

The Role of Empowerment in the Wellbeing of Cancer Patients



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Abstract

Background

The concept of patient empowerment, although acknowledged by the medical community as important, is rarely understood and seldom given priority in the illness trajectory of the cancer patient. A pilot study of a Shared Care Model amongst haematological cancer patients highlighted the fact that some patients spoke of a sense of empowerment and an overall sense of greater control when more fully included in the treatment and management of their condition.

Aims

The research which forms the basis of this thesis focused on the role of empowerment in the wellbeing of cancer patients. There were three objectives to be met by completing this research. Firstly, to demonstrate that empowerment is a uniquely identifiable concept and can be measured separately from other quality of life indicators. Secondly, the study sought to explore that concept that empowerment takes into account the way in which patients act upon their prognosis and optimise the outcomes of treatment. Thus it is believed that accessing tailored resources and support structures benefit cancer patients and those who are caring for them such as close family members and friends by helping the patient achieve an individual level of empowerment. Finally, the research sought to explore the concept that empowerment improves psychological outcome in patients. The benefits are increased empowerment and an active use of coping strategies amongst patients in order to regain a measure of control over their illness.

Methods

The Patient Empowerment Scale was developed to measure empowerment as an individual construct. The development of a measure to identify level of empowerment amongst cancer patients entailed the identification of markers for empowerment by the patient's use of support strategies and tailored resources. The scale was validated using the Rasch Extended Model. An extensive literature review and a series of in-depth interviews of Shared Care Model participants were completed in order to formulate the

Patient Empowerment Scale. The 28 item pilot scale was analysed using the RUMM program and statements which did not fit the model well were deleted from the final version of the scale. Other statements which were close in location and meaning were coalesced. This process resulted in a final 15 item Patient Empowerment Scale which was again validated using the Rasch Extended Model (RUMM program). The Patient Empowerment Scale (15 items) was shown to be a reliable measure of empowerment and fitted the model well.

A qualitative methodological approach sought to address and explore the second and third concepts. In addition, the concept of empowerment as it relates to motivation and self-efficacy was investigated qualitatively using in-depth interviewing technique. A phenomenological methodology was used to explore the 'lived experience of cancer patients' in regard to regaining control of their illness and the management thereof. Participants were interviewed using concepts identified for the Patient Empowerment Scale such as support strategies and use of resources. A series of interviews with breast cancer patients were conducted whereby patients responded to a number of questions. The questions explored areas such as support mechanisms in relation to cancer, their relationships with health professionals and significant others and their attitude toward and use of other resources and support systems such as support groups, spirituality, complementary therapies. In addition their views on acceptance and adaptation to their altered health status were explored.

Results

The research confirmed that it is feasible to measure empowerment as a separate quality of life indicator. Furthermore, that empowerment is linked to motivation and self-efficacy beliefs. The research also demonstrated that there are a number of core areas which are fundamental to regaining control and increasing empowerment for patients. These core areas are linked to support mechanisms, willingness to adapt and to access resources tailored to meet their needs.

Conclusion

Patient empowerment emerged as a key aspect of enhanced quality of life regardless of prognosis and improved psychological outlook.

Acknowledgements

“Like snowflakes, the human pattern is never cast twice. We are uncommonly and marvellously intricate in thought and action.”

-Alice Childress, playwright and actor.

This thesis has taken over five years to complete in addition to full time employment for the duration of the research. I have changed jobs three times within the university over that period of years and finally took refuge amongst like-minded people who appreciated the value of mixed methods research within the Department of General Practice here at UWA. There are a number of people who either deliberately or inadvertently kept me going throughout! Of those people, I would like to acknowledge my dearest husband who despite completing his own doctorate made sure I kept faith in myself despite my own self doubts. I would also like to thank my children sincerely for their down to earth normalcy regardless of study induced stress! Also for those colleagues and friends at work who were happy to do the ‘coffee run’ with me to keep the energy levels up!

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Chapter One

1.Introduction

Persons who are diagnosed with cancer will most often express their initial shock followed by a period where they sense a loss of control over their bodies and their lives. In order to regain control once again, the cancer patient adopts certain core strategies to utilise resources and support networks and help redress this imbalance. It is intended that by regaining a degree of control they will achieve a certain level of empowerment. However, the level to which each patient who uses these core strategies is empowered depends upon certain personal characteristics such as self-efficacy and the willingness and persistence needed to succeed.

Cancer is often perceived as one of the most disempowering illnesses. Aspects of the illness experience such as handing over treatment to a health care team are believed to impact upon the patient's ability to achieve a sense of empowerment. This is due to the necessity of having to accept certain regimens to survive and to hand over the management of one's illness to others. This process can render the patient and their family somewhat helpless in the face of a seemingly overwhelming illness. To this extent, the concept of patient empowerment is relatively new in the area of cancer research when compared with other major chronic diseases such as diabetes. However, regardless of prognosis, it has been noted that some cancer patients will remain very much in control of their situation whenever possible.

The concept of empowerment has remained a somewhat nebulous area amongst clinicians and they can be reluctant to acknowledge that it can positively affect the life of a patient once they are in control of certain aspects of their illness. Thus, this study set out to develop a self-administered measure of empowerment which would comprise a set of core strategies used by cancer patients to regain a sense of control over their condition and thus achieve a state of empowerment. Due to the fact that the concept of empowerment is closely associated with motivation, self-determination and self-efficacy, these concepts are also qualitatively explored. It is hoped that this will provide a greater understanding of which strategies are enablers to patient empowerment.

1.1 Rationale for the study

A pilot Shared Care project was conducted at the Haematology Centre of the Sir Charles Gairdner Hospital in 2000 (Ward et al. 2000). Patients who participated in the Shared Care project and were subsequently interviewed for the study highlighted a sense of empowerment and better control over their illness through greater involvement in the treatment regimen. Furthermore, most regarded being included more fully in the management of their condition as beneficial to their overall wellbeing. During the series of in-depth interviews, some patients spoke of empowerment in terms of being more fully included in their treatment and the day to day management of the illness. It was decided to explore the role that empowerment plays in the lives of cancer patients in terms of their ability to adapt and accept the illness and to function with a reasonable quality of life regardless of the prognosis. It was also intended that by validating a measure of empowerment, the more indefinable qualities associated with this concept would become clearer to clinicians and cancer patients themselves.

1.2 Development of a patient empowerment scale

Empowerment amongst cancer patients is recognized as an important means of regaining and maintaining a certain amount of control over their illness experience. However, empowerment is an ill-defined concept that often is spoken about in terms of individual means of coping without any definitive measure as to whether empowerment truly exists for the patient and to what extent. It was postulated that the development of a scale for measuring empowerment in an objective and quantifiable way would facilitate the understanding of the way in which empowerment is achieved and maintained by individual cancer patients. Objectivity therefore, would hopefully give credibility to the belief that empowerment is a very real and very important aspect of cancer patient coping strategies. The Institute for Objective Measurement (2002) has defined objective measurement as,

“An objective measurement estimate of amount stays constant and unchanging (within the allowable error) across the persons measured, across different brands of instruments, and across instrument users. The goal of objective measurement is to produce a reference standard common currency for the exchange of quantitative value, so that all research and practice relevant to a particular variable can be conducted in uniform terms.”

Thus the identification of markers for empowerment common to patients being treated for cancer would formulate a scale that could then be validated as a reliable measure of patient empowerment.

The exploration of the concept of wellbeing and empowerment in cancer patients necessitated a further qualitative section of the study in order to investigate more fully motivation, the support mechanisms and the resources utilised by cancer patients to maintain a sense of control over their illness. For this, a broader sample of patients was recruited in order to explore the components that were perceived by patients as important to them.

1.3 Objectives of the study

The Haematology Shared Care Model pilot project conducted at the Sir Charles Gairdner Hospital (Ward et al. 2000) demonstrated an improvement in the perceived quality of life for patients. Although the pilot Shared Care Model project was not a part of this doctorate, one concept that participants highlighted during the pilot project was that participation in the Shared Care Model made them feel ‘empowered’ to have a measure of control over the management of their cancer (Ward et al. 2000). Enhanced quality of life was achieved as a consequence of improved emotional wellbeing in terms of reduced levels of depression and anxiety experienced by the patients. Quality of life for patients was also improved in terms of empowerment demonstrated by an increased involvement in decision-making regarding the management of their illness and the successful ability to utilize strategies to enable them to feel that they were in control of their cancer.

