor behind seeking medical advice. In terms of social comparison and social baselines, this demonstrated prominence supports the addition of social baselines and the retention of social comparison baselines.

An examination of the HBCs that were the least commonly endorsed would suggest that social comparison baselines were rarely used. Nonetheless, they were still moderately to highly utilised. For example, the least utilised social comparison HBCs (healthy media images, and dissimilar people) were still reported as being used by 41% of the women in this study. Some social comparison HBCs, such as making comparisons against people with cancer who appear to be doing well, were endorsed by a significant proportion of the sample (in this case, 83%). Along with the significant relationships found between social comparison baselines and QoL in the previous study (Study 2a), retention of this subscale is justified.

An analysis of the descriptive data of HBCQ (v3) responses also offered support for the inclusion of the new social baselines subscale as well as the new distinction between positively and negatively directed HBCs. Indeed, one item in the social baselines subscale ('life enjoyment') was in the top five most utilised HBCs, and it was demonstrated that positively directed HBCs were significantly more frequently utilised than negatively directed HBCs. The difference in effect size was small to

moderate, indicating that any difference might contribute to future study outcomes, such as quality of life.

The greater endorsement of positively directed HBCs could offer a number of explanations. For example, the difference could be related to the peer interaction gained from the support group. Alternatively, it is possible that these women were using optimism as a coping mechanism. Indeed, both of these explanations have been supported in a recent study that suggests peer support is critical to positive outcomes in women with breast cancer, particularly in terms of optimism and personal growth (Dunn et al., 2009). Such links cannot be inferred from the data obtained within this study. Nevertheless, it does raise questions for further exploration.

4.5.2. Questionnaire Feedback

Feedback for the HBCQ (v3) was predominately positive. Participants generally found the questionnaire to be acceptable, short, and easy to complete. A few participants commented that some items seemed repetitive, which is fairly common in questionnaire studies, as well as being difficult to remedy. In order to minimise perceptions of repetitiveness, items reflecting similar concepts (such as appearance) will be alternated in the next version of the questionnaire. Evidence of best practice in questionnaire design supports this change since similar items can bias responses or cause respondent boredom (Mcoll et al., 2001).

Although the health evaluation mindset technique was perceived as having little purpose by some participants, the majority found it useful, particularly in terms of 'setting the tone' or providing 'thoughtful direction.' The colourful booklet format was positively received, as would be expected from best practice guidelines (McColl et al., 2001).

4.5.3. Participant Group

The inclusion criteria for this pilot study were broad, as the main aim was to test the HBCQ (v3) prior to administering it to a more closely defined group of respondents. Advantageously, however, the most common form of treatment undergone by this sample was chemotherapy. Since the next phase of this programme of research is to be conducted with women undergoing chemotherapy for breast cancer, this particular cohort were thus ideal contributors to the further refinement of the HBCQ (v3). It should be emphasised, however, that the sample comprised women who were members of a breast cancer support group: as such, they might not be representative of the wider population. Nonetheless, there is evidence that support groups of this kind are valid sources of data in health psychology research, particularly in terms of questionnaire development (Weinman et al., 1996; Rodrigues et al., 2007). Thus, the cohort involved in this research offered a fast and efficient method of preparing a questionnaire for administration within the clinical environment.

4.6. Conclusions

This chapter has outlined and discussed Study 3 of this programme of research, which has involved the refinement and pilot testing the HBCQ (v3) in women with breast cancer. In general, the evidence presented provides quantitative and qualitative support for the content validity, internal consistency, and acceptability of the HBCQ (v3). The questionnaire is thus considered ready for administration within the clinical environment.

Chapter 5 introduces a longitudinal study with women receiving chemotherapy for breast cancer. It presents the findings of the first phase of this study which examines the salience of HBCs, as well as any impact on quality of life, during a course of chemotherapy. Chapter 6 expands on these findings with an examination of the salience and stability of HBCs after chemotherapy. It is anticipated that this longitudinal methodology will provide insight into the stability or flexibility of HBCs throughout chemotherapy for breast cancer.

Chapter 5

Study 4a: Health Baseline Comparisons, Quality of Life, and Emotional Well-Being during Chemotherapy for Breast Cancer

The previous chapters have described the health baseline comparison concept (Chapter 1), the development of an initial tool (HBCQ) designed to measure this concept (Chapter 2), the testing of health baselines and quality of life interactions in breast and prostate cancer (Chapter 3), and the subsequent further refinement of the HBCQ (Chapter 4). This chapter introduces Study 4, which is a longitudinal examination of HBCs (using v3 of the HBCQ), and an exploration of whether they might account for changes in well-being amongst a sample of women with breast cancer undergoing a course of chemotherapy. This study consists of two stages: 1) Study 4a, which examines HBCs, QoL and emotional well-being during a course of chemotherapy for breast cancer (Time 1); and, 2) Study 4b, which examines HBCs, QoL and emotional well-being in a cross-section of the same sample of women, after a course of chemotherapy (Time 2). The rationale for these distinct stages is described later in this chapter, as are the findings of Study 4a. Study 4b will be reported in Chapter 6 along with a discussion of the overall findings of Study 4 (Time 1 and 2 data).

5.1. Introduction

Previous chapters present evidence for the frequent endorsement of HBCs when evaluating personal health status. Specifically, evidence suggests that people draw on a number of distinct HBCs when assessing their health:

> ➢ *Social baselines* (e.g. When thinking about how healthy I am, I take into consideration my ability to socialise with friends and family).

> ➢ *Social comparison baselines* (e.g. When thinking about how healthy I am, I take into consideration people who appear less healthy than me).

> ➢ *Biological baselines* (e.g. When thinking about how healthy I am, I take into consideration the natural ageing process).

> ➢ *Illness-specific baselines* (e.g. When thinking about how healthy I am, I take into consideration the signs and symptoms I might expect from this type of cancer).

> ➢ *Turning to others* (e.g. When thinking about how healthy I am, I take into consideration the positive feedback from my doctor).

Results so far have demonstrated that these HBCs have a small but significant role in predicting multidimensional QoL (Davies et al., 2008). Illness-specific baselines appear to have the strongest predictive power, playing a greater role in emotional well-being than some demographic (e.g. age) and illness-related factors (e.g. treatment type). This data provided evidence that subsequent research into the HBC concept might benefit from a more in-depth exploration of the emotional QoL aspects of the cancer experience.

Differences identified between breast and prostate cancer participants in illness-specific baselines and emotional well-being (3.4.5.) highlighted potential explanations for the interaction between HBCs and emotional well-being. For example, women with breast cancer endorsed illness-specific HBCs more than men with prostate cancer; they also reported significantly lower levels of emotional well-being than men, manifested by feelings of sadness, nervousness, and worries about dying or the condition getting worse. The predictive ability of illness-specific baselines and the finding that these were more frequently endorsed by women with breast cancer pointed towards focusing the research on this cohort.

Focusing further research on women with breast cancer was further supported in that the breast and prostate cancer data obtained in Study 2 were not comparable in terms of QoL outcomes; it was difficult to distinguish whether the HBC and QoL outcomes were gender- or disease-specific since the type of cancers under investigation were also predominantly gender-specific.

Although the strongest predictor of QoL outcomes in Study 2 was illness-specific baselines, attention should also be given to the other four types of HBC since all have informed HBC theory thus far. Social comparison baselines have been associated with QoL outcomes (3.4.6.a), and biological baselines have been found to predict functional well-being (3.4.7.e). Social baselines and turning to others have both been quantitatively (4.4.2.) and qualitatively (3.4.9.) endorsed by people with cancer. A study with a longitudinal design that focuses on one disease type has the potential to offer further insight into the impact of different baselines on QoL outcomes.

5.1.1. Measuring Quality of Life and Emotional Well-Being

Study 4 of the research programme will examine HBCs and QoL in women with breast cancer, with a greater emphasis placed on emotional well-being than previously. In order to achieve this, a measure of QoL that is less clinical and more biopsychosocial than the previously utilised FACT-G questionnaire has been identified, along with a dimension-specific questionnaire designed to measure emotional well-being by proxy of anxiety and depression. Both of these questionnaires were carefully selected in terms of their psychometric properties and operational characteristics.

The Quality of Life in Adult Cancer Survivors (QLACS) questionnaire (Avis et al., 2005) has produced favourable results in a Macmillan Cancer Support systematic review, as conducted by the author of this current programme of research (Davies, 2009). Selected for its positivist and holistic approach to QoL, the QLACS measures both generic and cancer-specific QoL, covering issues often lacking in other cancer-specific QoL measures (e.g. cognitive problems, appearance concerns, benefit-finding). The focus on survivorship by which the measure was designed is also consistent with current government initiatives, were people with cancer are seen as 'survivors' as opposed to 'patients' from diagnosis up until palliative care (Macmillan Cancer Support, 2008).

The Hospital Anxiety and Depression Scale (HAD*; Zigmond and Snaith, 1983), after many years of clinical use, remains a highly recommended psychological screening tool for people with cancer and other conditions (Herrmann, 1997). Its validity is also supported in a systematic review conducted by the author of this programme of research (Davies, 2009). The scale enables anxiety and depression to be assessed distinctly and was designed to detect anxiety and depression independent of physical symptoms. This is particularly important in the present research as the physical side-effects of chemotherapy are vast and thus likely to impact emotional well-being (Cleeland, 2008).

5.1.2. Longitudinal Methodology

To expand on the findings of previous research phases, Study 4 will utilise a longitudinal methodology in order to examine the stability (i.e. stay the same) and/or flexibility (i.e. change) of HBCs and QoL during and after a course of chemotherapy, a treatment that has been found to have negative implications for QoL (Cleeland, 2008; 2008; Nuzzo, Morabito, De Maio, et al., 2008). There are many advantages to the longitudinal approach in research design, including the ability to measure changes, differences, and patterns across time as well as the potential to imply causation and temporal ordering (Menard 1991). Since QoL is expected to change throughout the treatment process, any potential interactions between HBCs and QoL are expected to be more identifiable via a longitudinal approach. Therefore, Study 4 consists of two parts:

> *Study 4a:*   The salience of HBCs *during* chemotherapy for breast cancer, and associations with QoL, and emotional well-being.

> *Study 4b:*   The stability of HBCs, QoL, and emotional well-being *after* chemotherapy for breast cancer.

The data for Study 4a (time point 1), during chemotherapy, will be collected from women who are within one-month of their treatment commencing and no less than one month away from the end of treatment. The data for Study 4b (time point 2), after chemotherapy,

will be collected approximately two-months after the final course of chemotherapy. A course of chemotherapy traditionally ranges from four to six months duration (Breast Cancer Care, 2009), and so the duration between the two time points of questionnaire completion will range from six to eight months. The rationale for the first time point emerged from discussions with oncology experts within research sites, who explained the potential implications of collecting data any sooner than one-month into a course of chemotherapy, specifically the potential of data reflecting the initial shock of a diagnosis. The rationale for the second time point was also based on these discussions, as well as on literature suggesting that two-months post-chemotherapy would be apt for data being reflective of life after chemotherapy (i.e. the women would be likely to have adjusted to less frequent monitoring from health professionals) (Deshields et al., 2005; Kornblith, 2003).

As with previous studies carried out as part of this programme of research, the demographic (age and educational status) and illness factors (type and length of treatment, and co-morbidities) cited in the literature as being associated with QoL and emotional well-being outcomes will be elicited along with the abovementioned questionnaires (Kaplan and Baron-Epel, 2003; Macmillan Cancer Support, 2008; Wenzel et al, 1999). These variables will need to be accounted for in any findings.

The data for Study 4 will be analysed within and between the two measurement time points. In particular, whether HBCs are stable or flexible between time points will be examined via tests of difference. Additionally, whether the stability and/or flexibility of HBCs are associated with QoL and emotional well-being outcomes will provide insight into the possible role that HBCs might play in predicting these outcomes in women with breast cancer.

This chapter describes the aims and objectives of Study 4 and 4a, before presenting the cross-sectional data obtained in Study 4a, during a course of chemotherapy. Chapter 6 will present the post-chemotherapy results of Study 4b as well as explore comparisons between the data emerging from the two measurement time points.

5.2. Aims and Objectives

The aims of Study 4 were to:

➢ Identify and compare the most frequently endorsed HBCs during and after chemotherapy for breast cancer.

➢ Identify and compare any associations between HBCs, QoL, and/or emotional well-being (anxiety and depression) during chemotherapy for breast cancer, examining whether HBCs can predict these outcomes.

> Further refine the HBCQ (v3) by testing the instruments reliability at two different time points in the illness and treatment trajectory (during and after chemotherapy for breast cancer).

The aims of Study 4a were to:

> Identify the most frequently endorsed HBCs during chemotherapy for breast cancer.

> Identify any relationships between HBCs and both QoL and emotional well-being (anxiety and depression) during a course of chemotherapy for breast cancer.

> Identify the main HBC predictors of QoL and/or emotional well-being during chemotherapy for breast cancer.

> Further refine the HBCQ (v3), testing the instruments reliability in women receiving chemotherapy for breast cancer.

5.3. Method

5.3.1. Ethical Approval

Ethical approval was granted by Cranfield University (appendix Av) and the Hertfordshire Local Research Ethics Committee (appendix Avi). Bedford Hospital R&D and Milton Keynes Hospital R&D provided Trust approval (appendix Aiii and Avii).

5.3.2. Sample

Women with breast cancer who were willing to complete three questionnaires during chemotherapy were sought from the Primrose Oncology Unit of Bedford Hospital and the Macmillan Cancer Unit of Milton Keynes Hospital. On the basis of power calculations, fifty women with breast cancer who were undergoing chemotherapy were invited to participate in the study if they met the following inclusion criteria:

- had first time primary breast cancer.
- were undergoing chemotherapy.
- were within one-month of their treatment commencing and no less than one-month away from the end of treatment.

5.3.3. Questionnaires

e) Demographics

The demographic variables requested included: age (i.e. < 20; 21-30; 31-40; 51-60; 61 >) and highest educational level (i.e. no qualifications; GCSE/A-Level; undergraduate; postgraduate). In order to control for any co-morbidities, participants were asked *'Do you have any other persistent and enduring illness/es or medical condition/s?'* (i.e. yes; no; '*if so, please state what these are'*). Participants were also asked which type of chemotherapy they were receiving (adjuvant or neo-adjuvant) and how many cycles they had received so far.

f) HBCQ (V3)

The HBCQ (v3) was presented in an A5 booklet comprising 45-items measuring the utilisation of various health baseline comparisons (appendix Civ). The questionnaire comprised five subscales: Biological Baselines (9-items); Social Baselines (12-items); Social Comparison Baselines (8-items); Illness-Specific Baselines (10-items); and Turning to Others (6-items). All items within the subscales, as presented in Table 5.1, precede with the statement *'When thinking about how healthy I am, I consider . . .* , with responses being scored from 0-3 on a 4-point Likert scale ranging from 'Not at all'; 'A little'; 'Quite a bit'; 'Very much.' Higher scores represent greater use of a type of baseline.

The first page of the booklet presented the following statement, intended to invoke a health evaluation mindset:

"Often, we are not aware of how much we think about our health, even when confronted by substantial health difficulties. Before completing this questionnaire, please spend a few moments focusing on your current state of health."

Table 5.1: HBCQ (v3) Items per Subscale

Biological Baselines	Illness-Specific Baselines	Social Comparison Baselines	Social Baselines	Turning to Others
When thinking about how healthy I am, I consider:	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*
My healthy lifestyle choices (e.g. fruit in diet, regular exercise, moderate alcohol consumption, etc.)	The signs and symptoms I might expect from this type of cancer.	The healthy people I see in the media (e.g. celebrities, real-life stories, etc.)	The enjoyment and relaxation in my life.	The negative feedback from my doctor.
Signs of ill health in my appearance (e.g. overweight/underweight, pale complexion, hair condition, etc.)	People with the same type of cancer who seem to be doing well.	People who appear less healthy than me.	Any difficulties functioning at work.	My own positive health judgements.
The things I can do (e.g. exercise, hobbies, etc.)	Any side-effects of treatment (e.g. tiredness, etc)	People who appear similar to me (e.g. same age, gender, social class, etc.)	My ability to socialise (e.g. with friends and family)	The negative ways in which people respond to me (e.g. saying I look ill or being overly concerned, etc.)
My unhealthy lifestyle choices (e.g. fat in diet, no exercise, high alcohol consumption, etc.)	People with breast cancer who seem to not be doing so well.	The unhealthy people I see in the media (e.g. celebrities, real-life stories, etc.)	Any difficulties with intimacy.	The positive feedback from my doctor.
My past good health.	Any positive aspects of having cancer (e.g. appreciation of life, etc.)	Colleagues who appear healthier than me.	How well I am coping at that time.	The positive ways in which people respond to me (e.g. saying I look good, healthy, etc.)

Table 5.1 continued: HBCQ (v3) Items per Subscale

Biological Baselines	Illness-Specific Baselines	Social Comparison Baselines	Social Baselines	Turning to Others
When thinking about how healthy I am, I consider:	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*	*When thinking about how healthy I am, I consider:*
The things I cannot do (e.g. exercise, hobbies, etc.)	That I don't follow medical and lifestyle advice (e.g. don't change diet, don't take medication, etc.)	People who appear dissimilar to me in (e.g. different age, gender, social class, etc.)	Any difficulties socialising (e.g. with friends and family).	My own negative health judgements.
Signs of good health in my appearance (e.g. healthy weight, clear complexion, etc.)	My health before developing cancer.	People who appear healthier than me.	My ability to function well at work.	
My past ill health.	My prognosis.	Colleagues who appear less healthy than me.	Any difficulties coping at that time.	
The natural ageing process.	Benefits of treatment (e.g. destroying cancer cells, etc.)		My positive feelings about the future.	
	That I follow medical and lifestyle advice (e.g. change diet, take medication, etc.)		The stress in my life.	
			My concerns about the future.	
			My ability to be intimate.	

g) Quality of Life in Adult Cancer Survivors (QLACS; Avis et al., 2005)

The 47-item QLACS (appendix Eii) is one of the few cancer-specific outcome measures to explore the longer-term impact of cancer, with its focus on 'survivorship' as opposed to illness. The measure comprises seven Generic health-related QoL domains (i.e. Negative Feelings; Positive Feelings; Cognitive Problems; Sexual Problems; Physical Pain; Fatigue; and Social Avoidance), four Cancer-Specific domains (i.e. Appearance Concerns; Financial Problems; Distress over Recurrence; and Family-Related Distress), and a single domain of Benefits of Cancer. In the present study, Financial Problems and Sexual Problems were excluded. These outcome measures were not perceived as productive to the aims of this study and thus were excluded to reduce participant burden. This provided a total of 39-items distributed between four Cancer-Specific QoL subscales and six Generic QoL subscales.

Examples of items from each of these domains are *'In the past four weeks . . .* You felt blue or depressed (Negative Feelings); You felt happy (Positive Feelings); You had difficulty doing activities that require concentrating (Cognitive Problems); You had aches or pains (Physical Pain); You had the energy to do the things you wanted to do (Fatigue); You were reluctant to start new relationships (Social Avoidance); You felt unattractive because of your cancer or its treatment (Appearance Concerns); You worried about cancer coming back (Distress over Recurrence); You worried that your family members were at risk of getting cancer (Family-Related Distress); You appreciated life more because of having had cancer (Benefits of Cancer).' Responses were on a scale ranging from: 1 = never; 2 = seldom; 3 = sometimes; 4 = about as often as not; 5 = frequently; 6 = very often; 7 = always. Higher scores pertain to greater problems in a given QoL domain. The QLACS has demonstrated good test-retest reliability as well as good convergent validity with other measures designed to test QoL (Avis, Ip, and Foley, 2006; Carver et al., 2006; Pearce, Sanson-Fisher, and Campbell, 2008).

h) The Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983)

The HADS (appendix Eiii) is an internationally accepted instrument for rating psychological morbidity in a number of patient groups, including people with cancer (Stark et al., 2002; Fallowfield, 2000). It comprises 14-items (7 for Anxiety and 7 for Depression), with each subscale being designed to assess affective states independent of physical symptoms. Examples of subscale items are '*During the past week . . .* worrying thoughts go through my mind (Anxiety); I can laugh and see the funny side of things (Depression)'. Response options vary for each item, but pertain to how much a symptom has been experienced (e.g. 'not at all', 'sometimes' and 'very often'). In this study, both subscales will be measured separately, higher scores representing higher levels of anxiety or depression.

Many studies support the psychometric properties of this scale (Moorey et al., 1991; Kugaya et al., 1998; Mystakidou et al., 2005; Montazeri et al., 2003) and a review of over 200 studies utilising the HADS has found that a large number of these studies report 100% response rates (Hermann, 1997), indicating very high patient acceptability. Indeed, the scale can be completed in 2-6 minutes and scored in one minute.

5.3.4. Procedure

a) Bedford Hospital

Breast cancer patients attending their regular clinics were identified by Professor Thomas, Consultant Oncologist. Those patients interested in taking part in the research were directed to the Principal Researcher, who provided interested patients with a participant information sheet (appendix Biv) and questionnaire pack. The participant pack contained an invitation letter explaining the study to them and advising them to ask any questions they might have, a patient information sheet, two consent forms, the three questionnaires, and a list of cancer support groups for if participation in the study raised any sensitive issues for them. Patients were asked to take at least twenty-four hours to decide whether to consent to participation before signing both copies and returning one copy along with the first set of completed questionnaires in the stamp addressed envelope provided. The number of women provided with the questionnaire packs was recorded against the number of returned questionnaires in order to assess response rates.

b) Milton Keynes Hospital

The same procedure carried out at Bedford Hospital was followed at Milton Keynes Hospital. However, the Macmillan Information and Support Centre Manager, who is also a registered nurse with expertise in chemotherapy, introduced the study to women meeting the inclusion criteria. She also provided participant packs to all interested participants.

5.3.5. Methods of Statistical Analysis

An examination of the descriptive data for individual HBC items was conducted, followed by an examination of the internal consistency of the HBCQ (v3). Pearson's correlations were conducted to determine associations between the five HBC factors (e.g. social baselines; social comparison baselines; biological baselines; illness-specific baselines; and turning to others) and generic and cancer-specific QoL dimensions, as well as between the five HBC factors and emotional well-being (e.g. anxiety and depression). Finally, hierarchical multiple regressions were conducted in order to identify the HBC factors that were the strongest predictors of QoL and emotional well-being.

5.4. Results

5.4.1. Participant Demographics

Fifty participants were approached, 45 of whom agreed to participate in the study. This indicates a response rate of 90%. The demographic details of the 45 breast cancer participants can be seen in Figures 5.1 to 5.4, below. The majority of the sample was between 41 and 60 years of age (69%) with no co-morbidities (58%). Highest educational status was diverse, the highest percentage being GCSE/A-Level (38%) and an equal percentage of undergraduates or postgraduates (both 24%). For 71% of the sample, treatment type was adjuvant chemotherapy and thus following surgery. The number of treatment cycles received varied from 1-21, the mean being four cycles ($SD = 3.34$).
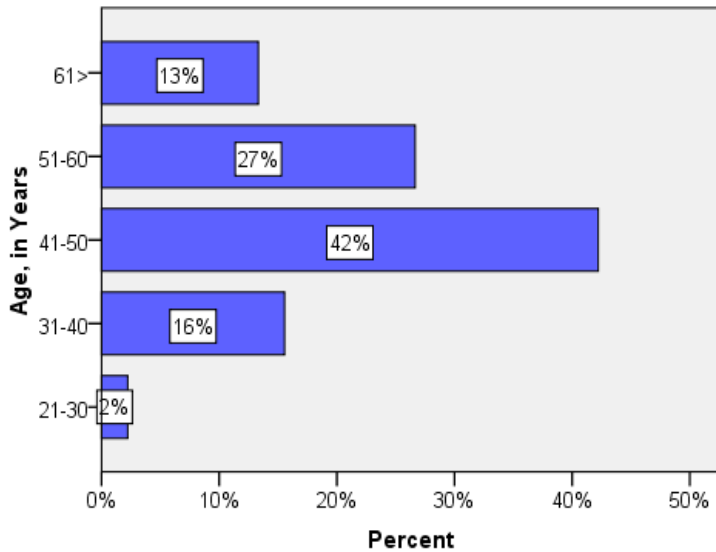
Figure 5.1: Age of Participants (n=45)
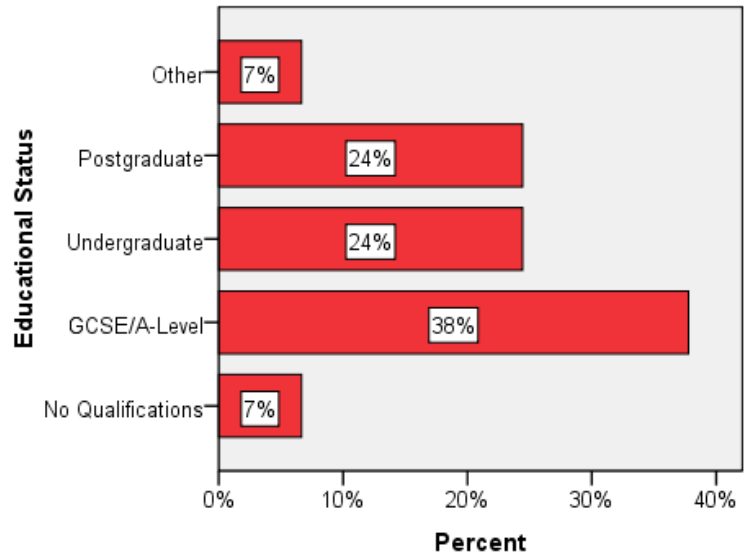
Figure 5.2: Educational Status of Participants (n=45)

123
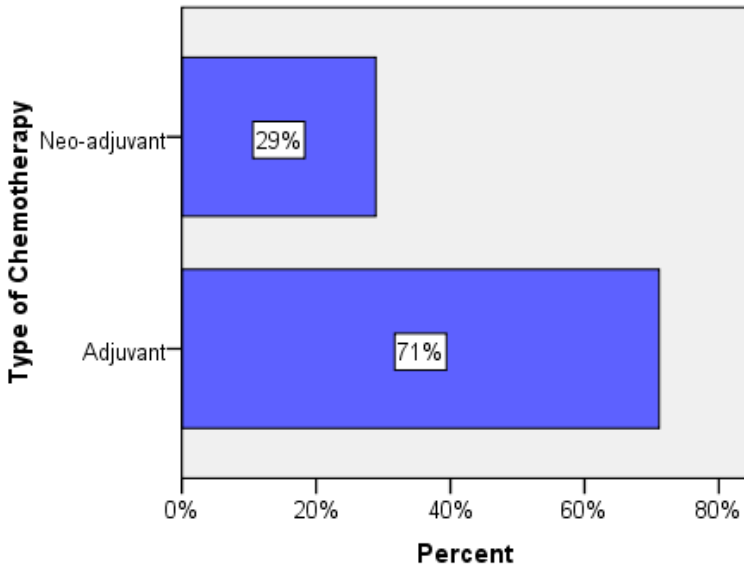
Figure 5.3: Type of Chemotherapy (n=45)
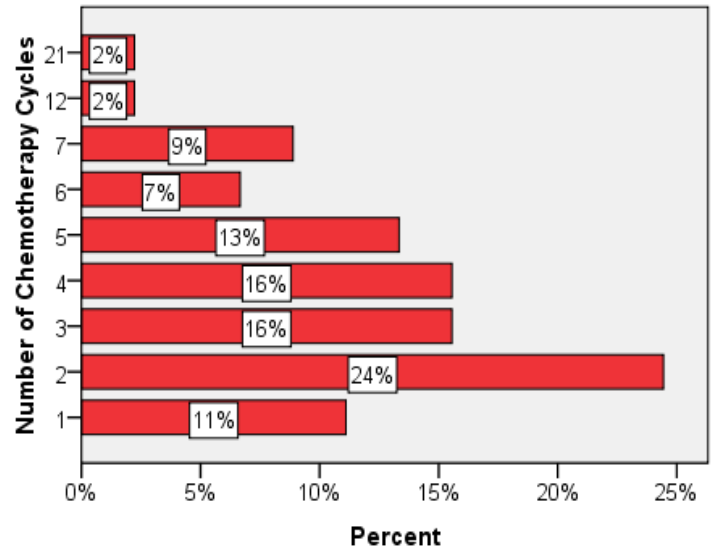
Figure 5.4: Number of Chemotherapy Cycles (n=45)

5.4.2. HBC Descriptive Data

Table 5.2 provides details of each HBC in descending mean order. As can be seen, HBCs are frequently used by this cohort of women undergoing chemotherapy for breast cancer, with percentages of use ranging from 38% (people who are dissimilar to me) to 100% (my adherence to medical advice; my own positive health judgments; treatment side-effects; my healthy appearance; and, my unhealthy appearance).

The least frequently utilised HBCs related to social comparison baselines (healthy people in the media; unhealthy people in the media; colleagues I perceive to be less healthy than me; people who are dissimilar to me) and one illness-specific baseline (my non-adherence to medical advice).

Table 5.2: Utilisation of HBCs, in Descending Mean Order of Strength of Endorsement (*n* = 45); endorsement per item ranged from 0 (not at all) to 3 (very much)

HBC *When thinking about how healthy I am, I consider:*	Mean (SD)	% A Little/Quite a Bit/Very Much	% Not at All	HBC *When thinking about how healthy I am, I consider:*	Mean (SD)	% A Little/Quite a Bit/Very Much	% Not at All
My adherence to medical advice	2.49 (.695)	100	0	My inability to do the things I enjoy	1.62 (1.093)	80	20
Other's positivity towards me	2.33 (.739)	98	2	My stress levels	1.60 (.915)	93	7
My own positive health judgments	2.31 (.668)	100	0	My inability to work	1.60 (.915)	78	22
The doctor's positivity about my health	2.31 (.763)	98	2	The doctor's negativity about my health	1.53 (1.079)	78	22
				My difficulty coping	1.53 (1.057)	80	20
Treatment benefits	2.31 (.900)	93	7	My own negative health judgments	1.51 (1.079)	80	20
Treatment side-effects	2.29 (.787)	100	0	My unhealthy lifestyle choices	1.47 (1.014)	84	16
Positivity about the future	2.27 (.780)	98	2	People with cancer who appear to not be doing well	1.44 (1.056)	78	22
My prognosis	2.27 (.837)	96	4				
My healthy lifestyle choices	2.27 (.837)	98	2	My difficulties being intimate	1.42 (1.076)	76	24
Expected symptoms	2.22 (.850)	98	2	My social difficulties	1.42 (1.033)	73	27
My ability to do things I enjoy	2.20 (.757)	98	2	The natural ageing process	1.40 (.963)	80	20
My enjoyment of life	2.20 (.726)	98	2	The intimacy in my life	1.33 (1.087)	71	29
My healthy appearance	2.09 (.763)	100	0	People I perceive to be similar to me	1.33 (.905)	82	18
My social abilities	2.07 (.915)	91	9				
My concerns about the future	2.04 (.952)	94	4	My past ill health	1.24 (1.090)	69	31
Positive aspects of the cancer experience	1.98 (1.011)	89	11	People I perceive to be less healthy than me	1.16 (.796)	80	20
My past health	1.91 (.949)	93	7	Other's negativity towards me	1.13 (.842)	88	22
That I am coping well	1.89 (.859)	96	4	People I perceive to be healthier than me	.89 (.745)	67	33
My unhealthy appearance	1.87 (.757)	100	0				
People with cancer who appear to be doing well	1.84 (.952)	89	11	Colleagues I perceive to be healthier than me	.82 (.806)	60	40
My health before cancer	1.82 (.960)	89	11	Healthy people in the media	.80 (.991)	49	51
My ability to work	1.71 (1.100)	80	20	Unhealthy people in the media	.78 (.795)	58	42
				My non-adherence to medical advice	.71 (.944)	47	53
				Colleagues I perceive to be less healthy than me	.67 (.640)	58	42
				People who are dissimilar to me	.40 (.539)	38	62

5.4.3.   Questionnaire Properties and HBCQ (v3) Development

The Cronbach's alpha for the HBCQ (v3) subscales ranged from low to high: Biological Baselines (9-items; α = 0.74); Social Baselines (12-items; α = 0.90); Social Comparison Baselines (8-items; α = 0.81); Illness-Specific Baselines (10-items; α = 0.80); and Turning to Others (6-items; α = 0.54). The QLACS and HADS were similarly high in internal consistency. All subscales of the QLACS had an alpha of 0.84 or more, and the HADS was 0.85 and 0.89 for the Anxiety and Depression subscales, respectively.

5.4.4. Relationships between HBCs and Quality of Life and Emotional Well-Being

Pearson's (r) product moment correlations were conducted to examine relationships between HBC factors, QoL, and emotional well-being. A correlation matrix is presented in Table 5.3. Any significant relationships between HBCs and generic and cancer-specific QoL and their dimensions are described below, as are any significant relationships between HBCs and emotional well-being (anxiety and depression).

f) Social Baselines

Generic QoL: Social baselines demonstrated a weak negative correlation with positive feelings ($r = -.34$, $n = 45$, $p < .05$), a weak positive correlation with fatigue ($r = .32$, $n = 45$, $p < .05$), and a moderate positive correlation with social avoidance ($r = .38$, $n = 45$, $p < .01$). The more social baselines were endorsed, the more positive feelings, fatigue, and social avoidance were reported.

Cancer-Specific QoL: Social baselines did not significantly correlate with any of the cancer-specific QoL dimensions.

Emotional Well-Being: Social baselines demonstrated a moderate positive correlation with anxiety ($r = .30$, $n = 45$, $p < .01$). The more social baselines were endorsed, the greater the anxiety. No significant correlations were found with depression.

g) Social Comparison Baselines

Generic QOL: Social comparison baselines demonstrated a weak positive correlation with negative feelings ($r = .31$, $n = 45$, $p < .05$) and with fatigue ($r = .30$, $n = 45$, $p < .05$). The more social comparison baselines were endorsed, the greater negative feelings and fatigue.

Cancer-Specific QoL: Social comparison baselines demonstrated a weak positive correlation with appearance concerns ($r = .32$, $n = 45$, $p < .05$) and with family-related distress ($r = .31$, $n = 45$, $p < .05$), and a moderate positive correlation with distress over recurrence ($r = .42$, $n = 45$, $p < .01$). The more social comparison baselines were endorsed, the greater appearance concerns, distress over recurrence, and family-related distress.

Emotional Well-Being: Social comparison baselines demonstrated a weak negative correlation with anxiety ($r = -.35$, $n = 45$, $p < .05$). The more social comparison baselines were endorsed, the less anxiety was experienced. No significant correlations were found with depression.

h) Biological Baselines

Generic QoL: Biological baselines demonstrated a weak positive correlation with negative feelings ($r = .31$, $n = 45$, $p < .05$), cognitive problems ($r = .34$, $n = 45$, $p < .05$), and social avoidance ($r = .30$, $n = 45$, $p < .05$), a moderate positive correlation with physical pain ($r = .48$, $n = 45$, $p < .01$) and fatigue ($r = .46$, $n = 45$, $p < .01$), as well as a weak negative correlation with positive feelings ($r = -.30$, $n = 45$, $p < .05$). The more biological baselines were endorsed, the more cognitive problems, negative feelings, pain, and social avoidance, as well as less positive feelings.

Cancer-Specific QoL: Biological baselines demonstrated a moderate positive correlation with distress over recurrence ($r = .40$, $n = 45$, $p < .01$) and a weak positive correlation with family-related distress ($r = .37$, $n = 45$, $p < .05$). The more biological

baselines were endorsed, the more distress over recurrence and family-related distress.

Emotional Well-Being: Biological baselines did not significantly correlate with either anxiety or depression.

i) Illness-Specific Baselines

Generic QoL: Illness-specific baselines demonstrated a weak positive correlation with physical pain ($r = .33$, $n = 45$, $p < .05$). The more illness-specific baselines were endorsed, the greater the pain.

Cancer-Specific QoL: Illness-specific baselines demonstrated a weak positive correlation with appearance concerns ($r = .30$, $n = 45$, $p < .05$), and a moderate positive correlation with distress over recurrence ($r = .46$, $n = 45$, $p < .01$) and family-related distress ($r = .44$, $n = 45$, $p < .01$). The more illness-specific baselines were utilised, the more appearance concerns, distress over recurrence and family-related distress.

Emotional Well-Being: Illness-specific baselines did not significantly correlate with either anxiety or depression.

j) Turning to Others

Generic QoL: Turning to others demonstrated a weak positive correlation with physical pain ($r = .30$, $n = 45$, $p < .05$). The more the baselines of turning to others were utilised, the more pain was experienced.

Cancer-Specific QoL: Turning to others demonstrated a moderate positive correlation with distress over recurrence ($r = .36$, $n = 45$, $p < .05$), a moderate positive correlation with family-related distress ($r = .39$, $n = 45$, $p < .01$), and a weak positive correlation with physical pain ($r = .30$, $n = 45$, $p < .05$). The

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more the baselines of turning to others were utilised, the more distress over recurrence and family-related distress.

Emotional Well-Being: Turning to others demonstrated a weak negative correlation with anxiety ($r = -.30$, $n = 45$, $p < .05$). The more the baselines of turning to others were utilised, the less anxiety was experienced.

Table 5.3: Correlations between HBCs, QoL and Emotional Well-Being during Chemotherapy for Breast Cancer (*n* = 45); Red correlations indicate significant correlations between outcome measures and not within

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Social Baselines	.00																
2. Social Comparison Baselines	.44**	.00															
3. Biological Baselines	.66**	.44**	.00														
4. Illness-Specific Baselines	.47**	.29	.56**	.00													
5. Turning to Others	.44**	.25	-.46**	.57**	.00												
6. Appearance Concerns	.27	.32*	.26	.30*	.11	.00											
7. Distress over Recurrence	.16	.42**	.40**	.46**	.36*	.45**	.00										
8. Family-Related Distress	.23	.31*	.37*	.44**	.39**	.22	.50*	.00									
9. Benefits of Cancer	-.22	.06	-.09	.11	.07	-.26	.13	.33*	.00								
10. Negative Feelings	.29	.31**	.31*	.27	.27	.52**	.53**	.10	-.29	.00							
11. Positive Feelings	-.34*	-.27	-.30*	-.14	-.08	-.55**	-.38**	.00	.59**	-.69**	.00						
12. Cognitive Problems	.26	.10	.34*	.22	.12	.31	.18	.05	-.39**	.43**	-.51**	.00					
13. Physical Pain	.28	.27	.48**	.33*	.30*	.43**	.37*	.22	-.23	.57**	-.41**	.47**	.00				
14. Fatigue	.32*	.30*	.46**	.25	.18	.36*	.38**	.18	-.12	.48**	-.52**	.58**	.69**	.00			
15. Social Avoidance	.38**	.18	.30*	.24	.10	.60**	.27	.11	-.36*	.62**	-.70**	.55**	.59**	.64**	.00		
16. Anxiety	-.30*	-.35*	-.21	-.21	-.30*	-.44**	-.47**	-.34*	.25	-.63**	.48**	-.24	-.29	-.21	-.44**	.00	
17. Depression	.17	.19	-.03	-.03	.13	.17	.27	-.06	-.28	.61**	-.47**	.20	.27	.09	.35*	-.43**	.00

*One-tailed correlations: *p < .05; **p < .01.*

5.4.5. Predicting Quality of Life and Emotional Well-Being from HBCs

In order to determine the health baseline comparisons that were the most significant predictors of multidimensional QoL and emotional well-being during chemotherapy for breast cancer, hierarchical regression analyses were conducted. In the first step of each analysis, age and educational status were entered in order to control for possible demographic effects that have been noted in the literature (Wenzel et al, 1999). In the second step, the treatment variables of co-morbidities, treatment type (adjuvant v's neo-adjuvant), and number of chemotherapy cycles were entered since these have also been identified within the literature as impacting on QoL (Kaplan and Baron-Epel, 2003; Macmillan Cancer Support, 2008). In the final step, the five health baseline comparison factors were entered.