Following on from the Shared Care project there are three main objectives to be achieved during the course of this research. They are as follows -

- Empowerment is a uniquely identifiable concept and can be measured separately from other quality of life indicators. Empowerment takes into account the way in which patients act upon their prognosis and optimise the outcomes of treatment.
- It is postulated that accessing tailored resources and support structures benefit cancer patients and those who are caring for them such as close family members and friends by helping the patient achieve an individual level of empowerment. The research aims to explore ways in which resources and support structures facilitate the process for cancer patients in regaining a measure of control.
- Empowerment can improve psychological outcome in patients. The benefits are increased empowerment and an active use of coping strategies amongst patients in order to regain a measure of control over their illness. The research aims to explore ways in which empowerment improves psychological outcome for cancer patients.

The first objective was to explore the theory of empowerment as a concept which is measurable independently from other quality of life indicators. Quality of life measures currently in use for cancer patients are scales measuring the physical and emotional impact of cancer and the social and cognitive functioning of the patient. Other scales which measure coping levels again differ from the empowerment concept in regard to the degree to which the patient seeks interaction from others in relation to the illness. In other words, a patient who 'copes' will accept the information provided by the doctor but is not motivated to ask any further questions or seek information and options beyond what has been provided. Therefore, the power residing in the provider of the information remains absolute. In contrast, an 'empowered patient' will be motivated to ask further questions and to seek solutions for themselves. They will also become adept in ascertaining what is and is not important to them in managing their illness. The empowerment scale seeks to highlight what distinguishes patients who utilise diagnosis and treatment outcomes to create strategies to manage positively their cancer experience. Furthermore, the level of empowerment is linked to the ability of patients to utilise those outcomes and to build upon positive experiences proactively.

A second objective seeks to explore the concept of support structures and tailored resources as enablers for patients to achieve a certain level of empowerment. Whereas one patient might be empowered on the level of access to resources such as books and information from health professionals, another may be more empowered by access to counseling services or assistance in decision-making alongside the health professionals involved in their care. Exploration of tailored resources and support structures enable an understanding about the motivation of patients to take control of their treatment and care. Furthermore, an awareness of what prevents other patients from being empowered and what creates an obstacle to their autonomy of thought and understanding regarding their illness can be developed. It is important in the process of empowering the cancer patient to understand what constitutes a supportive role in terms of family members/ significant others and health professionals. Therefore, perceptions by close family members and health professionals are also taken into consideration throughout the research project. This concept is best explored by qualitative methodologies within the context of constructing a more complete understanding of empowerment.

Finally a third objective will explore empowerment as a psychological outcome in patients. Consequences of empowerment affect both patient and to an extent the caregiver often resulting in a better quality of life. Patients will regard empowerment in terms of either survivorship following successful treatment or approaching death when treatment has been unsuccessful. Level of empowerment and degree of involvement by the patient will be demonstrated as an individualistic concept (Gattellari et al. 2001; Bergsma 2002). The quality of life of patients is improved through encouraging empowerment and by recognising and implementing coping strategies amongst patients.

1.4 Stages of the study

The study has been conducted in two main phases. During the first phase an extensive literature review was conducted in the areas of patient empowerment, motivation, self-efficacy and attitudinal measurement. This first phase builds upon the outcomes of a pilot shared care project with haematological cancer patients conducted in the year

2000 at Sir Charles Gairdner Hospital (Ward et al 2000). As such, a series of in-depth patient interviews with former shared care patients was conducted and major themes identified for inclusion in the Patient Empowerment Scale. These themes identified core coping strategies which served as markers for patient empowerment. The themes were then formulated into statements for patients to respond to in a self administered questionnaire. The questionnaires were analysed using the Rasch Extended Model (RUMM program).

The second phase involved the refining of statements which were then finalised for distribution to a larger sample of patients. At the same time, the concepts of empowerment as defined in the Patient Empowerment Scale were explored through further series of in-depth interviews with twenty breast cancer patients receiving chemotherapy treatment. The interview questions followed the markers making up the Patient Empowerment Scale (PES) to explore the concepts of empowerment and motivation further (Appendix 2).

1.5 Overview of methodology

Given the nebulous quality of the empowerment concept and the little known effect on cancer patients and their families it was important to approach the research using a mixed methods research framework. Thus, it was not only important to define the markers for patient empowerment using psychometric analysis. It was also relevant to the main objective of the research to explore the properties of empowerment using a more in-depth qualitative approach. Although survey methodology was central to conceptualising and operationalising the construct of empowerment, this approach did not provide the mechanism for exploring the reasons and beliefs which formed a person's understanding of how active participation in managing the illness could increase their sense of wellbeing through empowerment. Therefore, for the sake of clarity, it was decided to present each methodological framework within the relevant chapter rather than to present a separate chapter providing overall methodological approach.

1.6 Publications arising from the research

A number of peer reviewed publications and conference presentations from this research have arisen throughout the course of the thesis. Peer reviewed publications are as follows and are also included in the appendices in relation to corresponding chapters of the thesis:

Journal articles relating to this thesis:

1. **Bulsara, C**, Ward, A and Joske, D 2004, Identifying Coping Strategies amongst Cancer Patients receiving Treatment for Haematological Malignancies. *Journal of Clinical Nursing*, Vol. 13. pp251-58.
2. **Bulsara, C**, Ward, A and Joske, D April 2005, Patient Perceptions of the General Practitioner In Cancer Management". *Australian Family Physician*, Vol. 34, No. 4. pp299-300.
3. **Bulsara C**, Ward A, Styles I, Bulsara M 2006, The psychometrics of developing the Patient Empowerment Scale. *Journal of Psychosocial Oncology*, Vol. 24, No.2.pp1-16
4. **Bulsara, C**, Chan, A and Styles, I Second quarter, 2007. *Motivating Women with Breast Cancer to achieve empowerment by the use of support strategies* in *Motivating Health Behaviour*. Nova Publishers US. pp 161-176.
5. **Bulsara, C** and Styles, I November 2006, *Empowering patients: coping with cancer* in 'Advances in Psychology Research' Volume 48. Nova Publishers US. pp247-278.
6. **Bulsara, C**, Chan, A, Emery, JE, Ward, AE & Joske, D. 2008. Balancing self-reliance with the use of support mechanisms amongst breast cancer patients. *Austral-Asian Journal of Cancer*. Vol. 7, No. 3, July 2008. pp 65-70.

Conference presentations and posters relating to the thesis:

7. **Bulsara, C**, Ward, A, Styles, I, Bulsara, M and Joske, D Development of an Empowerment Measure. A poster for the General Practice and Primary Health Care conference in Brisbane June 2004.

8. **Bulsara C**, Ward A, Styles I, Bulsara M and Joske D. "Development of an Empowerment Measure". Oral presentation for the International Psycho-oncology conference Copenhagen Denmark Aug 2004.
9. **Bulsara C**, Assoc Professor Ward A and Joske D " Measuring Empowerment in the Chronically Ill". A poster presented at the General Practice and Primary Health Care conference in Canberra, June 2002.

CHAPTER TWO

2. Literature Review Part 1

2.1 Exploring empowerment as a concept

2.1.1 Individual and community empowerment

Empowerment was first defined as a community concept and is embedded in 'social action ideology' (Gibson 1991). The idea behind the concept is to encourage the individual to become proactive in taking control of and accepting responsibility for their future desired outcomes. They can do this on a collective level (eg workplace, community group) or on an individual level. Rappaport (1995) defines empowerment as the process by which individuals (similarly with organisations and / or communities) achieve mastery over issues and events which are of concern to them. Similarly, achieving empowerment is a process which requires the individual(s) concerned in taking a pro-active approach to the issues over which they wish to gain mastery.

2.1.2 The Context of Community Empowerment

Empowerment in the community setting has advantageous outcomes for all members of the community. It is often implemented through action research by giving the power back to the community to take control of their health and wellbeing. Maglcas (1988) attributes this concept of empowerment back to the 1980's when the World Health Organisation defined health promotion as "a process of enabling people to increase control over and improve their own health". Health promotion and the process of community engagement enable those who are less empowered or who effectively have less power to have some measure of control over their health. Health outcomes then become the responsibility of both the community and the individual rather than health outcomes being controlled by an outside body / organisation. A sense of ownership is thereby engendered within the community and the individual. As such, it has much

more value to each person resulting in a greater chance of successful outcomes for all involved. Molinari et al (1998) demonstrated that strong social networks and perceptions of community quality impact positively on one's health and contribute to a better overall health status. Another important aspect of empowerment and community has relevance for the field of psycho-oncology. That is, the sense of wellbeing brought about by positive social networks of support for the chronically ill. Studies have shown (House et al. 1988; Molinari et al. 1998; Chavis&Wandersman1990) that social networks and degree of support from an individual's own community such as family and close friends are strongly related to morbidity and mortality outcomes. Also, just as importantly, patient interaction with health professionals who are responsible for cancer treatments and management of side effects play a part in the enablement of empowerment (Toop 1998; Arora 2003). The importance of positive social networks will show a clear relationship to the process of empowerment in this study. The study will examine the process of empowerment both on an individual level and also within the social networks that the patient belongs to and interacts with. The study will also explore the relationship in particular between individual empowerment and self-efficacy. This concept is often referred to as 'inner strength' and 'self reliance'. Wallerstein (1992) notes that,

"Individual empowerment is often viewed as separate from the social system, similar to self esteem, individual competency, or self-efficacy."

Rissel (1994) defines psychological empowerment as 'a feeling of greater control over one's life'. Furthermore, Gibson (1991) notes that the concept of empowerment encompasses both social and individual factors. He writes,

"The concept of empowerment then captures not only the individual's responsibility in achieving health but also the effect of the social environment on personal health."

Cancer patients who successfully manage the physical and psychological side-effects of their illness are also impacted upon by their social environment in both positive and negative ways. This is particularly true in the early days following diagnosis and

treatment. Those who value using social environment and support networks to manage their illness are more likely to achieve a significant level of empowerment in terms of managing their illness (Zaza et al. 2005).

2.2 Individual empowerment in the health setting

The concept of patient empowerment has taken on increasing relevance within the health setting in recent years. The shift away from perception of the physician as solely in control of patient treatment outcomes has demonstrated that the balance of power is changing. Perkins & Zimmerman noted in 1995 that individual health interventions which seek to enhance a sense of empowerment require those involved to,

“...engage professionals as collaborators instead of authoritative experts.”

Thus, the patient is now more likely and able to contribute to decisions about their treatment and management of their condition than ever before (Charles et al. 1999; Snowden et al. 2000). Furthermore, they are more likely to expect the physician to include them in the consultation regarding treatment options and referral processes (Grumbach et al. 1999). The involvement of patients and provision of relevant information regarding their cancer enables them to regain control and feel more empowered in coping with the illness (Chang et al. 2004).

2.2.1 Historical perspective

Historically, rapid progress in the medical field earlier in the last century meant that the clinician was the only person with the skills and qualifications to direct patient outcomes (Roberts 1999). The patient usually did not have access to this knowledge and expertise and thus was expected to hand over his treatment and care to others who were keepers of specific knowledge pertaining to their health. However, later into the 20th century, a distrust of authority led people to begin asking questions and voicing their opinions. This translated across from the political sphere to the medical setting as well. Roberts (1999) noted that from the 1980's the US has witnessed many court cases reaffirming the patient and family's right to choose their treatment and outcomes. Thus the rights of

the patient to direct the course of their treatment and management thereof encouraged them to re-learn how to take control and believe in their own innate ability to manage their illness with guidance from the health professionals and significant others. This has led to a greater sense of empowerment for the patient. In addition, access to the Internet and other forms of knowledge outside of the health professionals' domain enable to patient to seek knowledge outside of the specialist consultation period (Air et al. 2007; Kirschning & von Karndorff 2007). Patients currently seek support through Internet self help groups and for many this form of support is regarded as an additional way of sharing information with others and of having some control over their illness (Mayer et al. 2007). The necessity for this type of support can extend beyond the treatment period for cancer survivors (Owen et al. 2005; Gooden & Winefield 2007). It is timely therefore, that physicians are aware of the growing necessity for guided Internet support and searching for cancer patients who are motivated to seek resources and support in coping with cancer (Mayer et al. 2007). It is a crucial aspect in attaining empowerment that the patient is motivated to seek out not only what is within his / her control but also ways of regaining aspects of their illness that they can control.

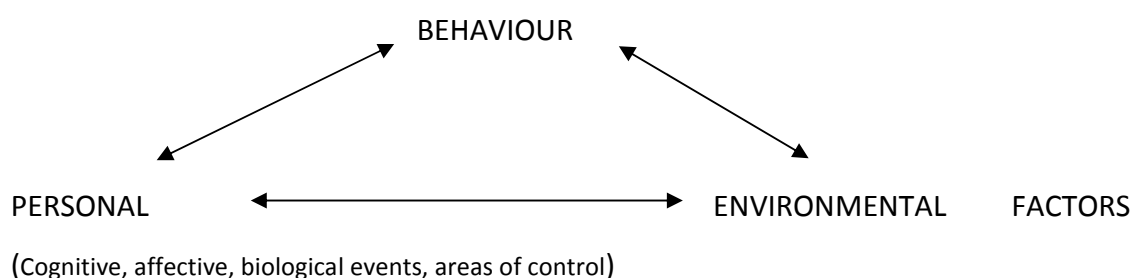
2.3 Motivation and Self-efficacy

This study examines the way in which motivation relates specifically to cancer and the ability of some cancer patients to regain control over the treatment and management of their illness. As such it's relevancy to this area of research is clear. It should be noted that empowerment is linked to motivation in that a patient needs to be positively motivated to seek solutions to their situation in a way that works best for them at an individual level. Bandura (1977, 1982) maintains that self-efficacy is positively linked to motivation whilst being regulated by behavioural intention and planning on the part of the individual. In relation to this, patients require the belief that within the context of their illness and it's treatment, they are able to exert the effort needed to achieve their own realistic goals in relation to managing the illness (self-efficacy). A theoretical formulation initially developed in the field of psychology, may be generalised to provide a framework within which to understand the most pertinent elements of empowerment in coping with life-threatening illnesses such as cancer. This theory is, Bandura's concept

of self-efficacy (Bandura 1994). Self-efficacy refers to the beliefs people have about their competence in being able to achieve certain goals. High self-efficacy is characterised by awareness of all pertinent aspects of a situation, personal goal-setting, perseverance, and confidence in one’s ability to reach valued goals. These characteristics can empower people to use a range of differing but appropriate strategies to achieve goals, and to use all pertinent resources to make decisions about how best to proceed. Further to this, in operationalising such goals through coping strategies, the patient engages in a self-regulatory process which ultimately leads them to achieve a sense of empowerment about their condition. Zimmerman (2002) noted that self-regulatory learning does not solely rely upon the person themselves to succeed but also includes the instruction, modelling and encouragement of others including peers. In this study, the role of significant others is shown to be crucial to patients in achieving this sense of empowerment through self-efficacy and self-regulation.

In 1977, Bandura first outlined the concept of self-efficacy. In 1986 the construct was embedded within the **social cognitive theory** of human behaviour which places it within a structural network of social influences (Bandura 1986). Furthermore, the theory stated that individuals are self-regulatory and self-reflective in reaction to their environment rather than being passive recipients of the environment acting upon and influencing their behaviour (refer Figure 2.3.1).

Figure 2.3.1 Social cognitive theory (Bandura 1986)



Although the concept of motivation and self-efficacy began in the area of educational psychology, it has since been researched more widely in regard to health management and health promotion (Bandura 1997; Kreuter & Strecher 1996). Bandura (1997)

highlighted the importance of a strong belief in the self to achieve positive outcomes when he noted that,

“Self belief does not necessarily ensure success, but self disbelief assuredly spawns failure.”