Details of the generic and cancer-specific QoL regressions are discussed below, along with any QoL domains where HBCs make a significant contribution. Details of the anxiety and depression regressions are also discussed below. Data is presented in Table 5.4.

e) Predictors of Generic QoL

Age and educational status, entered in the first step, were not significant predictors of generic QoL, whilst illness factors entered in the second step of the regression significantly explained 28% of the variance on generic QoL scores ($p<.01$). The HBC factors entered in step 3 explained a further 11% of the variance, but this was not significant. Examination of the betas indicated that co-morbidities (β = -.38) and type of chemotherapy treatment (β = .34) were the two significant predictors of this outcome ($p<.05$).

f) Predictors of Cancer-Specific QoL

Age and educational status, entered in the first step, were not significant predictors of Cancer-Specific QoL, whilst illness factors entered in the second step of the regression significantly explained 26% of the variance in Cancer-Specific QoL scores ($p<.01$). The HBC factors entered in step 3 together explained a further 21% of the variance ($p<.05$). Examination of the betas indicated that Social Comparison Baselines (β = .24) and Illness-Specific Baselines (β = .27) contributed the greatest to this outcome (p<.05). The final model was significant: F (10, 44) = 3.056, $p < .01$, explaining 47% of the variance in cancer-specific QoL (Adjusted R^2 = .32).

When Cancer-Specific QoL was divided into its four subscales, HBC predictors were found for distress over recurrence.

o Predictors of Distress over Recurrence

Age and educational status, entered in the first step, were not significant predictors of Distress over Recurrence, whilst illness factors entered in the second step of the regression significantly explained 25% of the variance in Distress over Recurrence ($p<.05$). Co-morbidities was the only

significant contributor ($p<.01$) out of the illness factors. The HBC factors entered in step 3 significantly explained a further 23% of the variance ($p<.05$). Examination of the betas indicated that Social Comparison Baselines (β = .28) and Illness-Specific Baselines (β = .31) contributed the greatest to this outcome ($p<.05$). The final model was significant: F (10, 34) = 3.187, $p <$ 0.01, explaining 48% of the variance in Distress over Recurrence (*Adjusted R^2* = .33).

g)   *Predictors of Anxiety*

Age and educational status, entered in the first step, were not significant predictors of anxiety, and neither were the illness factors entered in step 2.   The HBC factors entered in the third step together explained 25% of the variance in anxiety ($p<.05$). Examination of the betas indicated that only one HBC factor was a significant predictor of this outcome: Social Comparison Baselines (β = .39*, $p<.05$*). The final model was significant: F (10, 34) = 2.789, $p <$ 0.01, explaining 25% of the variance in anxiety (*Adjusted R^2* = .29).

h)   *Predictors of Depression*

Age and educational status, entered in the first step, were not significant predictors of depression. Illness factors entered in step 2 of the regression significantly explained 27% of the variance in depression ($p<.01$). The HBC factors entered in the third step were not significant predictors of depression. Examination of the betas indicated that only one illness factor was a significant predictor of this outcome: co-morbidities (β = -.52*, $p<.001$*).

Table 5.4: Hierarchical Regression Analysis of Predictors of QoL Outcomes (n = 45)

Predictor	Anxiety			Depression			Generic QoL		
	Beta	F	R^2 (change)	Beta	F	R^2 (change)	Beta	F	R^2 (change)
Step 1									
Age	-.36*	.87	(.04)	-.15	1.11	(.05)	-.22	.86	(.04)
Education	.10			.09			.12		
Step 2									
Treatment	.48	1.93	(.16)	.16	3.75**	(.27)*	.34*	3.70**	(.28)
Co-morbidities	-.27			-.46**			-.38*		
Cycles	-.15			-.10			-.03		
Step									
Social Baselines	-.21	2.79**	(.25)**	.16	2.07	(.05)	.02	2.57*	(.11)
Social Comparison Baselines	.39*			.05			-.01		
Biological Baselines	.16			.09			.10		
Illness-Specific Baselines	-.21			.06			.13		
Turning to Others	.11			-.09			.17		
Total R^2			**.45**			**.37**			**.43**

Predictor	Cancer-Specific QoL			Distress over Recurrence		
Step 1						
Age	-.27	.10	(.00)	-.15	1.60	(.07)
Education	-.12			-.20		
Step 2						
Treatment	.07	2.81*	(.26)**	.06	2.60*	(.18)*
Co-morbidities	-.43**			-.30		
Cycles	-.08			.09		
Step 3						
Social Baselines	-.01	3.06**	(.21)**	-.23	3.19**	(.23)*
Social Comparison Baselines	.24*			.28*		
Biological Baselines	.08			.17		
Illness-Specific Baselines	.27*			.31*		
Turning to Others	.04			.12		
Total R^2			**.47**			**.48**

**$p<.05$, **$p<.01$

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5.5. Discussion

Based on the aims of Study 4, which was primarily to identify and compare the stability and/or flexibility of HBCs with QoL and emotional well-being across the treatment trajectory (during and after chemotherapy for breast cancer), the specific aims of Study 4a were to: identify the most frequently endorsed HBCs during chemotherapy for breast cancer; identify any relationships between HBCs and both emotional well-being and QoL; identify the main HBC predictors of QoL and/or emotional well-being; and, further refine the HBCQ (v3) by testing the instruments reliability in women receiving chemotherapy for breast cancer.

The findings are discussed below.

5.5.1. *The Endorsement of HBCs during Chemotherapy*

Descriptive statistics confirmed previous studies within this programme of research by demonstrating the generally high levels of endorsement of HBCs in the evaluation of health status. Percentage of endorsement ranged from 38% (people who are dissimilar to me) to 100% (my adherence to medical advice; my own positive health judgments; treatment side-effects; my healthy appearance; my unhealthy appearance).

The five most frequently utilised HBCs (my adherence to medical advice; other's positivity towards me; my own positive health judgments; the doctor's positivity about my health; and, treatment benefits), three of which are turning to others provides support for the retention of this subscale despite its low internal consistency in the previous pilot study (Study 3).

The least frequently endorsed HBCs (healthy people in the media; unhealthy people in the media; my non-adherence to medical advice; colleagues I perceive to be less healthy than me; and, people who are dissimilar to me) consisted of four social comparison baselines. Social comparison baselines have tended to be the least frequently endorsed HBCs throughout the entire programme of research, but have nevertheless been retained due to still being endorsed by, in most cases, the majority of participants. Whether the lower endorsement of these HBCs can be explained by them playing a weaker role in health status evaluations or by responses being based on social desirability (Crowne and Marlowe, 1960), they remain consistently endorsed and therefore important influencing factors within the HBC concept.

Observation of the descriptive data suggests a potential difference between the endorsements of positively and negatively directed HBCs, the former being indicative of a positive mindset and the latter of a negative mindset. For example, the top five endorsed HBCs are all positively directed, participants using treatment benefits, doctor's positive feedback, and own adherence to medical advice to evaluate personal health status. Conversely, the five least endorsed HBCs comprise four

negatively directed HBCs, participants considering their non-adherence to medical advice and comparing themselves to those they perceive as being less healthy than themselves when evaluating their personal health status. This is consistent with the findings in Study 3 (4.4.4.) where this distinction was first recognised, providing evidence for the rationale of assessing the direction of HBCs. Whether these observed differences are significant will be statistically tested in the next chapter.

5.5.2. Relationships between HBCs and QoL and Emotional Well-Being

A number of significant correlations were identified between HBCs and the outcome measures of QoL and emotional well-being. Interestingly, HBCs correlated more strongly with generic QoL than cancer-specific QoL, as discussed next.

People who utilised social baselines when evaluating their health status tended to report higher levels of positive feelings, fatigue, social avoidance, and anxiety. When considering social baselines, it seems plausible that examining one's own social circumstances while undergoing chemotherapy might lead to social avoidance due to the perceived changes in social activity (e.g. restrictions due to pain or fatigue). Such an association would be best explored qualitatively via interpretative phenomenological analysis (IPA), the aim of this methodology being to explore in detail the processes through which people make sense of their own experiences (Chapman and Smith, 2002; Smith et al., 1997). This approach to further analysis of the HBC concept will be adopted in a later study within this programme of research.

People who utilised social comparison baselines when evaluating their health status tended to report higher levels of negative feelings, fatigue, appearance concerns, distress over recurrence, and family-related distress, as well as lower levels of anxiety. The literature highlights the use of upward and downward comparisons, the former of which is generally believed to predict negative feelings (Festinger, 1954) and the latter positive (Wills, 1981). However, in the current study, even though social comparisons were associated with negative outcomes, they were also associated with reduced anxiety. The literature indicates that people who are anxious have a greater motivation to make social comparisons, suggesting that these comparisons might be adaptive in terms of reducing these feelings (Bennenbroek et al., 2002). This is supported by the findings presented here. In the next chapter it will be possible to examine whether the direction of social comparison HBCs are associated with these outcomes.

People who utilised biological baselines when evaluating their health status tended to report higher levels of negative feelings, pain, social avoidance, cognitive problems, distress over recurrence, and family-related distress, as well as lower levels of positive feelings. It is likely that concentrating on one's physical symptoms and sensations will increase perceptions of physical problems such as pain, fatigue and cognitive problems, as appears to be the case in this cohort of participants. Indeed, hypervigilance is commonly reported among people with cancer and survivors of cancer (Jim and Jacobsen, 2008; Bush, 2009), with distress over recurrence reported as being almost universal among cancer survivors (Vickberg, 2003), as well as being

exacerbated by physical symptoms (Allen et al., 2009). It might be that during chemotherapy there is a heightened need for information about the likely physiological changes in order to prevent every treatment-related side-effect causing further distress about long-term survival. It is also interesting to consider that distress over recurrence starts to form even before the completion of treatment, when treatment efficacy has not yet been ascertained. This suggests that interventions aimed at relieving such distress to a more manageable level should, ideally, commence on diagnosis or at least on starting treatment.

People who utilised illness-specific baselines when evaluating their health status tended to report higher levels of pain, appearance concerns, distress over recurrence, and family-related distress. These associations are of no surprise considering the side-effects of cancer (e.g. hair loss) and the genetic risk factors associated with having breast cancer in the family, as discussed in Chapter 1 in terms of threat representations associated with a genetic predisposition (Nelkin and Lindee, 1996; Shiloh, Rashuk-Rosenthal, and Benyamini, 2002).

People who turned to others when evaluating their health status tended to report higher levels of pain, distress over recurrence, and family-related distress, as well as lower levels of anxiety. It is plausible that turning to others exacerbates fears over recurrence as well as family-related distress due to other people being a reminder of the risks associated with cancer, including mortality. The reduction in anxiety associated with this HBC is likely to be the result of the mechanisms involved in social comparison baselines and lower levels of anxiety, whereby turning to others reduces these feelings. With this in mind, there appears to be a dissonance within social comparison baselines and turning to others, both methods of evaluating health highlighting illness-related fears (e.g. appearance concerns, family-related distress) whilst at the same time providing some anxiety relief. This relief could plausibly be the result of identifying with others via upward social comparisons (Collins, 1996; Buunk and Ybema, 1997) and feeling less alone by turning to others. At the same time, turning to others might reduce feelings of anxiety by relieving some of the burden associated with evaluating one's health status during a time that is understandably extremely stressful anyway. Indeed, it is noted in the literature that patients often prefer to leave any decision-making to the health professional (Beisecker and Beisecker, 1990), despite the common belief that all patients want to be involved in decisions about their healthcare.

To expand on appearance concerns, found to be associated with both social comparison baselines and illness-specific baselines, the findings reported here are supported by the literature. Social comparisons, in particular, are renowned for their potential to cause appearance dissatisfaction (Want, Vickers and Amos, 2009). Similarly, illness-specific baselines, which are likely to prompt thoughts of appearance-related side-effects of cancer or its treatment, are plausible contributors to appearance concerns. Indeed, as discussed in Chapter 1, alopecia is consistently rated as being one of the most distressing side-effect of chemotherapy (Boehmke and Dickerson, 2005; Browall, Gaston-Johansson, and Danielson, 2006).

It is important to acknowledge, however, the risk of a type 1 error resulting from the number of correlations conducted. It is possible that some of these associations are significant due to chance alone. On the other hand, the predictive models identified via multiple regression analyses do support these associations.

With this high endorsement of HBCs, along with several significant associations with QoL and emotional well-being, the predictive validity of HBCs were examined via multiple regression analyses. A discussion of the findings from these regressions follows.

5.5.3. Predicting QoL and Emotional Well-Being via HBCs

The HBC factors together accounted for 25% of the variance in anxiety, with social comparison baselines being the only significant contributor to this outcome. It was surprising that demographic and illness factors failed to make any significant contribution to the final model. A possible explanation is that treatment-related anxiety is eased during chemotherapy, when action is being taken to combat the cancer and when patients are in regular contact with health professionals. Indeed, interviews with cancer survivors have demonstrated treatment to be a time when the main focus is managing the side-effects of treatment, whereas post-treatment is a common period of emotional crisis due to withdrawal of medical support (Shapiro, Angus, and Davis, 1997). A potential explanation for social comparison baselines being the only significant contributor to variance in anxiety outcomes is the frequent contact with other cancer patients during the treatment process. This is something that has been noted in the literature, where social comparisons are made whilst in the oncology waiting room (Stanton, Danoff-Burg, and Cameron, 1999).

Co-morbidities were the largest significant contributor to cancer-specific QoL, explaining 26% of the variance in this outcome. Nevertheless, the contribution of HBCs was similar, explaining 21% of the variance in cancer-specific QoL and creating a model that can predict 47% of the variance in this outcome. The two HBC factors significantly contributing to this outcome were social comparison baselines and illness-specific baselines, the latter coming of no surprise since using the illness experience to evaluate health status is likely to impact QoL specific to that illness. In terms of social comparisons, it might be that the degree of identification with other people who have cancer impacts cancer-specific QoL either positively or negatively (Collins, 1996).

Interestingly, the role of HBCs in cancer-specific QoL outcomes was primarily in terms of distress over recurrence, which could be argued as being a proxy for measuring anxiety. The HBCs together significantly explained 23% of the variance in distress over recurrence, with social comparison baselines and illness-specific baselines being the only significant contributors to this outcome. The descriptive statistics indicated that although social comparisons were the least endorsed HBCs, they were still used by 38% (people who are dissimilar to me) to 89% (people with cancer who appear to be doing well), providing a great deal of scope for anxiety-provoking comparisons to be made when evaluating health status. It is likely that

certain types of social comparison will enhance distress over recurrence; as noted previously in this chapter as well as in 1.7.1., social comparisons can have positive or negative outcomes depending on the HBC adopted in the formation of a perceived health status. In combination with the 25% variance explained by illness factors, the final model significantly explained a 48% of the variance in distress over recurrence.

Co-morbidities independently predicted levels of depression, posing important implications for clinical practice. People with cancer who present with co-morbidities might require screening or monitoring in order to elicit whether psychological support is warranted. This is supported via the finding that co-morbidities also predicted generic QoL via relationships with negative feelings, cognitive problems, fatigue, physical pain, and social avoidance. Co-morbidities were also implicated in cancer-specific QoL, explaining 26% of the variance in this outcome. There is clearly a need for greater physical and emotional support for women receiving chemotherapy for cancer, but who also have co-morbidities.

In this cohort of women, the majority reported having no co-morbidity. The co-morbidities that were reported ranged from conditions such as glaucoma, diabetes, polycystic ovary syndrome, and asthma, as well as conditions that might be exacerbated by the stress of cancer, such as high blood pressure. More research is needed into the additional QoL impact of specific co-morbidities in people with cancer. Additionally, greater insight is required into the HBC construct when multiple conditions are present.

Participants' chemotherapy was either adjuvant (following surgery) or neo-adjuvant (prior to surgery), with the majority receiving the former. It is possible that the order in which treatment is received impacts on levels of anxiety, depression, QoL, and possibly on the HBCs used. However, this was controlled for in the multiple regression analyses, as justified via the finding that type of treatment along with co-morbidities significantly explained 28% of the variance in generic QoL. Specifically, type of treatment along with co-morbidities significantly explained 15% of cognitive problems and 37% of fatigue. Cognitive problems and fatigue are two of the most frequently reported side-effects of cancer and its treatment (Portenoy and Miaskowski, 1998; Nelson et al., 2008) and thus this finding could inform the various levels of symptomatic support provided to people with cancer at different times of the illness trajectory.

Age and educational status did not play a significant role in predicating QoL and emotional well-being outcomes. This is not consistent with the literature and might be due, in the case of educational status, to misreporting. In 3.5.6., it was highlighted that a higher than expected number of participants indicated they were educated to postgraduate level, which was hypothesised as being due to a misunderstanding in semantics. In this study, efforts were made to rectify this, by providing examples next to the various educational status options. For example, the option of postgraduate was followed by 'e.g. Masters; PhD.' However, the number of participants reporting to be of postgraduate level education was still higher than would be expected in this cohort. Therefore, the findings pertaining to educational status and QoL outcomes should be interpreted with caution. It is possible that respondents' answers on this

item were influenced by social desirability factors (Crowne and Marlowe, 1960), although this was not a recognised limitation when the HBCQ (v3) was pilot tested prior to this study (Chapter 4).

5.5.4.   *Psychometric Properties of the HBCQ (v3)*

The Cronbach's alpha for the HBCQ (v3) was low for turning to others and high for all other subscales, demonstrating the maintenance of psychometric properties in four subscales. Furthermore, despite the low alpha of the turning to others subscale, it was greatly improved from previous studies conducted in this programme of research. Along with the descriptive statistics that support the retention of this subscale despite its low internal consistency, this improvement provides further support for its inclusion in this research. Turning to others is clearly an important method of health status evaluations when in the midst of a personal life crises, as is the case when receiving chemotherapy for breast cancer.

5.6.   Conclusions

This chapter has outlined the aims and objectives of Study 4, as well as discussed the findings from Study 4a. This study involved the exploration of HBCs adopted during chemotherapy for breast cancer and any association with QoL and emotional well-being. Chapter 6 introduces the second part of this longitudinal study, Study 4b, where the salience and stability of HBCs two-months post-chemotherapy will be explored, as will any associations with QoL and emotional well-being. In turn, comparisons between the two measurement time points will be assessed.

Chapter 6

Study 4b: A Longitudinal Investigation of HBCs, QoL, and Emotional Well-Being during and after Chemotherapy

The previous chapter described the aims and objectives of Study 4 (4a and 4b): an examination of HBCs, QoL and emotional well-being, both cross-sectionally and longitudinally in a sample of women during and after chemotherapy for breast cancer. The preceding chapter presented data examining HBCs and QoL at one point in time during a course of chemotherapy. The present chapter firstly summarises these findings and subsequently builds on them by presenting longitudinal data from all of those women in Study 4a who also provided post-chemotherapy data (i.e. the analysis conducted in the previous chapter has been repeated on the whole sample of those who provided data at the two time points). The findings of 4b will be presented and discussed with reference to those of 4a.

6.1.   Introduction

In Study 4a (Chapter 5), HBCs, QoL, and emotional well-being (anxiety and depression) were measured in women with breast cancer who were experiencing chemotherapy (n=45). Participants were within one-month of their treatment commencing and no less than one-month away from the end of treatment. The use of specific HBCs was frequently endorsed by this cohort of women and, furthermore, analysis of the cross-sectional data demonstrated that some HBC factors were significant predictors of QoL and emotional well-being. Most notably, social comparison baselines explained 25% of the variance in anxiety, making a higher contribution than any demographic or illness variables. Social comparison baselines, together with illness-specific baselines, made significant contributions to cancer-specific QoL, together explaining 21% of the variance in this outcome. Along with the 26% of variance significantly explained by co-morbidities, the final model accounted for 47% of cancer-specific QoL.

Interestingly, the role of HBCs in predicting cancer-specific QoL outcomes was primarily in terms of the subscale assessing distress over recurrence. Social comparison baselines and illness-specific baselines together accounted for 23% of the variance in this outcome. In combination with the 25% variance explained by co-morbidities, the final model accounted for 48% of the variance in cancer-specific QoL. The category of illness-specific baselines is a plausible predictor of distress over recurrence during a course of treatment, as the patient's attention is likely to be focused on the cancer itself.   However, the contribution of social comparison baselines to this outcome is not so easy to explain. It is possible that women compare their health to that of other women whose cancer has

recurred, drawing on perceived similarities between themselves and these other women in terms of symptomology or other external or internal 'markers' of disease progression. Indeed, evidence does exist that social comparisons with women who have experienced a recurrence can exacerbate fears of having a recurrence oneself (Vickberg, 2003).

Research indicates that distress over recurrence is universal among cancer survivors (Simard and Savard, 2009); this often leads to hypervigilence to what may be 'normal' physical sensations (Roth et al., 2005; Allen et al., 2009; Bush, 2009). The moderate positive correlation between biological baselines and distress over recurrence found in Study 4a provides some tentative support for this effect (5.4.4.c). In theory, distress over recurrence is likely to be greater post-chemotherapy, during the survivorship period (Mullan, 1985; CDC, 2004). In contrast, social comparisons are likely to be more salient during chemotherapy, when more time is spent with other women in waiting rooms, etc., receiving the same treatment (Buunk and Ybema, 1997; Van der Zee et al., 1998).

Mullan (1985) was the first to propose a three-stage model describing the progression of events experienced by someone with cancer. These are the acute stage, the extended stage, and the permanent stage. The acute stage encompasses diagnosis and treatment. The extended stage involves remission or the completion of treatment; for the patient, this is a time of 'watchful waiting,' which may involve considerable anxiety as to whether any sensations or symptoms experienced are a sign of recurrence. The permanent stage involves permanent progression towards survivorship or, as Mullan defines it, *"activity of the disease or likelihood of its return is sufficiently small that cancer can now be considered permanently arrested"* (Mullan, 1985, p.272). The Lance Armstrong Foundation (CDC, 2004) further defines these stages as living 'with,' 'through,' and 'beyond' cancer, living 'through' cancer being the 'extended' phase referred to by Mullan (1985). The present study (4b) will focus on the use of HBCs and QoL during the acute and the extended stage.

6.1.1.   *Longitudinal Design*

The previous study found significant relationships between specific HBCs and anxiety and cancer-specific QoL. Nonetheless, as this study relied on cross-sectional, correlational data, the direction of causation could not be established. Moreover, any fluctuations in HBCs and outcome measures during and after the treatment process could not be investigated. The extent to which these findings transfer to post-chemotherapy outcomes could provide valuable insight into how HBC theory might inform interventions to enhance well-being during this stressful period. Indeed, with cancer survivorship being on the increase, post-treatment QoL initiatives have been highlighted as a government priority (NCSI, 2009). In order establish facilitate between treatment and post-treatment measures, a longitudinal approach to data analyses is required. The data for Study 4a (Time 1), during chemotherapy, was collected from women (n=45) who were within one month of their treatment commencing and no less than one month away from the end of

treatment. The data for the present study, Study 4b (Time 2), after chemotherapy, was collected from a cross-section of Time 1 respondents (n=35), approximately two months after the final course of chemotherapy. It is the data from this cross-section of Time 1 and Time 2 respondents that are presented within this chapter.

A course of chemotherapy ranges from four to six months duration (Breast Cancer Care, 2009), therefore the duration between the two time points of questionnaire completion ranged from six to eight months. The rationale for obtaining data during these two time points was based on the advice of oncology experts. The risks of obtaining data from patients any sooner than one month into a course of chemotherapy was highlighted, as assessments of well-being are likely to reflect the initial shock of diagnosis. A review of the literature also suggested that it would be most appropriate to collect follow-up data two months post-chemotherapy, as people are more likely to have resumed 'normal' life and adjusted to less frequent interaction with health professionals (Deshields et al., 2005; Kornblith, 2003).

These two measurement time points are referred to within the literature as 'active treatment' (during chemotherapy) and the survivorship period (after primary treatment) (Mullan, 1985; CDC, 2004), indicating a transition from 'patient' to 'survivor.' The literature demonstrates that changes in health perceptions, health status, QoL, and emotional well-being are likely to occur during this trajectory (Allen et al., 2009). It is therefore anticipated that QoL, emotional well-being, and possibly HBCs, will change during this time.

Study 4a examined HBCs adopted during chemotherapy for breast cancer as predictors of QoL and emotional well-being during the same point in time (Time 1 $\rightarrow$ Time 1). The present study, Study 4b, examines HBCs adopted during chemotherapy as predictors of QoL and emotional well-being at a different point in time - post-chemotherapy (Time 1 $\rightarrow$ Time 2), as well as HBCs adopted post-chemotherapy as predictors of QoL and emotional well-being during the same period in time (Time 2 $\rightarrow$ Time 2). Regression data from Study 4a suggests that social comparison and illness-specific baselines adopted at Time 1 will be significant predictors of cancer-specific QoL, distress over recurrence, and anxiety at Time 2 as well as Time 1. Equally, it could be hypothesised that social comparison and illness-specific baselines adopted at Time 2 will be significant predictors of cancer-specific QoL, distress over recurrence, and anxiety during the same point in time. Mean changes between HBCs endorsed and QoL and well-being outcomes during and after treatment will also be examined in terms of differences between Time 1 and 2.

As highlighted in Chapter 5, there are many advantages to a longitudinal research design. These include the ability to measure changes, differences, and patterns across time, as well as the potential to imply causation and temporal ordering (Menard 1991). Since QoL is expected to change throughout the treatment process (Lee and Choi, 2007; O'Connor et

al., 1990), measuring HBCs along the same continuum is anticipated to offer a design likely to capture any interactions between these two variables.

As with previous studies carried out as part of this programme of research, the demographic (age and educational status) and illness factors (type and length of treatment, and co-morbidities) cited in the literature as being associated with QoL and emotional well-being outcomes (Kaplan and Baron-Epel, 2003; Wenzel et al, 1999) will be elicited along with measures of HBCs, QoL (generic and cancer-specific), and emotional well-being (anxiety and depression). These variables will need to be accounted for in any findings.

In the following section, the aims and objectives of Study 4b are presented, followed by the methodology. The results of post-treatment (Time 2) data will subsequently be presented, followed by a comparison of data collected during (Time 1) and after treatment (Time 2), when respondents have made the objective transition from 'patient' to 'survivor.'

6.2. Aims and Objectives

The aims of this study were to:

➢ Identify the most frequently endorsed HBCs after a course of chemotherapy for breast cancer.

➢ Identify the main HBC predictors of QoL (generic and cancer-specific) and/or emotional well-being (anxiety and depression) after a course of chemotherapy for breast cancer. The hypotheses are that social comparison and illness-specific baselines adopted at Time 1 will be significant predictors of cancer-specific QoL, distress over recurrence, and anxiety at Time 1 and Time 2 in the whole sample of women who completed questionnaires at both time points. Also, social comparison and illness-specific baselines adopted at Time 2 will be significant predictors of cancer-specific QoL, distress over recurrence, and anxiety during the same point in time.

➢ Compare group level changes between HBCs endorsed and QoL and well-being outcomes between Time 1 and 2.

➢ Test the validity of the HBCQ (v3) in explaining QoL and emotional well-being outcomes after chemotherapy (Time 2).

6.3. Method

6.3.1. Ethical Approval

Ethical approval was granted by Cranfield University at Silsoe (appendix Av) and the Hertfordshire Local Research Ethics Committee (appendix Avi). Bedford Hospital R&D and Milton Keynes Hospital R&D provided Trust approval appendix (Aiii and Avii).

6.3.2. Sample

Women with breast cancer (n=35) who completed questionnaires whilst undergoing chemotherapy and whom had agreed to be contacted post-chemotherapy were included in this study if they met the following inclusion criteria.

Inclusion criteria:

- had taken part in Study 4a, during chemotherapy
- had first time primary breast cancer
- were at least two-months post-treatment
- had no disease metastasis since completion of the first set of questionnaires (Time 1)
- had no changes in disease or treatment since Time 1 rendering original consent morally unusable.

6.3.3. Questionnaires

Self-reported demographic (age; marital status) and medical (type of treatment – adjuvant versus non-adjuvant; number of chemotherapy cycles; co-morbidity) variables utilised in Study 4a were sought in this study, as control data for hierarchical multiple regressions. This data was collected along with the administration of the three questionnaires described in 5.3.3.: the HBCQ (v3); the QLACS; and, the HADS. Briefly, the HBCQ (v3) comprises five domains (i.e. social baselines; social comparison baselines; biological baselines; illness-specific baselines; turning to others) and the HADS two domains (anxiety and depression). The QLACS comprises the two domains of generic and cancer-specific QoL, the former comprising negative feelings, positive feelings, cognitive problems, pain, social avoidance, and fatigue, and the latter comprising family-related distress, distress over recurrence, and appearance problems. Higher scores represent greater endorsement of a HBC, greater levels of anxiety or depression, and greater problems within a specific domain of QoL.

6.3.4. Procedure

When consenting to take part in Study 4a, participants also provided separate consent to take part in Study 4b. The initial recruitment of participants from Bedford and Milton Keynes Hospitals' was described in Chapter 5 (5.3.4.). When each participant was approaching two months after completion of the first set of questionnaires (i.e. approaching Time 2), the hospital treating the patient was contacted to ensure that she was in a position to continue with the study. At Time 2, a follow-up letter, second consent form, and the three questionnaires (HBCQ; QLACS; HADS) were posted to patients homes along with a stamped addressed envelope to return completed questionnaires.

6.3.5. Methods of Statistical Analysis

Only data from participants who completed questionnaires at both points in time was included in the analysis.

Further testing of the HBCQ (v3) was carried out via an analysis of internal consistency (Cronbach's alpha) and reproducibility (test-retest correlations). This was followed by an examination of the HBC descriptive statistics in order to identify strength of HBC endorsement in this cohort at Time 1 and Time 2, and then paired samples t-tests to identify any significant differences between mean scores on each scale at two points in time. Finally, hierarchical multiple regression analyses were conducted to test the hypotheses that:

> ➢ Time 1 social comparison and illness-specific baselines will be significant predictors of Time 1 and 2 cancer-specific QoL, distress over recurrence, and anxiety.

> ➢ Time 2 social comparison and illness-specific baselines will be significant predictors of Time 2 cancer-specific QoL, distress over recurrence, and anxiety.

6.4. Results

6.4.1. Participant Demographics

Out of 45 women who took part in Study 4a, all provided consent to take part in Study 4b, 35 of whom were eligible. Of the ten ineligible women, four were receiving extended treatment beyond the study end date, four had developed metastatic cancer, and two were experiencing cancer-related fatigue and felt too tired to participate.

The demographic details of eligible participants are presented in Figures 6.1-6.4. The majority of the sample was between 41 and 60 years of age (66%; n=23) and educated to GCSE/A-Level and beyond (89%; n=31). Sixty-six percent reported having no co-morbidities (n=23). For 91% (n=32) of the sample, treatment type was adjuvant chemotherapy, indicating that they had already received surgery. The total number of chemotherapy cycles undergone by participants varied from 3-16, with the mean being 6.6 cycles; this was controlled for in data analysis.
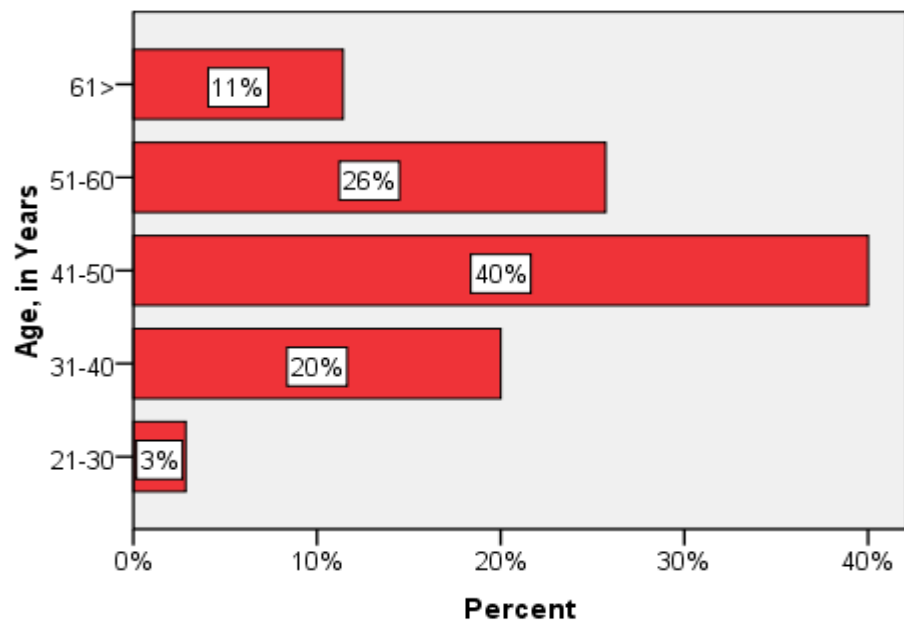
Figure 6.1: Age of Participants (n=35)
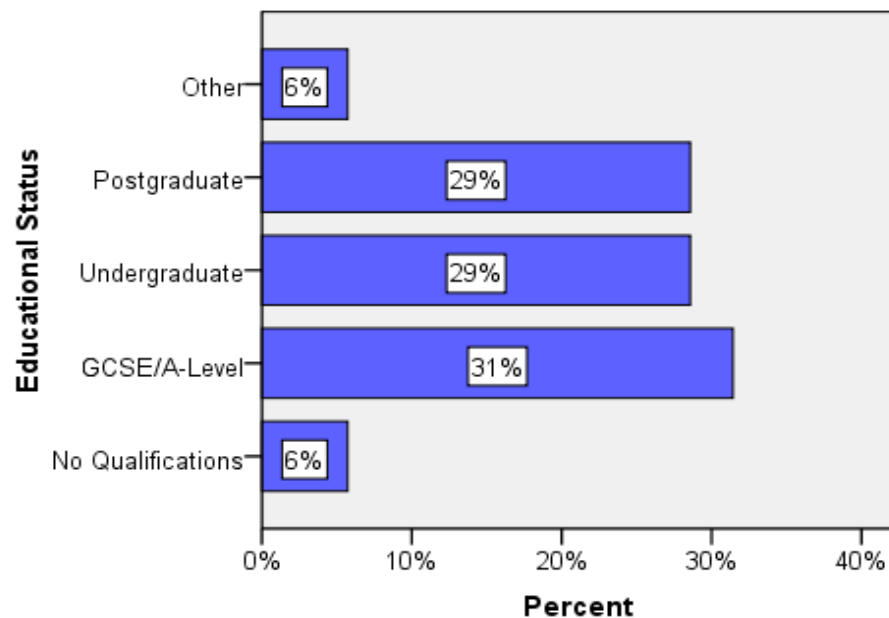
Figure 6.2: Educational Status of Participants (n=35)
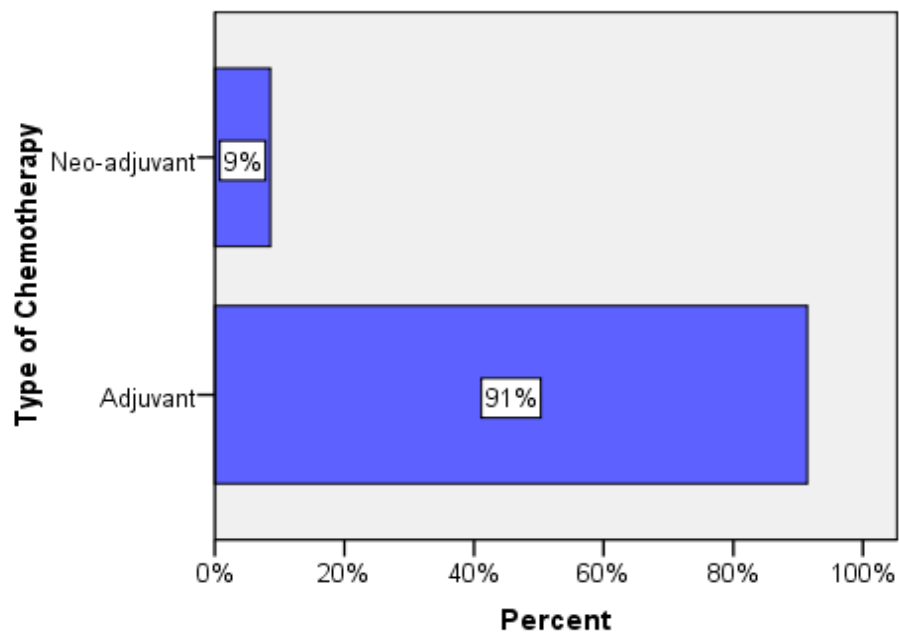
Figure 6.3: Type of Chemotherapy (n=35)

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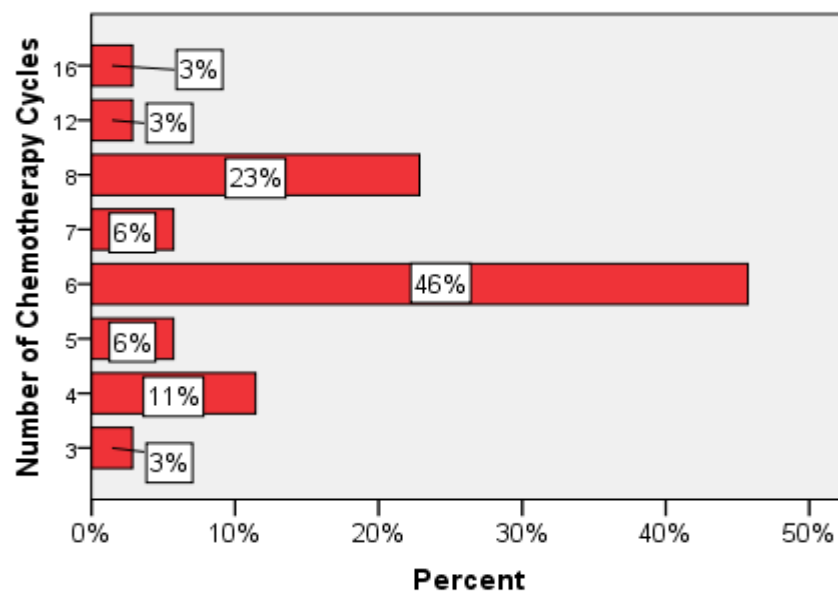
Figure 6.4: Number of Chemotherapy Cycles (n=35)

6.4.2. HBCQ Refinement

In keeping with the continued refinement of the HBCQ throughout this research programme, the internal consistency of the HBCQ (v3) at Time 1 and Time 2 was examined for the sample of women who took part in both time points (n=35). As illustrated in Table 6.1, with one exception, the subscales had an acceptable level of internal consistency at Times 1 and 2. However, although the alpha for the turning to others subscale was low at Time 1, it improved considerably at Time 2. Changes in the internal consistency of the other subscales were fairly marginal.

Table 6.1: Cronbach's Alpha of HBCQ (v3) during (Time 1) and after (Time 2) Treatment (n=35)

Subscale	Time 1	Time 2
Social Baselines	0.90	0.87
Social Comparison Baselines	0.79	0.85
Biological Baselines	0.76	0.73
Illness-Specific Baselines	0.80	0.77
Turning to Others	0.43	0.71

In refining the psychometric properties referred to in 2.1. during the initial development of the HBCQ (i.e. reliability, validity acceptability, feasibility, etc.), the HBCQ (v3) has demonstrated further evidence of reliability. Reproducibility has also been supported via a significant test-retest correlation of 0.78 for the Total HBCQ, and satisfactory test-retest reliability for each subscale (Table 6.2). The test-retest reliability for the construct as a whole is fairly high, but those for some subscales are low, suggesting that they are not necessarily stable and may be more responsive to environmental change.