As a basic concept underpinning motivation and self-efficacy within a health setting, this statement highlights the importance of the individual’s belief in their own ability to exact a measure of control over the management of their condition or illness. Motivation is strongly linked to self-efficacy through a belief in one’s ability to complete a task successfully and by possessing the drive (motivation) to achieve one’s goals. Pajares (1997) notes that self-efficacy determines how much effort a person will exact, how long they will persevere in trying to succeed and also how resilient they are in the face of difficult or adverse situations.

2.3.1 Intrinsic motivation

Research within the fields of education and health has demonstrated that autonomy and effectance are central determinants in the process of motivation (Ryan & Deci 2002; Deci & Ryan 1981). As children, we learn most effectively by our utilisation of self-motivation and the desire to gain mastery over a situation or task. In addition, it is essential for our social structures to be supportive of the learning process and takes place in an autonomous rather than a controlling way in order for it to be most successful. Activities are also influenced by our social surroundings and have to be meaningful for us to engage (effectance). Positive feedback from others around us is crucial to achieving our outcomes from the task at hand. Furthermore, Deci & Ryan (1981) maintain that positive feedback is essential for intrinsic motivation to occur. Intrinsic motivation values the task for itself rather than for any external praise or reward (Biggs & Moore 1993). This study will also highlight through the findings of in-depth interviews that patients acknowledge their ability to achieve self-reliance in having control over certain aspects of their illness. Those who seek to closely control the person, whether teachers (field of education) or in this case health professionals,

jeopardise intrinsic motivation in the individual and interfere with the person's sense of self-competence.

However, in developing self-efficacy it is also important to keep in mind that balance and the ability to scale back goals and be aware of one's limitations (self-reflect) are also an essential part of achieving a level of empowerment. Carver & Sheier (1981) noted that not all internal events are self-determined and certain self-imposed standards can be detrimental. In other words, acting out what we believe that others expect of us can negatively affect how we behave. Once again, the ability to draw upon self-reliance for a cancer patient becomes crucial in avoiding too great a focus on the opinions of others such as the health care team or family members and trying to meet their expectations.

2.3.2 The psychological process by which self-efficacy affects human functioning

Understanding the process by which a patient examines their own capabilities is a starting point to achieving a sense of empowerment. As the literature shows, patients with a strong sense of self-efficacy are more likely to put the extra effort into setting realistic goals to manage their condition (Maes & Karoly 1995; Schmitz , Saile & Nilges 1997; Lev et al. 2001).

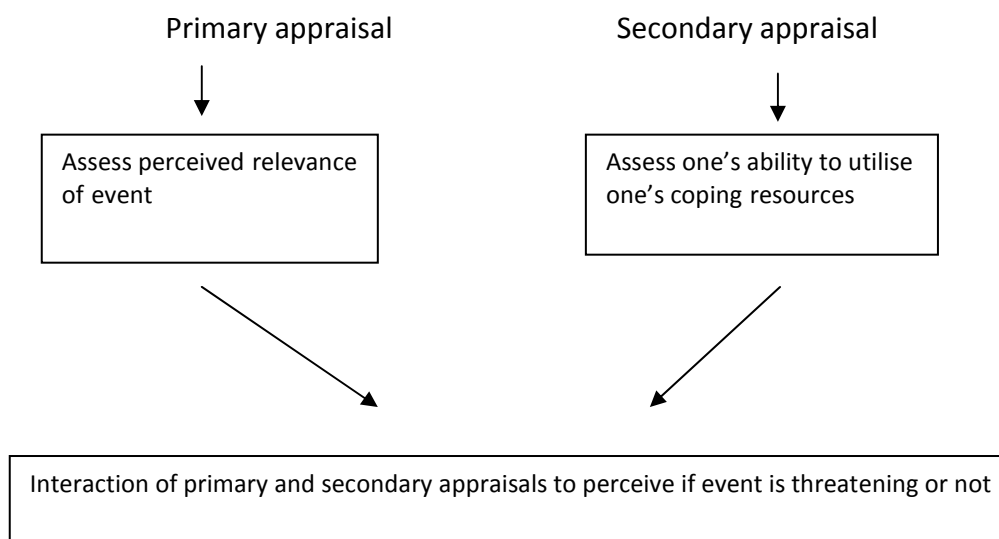
Understanding the process by which self-efficacy affects human actions is important in recognising why some patients continue to exert effort over their physical and psychological setbacks in contrast to others who give up. The process has four components as previously noted in Figure 1 shown above. Namely, cognitive (appraising one's capabilities), motivational (beliefs about what can be done to cope with the situation), affective (the actions that one takes as a result of the motivational and cognitive process) and selection processes (selecting areas which can be controlled) in an effort to appraise and act upon the situation. These are explained below within a health context.

2.3.3 Cognitive process

A person will set goals by appraising their own capabilities. Thus when a person exhibits a higher level of self-efficacy they have a stronger commitment to achieving those goals

which they also set more realistically through the process of cognitive appraisal. Lazarus & Folkman (1984) have noted that cognitive appraisal comprises both primary and secondary appraisal as shown below in Figure 2.3.2. The initial or (primary) appraisal of the event or task by the patient will help the patient identify how important the event is to him or her. The secondary appraisal will enable the patient to gauge whether he / she believes that they have the ability to cope with the task or event.

Figure 2.3.2 Lazarus & Folkman Cognitive Appraisal Model (1984)



Such interaction will produce corresponding patterns of arousal within the individual whether these are stressful interactions or not. Despite, the occasional and inevitable setbacks, a highly motivated individual will have the ability to maintain determination to achieve those goals despite the setbacks encountered (Biggs & Moore 1993). If goals become unachievable the individual will realistically re-evaluate the goals whilst still maintaining a strong belief in their own overall abilities. However, persons who have greater self doubt will become more erratic in their thinking and thus lose sight of the goal they have set for themselves and their ability to meet that particular challenge in achieving the goal.

Hemenover & Dienstbier (1998) maintain that there are certain personality dimensions which will be linked to the type of reaction experienced by the individual to a specific event. These are namely, hardiness, locus of control, self-efficacy and helplessness. Stress undoubtedly impacts negatively on both psychological and physiological health

through appraisal induced anxiety. Furthermore, cognitive appraisals such as anxiety and stress will impact negatively on any attempt at coping by the individual. At the extreme, when an individual attributes their negative outcomes in the face of the illness experience to stable (inflexible / cannot be altered), internal (self controlled) and global (external) causes they are most likely to exhibit unsatisfactory coping resources. Eventually, due to a perceived inability to control or influence negative events they become passive in the face of illness in a display of 'learned helplessness'. Conversely, as noted by Hemenover & Dienstbier (1998), problem focused coping in the face of illness is associated with greater good health and improved recovery time. In this study they observed that by using the GAM (General Appraisal Measure) that they were able to demonstrate that as stressfulness scores increased, the perceived coping scores decreased. In terms of the Shared Care model, what the clinicians attempt to do is to provide the patient with the necessary coping skills using resources to handle setbacks and difficulties throughout their illness and treatment regimen. The contribution of others to giving the patient the self-belief that they can exact a measure of control over what is happening to them will also engender a greater ability to cope with and manage the situation, thereby enabling the process of empowerment to take place. Self-efficacy beliefs are instrumental in directing causal attributions amongst individuals (Lowery et al. 1993). Whereas those who have high self-efficacy will attribute failures to a lack of sufficient effort on their own part rather than lack of ability, those who have lower self-efficacy beliefs will attribute the failure or setback to their overall lack of ability. In other words, the event is seen to be outside of their control. In addition to the perceived level of ability, the patient will also be affected by the explanations regarding their situation. This is referred to as 'causal attribution'.

2.3.4 The relevance of causal attribution theory to cancer.

The process of causal attribution / reasoning that takes place initially after the diagnosis is crucial in assisting the patient to regain control of their life. Causal attribution relates to the explanations and causes to which a person attributes their success or failure within a given task. In the case of cancer patients, most will try to attribute their cancer to an underlying reason once they receive the diagnosis. This is a normal but self-

defeating act as it is unlikely that the true cause will be known for most patients. Nonetheless, it is a part of the adjustment and empowerment process to experience a transient period after diagnosis of attempting to find a cause for the cancer. Patients often go through a period of wondering “why me?” once they receive their diagnosis and try to recall a possible cause from past lifestyle and circumstances.

A meta-analysis conducted by Roesch & Weiner (2001) assessed the relationship between causal attributions, coping and psychological adjustment in persons who were undergoing treatment or who had a physical illness. The meta-analysis found that individuals who attributed the cause of their illness as internal (relating to self), unstable (things *could* change for the better) and controllable were better able to cope and adjust than those who attributed their illness to external circumstances, unlikely to change (stable) and uncontrollable causes.

Lowery et al. (1993) noted that cancer patients, having experienced the shock of diagnosis, had a basic need to recover their assumptions about the way in which they interact with their surroundings. Cancer patients who are unable to move beyond the causal attribution stage (the ‘why me?’ stage) are more likely to experience anxiety, depression and withdrawal. This will ultimately result in the patient reverting back to a state of learned helplessness in the face of their own inability to cope with the diagnosis and illness trajectory in a situation which they perceive that they cannot control.

2.3.5 Learned Helplessness

Miller & Norman (1979) distinguished three features of learned helplessness in humans. These were namely:

- 1 Reduced motivation;
- 2 Impaired ability to learn how to control a situation;
- 3 Strong fear rapidly leading to depression.

The concept of learned helplessness can be explained in terms of attribution theory. That is, a person will attribute their lack of ability (rather than lack of effort) to cope with a situation as a reason for failure and will ultimately predict failure before even trying (Dweck & Repucci 1975). However, some kinds of learned helplessness are limited

to specific contexts. The pattern of helplessness can be changed by altering the attributions (what patients attribute the cause of their illness to). Given that most cancer patients will experience a loss of control when diagnosed with the illness, it is conceivable that for some a sense of helplessness can manifest (Mok & Martinson 2000; Seeman & Seeman 1983). Thus it is important for the person with cancer to be given, when possible, the information and resources to gain control over elements of their treatment and care. It is also vital that they come to terms with the inability to 'know for sure' why they now have cancer and whether they could have done anything differently to prevent the illness.

2.3.6 Motivational process

Self-beliefs about efficacy will regulate the motivational process. Persons form beliefs about what they can do and set goals for themselves to plan how they will approach the particular task. Although it is recognised that total control is not possible in a chronic illness such as cancer, it is still possible for the patient to have a sense of control over certain areas. It is important that they can still feel that they are involved and most importantly informed in the management of their condition. This can occur in areas such as the use of complementary therapies and seeking access to relevant information through self help groups or use of the Internet. Bandura (1984) maintains that goals (personal standards) which are regulated by motivation are controlled by three self influence types.

- Reactions to one's performance whether this be satisfaction or dissatisfaction.
- Perceived self-efficacy in attaining one's goals.
- The ability to readjust one's goals depending on personal progress.

2.3.7 Affective process

A person's beliefs in their ability to cope in a situation (self-efficacy) will affect the amount of stress or depression that they experience in relation that event. This is particularly true of difficult or stressful situations such as those experienced by cancer patients. It is the perceived ability by a person to exact a measure of control over their situation through self-efficacy that affects anxiety levels. These people will dwell on

their own deficiencies to cope with a situation rather than their abilities to attempt a sense of control. Anxiety arousal is also controlled by the person's perception of their ability to control disturbing thoughts. Bandura (1984) quotes a proverb to illustrate this point.

"You cannot prevent the birds of worry and care from flying over your head but you can prevent them from building a nest."

Bandura propounds guided mastery experiences as a means of achieving personality change and enhancing quality of life. Mastery experiences are structured in ways to build coping skills and strengthen the belief in a person that they can exercise control over a potential threat. This can be achieved by modelling of the situation to view how others have coped in similar circumstances. This may be a reason why self help groups and structured support groups are particularly favoured by many of those with a chronic illness and / or their carers and significant others.

2.3.8 Selection process

People also select situations and circumstances which they feel they can control. Nonetheless there are areas within the course of their treatment through which they can learn to exact a measure of control by guided mastery and social support mechanisms. In the course of this study I will focus less upon this aspect of self-efficacy due to the somewhat uncontrollable circumstances in which cancer patients find themselves due to the fact that their ability to select is limited by the illness trajectory and the treatment regimen.

2.4 The impact of self concept and self-efficacy

"You gain strength, courage and confidence by every experience in which you really stop to look fear in the face.

You must do the thing which you think you cannot do."

- Eleanor Roosevelt

It is important to understand the difference between self-concept and self-efficacy. For the purposes of empowerment, this is particularly relevant in understanding ways in which cancer patients regain control of their situation. The ways in which this relates to either self-concept or self-efficacy will ultimately lead to patient empowerment or disempowerment. In the same way, developing and encouraging a sense of self-efficacy in relation to cancer trajectory will imply that although the patient may suffer setbacks from time to time, sufficient self-efficacy beliefs will ensure that the patient and his / her family learn to realistically reset their goals in relation to the prognosis. For most, this will entail adjusting to short-term goals rather than longer lifetime plans and to reaching a stage of acceptance beyond the earlier stages of shock, denial and anger.

Bandura (1994) maintains that setbacks are a desirable aspect of learning to master a situation. He writes,

“After people are convinced that they have what it takes to succeed, they persevere in the face of adversity and quickly rebound from setbacks. By sticking it through tough times they emerge stronger from adversity.”

2.4.1 Ability to accept and adapt Goal setting

Cancer patients often have difficulty in adjusting to the diagnosis and treatment. Those who learn to accept their diagnosis and adjust to the treatment and changes in lifestyle are often the most successful at achieving a high level of self-efficacy in re-calibrating their goals regardless of prognosis. Self-efficacy spans a number of support strategies and resources for the patient. Persons who show a high level of self-efficacy believe that they are able to master new and challenging situations through effort and determination (Schwarzer & Fuchs 1995). Equally importantly, in the face of failure, they are able to regain equilibrium and be prepared to try again when required without fear of recurrent failure.

As previously stated, there is a vital difference between self-concept and self-efficacy as it relates to empowerment. Self-concept is an appraisal of oneself which is linked to a sense of self-worth. The judgement is generally self-evaluative and is not context or situation specific. It is also independent of goal setting and the ability of a patient to achieve individual goals. Thus, self-concept is primarily an evaluation of the self which is

linked to ideas which the individual has regarding his or her self-worth. The notion of self-concept relates to a person's belief about their abilities across all domains of knowledge.

Conversely, the theory of self-efficacy relies upon one's ability to set goals which are achievable and the perceived amount of effort required to succeed. The concept of realistic goal setting underpins the theory of self-efficacy. Self-efficacy is related specifically to the task or context at hand and the way in which the individual believes that they are capable of completing that task proportionate to the amount of effort they put in (Hofsetter et al. 1990). Bandura's definition of self-efficacy (1986) outlines the task specific focus of the concept.

"Self-efficacy is the belief in one's capabilities to organise and execute the sources of action required to manage prospective situations."

The Bandura model explores the ways in which a person's beliefs about the self-function operates independently of domain of knowledge. This is largely due to the fact that a person's self-efficacy beliefs are not controlled by outside influences (related instead to self-concept) but rather by the person's internal belief about their ability to cope with new situations.

However, there are some studies which caution against the emphasis on self-efficacy and 'blind optimism'. A study by Lowery et al (1993) revealed that a person's beliefs about their own self-efficacy in a health setting may largely be hampered by the realities of lack of treatment options and negative prognosis. In this situation, a strong belief in one's own ability to control the situation is not particularly helpful. Rothbaum et al (1987) highlighted the fact that the cancer patient needs to acquire a balance between his/ her own sense of control (what the patient is *actually* able to control) and the control held by significant others (eg clinicians). Lowery et al (1993) noted that patients still felt in control of improving their health habits, complying with treatment and adopting a positive attitude to their treatment. Once the acceptance of limitations and adaptation is understood, the ability to set realistic goals and be clear about what type of goals are achievable is vitally important in preventing negative psychological impacts such as anxiety and depression in the cancer patient (Carver, Scheier & Weintraub

1989). In addition, a theory outlined in a paper by Helen Street (2002), notes that persons who more often pursue abstract or 'higher level' goals (e.g. happiness, wellbeing) are more prone to depression whether they perceive the goals to have been reached or not. This is particularly the case when a person pursues their abstract goal (wellbeing) by using concrete goals (e.g. getting through treatment) in an unrealistic way. Street writes that those persons who realise that happiness and other similar concepts are states of mind rather than goals to be achieved are much more likely to acknowledge the more negative effects of day to day living as transient and not linked to the achievement of realisable goals. The field of education mirrors this theory. A study by Carole Ames (1990) notes the following important aspects of self-efficacy and goal setting,

“Self-efficacy responds positively when they (persons) learn to set short term goals and are shown realistically how to make progress towards those goals.”