Table 6.2: Reproducibility of HBCQ (v3) - during (Time 1) and after (Time 2) Treatment (n=35)

Subscale	Test-Retest Reliability
Social Baselines	0.79
Social Comparison Baselines	0.46
Biological Baselines	0.63
Illness-Specific Baselines	0.66
Turning to Others	0.56
Total HBCQ	0.78

6.4.3. HBC Descriptive Data

Table 6.3 provides details of each HBC in descending mean order of endorsement for Time 2, with higher means indicating more salient endorsement. As can be seen, HBCs are frequently endorsed by this cohort of women post-chemotherapy, with strength of endorsement ranging from 43% (people who are dissimilar to me; my non-adherence to medical advice) to 100% (my adherence to medical advice; my ability to do the things I enjoy; the doctor's positive comments about my health; other's positivity towards me; expected symptoms; and, that I am coping well).

Table 6.3: Utilisation of HBCs Post-Chemotherapy (Time 2), in Descending Mean Order of Strength of Endorsement (*n* = 35)

HBC *When thinking about how healthy I am, I consider:*	Mean (SD)	% A Little	% Quite a Bit/Very Much	% Not at All	HBC *When thinking about how healthy I am, I consider:*	Mean (SD)	% A Little	% Quite a Bit/Very Much	% Not at All
My enjoyment of life	2.43 (.778)	9	88	3	My stress levels	1.57 (.948)	40	49	11
Treatment benefits	2.26 (.852)	17	80	3	My health before cancer	1.57 (.850)	17	74	9
My adherence to medical advice	2.26 (.780)	34	66	0	My difficulty coping	1.54 (.886)	29	57	14
My ability to do things I enjoy	2.23 (.690)	49	51	0	My inability to work	1.51 (1.067)	31	49	20
My healthy lifestyle choices	2.23 (.770)	11	86	3	My own negative health judgments	1.46 (.886)	37	49	14
My prognosis	2.17 (.923)	17	77	6	My inability to do the things I enjoy	1.37 (1.031)	26	48	26
The doctor's positivity about my health	2.17 (.747)	43	57	0	My past ill health	1.37 (.910)	49	46	14
					The intimacy in my life	1.34 (.998)	34	43	23
Positivity about the future	2.09 (.919)	11	80	9	My social difficulties	1.34 (1.136)	23	46	31
Other's positivity towards me	2.03 (.747)	46	54	0	People with cancer who appear to not be doing well	1.31 (.963)	20	63	17
My unhealthy appearance	2.00 (.686)	14	83	3					
My concerns about the future	1.97 (.822)	26	71	3	People I perceive to be similar to me	1.26 (.919)	46	34	20
Expected symptoms	1.97 (.664)	57	43	0					
That I am coping well	1.94 (.873)	14	77	9	My difficulties being intimate	1.23 (1.031)	34	37	29
Positive aspects of the cancer experience	1.94 (.938)	34	57	9	The natural ageing process	1.20 (.868)	49	31	20
					People I perceive to be healthier than me	1.06 (.838)	49	28	26
My own positive health judgments	1.91 (.951)	14	75	11	Colleagues I perceive to be healthier than me	1.03 (.923)	34	32	34
Treatment side-effects	1.89 (.900)	51	40	9	Other's negativity towards me	.91 (.853)	37	26	37
My healthy appearance	1.89 (.832)	23	71	6	People I perceive to be less healthy than me	.83 (.707)	49	16	34
My past health	1.86 (.912)	23	68	9					
My social abilities	1.77 (1.031)	23	63	14	Healthy people in the media	.71 (.893)	23	23	54
People with cancer who appear to be doing well	1.74 (1.010)	31	52	11	Colleagues I perceive to be less healthy than me	.60 (.651)	43	8	49
My ability to work	1.63 (1.031)	17	52	31	Unhealthy people in the media	.57 (.655)	40	9	51
My unhealthy lifestyle choices	1.63 (.843)	26	63	11	My non-adherence to medical advice	.51 (.658)	40	3	57
The doctor's negativity about my health	1.63 (1.003)	31	55	14	People who are dissimilar to me	.49 (.612)	37	6	57

Table 6.4 shows that the HBCs endorsed during chemotherapy (Study 4a) and post-chemotherapy (Study 4b) are relatively similar. However, the variable test-retest correlations between the HBC subscales measured at Times 1 and 2 indicate some variability over time. As can be seen, adherence to medical advice was more salient during chemotherapy (Time 1), whilst enjoyment of life was more salient post-chemotherapy (Time 2). Making comparisons with healthy people in the media was the least salient HBC both during (Time 1) and after (Time 2) chemotherapy. Interestingly, there appears to be an emphasis on turning to others during chemotherapy (other's positivity towards me; my own positive health judgments; the doctor's positivity about my health), in contrast to a greater emphasis on biological baselines (my healthy lifestyle choices; my ability to do the things I enjoy) or illness-specific baselines (my adherence to medical advice; treatment benefits) post-chemotherapy.

Table 6.4: HBCs Endorsed During and Post-Chemotherapy, in Descending Mean Order of Strength of Endorsement

Level of Endorsement	During Chemotherapy (Time 1)	Mean (SD)	Post-Chemotherapy (Time 2)	Mean (SD)
Most Frequently Endorsed HBCs	My adherence to medical advice	2.49 (.695)	My enjoyment of life	2.43 (.778)
	Other's positivity towards me	2.33 (.739)	Treatment benefits	2.26 (.852)
	My own positive health judgments	2.31 (.668)	My adherence to medical advice	2.26 (.780)
	The doctor's positivity about my health	2.31 (.763)	My ability to do things I enjoy	2.23 (.690)
	Treatment benefits	2.31 (.900)		
			My healthy lifestyle choices	2.23 (.770)
Least Frequently Endorsed HBCs	Healthy people in the media	.80 (.991)	Healthy people in the media	.71 (.893)
	Unhealthy people in the media	.78 (.795)	Colleagues I perceive to be less healthy than me	.60 (.651)
	My non-adherence to medical advice	.71 (.944)	Unhealthy people in the media	.57 (.655)
	Colleagues I perceive to be less healthy than me	.67 (.640)	My non-adherence to medical advice	.51 (.658)
	People who are dissimilar to me	.40 (.539)	People who are dissimilar to me	.49 (.612)

6.4.4. Tests of Difference – During and Post-Chemotherapy

In order to compare the mean scores obtained during Times 1 and 2, paired samples t-tests were carried out on the five HBCQ (v3) subscales, QoL (generic and cancer-specific), and emotional well-being (anxiety and depression). Table 6.5 presents the mean, t, degrees of freedom (df), and level of significance (p) of any differences between the two data points. Cohen's suggested interpretation of effect size was utilised, whereby an effect size of 0.2 to 0.3 is small, around 0.5 is medium, and 0.8 to 1.0 is large.

Table 6.5: HBC, QoL and Emotional Well-Being Differences between Time 1 (T1) and Time 2 (T2) (n=35; df=34).

Variable	Mean (SD)	t	Significance (p)
T1 Social Baselines T2 Social Baselines	20.66 (7.95) 20.37 (7.35)	.34	.74 (ns)
T1 Social Comparison Baselines T2 Social Comparison Baselines	6.54 (3.95) 6.54 (4.40)	.00	1.00 (ns)
T1 Biological Baselines T2 Biological Baselines	16.17 (4.83) 15.77 (4.30)	.60	.55 (ns)
T1 Illness-Specific Baselines T2 Illness-Specific Baselines	18.74 (5.50) 17.63 (4.93)	1.53	.14 (ns)
T1 Turning to Others T2 Turning to Others	10.80 (2.68) 10.11 (3.34)	1.41	.17 (ns)
T1 Generic QoL T2 Generic QoL	83.17 (19.74) 76.03 (26.29)	2.08	.05*
T1 Cancer-Specific QoL T2 Cancer-Specific QoL	44.23 (15.61) 43.60 (15.75)	.42	.68 (ns)
T1 Anxiety T2 Anxiety	7.66 (4.22) 9.74 (4.69)	-2.46	.02**
T1 Depression T2 Depression	5.63 (4.66) 6.23 (3.39)	-.76	.45 (ns)

Higher means indicate greater use of a HBC, worse QoL, and more anxiety and depression.

* Significant at the .05 level; ** significant at the .01 level; ns = not significant.

d) HBCs

No significant differences were detected between levels of HBCs adopted during chemotherapy and those adopted post-chemotherapy.

e) QoL

The mean difference between generic QoL during and post-chemotherapy was 7.14 and the 95% CI for estimated population mean difference between .158 and 14.13 (effect size = 0.31). A paired samples t-test demonstrated the difference to be significant, confirming that generic QoL was likely to be poorer during chemotherapy than post-chemotherapy ($t = 2.08$, $df = 34$, $p < .05$). No significant differences were found for cancer-specific QoL between the two time points.

f) Emotional Well-Being (HADS)

The mean difference between the anxiety subscale of the HADS measured during and post-chemotherapy was -2.09 and the 95% CI for estimated population mean difference between -3.81 and -.36 (effect size = -0.47). A paired samples t-test demonstrated the difference to be significant, confirming that anxiety was likely to be higher post-chemotherapy compared to during chemotherapy ($t = -2.46$, $df = 34$, $p < .05$). No significant differences were found for the depression subscale of the HADS.

6.4.5. Predicting QoL and Emotional Well-Being Outcomes via HBCs

Relationships between HBCs and the outcomes (QoL and emotional well-being) at one point in time during treatment for breast cancer were provided in Study 4a. In order to provide a more direct focus for testing this interaction, hierarchical multiple regression analyses were conducted to examine whether HBCs adopted during chemotherapy can predict outcomes during the same period of time and at post-chemotherapy, as well as whether HBCs adopted post-chemotherapy can predict outcomes during the same period of time.

As with the models tested in Study 4a, in the first step of each analysis age and educational status were entered in order to control for possible demographic effects. In the second step, the treatment variables of co-morbidities, treatment type (adjuvant v's neo-adjuvant) and number of chemotherapy cycles were entered. In the final step, the five health baseline comparison factors were entered. This process was carried out to assess the predictive validity of: HBCs adopted *during* chemotherapy on outcome variables *during* chemotherapy (Time 1 → Time 1); HBCs adopted *during* chemotherapy on outcome variables *post*-chemotherapy (Time 1 → Time 2); and, HBCs adopted *post*-chemotherapy on outcome variables *post*-chemotherapy (Time 2 → Time 2).

Details of F values, Beta weights, and significance levels of predictive models are presented in Tables 6.6 – 6.10, including models to predict generic and cancer-specific QoL, as well as anxiety and depression. A separate regression was conducted with the cancer-specific QoL domain Distress over Recurrence, as HBCs were a significant predictor of this outcome in

Study 4a. Figure 6.5 illustrates all outcomes significantly predicted by HBCs adopted during and post-chemotherapy.

a) Cancer-Specific QoL

Cancer-Specific QoL during Chemotherapy (Time 1 → Time 1): A significant model emerged, explaining 57% of the variance in cancer-specific QoL during chemotherapy: $F(10, 24) = 5.51$, $p < 0.001$. Together, HBCs contributed 40% to the incremental variance. Age, entered in Step 1 of the regression, was the only demographic predictor significantly contributing to the model ($\beta = -.35$). Considering that higher QoL scores indicate greater problems within this domain, younger women tended to report worse QoL. In Step 2, co-morbidities was the only illness-related factor significantly contributing to the model in a negative direction ($\beta = -.47$). In Step 3, the largest HBC contributors to the overall model were, in order of strength of contribution, illness-specific baselines ($\beta = .43$), turning to others ($\beta = -.39$), and social comparison baselines ($\beta = .35$); all of these contributions were statistically significant. Considering that higher HBC scores represent greater endorsement of a HBC, the more illness-specific and social comparison baselines were used, the worse the cancer specific QoL. In contrast, the more turning to others when evaluating personal health status, the better cancer-specific QoL.

Cancer-Specific QoL Post-Chemotherapy (Time 1 → Time 2): When exploring the ability of HBCs adopted during chemotherapy to predict cancer-specific QoL after chemotherapy, a significant model emerged: $F(10, 24) = 3.75$, $p < 0.01$. The model explains 45% of the variance in cancer-specific QoL post-chemotherapy, with HBCs contributing 36% to this variance. Neither of the demographic variables entered in Step 1 of the regression significantly contributed to the model. In Step 2, co-morbidities were the only illness-related factor that significantly contributed to the model in a negative direction ($\beta = -.50$). When the HBCs were entered in Step 3, the only significant HBC contributor was social comparison baselines ($\beta = .45$); the more these were utilised during chemotherapy, the worse the cancer-specific QoL after treatment.

Cancer-Specific QoL Post-Chemotherapy (Time 2 → Time 2): None of the demographic, treatment-related or HBC variables entered in any of the three steps significantly contributed to post-chemotherapy cancer-specific QoL.

Table 6.6: Hierarchical Regression Analysis of Predictors of Cancer-Specific QoL Outcomes During and Post-Chemotherapy (n = 35)

Predictor	Cancer QoL 1 (T1-T1)			Cancer QoL 2 (T1-T2)			Cancer QoL 2 (T2-T2)		
	Beta	F	R^2 (change)	Beta	F	R^2 (change)	Beta	F	R^2 (change)
Step 1									
Age	-.35*	.38	(.02)	-.24	.66	(.03)	-.01	.59	(.04)
Education	-.10			-.21			-.16		
Step 2									
Treatment	.14	2.42	(.28)*	.02	1.99	(.22)	.06	.70	(.05)
Co-morbidities	-.47**			-.50**			-.12		
Cycles	.03			.10			.07		
Step 3									
Social Baseline	.32	**5.51***	**(.40)***	.44	**3.75**	**(.36)**	.15	1.06	(.28)
Social Comparison Baseline	**.35*			**.45**			.28		
Biological Baselines	.01			-.20			.15		
Illness-Specific Baselines	**.43**			.30			.06		
Turning to Others	**-.39*			-.36			-.02		
Adjusted R^2			**.57***			**.45**			.10

* p<.05, **p<.01, ***p<.001

As can be seen in Table 6.6, HBCs adopted during chemotherapy were significant predictors of cancer-specific QoL outcomes during the same period and two months post-chemotherapy. The strongest HBC contributors varied across time points, with illness-specific baselines, turning to others, and social comparison baselines utilised during chemotherapy significantly contributing to cancer-specific QoL during the same period. However, only one of these HBCs continued to significantly contribute to post-chemotherapy cancer-specific QoL: social comparison baselines. In contrast, HBCs adopted post-chemotherapy were not significantly predictive of cancer-specific QoL during the same period.

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b)   Distress over Recurrence

Distress over Recurrence during Chemotherapy (Time 1 → Time 1): Age and educational status, entered in the first step, were not significant predictors of Distress over Recurrence, nor were illness factors entered in the second step. The HBC factors entered in step 3 explained 32% of the variance ($p<.05$). Examination of the betas indicated that illness-specific baselines ($β = .423$) were the only significant contributor to this outcome and this contribution was only marginally significant ($p<.05$). The more illness-specific baselines were utilised, the more distress over recurrence. The final model was significant: $F(10, 34) = 2.74$, $p < 0.05$, explaining 34% of the variance in Distress over Recurrence.

Distress over Recurrence Post-Chemotherapy (Time 1 → Time 2): None of the demographic, treatment-related or HBC variables entered in any of the three steps significantly contributed to post-chemotherapy cancer-specific QoL.

Distress over Recurrence Post-Chemotherapy (Time 2 → Time 2): None of the variables entered in any of the three steps significantly contributed to post-chemotherapy cancer-specific QoL.

Table 6.7: Hierarchical Regression Analysis of Predictors of Distress over Recurrence During and Post-Chemotherapy (n = 35)

Predictor	Distress over Recurrence 1 (T1-T1)			Distress over Recurrence 2 (T1-T2)			Distress over Recurrence3 (T2-T2)		
	Beta	F	R^2 (change)	Beta	F	R^2 (change)	Beta	F	R^2 (change)
Step 1									
Age	-.19	.69	(.04)	-.26	1.72	(.10)	-.06	1.61	(.09)
Education	-.23			-.28			-.29		
Step 2									
Treatment	.12	1.60	(.18)	.09	1.21	(.07)	-.18	1.41	(.10)
Co-morbidities	-.36			-.22			-.19		
Cycles	-.01			-.09			.20		
Step 3									
Social Baseline	.22	**2.74***	**(.32)***	.22	1.58	(.23)	.16	1.20	(.14)
Social Comparison Baseline	.29			.34			.20		
Biological Baselines	.04			.04			-.23		
Illness-Specific Baselines	**.23***			.23			.18		
Turning to Others	-.37			-.38			.08		
Adjusted R^2			**.34***			.15			.06

*** *p*<.05, ***p*<.01, ****p*<.001**

As can be seen in Table 6.7, HBCs adopted during chemotherapy were significant predictors of the cancer-specific QoL domain of distress over recurrence during the same period, but not two months post-chemotherapy. The only significant contributor was illness-specific baselines, with greater use of these baselines predicting greater distress over recurrence. HBCs adopted post-chemotherapy did not predict distress over recurrence during the same time point.

c) Generic QoL

Generic QoL during Chemotherapy (Time 1 → Time 1): The model explained 36% of the variance in generic QoL during chemotherapy, which was of marginal significance: $F_{(10, 24)}$ = 2.92, $p < 0.05$. Neither of the demographic variables entered in Step 1 of the regression made a significant contribution to the model. In Step 2, treatment type significantly contributed to the model ($β$ = .38). In Step 3, HBCs did not significantly contribute to the overall model.

Generic QoL Post-Chemotherapy (Time 1 → Time 2): When testing the ability of HBCs adopted during chemotherapy to predict generic QoL after treatment, a marginally significant model emerged: $F_{(10, 24)}$ = 2.27, $p < 0.05$. The model explained 27% of the variance in generic QoL post-chemotherapy. Neither of the demographic variables entered in Step 1 of the regression significantly contributed to the model. In Step 2, co-morbidities was the only illness-related factor significantly contributing to the model ($β$ = -.59). In Step 3, HBCs did not significantly contribute to the overall model.

Generic QoL Post-Chemotherapy (Time 2 → Time 2): None of the variables entered in any of the three steps significantly contributed to post-chemotherapy cancer-specific QoL.

Table 6.8: Hierarchical Regression Analysis of Predictors of Generic QoL Outcomes During and Post-Chemotherapy (n = 35)

Predictor	Generic QoL 1 (T1-T1)			Generic QoL 2 (T1-T2)			Generic QoL 2 (T2-T2)		
	Beta	F	R^2 (change)	Beta	F	R^2 (change)	Beta	F	R^2 (change)
Step 1									
Age	-.25	1.42	(.08)	-.28	.66	(.04)	-.17	.67	(.04)
Education	.27			.16			.18		
Step 2									
Treatment	**.38***	**4.08****	**(.33)****	.26	**3.57****	**(.34)****	-.06	1.08	(.12)
Co-morbidities	-.37			**-.59****			-.20		
Cycles	.04			-.10			.23		
Step 3									
Social Baseline	.01	2.92*	(.14)	.20	2.27*	(.11)	-.00	1.36	(.21)
Social Comparison Baseline	.08			.11			.06		
Biological Baselines	.20			-.06			.32		
Illness-Specific Baselines	.18			.31			.35		
Turning to Others	.02			-.39			-.52		
Adjusted Total R^2			**.36***			**.27***			.26

* $p<.05$, ** $p<.01$, *** $p<.001$

As can be seen in Table 6.8, neither HBCs adopted during chemotherapy nor post-chemotherapy predicted generic QoL outcomes at either time point. However, illness-related variables predicted generic QoL outcomes. During chemotherapy, type of treatment significantly contributed to a model explaining 36% of the variance in this outcome. This protective effect of type of treatment disappeared post-chemotherapy, with co-morbidities now significantly contributing to a model explaining 27% of the variance in post-chemotherapy generic QoL outcomes.

d) Anxiety

Anxiety during Chemotherapy (Time 1 → Time 1): A marginally significant model emerged, explaining 48% of the variance in anxiety during chemotherapy: $F_{(10, 24)} = 2.23$, $p < 0.05$. HBCs contributed 29% to the incremental variance. Neither the demographic variables entered in Step 1 nor the illness-related variables entered in Step 2 significantly contributed to the model. In Step 3, the only significant HBC predictor of anxiety was social baselines (β = .28); the more these baselines were used, the more anxiety experienced.

Anxiety Post-Chemotherapy (Time 1 → Time 2): None of the variables entered in any of the three steps obtained at Time 1 significantly contributed to post-chemotherapy anxiety.

Anxiety Post-Chemotherapy (Time 2 → Time 2): No significant model emerged when examining the predictive ability of post-chemotherapy HBCs for anxiety measured during the same period.

Table 6.9: Hierarchical Regression Analysis of Predictors of Anxiety Outcomes During and Post-Chemotherapy (n = 35)

Predictor	Anxiety 1 (T1-T1)			Anxiety 2 (T1-T2)			Anxiety 1 (T2-T2)		
	Beta	F	R^2 (change)	Beta	F	R^2 (change)	Beta	F	R^2 (change)
Step 1									
Age	-.36	1.34	(.07)	.16	2.39	(.13)	.32	2.47	(.13)
Education	.06			-.32			-.50		
Step 2									
Treatment	.12	1.40	(.12)	-.02	2.45	(.07)	-.16	2.38	(.13)
Co-morbidities	-.21			.16			-.31		
Cycles	.07			.31			.41*		
Step 3									
Social Baselines	**.28***	**2.23***	**(.29)***	.32	1.16	(.12)	.43	1.75	(.15)
Social Comparison Baselines	.28			.11			.08		
Biological Baselines	.08			.07			-.05		
Illness-Specific Baselines	.23			.01			-.52*		
Turning to Others	-.20			-.09			.15		
Adjusted R^2			**.48***			.05			.16

* $p<.05$, ** $p<.01$, *** $p<.001$

As can be seen in Table 6.9, social baselines adopted during chemotherapy were significantly predictive of anxiety outcomes during the same time point. However, these baselines were not significantly predictive of post-chemotherapy anxiety. Furthermore, post-chemotherapy HBCs were not significantly predictive of anxiety during the same time period.

e) Depression

Depression during Chemotherapy (Time 1 → Time 1): None of the variables entered in any of the three steps significantly contributed to depression during chemotherapy.

Depression Post-Chemotherapy (Time 1 → Time 2): A marginally significant model emerged, explaining 27% of the variance in depression post-chemotherapy: $F_{(10, 24)} = 2.56$, $p < 0.05$. The HBCs entered in Step 3 contributed 18% to this. Neither of the demographic variables entered in Step 1 of the regression significantly contributed to the model. In Step 2, number of chemotherapy cycles was the only illness-related variable significantly contributing to the model ($\beta = .45$). In Step 3, illness-specific baselines were the only HBCs significantly contributing to the overall model in a negative direction ($\beta = -.38$); the more these baselines were utilised, the less depression experienced.

Depression Post-Chemotherapy (Time 2 → Time 2): No significant model emerged when examining the predictive ability of post-chemotherapy HBCs for depression during the same period.

Table 6.10: Hierarchical Regression Analysis of Predictors of Depression Outcomes During and Post-Chemotherapy (n = 35)

Predictor	Depression 1 (T1-T1)			Depression 2 (T1-T2)			Depression 2 (T2-T2)		
	Beta	F	R^2 (change)	Beta	F	R^2 (change)	Beta	F	R^2 (change)
Step 1									
Age	-.16	1.40	(.08)	.21	2.57	(.14)	.20	1.58	(.09)
Education	.18			-.21			-.31		
Step 2									
Treatment	.11	2.31	(.21)	-.12	2.56*	(.17)	-.14	1.13	(.13)
Co-morbidities	-.31			.02			-.49**		
Cycles	.05			.45*			.15		
Step 3									
Social Baseline	.13	1.62	(.12)	.17	**2.29***	**(.18)***	.11	1.85	(.21)
Social Comparison Baseline	.11			.15			.35		
Biological Baselines	.48			.38			.26		
Illness-Specific Baselines	-.11			**-.38***			.56*		
Turning to Others	-.20			-.04			-.26		
Adjusted R^2			.16			**.27***			.19

* $p<.05$, ** $p<.01$, *** $p<.001$

As can be seen in Table 6.10, HBCs adopted during chemotherapy were not significantly predictive of depression outcomes during the same time point, but they were predictive of post-chemotherapy depression. The strongest contributor was illness-specific baselines. These baselines, when adopted post-chemotherapy, contributed to post-chemotherapy depression, but the overall model was not significant.

Figure 6.5: Diagram Illustrating HBC Predictors of QoL and Emotional well-Being, identified from multiple regression analyses (SCB = social comparison baselines; SB = social baselines; ISB = illness-specific baselines; TTO = turning to others); * *p*<.05, **p<.01.
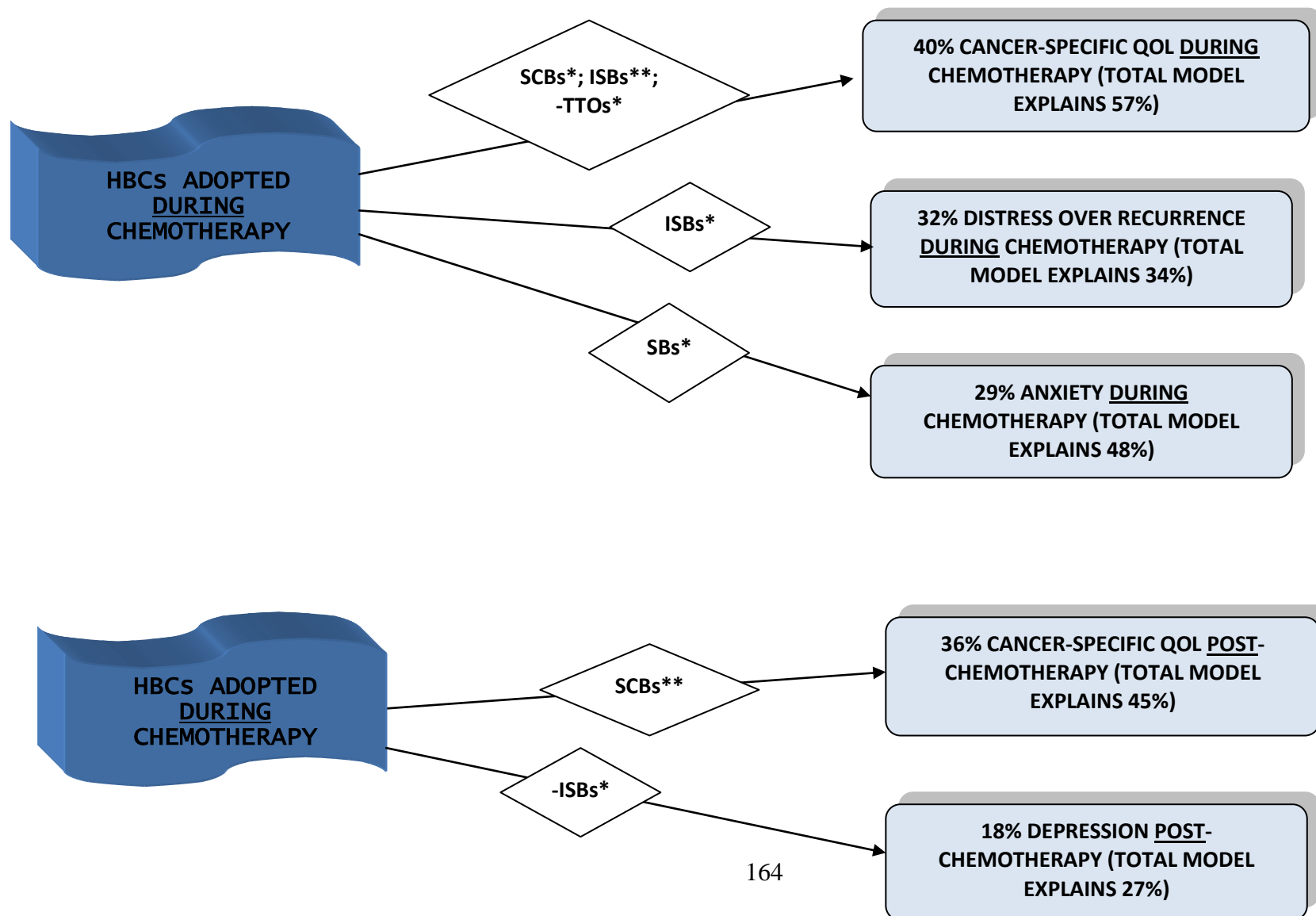
6.5. Discussion

Study 4b had several aims: 1) to compare the most frequently endorsed HBCs during a course of chemotherapy (Time 1) for breast cancer with the most frequently endorsed HBCs post-treatment (Time 2); 2) to utilise data from Study 4a to predict that HBCs adopted at Time 1 can predict Time 1 and Time 2 outcomes, and that HBCs adopted at Time 2 (post-chemotherapy) can predict outcomes during the same point in time (e.g. social comparison illness-specific baselines can significantly predict cancer-specific QoL, distress over recurrence, and anxiety). The study also examines the validity of the HBCQ (v3) in measuring HBCs cross-sectionally and longitudinally. The findings have provided insight into the salience and role of HBCs at two different time points (i.e. during treatment when the individual is a patient and post-treatment when the individual enters survivorship).

6.5.1. The Endorsement of HBCs Post-Chemotherapy Compared to During Chemotherapy

The descriptive statistics of HBCs endorsed post-chemotherapy indicated that the means were slightly higher at Time 1 than Time 2. Turning to others appeared to be more frequently endorsed during chemotherapy, whilst a mixture of social (e.g. my ability to do things I enjoy), illness-specific (e.g. treatment benefits), and biological (e.g. my healthy lifestyle choices) baselines were more frequently endorsed post-chemotherapy. Nonetheless, no statistically significant differences between mean scores on any of the HBC subscales were found. This could be because no significant difference exists or that the sample size of this study was too small. It will be necessary to study larger groups' pre, during, and post-chemotherapy in order to establish whether any significant differences exist.

It could be hypothesised that using HBCs that involve turning to others during treatment for cancer, might reduce anxiety at that time but lead to greater distress post-chemotherapy when there may not be as many people to turn to. During this time, people may need to rely on their own methods of evaluating their health status rather than seek reassurance from healthcare professionals (Cardy, 2006). Further research is required to examine this issue and the extent to which this process is related to well-being and QoL. Interventions to help people adopt more realistic health evaluations may be an option, and HBC theory might help inform such interventions. Facilitating an individual's ability to evaluate their own health status during treatment, possibly by encouraging the use of health self-management skills such as symptom monitoring or problem identification, is likely to lead to a greater sense of self-efficacy in being able to do so post-treatment. This hypothesis complements current government initiatives to integrate self-management skills into oncology; this has been extensively examined in publications by the author of this current programme of research, as commissioned by the Department of Health (Davies, 2009; Davies and Batehup, 2009; Davies and Batehup, 2010). Ways by which HBC theory might be utilised in clinical settings will be further discussed in the final chapter.

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6.5.2. QoL and Emotional Well-Being Post-Chemotherapy Compared to During Chemotherapy

No significant differences were found between the HBCs utilised during chemotherapy and those utilised post-chemotherapy, suggesting that HBCs are reasonably stable across time. However, whilst test-retest reliability for the HBC construct unidimensionally was fairly high, those for specific subscales were low (social comparison baselines = 0.46; turning to others = 0.56), suggesting that they may be more flexible to environmental change. Unfortunately, data is not available pre-diagnosis in order to detect HBCs prior to the initial diagnosis and cancer journey. Such data could prove useful in terms of identifying whether a health crisis leads to immediate HBC adjustments, or adjustments that are slower, or whether the HBCs adopted during treatment remain the same as pre-diagnosis. Furthermore, it might prove useful to consider whether patients who are slower to adjust their HBCs to accommodate chronic or life-threatening illness after diagnosis would be worse off in terms of QoL or emotional well-being.

Some evidence was found that patients' generic QoL improved after a course of chemotherapy, but the mean difference was marginally significant only. Despite improved generic QoL, the overall levels of anxiety were significantly greater post-chemotherapy than during chemotherapy. Regression data demonstrated HBCs predicted anxiety during chemotherapy but not post-chemotherapy; this may account for the additional variance and thus it is necessary to explore which other factors might be implicated. Post-treatment has been identified as a 'teachable moment' (Ganz, 2005; Demark-Wahnefried et al., 2005), where people adopt new health behaviours likely to improve generic health, and thus generic QoL. This suggests that health and QoL interventions are required post-chemotherapy. Indeed, evidence suggests that cancer survivors would like more support in terms of general health issues such as diet and exercise (National Cancer Survivorship Initiative, 2009). As the differences in QoL were marginal only, more research is needed to examine these issues in a larger sample before firm conclusions can be made. Nonetheless, as anxiety significantly increased from Time 1 to Time 2 it would suggest that this is a time where interventions might be fruitful.

When combined with the descriptive data, it is plausible that turning to others during chemotherapy might have eased anxiety and that as this HBC reduced post-chemotherapy, anxiety was exacerbated. The time of transition from active treatment to follow-up is associated with distress due to the loss of frequent medical monitoring and support, and the shift in responsibility to the individual, resulting in feelings of abandonment, vulnerability and the loss of a 'safety net' (Ward et al., 1992). Further research would be required to ascertain the validity of this hypothesis, but the literature on adjustment to survivorship does indicate that it would be worth further exploration (Cardy, 2006; Carver et al., 2006; Foley et al., 2006; Rosedale, 2009).

6.5.3. Predicting QoL and Emotional Well-Being via HBCs

HBCs adopted during chemotherapy were significant predictors of cancer-specific QoL outcomes during the same period and two months post-chemotherapy. The strongest HBC contributors varied across time points, with illness-specific baselines, turning to others, and social comparison baselines utilised during chemotherapy significantly contributing to cancer-specific QoL during the same period. However, only one of these HBCs continued to significantly contribute to post-chemotherapy cancer-specific QoL: social comparison baselines. A tendency to adopt social comparison baselines during chemotherapy may require interventions not only to improve cancer-specific QoL during this time, but also post-treatment.

In contrast, HBCs were not significant predictors of generic QoL at either time point. Treatment type significantly contributed to generic QoL during chemotherapy, whilst co-morbidities significantly contributed to post-chemotherapy generic QoL outcomes. It is rational that treatment type might be more influential in QoL during the treatment phase and that this effect might be overridden by co-morbidities after treatment has finished. Indeed, co-morbidity and the long-term consequences of cancer and its treatment are where many of survivor's supportive care needs lie (Landier, 2009). In contrast, when receiving chemotherapy the treatment dominates the patients' world, as not only are there many side-effects to cope with but the treatment is extremely time-consuming in nature.

In terms of emotional well-being, HBCs adopted during chemotherapy were predictors of anxiety outcomes during the same time point, the only significant contributor being social baselines. However, these baselines did not significantly predict post-chemotherapy anxiety. Furthermore, post-chemotherapy HBCs did not significantly predict anxiety during the same time period. A possible explanation is that the social implications of cancer and its treatment are more prominent during the treatment phase. Indeed, as discussed in Chapter 1, patients are confronted by many social implications throughout the cancer trajectory, including appearance concerns or returning to work (Luoma and Hakamies-Blomqvist, 2004; Maunsell, Brisson, Dubois, Lauzier, and Fraser, 1999).

Related to cancer-specific QoL and anxiety is distress over recurrence, with illness-specific baselines significantly explaining 32% of this outcome during chemotherapy, but not making a significant contribution post-chemotherapy. This would suggest that distress over recurrence starts soon after diagnosis, before the cancer has been treated. In other words, the women within this cohort were concerned that the cancer could not be treated and might metastasise. It is possible that illness-specific baselines contribute to this by focusing attention on symptoms specific to cancer, resulting hypervigilence. Thus, it might be beneficial to assess patient need in terms of distress over recurrence as soon as is possible within the treatment trajectory, so that action can be taken as and when problems arise, helping people to cope with the illness they do have as opposed to worrying about one they might have. For example, discussing lifestyle changes that can be made post-treatment in order to prevent cancer

recurrence is likely to focus thinking towards health and well-being as opposed to subsequent illness.

HBCs adopted during chemotherapy were not significant predictors of depression during the same time point, but they did predict post-chemotherapy depression. The only significant contributor was illness-specific baselines, suggesting that too much focus on the illness when evaluating one's health status might have implications for future emotional well-being. Interestingly, the more illness-specific baselines were utilised the less depression experienced, even though the same baselines predicted greater anxiety. Further research is required to understand this difference in direction of prediction, as well as the adaptive properties of depression versus anxiety at different points of time.

6.5.4. Comparisons between HBC Predictors during and after Chemotherapy

Chapter 5 provided cross-sectional data obtained from 45 women during a course of chemotherapy. HBCs accounted for 25% of the variance in anxiety and 21% of the variance in cancer-specific QoL. The present chapter presents both cross-sectional and longitudinal data obtained from 35 of the original sample, whereby HBCs during treatment were used to predict well-being and QoL outcomes post-treatment, and whereby relationships between HBCs and well-being outcomes measured post-treatment were also examined. In this study, HBCs adopted during chemotherapy explain 40% of cancer-specific QoL during this time and 36% post-chemotherapy, as well as 29% of anxiety during chemotherapy. This suggests that HBCs can predict well-being longitudinally.

Social comparison baselines, illness-specific baselines, and turning to others were the only significant HBC predictors of cancer-specific QoL during chemotherapy, whilst this changed to social comparison baselines being the only HBC predictor of post-chemotherapy cancer-specific QoL. Whilst social comparison baselines remained important for predicting cancer-specific QoL at both time points, illness-specific baselines and turning to others lost their predictive ability for post-chemotherapy outcomes. This might be explained by the 'sick/patient role' often experienced during the treatment process, as well as by frequent medical appointments and contact with health professionals (Haigh, 2007). It could be argued that during such a time illness-specific baselines are likely to be important influencing factors for health outcomes. Indeed, illness-specific baselines adopted during chemotherapy were predictive of distress over recurrence in both Study 4a and 4b.

Social baselines adopted during chemotherapy were the only HBCs significantly contributing to anxiety during the same period. Social benchmarks are likely to be key determinants of how personal health status is assessed (e.g. I cannot work today; I cannot attend the family dinner, etc.), and yet social benchmarks are reduced after a cancer diagnosis due to the physical, psychological, and logistical implications of the treatment process. So to continue using these baselines, which are understandably very different to pre-diagnosis, is more likely to result in negative health outcomes and a

focus on functional loss that might be temporary. Indeed, after treatment has ceased it is common for cancer survivors to find social reintegration difficult, to the extent that this has been referred to as a gap in healthcare services (National Cancer Institute, 2004). It is possible that this difficulty with social reintegration is pre-recognised, thus causing anxiety, or that the anxiety is a contributing factor to the difficulties confronted when attempting to become socially reintegrated. A valuable study would be one which examines how adjusting this baseline in women undergoing chemotherapy might reduce anxiety levels.

Illness-specific baselines utilised during chemotherapy were the only HBC that significantly contributed to depression post-chemotherapy, suggesting that intervening with illness-specific baselines during treatment might be an effective method of staving off post-treatment depression. However, further research would be necessary to test this.

Consistent with Study 4a, age and educational status played a surprisingly small and insignificant role in QoL and emotional well-being outcomes, despite evidence in the literature suggesting that age and educational status are influential in QoL outcomes (Gil et al., 2007; Knight et al., 2007). This suggests that demographic variables are less fundamental than HBCs and illness variables (i.e. treatment type, co-morbidities, number of chemotherapy cycles) in assessing or intervening with QoL outcomes in women with breast cancer who are receiving a course of chemotherapy.