2.5 The realisation of empowerment

2.5.1 The central role of social support

The role that significant others play in supporting the patient was previously mentioned as a core aspect of regaining control and achieving empowerment. Research has focused on a number of aspects of social support, primarily from family and close friends (Friedman et al. 2006; Schroevers et al. 2003; Gass et al. 2007; Sultan et al. 2004). Nonetheless, once the diagnosis is received, the patient must also develop trust from a new set of individuals and in particular health professionals, who will also play a significant role in the patient's life once treatment commences (Helgeson 2003). As such, a relationship develops based on trust and reliance on the health professional's specialist knowledge that is shared with the patient (Kruijver et al. 2001). One exception to this in regard to emotional support may occur when the patient has had a long term relationship with their general practitioner. Studies into the role of the general practitioner in the care of a patient post hospitalisation show that many are relied upon for emotional support through clarification of medical treatments and outcomes and as

an advocate for the patient through open communication with the specialist team (Anvik et al. 2006). A study by Peters-Golden (1982) of breast cancer patients, identified social support as an important factor in achieving positive psychological outcomes of cancer. Walker et al (1977) defined a social support network as,

“A set of personal contacts through which the individual maintains his / her social identity and receives social support, material aids and services, information and new social contacts.”

Further to this, research has long shown that such support networks take on more importance during times of crisis and that the diagnosis of cancer increases a greater need for social support (Hirsch 1979). In addition, those seeking support are seeking to bolster feelings of self esteem and ability to overcome difficulties (Curbow & Somerfield 1991). Thus, the role of social support cannot be understated in empowering the patient.

The significance of self-help and support groups has been widely researched in recent years (Gottlieb & Wachala 2007; Schroevers et al. 2003; Presberg & Levenson 1993). Studies note that the benefits of attending support groups are in meeting others in a similar situation (Rankin et al 2004), reducing anxiety and patient fears (Ahlberg & Nordner 2006) and providing a sense of belonging (Ussher et al. 2006). The Internet has also been discussed as a means of sharing and offering support amongst patients. Although some studies have shown that the success of Internet support groups may currently be dependant on socio-economic status of those contributing; that is, those who are of higher educational and economic status (Gooden & Winefield 2007; Fogel et al. 2002); it nonetheless shows a number of benefits to the patient. These include, coping strategies, sharing distress and encouraging others. A study by Mayer et al (2007) demonstrated that although patients are actively involved in sourcing information, such as Internet searching, for themselves, most prefer to either seek or have the advice endorsed by their clinician. Given the increasing use of Internet and other electronic media in patient care and education, the ability of patients to utilise these resources in a guided way through a supportive health care team could be increasingly beneficial in the future (Mayer et al. 2007; Hoybye et al. 2005).

2.5.2 Social role models and self-efficacy

Social role models are also an important aspect of building greater self-efficacy. As Peters-Golden (1982) noted,

“Seeing people similar to oneself succeed by sustained effort raises the observer’s beliefs that they too possess the abilities to master comparable activities to succeed.”

Thus social support structures are essential in maintaining a sense of control and optimism amongst cancer patients. There is something to be gained by patients who then support other patients in striving for empowerment. The patient who is able to support another patient is further empowered in that they believe that they have enough control over their illness to be able to support others in a similar situation (Bulsara et al. 2003).

2.5.3 Social persuasion and self-efficacy

The third way in which self-efficacy is initiated is by ‘social persuasion’. People are provided with the support of others whose opinions they value in believing that they can achieve their goals and that they do have the capabilities necessary to control their situation to a certain extent.

“To the extent that persuasive boosts in perceived self-efficacy lead people to try hard enough to succeed, they promote the development of skills and a sense of personal self-efficacy.”

An important aspect of self-efficacy which is relevant to cancer patients is the fact that Bandura (1994) places emphasis on the fact that self-efficacy should rely on using the advice and encouragement of others for measures of self improvement. Thus, they involve intrinsic motivation rather than comparing oneself to others negatively in similar situations.

It is an essential component of achieving self-efficacy through social persuasion that the patient has regard for the opinions and persuasion of the other person. As such, the

opinions of health professionals, counselling support and significant others all have a role to play in ensuring that the patient regains a sense of control over their condition (Luszczynska et al. 2005). Studies which focus on the supportive role of the health professional also highlight the fact that patients hold clinicians in higher regard who are able to maintain positivity and a belief in the ability of the patient to overcome difficulties (Bulsara et al 2006).

2.5.4 Information seeking and use of resources

Patients who are newly diagnosed with cancer usually seek as much information as they possibly can about their illness (Fallowfield 1997) regardless of prognosis (Elger & Harding 2002). However, the plethora of information can be overwhelming and may create greater anxiety in some patients depending on their ability to recognise relevant information amongst many sources (Butow et al. 1997). Thus, clinicians and other health professionals need to be aware of the patient's ability to utilise information and to discard other information that may not be relevant for them. Furthermore, patients who receive more personalised or targeted information such as a patient held record in the Shared Care model (Ward et al. 2000) or similar resource model (Jones et al. 2006) are less anxious about their treatment outcomes. Participation in the management of their condition has been shown to provide a greater sense of control for some patients (Charles et al. 1999) although degree of participation is dependant upon the individual patient's needs.

2.5.5 Decision making involvement

Similarly, there is a great deal of diversity amongst cancer patients in regard to their level of willingness to be involved in decision-making about their treatment options. Some studies have shown that most patients, although wanting to be kept informed are nonetheless reluctant to be involved in making actual choices around their treatment (Degner 1997; Ende et al. 1989). Undoubtedly, some patients have few options available to them in this regard. However, when the health care team are able to provide relevant information regarding the treatment itself and the likely side effects, patients believe that they are better informed and less anxious when giving consent to receive a specific

type of treatment. In addition, greater emphasis is currently placed upon full disclosure to the patient regarding all benefits and risks associated with a particular treatment (Holman et al. 2000; Charles et al. 1999). This necessitates closer co-operation between the clinician and the patient and facilitates open, frank discussion thereby developing a relationship of trust (Fallowfield et al. 1994; Fincham et al. 2005). Although the patient may not entirely rely on the health care team for emotional or psychological support, they are the main contact and source of information and resources used to cope with the treatment and side effects thereof.

2.5.6 Complementary therapies utilised by cancer patients

Many patients use complementary therapies to relieve some of the physical and psychological distress resulting from treatment and the illness itself (Lawsin et al. 2007; Sharples et al. 2003; Dilhuydy 2003). It is speculated that the use of complementary therapies are an aspect of managing the illness where patients are able to maintain a sense of control (Delmar et al. 2006). In the ideal clinician–patient dynamic the clinician will be fully aware of a patient’s intention to explore the use of complementary therapies whilst receiving treatment (Roberts et al. 2005; Stuifbergen & Harrison 2003). However, this may not occur depending on the relationship between patient and doctor (Giveon et al. 2004). Patients may not feel comfortable in disclosing the use of complementary therapies with their health care team.

Patients will use a range of complementary therapies for a number of reasons and access to complementary therapies provides a measure of control for which they are solely responsible for decisions made (Bishop & Yardley 2004). Thus, although the clinician may be informed as to patient’s use of therapies, the patients is largely in control of what and when therapies are sought out. For many patients complementary therapies are used to improve health and wellbeing in order to maintain optimal health whilst treatment is in progress (Molassiotis et al. 2005). In some cases, patients access therapies such as massage, Reiki and other forms of spiritual and ‘energy’ healing as a result of the impact of the cancer diagnosis when patients speak of re-examining their values and their goals in life. By questioning the reasons for being diagnosed with cancer, spiritual comfort is sought from these sorts of therapies (Foster 2006). Energy

healing can also provide the willpower and inner strength to overcome the illness by attuning to the mind (Ritvo et al. 1999) and revisiting spiritual beliefs (McGrath 2004).

2.5.7 Acceptance and adaptability

In order to facilitate the uptake of resources and support mechanisms, the most crucial aspect of achieving empowerment is that it is more positively focused upon addressing issues in order to find solutions. As was noted earlier, this differs to 'coping' with the illness because the patient moves beyond acquiescence (without questioning) to face confronting issues, ask questions and seek solutions to their situation. For this reason, as will be seen in this study, to achieve a level of empowerment, the patient must move beyond the stage of shock and denial to accept the illness and look to ways of making the process of receiving treatment and managing day to day living easier for themselves and those who are part of that process.

The final stage of this acceptance occurs when the patient is able to offer support to others who are not yet at the acceptance stage of the illness. Kieffer (1984) has defined empowerment as a process of 'becoming'. He identifies four levels in this process. These are outlined as:

Level 1 – the era of entry – this is the stage when the individual is exploring new issues and boundaries and where the power structures are 'demystified'. For the cancer patient this is the stage when diagnosis is received and cancer treatment is about to begin and where options are considered.

Level 2 – the era of advancement – this is the stage when mentoring relationships take place and supportive peer relationships are strengthened. Cancer patients will go through this stage whilst receiving their treatment when they learn to accept help and support from significant others in their lives. They also learn to prioritise what is important to them and to discard what is no longer relevant.

Level 3 – the era of incorporation – activities are focused on confronting and contending with the permanence and painfulness of structural and institutional barriers to self-determination. The cancer patient will recognize this stage when the reality of their situation sets in. Some friends and family may not be as available and supportive as when the diagnosis and treatment began. Patients may also wish to seek some

complementary therapies out and trial other treatment options. Kieffer has compared this to adolescence where the patient is effectively testing the boundaries. This also leads to further acceptance of the illness and a willingness to accept one's limits.

Level 4 – the era of commitment – this is a stage when the individual can integrate their knowledge and new found skills into reality and the structure of their new world. This stage is handled by cancer patients in their ability to work with the diagnosis and prognosis to utilize their own coping skills in managing the daily realities of their treatment and the illness. The process described by Kieffer demonstrates how the individual and in this case the cancer patient can learn to accept and work within the system by using their own abilities and the support of others to achieve empowerment. This process is embedded within the domains of motivation and self-efficacy.

2.6 Conclusion

2.6.1 Implications for cancer patients

The role of self-efficacy and motivation in the empowerment of cancer patients clearly has tremendous implications for the field of cancer research. They impact upon the patient's ability to come to terms with their diagnosis and treatment regimen and also to manage their illness. It is also of importance for the cancer patient to exact some measure of control over their condition and achieve a level of empowerment. Furthermore, the setting of short term goals by patients initially interviewed for this research proved more effective as a coping strategy than having unrealistic expectations of the future. This is highlighted further by Bandura (1986),

“Success and failure are largely determined in terms of personal standards. The higher the self standards, the more likely will given attainments be viewed as failures, regardless of what others might think.”

Realistic goal setting is highlighted in a study by Nelson-Jones & Cosolo (1994). This study notes the importance of the role that health professionals can play in addressing 'thinking skills weaknesses' demonstrated by patients. One aspect of this role is to

prevent the patient from setting unrealistic goals in relation to management of their illness.

Clearly, a number of support mechanisms and coping strategies impact upon patient ability to regain control over their condition and to build a sense of empowerment using these strategies. The study will identify and explore both qualitatively and quantitatively the stages and the strategies utilised by patients in working towards individual empowerment.

Literature Review Part II

2.7 Development of the Patient Empowerment Scale

In exploring the role of empowerment in the wellbeing of cancer patients, the ways in which patients adopt support strategies in order to regain a measure of control over their illness are evident both from the literature review and the qualitative pilot study using in-depth interviewing technique regarding the Shared Care model (Ward et al. 2000). Nonetheless, the nebulousness of the concept implied that a validated instrument to assess the empowerment level of a patient would progress the understanding of empowerment beyond the perception of an intangible state of mind. It is postulated that the concept of empowerment differs from the concept of coping. As noted in the introduction, empowerment implies the ability to proactively take control of a situation and utilise elements which enable empowerment to occur. This study sought to define the enabling elements so that they could act as markers for an empowerment scale. The study was based on the premise that empowerment is a unique construct which cannot be measured by other scales such as the coping scale (COPE) (Carver, Scheier & Weintraub 1989), decision making preferences scale (Degner L 1998) and ability to adjust / mental health scales (Mental Adjustment to Cancer and the Hospital Anxiety and Depression Scale) (Watson et al. 1988; Zigmond & Snaith 1983). This section of the literature review will examine the theoretical basis to the development of the Patient Empowerment Scale using the Rasch Extended Model.

2.7.1 General principles of scale development

The development of a scale to measure health related outcomes requires a number of stages to arrive at a scale which can be validated. Initially, an exploration of the concept is undertaken. As noted in the previous section, the scale to measure empowerment was undertaken given that it was believed that the concept could not be measured by other existing scales. As such, and in keeping with other attitudinal states of mind, it should be conceivable that when the markers for empowerment have been defined and

operationalised, that the Patient Empowerment Scale would indicate patient levels of empowerment. The Patient Empowerment Scale (PES) seeks to measure the relationship of the individual to the stimulus through responses to, in this case, a set of support and resource related statements.

In the case of cancer patient resource and support strategies, the inclusion of stimuli such as family support, religion, spiritual beliefs and information seeking amongst others are most relevant.

The items developed for this scale will be detailed further on in the thesis. However, as a background, a number of basic principles of scale development will be outlined here.

Scale Design

Edwards (1957) specified that an attitude scale is made up of items which were carefully selected in accordance with certain criteria and are called 'statements'. He further considered that items could be developed from a number of sources which included:-

- The researcher
- The reading of literature relevant to field of investigation
- Relevant individuals (similar to group of interest)

The concept to be measured will be explored in depth through intensive literature searching and defining of the variable. This stage consists of identifying which population the variable is appropriate for and in what ways the population interacts with the variable (Dawis R 1987). In order to best explore the properties of the variable in relation to the population, a qualitative approach using focus groups and in-depth interviews are used to develop the initial set of items (statements) which are identified as of importance to the population (Dawis R 1987; Streiner & Norman 1995).

Items developed for the scale consist of a statement, as noted above, and a set of responses for each item (Ludlow L H 2002). Each statement will also have relevance for the respondent.

At the point when items are developed into statements, face and content validity are sought. This determines whether the statements that form the scale are believed to be measuring the construct which they purport to be measuring (Brown F 1970).

Face and content validity

Face validity and content are mechanisms by which items are scrutinized both by persons with expertise in the area / concept to be measured and by those from a population who are most likely to be asked to respond to the scale items (Streiner DL & Norman GR 1995). The intention of face and content validity are to trial the items to be used to assess whether they are actually measuring what they are intended to measure. It is a subjective judgement usually conducted before the scale is actually distributed to the population to be studied and is often conducted amongst experts in the field.

Construct validity

Attitude constructs cannot be measured physically as with other measures such as weight, blood pressure and similar. As such, they are not readily observable. Attitude as a psychological concept is discussed in greater detail in Section 2.7.2. However, construct validity purports to validate that the scale construct measures the attitude or other psychological concept that it claims to measure. As Streiner and Norman (1995) explain, a hypothetical construct (such as empowerment) is a 'mini theory to explain relationships between behaviours or attitudes'.

Ways in which constructs are validated in an ongoing process which explores the properties of the scale and determines whether the statements and their responses from participants are operating in the way that one would expect of that particular construct. For the purposes of this study, the Rasch Model was used as a mechanism for establishing the initial construct validity for the Patient Empowerment Scale.

Scale Development

The development of the scale consists of collecting data by distributing the questionnaire (scale) to the target population and analysing their responses to determine if the statements are appropriate and relevant to the target population (Ludlow L H 2002). This research used the Rasch Extended Model for the development of the Patient Empowerment Scale as outlined in greater detail on Page 42 of the thesis. The Rasch Model postulates that the response to an item consists of two parameters.