6.5.5. Study Limitations

This study obtained data at two time points: during and after a course of chemotherapy. There was approximately six to eight months gap between data points. A limitation of this is that measuring two time points does not facilitate the identification of consistent patterns, but more so provides data that might indicate a pattern and thus requires further, more extensive research. In this study, the predictive ability of HBCs utilised during chemotherapy was higher than the predictive ability of HBCs adopted post-chemotherapy. A longer study period with another measurement time point, either before treatment or further into the survivorship period might have assisted in determining temporal ordering and causation of HBCs and QoL outcomes.

Another study limitation is the sample size used in this study. In the main, the contributions made to the variance in QoL and emotional well-being were marginally significant only. This could, in part, be due to the statistical techniques used in this study requiring more power and thus a larger sample size. Although a few of the HBCs, namely social comparison baselines, illness-specific baselines, and social baselines, predicted a substantial amount of variance in outcomes, the small sample resulted in low power. A larger sample and additional measurement time points could provide a deeper insight into the direction of interactions between HBCs and QoL outcomes, as well as provide a more accurate indication of the strength of these interactions. These limitations will be discussed further in the final discussion.

6.5.6. Refinement of the HBCQ (v3)

The HBCQ (v3) demonstrated satisfactory internal consistency and reproducibility throughout Study 4, with stronger internal consistency being present post-chemotherapy. The continued refinement of the HBCQ (v3) throughout this programme of research offers evidence of rigorous efforts to enhance the psychometric and operational properties of this measure.

6.6. Conclusions

Following on from Chapter 5, which presented data from participants undergoing chemotherapy, this chapter has expanded on findings by exploring differences and interactions with post-chemotherapy data. Some HBCs adopted during chemotherapy were marginally significant predictors of cancer-specific QoL (social comparison baselines; illness-specific baselines; turning to others), distress over recurrence (illness-specific baselines), and anxiety (social baselines) during the same period. Furthermore, some HBCs adopted during chemotherapy werre marginally significant predictors of post-chemotherapy cancer-specific QoL (social comparison baselines) and depression (illness-specific baselines).

The next chapter presents qualitative data obtained from a small sample of women who took part in this study. Chapter 7 presents six case studies based on semi-structured personal interviews that were based around the HBC questionnaire and designed around the individual data provided by participants. The quantitative data presented in these two chapters will be consolidated with the qualitative data from these interviews. An interpretative phenomenological approach will be utilised to analyse the qualitative data, to seek answers to questions identified from the quantitative data, with the aim of strengthening the concept of health baseline comparisons and contributing to the growing theory.

Chapter 7

Study 5: Experiences of Health Baseline Comparisons in Breast Cancer Survivors – an Interpretative Phenomenological Analysis

Chapter 6 presented longitudinal quantitative data that examined relationships between HBCs, QoL, and emotional well-being in early stage breast cancer patients during and after a course of chemotherapy. Study 5 expands on this data via semi-structured interviews with a sub-sample of the women who took part in this longitudinal study. The aim of this study was to gain deeper insight into the meanings of health and the experience of illness during the illness trajectory and explore the mechanisms by which HBCs may work over time. An individual case study approach was adopted and interpretative phenomenological analysis was utilised to analyse the data. Before presenting the details of Study 5, the findings from Study 4 will be briefly summarised, together with the relevant evidence from previous studies. This will be followed by the rationale for the present study. The findings will then be presented and discussed.

7.1.   Introduction

This programme of research has thus far provided support for the existence of five types of health baselines used in the evaluation of health status, e.g. When thinking about how healthy I am, I consider: my ability to socialise (social baselines); people who appear healthier than me (social comparison baselines); the natural ageing process (biological baselines); my prognosis (illness-specific baselines); the positive feedback from my doctor (turning to others). In particular, Study 4, demonstrated that HBCs are frequently endorsed by women with early stage breast cancer who are undergoing a course of chemotherapy. Indeed, this is where HBCs have demonstrated the greatest impact throughout this programme of research, with some of the HBCs adopted during chemotherapy being marginally significant predictors of a number of QoL and emotional well-being outcomes both during the same period and two-months post-chemotherapy.

The findings presented thus far have the potential to inform the development of QoL and emotional well-being interventions in people with cancer, and potentially those with other chronic illnesses. Nevertheless, with the exception of patient feedback in the development of the Health Baseline Comparison Questionnaire (HBCQ), the knowledge surrounding the concept of HBCs has been gained primarily via quantitative data. The theory has therefore been missing a more subjective component that could help gain further insight into the underlying dynamics of health status evaluations during and after illness.

Traditionally, assessing health-related theories and outcomes has been approached, in the main, via the use of objective clinical data or through self-report questionnaires

(Higginson and Carr, 2001). The former does not take into account subjective experiences, whilst the latter often provides little opportunity for interpretation and lacks richness. However, there has been a noticeable increase in the use of qualitative approaches within health psychology; these are more interpretive or constructivist in nature than quantitative approaches and have the potential to verify quantitative findings and add meaning to these findings. In turn, this can facilitate the building of theory via richer data that captures people's real life experiences.

7.1.1. Combining Quantitative and Qualitative Methodology

One of the key differences between quantitative and qualitative approaches to measuring subjective health status and QoL is in level of internal validity (i.e. the validity of causal inferences) and external validity (i.e. the validity of generalising inferences to real-life situations). Quantitative methods generally have high levels of internal validity, meaning that strong conclusions and often causal inferences can be made (McGrath and Johnson, 2003). This is achieved by using precise psychometrically validated measures or controlling variables via experimental conditions; thus, alternative explanations for results are controlled or excluded. However, increased internal validity can come at the cost of reduced application to real-life situations (i.e. reduced external validity). In contrast, qualitative data is usually analysed within the context of real-life, sometimes at the cost of precision and control of research variables. The benefits of this approach, however, are that examining phenomena in context enhances the identification of meanings, processes, and relationships that might be fundamental in understanding the concept being explored. It also allows richer data that captures people's real life experience to be gathered.

Despite the fundamental differences between quantitative and qualitative approaches, there has been recognition of the merits of combining the two approaches when conducting a programme of research (Yardley and Bishop, 2008). This is discussed in more depth in the introduction to this current programme of research, with emphasis being on the inclusion of a qualitative component alongside quantitative measures being useful in providing richer data to provide greater insight into the HBC concept (Chapter 1; 1.3.1.).

7.1.2. Interpretative Phenomenological Analysis

IPA will be used in Study 5 to analyse data from semi-structured interviews, which have been described as the exemplary vehicle for IPA (Smith and Osborn, 2003). The aim of IPA is to explore in detail the processes through which people make sense of their own experiences (Chapman and Smith, 2002; Smith et al., 1997). IPA is believed to have particular relevance to health psychology (Smith et al., 1999) and has been recommended for use in research concerned with *"complexity, process or novelty,"* (Smith and Osborn, 2003, p. 53). It could be argued that HBC theory fulfils all of these criteria; it is novel, complex, and also endeavours to capture a process, therefore making IPA an appropriate methodology for the current study. The appropriateness of IPA to this study is further supported by a systematic review describing studies within

health psychology that have adopted this technique (Brocki and Wearden, 2006). A number of the identified studies explore similar concepts to those included in the current study, such as subjective health (Chapman, 2002), the psychosocial impact of illness (Duncan et al., 2001), illness representations (Green et al., 2004), and QoL (Wilson et al., 2004).

IPA involves a systematic analysis of interview data, whereby five steps are followed: 1) the first transcript is read several times, with interesting or significant data being noted in the left hand margin along with preliminary interpretations; 2) any themes are identified, labelled and noted in the right hand margin; 3) emerging themes are clustered into super-ordinate (i.e. prominent) and subordinate (i.e. less prominent) themes; 4) a summary table is produced of super-ordinate and subordinate themes, with supporting quotations from the transcript; and, 5) the second transcript is read with the identified themes from the first transcript acting as a guide, but with the expectation that further themes are likely to emerge. A cyclical process is adopted, whereby new themes from each transcript are checked against previous transcripts (Biggerstaff and Thompson, 2008).

Whilst this method of analysis is systematic and revealing, it is also extremely time-consuming. Hence, studies utilising IPA tend to comprise a small sample of participants; this will be the case in the current study. In general, IPA sampling tends to be purposive as a small sample size can provide a sufficient perspective given adequate contextualisation (Smith and Osborn, 2003). In this respect, IPA differs from other methodologies, such as grounded theory, as the aim is to select participants in order to clarify a particular research question, and to develop a full interpretation of the data (Touroni and Coyle, 2002). As MacLeod, Craufurd and Booth (2002), a 'maximum variety sampling' technique will be used in the current study; participants will be selected if their HBC and QoL scores during and after chemotherapy are relatively distinct (e.g. reflecting stability or difference between the two measurement time points). This approach was taken to gather comparative information regarding the potential underlying mechanisms for HBC fluctuations, as well as the impact this might have on QoL.

Purposive sampling, in this case heterogeneity sampling, can be very useful for gaining diverse data from a target population, as well as for including examples of all potential outcomes (i.e. stable or fluctuating HBCs). The primary aim of this study is to gain a broader insight into the HBC concept and such sampling appears an effective method for meeting this aim (Trochim and Donnelly, 2007).

7.1.3. Semi-Structured Interviews

The interviews adopted to obtain data for IPA will be designed around the quantitative data provided by participants at the two time points in Study 4 (during and post-chemotherapy). For example, on presenting the mean data of HBCs and QoL, per participant, both during and after chemotherapy, differences and similarities between scores during the two time points will be used to inform the questions posed to

participants. (e.g. I can see from your responses that you used biological factors extensively during treatment, but then this reduced after treatment. Do you know why this change might have occurred and can you tell me more about this?). A standardised interview will be devised to facilitate interviews.

Semi-structured interviews are more flexible than standardised methods of research such as structured interviews or surveys (Economic and Social Data Service, 2009). Although some established general topics form the basis of an interview schedule, semi-structured interviews generally allow for the exploration of emergent themes and ideas rather than relying solely on concepts and questions defined in advance of the interview. Whilst a general format and order of questions is devised in order to allow comparisons between participants, there is also the scope for pursuing and probing for novel, relevant information, through additional questions and prompts. In turn, this increases the engagement of the interviewer in the process, which can be more comfortable for the interviewee as the dynamic is conversational rather than formal. The value of this is that participants are less likely to place limitations on the information they feel comfortable enough to share when in a more relaxed and less artificial environment (Legard, Keegan, and Ward, 2003).

The limitations to the generalisable nature of the collected data are recognised, hence efforts to increase generalisability via diverse sampling. Also, any interpretations of data will primarily be used to inform and refine HBC theory for further testing as opposed to making any generalisations. In particular, it is anticipated that this study will provide insight into potential testable HBC interventions designed for maintaining or promoting QoL during the cancer experience.

Overall, semi-structured interviews with a purposive sample of participants from Study 4, with the analysis of transcripts via IPA, meets the aims of this study, which are described next.

7.2. Aims and Objectives

The aims and objectives of Study 5 were:

➢ To gain insight into subjective experiences of health status evaluations during and after a course of breast cancer chemotherapy.

➢ To accumulate qualitative support for the HBC concept and the validity of the five HBC factors elicited within the HBCQ (social baselines; social comparison baselines; biological baselines; illness-specific baselines; turning to others).

7.3. Method

7.3.1. Ethical Approval

Ethical approval was granted by Cranfield University at Silsoe and the Hertfordshire Local Research Ethics Committee. Bedford Hospital R&D and Milton Keynes Hospital R&D provided Trust approval.

7.3.2. Sample

In keeping with the idiographic focus of IPA, where ten participants is at the higher end of most recommendations for sample size (Smith et al., 1999), five participants were interviewed. These five participants were purposively selected due to their different HBCQ and QoL responses, for example, stable responses versus changing responses or more salient use of one type of HBC compared to another. This approach was taken to diversify the potential insight gained into the HBC concept. Selection was pragmatic and convenient in that observed differences in mean responses formed the basis of selection. Participants were assigned pseudonyms of three-letters in order to maintain anonymity whilst personalising their experiences. This was achieved by taking three letters from the participants' full first name and rearranging them to for a three-letter pseudonym.

7.3.3. Interview Schedule

The interviews were predominantly guided by the participants and the areas of the HBCQ which they chose to discuss. An interview schedule was developed by the researcher and tailored to individual interviewee HBCQv3 responses and any responses to interview questions. In other words, interview questions were developed from observed changes (or lack thereof) in mean HBC, QoL and emotional well-being (anxiety and depression) scores during and after a course of chemotherapy, enquiring of the participant their personal thoughts regarding any identified changes, as described in the introduction. Probes were used to maintain the 'flow' of the interview. Interview questions are presented in Figure 7.1, with the full interview schedule in appendix Eiv.

Figure 7.1: Interview Questions

1. How are you feeling today?

2. Thank you again for completing this questionnaire. Can you tell me how you found it?

3. Was there anything in particular that you would like to discuss about the questionnaire or your answers before I go into the questions more specifically?

4. The questionnaire asked you questions about the type of things that influence how healthy you think you are. Can you tell me which of these seemed most relevant to you?
   Probe: Can you expand on this at all?

5. I can see from your questionnaire responses that you focus on (insert as appropriate, e.g. biological factors) when thinking about how healthy or unhealthy you are.
   Probe: Could you tell me a little more about this?

6. I can see from your questionnaire responses that you least focus on (insert as appropriate) when thinking about how healthy or unhealthy you are.
   Probe: Could you tell me a little more about this?

7. I can see from your responses that you used (insert as appropriate) extensively/very little, but then this reduced/increased after treatment.
   Probe: Do you know why this change might have occurred?

8. Has the way you think about your health changed since being diagnosed with cancer?
   Probe: Are there factors related to your general health that you consider now, but that you didn't use to consider?

9. I can see from your questionnaire responses that you focus on (insert as appropriate, e.g. biological factors) when thinking about how healthy or unhealthy you are.
   Probe: Could you tell me a little more about this?

10. I can see from your questionnaire responses that you least focus on (insert as appropriate) when thinking about how healthy or unhealthy you are.
    Probe: Could you tell me a little more about this?

11. I can see from your responses that you used (insert as appropriate) extensively/very little, but then this reduced/increased after treatment.
    Probe: Do you know why this change might have occurred?

12. Has the way you think about your health changed since being diagnosed with cancer?
    Probe: Are there factors related to your general health that you consider now, but that you didn't use to consider?

Figure 7.1 continued: Interview Schedule

13. Do you feel your responses to the questionnaire differed at the two points of completion?
   Probe: In what ways? How would you explain this change?

14. During your treatment, how much focus has been placed on your health?
   Probe: Would you like to see any changes in the way your general health and cancer health are approached throughout the cancer experience?

15. Do you feel that knowledge of your questionnaire responses could in anyway assist doctors in helping you either during or after treatment?
   Probe: Please explain.

16. Thank you for answering my specific questions. Are there any other issues you would like to talk about or expand on?

7.3.4. Procedure

The five participants were sent an interview invitation and a further consent form. All five people who were invited to participate in the study agreed to do so and returned the consent form.

The interviews lasted no longer than one hour and were conducted with participants either at the hospital or in their own home, depending on patient preference. Initially, patients were thanked for their participation and reminded that, as stated in their participant information sheets, they could withdraw from the interview at anytime or request breaks. All five participants agreed to the interview being recorded. For those interviews being carried out within the patients' home, safety measures were taken to ensure that the location of the interviewer was known at all times.

During the interview, participants were encouraged to refer to their completed questionnaires (HBCQ; QLACS; HADS) from Study 4. The data collected after chemotherapy is approximately two-months post-treatment. A course of chemotherapy traditionally ranges from four to six months duration (Breast Cancer Care, 2008), and so the duration between the two time points of questionnaire completion ranged from six to eight months.

On completion of the interview, patients were thanked and provided with details of support groups in the event that the interview had raised any issues they needed to discuss further. For those interviews carried out within the hospital, a Breast Cancer Nurse trained in counselling was available if needed.

7.3.5. Methods of Analysis

Each interview was transcribed verbatim before being analysed via interpretative phenomenological analysis (Smith and Osborn, 2003; Willig, 2001). This process is described in Figure 7.2. On identifying the super-ordinate and subordinate themes emerging from each interview transcript, narrative accounts were used to form individual case studies. This was followed by a shared experience narrative, where super-ordinate and subordinate themes between interviewees were merged and examined together. Transcripts were read with the aim of providing support for HBC factors as well as providing deeper insight into changes in HBCs and QoL from during chemotherapy to post-chemotherapy.

One transcript was independently themed by another health psychology researcher[6] for cross-validation purposes; an acceptable level of concordance was achieved ($K = 0.83$) (Cohen, 1968). Furthermore, narratives were presented to participants to validate the interpretation of their interview data, all of them agreeing with the initial interpretation. This method of verifying researcher interpretation has been supported for research aimed at providing insight into the subjective experiences of participants (Patton, 1999).

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[6] Holds a Masters in Health Psychology and is currently completing a PhD within the field. Areas of expertise include interpretative phenomenological analysis and thus the categorisation and analysis of qualitative data.

Figure 7.2: The Process of IPA

1) The first transcript was read several times. Interesting or significant data was noted in the left hand margin, along with preliminary interpretations.

2) Themes were identified, labelled and noted in the right hand margin.

3) Emerging themes were clustered into super-ordinate (i.e. prominent) and subordinate (i.e. less prominent) themes.

4) A summary table was produced of super-ordinate and subordinate themes, with quotations from the transcript.

5) The second transcript was read with the identified themes from the first transcript acting as a guide, but with the expectation that further themes would emerge.

6) A cyclical process was adopted: new themes from each transcript were checked against previous transcripts.

7) All themes related to the phenomenon under investigation (i.e. HBC theory) were translated into a narrative account with verbatim extracts and formed into case studies.

7.4. Results

7.4.1. Patient Narratives

Each of the following five case studies includes the demographic and medical details of each interviewee, followed by a table illustrating their mean questionnaire scores, including means for the HBC factors (social baselines; social comparison baselines; biological baselines; illness-specific baselines; turning to others), QoL (generic; cancer-specific), and emotional well-being (anxiety and depression), as measured during and after chemotherapy in Study 4. Super-ordinate themes are presented, followed by subordinate themes and any observations utilised in the interpretation of data. The five case studies are followed by a shared experience narrative, where themes shared between the five transcripts are described and discussed.

a) **Case Study One: Mel**

Name: Mel
Age: 51-60 years
Marital Status: Married
Educational Level: Undergraduate
Treatment: Bilateral mastectomy pre-chemotherapy; due to have more reconstructive surgery post-chemotherapy.
Chemotherapy Cycles: 4
Co-morbidity: Glaucoma

The mean frequency of measured HBC, QoL, and emotional well-being variables during and after chemotherapy are displayed in Table 7.1. Social baselines and illness-specific baselines were adopted more often during chemotherapy than post-chemotherapy, with quite a large difference for social baselines. The use of HBCs in general was less frequent post-chemotherapy. In turn, Mel experienced an improvement in all domains of QoL and emotional well-being, especially generic QoL and depression.

Table 7.1: Case Study 1: Mean Frequency of Outcome Variables

VARIABLE	DURING CHEMOTHERAPY	AFTER CHEMOTHERAPY	DIFFERENCE
Social Baselines	27	19	↓8
Social Comparison Baselines	3	6	↑3
Biological Baselines	21	17	↓4
Illness-Specific Baselines	22	10	↓12
Turning to Others	14	9	↓5
Generic QoL	116	50	↓66
Cancer-Specific QoL	59	47	↓12
Anxiety	8	1	↓7
Depression	15	3	↓12

Higher means represent greater HBC frequency, more QoL problems, and greater anxiety or depression; ↓ = reduction in scores post-chemotherapy; ↑ = increase in scores post-chemotherapy.

Fifteen themes emerged from Mel's interview transcript, which were clustered into five themes of three super-ordinate (i.e. resilience; treatment; information-seeking) and two subordinate (i.e. sense of social cohesion; loss).

- **SUPER-ORDINATE THEMES**

Resilience: Resilience in the form of strength was a theme that was introduced early in the interview, with Mel stating that she felt *"happy and strong."* The importance of strength and resilience in Mel's life was supported by her stating that during chemotherapy she didn't need to use social comparison baselines because *"I know my body's own strengths and weakness."* However, for Mel social comparisons appeared to become more valuable after treatment as a tool for seeing *"if my strength and fitness have returned to the levels I experienced before chemotherapy."* This suggests that in some cases illness can motivate the adoption of social comparison HBCs, an observation worth noting considering that social comparison baselines adopted during chemotherapy have been found to be marginally predictive of cancer-specific QoL during chemotherapy and a course of chemotherapy (6.4.5.a).

In this instance, however, social comparisons as a health baseline were a positive experience for Mel, for example as she remarked: *"Not only was I able to keep up with everyone [during a hike], I was actually in better shape than some of them."* There is a clear use of downward comparisons resulting in positive self-evaluations (Wills, 1981), illustrating that those social comparison HBCs termed negatively directed (e.g. comparing oneself to someone who appears less healthy) might actually be far from negative in terms of personal health status evaluations and feelings of resilience.

Resilience appeared to be a very important theme for Mel as she stated: *"I am committed to doing everything in my power to keep myself healthy and strong."* This statement suggests that physical strength and endurance are themselves an important HBC when Mel is evaluating her health status; weakness, or lack of physical resilience, of the body might signal that she is unhealthy.

Encapsulated in this theme are physical and emotional resilience. Physically, Mel places a huge emphasis on exercise. Using terms such as *"rigorous," "plenty"* [of energy], and *"active,"* Mel presented herself as someone on a 'mission' to test her physical strength, even stating that *"I feel like there are no limits to my activities"* when describing her exercise habits post-chemotherapy. Again, limitations appear to be a HBC for Mel, which in themselves indicate to her that she is unhealthy. This physical mission appeared to be motivated by a number of factors: attempts to avoid negative emotions *("During chemotherapy I was more depressed because I physically felt depleted";"positive well-being comes with an active lifestyle"*); attempts to avoid reminders of illness and cancer (*"Afterward* [treatment], *physically I felt much better, so I put illness factors behind me"*); and, fundamentally, to make up for lost time, hence the eagerness and passion in her tone.

Emotionally, Mel perceives physical resilience and happiness as being associated, as well physical weakness and depression being associated. In recognising this mind/body link, Mel states that she is *"happy and strong today,"* hypothesising that *"the negative feelings were related to the pain, fatigue, and depression I had during chemotherapy"* and *"when you have less pain and fatigue, you are much more optimistic about life in general."* When physical symptoms were not so evident, Mel began to feel better emotionally, providing her with hope, or in her own words *"I could see light the end of the tunnel."*

Treatment: Mel made frequent references to treatment, very rarely highlighting any implications of the disease itself, unless it was related to the treatment. Frequently commenting on the side-effects of chemotherapy (negatively directed illness-specific baselines), Mel indicated that *"The only thing I can attribute the depression to is the combination of surgery and a round of chemotherapy three days later."* It would be understandable for a cancer diagnosis alone to cause depression, but Mel seemed much more able to cope with this than the *"pain, fatigue, and debilitating weakness"* associated with treatment (biological and illness-specific baselines). In fact, *"When the next two rounds of chemo didn't affect me as badly, I could see light at the end of the tunnel."* Rather than the diagnosis taking away hope in the form of the *"light at the end of the tunnel,"* the physical and emotional side-effects of treatment clouded Mel's vision of the future. Mel even referred to the difficulties she faced *"resisting putting those chemo poisons in my body."* The diagnosis, in some ways, had more positive outcomes in that *"because I have faced a life-threatening shock when I got my diagnosis, I now more fully appreciate each day that I am able to live my life in good health"* (positively directed illness-specific baseline). As Mel insightfully comments, *"Cancer has a way of distilling life down to the things which are really important."* This comment is highly reflective of the benefit-finding phenomenon often reported in people who have experienced cancer (Andrykowski, Brady and Hunt, 1993; Cordova et al., 2001). It also supports the idea of positively and negatively directed HBCs being a 'mindset.' In Mel's case, thinking positively about the illness experience via positively directed illness-specific baselines seems to have assisted her in adjusting to the experience.

When asked whether either the diagnosis or treatment influenced her perceived health the most, Mel acknowledged that *"The diagnosis was a total shock to the system"* but *"It is the treatment and results of treatment that really made me feel unhealthy."* This was mainly related to the fact that *"There were no symptoms"* to the cancer, but there were many symptoms resulting from treatment side-effects. This highlights the extensive use of physical reference points (i.e. biological baselines) and symptoms (i.e. illness-specific baselines) in health judgements. A person can have a disease and not feel 'unhealthy' because biological baselines do not always alert to a problem. Similarly, treatment that is being provided to facilitate health can result in a person feeling unhealthy because of the resulting side-effects that are detected via biological HBCs. This would suggest that biological baselines are not always the most accurate indicators of actual health status.

Information-Seeking: Mel demonstrated a pro-active approach to information-seeking: *"When I first got the diagnosis, I spent hours, days, weeks on the internet getting as much information as I could about breast cancer diagnosis and treatment."* It became clear that such pro-active information-seeking was not purely to obtain information but also to distract from the *"very surreal stress-filled weeks."* Another potential motivation behind information-seeking was a need for Mel to prepare herself: *"I wanted specifics, including details about my type of cancer, all the latest research paper findings, and explanations about my test results." "Not that this information gives me any more control over my situation, but it really helped me to understand what I was facing and why . . . and what I should expect."* Mel clearly needed answers to questions about the 'unknown,' with uncertainty being a commonly reported experience after a cancer diagnosis (Brashers, 2001; Penrod, 2007). Information seemed Mel's best way of obtaining answers and easing some of the uncertainties she was confronted with. It is also worth noting that Mel was not seeking basic or lay information but *"all the latest research papers and findings."* This challenges the concept of keeping academic and clinical data for professionals and more basic simplified

information for patients. Indeed, Mel was very proud of the depth of her cancer knowledge, sharing details about causal factors of cancer and referring to *"epigenetic changes in our bodies"* and *"the cumulative effect of exposure to a chemical."* *"Knowledge, for me, is power,"* Mel explained; *"It helped me to make informed choices."* Indeed, information-seeking confirmed for Mel that *"Now I know that I have done all I can to prevent cancer recurrence."* Mel presented herself as being very much the 'expert patient' for which the NHS is striving to promote (DH, 2009b).

- **SUBORDINATE THEMES**

Sense of Social Cohesion: Sense of social cohesion within society was a recurring theme within Mel's transcript, with Mel confirming the importance of being able to *"engage"* with society in her response to a question regarding the most important influencing factor in her health judgements: *"Health issues which affect my ability to do things I want to do and the enjoyment I get out of being with family and socialising are important."* Furthermore, when thinking about changes in health outcomes during and after chemotherapy, namely improved QoL (both generic and cancer-specific) and emotional well-being (both anxiety and depression) post-chemotherapy, Mel noted that such changes would have been due to her being *"able to more fully participate in living my life"* post-chemotherapy; during chemotherapy her sense of social cohesion was limited by the fact that *"when I was feeling and looking miserable, I didn't want to be around lots of people or go to social functions."* Mel is now participating in social activities more than post-diagnosis, eagerly sharing that *"I feel healthy enough to walk 60 miles over three days in September to raise money for breast cancer research."* When probed as to the personal gains of participating in such an event, Mel adds further to the super-ordinate theme of resilience: *"Participating in a physically demanding event proves to me that I am strong again and makes me feel healthy."* Both participation and strength are evidently important HBCs for Mel. When asked to expand on the role of participation within society in her perceived health status, Mel explained how *"I wasn't able to carry out my usual activities"* and how *"As I have always been a very strong, self-sufficient, and independent woman this made me feel unhealthy and frustrated at my loss of control."* Sense of social cohesion or ability to engage with society, as a way of evaluating health status, thus seems related to routine, independence and control; all of those aspects of 'being' that create autonomous and self-directed individuals.

Loss: The loss of present and future health was important within Mel's transcript, possibly linked to her use of past illness (negatively directed biological HBC), as reflected in the HBCQ. Stating that *"I have never been sick in my life,"* Mel highlighted her use of past well-being as a baseline for evaluating her present ill health, resulting in an incongruence and unfamiliarity of the illness experience and the 'sick role.' This evidently had a negative impact on Mel's emotional well-being as *"I had no patience (with myself) for not feeling well"* as well as clouding the future in that *"I couldn't imagine living with pain, debilitating weakness, and depression."* Using a positively directed biological baseline, like past good health as opposed to past illness (the difference being in mindset and 'framing'), Mel might have been more inclined to use the fact that she has extensive past experience of good health as beneficial in terms of her future health potential.

Mel does, however, demonstrate HBC adjustments through her comment that *"Afterward* [chemotherapy], *physically I felt much better, so I put illness factors behind me."* Placing cancer in the past allows Mel to live in the present and plan for the future: *"I am looking*

ahead to a full and bright future" and *"I am also enjoying living in the moment much more."* This might provide one explanation of the significant increase in generic QoL post-chemotherapy (6.4.4.b), when a focus returns to the future as opposed to the belief that there is no future. If she was to continue focusing on past illness (i.e. the cancer), it is likely that Mel's perception of *"I expect to live a long and active life"* would not exist. This highlights the importance of helping people with cancer to adjust HBCs to the present once they are in remission, so that they can focus on the future as opposed to the past, and on gains as opposed to losses: Mel feels that *"except for this cancer diagnosis, I am very healthy – low BMI, low blood pressure, low cholesterol."* However, it is important to note that the cancer experience should not be completely neglected as present health behaviours and choices require knowledge of risk of recurrence and personal actions to reduce such risks.

OBSERVATIONS: Mel was very enthusiastic in her speech, adopting a positive and colourful language (i.e. use of words such as 'full,' 'bright,' 'long' [future], etc.). She appeared to be emphasising and absorbing the positive, possibly in order to overshadow any negative experience (for which she did admit to experiencing), sounding somewhat defensive.

From Mel's perspective, it does appear that prior to cancer Mel had a health-orientated (positively directed/framed) HBC and that this became illness-orientated during treatment, returning to health-orientated post-treatment. When this was proposed to Mel, she agreed that *"I think I am very health-oriented and always have been"* and that during treatment *"Maybe I seemed to be paying more attention to ill health because I'm not used to it."* It could be argued that the flexibility in Mel's HBC, as evidenced in her reduced need for social comparisons and illness-specific baselines post-treatment, has contributed to her ability to distinguish that *"Even if you have a terminal illness, your mind can allow you to feel healthy and fulfilled, if you are at peace with yourself and your life."*

b) <u>Case Study Two: Lou</u>

Name: Lou
Age: 51-60 years
Marital Status: Married
Educational Level: Postgraduate
Treatment: Surgery (lumpectomy) and radiotherapy pre-chemotherapy
Chemotherapy Cycles: 6
Co-morbidity: None

The mean frequency of measured HBC, QoL, and emotional well-being variables during and after chemotherapy are displayed in Table 7.2. All HBCs were minimally reduced post-chemotherapy, with social comparisons showing the greatest reductions. In fact, whilst Lou used social comparison baselines during chemotherapy she didn't use them at all post-chemotherapy. Generic QoL improved slightly post-chemotherapy, whilst cancer-specific QoL appears to have worsened slightly; overall QoL remained relatively stable, as did anxiety. A small increase in depression post-chemotherapy is evident, although depression levels are low at both time points.

Table 7.2: Case Study 2: Mean Frequency of Outcome Variables

VARIABLE	DURING CHEMOTHERAPY	AFTER CHEMOTHERAPY	DIFFERENCE
Social Baselines	22	18	↓4
Social Comparison Baselines	9	0	↓9
Biological Baselines	14	10	↓4
Illness-Specific Baselines	11	10	↓1
Turning to Others	10	7	↓3
Generic QoL	65	57	↓8
Cancer-Specific QoL	38	45	↑7
Anxiety	5	5	0
Depression	0	1	↑1

Higher means represent greater HBC frequency, more QoL problems, and greater anxiety or depression; ↓ = reduction in scores post-chemotherapy; ↑ = increase in scores post-chemotherapy.

Eleven themes emerged from Lou's interview transcript, which were clustered into four themes of two super-ordinate (i.e. sense of social cohesion; resilience) and two subordinate (i.e. engaged clinician; generic health versus cancer-specific health).

- **SUPER-ORDINATE THEMES**

Sense of Social Cohesion: Like Mel, sense of social cohesion was a prominent theme within Lou's transcript, perhaps because *"the more I can do, the better I feel."* For Lou, social cohesion and participation within society is multifaceted, including: present day participation (i.e. *"the more I can do, the better I feel")*; future participation (i.e. *"I had time to train with my project for next year's fair"),* emphasising hope for the future rather than a morbid preoccupation; and participation in the cancer experience (i.e. *"I seem to have a brighter attitude during chemo, like yes we are doing something"*).

Lou demonstrates positive affect outcomes of participation/social cohesion and negative affect outcomes of perceived lack of participation. Social cohesion is also a fundamental health baseline for Lou in that *"I know I'm healthy because I can still make a difference."* When probed about her definition of 'making a difference,' Lou described it as *"contributing to the common good, helping others."* If she cannot contribute to society and is not useful to society, then she is unhealthy and thus not useful within the macro system. This might explain the quantitative data demonstrating that social baselines adopted during chemotherapy were the strongest HBC predictor of anxiety during the same time period (5.4.5c). When social cohesion is so important to a person's sense of health and well-being, the social implications so common with cancer treatment (1.8.4.) are an understandable cause of anxiety.

Smiling, a form of social interaction, is linked to social cohesion within Lou's transcript, indicating to Lou that *"I can still enjoy, my mind is sharp, body's pretty good . . . I can smile because I can do the things I love."* Smiling is an important health indicator for Lou, both emotionally and physically. If she was lacking physically or mentally in a way that impacted her sense of social cohesion, it is likely that she would not be able to smile and this would be her personal indicator of being unhealthy; hence, this is why it is incorporated into her medical consultations (see 'Engaged Clinician' below). In this sense, smiling fits into the HBC framework.

Lou encapsulates the importance of sense of social cohesion in the following quote: *"Life is a puzzle; let's solve it. Situations are a game; let's solve them."* She wants to be involved in the challenges of life, not be a passive bystander. Interestingly, Lou's search for a sense of social cohesion is evident in her use of social comparison baselines. Whilst Lou claims that *"I judge my health on how I feel not so much on those around me,"* her transcript is dominated by social comparisons, perhaps reflecting her self-confessed *"competitive nature."* Viewing herself as *"a bit different"* from other people, Lou proudly professed that *"I tend to be a bit more tough than some of my peers"* and proceeds to share situations that have tested her physical resilience but where in her words *"another person would have been in bed for a week."* Lou also describes herself, with pride, as being *"a bit of an 'abnormality . . . because chemo doesn't seem to bother me,"* again highlighting her 'toughness' compared to others. As with Mel, there appears to be some defensiveness.

On closer observation of the transcript, it appears that Lou doesn't so much evaluate her health status against other people but more so her coping. With this in mind, and taking into consideration data obtained from the HBCQ at two points in time, it is likely that although Lou frequently refers to social comparisons she is correct in her perception that she does not

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compare her health to that of others. Lou's social comparison activities are much more evident during chemotherapy than afterwards, perhaps because prior to her cancer diagnosis *"I really don't have a true peer group for comparison."* It appears that it isn't until Lou developed cancer and was confronted with a peer group that she adopted social comparison baselines. Indeed, peer modelling and social comparisons have recently been integrated into self-management programmes for cancer survivors due to evidence that they can enhance adaptive coping (Davies and Batehup, 2010).

On the other hand, Lou does actively avoid situations that might influence social comparisons or remind her of her condition, firmly stating that *"I stay away from 'sick' people,"* clearly categorising herself as the opposite (i.e. healthy). It is possible that this is because Lou thrives off being different from others and yet being around sick people reminds her of her own mortality – *"all life is temporary"* and *"no one gets out alive."* Over all, any social comparisons that Lou does actively seek are downward comparisons, allowing her to maintain a sense of superiority and strength in the face of adversity (Wills et al., 1981).

Resilience: Closely integrated into the theme of social comparisons was resilience. Lou described herself as having a *"bull like temperament,"* which she validated externally by indicating that *"my chemo nurse used to call it 'farmer temperament' – she'd say you could put acid in a farmer's veins and the next day they would be out on the tractor."* Lou appeared to be very keen to demonstrate her own resilience and ability to *"not let little things get you down."* It could be argued that this was her way of coping with lack of control; this is exemplified by her statement, *"you play the cards you are dealt . . . you can't change some hands, you just have to live with it and make the best."* This belief mirrors a strongly internal health locus of control (Wallston, Wallston, and DeVellis, 1978), whereby Lou accepts the responsibility of living the best she can under the circumstances. It is likely that an individual's health locus of control will impact the type of HBC adopted, for example whether one turns to others or makes their own health judgments, raising an area for further investigation.

Lou not only expects resilience from herself (i.e. *"unless I can't crawl, I'm up and around"*), but also from others (i.e. *"unless they are in the final throes of death . . . I want to tell them to get off their duff and do something for themself"*). Resilience is so important to Lou that a perceived lack of it implies personal weakness that she firmly states that *"if they are showing weakness instead of true sickness, they pretty much disgust me."* This is a powerful statement to make and appears to be related to QoL as the previously expressed attitude towards 'weakness' is substantiated further by stating that her quality of life has been enhanced by a similarly strong attitude of *"not sitting on the pity pot."* This 'no-nonsense attitude' begs the question of whether Lou allows herself to experience the natural emotional turmoil that so often comes with a cancer diagnosis. Instead, there appears to be a huge amount of defensiveness. Using the ability to smile to assess her health status (i.e. *"I know I'm healthy because I can still smile"*) may superficially increase QoL, but the context of Lou's transcript infers that there is almost a personal pressure to smile and remain resilient.

- **SUBORDINATE THEMES**

Engaged Clinician: Lou makes it clear on one hand that *"I don't take a doctor's word as law,"* but also clear that *"with my doctor's help my lifestyle has become even more healthy."* This suggests that Lou wants to work with her doctor as part of a team rather than merely accept the doctor's word as 'law.' Lou utilises the baseline of turning to others, but also turns to herself. In fact, Lou clearly has a very collaborative and communicative relationship with her doctor, making statements such as *"my doctor knows me and knows unless I can't crawl, I'm up and around"* and *"Dr L and I have talked about this and we believe . . ."* As with the 'expert patient' initiatives previously discussed, 'co-creating' health (i.e. patient/doctor partnership) is another government priority (Coulter and Ellins, 2006), for which Lou appears to be actively demonstrating in her approach to her health and healthcare.

It is possible that Lou's trust in her doctor's lifestyle advice is related to her perception that *"his work is his definition of being"* and the fact that she can relate to this because *"the same could be said for me."* Their relationship is likely to also be enhanced by the interesting observation that Lou's doctor appears to be sensitive to her personal health baselines during consultations. As an example, Lou's personal baseline of *"I know I'm healthy because I can still smile"* is utilised within the consultation when *"we even use this as a benchmark, one of my doctors will ask 'life still funny?' and if the answer is 'yes' we go on to the business at hand; if 'no', he asks what's wrong."* This demonstrates the potential application of HBC theory within a clinical setting and would be worth exploring further. It also indicates that clinicians might instinctively use the patients' personal baselines for evaluating health status, maybe unconsciously grasping what is normal and not normal for a patient. In this instance, Lou describes such a doctor-patient relationship as *"we look at strategy and tactics for maintaining and preserving my good health while keeping my cancer load to a minimum."*

When asked if her doctor uses any other personally-relevant and important benchmarks during consultations, Lou says *"He checks in on how my job is going, how work is doing. He knows my three important areas: husband, work, and horses."* This style of communication makes Lou feel that *"He treats me as if I have a brain, which is wonderful."* Using HBCs within the clinical setting appears to have contributed to the development of a collaborative partnership between doctor and patient whereby *"We go through differential diagnosis and look at test results together. He educates me about what to look for in blood work."* This is important if healthcare advice is to be consistent with a patient's health cognitions.

Generic Health versus Cancer-Specific Health Distinction: Lou makes a clear distinction between the cancer and her general well-being, keenly highlighting this distinction during the interview. This implies an attempt to illustrate that there is more to her than cancer. This distinction is evident from the first question when Lou talks about her day, sharing that *"sometimes if I am low, and it happens occasionally, not just from breast cancer but from life in general, a few minutes on the farm puts things in focus."* When explaining how she has found herself resting more since her diagnosis, Lou theorises that *"who's to say if that is cancer-related or just normal aging, or even me getting a bit smarter."* These quotes in particular suggest that Lou is keen to resist attributing any physical or emotional symptoms to cancer; it appears that she needs to keep a distance from the cancer and not allow it to define her. Using a variety of HBCs when evaluating why she might be resting more enables Lou to have options beyond this being a sign of ill health. In fact, when discussing the difference between the two points of questionnaires completion, in particular a decrease in positive feelings post-chemotherapy, Lou's first reaction is *"not related to my cancer."* However,

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this statement does illustrate that although Lou must maintain a distinction between her cancer experience and general life experience, she is willing to own her experience, referring to it as *"my cancer."* Putting this within the context of the entire transcript, Lou has referred to the cancer as a *"demon we* [herself and the doctors] *had to go against"* and thus maintaining the distinction described here appears to have an important role in allowing Lou to keep this *"demon"* segregated to one aspect of her life.

When probed as to the importance of maintaining this self-imposed distinction between her general and cancer-specific health, Lou shared that *"I had a life before cancer and I will continue to have a life."* This suggests that without this distinction Lou would be handing her life over to the cancer. On the other hand, keeping a barrier between her general and cancer-specific life appears to empower her to still enjoy life rather than have it dominated by the cancer experience. The distinction also allows Lou to be grateful for the fact that *"I am truly blessed because I have always been a healthy person. I have a serious form of cancer, but am still healthy."* In contrast to Mel, who used negatively directed biological baselines (i.e. past illness), Lou uses positively directed biological baselines (i.e. past health), which seems to have emphasised her ability to achieve and maintain health as opposed to being taken over by illness; the cancer is but one example of a challenge to her extensive past experience of health. Lou is evidently not using the cancer as a HBC and thus can identify strengths in her health: *"The distinction between general and cancer health keeps me grounded, focused and keeps me from being an alarmist."*

OBSERVATIONS: Lou demonstrated a number of personal HBCs which allowed her to make a distinction between her generic and cancer-specific health status, even to the extent of using particularly important personal HBCs in collaboration with her doctor and thus guiding the consultation. The interview also emphasises the importance of not defining a person solely in relation to their cancer experience.

Lou's transcript suggests a health-oriented approach to life (i.e. a reliance on positively directed HBCs), which Lou agreed with when asked. She also felt that *"this orientation has gotten stronger"* in that the cancer experience has resulted in some changes: *"I eat better and research more. I talk more openly about concerns with my team of doctors. It's coming naturally to me."*

Interestingly, Lou referred to the HBCQ as a 'tool,' stating that *"the tool actually helped me put a few things in focus."* When probed as to whether she felt such a tool could be implemented within the clinical setting, Lou was very enthusiastic, stating *"Most definitely, it would help people focus, define for themselves what is important."* This is highly encouraging for the potential future utilisation of the HBCQ in QoL interventions.

c) **Case Study Three: Kay**

Name: Kay
Age: 41-50 years
Marital Status: Married
Educational Level: Postgraduate
Treatment: Surgery pre-chemotherapy
Chemotherapy Cycles: 8
Co-morbidity: Polycystic Ovary Syndrome (i.e. cysts on the ovaries), and high blood pressure and cholesterol.

The mean frequency of measured HBC, QoL, and emotional well-being variables during and after chemotherapy are displayed in Table 7.3. All but one variable (social baselines) showed a minimum decrease post-chemotherapy, social comparison baselines, illness-specific baselines, and Total QoL more so. No large changes are evident in QoL, although it does slightly improve in all domains post-chemotherapy. Depression also seems to reduce slightly post-chemotherapy.

Table 7.3: Case Study 3: Mean Frequency of Outcome Variables

VARIABLE	DURING CHEMOTHERAPY	AFTER CHEMOTHERAPY	DIFFERENCE
Social Baselines	25	25	0
Social Comparison Baselines	8	2	↓6
Biological Baselines	21	19	↓2
Illness-Specific Baselines	24	15	↓9
Turning to Others	15	12	↓3
Generic QoL	85	79	↓6
Cancer-Specific QoL	67	61	↓6
Anxiety	10	9	↓1
Depression	5	2	↓3

Higher means represent greater HBC frequency, more QoL problems, and greater anxiety or depression; ↓ = reduction in scores post-chemotherapy; ↑ = increase in scores post-chemotherapy.

Eleven themes emerged from Kay's interview transcript, which were clustered into five themes of two super-ordinate (i.e. sense of social cohesion; loss) and three subordinate (i.e. treatment; generic health versus cancer-specific health; information-seeking).

- **SUPER-ORDINATE THEMES**

Sense of Social Cohesion: Kay's transcript suggests that one of her greatest challenges in terms of the cancer experience was the impact that treatment side-effects had on her self-identity and her sense of social cohesion with others. Kay shares that *"I thrive on routine and being myself"* and that *"Not feeling well enough to follow my normal routine (work, etc.) impacts how I see my health every day."* Sense of social cohesion is so important to Kay in terms of her health that the ability to maintain a routine that shapes her identity is utilised most frequently as a way of evaluating health statues, rendering social comparison HBCs, in Kay's opinion, useless*: "I'm not sure I see the point in comparing myself to other people . . . it really only matters what I feel and what it means to me and my health."* Nevertheless, Kay did still adopt social comparison HBCs to some extent during treatment, with a positive outcome:*"Comparing my side-effects during chemo with others helped me to realise what I was going through was normal"* as well as providing reassurance that *"there are many women who have gone through similar experiences as me and have survived a long time afterwards."* Replacing the lost 'normality' of routine with a new 'normality' of daily treatment side-effects appeared to be an effective method of maintaining a sense of health. Furthermore, rather than upward social comparisons resulting in feelings of inferiority, they assisted Kay in focusing on survival rather than mortality. This, again, could be related to mindset, with Kay using positively directed social comparisons and illness-specific baselines to assess her health status.

These quotes also suggest that during periods of uncertainty, such as during cancer treatment, those who are not prone to social comparison HBCs are more likely to utilise them during these periods. Indeed, this is consistent with the interpretations made from Lou's transcript (Case Study 2) and the literature that outlines the use of social comparisons among people who are under threat (Gibbons and Gerrard, 1991; Wood, Taylor, and Lichtman, 1985; Wood, 1989).

Loss: The theme of loss is mainly referred to in terms of mortality and thus a loss of life and future. Kay recognises that *"life does not last forever"* and this subsequently presents many implications in terms of her customary future-oriented thinking. Acknowledging her own mortality, Kay states that *"I get a little more apprehensive of a serious illness cutting it* [her life] *short,"* an apprehension that results in *"having a serious illness, symptoms and prognosis are going to be highly important to me* [when evaluating her health status].*"* Kay appears to be so focused on her future, or perceived lack of future, that she is overcome with health anxiety. It could be argued that Kay's anxiety prevents her from adopting a baseline that enables her to monitor her health effectively. She does not have a stable or reliable HBC that she can trust and thus is in a continuous state of health anxiety, with her statement that "*it is always in the back of my mind to look for symptoms of more serious problems"* reflecting the hypervigilance that can result from an over-emphasis on biological baselines, as observed in previous studies within this programme of research (Study 4a; 5.5.2.).

Whilst Kay is apprehensive about the future, she also finds hope in the healing powers of time and her belief that *"It will take time for everything to return to 'normal'."* In fact, it appears that Kay hopes time will completely erase the cancer experience: *"it will feel like the past year never happened at all."* She also does not want her cancer experience being assimilated into her future; she wants to leave it behind, to the extent of completely eradicating it from her life. It appears that she wants to replace her perceived loss of a future, with a loss of anything to do with the cancer experience.

- **SUBORDINATE THEMES**

Treatment: As with Mel (Case Study 1), Kay's transcript suggests that she had more difficulty coping with the treatment than the cancer itself. Whilst discussing *"being sick from treatments,"* she also notes that the *"cancer showed up with no symptoms at all."* Kay's questionnaire responses suggest that she utilised illness-specific HBCs more during treatment than afterwards, and when probed on this she clarifies that *"I was feeling more noticeable illness factors during chemo"* and *"When it's all over it's easy to not think about that stuff anymore."* Thus, it appears that not only can treatment side-effects be utilised to evaluate health status, but so can the practicalities of having treatment. In other words, merely having treatment is a reminder of illness.

In terms of other issues surrounding treatment, Kay highlights how treatment has interrupted her routine and the implications this has had on her health: *"Unfortunately I had to put a hold on exercise and my weight and general well-being has suffered because of that."* This indicates a worsening of general health due to a focus on cancer-specific health. This raises the question of whether helping people with cancer to focus on aspects of their general health might help them cope better, as was the case with Lou (Case Study 2) who expressed a need to distinguish between the two in order to maintain an identity beyond the cancer. There is also the danger that focusing on cancer-related health might encourage the development of other forms of illness. Kay has high cholesterol and blood pressure, a precursor to coronary heart disease (CHD), which may be compounded with lack of exercise and weight gain, highlighting the importance of cancer not overshadowing these other health issues.

Generic Health versus Cancer-Specific Health: Kay presents two distinctions that are important to her, a) between the physical and mental, and b) between general and cancer-specific health. The former distinction is presented on commencing the interview, with Kay reporting how she is *"Physically feeling ok, mentally feeling so-so."* The differentiation between general and cancer-specific health, as also noted by Lou (Case Study 2), was the more prominent distinction made by Kay: *"I feel my general health is separate from the cancer-specific problems"* and *"Non-cancer issues take a backseat to cancer issues during treatment. Now that's pretty much done I have to focus on my non-cancer health issues."* As noted in Case Study 1 with Mel, this quote provides some insight into factors other than illness that might explain the increase in generic QoL post-chemotherapy (6.4.4.b), this being the implications of, understandably, much of the focus being on cancer-specific health during treatment.

Information-Seeking: Kay demonstrated three methods of information-seeking, one being via social comparisons, one being via personal research endeavours, and the other being via online support groups. In the context of the transcript, Kay made social comparisons to gather information pertaining to side-effects of chemotherapy, stating that referring to others helped her see that *"many other people had the same effects."* In this instance, Kay appears to be using other's side-effects as a baseline for evaluating her own side-effects, combining social comparison and biological HBCs in an effort to 'normalise' her experience. The personal research was motivated by the fact that *"I did a lot of research on my own to answer questions I may have had"* and the online support group provided a similar function: *"I also subscribed to an online support group . . . That helped a lot with questions and concerns."* Utilising a variety of information-seeking strategies, Kay felt well informed and could not

think of any other information that would have helped her during or after her diagnosis and treatment.

OBSERVATIONS: Whilst Kay expressed great efforts at seeking information that would facilitate her understanding and coping, it is questioned as to whether she was utilising the most helpful and reliable information available. Carrying the common misbelief that *"Unfortunately I had to put a hold on exercise and my weight . . . [during treatment],"* Kay had very little control over maintaining a sense of health and well-being during the cancer experience. She did not refer to health professionals having any involvement in her information-gathering endeavours and thus closer collaboration with her care team might have increased Kay's health literacy and sense of control. Evidence is growing that closely monitored and tailored lifestyle interventions, such as exercise or changes in diet, can be implemented during treatment and can, in fact, have positive clinical and patient-reported outcomes (Davies and Batehup, 2010; Thomas, Davies, and Batehup, 2010).

d) <u>Case Study Four: Nia</u>

Name: Nia
Age: 41-50 years
Marital Status: Married
Educational Level: Postgraduate
Treatment: Lumpectomy pre-chemotherapy.
Chemotherapy Cycles: 8
Co-morbidity: Lyme Disease (i.e. an infection from a tick bite).

The mean frequency of measured HBC, QoL, and emotional well-being variables during and after chemotherapy are displayed in Table 7.4. Nia's HBCs remained relatively stable throughout the two measurement time points, as did her QoL. However, moderate improvements in anxiety and depression are evident.

Table 7.4: Case Study 4: Mean Frequency of Outcome Variables

VARIABLE	DURING CHEMOTHERAPY	AFTER CHEMOTHERAPY	DIFFERENCE
Social Baselines	26	24	↓2
Social Comparison Baselines	8	10	↑2
Biological Baselines	16	17	↑1
Illness-Specific Baselines	17	19	↑2
Turning to Others	12	9	↓3
Generic QoL	117	115	↓2
Cancer-Specific QoL	75	70	↓5
Anxiety	12	3	↓9
Depression	13	8	↓5

Higher means represent greater HBC frequency, more QoL problems, and greater anxiety or depression; ↓ = reduction in scores post-chemotherapy; ↑ = increase in scores post-chemotherapy.

Seven themes emerged from Nia's interview transcript, which were clustered into five themes of three super-ordinate (i.e. loss; negative affect; treatment) and two subordinate (i.e. sense of social cohesion; engaged clinician).

- **SUPER-ORDINATE THEMES**

<u>Loss:</u> Nia feels that *"cancer has diminished my opportunities and my time"* through the fact that she feels *"not quite well enough"* to partake in those activities that she would like to. When prompted to expand on the meaning of 'well enough,' Nia clarifies that *"I want to be able to do all that I was able to do before, and I see these diminished opportunities as lack of health."* She indicated that the cancer has diminished *"enjoying social activities and doing*

things I like." The treatment has meant that *"I was not able to spend time with friends, travel, go to meetings for work, do activities with my kids and generally do the little fun things of life."* This sense of diminishment, or loss, appears to have seeped into numerous areas of Nia's life, from how she feels, to time with friends and family, and even into her working life, leading Nia to emphasise *"how isolated the cancer patient can become."* This feeling of isolation might account for the sense of social cohesion sought by the previous interviewees and as sought by Nia (see subordinate themes).

There are also frequent references to diminished health, with Nia being keen to emphasise that although she doesn't *"feel well,"* she doesn't exactly feel 'ill': *"I do not necessarily feel awful, just not quite well enough"; "while I still have some longer-term side-effects, I can truly say that I feel fine."* When probed about the meaning of 'fine', Nia demonstrates her use of biological and social HBCs: *"Hmm . . . I am not in any major pain* [biological], *I can work* [social], *I can take care of my kids* [social and biological], *I don't have any significant symptoms* [biological] *. . . I am fine."* Drawing on HBCs in this multidimensional way appears to be effective in helping Nia feel better, or in her words, to feel 'fine.' It is almost as though she has a checklist of personal health indicators that she can 'tick' off. In contrast, focusing on one HBC, as is the case when describing how she is *"not quite well enough,"* it could be interpreted that Nia sets herself up for failure; using her past abilities as a HBC leaves very little scope for adjustment to changes in health status. There is a suggestion that even if she ticks the boxes of no symptoms, can work, etc. there is some meta-feeling of not being quite right that she cannot attribute to anything specific.

Interestingly, Nia indicated how *"You lose this ability to enjoy some of the little things in life because the focus is on the big things, and the little things kind of slide back. However, sometimes these little things really define quality of life better than the big things."* In this sense, it might be that a focus on the little things, which are overshadowed by the cancer experience, could facilitate coping, adjustment, and QoL.

Negative Affect: Fear and anxiety are prominent themes within Nia's transcript and she is very descriptive about where these fears are directed: *"I think there is a lot of fear going into treatment – fear of the unknown, fear of the side-effects of treatment, fear of being unable to recover."* This quote in particular encapsulates fear of the known (i.e. possible side-effects) and fear of the unknown (i.e. possible remission), indicating how information and knowledge can create just as much fear in some people as lack of knowledge. Nevertheless, the unknown appears to contribute more to the fear and anxiety since even with the knowledge of potential side-effects, Nia was unaware of which of those side-effects she might experience: *"Going into chemo I was well aware of potential side-effects but I had no idea how much it would affect me overall. I was very anxious about the negative possibilities."* Nia also illustrates how the fear and anxiety she experienced were primarily related to treatment rather than the actual cancer diagnosis, echoing the other interview transcripts: *"Those feelings diminished for me after treatment since I was able to handle it all fairly well."*

Treatment: As with the majority of interviewees, Nia places a big emphasis on her treatment experience, explaining how the treatment regime impacted her life on a number of levels. She notes that *"there is a lot of fear going into treatment"* but that *"everything went fairly smoothly."* Of most impact were the logistics: *"Managing the day to day reality of doctor's appointments and health insurance can be overwhelming, especially when somebody doesn't feel well as during chemo . . . these logistics can take up a lot of time and become extremely stressful."* Much of this stress seemed to be related to *"having to spend most of my time on*

treatment or treatment-related side-effects.” These logistical problems interfered with Nia's social life and made her feel isolated from friends, family, work, and hobbies. Nevertheless, Nia remains hopeful: *“I would let people who are just starting their treatment know that this is all very doable.”*

- **SUBORDINATE THEMES**

<u>*Sense of Social Cohesion*</u>*:* When describing the implications of cancer, Nia refers to how *“well meaning people, friends and relatives, have a hard time visualising how isolated the cancer patient can become”* and how *“few people think of jumping in and helping with simple things like doctor's appointments, going out for coffee or dinner, or even simple shopping.”* When expanding on this feeling of isolation, Nia explains that *“I don't think it affects my sense of health, but it does affect the sense of well-being in terms of quality of life when undergoing treatment and not feeling well.”* Similarly, for friends and family to provide small gestures such *as “go with me to the park or bring over a video and popcorn,”* the same role applies: *“I think none of these actions would actually affect how healthy I feel, but they would make me feel better.”* Social support appears to have an important protective role in Nia's QoL or ability to cope with feeling ill by preventing the loss of social cohesion so often encountered by cancer patients, as demonstrated in the other case studies as well as within the literature (Rosedale, 2009).

<u>*Engaged Clinician*</u>*:* Nia pays particular attention to her belief that *“I had a great team of medical professionals along the way”* and comments on how *“My trust in medical team has made a huge impact in relieving stress and anxiety.”* This is important to note due to anxiety (negative affect) being a super-ordinate theme in Nia's transcript. The support of a medical team evidently helped ease some of Nia's anxiety, which is reassuring considering that even with this she has expressed feeling a great deal of fear and stress; this is likely to have been worse without the support of a medical team who Nia feels *“have my best interest in mind and take good care of me.”*

OBSERVATIONS: Nia was not as forthcoming as the other interviewees and needed prompting to expand on her answers. This appeared to be due to her 'holding back' and not being explicit in the issues discussed, hence her explanation of how *“I do not necessarily feel awful, just not quite well enough”* as though this somehow takes away from the validity of her comments. Perhaps there is a lack of confidence or a desire to put on a 'brave face' or, alternatively, she may have had no more to say.

Of particular interest was Nia's inability to answer questions pertaining to which parts of the HBCQ were most relevant to her and whether she felt her responses to the HBCQ changed over time. This might indicate a lack of interaction with the HBCQ not evident with the other interviewees. It would be interesting to explore whether this also reflects a lack of interaction with her health and well-being, or an external locus of control.

e) Case Study Five: Liz

Name: Liz
Age: 41-50 years
Marital Status: Single
Educational Level: Undergraduate
Treatment: Bilateral mastectomy pre-chemotherapy.
Chemotherapy Cycles: 6
Co-morbidity: Developed a blood clot in the groin post-chemotherapy.

The mean frequency of measured HBC, QoL, and emotional well-being variables during and after chemotherapy are displayed in Table 7.5. As with the previous case study, Liz presents relatively stable means across time points. She used social baselines and illness-specific baselines slightly more post-chemotherapy, whilst her use of biological baselines decreased slightly post-chemotherapy. Her cancer-specific QoL remained the same, whilst her generic QoL improved a little. The greatest improvement post-chemotherapy is in depression.

Table 7.5: Case Study 5: Mean Frequency of Outcome Variables

VARIABLE	DURING CHEMOTHERAPY	AFTER CHEMOTHERAPY	DIFFERENCE
Social Baselines	14	19	↑5
Social Comparison Baselines	6	6	0
Biological Baselines	14	9	↓5
Illness-Specific Baselines	9	15	↑6
Turning to Others	8	8	0
Generic QoL	102	96	↓6
Cancer-Specific QoL	71	71	0
Anxiety	9	7	↓2
Depression	16	9	↓7

Higher means represent greater HBC frequency, more QoL problems, and greater anxiety or depression; ↓ = reduction in scores post-chemotherapy; ↑ = increase in scores post-chemotherapy.

Twenty-eight themes emerged from Liz's interview transcript, which were clustered into five themes of three super-ordinate (i.e. loss; resilience; negative affect) and two subordinate (i.e. sense of social cohesion; treatment).

- **SUPER-ORDINATE THEMES**

Loss: The central theme throughout Liz' transcript is that of loss; loss of control, independence, future plans, security, and choice. The main loss she expresses is in controlling and directing her own life course: *"Having to be at appointments, having to have tests,*

having to deal with side-effects. I was in what I call my robot mode. I had schedules to meet and I was told 'go here, go there,' and I did." In a sense, Liz lost her identity, as clearly highlighted in her observation *that "the specialists are focused on the tumour, the cancer, the treatment . . . there just happens to be a person attached to those."* This is fitting to Shontz' (1975) sequence of reactions post-diagnosis, as discussed in 1.8.3., which includes a stage of shock manifested by behaving in an automatic fashion and experiencing a sense of detachment from the situation.

The transcript suggests that Liz feels as though she has no choice but to follow certain regimens and 'obey' doctor's orders. She evidently does not like this *"robot mode,"* but it becomes so familiar to her that when it diminishes after chemotherapy she feels lost and abandoned: *"How I describe it is like being in a row boat with only one oar. You can paddle as fast as you want but you are still only going in circles with no direction and nobody to help you find that direction."* This feeling of abandonment is frequently reported in the survivorship literature, especially during the period of transition from cancer 'patient' to cancer 'survivor' (Cardy, 2006; Manicom, 2010). The cancer diagnosis and subsequent treatment appears to have removed the control Liz had over her life at that time, but also diminished her perceived ability to control and direct her life effectively once she had completed treatment, hence her question of *"What the hell am I supposed to do now?"*

The loss of direction expressed by Liz extends to her revising her future plans: *"I used to dream about what I would do once I retired"* (note the past tense). Sadly, *"My planning for the future has become clouded with 'will I be there . . . ?'"* However, when considered in context, the transcript does demonstrate efforts to regain some of the control that has been lost: *"While I cannot change the fact that I may die of cancer, I can try to change the strength of my body by doing walking and Aqua Fit."* This sense of regaining some control in the direction of her life seems empowering for Liz: *"I've fought cancer . . . Nothing, no embarrassment of my physical body, no embarrassment of my weakened stamina will prohibit me from doing what I want. No longer will I be governed by what I 'should'."* This quote implies a sense of freedom and empowerment, particularly freedom from the constraints of modern society (e.g. body weight, expectations of others).

Nevertheless, all of these perceived losses have left Liz *"grieving over the losses of the last year."* She may not have lost someone through death, but her transcript suggests that part of herself and her life has died throughout the cancer experience; she is going through a period of bereavement. The grief expressed by Liz supports research cited in 1.8.3., whereby Kubler-Ross' (1970) stages of grief are discussed in terms of adjustment to cancer. In considering these stages of grief (e.g. denial; anger; bargaining; depression; acceptance), it might be interpreted from Liz' transcript that she has experienced the depression associated with the process. It would be interesting to investigate whether HBCs play a role in progression through these stages, and this is a possible avenue for future research. Can some HBCs speed up the grieving process or assist in coping with the grieving process? Is it possible that they might also facilitate denial?

Liz expresses some anger over her lack of control throughout the cancer experience, anger notably being one of the stages of the grieving process (Kubler-Ross, 1970). On explaining how others have commented on her bravery, Liz firmly states how such comments make her feel: *"I just want to smack them. I am not brave, I am not courageous. What other options did I have?"* Liz makes it clear that she did not have a choice over developing cancer and thus does not feel that bravery is something she had a choice over either. Interestingly, Liz

feels that health is controllable whilst illness is not: *"health is a proactive activity and illness is a reactive activity,"* illustrating the potential for helping patients focus on health throughout the illness experience (i.e. focus on what they do feel they have some control over). There is also the potential for educating people about those areas of illness that they can, to some extent, control such as illness prevention and illness self-management. After all, as has been demonstrated here, when Liz enhances her perceived control over her health via exercise classes, she does feel much more empowered and less at the mercy of the cancer. Prior to this *"With cancer, you are somewhat needy which was very hard for me. I wanted to be the independent person that I was before cancer and I could not always do that. For me, this was humiliating."*

Resilience: Liz describes cancer as *"the beast"* and her body as *"the vessel that betrayed me."* In turn, she describes chemotherapy as a *"poisonous onslaught,"* an onslaught from herself and the doctors in the fight against the *"beast"* and the body that *"betrayed"* her. Liz states that *"I felt that the chemo was my most potent act of fighting the cancer . . . during chemo you are in a fight with a bunch of doctors watching your every move."* In this sense, the doctors are personified as being Liz' army and the chemotherapy their weapon. Any side-effects, no matter how unpleasant, were merely a sign that the weapon was effective: "*I think that I came to a place where the bald head was reality and was evidence that the drugs were doing what they were supposed to be doing."* This demonstrates how adapting HBCs to changes in health might facilitate adjustment to cancer. The appearance-related HBC (biological baseline) of a bald head would usually be a sign of ill health, whilst within the chemotherapeutic environment it can be a sign of treatment, of fighting the illness in an effort to improve health.

This team effort against the 'beast' also seems to provide an explanation for the negative affect post-chemotherapy: *"I think that during the active part of the journey each milestone to the end of the treatment was positive. However, when I was on my own without medical people watching my every move, my every bodily function, I felt like I was in a black hole."* Without her 'soldiers' and her 'weapons,' Liz struggles to cope post-chemotherapy. Her descriptions create a vision of a battle field, the cancer patient fighting for her survival. The survival instinct is encapsulated in the following quote: *"After chemo we are again permitted to sense our body. This sensing is heightened by our new knowledge that cancer may come back."* Just as a soldier *"We now know that we have to be extra vigilant."* These extracts highlight the potential utility of post-chemotherapy interventions aimed at facilitating people with cancer to adjust their HBCs, or re-establish a HBC, in order to enable them to monitor their health and well-being without the medical input gained during treatment.

The fact that Liz lives alone appears to be an important motivation to remain strong and resilient: *"I live alone and thus, I felt I had to remain independent, I had to keep up the strong and confident one."* Interestingly, those interviewees who had family appeared fearful of becoming dependent on their family. In contrast, it appears that being alone can result in fear that there is no one around if the battle for independence is lost.

Negative Effect: On commencing the interview by asking Liz how she is feeling today, her response was *"I am tired and somewhat distracted."* As the interview transpired it became clear that Liz was experiencing depressive symptoms. Not only did she identify this directly in her statement that *"I have become significantly depressed after the end of treatment,"* but the depression is also evident in her description of post-chemotherapy being *"a black hole to an extent"* because *"I have to guard what I say to whom."* Indeed, other people's reactions

to the cancer appear to make her feel unable to express her negative affect: *"every now and then I'd just like to have someone say 'this just isn't fair and you have been through hell.' I am not superwoman and every now and then I just need to be a wimp and not preset the face of strength and everything is alright."* In this sense, the pressure to follow the *"script running through my head about what I should gauge and what I should say"* not only prevents Liz from sharing her negative affect but in some ways also contributes to it.

To place the depression into context, it seems to be highly related to Liz's perceived pressure to achieve benefit-finding from the cancer experience, a pressure that is extremely prevalent (Ehrenreich, 2010): *"Where is that gift of cancer? People talk about everyday being a gift . . . I didn't feel that."* As if to cope with this lack of 'gift,' Liz later refers to it as *"the wives tale of the gift of cancer."* Rather than *"The infamous 'they' speak of never being so alive as after they had cancer, never being so happy as after cancer"* Liz has found that the experience has made her reflect on what she hasn't got in life: *"I do not have children, I do not have a family; I am solely alone. There is nobody when I walk through the door that truly asks 'how was your day?'"* On the other hand, people around Liz *"are telling me that I have changed because of this experience. That I am more open, more vulnerable and more willing to say what I want rather than just going with the crowd."* Hence, the 'gift' may be apparent to others but not the person with cancer, leading Liz to contemplate that *"Maybe the gift is not in a nice neat package, but comes like a puzzle . . . over time and with trying pieces that don't fit and having to keep searching until you find the piece that fits appropriately into your puzzle."* Since Liz uses the *"ability to be happy"* as a HBC, her depression is likely to be impacting on her current health perceptions, perhaps making her feel worse. Fortunately, she is having treatment: *"I chose to go to a counsellor who specifically works with cancer patients."*

As well as depression, the transcript also clearly highlights an anxious preoccupation that started post-chemotherapy when *"I now had time to reflect and say 'huh, what do you mean I might die?'"* This provides further insight into the quantitative finding that anxiety significantly increases post-chemotherapy (8.4.4.c). On describing her post-chemotherapy mindset, Liz describes being overwhelmed by questions: *"After chemo it was a black hole to an extent. Did the chemo work? Did it do its job? What were the lingering affects? Would the neuropathy go away? How long until I got hair? What about my blood clot?"* Liz is not only confronted with psychological anxiety in the form of a bombardment of questions, but she is also confronted with physical anxiety: *"I think most survivors struggle, especially in the first couple of years, with every ache, every cough being a fear that the beast is back."* This quote is interesting for two reasons. Firstly, despite her self-reported depression Liz does see herself as a *"survivor"* rather than a victim. Secondly, Liz appears to use other cancer patients to justify her own anxious preoccupation with physical symptoms.

Over all, the general message from Liz appears to be that the treatment process is so overwhelming that it isn't until afterwards, when things have slowed down, that people with cancer *"now have time to think and to have your mind play the games."* Just as Liz believed her body had betrayed her, she also seems to have lost trust in her mind, feeling as though it is playing games with her and making her anxiously preoccupied.

The potential reasons for this anxious preoccupation are consistent with Leventhal's self-regulatory model of illness, discussed in 1.1., Liz referring to the *"new knowledge that cancer may come back; we felt fine before and still got cancer."* This challenges the notion of being able to assess one's health status effectively since, as Liz and many of the other

interviewees have pointed out, the cancer can be asymptomatic. It also challenges the individual's self-efficacy in terms of being able to assess their health status. If something as serious as cancer managed to develop, what chance do they have detecting other illnesses? This doesn't stop Liz from trying though, hence the anxious preoccupation: *"We now have to be vigilant and listen to our bodies. We are listening, sometimes to the point of feeling like a hypochondriac."* This preoccupation is also reflected in representations of illness severity. When presented with symptoms, Liz asked herself *"Was it pneumonia or did I have lung metastasis?"* Liz went on to share that *"And yes, it was only pneumonia,"* reflecting that *"Funny how pneumonia was a good thing."* Illness severity representations have shifted due to the cancer experience, with something as serious as pneumonia being a relief as opposed to something to fear. This, perhaps, highlights that there can be no reliable baseline to detect cancer.

The anxious preoccupation also manifests itself in activity restriction and avoidance with Liz stating that she has *"less confidence in making plans, even for next week. What if I fall asleep?"* There appears to be a constant stream of worry, *"worrying about recurrence, worrying about making it to next year"; "I am having tingling in my legs – is that normal? I have blotchy red spots on my face – is that normal?"* As demonstrated throughout the transcript the majority of anxious preoccupation concerns cancer recurrence and mortality. As Liz so articulately shares, *"I think that we all know, in our minds, that we will die. However, I have now been hit over the head with that knowledge as more than an abstract joke – like death and taxes."*

- **SUBORDINATE THEMES**

Sense of Social Cohesion: When asked which was the most personally significant health baseline in the questionnaire, Liz contemplates *"Hmmm, likely the ones related to work"* and explains that *"Given that I am a driven individual, and single, my work reputation and my work forms much of my sense of satisfaction and self."* In context with the entire transcript, work appears to define Liz' health not only in terms of the activity itself but also in terms of the resulting social network: *"My social network is critical to my emotional well-being. While time alone is important, my well-being as a human is strongly linked to outside of my home."* Liz refers to *"frustration around not being able to return to my profession because of side-effects"* and also to her *"lessened freedom because of income,"* indicating that financial circumstances are also important in terms of Liz's perceived health status. It could be interpreted that when Liz is earning money, she has more freedom, and thus feels happier and healthier; earning one's own money could be viewed as an important element of independence.

Interestingly, work becomes more negative as Liz shares her story, whereby during treatment she was *"trying to keep stress down by not working"* and also later contemplating *"I think that cancer and the potential of death leads one to reflect on their life. Was my job good enough? No, it wasn't, but what else would I do? I don't know."* This begs the question of whether stress levels are a sign of health for Liz, and when probed about this she does clarify that *"I wouldn't say healthy, but may say alive."* It appears that if she isn't stressed, she doesn't feel 'alive' or enthused by life, and thus she perceives herself to be unhealthy. She goes on to explain that *"Work is a familiar stress and provides some level of comfort in itself that it is familiar and both my mind and my body will recognise it,"* indicating unfamiliar stress as a determinant of illness.

Although work dominated Liz's references to activities of daily living, she did refer to other activities. For example, on explaining why she utilised biological baselines more after chemotherapy she states that *"At this point I had to focus on merely getting stamina enough to do housework, to get to the shopping and to be able to sustain some sort of normal activity in my daily life."* This demonstrates a, perhaps, automatic HBC adjustment in terms of current health priorities. Work was Liz's main HBC pre-chemotherapy, but to maintain this post-chemotherapy would, arguably, not have been effective or health-orientated. Liz needed to re-evaluate her health benchmark in line with the physical changes resulting from chemotherapy.

***Treatment*:** Describing the cancer diagnosis as *"somewhat abstract and unseen,"* Liz describes how treatment side-effects are a greater problem for her. *"The side-effects are, or can be, long-term and immediate . . . having no hair, being fatigued, unable to concentrate are immediate and in the here and now"* whilst the cancer itself *"is still not a visible and tangible notion."* In this context, treatment side-effects make the cancer a reality to both the person with cancer and others: *"People around me react both visibly and with words as regards to my side-effects."* The treatment side-effects also appear to impact on health baselines, Liz stating that *"it feels like you are on alert to a 'what side-effects' list. We are provided drugs to deal with nausea, drugs for nerve pain, drugs for bone pain, drugs for . . . . . whatever."* It is likely that potential side-effects become a health baseline before they are even experienced, the patient becoming sensitised or primed to certain symptoms, to the extent that they can no longer adequately listen to their body: *"It felt like while yes, I needed to tell my medical team the side-effects but . . . that only after the onslaught of medical people, scanners, blood tests, MRI machines, heart tests . . . was I able to take a deep breath, to relax and to actually ponder what my body was doing – absent the chemo running through my body, absent the drugs to deal with side-effects, absent the radiation burn and such. Without all the drugs, without all the poking and prodding, how did it feel?"* Although patients, of course, need information on potential side-effects it is arguable that the focus should be on facilitating patients to listen to their own bodies via their personal HBCs as opposed to being hyper-vigilant to potential side-effects.

OBSERVATIONS: Interestingly, Liz often spoke in the third person, as though distancing herself from the experience. She also often referred to *"we,"* as though justifying her own thoughts and feelings via using the plural to suggest that others feel the same way and thus she is expressing a consensus. Indeed, the transcript reads as though Liz is telling the listener a story, something from the past, possibly in an effort to distance herself from the experience and *"pretend that all this did not happen,"* something Liz openly admits to trying to do. On the other hand, there is a growing awareness of the role that narratives (e.g. storytelling) can play in helping people cope with cancer since they can be used to objectify and distance oneself from problems in order to gain understanding, establish meaning, develop greater self-knowledge and decrease emotional distress (Carlick et al., 2004; Hoybye et al., 2005). It might be that Liz is, perhaps unknowingly, reaching out for meaning.

Liz appears to be relatively illness-orientated (i.e. frequently using negatively directed HBCs), but when asked her orientation she states that *"I think before, that I really did not think about it at all and only dealt with illness issues should they arise. Maybe having to consider what is going on with my body has changed the thought from illness prevention to health maintenance."*

Further support has been obtained for the content validity and respondent acceptability of the HBCQ, with Liz indicating that *"It was better than many questionnaires I have seen before in that it asked some relevant daily issue questions."* When asked if she felt it could be useful in clinical practice, Liz said that *"I am not sure that it would be helpful to oncologists and surgeons"* whilst interestingly noting that it may be useful for her GP as a *"generic follow-up – in order to maybe ask timely questions and to earlier address potential depression issues."* This is an interesting suggestion that might facilitate current initiatives to move cancer follow-up into primary care via patient-initiated referrals, which would ultimately require additional support for GPs (Davies and Batehup, 2009).

7.5. Synthesis of Case Studies – The Shared Experience

When combining the five case studies, eight themes emerged, four of which were super-ordinate and four of which were subordinate:

Table 7.6: Super- and Sub- Ordinate Interview Themes

Super-Ordinate Themes	Subordinate Themes
Sense of social cohesion	Generic versus cancer-specific health
Resilience	Negative affect
Loss	Engaged clinician
Treatment	Information-seeking

The strongest theme to emerge was that of 'Sense of social cohesion,' with all five interviewees referring to this as a baseline used when evaluating health status. 'Loss' and 'Treatment' closely followed, as did 'Resilience.' The subordinate themes emerging within the group were 'Negative affect,' 'Generic versus cancer-specific health,' 'Engaged clinician,' and 'Information-seeking.' Of particular interest was the interpretation that the four super-ordinate themes all appear to be utilised as indicators of health status, whilst the four subordinate themes appear to be related to health baselines in a more dynamic way. For example, it appears that negative affect can be either an outcome of health baselines or a health baseline in itself. In terms of generic versus cancer-specific health, this theme appears to influence the choice of HBC, with some participants using different HBCs to evaluate distinct aspects of health status.

An example of a super-ordinate theme can be seen in transcript five where Liz uses sense of social cohesion to gauge her well-being: *"My social network is critical to my emotional well-being. While time alone is important, my well-being as a human is strongly linked to outside of my home."* An example of a subordinate theme being a mechanism underlying health baseline formation is demonstrated in transcript three, where Kay uses information gained from social comparisons to evaluate certain treatment side-effects as being the 'norm' rather than something of concern: *"many other people had the same effects."*

Each of these themes are outlined below, with a more in-depth exploration within the discussion.

7.5.1. Super-Ordinate Themes

Sense of Social Cohesion: Sense of Social Cohesion was a theme that emerged in all five transcripts, most notably in the form of interviewees referring to their level of participation or belonging in society as being an indicator of their health status. For example, it appeared that the more they felt able to contribute to society in the form of employment, socialising, volunteering, etc., the healthier they judged themselves to be. In this sense, a feeling of usefulness appears to be related to perceived health status, perhaps drawing links to research on ageing and the sense of loss of social cohesion often experienced by the elderly

or retired (Cannuscio, Block and Kawachi, 2003). In fact, a key benefit obtained from cancer support groups is the establishment of a sense of acceptance and belonging, in contrast to the isolation often experienced outside of the group (Ussher et al., 2006). In terms of this research, reverse causality might play a role in that people who are healthier are generally more able to participate socially, similar to the healthy worker effect (Li and Sung, 1999). Nevertheless, in the context of the transcripts, the utilisation of social integration as a benchmark for health assessments appears to be a valid interpretation.

Implicit in the theme of sense of social cohesion was the use of social comparison HBCs, which appeared to act as an attempt to achieve a sense of belonging in new and challenging health circumstances. Two of the interviewees (Kay and Lou) claimed that they did not use social comparisons to evaluate their health status, but then go on to provide evidence of such cognitions during and after chemotherapy. This is consistent with literature demonstrating that people are often reluctant to admit they compare themselves to others (Wood et al., 1985; Wilson and Ross, 2000), although others have suggested that some people do genuinely just lack an interest in social comparison information (Hemphill and Lechman, 1991).

In summary, the literature acknowledges the common use of upward and downward social comparisons in people with cancer, as outlined in 1.5.2., but the theory that these comparisons are a method of reaching health judgements that facilitate a sense of social cohesion is novel.

Loss: The prominence of personal loss as an indicator of health status was multifaceted, with the case studies illustrating the extent to which loss impacts on perceived health status. The transcripts highlight an overwhelming sense of loss in many different spheres of self and life; almost any loss appears to lead to a diminished sense of health, be this loss of something from the past (i.e. familiar routine), present (i.e. social network), or future (i.e. long-term goals). Whatever the loss might be, it is plausible to infer that a process of grieving will be required, hence the depressive symptomology experienced by some of the ladies who were interviewed. This sense of bereavement and subsequent emotional distress might, however, be indicative of health and well-being, or a step towards improved well-being. According to Freud, a healthy adjustment to loss via the grieving process requires a certain amount of struggle and emotional turmoil (Freud, 1957).

Resilience: Resilience emerged as an important way of maintaining a sense of health whilst in the grips of disease. Metaphors were used that invoked war against a disease that is attacking the body, in many ways being synonymous with the more established concept of 'fighting spirit' (Greer, 2000). Resilience was clearly an important component of self-image for some of the ladies who were interviewed and if they didn't see themselves as resilient their sense of self was destroyed, as was their sense of health and well-being. One interviewee, Lou, was reliant on her resilience to emphasise her independence from the 'sick role' that she perceived other people to belong to.

Yet, at the same time, resilience could be interpreted as being a health baseline that is 'socially-inflicted' or socially desirable, creating feelings of ill health when perceived resilience is low and feelings of despair are high. In turn, this might result in denial of sadness and despair in order to avoid the potential feelings of deteriorating health that might

accompany these feelings. The transcripts do suggest that to express such emotions would be a sign of weakness, of giving up, and of succumbing to the disease as opposed to fighting it.   A poignant example of this dissonance between externalised resilience and internalised despair is demonstrated in a comment by Liz: *"every now and then I'd just like to have someone say 'this just isn't fair and you have been through hell.'*

Treatment: Interestingly, treatment side-effects were more frequently utilised as an indicator of health than the cancer diagnosis was used. A possible explanation for this is that a person can have cancer and feel fine until undergoing treatment; the medical profession induce symptoms via treatment, raising implications in terms of people losing self-efficacy in their ability to evaluate their health status. Another key issue here is hyper-vigilance to physical sensations, where people are not able to trust their bodily sensations (due to their cancer being initially asymptomatic). This questions the role of HBCs in this context as there can be no baseline for something that is not tangible. As such, this may cause distress as people may be searching for a pre-existing baseline and be anxious as this is not possible.

This also illustrates the influence of biological baselines in evaluating health status; evaluating health during treatment, when physiological indicators are present, seems to be more frequent and have more impact than pre-treatment evaluations of health status when less physiological factors are evident. Illness-specific baselines in the form of treatment benefits and side-effects were in the top ten most frequently endorsed HBCs during chemotherapy (5.4.3.), with treatment benefits being the second most frequently endorsed HBC post-chemotherapy (6.4.3.). The increase in treatment benefits and reduction in treatment side-effects as health status benchmarks post-chemotherapy is likely to reflect the decrease in physiological indicators that are induced during the treatment process. Further research with a specific focus on the role of treatment on health status evaluations is likely to provide some valuable insight into the natural reliance on biological baselines and the implications of treatment-induced side-effects on this.

7.5.2. Subordinate Themes

Generic versus Cancer-Specific Health: The theme of generic versus cancer-specific health was an interesting phenomenon, since many health status and QoL measures already make this distinction. The transcripts demonstrated how when using HBCs, some people will evaluate their generic and cancer-specific health separately and use different HBCs for each. Indeed, this appears to be a way in which some of these women managed to hold onto perceptions of health whilst fighting an illness: *"I am truly blessed because I have always been a healthy person. I have a serious form of cancer, but am still healthy"* (Lou).

This distinction between different dimensions of health is an important finding for clinical practice, since after cancer treatment one of the biggest challenges is helping cancer survivors to adopt a healthy lifestyle (Thomas, Davies, and Batehup, 2010). One participant expresses how post-treatment she found herself trying to amend those aspects of her general health that she had placed to one side while prioritising her cancer-specific health: *"Unfortunately I had to put a hold on exercise and my weight and general well-being has*

suffered because of that" (Kay). Maintaining her general health as best she could while undergoing cancer treatment might have offered Kay some sense of control over her health and well-being. Incorporating issues around general health into care plans might empower patients to focus on some of the strengths in their health, as well as making return to health easier once treatment is over and they are confronted with some of the long-term effects of cancer treatment (Ganz, 2001).

There appears to be a general belief that whilst undergoing cancer treatment, lifestyle choices need to focus on the cancer, leaving general health a relatively neglected area of cancer recovery. Clinicians rarely discuss general and lifestyle-related health through fear of burdening the patient (Ganz, 2005). However, the evidence suggests that patients would value such input from diagnosis onwards (DH, Macmillan Cancer Support, and NHS Improvement, 2010b).

Negative Affect: The theme of negative affect was related to the often traumatic experience of cancer and treatment. In particular, HBCs involving the super-ordinate themes of social devaluation, loss, treatment side-effects, and societal pressures pertaining to resilience appeared related to negative affect in the form of anxious preoccupation and depressive symptomology. This is where hyper-vigilance again arises, potentially as a cause and outcome of negative affect. If this interpretation of the data is correct, then an understanding of the HBCs utilised by people with cancer could play an important role in facilitating coping and thus improving psychological well-being.

Importantly, negative affect may also be a HBC in its own right as people may make health judgements based on their feelings of happiness and sadness. Indeed, Lou and her doctor often evaluated her health and well-being via her ability to smile, demonstrating the importance of assessing the psychological well-being of people with cancer during consultations. Psychological support is a frequently reported unmet need, yet it can play a fundamental role in identify physical needs and concerns that the patient might have (Armes et al., 2009). A more holistic approach to cancer care is needed, as highlighted in the recent 2010 Cancer Vision document (DH, Macmillan Cancer Support, and NHS Improvement, 2010b).

Engaged Clinician: Whilst having an engaged and patient-centred clinician was not a health baseline in and of itself, it did appear to play an important role in the formation of HBCs (i.e. via information provision) and the efficacy of HBCs. There was a tendency for at least one clinician to use the patient's personal health baselines to assess her needs for that particular consultation, and this approach was highly valued by the patient in question, Lou. In many ways, this approach empowered Lou by making her feel like she was part of a team. She was especially grateful for being made to feel like a person with thoughts, feelings, and the capability to receive and use information provided to her. This approach will be explored further in the final discussion of this thesis as a potentially feasible application of HBC theory during a time when the 'expert patient,' patient-centred care, and the patient/clinician partnership are all government priorities (Coulter and Ellins, 2006).

Information-Seeking: Information-seeking appeared in a variety of formats – seeking written information; asking questions of healthcare professionals; turning to others to evaluate one's health status; making social comparisons; and searching the internet. This supports

evidence suggesting people with cancer want to be informed, as opposed to passive bystanders in their healthcare (Coulter and Ellins, 2006). In many ways, information-seeking emerged as an important component of health baseline comparison theory, with health baselines or the establishment of the most appropriate baseline being another mode of information-seeking. Information based on past experience or information obtained from others who have experience with a particular illness, symptom, or treatment, is needed in order to form a health baseline and evaluate personal health status. In this sense, the need or desire to evaluate health status via HBCs is an important motivator in seeking health-related information.

7.6. Discussion

This study aimed to gain insight into subjective experiences of health status evaluations during and after a course of breast cancer chemotherapy, as well as to elicit qualitative support for the HBC concept and the five core HBC factors. This was achieved at an individual level and a group level with five purposively selected breast cancer survivors who took part in Study 4b (Chapter 6). Semi-structured interviews were used to elicit the experiences of these women, whilst interpretative phenomenological analysis was used to contextualise and add meaning to their experiences.

The HBC concept has been considerably expanded, highlighting the value of using qualitative data to complement quantitative findings. Furthermore, the novel method of using an individualised schedule whereby data obtained from patients at different time points can be used to provide a framework to interviews to will elucidate the illness process.

This discussion highlights the expansion of the HBC concept, as well as presents evidence pertaining to the five HBC factors elicited via the HBCQ, including changes in HBCs over two points in time: during and post-chemotherapy. Subsequently, changes in QoL and emotional well-being are also discussed. Insight gained from the subjective experiences of HBCs and QoL, as provided within and between case studies will be included throughout the discussion. The potential utility of these findings in healthcare settings will be described, as will any research limitations. The implications of the findings of this study, together with the other four studies that form this thesis, will be discussed in the final chapter.

7.6.1. The Validity of the HBC Concept

- *Social Baselines*

The dominant theme of sense of social cohesion is consistent with social baselines. Sense of social cohesion emerged within all five interviews and was important to sense of physical and emotional well-being. This supports the later addition of a social component to the original HBCQ (4.1.1.b). Nevertheless, sense of social cohesion as a HBC went beyond ability to work and socialise, as encapsulated via social baselines, but reflected a need to be able to participate fully within society in a way that was perceived as useful and productive. It is believed that the social baselines measured within the HBCQ might not currently reflect the sheer importance of sense of social cohesion in making health status evaluations and

thus further exploration of this clearly influential health baseline is warranted. It might be that whilst a questionnaire would be useful, using the HBC framework through which patients can explore their individual HBCs and elaborate on the factors might offer greater utility.

Evidence was found that social baselines tended to be more salient during chemotherapy than afterwards, possibly indicating that social aspects of health are more pertinent during this time. It could be argued that social baselines are less accessible during treatment, when less time socialising with friends and family, time off work, and interference with social activities are generally more prevalent. Hence, it might be expected that such baselines would lessen during this time. However, it appears from the interviews that it is the lack, or 'loss,' of these social interactions within wider society that are used as health baselines rather than social interactions themselves. In other words, reduced time with friends and family, time off work, and less time spent on social activities and hobbies are an indication of worse health for some people. Ironically, the *loss* of health baselines or that were once used to evaluate health status become the new health baselines (i.e. loss of social interaction replaces social interaction). Unfortunately, such baselines are likely to produce negative outcomes in terms of perceived health status as reduced social activities are an inevitable aspect of cancer treatment (Malone, Harris and Luscombe, 1994; Shannon and Bourque, 2006).

In Study 4b (Chapter 6), social baselines during chemotherapy were marginally significant predictors of anxiety during the same period (6.4.5.d), possibly indicating that a loss of personally important social resources might be a cause of unease for women undergoing treatment for breast cancer. This is perhaps a gap in supportive care that has been missed since treatment is a time when the focus is primarily on assisting patients to cope with side-effects. Nevertheless, there are a number of viable interventions that could be tested that might help ease anxiety during this time. For example, encouraging women to think about their social life and those aspects that they intend to re-establish post-treatment might enhance feelings of joyful anticipation as opposed to anxiety and despair at a perceived loss. It might even be a useful time to re-evaluate social priorities and set personal goals for when women are ready to find their 'new normal.'

- *Social Comparison Baselines*

In interpreting social comparison baselines that were evident within all five interviews, a pattern emerged whereby illness was revealed as motivating social comparison HBCs due to the uncertainty surrounding the experience. In fact, some interviewees reflected on how they did not use social comparison baselines pre-cancer but did use them during their cancer experience when comparisons with other people with cancer became more salient as an important referent. It is worth noting here that self-reported social comparisons are subject to social desirability as people may not want others to see them as being easily influenced by other people (Wood and Wilson, 2003). Nevertheless, the findings here do support literature discussed in 1.5.2., whereby downward social comparisons are especially prevalent in threatened populations (Gibbons and Gerrard, 1991; Wood, 1989). For example, research conducted in different types of support groups found that people involved in dangerous health behaviours such as eating disorders or smoking showed a preference for having other members in their group who had more serious problems (Gerrard, Gibbons, and Boney McCoy, 1993; Gibbons, Gerrard, Lando, and McGovern, 1991). Similarly,

DeVellis et al. (1991) found that people with arthritis often preferred to read about another patient who had worse arthritis than they had. This indicates HBCs might play a role in the development of cognitive dissonance and the maintenance of unhealthy behaviours. This is an important finding considering that in this research social comparison baselines adopted during chemotherapy were a predictor of anxiety (5.4.5c), cancer-specific QoL (5.4.5b), and distress over recurrence during chemotherapy (5.4.5b).

Analysis of the transcripts suggests that social comparisons played a primarily positive role during cancer treatment. For example, it appeared particularly frequent for some interviewees to utilise social comparison HBCs to assess side-effects of treatment or monitor their return to health after a course of treatment. One explanation for this is that social comparisons tend to be used in a number of ways: either as a direct HBC (e.g. Mel compared her physical fitness to other people taking part in a hike she was involved in), or as a way of gathering information to form a HBC (e.g. Kay used information gained from social comparisons to evaluate certain treatment side-effects as being the 'norm' rather than something of concern). This supports research indicating that the outcomes of social comparisons are dependent on the motives behind the comparisons (Wood, 1989). For example, they can be motivated by self-enhancement (i.e. to make oneself feel better) or self-improvement (i.e. to learn from). Mel appeared motivated by self-enhancement and the need to feel better about her physical condition, whilst Kay was motivated by self-improvement and the desire to adopt active coping strategies.

In returning to the literature on social comparisons, a tendency towards upward (Festinger, 1954) or downward (Wills, 1981; Collins, 1996) comparisons was not evident in the data. On the other hand, support for the use of both types of comparison was found and evidence provided for both potentially offering advantages and disadvantages (Major, Testa, and Blysma, 1991; Buunk et al., 1990). For example, one interviewee clearly benefited from utilising downward comparisons to distance herself from the 'cancer patient' identity. A potential explanation for this is the tendency for social comparisons utilised for self-evaluation purposes to involve either assimilation (i.e. the identification of similarities with a comparator) or contrast (i.e. the identification of differences with a comparator). It has been shown that contrast with a downward comparison, as evident in Lou's use of social comparisons to distance herself from the 'patient role,' can increase mood and result in positive self-evaluations (Buunk et al., 1990; Brown, Novick, and Kelley, 1992).

Social comparison baselines utilised during treatment have been found to be a marginally significant predictor of cancer-specific QoL during the same period as well as a strong predictor of post-chemotherapy cancer-specific QoL (6.4.5.a). The contribution of social comparison HBCs to future cancer-specific QoL provides a vehicle for interventions aimed at enhancing QoL either during or after cancer treatment. It is plausible that to enhance QoL during treatment will also enhance it afterwards, given the consistent role of social comparison baselines in this outcome. Further research on the direction of the social comparison HBCs (upward or downward; assimilation or contrast) used by the women in this study, as well as the motivation behind them (self-enhancement or self-improvement), would be highly beneficial in providing insight into those HBCs that might contribute to improved QoL.

Despite past negative connotations associated with social comparisons, primarily due to media images that have been found to be related to unhealthy behaviours (van den Berg et al., 2007), social comparisons are being recognised as offering therapeutic properties to people with cancer. For example, Stiegelis et al. (2004) used social comparison based information such as short stories of other patients in an effort to increase perceived mastery to self-manage. The social comparison stories were popular, especially those comprising examples of other people with the same type of tumour. In this instance, social comparisons motivated by self-improvement resulted in beneficial outcomes for cancer survivors. Other studies have demonstrated the benefits of peer modelling via the provision of social comparison information (Stanton et al., 2005), demonstrating the potential utility of the findings within this current programme of research.

- ***Biological Baselines***

Perhaps unsurprisingly, using biological baselines to evaluate health status was frequently adopted by interviewees. Biological indicators of health are, after all, explicit messages of health improvement or deterioration. The data suggests that monitoring physical signs and symptoms appears to be a relatively natural and automatic process, which might explain why other studies within this programme of research have found them to have little predictive validity in terms of QoL outcomes; they are being used so frequently and automatically that they are less sensitive to changes in health that might impact QoL. In other words, they are subtly being adjusted to changes in health status on a regular basis, most notably as part of the aging process. In contrast, other health baselines, for example social baselines, might require a more drastic or sudden change in order to alert someone to a health danger. Whilst they were slightly more salient during treatment, which is understandable considering the physiological implications of chemotherapy, they were generally relatively stable across the two time points.

Interestingly, evidence was found that the use of biological baselines during chemotherapy resulted in distress since cancer treatment evidently causes a number of sudden and sometimes extreme biological changes that are a response to the treatment not the disease. One interviewee reported how she was depressed during treatment when she was frequently utilising biological baselines. This supports the findings of Study 4a whereby weak to moderate positive relationships were found between biological baselines and negative feelings and distress over recurrence (5.4.4c), the latter likely being exacerbated through hyper-vigilance and anxiety related to treatment side-effects.

The implications of this hyper-vigilance to biological baselines are especially important in terms of psychological well-being and sense of control under adverse circumstances. The way in which a person interprets physiological feedback can have a huge impact on their sense of self-efficacy, a component of social cognitive theory found to play a fundamental role in health and well-being (Bandura, 1997). For example, a person with high self-efficacy may engage in more health-related activity when an illness occurs, whereas a person with low self-efficacy might feel hopeless in such situations (Sue, Sue, and Sue, 2006). Health behaviours such as smoking cessation, physical exercise, healthy eating, and breast self-examination are, among others, dependent on a person's level of perceived self-efficacy (Conner and Norman, 2005). It is thus important to be aware of changes in HBCs that might

result from cancer treatment and be able to facilitate the accurate interpretation of these baselines.

- *Illness-Specific Baselines*

The distinction between illness-specific and biological baselines became less evident when these dimensions were explored qualitatively. After all, many illness-specific baselines are symptomatic and physiological in nature (i.e. treatment side-effects); they have a biological component. Further clarification of these concepts will be important in any further HBC research.

Nevertheless, many examples of illness-oriented thinking were provided throughout the interviews, especially when discussing issues surrounding treatment. Many such issues were primarily based on the practicalities of how treatment dominated the interviewees' schedule of activities, hindering social activities and generally preventing them thinking beyond the illness. These practicalities might be a way of better distinguishing biological and illness-specific baselines, the former being physiological and the latter including some of the more practical aspects of the cancer experience, such as the treatment time and costs incurred by people with cancer.

As well as demonstrating a similarity with biological baselines, illness-specific baselines also seemed to merge to varying degrees with the other baseline factors. For example, illness-specific baselines became an aspect of social activities and relationships (social baselines), people compared themselves to others with the same tumour type (social comparisons), and they turned to cancer specialists when evaluating their health status (turning to others). In many ways, illness-specific baselines were encapsulated both within the illness-specific baselines subscale and within the other four subscales. This raises the question as to whether a separate subscale was required, although for the HBCQ to be useable between conditions then a separate subscale is supported for specificity purposes.

Illness-specific baselines used during treatment have been found to be marginally significant predictors of lower cancer-specific QoL and worse distress over recurrence during the same period, as well as increased depression post-treatment. Illness-specific baselines thus tend to result in negative QoL and emotional well-being outcomes, supporting the previously discussed idea of helping patients to take into consideration their general health as well as their cancer specific health (7.5.2.). In other words, the utilisation of 'health-specific' baselines in the form of cognitions and behaviours specifically related to health (e.g. exercise, nutrition, screening) might in part balance QoL via a consideration of health and illness, not just illness; and also, those aspects of health that can be controlled (i.e. lifestyle choices), not just those that cannot be controlled (i.e. side-effects of treatment). As shown, interviewees already had a tendency to distinguish cancer-specific and general health, so any interventions adopting this approach are likely to involve further clarifying the difference between these dimensions of health and well-being. The HBCQ already elicits health-specific baselines via items pertaining to lifestyle choices and adherence to medical advice, however, these have been included in other subscales as opposed to being categorised distinctly. This will be considered in more detail in the final chapter as a potential further area of investigation.

- ***Turning to Others***

As with social comparison HBCs, the interviews revealed that, understandably, turning to others when evaluating personal health status was more likely when in a healthcare setting, possibly due to the anxiety and uncertainty often associated with the medical environment (Cooper and Foster, 2008). The need to frequently interact with health professionals facilitated turning to others and the reliance on others to assess and monitor health status. The interview with Liz highlighted this issue, indicating that distress may arise when patients are no longer interacting with clinicians on a regular basis and they have no alternative but to rely on their own personal judgements of their health status. As previously discussed, this may compound anxiety relating to recurrence where the original disease was asymptomatic. On spending so much time with health professionals carrying out medical tests, providing treatment, and monitoring health, interviewees sometimes felt abandoned post-chemotherapy, a reaction reported in the literature (Cardy, 2006). This feeling of abandonment appeared to be exacerbated by a loss of trust in their biological baselines caused by the cancer initially being asymptomatic.

As discussed in terms of social baselines, social integration is often limited during treatment, be that due to time off work or less time to socialise, and this might have indicated a potential for increases in turning to others post-chemotherapy when social integration might be re-established. However, turning to others decreased, supporting evidence that suggests cancer survivors often experience a reduction in social interactions that continue after treatment (Bloom et al., 2004). This might also, in part, explain why turning to others during treatment was a marginally significant predictor of cancer-specific QoL during the same period. Turning to others when evaluating health status might have been beneficial in terms of the social aspect of the baselines as opposed to the health status evaluation in and of itself. By turning to others, it is plausible that these women felt less alone despite their reduced social integration outside of the hospital. In this sense, the reduction post-chemotherapy does not necessarily indicative of any negative implications for QoL as they might actually have been meeting a need much larger than health status evaluation – they might have been meeting a social need. However, this is speculative, based on the interview transcripts pertaining to feelings of isolation and a reliance on medical input; further research would be needed to establish if such a relationship did exist.

7.6.2. Changes in QoL and Emotional Well-Being

Any changes in HBCs post-treatment when compared to during treatment were discussed in the preceding section. However, there were also some interesting patterns within the QoL and emotional well-being data. QoL and emotional well-being generally improved for all interviewees post-treatment when compared to during treatment, with the exception of two ladies: one individual experienced a moderate deteriorating in cancer-specific QoL and a small deterioration in depression and another experienced no change in cancer-specific QoL. Any changes, positive or negative, were small to moderate in all but one interviewee, whose generic QoL improved by 66 points and cancer-specific QoL by 12 points. This individual did present with the largest change in illness-specific baselines when compared to the other interviewees, with her use illness-specific baselines reducing by 12 points post-chemotherapy. Since this baseline was a moderate predictor of cancer-specific QoL and

post-chemotherapy depression (which also improved along with QoL), this could be a fruitful avenue of research – a reduction in illness-specific baselines might, in part, explain the large improvements in QoL and emotional well-being experienced by this woman.

7.6.3. Further Considerations for HBC Theory

The HBC concept has been supported via richer narratives highlighting the utilisation of all five HBCs. In addition, potential areas for further research have been identified.

As noted in 7.6.1., the importance of the super-ordinate theme of sense of social cohesion is not felt to be adequately captured by the HBCQ. Most interviewees generally perceived their role within society to be a fundamental indication of health status. The general feeling was that if they could not contribute to society and be useful to society, then this was a potential sign of illness.

Resilience and strength, another super-ordinate theme, is measured via the HBCQ via items pertaining to physical and coping ability. However, the use of the word 'strength' was so prominent within the transcripts that this might be an important and meaningful term to use in the questionnaire or to explore via a qualitative element of assessment. Physical and mental resilience appeared to be of equal importance to those interviewees who used this to evaluate their health status. However, the sheer importance of resilience appeared to be based on the belief that people with cancer are, or should be, resilient. There was a sense of pressure to be strong, at least externally, in order to protect the self and others. This echoes an argument made by Ehrenreich (2010) that highlights a culture that encourages the denial of feelings and the 'sugar-coating' of illness (Ehrenreich, 2010).

The same 'pressure' experienced in terms of resilience was evident in other areas, such as benefit-finding. In one interview, the lack of benefit-finding became a huge concern for the interviewee, increasing feelings of isolation and depression. Whilst benefit-finding is an interesting and, arguably, positive outcome of the cancer experience, it appears essential not to place too much emphasis on this. To do this, is to risk isolating people who feel unable to adopt this mindset, as well as encouraging people to ignore stronger feelings that they might benefit from exploring, such as grief. Indeed, benefit-finding or seeing cancer as a 'gift' has become somewhat normalised within society, leaving some women feeling that they are 'wrong' for not perceiving the cancer experience as a 'gift' (Ehrenreich, 2010). Taken to the extreme, some women are repeatedly confronted with research demonstrating potential survival benefits of a positive attitude, leaving them unable to express negative emotions without some fear of cancer progression or self-blame for any progression.

This brings us onto the super-ordinate theme of loss as a health baseline, which is measured throughout all subscales in terms of past- or future-oriented items, as well as items pertaining to disability or problems with work and socialising. Nevertheless, since loss was so prevalent consideration needs to be made in terms of measuring loss more explicitly, again possibly via adding a qualitative element to measuring HBCs. Loss encapsulated so many areas within the transcripts and was evidently a fundamental benchmark for evaluating health status. Indeed, loss of control was frequently referred to, especially when expressing negative affect. Interestingly, one interviewee generally felt that health is controllable whilst

illness is not, suggesting that an individual's health locus of control might impact the type of HBC adopted, or vice versa, raising an area for further investigation. It might even be a HBC (i.e. when thinking about how healthy I am, I take into consideration the amount of control I have over my health). Alternatively, it might integrate into the already established turning to others subscale, turning to others when evaluating personal health status being an external locus of control, and turning to oneself being an internal locus of control.

This lack of control was further evidenced within the shared unease associated with the cancer being asymptomatic, as expressed by three of the women. The fact that cancer was often diagnosed when no symptoms were present made these ladies feel betrayed by their own bodies. In turn, this challenged their HBCs and their trust in their own ability to evaluate their health status. This seemed to exacerbate anxiety levels immensely, particularly post-treatment, leading to anxious preoccupation and hyper-vigilance. This provides further insight into the quantitative finding that anxiety significantly increases post-chemotherapy (6.4.4.), supporting recent initiatives to enhance survivorship support and increase self-management self-efficacy post-treatment (Davies and Batehup, 2010). There does certainly seem to be a need for post-treatment support for self-management, with the consideration of personal health status evaluations.

The subordinate theme of generic versus cancer-specific health raised some interesting theoretical considerations for HBC theory. The transcripts illustrated how some people evaluate their general and cancer-specific health separately, drawing on different HBCs for these distinct dimensions of health. This emerged as being an effective approach to health evaluations, enabling some of the women to maintain a sense of well-being in the face of illness. This poses a number of theoretical questions, such as: How do people distinguish HBCs utilised for different dimensions of health? Do people have a tendency to use specific HBCs across all dimensions of health or do they have separate HBCs for different dimensions? During illness, do people partake in a dual-HBC mechanism of health status evaluation (i.e. using separate HBCs or combinations of HBCs for generic versus cancer-specific health status)? There is clearly a need to examine these questions in more depth, since the applicability of this distinction within the provision of healthcare might provide QoL benefits by increasing focus on general health and lifestyle choices; it could be argued that this would subsequently show benefits for cancer-specific QoL since lifestyle plays an important role in cancer progression and recurrence (Thomas, Davies, and Batehup, 2010).

Whilst cancer challenged the interviewees trust in their HBCs, the experience also frequently resulted in greater health-orientation and the uptake of health behaviours such as exercise or change in diet. Completing breast cancer treatment has been referred to as a *'teachable moment'* for lifestyle change (Damush, Perkins, and Miller, 2006; Demark-Wahnefried et al., 2005), with these interviews supporting this and indicating a prime time to intervene in health and well-being outcomes. This further complements the idea of integrating the concept of health baseline comparisons into self-management support for cancer survivors, facilitating their transition to survivorship and the re-establishment of confidence in evaluating personal health status.

7.6.4. Measuring Health Baseline Comparisons

This study highlights that whilst the HBC questionnaire may have some utility in capturing salient issues during the cancer experience that might predict QoL, an individualised and more phenomenological approach is likely to be more useful. For example, an approach where clinicians explore health-related baselines with their patients might draw out HBCs utilised during a change in health status, as well as the impact of these baselines on overall health and well-being. Where HBCs might appear detrimental to patient outcomes, a cognitive-behavioural approach might be useful where more adaptive HBCs are required. This will be explored in more depth in the next chapter.

7.6.5. Study Limitations

Limitations of this research are evident insofar as the researcher understandably entered the interviews with concepts and beliefs that might have tainted the subjective nature of the data obtained. However, IPA was utilised to analyse the data specifically due to this methodology acknowledging that *"access* [to the participant's personal world] *depends on and is complicated by the researcher's own conceptions . . . required in order to make sense of that other personal world through a process of interpretative activity"* (Smith, Jarman and Osborn, 1999, pp. 218-219). The term 'interpretative phenomenological analysis' is thus used to reflect the dual facets of the approach and the joint contributions of both the participant and the researcher in the formation of the final narrative, or in this instance, the final case study (Osborn and Smith, 1998). This dual facet of the IPA approach was at the forefront of the current research analysis, with numerous steps being taken to maintain the subjectivity of the participants' experiences. Cross-validation of identified themes was conducted by a Health Psychologist, as well as post-interview correspondence with interviewees to confirm their satisfaction with any interpretations. Therefore, whilst interpretation bias could not be eliminated completely, steps were taken to minimise it as much as possible.

A further limitation might have been in the relatively small number of interviews. However, saturation of data was apparent by the final interview, whereby no new information was being obtained. This indicates that, in line with other IPA research, this small number was sufficient for the purpose of providing qualitative data to accompany quantitative findings. Nevertheless, it is acknowledged that the findings presented in this chapter represent only the experiences of those who volunteered for the study, which may not be representative of the general population of women with cancer. The participants were, however, selected for maximum variety and, also, they were asked to participate and accepted as opposed to putting themselves forward for the interviews; this in some ways increases the representativeness of findings.

7.7.   Conclusions

In conclusion, Study 5 has offered insight into health baseline comparison theory via case studies describing the subjective experiences of five breast cancer survivors who provided HBC and QoL data during chemotherapy and post-chemotherapy. When corroborated with quantitative data of previous studies within this programme of research, the HBC concept has been supported and information gained for further understanding the five HBC factors and the ways in which they might change during illness. In turn, the utility of this thesis has been made more explicit, and the addition of a qualitative element to eliciting patient HBCs has emerged as a potential method for improving the feasibility of the theory within clinical practice.

Whilst the potential applicability of HBC theory within the clinical environment has been cited throughout this chapter, the wider details and implications will be discussed in Chapter 8. Chapter 8 summarises the findings of each of the studies conducted throughout this programme of research, as well synthesises these findings in a discussion of potential future HBC applicability and research.

Chapter 8

Discussion: Consolidating Evidence for Health Baseline Comparisons in Psycho-Oncology

This programme of research explored the concept of health baseline comparisons (HBCs) and, more specifically, the comparative baselines or benchmarks utilised when people evaluate how healthy or unhealthy they are. The primary aim was to establish the existence, salience, and type of comparative baselines adopted by people evaluating their health status, and to examine any simultaneous changes in these baselines and well-being outcomes. This was achieved by applying the health baseline comparison concept to cancer and exploring the salience of different types of baseline during and after a course of chemotherapy. The final chapter of this thesis reviews these aims and objectives in more depth, describing each of the five studies comprising this thesis. The findings are summarised and discussed in relation to those of previous research. Implications of the findings will then be examined, together with their potential application within practice. The strengths and limitations of the research are critically discussed and ideas for future research presented.

8.1. Background

In light of limitations inherent in previous research in the field, most notably gaps within social cognitive models of health and illness and the literature on subjective health status (1.4.), this programme of study examined one of the cognitive processes proposed to occur prior to the appraisal of health status. In order to evaluate health status, it is argued that a comparative baseline is invoked, drawing on a wide range of factors. This process has been termed 'Health Baseline Comparisons' (HBCs).

A cancer-specific approach was adopted to investigate the health baseline comparisons construct; this included an examination of the role played by HBCs in multidimensional quality of life (QoL) outcomes. The overall objective was to utilise a range of quantitative and qualitative methodologies to systematically investigate the extent and type of HBCs adopted by individuals with cancer, as well as any health and well-being implications resulting from these HBCs. As the only previous research on HBCs was exploratory (Davies and Kinman, 2006), the research questions adopted were necessarily broad:

➤ Which health baseline comparisons are most likely to be adopted by individuals with cancer?

➤ What is the impact of different health baseline comparisons on multidimensional QoL outcomes?

➤ How stable are health baseline comparisons throughout cancer treatment?

In order to answer these questions, five studies were conducted to develop and refine the HBC concept by examining the extent and nature of HBCs adopted by individuals with

cancer. Cross-sectional and longitudinal data was utilised that was obtained by quantitative and qualitative methodologies. The overall aims of the research were to extend the identified health models and health outcomes in two ways:

1) the development of a theory that has the potential to enhance insight into subjective evaluations of health status: i.e. Health Baseline Comparison Theory.

2) the design of a questionnaire to measure the baselines adopted to evaluate health status: the Health Baseline Comparison Questionnaire.

It was anticipated that the theory might provide further insight into the factors that influence perceived health status and, accordingly, the measurement of subjective health outcomes. The questionnaire, refined on the basis of several studies, has the potential to provide insight into the most influential comparative baselines that contribute to evaluations of personal health status and how these factors might change during the course of a chronic and, indeed, life-threatening illness.

The five studies that were designed to meet these aims and objectives are summarised in the following section. This is followed by an exploration of the practical utility of the findings within the healthcare setting.

8.2. Summary of the Findings

8.2.1. Study 1: Testing the Utility of HBC Theory - The Development and Pilot Testing of the Health Baseline Comparison Questionnaire (HBCQ)

Study 1 (Chapter 2) examined the HBC concept via the development and refinement of the first pilot version of the HBCQ (v1). With the assistance of a small convenience sample (n=26) of staff and students from Cranfield University, a self-report measure designed to assess HBCs adopted by people when evaluating their health status was tested. The HBCQ (v1) was developed from a review of the literature pertaining to subjective health status, with consideration of factors such as detection of illness via symptoms or comparisons with others (Kelly and Ratner, 2005; Morris, Wheatley, and Ingram, 2008). This study built on postgraduate research that initially explored the HBC concept, conducted by the author (Davies and Kinman, 2006). The HBCQ (v1) was initially tested with people who had a persistent and enduring health condition, such as diabetes or asthma, and those who did not as the original rationale was to explore the HBCs adopted by people who were and were not ill but, as described below, the findings led to a focus on people with a chronic illness: i.e. cancer.

In this study, the HBCs that were most frequently endorsed were those relating to 'past health' and 'past illness.' Differences were found between people with and without a chronic illness; people with no chronic illness unanimously drew on past health status when evaluating their present health status, whilst people with a chronic illness unanimously drew on past experiences with illness. With the exception of items relating to turning to friends and family, all other HBCs had an acceptable level of agreement, suggesting that these baselines were widely used by respondents with a chronic illness as well as those without.

The main difference between the two groups appeared to be in terms of the implications of taking into consideration other people's health status when evaluating one's own health. Specifically, this tendency correlated with positive outcomes (i.e. better perceived QoL) in those with a chronic illness, but negative outcomes (i.e. lower perceived QoL) in those without. This supports literature on social comparisons, which suggests that people are motivated to make social comparisons for the purpose of either self-improvement (e.g. to learn coping skills) or self-enhancement (e.g. to increase feelings of superiority) (Taylor and Lobel, 1989). In the current research, it could be argued that those with a chronic illness were motivated by self-improvement and those without a chronic illness were motivated by self-enhancement. The former is likely to lead to positive outcomes since the motivation behind the comparison is specifically to find life-enhancing skills or skills that will facilitate adjustment to illness.

Participants without a chronic illness were more likely to endorse turning to others (such as friends and family) and the use of the media when evaluating health status. The media was in the top five HBCs endorsed by people without a chronic illness, but this baseline was less commonly drawn upon by those with a chronic illness. This is likely to be due to people with a chronic illness being 'experts' in their own condition and thus relying less on others to inform their judgments about subjective health status; chronic illness can enhance independence with medical care, hence the development of the 'expert patient' programme, which was motivated by the fact that some health professionals felt that their patients knew more about their health condition than they did (DH, 2009b).

Overall, the findings of Study 1 demonstrated not only the high endorsement of a variety of HBCs, but also that the type and strength of HBCs vary between individuals and according to actual health status. Furthermore, HBCs were significantly related to perceived QoL in different ways between groups, suggesting that their role may vary across the health trajectory. Since differences were evident between groups, the decision was made to focus subsequent research on chronic illness (i.e. cancer). It was anticipated that this would provide a setting where health baselines were being challenged by natural and treatment-induced changes in health, making them more readily accessible for evaluation.

8.2.2. Study 2a and 2b: Health Baseline Comparisons and Quality of Life in People with Breast and Prostate Cancer

Study 2a (Chapter 3) aimed to refine HBC theory and examine the relationship between different HBC categories and QoL. Building on Study 1, a clinical sample of people with breast (n=102) and prostate (n=112) cancer of various tumour and treatment stages was utilised. The structure of the HBCQ (v2), which was modified based on Study 1, was examined. An exploratory principal components factor analysis of the HBCQ (v2) produced a five factor solution, explaining 62% of variance in health baselines. The five factors were:

- *Social comparison baselines* (e.g. media images, people perceived to be superior/inferior in health)
- *Biological baselines* (e.g. symptoms, appearance, fitness)
- *Illness-specific baselines* (e.g. side-effects of treatment, prognosis)

- *Turning to others* (e.g. doctor's feedback, reaction of friends and family).
- *No comparisons* (e.g. making no comparative assessment)

The 'no comparisons' factor was excluded from the analysis in this study and from subsequent stages of the research programme, as it was a psychometrically weak factor and was being measured indirectly via the strength of endorsement (if any) given to other HBC factors. The HBC construct was refined by categorising health baselines according to these factors, facilitating a more in-depth examination of levels of endorsement and associations with health outcomes.

People with breast and prostate cancer showed a high level of endorsement for a number of HBCs, the five most frequently endorsed being: my lifestyle; the things I can do; my level of fitness; my appearance; and, the treatment I am undergoing. These are primarily biological and illness-specific baselines. Significant, but moderate, relationships were found between specific HBCs and multidimensional QoL, primarily social comparison baselines, biological baselines, and illness-specific baselines. Illness-specific and biological baselines were also found to make a modest significant contribution in predictive models of QoL outcomes in people with breast and prostate cancer. Primarily, illness-specific baselines were moderate predictors of emotional well-being, physical well-being, and overall QoL, whilst biological baselines were moderate predictors of functional well-being. In all cases, however, although significant, the contribution to these outcomes was small.

Study 2b (Chapter 3) built on the quantitative data obtained in Study 2a by obtaining richer, qualitative accounts of how HBCs were utilised when making personal health status evaluations. These comments were explored via thematic content analysis. Data strongly supported four of the identified HBC factors: social comparison baselines; biological baselines; illness-specific baselines; and turning to others. Support was also found for the exclusion of the 'no comparisons' factor.

The qualitative data also informed the further refinement of the HBC construct by highlighting baselines that were not included in the HBCQ (v2). Seven additional themes were identified that tended to draw upon the 'social' context. These were used to develop a 'social baselines' factor used in subsequent studies. This category encapsulated:

- Relationships (e.g. home/family life)
- Employment (e.g. ability to work, stress at work)
- Activities of daily living (e.g. shopping, cooking)
- Mood (e.g. desire to get out of bed; ability to enjoy social activities)
- Religion (e.g. spiritual connectedness)
- Environmental (e.g. pollution)
- Holistic (e.g. biopsychosocial considerations)

One limitation of Study 2 was the difficulty in distinguishing between gender and cancer differences, as cancer type was gender-specific[7]. In this study, women with breast cancer reported significantly poorer QoL than men with prostate cancer. Women also tended to

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[7] Men can also develop breast cancer, but this rare.

more strongly endorse the use of illness-specific baselines, the baseline that explained the most variance in QoL. This potentially confounding factor influenced the decision for subsequent studies within this programme of research to focus on women with breast cancer. It also highlighted the need to focus on emotional well-being, as this was the QoL domain that was most associated with HBCs in women with breast cancer.

8.2.3. Study 3: Further Development of the HBCQ for use with Women Receiving Chemotherapy for Breast Cancer

The findings of Study 2 highlighted a need to expand the HBC concept to include social baselines. Study 3 (Chapter 4) aimed to pilot test a modified version of the questionnaire in order to refine the HBC construct further. The response format of the questionnaire was adapted to elicit actual use of HBCs as opposed to level of endorsement (i.e. the Likert-scale was changed from 'strongly agree' and 'agree' to 'always' and 'sometimes,' etc.). The resulting questionnaire was then piloted with a sample of women with breast cancer (n = 54) from a local support group in order to obtain feedback on its content and format prior to utilising it longitudinally in a clinical sample.

An analysis of the descriptive data of the HBCQ (v3) responses provided support for the inclusion of social baselines. All subscales, with the exception of the turning to others subscale, had an acceptable Cronbach's alpha. Moreover, all subscales, again with the exception of turning to others, either equalled or exceeded the alpha of those found in Study 2, which used the HBCQ (v2). Although lacking internal consistency, the turning to others subscale was retained due to a high endorsement of the items within it. Feedback for the questionnaire was predominately positive, with participants generally reporting it to be acceptable, short, and easy to complete.

8.2.4. Study 4: Health Baseline Comparisons, Quality of Life, and Emotional Well-Being during and after Chemotherapy for Breast Cancer

Study 4 comprised two stages, the aims of which were to capture the following data:

➢ *Study 4a:* The salience of HBCs *during* (Time 1) chemotherapy for breast cancer, and associations with QoL and emotional well-being.

➢ *Study 4b:* The stability of HBCs, QoL, and emotional well-being *after* (Time 2) chemotherapy for breast cancer, as well as changes between Time 1 and 2.

Study 4a (Chapter 5) examined HBCs, QoL (generic and cancer-specific), and emotional well-being (depression and anxiety) in a sample of women who were undergoing a course of chemotherapy for breast cancer (n = 45). The rationale was that the many side-effects of this treatment were likely to affect health and QoL (Cleeland, 2008; Nuzzo, Morabito, De Maio, et al., 2008) and thus provide an opportunity to explore any changes in HBCs and QoL that might result from challenges to health (i.e. symptoms and side-effects induced by cancer treatment).

Descriptive statistics supported the findings of previous studies within this programme of research by finding generally high levels of endorsement of HBCs when evaluating health status during a course of chemotherapy. The five HBCs most frequently utilised were: my adherence to medical advice; other's positivity towards me; my own positive health judgments; the doctor's positivity about my health; and, treatment benefits.

Social comparison baselines were found to be marginally significant predictors of anxiety, explaining 25% of the variance in this outcome. These baselines made a higher contribution than any demographic (i.e. age, education) or illness (i.e. co-morbidities, chemotherapy cycles) variables. Social comparison baselines, along with illness-specific baselines, were also marginally significant predictors of cancer-specific QoL, explaining 21% of the variance in this outcome. Along with the 26% of variance significantly explained by co-morbidities, the final model accounted for 47% of cancer-specific QoL.[8]

Interestingly, the role of HBCs in predicting cancer-specific QoL outcomes was primarily in terms of distress over recurrence. This outcome is frequently expressed by people with cancer (Foster et al., 2009; Vickberg, 2003). Social comparison baselines and illness-specific baselines were marginally significant predictors of this outcome, explaining 23% of the variance. In combination with the 25% variance explained by co-morbidities, the final model explained 48% of the variance in distress over recurrence.

Study 4b (Chapter 6) examined HBCs, QoL, and emotional well-being two-months post-chemotherapy (during the survivorship period), to make comparisons across time points by comparing data from Study 4a with data from Study 4b.

In comparing the data obtained during chemotherapy with that obtained post-chemotherapy (n=35), a number of differences emerged. The descriptive statistics indicated that turning to others was more frequently endorsed during chemotherapy, whilst a mixture of social, illness-specific, and biological baselines was most frequently endorsed post-chemotherapy. However, the difference between these means did not meet statistical significance. The test-retest reliability for the HBC construct unidimensionally was fairly high, but those for specific subscales were low (social comparison baselines; turning to others), suggesting that they may be more flexible to environmental change. Indeed, the literature suggests that social comparisons are salient during illness and can be influenced by a change in environment. People with cancer can find that their environment and external world changes drastically as they spend more time in the hospital waiting room and less within familiar surroundings (Collins, Dakof, and Taylor, 1988).

No significant differences were found for cancer-specific QoL or depression between times 1 and 2. In contrast, levels of generic QoL were significantly better post-chemotherapy than during chemotherapy, whereas anxiety was significantly worse post-chemotherapy than during chemotherapy. An explanation for the improvement in generic QoL might be due to a refocus on general QoL factors once treatment ceased and the person was spending less time in a clinical environment. In terms of the increased level of anxiety, this is consistent with the literature, where post-treatment is marked by feelings of abandonment, anxiety due

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[8] These findings were published in Health Psychology Update (Davies et al., 2008).

to perceived loss of medical support, and distress over recurrence (Cardy et al., 2006; Vickberg, 2003).

HBCs adopted during chemotherapy were moderately significant predictors of cancer-specific QoL outcomes (by 40%) during the same period and two-months post-chemotherapy (by 36%). The HBCs that made the strongest contribution to the variance differed across time points, with illness-specific baselines, turning to others, and social comparison baselines utilised during chemotherapy making a significant contribution to cancer-specific QoL during the same period. More specifically, illness-specific baselines adopted during chemotherapy significantly explained 32% of the variance in distress over recurrence (a component of cancer-specific QoL) during the same period. Only one HBC continued to significantly contribute to cancer-specific QoL post-chemotherapy; this was social comparison baselines. A possible explanation for this change is that people tend to carry out social comparisons for a number of purposes, both within and external to the domain of health (Gibbons and Buunk, 1999). This suggests that social comparisons may remain influential after treatment. On the other hand, illness-specific baselines and turning to others are likely to be more frequent when in an environment associated with illness and being cared for by others, as is the case during treatment.

In terms of emotional well-being, social baselines adopted during chemotherapy were moderately significant predictors of anxiety outcomes (by 29%) during the same time point. However, these baselines were not significant predictors of anxiety measured post-chemotherapy. Furthermore, post-chemotherapy HBCs were not significant predictors of anxiety during the same time period. Social baselines were found to be relatively stable between time points, suggesting that anxiety naturally increased post-chemotherapy independent of any potential social baseline influences. Indeed, the literature suggests loss of medical support, fear of recurrence, and efforts to establish a 'new normal' are plausible explanations for this increase in anxiety (Foster et al., 2009).

8.2.5. Study 5: Experiences of Health Baseline Comparisons in Breast Cancer Survivors – an Interpretative Phenomenological Analysis

Study 5 (Chapter 7) comprised semi-structured interviews with a small purposive sample of women (n=5) who provided HBC and QoL data during and post-chemotherapy (Study 4). These interviews formed individual case studies that were analysed via interpretative phenomenological analysis (IPA). The use of semi-structured interviews and IPA allowed for the unique HBC and QoL experiences to be elicited from the women in this study, providing insight into how they make sense of their own health status evaluations.

The interview transcripts not only elicited further support for the five HBC factors, but also provided an array of new insights into the very individualised use of health baselines in women with breast cancer, both during treatment and into the survivorship period. Four super-ordinate themes and four subordinate themes pertaining to subjective health status evaluations emerged:

Super-ordinate:	Subordinate:
Sense of social cohesion	Negative affect

Loss	Generic versus cancer-specific health
Treatment	Engaged doctor
Resilience	Information-seeking

Sense of social cohesion emerged most notably in the form 'participation,' 'sense of belonging' or 'contribution' to society. For example, it appeared that the more the interviewees felt able to contribute to society in the form of employment, socialising, volunteering, etc., the healthier they judged themselves to be. Active engagement with the world was a sign of health and well-being. This supports research demonstrating correlations between social capital and perceived health, with participation in social groups being one of the key components of social capital (Abbott, 2010).

Resilience as a form of fighting spirit in a war against a disease that was perceived to be attacking the body emerged as an important motivation in maintaining a sense of health whilst in the grips of disease. Yet, at the same time, resilience for some of the women could be interpreted as being socially-inflicted or socially desirable (Ehrenreich, 2010). The transcripts suggested that to express vulnerability could be seen as a sign of weakness, of giving up, and of succumbing to the disease. Indeed, perceptions of pressure regarding benefit-finding emerged from the data, together with a perceived expectation on the part of others, for these women to see the positive side of their experience.

Loss and a sense of bereavement were also expressed by most of the interviewees, with transcripts highlighting the impact of these factors in terms of a diminished sense of health and well-being. Loss was multifaceted, encapsulating loss of things from the past (i.e. familiar routine), present (i.e. social network), and future (i.e. long-term goals). This supports Prospect Theory and the concept of loss-aversion, which posits that humans are highly influenced by loss (Kahneman and Tversky, 1979). Indeed, influencing factors in health status evaluations have been demonstrated to change according to age and illness, particularly in terms of maintaining a gain-framed comparator (Kaplan and Baron-Epel, 2003). Loss is also one of the stages in Shontz' (1975) proposed sequence of reactions following the diagnosis of a chronic illness. Overall, the data within this research suggests that feelings of loss and their impact on health status and QoL is prolonged and can remain significant into the survivorship period.

Interestingly, treatment side-effects were more frequently utilised as an indicator of health than the cancer diagnosis was, as symptoms not present at diagnosis were induced via treatment, prompting health status evaluations. Another interesting observation emerging from the transcripts was the distinction between generic and cancer-specific health, where different HBCs were being utilised in assessments of generic versus cancer-specific health. Recent research presented at the 2010 International Conference on Support for Self-Management of Health highlights that people living with a chronic illness tend to fluctuate between life-orientation (e.g. attempts to adjust to illness within the context of one's life) and disease-orientation (e.g. attempts to eliminate symptoms of illness) (Audulv, 2010), which could be argued as being synonymous with the focus on generic (i.e. life-orientated) versus cancer-specific (i.e. disease-orientated) health highlighted within the current programme of research.

Negative affect emerged as potentially being a health baseline in itself as well as an outcome of health status evaluations. In particular, HBCs involving the super-ordinate themes of social devaluation, loss, treatment side-effects, and societal pressures pertaining to resilience and benefit-finding, appeared related to negative affect in the form of anxious preoccupation and depressive symptomology. Those women with a supportive and informative medical team appeared to express less negative affect, which leads on to the final two themes: the 'engaged doctor' and 'information-seeking.' The engaged medical professional is synonymous with the concept of 'patient partnership in care' (Powell et al., 2009) or 'co-creating health' (Grazin, 2009), two concepts that promote patient-centred care via a partnership between the patient and their doctor. Within this model of healthcare, the patient and professional are both perceived as experts who can each bring knowledge or experience to the relationship (Grazin, 2009). An example of this was presented in one case study within the current programme of research, where the doctor was aware of the health baselines utilised by the patient and thus used them to evaluate her well-being and guide the consultation process. Information-seeking was interpreted as playing an important role in the formation of HBCs, as well as in attempting to regain a sense of control through increasing knowledge about the disease and its management. The information-seeking behaviours demonstrated by the women in Study 5 emphasis the well-known phrase, 'knowledge is power.'

The findings of Study 5, when synthesised with those of the previous studies, provided further insight into the HBC construct and how it may be measured. Several areas for future research also emerged, which will be discussed later in this chapter.

8.2.6. Synthesis of Findings

The five studies conducted in this programme of research have provided insight into how health baselines are used as comparative benchmarks when evaluating personal health status. Based on the findings of this research, these HBCs can be categorised into five factors that reflect a biopsychosocial perspective to subjective health and which can be self-constructed or socially influenced:

Social Baselines – using social baselines to evaluate personal health status (e.g. work, social life, and social cohesion).

Social Comparison Baselines – using information gained from comparing oneself to others to evaluate personal health status (e.g. media images, people perceived to be superior/inferior in health).

Biological Baselines – using biological signals to evaluate personal health status (e.g. symptoms, appearance, and mood).

Illness-Specific Baselines – using information pertaining to the illness experience to evaluate personal health status (e.g. side-effects of treatment, prognosis).

Turning to Others – *using information gained from others to evaluate personal health status (e.g. doctor's feedback, reaction of friends and family).*

Evidence has been provided that people do not necessarily favour a particular type of baseline when evaluating their health status; several are often utilised simultaneously. Nonetheless, the type and strength of HBC can change over time or, indeed, be affected by an experience of illness or its treatment. Furthermore, as demonstrated in people with and without a chronic condition (Study 1), in people with breast and prostate cancer (Study 2), and in women undergoing chemotherapy for breast cancer (Studies 4 and 5), some of these HBCs (e.g. social comparison baselines; illness-specific baselines) can be moderately significant predictors of QoL and emotional well-being outcomes.

The social cognition models discussed in Chapter 1 (1.2.), which motivated this research due to identified gaps in explaining an important cognitive process involved in subjective health status (i.e. HBCs), can be further critiqued with the findings obtained from this research. In particular, models such as the Health Belief Model (HBM; Rosenstock, 1966) and Protection Motivation Theory (PMT; Rogers, 1975) do not account for the multidimensionality of health status and health status evaluations. For example, they do not account for the influence of co-morbidity or past illness experience on the beliefs and behaviours associated with another health threat. Nor do they take into consideration that people with a chronic illness might have different cognitions and behaviours for generic health versus condition-specific health. This is clearly an important distinction in terms of coping, as well as in terms of perceived threat, as indicated within the current research.

The data presented within this thesis supports the concept of fear-arousal presented in the PMT, hence the hypervigilance expressed by participants who were fearful of recurrence and the unpredictability of cancer (i.e. it often occurred without symptoms). It also supports the theory of fear motivating adaptive responses to threat (Floyd, Prentice-Dunn, and Rogers, 2000), since participants in the current research demonstrated a number of adaptive responses motivated by fear of recurrence, including the adoption of biological baselines as a form of symptom surveillance. However, the PMT does not take into consideration the fact that these 'adaptive' responses can become maladaptive. For example, the data in this research suggests that people can become overly focused on the illness, sometimes at the cost of taking care of generic health or health issues related to co-morbidities. In this sense, fear can motivate a preoccupation with the fear-inducing factor (i.e. cancer recurrence). This is supported by the literature, which demonstrates that hypervigilance and hypochondria are common in cancer survivorship (Alfano et al., 2006). It is possible that hypochondria is, in part, caused by over-use of biological baselines.

In support of Seydel et al.'s (1990) critique of the PMT, this study indicates that people are mainly motivated by benefit-finding, positive reinterpretation, and the learning of effective coping responses, rather than being motivated by fear. Fear, particularly in the form of fear of loss, does play a significant role in health behaviours and cognitions, but appears to be more of a hindrance than a motivating force. This also supports Sheeran and Abraham's (2003) critique of the HBM, which highlights that fear can be counteractive in the adoption of health behaviours.

The findings in this research do support the theories underlying the social cognition models, that people assess their susceptibility to an illness threat. However, the findings add to our understanding of the mechanisms within this process, showing that it is not necessarily a linear process; people also assess their susceptibility retrospectively, after the development of an illness, questioning why they had not recognised their own susceptibility previously and taken preventive measures. This search for meaning has been found to be associated with subsequent feelings of self-blame (Dirksen, 2008). This retrospective appraisal of illness susceptibility also points to a preceding process, this being HBCs and an evaluation of health status. This raises the question of whether a different HBC might have detected susceptibility. For example, a person might have assessed their health and susceptibility to illness via a baseline of experience of 'good health,' whilst not considering the baseline of a 'family history' of a particular illness. If models such as the HBM included the initial cognitive stage of health baseline comparisons in their explanations for health behaviours, further opportunities for interventions would potentially be available. Indeed, it could be argued that cues to action, a component of the HBM, are not merely education, symptoms, and media information, but also the HBCs employed in evaluating health status.

The insight gained into social cognitive models of health, as well as the potential application of the HBC construct to these models, raises a number of implications for practice and further research. These implications are discussed next.

8.3. Implications of Research

The quantitative and qualitative findings of this programme of research suggest that HBC theory offers further understanding into social cognitive theories of health, and also has potential utility within the healthcare context. It could be argued that the most feasible application of the concept might be as a framework within self-care and healthcare provision since changes in HBCs appeared to be motivated by efforts to self-regulate and adjust to changes in health. Examples of such practical applications are discussed in relation to established literature.

8.3.1. Facilitating Health Status Evaluations

This research has highlighted a discrepancy between those health baselines people tend to use most often when evaluating their health status and actual markers of ill health or, at least, health deterioration. To clarify, people, in the main, tend to evaluate their health via biological baselines, as indicated by the seeking of medical advice due to symptom presentation. Yet, there are some diseases, including many cancers, which are frequently (but certainly not always) asymptomatic. Thus, once an asymptomatic disease is diagnosed as potentially life-threatening, people can experience considerable uncertainty and health anxiety, which in turn can lead to hypervigilance. Indeed, hypervigilance is commonly reported among people with cancer, particularly during the survivorship phase (Roth et al., 2005; Bush, 2009) where distress over recurrence is almost universal among cancer survivors (Simard and Savard, 2009). Furthermore, despite pre-diagnosis biological indicators of disease sometimes being non-existent, distress over recurrence is exacerbated

by physical symptoms (Allen et al., 2009), possibly indicating desperate efforts to establish familiarity in the form of symptoms equating with illness.

Support for the inference that participants were attempting to achieve health homeostasis can be found in the self-regulatory model of illness. This assumes that given a health crisis or general change in health status, an individual will be motivated to solve this problem and to re-establish a state of normality (Leventhal, Brissette, and Leventhal, 2003). Also referred to as the 'common sense' model of illness, the association between symptoms and illness makes cognitive sense to an individual. When this common sense understanding of illness, as necessarily presenting with clear symptoms of biological change, is threatened it is understandable that people with cancer might lose trust in their body's ability to alert them to illness, and thus take steps to reduce anxiety via becoming overly sensitive to biological indicators of illness detected via biological baselines.

A tendency towards hypervigilance in cancer survivors is likely to be costly for the NHS. People with health anxieties often consult their GP with what are likely to be minor symptoms and undertake expensive screening procedures in order to provide reassurance (Williams, 2004). Equally, high health anxiety can predict avoidance of health-seeking behaviours, leading to delayed diagnosis (Arndt et al., 2003; Burgess et al., 2001; Lam et al., 2009). Clearly, interventions that might reduce or prevent the common problems of anxious preoccupation and hypervigilance to health symptoms are required. A practical application of the HBC construct might be to assist people in understanding how to achieve some clarity regarding their illness and treatment experience. This might be as simple as empathising with the confusion the person might be experiencing, and then providing information, verbally or via written material as to how they can evaluate their health more adaptively (as opposed to being hypervigilant). This might include providing information on how to detect signs of recurrence or how to evaluate one's health when undergoing a treatment regime that invokes symptoms.

Videotapes are another cost-effective mode of delivery and have been cited as being effective in providing role models for adaptive coping and the delivery of health information to people with cancer (Burish, Snyder, Jenkins, 1991; Mykityshyn, Fisk, and Rogers, 2002; Stanton et al., 2004). Peer modelling initiatives are often designed to enhance self-efficacy (i.e. self-confidence), something which might be low in people who have been confronted by a discrepancy between their common sense understanding of disease and their reality. Therefore, a peer modelling intervention designed to enhance skills at detecting recurrence or evaluating health while undergoing treatment might help improve self-efficacy to effectively judge one's health status. In turn, this might increase feelings of control, a need often cited within the literature and also highlighted within the current research (Donohue, 2009; Henselmans et al., 2010).

The HBC questionnaire might initially be used for screening, enabling risk stratification based on needs and vulnerabilities. Where issues of concern are raised, follow up with a personal interview could be used to explore the findings and the type of influences that people draw upon when evaluating their health status. The extent to which these are adaptive or maladaptive could also be explored and the appropriate interventions provided. For example, people who are screened as being preoccupied with biological baselines might require psychological assistance in coping with fear over recurrence, whilst people screened

as focusing on baselines indicative of what they can no longer do might benefit from a self-management programme aimed at facilitating adjustment to illness. The provision of cancer aftercare based on individual assessment of need and risk is high priority for the Department of Health, demonstrating a practical and feasible application of the findings within this programme of research (Davies and Batehup, 2010; DH, Macmillan Cancer Support, and NHS Improvement, 2010b).

8.3.2. Adherence to Medication and Medical Advice

Insight into the factors that people draw upon to evaluate their health status might also have implications for adherence to medication and health advice, especially where illness-specific baselines inform decisions regarding medication. For example, some illnesses are masked by medication, again challenging common sense assumptions of illness being symptomatic. The HBC construct could be utilised in the formation of health education interventions aimed at helping people on medication to learn new ways of evaluating their health status when symptoms are being controlled by medication or changes in lifestyle. A practical example might be the provision of a brief statement included on information provided alongside medication. Whilst medication does come with indicators of health issues, such as side-effect warnings, it does not currently warn of the dangers of stopping medication because one feels more 'healthy.' This might be one contributing factor to low adherence with medication (Heather et al., 2002).

It could also be argued that a change to health promotion and educational messages is required, with a view to enhancing the public's health literacy – i.e. the way they evaluate their health and take care of their health. The HBC construct might provide an apt method of highlighting the multidimensional components that can be involved in health status evaluations (i.e. not just symptoms, but also social and psychological factors). As discussed in Study 5 (Chapter 7), the HBCQ was seen to be a useful tool for helping women to recognise the methods they use to evaluate their health status and how this might affect them. This highlights the potential for the provision of leaflets or written information pertaining to HBCs and the adjustment of HBCs in light of the 'masking' effect of many medications.

8.3.3. Patient Partnership in Care

The HBC framework has been shown to be useful in helping some people gain insight into their personal baselines and how these might fluctuate during health and illness. The framework might also offer an effective way of informing healthcare professionals of the baselines that their patients draw upon, so that consultations and medical advice can be tailored according to patient need. Such insight might also help medical professionals appreciate their patients' perspective and also enable them to challenge or foster the use of particular baselines that might be maladaptive or adaptive at particular stages of the disease process. Many of the problems associated with patient-clinician communication or healthcare provision are the result of incongruent beliefs and approaches to health, for example, the degree to which patients and clinicians hold similar attitudes and beliefs has been found to be a strong predictor of trust in the clinician and compliance with health advice (Krupat et al., 2001). For example, a clinician might focus on a symptom that is of less

priority to the patient in terms of their quality of life (i.e. clinicians might assume that perceived health can be enhanced via pain reduction, whilst the social baseline of returning to work would offer the patient greater health and quality of life outcomes). Thus, using the HBC framework could potentially increase understanding between patients and clinicians and strengthen their mutual relationship by enabling them to work towards the same health goals. The findings reported in this thesis suggest that HBCs are very individualised, highlighting the importance of establishing patient HBCs in order to provide personalised, tailored healthcare and advice, and subsequently improve health outcomes.

A novel application of HBC theory would be to provide doctors with mean HBC data pre-consultation so that they can establish how best to engage with their patient. Offering QoL data to doctor's pre-consultation has proved successful in research by Velikova (2004), and routine assessment of QoL has been found to improve clinician-patient communication and result in better QoL and emotional well-being in some people with cancer. This has created initiatives towards making real-time patient questionnaire data available pre-consultation (Boyes et al., 2006; Valikova, 2008). Utilising HBC data in a similar way might provide benefits such as saving clinician time by guiding and focusing the consultation. Indeed, one of the participants in Study 5 reported that insight into her personal health baselines was successful in helping her doctor work in a patient-centred way; it led to a feeling of teamwork and empowerment, and in turn enhanced her confidence in the doctor.

In terms of facilitating communication between patients and healthcare professionals, both the HBC construct and the HBCQ offer practical applications. The completion of questionnaires pre-consultation has been found to provide people with an opportunity to highlight issues they are happy to report in writing but would not be comfortable mentioning verbally. For example, emotional symptoms or side-effects of treatment often remain undetected, as they may be seen as embarrassing or unimportant (Butow et al., 2002). Concordance with the methods used by patients in evaluating their health status might be one way of promoting the discussion of important issues in a timely and efficient manner.

Participants themselves generally found the HBCQ to be a useful tool that could be implemented within the clinical environment in several ways, for example, to *"help people focus, define for themselves what is important,"* as well as being *"helpful to oncologists and surgeons but more as a generic follow-up – in order to maybe ask timely questions and to earlier address potential depression issues."* This suggestion is feasible since quantitative data has demonstrated that illness-specific baselines were marginally significant predictors of post-chemotherapy depression. Furthermore, this practice might also encourage patients to engage with their health at a deeper level so that they can get the most from the consultation. Another respondent highlighted the potential use of the HBCQ within primary care. General practitioners have a challenging new role due to the increase in survivorship and the need for long-term follow-up, and so tools such as the HBCQ, which might assist them within the consultation process, might also increase their confidence in working with this patient group (Grunfeld, 2005).

8.3.4. *Enhancing Personal Control in Survivorship*

Participants highlighted the salience of various kinds of personal loss during their experience with cancer. This emphasises the importance of grief and bereavement research, as well as

the potential benefits of grief counselling for people living with cancer or in the survivorship stage. The HBC framework could potentially be used to develop counselling strategies similar to the cognitive-behavioural approach. For example, as well as the provision of support for perceived loss, the HBC framework could be used to help survivors reframe their thinking to consider the life domains that remain unchanged, or have even been enhanced by the cancer experience. More specifically, the framework could be used to establish the extent to which people evaluate their health status based on what they can no longer do and how this knowledge can be used to enhance well-being.

A practical application might build on the finding that participants, in general, made a distinction between generic and cancer-specific health when describing the influences they draw on to evaluate their health status. The utilisation of various health baselines was sometimes dependent on whether generic or cancer-specific health was being evaluated, which appeared to be a coping mechanism; for some women, accepting a diagnosis of cancer did not necessarily mean that they saw themselves as being globally unhealthy. Some women were able to identify strengths within their health more generally, which in turn reduced the likelihood of the 'sick role' or learned helplessness being adopted.

Helping patients reframe their thinking in terms of generic and cancer-specific health might also provide an opportunity for helping them focus on the areas of illness that they can control to some extent, such as illness prevention (generic health) and illness self-management (cancer-specific health). The post-treatment stage has been described as a 'teachable moment,' where cancer survivors are more likely to utilise information provided to them in an effort to regain control over their lives; this perspective has resulted in a rapid increase in the number of self-management interventions being developed for cancer survivors (Demark-Wahnefried et al., 2005). Lifestyle interventions in particular are expanding within the field of psycho-oncology. The findings of the present research might help inform such interventions. For example, it is plausible that generic health HBCs (i.e. I have a healthy diet; I exercise regularly) might not only improve perceptions of control over general health, but also facilitate coping with the illness experience.

8.4.   Research Limitations

This thesis has a number of strengths. As discussed above, the findings of this programme of research has made a novel contribution to the understanding of how people evaluate their health status. The findings have many practical implications and applications in clinical settings. A range of methodologies, both quantitative and qualitative have been utilised. As with any programme of research, however, several weaknesses can be identified. The strengths and weaknesses of the present research programme are discussed below.

8.4.1. Research Strengths

The key strength of this programme of research is in the formation of a new concept with potential applications within the fields of health psychology and psycho-oncology. The HBC construct has been explored and systematically developed throughout the studies presented in this thesis through the use of questionnaires and qualitative data obtained from open-

ended questions and interviews. As well as capturing a construct that is of interest to the field of health psychology, evidence has been found that the HBC captures the experiences of people who have cancer or who are entering the survivorship stage.

Fairly large numbers of participants were sampled in each of the five studies. This enhances the representativeness of findings, as well as its practical application. The quantitative data obtained in each of the studies informed the continued psychometric development of the HBCQ. However, a further strength of the research is that participants were involved in developing the HBC concept itself. This was accomplished by their endorsement of the HBCs measured by each version of the questionnaire and their feedback relating to baselines that were not adequately captured within these scales. This process provided participant validation for the HBC construct as well as a form of triangulation which adds rigour to qualitative research (Mays and Pope, 1995; Jordan, Buchbinder, and Osborne, 2010). In turn, this has highlighted the potential social value of the construct, since HBCs were strongly endorsed within all five studies and comments were made about the relevance of the items measured within the HBCQ and the way in which it helped participants to reflect on their own health status evaluations.

The utilisation of different research methodologies is a further strength. This avoids mono-method bias and reduces the risk of making false assumptions from data, as highlighted in literature on methodological triangulation (Risjord et al., 2002). In this programme of research, a cross-sectional design was utilised, followed by a longitudinal design. All studies included a quantitative and qualitative component. Self-report questionnaires followed by semi-structured interviews and in-depth case studies were particularly fruitful in providing depth and insight into the HBC construct and its potential applicability. It is notoriously difficult to obtain a clinical sample, much less follow them through time with repeated measures (Young, Powers, and Bell, 2007).

The studies reported in this thesis used a clinical sample and managed to obtain respectable sample sizes from an oncology clinic for all but one study. This provides valuable real-world insight into representations of health and disease by people with cancer. The approach adopted also highlights the value in adopting a mixed methods design when developing a concept (Yardley and Bishop, 2008), as well as reflects the important role of the patient in developing and refining health-related concepts and providing valuable input into how concepts such as HBCs might be utilised in healthcare settings.

8.4.2. Research Weaknesses

Any exploratory research that aims to develop and test a novel concept with a clinical sample will have weaknesses. In hindsight, whilst the research comprised a sufficient number of participants throughout, in Study 4 (Chapters 5 and 6) the most appropriate method of data analysis was not adopted for the number of participants. Secondarily to examining the HBC concept, multiple regressions were used to examine the role of HBCs in QoL and emotional well-being outcomes. An identified weakness is that the size of the sample in Study 4a (n=45) and Study 4b (n=35) meant that the validity of conducting the multiple regressions reported in Chapters 5 and 6 is questionable. The lack of statistical power may have resulted in the small proportion of QoL variance explained by HBC

subscales. Future research should employ larger sample groups to explore the contributions made by different types of HBCs to patient well-being in a more valid manner.

Whilst the longitudinal design of Study 4 provided valuable insight into the stability of HBCs during and post-chemotherapy, an additional measurement time-point, either before treatment or later in the survivorship period might have helped establish cause and effect over time. Further insight might have been gained into the extent to which HBCs are responsive to environmental change, the specific dimensions that are most malleable and those that are the strongest predictors of QoL outcomes. This might have provided greater insight into the potential application of HBC theory. The most interesting and potentially useful approach would have been to measure HBCs before diagnosis, but for obvious reasons this was not feasible within the current programme of research.

This research programme relied exclusively on self-reports to obtain information on HBCs, QoL, and emotional well-being. Although self-report methodology has been frequently criticised, it is widely recognised to be an effective method of data collection within health psychology and psycho-oncology (Baker and Brandon, 1990; Stone, Shiffman, and DeVries, 1999). Self-report data is mainly recommended for measuring real-time cognitions, behaviours, or beliefs, as these are accessible to the participant and less likely to be subjected to bias or forgetting (Schwarz, 2000). For this reason, real-time cognitions and QoL were sought in this programme of research, with limited retrospective exploration during interviews.

In terms of the validity of obtaining self-reports of HBCs and QoL outcomes, it could be argued that participants are in the best position to assess their health status evaluation methods as well as their physical and emotional well-being (Larsen and Fredrickson, 1999). Indeed, it is difficult to conceive how concepts that are essentially subjective, such as health baseline evaluations and estimations of QoL and psychological well-being, can be measured in any other way. Objective estimates of QoL by physicians have not necessarily been found to concur with those of patients (Rodriguez et al., 2003; Wilson et al., 2000). There is the issue of mood or, more specifically, negative affect influencing self-reports, however, many studies have concluded that the confounding influence of negative affect does not overly distort self-report data (Chen and Spector, 1991; Schonfield, 1996; Spector et al., 2000). Furthermore, steps recommended for increasing the accuracy of self-report data, such as ensuring question comprehension (Schwarz, 1999), were taken in the development and refinement of the primary measurement tool.

Perhaps the greatest limitation within this programme of research is the low level of variance in QoL and emotional well-being outcomes explained by HBCs. Furthermore, several HBCs failed to account for any variance in these outcomes. It could be argued, however, that QoL might not have been the most appropriate outcome to have utilised throughout this programme of study. The strong endorsement of many of the HBC subscales and the qualitative data presented in this thesis indicates that the construct has captured something meaningful to people with a chronic and life-threatening illness. Future research might examine the HBC framework in relation to other outcomes related to health and well-being. These might include adjustment to cancer, coping style, health locus of control, or the uptake of health behaviours that might improve health status evaluations, both cancer-specific and generic. The role played by HBCs in successful and unsuccessful adaptation to cancer might

be a particularly appropriate focus of further study. Indeed, the concept of HBCs is based on the fact that health baselines require adjustment as people are confronted with natural or unexpected changes in health resulting from ageing or illness.

Adjustment to changes in health status can be both behavioural (i.e. making changes to lifestyle, as is needed after a diagnosis of diabetes) or psychological (i.e. moving towards acceptance of uncontrollable changes in health, such as less energy resulting from ageing). Whilst psychological outcomes were measured within this programme of research via the Hospital Anxiety and Depressions scale (HADS), this instrument might be too sensitive as it is designed to capture clinical symptoms of psychological health rather than more general psychological distress. A sub-clinical tool, such as the General Health Questionnaire (GHQ; Goldberg, 1978) or a broader measure of psychological well-being such as the Mental Adjustment to Cancer Scale (MACS; Watson et al., 1988) might be more appropriate in future research. An examination of the relationship between HBCs and more specific affective phenomena might also be fruitful. The findings presented in this thesis highlight significant relationships between HBCs and specific aspects of psychological well-being such as fear over recurrence, rather than anxiety in general. This would suggest that a disease-specific measure might be more appropriate than one that is generic.

Despite the limitations highlighted above, the overall programme of research remains of potential value. When quantitative variance is corroborated with the interviews, the five core HBC factors have been supported and expanded upon. Insight has been gained into how these might change during illness. In turn, the utility of the HBC construct has been made more explicit. Indeed, the use of HBCs in medical consultations has been shown to be feasible through accounts of such interactions already taking place. Furthermore, the addition of a qualitative element to eliciting patient HBCs has emerged as a potential method for enhancing the feasibility of the theory within clinical practice. The HBCQ offers potential utility as an educational tool, a method of improving patient/professional communication, and as a screening tool for HBC identification and stratification to appropriate aftercare services. Additionally, qualitative methodology, possibly IPA, would provide further insight into the unique experiences of patients and help identify any support they might need in terms of health status evaluations and subsequent health outcomes.

8.5. Emerging Issues and Directions for Future Research

In gaining further insight into health baseline comparisons, a number of areas for future research have emerged.

8.5.1. Health and Illness Orientated HBCs

One area where further research might be fruitful is the direction of HBCs (i.e. the extent to which people's baselines are positively or negatively focused). The former is proposed as indicating a positive mindset that is health orientated and the latter a negative mindset that is illness orientated: e.g. consideration of negative treatment side-effects versus positive treatment outcomes; consideration of past health versus past illness, etc.). This issue was

highlighted from the salience of social comparison baselines. Previous research in health psychology and other areas have found that social comparisons are either 'upward' or 'downward' (i.e. comparisons with people who are perceived as superior or inferior on the comparative domain, respectively). There is a wealth of research demonstrating the negative impact of upward comparisons, such as using these comparisons as a way of 'self-handicapping' (Sheppard and Taylor, 1999). A body of research also demonstrates the positive impact of downward comparisons, such as the alleviation of negative affect (Gibbons and Gerrard, 1997) or increased satisfaction with one's own circumstances (Buunk et al., 2001). In contrast, other researchers have tested the hypothesis that negative and positive outcomes are not the result of the direction of these social comparisons, but more so whether they are motivated by a desire to *contrast* or *identify* with the comparator (Brown, Novick, and Kelley, 1992).

The implications of comparative directions in self-evaluation processes highlighted within the literature are clearly vast and thus greater insight into the impact of different HBC mindsets (i.e. health and illness orientated) might shed light on some of the differences between the outcomes obtained during and post-treatment. For example, social comparison baselines adopted during treatment were the only HBCs to remain significant predictors of cancer-specific QoL during the same period and longitudinally. Is this because their direction remained stable whilst other HBCs changed from being health orientated to illness orientated or vice versa? Furthermore, which factors, internal or external, contribute to a shift from health orientated HBCs to illness orientated, and vice versa? In the literature on self-management of chronic illness, research by Audulv (2010) suggests that people can fluctuate between health and illness orientated behaviours. For example, efforts to be health orientated can lead to the cessation of illness orientated behaviours (e.g. medication taking), which ultimately leads to health deterioration and a need to be illness orientated in order to attend to returning symptoms. In other words, there is an adaptive illness orientation and a maladaptive illness orientation that needs to be differentiated.

In the current programme of research, there was some evidence within the interviews that being confronted with a cancer diagnosis contributed to a shift towards health orientation, supporting the hypothesis that threats to health can trigger adjustments in HBCs. Whether this leads to cyclical fluctuations between health and illness orientated cognitions, as described in the example of self-management (Audulv, 2010), remains a complex question requiring further research. Given the health implications of upward and downward social comparisons, such insight could prove highly beneficial in terms of expanding the utility of the HBC framework and providing scope to intervene at important periods throughout the illness trajectory.

8.5.2. Illness Prevention

In this study the HBCs of people experiencing a chronic and life-threatening illness have been explored. However, the theory might also enhance understanding of how 'healthy' people evaluate their health status and any implications this might have for future health or illness. Thus, rather than examine HBCs solely in terms of reaction or adjustment to illness, HBCs could be examined from a preventative angle. In particular, the ways in which different HBCs contribute to positive and negative health behaviours, such as health

screening, smoking, exercise, and changes in diet, would be of interest. Which HBCs motivate behaviour change?

8.5.3. HBCs throughout the Lifespan

An understanding of how HBCs change from childhood to adolescence, through to adulthood and old age might provide insight into the ways in which HBCs adjust naturally and in response to health crises. Such research might also examine how HBCs develop along with the individual and their interaction with society. Do HBCs emerge from innate interactions with bodily signals such as hunger, or are they learnt through observation and social influences? A tendency to adjust ones HBCs to accommodate current conditions or health challenges might be adaptive. This would be indicative of situational flexibility, which has been a strong predictor of health status (Myers, 1998; Rozanski and Kubzansky, 2005). However, a tendency to adjust ones baselines too readily may result in an over-reaction to a minor health problem.

According to Maslow's (1943) hierarchy of needs, responding to physiological indicators such as hunger, thirst, and fatigue would be responding to our greatest needs and thus achieving homeostasis. Not only are these needs easily detected, but they must be responded to in order to survive. Therefore, it could be argued that HBCs are formed at a very early stage. On the other hand, it could also be argued that these needs are initially learnt via social input, such as being fed when one is crying, which in turn enhances feelings of well-being. This might indicate that early social input is necessary for the initial establishment of HBCs. It is likely that HBCs are influenced at an early age by parents and other external inputs such as the media, as has been found with children's health knowledge (Bendelow, Williams, and Oakley, 1996; Tinsely, 1992). The impact of these social influences might prove an interesting future direction for insight into the formation of HBCs.

Along the same continuum, it could be argued that HBCs are more significant as one ages and is confronted with progressive and enduring changes in health status. There is not always a clear line between signs of ageing and deteriorating health (Vincent et al., 2003), and using the HBC framework to facilitate successful ageing might be worth exploring. An increase in longevity has resulted in a subsequent increase in the number of people living with long-term conditions (DH, 2010a). This is projected to rise rapidly in coming years. The extra years of life are not usually healthy ones, however, but spent living with one or more chronic conditions. The HBC construct might help develop ways of helping people adjust to normal ageing and age-related conditions.

In summary, several potential applications of the HBC concept have been identified. However, before any interventions are trialled, ideally, the next research stage would be to further refine HBC theory into a model of health. Before this, however, it would be useful to share the ideas presented within this thesis with clinicians and other health professionals. In particular, valuable feedback could be gained on the potential utility of the HBC concept in facilitating patient-clinician interactions. This could be taken forward via a focus group aimed at discussing the feasibility of such an approach to the patient-clinician relationship. Similarly, such focus groups could be held with patients. Any feedback might assist in refining the HBC concept into a model, which can then be used to inform the development of

interventions. Interventions based on underlying theoretical frameworks can be tested more rigorously, enhancing external validity and practical application (White et al., 2009). The emerging model would require further testing within the field of health psychology and within different contexts.

8.6. Conclusions

This thesis has made a number of significant and original contributions to knowledge within the fields of health psychology and psycho-oncology. Firstly, insight has been gained into the ways in which people evaluate their health status. Secondly, significant relationships between specific HBCs and the QoL and emotional well-being of people with cancer have been highlighted. Thirdly, the potential application of the construct beyond psycho-oncology has been explored, with emphasis placed on health promotion as well as illness interventions. Finally, this thesis has contributed to knowledge in a more theoretical sense, providing a novel concept that provides new insight and knowledge into established models of health and subjective health status. The potential to develop HBC theory into a model has been offered as the next ideal stage of research into health baseline comparisons.

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APPENDICES A

ETHICAL APPROVAL

Appendix Ai: Study 1 Ethical Approval from Cranfield University

Cranfield Health

Cranfield
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25 May 2006

Nicola Davies
Cranfield Health
Cranfield University
Silsoe
Bedfordshire
MK45 4DT

Direct line: +44 (0) 1525 863450
Direct fax: +44 (0) 1525 863533
Email: s.primrose@cranfield.ac.uk

Dear Nicola

Project Reference No 01/06 : The Development of a Health Evaluations Questionnaire

Thank you for submitting the requested amendments to the above project, I can confirm that I am happy to take Chairman's Actions approving the study can go ahead.

Yours sincerely

Dr Sandy Primrose
Chairman, Cranfield Health Ethics Committee

THE QUEEN'S
ANNIVERSARY PRIZES
FOR HIGHER AND FURTHER EDUCATION
2005

268

Appendix Aii: Study 2 Ethical Approval from Cranfield University

Cranfield Health

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12 October 2006

Nicola Davies
Cranfield Health
Cranfield University
Silsoe
Bedfordshire
MK45 4DT

Direct line: +44 (0) 1525 863450
Direct fax: +44 (0) 1525 863533
Email: s.primrose@cranfield.ac.uk

Dear Nicola

Project Reference No 04/06 :   An Investigation into Possible Correlations between Health Evaluations and Quality of Life in Oncology

Thank you for submitting the requested amendments to the above project, I can confirm that I am happy to take Chairman's Actions approving the study can go ahead.

Yours sincerely

Dr Sandy Primrose
Chairman, Cranfield Health Ethics Committee

THE QUEEN'S
ANNIVERSARY PRIZES
FOR HIGHER AND FURTHER EDUCATION

2005

Appendix Aiii: Study 2 Ethical Approval from Bedford Hospital R&D

Bedford Hospital **NHS**

NHS Trust

Research and Development Department
Crown House
Britannia Road
Bedford
MK42 9DJ
01234 355 122
Ext: 5855 / 5965

30th June 2006

Miss Nicola Davies
Mailbox 534
4B Doug Harris Way
Cranfield University
Barton Road
Silsoe
Bedfordshire
MK45 4DT

Dear Miss Davies

RE: The Role of Health Evaluations in Oncology: Quality of Life and Patient Choice.

Thank you for submitting your research project.

I am happy for your research project to commence.

Yours sincerely

Mr Ed Neale FRCOG
Medical Director

Appendix Aiv: Study 3 Ethical Approval from Cranfield University

Cranfield Health

Cranfield
UNIVERSITY

27 September 2007

Nicola Davies
Cranfield Health
Cranfield University
Silsoe
Bedfordshire
MK45 4DT

Dear Nicola

Project Reference No 06/07: Pilot Testing Version 2 on the Health Baseline Comparison Questionnaire

Thank you for submitting the requested amendments to the above project, I can confirm that I am happy to take Chairman's Action approving the study can go ahead.

Yours sincerely

Dr Sarah Morgan
Acting Chair, Cranfield Health Ethics Committee

Appendix Av: Study 4 Ethical Approval from Cranfield University

21 November 2007

Nicola Davies
Cranfield Health
Cranfield University
Silsoe
Bedfordshire
MK45 4DT

Dear Nicola

Project Reference No 10/07: Health Baseline and Quality of Life Fluctuations throughout Breast Cancer Chemotherapy

Thank you for submitting the requested amendments to the above project, I can confirm that I am happy to take Chairman's Action approving the study can go ahead.

Yours sincerely

Dr Claire Turner
Acting Chair, Cranfield Health Ethics Committee

Appendix Avi: Study 4 Ethical Approval from Hertfordshire Local Research Ethics Committee

Hertfordshire REC
Location Code Q7
Via QEII Hospital Post Room
Howlands
Welwyn Garden City
Herts
AL7 4HQ

Telephone: 01707 362583
Facsimile: 01707 394475
17 January 2008

Miss Nicola J Davies
PhD Researcher
Cranfield University
18 Mitchell Road, Wharley End,
Cranfield
Bedfordshire
MK43 0TE

Dear Miss Davies

Full title of study:	**Health Baseline Fluctuations throughout Breast Cancer Chemotherapy: Quality of Life Implications**
REC reference number:	**07/H0311/212**

Thank you for your letter of 05 January 2008, responding to the Committee's request for further information on the above research and submitting revised documentation. The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion
On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites
The Committee has designated this study as exempt from site-specific assessment (SSA. There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval
The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Appendix Avi continued: Study 4 Ethical Approval from Hertfordshire Local Research Ethics Committee

Approved documents
The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		30 November 2007
Investigator CV		24 November 2007
Protocol	V2	05 January 2008
Covering Letter		27 November 2007
Letter from Sponsor		22 November 2007
Compensation Arrangements		22 November 2007
Interview Schedules/Topic Guides	V1	17 November 2007
Questionnaire: HBCQ	V2	26 November 2007
Questionnaire: HADS		
Questionnaire: QLACS		
Letter of invitation to participant	V1	17 November 2007
Participant Information Sheet	V2	05 January 2008
Participant Consent Form: CI Copy	V1	08 November 2007
Participant Consent Form: Participant Copy	V1	08 November 2007
Participant Consent Form: Interview CI Copy	V1	08 November 2007
Participant Consent Form: Interview Participant Copy	V1	08 November 2007
Response to Request for Further Information		05 January 2008
Letter re Data Storage		03 January 2008
Support Groups Information	V1	24 November 2007
Supervisor CV		
Invitation Letter Interview	V1	17 November 2007

R&D approval
All researchers and research collaborators who will be participating in the research at NHS sites should apply for R&D approval from the relevant care organisation, if they have not yet done so. R&D approval is required, whether or not the study is exempt from SSA. You should advise researchers and local collaborators accordingly.

Appendix Avi continued: Study 4 Ethical Approval from Hertfordshire Local Research Ethics Committee

Guidance on applying for R&D approval is available from http://www.rdforum.nhs.uk/rdform.htm.

Statement of compliance
The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review
Now that you have completed the application process please visit the National Research Ethics Website > After Review
Here you will find links to the following
   a) Providing feedback. You are invited to give your view of the service that you have received from the National Research Ethics Service on the application procedure. If you wish to make your views known please use the feedback form available on the website.
   b) Progress Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
   c) Safety Reports. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
   d) Amendments. Please refer to the attached Standard conditions of approval by Research Ethics Committees.
   e) End of Study/Project. Please refer to the attached Standard conditions of approval by Research Ethics Committees.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nationalres.org.uk.

With the Committee's best wishes for the success of this project
Yours sincerely

Dr Steve Eckersall
Chair

Copy to: Professor Clifford Friend
                      Cranfield University
                      Cranfield
                      Bedfordshire
                      MK43 0AL

                      Dr Mohammed Wasil
                      Assisant Director R&D
                      Bedford Hospital NHS Trust
                      Crown House
                      Brittania Road
                      Bedford MK40 2AW

Appendix Avii: Study 4 Approval from Milton Keynes Hospital

Dr. Jill A. Stewart F.R.C.R.

Northamptonshire Centre for Oncology   The Saxon Clinic
Northampton General Hospital   Saxon Street
Cliftonville   Eaglestone
Northampton   Milton Keynes
NN1 5BD   Bucks
                                                                          MK6 5LR

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Tel: 01604 545238
e-mail jillastewart@doctors.org.uk   Tel: 01908 665533
Mobile   07967 103823   Fax No: 01908 608112

6/11/2007

Nicola Davies   BSc (Hons); MSc Comm.
PhD Researcher,
Health Psychology Consultancy.

Dear Nicola,

Thank you for advising us on your proposed study on quality of life for breast cancer patients undergoing chemotherapy.

I confirm that I would be very happy for you to approach the patients under my care at the Macmillan Unit in Milton Keynes Hospital.

Best wishes with the study,
Yours sincerely,

Dr. Jill Stewart.
Consultant Clinical Oncologist.
GMC 1601880.

APPENDICES B

PARTICIPANT INFORMATION

Appendix Bi: Study 1 Participant Information Sheet

<u>**Participant Information Sheet**</u>
<u>**The Development of a Health Evaluations Questionnaire**</u>

You are being invited to take part in a research study. Before deciding whether you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully and to discuss it with friends, family and health professionals if you wish. Please also feel free to contact myself on the details provided at the end of this information sheet if any of the information is not clear or if you would like further information.

Consumers for Ethics in Research (CERES) publish a leaflet entitled 'Health Research and You'. This leaflet gives more information about health research and looks at some of the questions you may like to ask. A copy can be obtained from CERES, PO Box 1365, London, N16 0BW or http://www.ceres.org.uk/order.htm.

Thank you for taking the time to read this.

What is the purpose of the study?
The study aims to pilot test a questionnaire developed to identify the various ways in which individuals evaluate their health status. The questionnaire is to be applied in a clinical setting at a later date in an effort to improve quality of life for cancer patients.

Why have I been chosen?
You have been chosen to assist with this study due to the unique experience and insight you can offer on the ways in which you personally evaluate your health status. Your participation in this study will enhance the quality of a questionnaire to be applied in a clinical setting with cancer patients in the near future.

Do I have to take part?
Taking part in the study is entirely voluntary. If you decide to take part you will be given this information sheet to keep and will further be asked to sign two consent forms, one for your retention and one for the retention of the researcher. If you do decide to take part, you are not obliged to answer any questions you are uncomfortable with.

What will happen to me if I take part?
By consenting to take part in the study you will be agreeing to complete a questionnaire asking questions about the approaches you adopt when evaluating your health status. The questionnaire can be completed in the comfort of your own home and returned the Principal Investigator's mailbox. Taking part in the study will incur no financial costs to yourself and should take no longer than 20 minutes of your time.

What are the possible benefits of taking part?
On a personal level, taking part in this study could give you a better insight into the ways in which you approach your health and any changes you may like to make to this approach. On a larger scale, the information gained from this study may help in the treatment of cancer patients in the form of improved information provision, as well as enhanced patient choice and quality of life.

Appendix Bi continued: Study 1 Participant Information Sheet

What are the possible disadvantages and risks of taking part?
We are always required to tell you about any risks to you should you agree to take part in research. However, in this instance no such risks are foreseen.

What arrangements are made for negligent harm?
If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay for it. If you have concerns about the way you have been treated in relation to this study, please contact: Clifford Friend, Head, Cranfield Health, Cranfield University, MK45 4DT.

Will my taking part in this study be kept confidential?
If you consent to take part in the study all information which is collected about you will be kept strictly confidential and will be kept on a password protected laptop. Completed questionnaires will be identifiable by participant numbers rather than names, ensuring confidentiality of any paper copies. Further to this, data will be safely destroyed once the study is completed.

What will happen to the results of the research study?
The full study is expected to be completed by the end of January 2009, with any findings being presented for publication and distribution within the health sector. Names will be removed from any publications or reports, ensuring anonymity and confidentiality for all participants. Further, participants will be provided with the opportunity to request a copy of published results.

Who is organising and funding the research?
The research is being funded by Cranfield University.

Who has reviewed the study?
Cranfield Health Ethics Committee.

Contact for Further Information

The Primary Researcher, Nicola Davies (BSc, MSc Comm), or Research Supervisor, Dr. Tracey Bailey, can be contacted at any time prior to or during study participation:

Nicola Davies,	Dr. Tracey Bailey
Mail Box 534, 4B Doug Harris Way,	Lecturer in Biomedicine
Cranfield University,	Cranfield Health
Barton Road,	Cranfield University, Silsoe
Silsoe,	Beds., MK45 4DT
Bedfordshire,	01525 863561
MK45 4DT	t.a.bailey@Cranfield.ac.uk
07929 019045	
n.davies.s06@cranfield.ac.uk	

Appendix Bii: Study 2 Participant Information Sheet (where information differs from appendix Bi).

Participant Information Sheet
Health Evaluations and Quality of Life in People with Cancer

What is the purpose of the study?
The study aims to provide insight into ways in which quality of life can be improved for individuals experiencing cancer and any subsequent treatment.

What will happen to me if I take part?
By consenting to take part in the study you will be agreeing to complete two questionnaires, which should take no longer than 15 minutes of your time. These questionnaires can be completed during your visit to the Primrose Unit or you can take them home to complete them at your leisure. If the latter option is preferred, a prepaid self-addressed envelope will be provided for the return of completed questionnaires. Taking part in the study will incur no financial costs to yourself.

What if new information becomes available?
Sometimes during the course of research, new information becomes available about patients. This could include information regarding difficulties with coping or the emergence of behaviours detrimental to the patient's treatment, just to name two. If such information does become available, your Oncologist will discuss this with you.

What if something goes wrong?
The NHS does not have any indemnity arrangements for patients should any adverse event occur during the investigations of treatment process of any illness or condition. Neither are there any special indemnity arrangements for patients who are participating in research studies. However, should something go wrong and you suffer harm due to negligence of any employee of the Trust it would be open to you to pursue the matter through the NHS complaints procedure in exactly the same way as you would be able to do if you were receiving standard NHS treatment and were not participating in a research study. (Bedford Hospital NHS Trust Indemnity Clause).

What will happen to the results of the research study?
The full study is expected to be complete by the end of January 2009, with any findings being presented for publication and distribution within the health sector. All participants will be provided with the opportunity to request a copy of published results.

Who has reviewed the study?
The study has been reviewed by Bedford Hospital Research and Development Ethics Committee. All steps have been taken to ensure the research is safe and of minimal patient burden.

Appendix Biii: Study 3 Participant Information Sheet (where information differs from appendix Bi).

<u>**Participant Information Sheet**</u>
<u>**The Pilot Testing of a Health Evaluations Questionnaire**</u>

What is the purpose of the study?
The study aims to pilot test a questionnaire developed to identify the various ways in which individuals evaluate their health status. The questionnaire is to be applied in a clinical setting in an effort to improve quality of life for cancer patients.

Why have I been chosen?
The cancer support group for which you are a member was invited to approach its members for feedback on a new health questionnaire to be used with cancer patients. You have been chosen to assist with this study due to the insight you can offer on the ways in which you personally evaluate your health status. Your participation in this study will enhance the quality of a questionnaire to be applied in a clinical setting with cancer patients in the near future.

What will happen to me if I take part?
By consenting to take part in the study you will be agreeing to complete a questionnaire asking questions about the approaches you adopt when evaluating your health status. The questionnaire can be completed in the comfort of your own home and returned the Principal Investigator's email address. Taking part in the study will incur no financial costs to yourself and should take no longer than 20 minutes of your time.

Appendix Biv: Study 4 Participant Information Sheet (where information differs from appendix Bi).

<div align="center">

Participant Information
Health Judgements and Quality of Life during and after Chemotherapy

</div>

What is the purpose of the study?
The study aims to provide insight into the ways people with breast cancer think about their health and any impact this may have on their quality of life. It is hoped that any findings can be used to improve quality of life for individuals experiencing cancer and any subsequent treatment.

What will happen to me if I take part?
By consenting to take part in the study you will be agreeing to complete three questionnaires at two separate points in time: during chemotherapy and approximately two months after chemotherapy. Each set of questionnaires should take no longer than 30 minutes of your time. These questionnaires can be completed during your visit to the Primrose Unit or you can take them home to complete them at your leisure. If the latter option is preferred, a prepaid self-addressed envelope will be provided for the return of completed questionnaires. Taking part in the study will incur no financial costs to yourself.

You will also be provided with the opportunity to take part in an interview of no longer than 40 minutes, if you wish to expand on any of the questionnaire responses. This interview will take place at the Primrose Unit during one of your visits to the Unit. You will have the opportunity to make requests about the timing and recording of the interview. Furthermore, taking part in the questionnaires does not obligate you to take part in an interview.

Will any consideration be taken in terms of changes in my ability to consent?
If for any reason there is a loss in your ability to provide informed consent to take part in this study, for your own safety your participation in the study will cease and any previously provided information you have provided from yourself will be safely destroyed.

Will my taking part in this study be kept confidential?
The Chief Investigator and your Oncologist will be the only people aware of your participation in the study. The Chief Investigator and research supervisors will have access to your questionnaires, but only the Chief Investigator and your Oncologist will know your identity. Your questionnaire data will be kept on a password protected laptop or in a locked cabinet that only the Chief Investigator can access. No names or personal details will be included in any publications and data will be analysed by patient numbers or pseudonyms. All personal data will be safely destroyed at the end of the study, including any tape-recorded data from interviews. The latter will be either be safely destroyed or over-written after all data has been analysed. No data will be kept beyond five years, in regulation with Cranfield University's data retention policy.

Who has reviewed the study?
The study has been reviewed by Cranfield University Ethics Committee, Bedford Hospital Research and Development, and the Hertfordshire Local Research Ethics Committee. All steps have been taken to ensure the research is safe and of minimal patient burden.

APPENDICES C

HBCQ, VERSION 1-4

Appendix Ci: Study 1 Pilot HBCQ (v1)

<u>My Health</u>

We all have different beliefs and approaches to our health. Please complete this questionnaire by **ticking** the boxes most representative of YOUR personal beliefs and approaches to <u>YOUR</u> health, selecting **<u>ONE</u>** answer per question.

1. When evaluating my health, I take into consideration the health of people I know.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

2. When evaluating my health, I take into consideration what is portrayed in the media as being healthy or unhealthy.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

3. When evaluating my health, I take into consideration my past health.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

4. When evaluating my health, I take into consideration my age.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

5. When evaluating my health, I take into consideration personal circumstances in my life.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

6. When evaluating my health, I take into consideration the health of people who appear healthier than myself.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

7. When evaluating my health, I take into consideration the health of people who appear less healthy than myself.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

8. When evaluating my health, I take into consideration the health of people with the same medical condition as myself.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

9. When evaluating my health, I take into consideration the health of people who do not have the same medical condition.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

10. When evaluating my health, I take into consideration the health of people who are similar to myself.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

11. When evaluating my health, I take into consideration the health of people who are dissimilar to myself.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

12. When evaluating my health, I do not take into consideration other people's health.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

13. When evaluating my health, I take into consideration my previous personal experiences with illness.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

1. When evaluating my health, I take into consideration my mood at that particular point in time.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

2. When evaluating my health, I take into consideration my long-term mood status.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

16. I have more trust in my family's ability to evaluate my health than my own ability.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

17. I have more trust in my friend's ability to evaluate my health than my own ability.

☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

18. I have more trust in my doctor's ability to evaluate my health than my own ability.
☐Strongly Agree ☐Agree ☐Don't Know ☐Disagree ☐Strongly Disagree

19. What other factors, if any, do you take into consideration when evaluating your health?

20. How would you rate your overall health?

Very Poor   1   2   3   4   5   6   7   Excellent

Please provide an explanation for this rating, including any information that is relevant to YOU:

21. How would you rate your overall quality of life?

Very Poor   1   2   3   4   5   6   7   Excellent

Please provide an explanation for this rating, including any information that is relevant to YOU:

Personal Details

The following information is purely for interpretation of data and will not be used in any other way.

Age, in Years:

☐20 or under   ☐21-30   ☐31-40   ☐41-50   ☐51-60   ☐61+

Gender: ☐Male   ☐Female

Marital Status:

☐Single   ☐Long-Term Relationship   ☐Married   ☐Divorced
☐Widowed

Educational Level:

☐No Qualifications   ☐GCSE/A Level   ☐Undergraduate
☐Postgraduate

Do you have a persistent and enduring illness or medical condition, such as asthma, diabetes, arthritis, etc.?

☐Yes   ☐No

If so, please state what this medical condition is:

Duration of Illness/Medical Condition: **Years**

Appendix Cii: Study 2 HBCQ (v2)

My Health

We all have different beliefs and approaches to our health. Please complete this questionnaire by **ticking** the boxes most representative of YOUR personal beliefs and approaches to <u>YOUR</u> health in general, selecting **ONE** answer per question. Some of the questions may sound similar, but please answer each one. There are no right or wrong answers.

My Health	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
1. When thinking about how healthy I am, I take into consideration my lifestyle (e.g. diet, exercise, smoking, alcohol consumption, etc.)					
2. When thinking about how healthy I am, I take into consideration my appearance (e.g. skin colour, hair condition, weight, etc.)					
3. When thinking about how healthy I am, I take into consideration what I *can* do (e.g. hobbies, physical and social activities, etc.)					
4. When thinking about how healthy I am, I take into consideration my physical fitness (e.g. exercise level, strength, stamina, etc.)					
5. When thinking about how healthy I am, I take into consideration the health of people I know (e.g. friends, family, etc.)					
6. When thinking about how healthy I am, I take into consideration what I see in the media (e.g. health advice/warnings, diet fads, celebrity etc.)					
7. When thinking about how healthy I am, I take into consideration my past health/ ill health.					
8. When thinking about how healthy I am, I take into consideration my age.					
9. When thinking about how healthy I am, I take into consideration how I feel at that particular time (e.g. present mood, stress experienced, etc.)					
10. When thinking about how healthy I am, I take into consideration the health of people who appear healthier than myself.					
11. When thinking about how healthy I am, I take into consideration the health of people who appear less healthy than myself.					

Appendix Cii continued: Study 2 HBCQ (v2)

My Health	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree
12. When thinking about how healthy I am, I take into consideration the health of people with the same type of cancer.					
13. When thinking about how healthy I am, I take into consideration the health of people without cancer.					
14. When thinking about how healthy I am, I take into consideration the symptoms I expect to experience from this type of cancer.					
15. When thinking about how healthy I am, I take into consideration the type of treatment I am undergoing (e.g. radiotherapy, medication, etc.)					
16. When thinking about how healthy I am, I take into consideration the side-effects of my cancer treatment (e.g. tiredness, nausea, etc.)					
17. When thinking about how healthy I am, I take into consideration how many times I am required to visit the hospital.					
18. When thinking about how healthy I am, I take into consideration the health of people who are dissimilar to myself.					
19. When thinking about how healthy I am, I do not take into consideration other people's health.					
20. I have more trust in my friend's and family's ability to make decisions about my health than my own ability.					
21. I have more trust in my doctor's ability to make decisions about my health than my own ability.					

22. **Please add any further comments you would like to share about how you approach judging your health.**

Appendix Ciii: Study 3 HBCQ (v3)

Health Baseline Questionnaire

Nicola Davies, PhD Researcher
Cranfield University
26 The Crescent
Wharley End
Beds., MK43 0SU
Phone: 07989 195560
Email: n.davies.s06@cranfield.ac.uk

Often, we are not aware of how much we think about our health, even when confronted by substantial health difficulties. Before completing this questionnaire, please spend a few moments focusing on your current state of health. Please answer each item. There are no wrong or right answers.

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
My healthy lifestyle choices (e.g. fruit in diet, regular exercise, moderate alcohol consumption, etc.)				
My unhealthy lifestyle choices (e.g. fat in diet, no exercise, high alcohol consumption, etc.)				
Signs of good health in my appearance (e.g. healthy weight, clear complexion, etc.)				
Signs of ill health in my appearance (e.g. overweight/ underweight, pale complexion, hair condition, etc.)				
The things I can do (e.g. exercise, hobbies, etc.)				

Appendix Ciii continued: Study 3 HBCQ (v3)

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The things I cannot do (e.g. exercise, hobbies,, etc.)				
My past good health				
My past ill health				
The natural ageing process				

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The signs and symptoms I might expect from breast cancer				
Any positive aspects of having cancer (e.g. appreciation of life, increased closeness to friends/family, etc.)				
Any side-effects of treatment (e.g. tiredness, nausea, etc.)				
Any benefits of treatment (e.g. destroying cancer cells, etc.)				
People with breast cancer who seem to be doing well				
People with breast cancer who seem to not be doing so well				
My health before developing cancer				

Appendix Ciii continued: Study 3 HBCQ (v3)

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The healthy people I see in the media (e.g. celebrities, real-life stories, etc.)				
The unhealthy people I see in the media (e.g. celebrities, real-life stories, etc.)				
People who appear healthier than me				
People who appear less healthy than me				
People who appear similar to me (e.g. same age, gender, social class, etc.)				
People who appear dissimilar to me in (e.g. different age, gender, social class, etc.)				
Colleagues who appear healthier than me				
Colleagues who appear less healthy than me				

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The enjoyment and relaxation in my life				
The stress in my life				

Appendix Ciii continued: Study 3 HBCQ (v3)

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
Any difficulties coping at that time				
My ability to socialise (e.g. with friends and family)				
My difficulties socialising (e.g. with friends and family)				
My ability to function well at work				
Any difficulties coping at that time				

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The positive opinions of people close to me (e.g. friends, family, etc.).				
The negative opinions of people close to me (e.g. friends, family, etc.).				
The positive feedback from my doctor.				
The negative feedback from my doctor.				
My own positive health judgements.				
My own negative health.				

Appendix Civ: Study 4 HBCQ (v3)

<p style="color:blue; text-align:center;">**Health Baseline Questionnaire**</p>

Often, we are not aware of how much we think about our health, even when confronted by substantial health difficulties. Before completing this questionnaire, please spend a few moments remembering a time when you were focusing on your health.

Please answer the items you feel able to, but feel free to leave any items you are uncomfortable with. There are no right or wrong answers.

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The enjoyment and relaxation in my life				
Any difficulties functioning at work				
My ability to socialise (e.g. with friends and family)				
Any difficulties with intimacy				
How well I am coping at that time				
Any difficulties socialising (e.g. with friends and family)				
My ability to function well at work				
Any difficulties coping at that time				
My positive feelings about the future				
The stress in my life				
My concerns about the future				
My ability to be intimate				

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The healthy people I see in the media (e.g. celebrities, real-life stories, etc.)				
People who appear less healthy than me				
People who appear similar to me (e.g. same age, gender, social class, etc.)				
The unhealthy people I see in the media (e.g. celebrities, real-life stories, etc.)				
Colleagues who appear healthier than me				
People who appear dissimilar to me in (e.g. different age, gender, social class, etc.)				
People who appear healthier than me				
Colleagues who appear less healthy than me				

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The negative feedback from my doctor				
My own positive health judgements				

Appendix Civ continued: Study 4 HBCQ (v3)

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The negative ways in which people respond to me (e.g. saying I look ill or being overly concerned, etc.)				
The positive feedback from my doctor				
The positive ways in which people respond to me (e.g. saying I look good, healthy, etc.)				
My own negative health judgements				

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
My healthy lifestyle choices (e.g. fruit in diet, regular exercise, moderate alcohol consumption, etc.)				
Signs of ill health in my appearance (e.g. overweight/underweight, pale complexion, hair condition, etc.)				
The things I can do (e.g. exercise, hobbies, etc.)				
My unhealthy lifestyle choices (e.g. fat in diet, no exercise, high alcohol consumption, etc.)				
My past good health				
The things I cannot do (e.g. exercise, hobbies, etc.)				
Signs of good health in my appearance (e.g. healthy weight, clear complexion, etc.)				
My past ill health				
The natural ageing process				

Appendix Civ continued: Study 4 HBCQ (v3)

When thinking about how healthy I am, I consider:	Not at All	A Little	Quite a Bit	Very Much
The signs and symptoms I might expect from this type of cancer				
People with the same type of cancer who seem to be doing well				
Any side-effects of treatment (e.g. tiredness, etc)				
People with breast cancer who seem to not be doing so well				
Any positive aspects of having cancer (e.g. appreciation of life, etc.)				
That I don't follow medical and lifestyle advice (e.g. don't change diet, don't take medication, etc.)				
My health before developing cancer				
My prognosis				
Benefits of treatment (e.g. destroying cancer cells, etc.)				
That I follow medical and lifestyle advice (e.g. change diet, take medication, etc.)				

APPENDICES D

FEEDBACK QUESTIONNAIRES

Appendix Di: Study 1 Feedback Questionnaire

<u>**Questionnaire Feedback**</u>

Approximately how long did it take you to complete this questionnaire?

☐Under 5 minutes   ☐5-10 minutes   ☐10-15 minutes
☐15-20 minutes   ☐Over 20 minutes

How would you rate the ease with which you were able to complete this questionnaire?

☐Very Easy   ☐Easy   ☐Don't Know   ☐Difficult   ☐Very Difficult

What did you find particularly easy about the questionnaire?   Please consider both structure and content.

What did you find particularly difficult about the questionnaire? Please consider both structure and content.

Do you have any further comments about how this questionnaire could be improved?

Thank you again for your help.   Please remember to send the completed questionnaires and consent forms to Mailbox 534.

Appendix Dii: Study 3 Questionnaire Feedback (where information differs from appendix Di).

<u>**Questionnaire Feedback**</u>

How useful was the aid on the front of the questionnaire, aimed at helping you to get into the frame mind of when you think about your health? (i.e. *"Often, we are not aware of how much we think about our health, even when confronted by substantial health difficulties. Before completing this questionnaire, please spend a few moments focusing on your current state of health."*)

☐Very Useful   ☐Useful   ☐Unsure   ☐Useless   ☐Very Useless

Please expand. For example, what else might you have found useful prior to completing the questionnaire?

What did you think of the booklet format?

☐ Excellent   ☐Good   ☐Unsure   ☐Bad   ☐Terrible

APPENDICES E

QUALITY OF LIFE QUESTIONNAIRES AND INTERVIEW SCHEDULE

Appendix Ei: Study 2 Quality of Life Questionnaire (Fairclough and Cella, 1996)

FACT-G (Version 4)

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

	PHYSICAL WELL-BEING	Not at all	A little bit	Some -what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family...............................	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill...	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some -what	Quite a bit	Very much
GS1	I feel close to my friends..	0	1	2	3	4
GS2	I get emotional support from my family....................	0	1	2	3	4
GS3	I get support from my friends...................................	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
	I am satisfied with my sex life	0	1	2	3	4

Appendix Ei continued: Study 2 Quality of Life Questionnaire

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some -what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness........	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying...	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some -what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

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Appendix Eii: Study 4 Quality of Life Questionnaire (Avis et al., 2005)

QLACS (Quality of Life in Adult Cancer Survivors)

INSTRUCTIONS: We would like to ask you about some things that can affect the quality of people's lives. Some of these questions may sound similar, but please be sure to answer all questions you feel comfortable with. Below is a scale ranging from "never" to "always". Please indicate how often each of these statements has been true for you in the past four weeks.

| 1 = Never | 2 = Seldom | 3 = Sometimes | 4 = About as often as not |
| 5 = Frequently | 6 = Very Often | 7 = Always | |

In the past 4 weeks …							
1. You had the energy to do the things you wanted to do.	1	2	3	4	5	6	7
2. You had difficulty doing activities that require concentrating.	1	2	3	4	5	6	7
3. You were bothered by having a short attention span.	1	2	3	4	5	6	7
4. You had trouble remembering things.	1	2	3	4	5	6	7
5. You felt fatigued.	1	2	3	4	5	6	7
6. You felt happy.	1	2	3	4	5	6	7
7. You felt blue or depressed.	1	2	3	4	5	6	7
8. You enjoyed life.	1	2	3	4	5	6	7
9. You worried about little things.	1	2	3	4	5	6	7
10. You didn't have energy to do the things you wanted to do.	1	2	3	4	5	6	7
11. You were bothered by pain that kept you from doing the things you wanted to do.	1	2	3	4	5	6	7
12. You felt tired a lot.	1	2	3	4	5	6	7
13. You were reluctant to start new relationships.	1	2	3	4	5	6	7
14. Your mood was disrupted by pain or its treatment.	1	2	3	4	5	6	7
15. You avoided social gatherings.	1	2	3	4	5	6	7
16. You were bothered by mood swings.	1	2	3	4	5	6	7
17. You avoided your friends.	1	2	3	4	5	6	7
18. You had aches or pains.	1	2	3	4	5	6	7
19. You had a positive outlook on life.	1	2	3	4	5	6	7
20. You were bothered by forgetting what you started to do.	1	2	3	4	5	6	7
21. You felt anxious.	1	2	3	4	5	6	7
22. You were reluctant to meet new people.	1	2	3	4	5	6	7
23. Pain or its treatment interfered with your social activities.	1	2	3	4	5	6	7
24. You were content with your life.	1	2	3	4	5	6	7

Appendix Eii continued: Study 4 Quality of Life Questionnaire

The next set of questions asks specifically about the effects of the cancer or its treatment. Again, for each statement, indicate how often each of these statements has been true for you in the past four weeks.

1 = Never   2 = Seldom   3 = Sometimes   4 = About as often as not
5 = Frequently   6 = Very Often   7 = Always

In the past 4 weeks …							
25. You appreciated life more because of having had cancer.	1	2	3	4	5	6	7
26. You worried that your family members were at risk of getting cancer.	1	2	3	4	5	6	7
27. You realized that having had cancer helps you cope better with problems now.	1	2	3	4	5	6	7
28. You were self-conscious about the way you look because of your cancer or its treatment.	1	2	3	4	5	6	7
29. You worried about whether your family members might have cancer-causing genes.	1	2	3	4	5	6	7
30. You felt unattractive because of your cancer or its treatment.	1	2	3	4	5	6	7
31. You worried about dying from cancer.	1	2	3	4	5	6	7
32. You were bothered by hair loss from cancer treatment.	1	2	3	4	5	6	7
33. You worried about cancer coming back.	1	2	3	4	5	6	7
34. You felt that cancer helped you to recognize what is important in life.	1	2	3	4	5	6	7
35. You felt better able to deal with stress because of having had cancer.	1	2	3	4	5	6	7
36. You worried about whether your family members should have genetic tests for cancer.	1	2	3	4	5	6	7
37. You felt people treated you differently because of changes to your appearance due to your cancer or its treatment.	1	2	3	4	5	6	7
38. Whenever you felt a pain, you worried that it might be cancer again.	1	2	3	4	5	6	7
39. You were preoccupied with concerns about cancer.	1	2	3	4	5	6	7

Appendix Eiii: Study 4 Emotional Well-Being Questionnaire (Zigmond and Snaith, 1983*)

Hospital Anxiety and Depression Scale (HADS)

Instructions: We are aware that emotions play an important part in most illnesses. Please read each statement and circle the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

I feel tense or wound 'up'	Most of the time	A lot of the time	From time to time, occasionally	Not at all
I still enjoy the things I used to enjoy	Definitely as much	Not quite so much	Only a little	Hardly at all
I get a sort of frightened feeling as if something awful is about to happen	Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
I can laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all
Worrying thoughts go through my mind	A great deal of the time	A lot of the time	From time to time, but not too often	Only occasionally
I feel cheerful	Not at all	Not often	Sometimes	Most of the time
I can sit at ease and feel relaxed	Definitely	Usually	Not often	Not at all
I feel as if I am slowed down	Nearly all the time	Very Often	Sometimes	Not at all
I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all	Occasionally	Quite often	Very often
I have lost interest in my appearance	Definitely	I don't take as much care as I should	I may not take quite as much care	I take just as much care as ever
I feel restless as I have to be on the move	Very much indeed	Quite a lot	Not very much	Not at all
I look forward with enjoyment to things	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
I get sudden feelings of panic	Very often indeed	Quite often	Not very often	Not at all
I can enjoy a good book or radio or TV program	Often	Sometimes	Not often	Very seldom

Appendix Eiv: Study 5 Interview Schedule

<u>Interview Schedule</u>

Questions will be guided by the participants and the areas of the HBCQ which they would like to discuss. Interviewees will be provided with their completed questionnaire for referral.

If participants have difficulty guiding the interview themselves, here is an example of how the interview will commence and finish, as well as a few example questions and probes. Ultimately, questions will be closely based on the questionnaire items participants most strongly agreed or disagreed with in order to obtain an explanation of these responses.

Verbal information: Thank you very much for taking the time to come and talk to me. I appreciate your help with my study. I want you to know that you can stop the interview at any time, whether you just want a break or want to stop the interview completely. Whether or not you continue with the study will not affect your treatment in any way.

The interview will be based on your responses to a questionnaire you answered a few months ago. I will not ask you about any questions you chose not to answer or have no opinions you want to discuss, but I will ask you to expand on the questions you did answer. If at any time I ask you about any issues you would rather not discuss, please let me know and we will move on to the next question. Furthermore, if you are affected by any of the issues discussed today, there is a Breast Cancer Nurse who I can arrange for you to see.

In your consent form, you expressed that you have no objection to the interview being recorded via tape recorder/written. We will now start the interview.

17. How are you feeling today?
18. Thank you again for completing this questionnaire. Can you tell me how you found it?
19. Was there anything in particular that you would like to discuss about the questionnaire or your answers before I go into the questions more specifically?
20. The questionnaire asked you questions about the type of things that influence how healthy you think you are. Can you tell me which of these seemed most relevant to you?
    Probe: Can you expand on this at all?
21. I can see from your questionnaire responses that you focus on (insert as appropriate) when thinking about how healthy or unhealthy you are.
    Probe: Could you tell me a little more about this?
22. I can see from your questionnaire responses that you least focus on (insert as appropriate) when thinking about how healthy or unhealthy you are.
    Probe: Could you tell me a little more about this?
23. I can see from your responses that you used (insert as appropriate) extensively/very little, but then this reduced/increased after treatment.
    Probe: Do you know why this change might have occurred?

24. Has the way you think about your health changed since being diagnosed with cancer?
    Probe: Are there factors related to your general health that you consider now that you didn't use to? How about in terms of cancer?
25. Do you feel your responses to the questionnaire differed at the two points of completion?
    Probe: In what ways? How would you explain this change?
26. During your treatment, how much focus has been placed on your health?
    Probe: Would you like to see any changes in the way your general health and cancer health are approached throughout the cancer experience?
27. Do you feel that that knowledge of your questionnaire responses could in anyway assist doctors in helping you either during or after treatment?
    Probe: Please explain.
28. Can you think of any information that would have helped you during or after your diagnosis and treatment?
29. Thank you for answering my specific questions. Are there any other issues you would like to talk about or expand on?

Thank you again for your time. I provided my contact details and the details of some support groups at the beginning of the study. I will supply these details again in case you wanted to discuss any of the issues raised here with some of the support groups or to contact myself about the study.