Namely, the item parameter and the person parameter which are considered in the analysis. The two parameters are a result of the endorsement of the attitude and the attitude of the respondent. Thus, the Rasch Model was selected as the most appropriate means of examining the psychometric properties of the scale items such as validity and reliability, and of investigating how respondents were interacting with (responding to) each statement (Dawis R 1987). The preliminary analyses used the Rasch Model to identify the items which best discriminate persons with high or low level of the attitude to be measured. This then forms the final version of the scale to be further tested for reliability across target populations.

2.7.2 Definition of Attitude

An attitude has been defined by Thurstone (1946) as,

“The degree of positive or negative effect associated with some psychological object.”

A more in-depth definition of attitude by Triandis (1971) notes that an ‘attitude’ is obtained by inference from what a person says accompanied by how he/she feels about the way he /she will behave towards a stimulus. Empowerment is not directly observable and must therefore be defined in an operational way. That is, by developing a measure to quantify this construct. The stimuli which Triandis has highlighted are, in this context, the various resource and support strategies identified by patients and represented in the scale such as use of resources, information, support and so on. A patient’s attitude to those stimuli will be demonstrated as affective in terms of whether they express sympathy (agreement) with a particular belief in regard to the stimuli. Also, attitudes can be expressed both cognitively as verbal statements in response to a belief (such as stating that the health professional has confidence in the patient’s ability to cope) and behavioural as overt actions (such as adapting the pace of lifestyle or attending a support group).

2.7.2 Attitude Theory

Rosenberg & Hovlans (1966) conceptualized an attitude which follows a clear process in determining ways in which a person responds to particular stimuli. There are three components which provide a framework for this particular attitude theory and which would potentially affect the way a patient will respond to statements outlined in the empowerment scale. The three components are conceptualised in a schematic model of attitudes by Rosenberg & Hovlans (1966) shown below (Refer Figure 2.7.1).

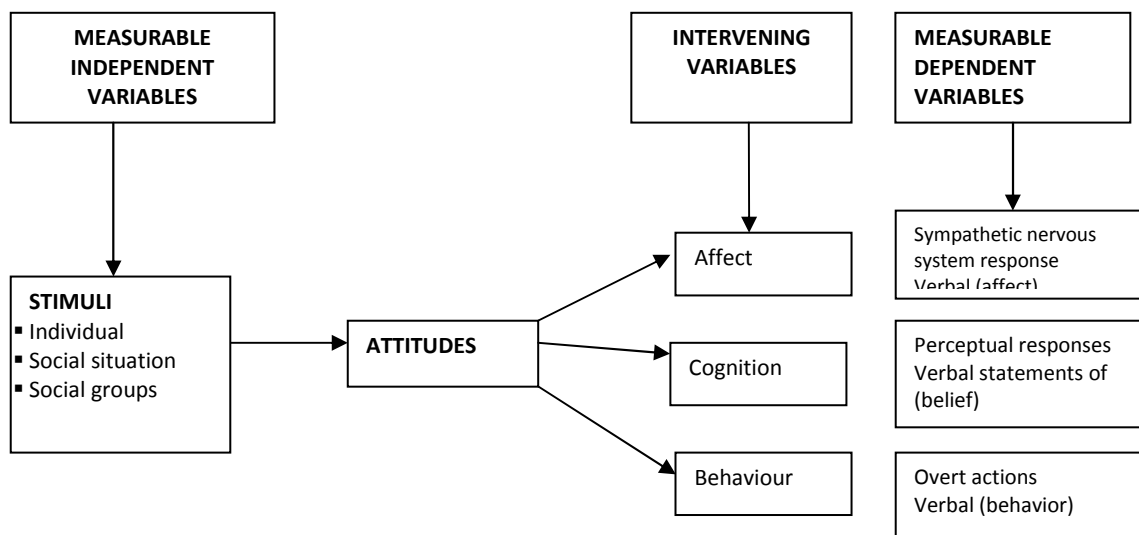


Figure 2.7.1 Rosenberg and Hovlans Schematic Model of Attitudes (1966)

In attempting to establish a psychometric measurement of attitude, variables which are independent of the person such as environmental factors (stimuli which a person has no control over) create the individual's attitude towards a situation / task. According to Rosenberg & Hovland, an attitude is conceptualised in three ways. Namely, affect (the way in which the individual feels about a situation), cognition (what the individual believes /understands about the situation) and behavioural variables (the actions performed by the individual in response to the situation). These variables become measurable through a reaction either verbally or by overt, observable actions of the individual to the situation or task.

In addition to this, Rotter (1967) specified that attitudes were related to expectancies of outcomes such as reinforcement or reward. Reward is governed by either an internal or external locus of control. Therefore, a person with internal locus of control, which is the ideal, will see any outcomes as a result of their own efforts (Rotter, 1967). Those, however, with an external locus of control will view outcomes as largely outside of their control and attribute them to luck, chance or fate. It is logical for the researcher to identify the connection between Rotter's theory of attitude to cancer patients who may be lacking a strong sense of empowerment and who will thus attribute treatment outcomes and any difficulties experienced in managing their illness as largely outside their control. This, in turn leads to a sense of disempowerment in relation to managing the illness.

Triandis (1971) noted that the behaviour of an individual is governed by the following elements and incorporates earlier work in this area by Rosenberg & Hovland and Rotter. Namely, behavior is linked to

- Attitudes
- Norms
- Habits
- Expectancy about reinforcement.

Triandis (1971) maintained that when all four elements are present, the individual will display consistent behaviour. He also noted, that it is possible to change more negative attitudes and thus to transform subsequent behaviour amongst individuals. Changing negative to more positive and realistic attitudes amongst patients is a desirable outcome in studies such as the Shared Care Model upon which this research is founded. This is achieved by providing tailored resources and support strategies most relevant to individual cancer patients. The endpoint is the creation of a more empowered and engaged person who takes an active role in managing their condition. However, maintaining the positive attitude is challenging in the face of a life limiting condition such as cancer and is discussed in the next section.

2.7.3 Affecting attitude change

It may be possible to change patient beliefs in order to incorporate a set of more positive and empowering attitudes towards the illness. However, it is important to maintain those positive attitudes in the long term once the change has occurred. This is ultimately a more challenging aspect of cancer management. Festinger (1964) noted that attitude change cannot be maintained unless the environment remains supportive of the behavioural change that accompanies the attitude change. That is to say, once a person is removed from a situation that modifies his/her behaviour, he/she may revert to original attitudes if they are consistent with more fundamental values held by that individual. It is speculated that this may highlight the importance of others outside of the hospital setting such as the family GP or close family members. Furthermore, support groups can assist in reinforcing positive attitudes amongst members thereby facilitating the empowerment process.

2.7.4 Active Participation Theory

The role of tailored resources and patient support networks cannot be understated. Changing attitudes and behaviour can be achieved by creating conditions of group participation (Lewin 1947). Lewin maintained that expressing one's commitment and support for certain strategies is ultimately more effective than making a private commitment. Current research also notes that cancer patients can seek out group support in the face of uncertainty (Pistrang et al. 1999; Dunn et al. 1999; Rankin et al. 2004). Asking 'how am I doing?' and reinforcement from other group members maintains support for positive behaviours (Ussher et al. 2006). Over time, they become adept at identifying unrealistic outcomes and recalibrating more realistic goals. Positive reinforcement may serve the purpose of changing a patient's attitudes for the better. As Triandis (1971) notes,

"When a subject is rewarded for a response his attitudes may also change."

This highlights the importance of doctor-patient communication in asking for and the provision of information in addition to the relevance of shared decision making where appropriate with a patient. The role of positive reinforcement at corresponding level to a person's state of health is highly successful. However, the key to maintaining positive patient outcomes is a realistic level of encouragement. Most patients prefer to receive the truth about their prognosis and have realistic goals set (Hickner et al. 2007). This research demonstrates the significance of acceptance and realism in the face of what is or is not achievable for an individual patient.

2.8 Exploring empowerment through qualitative methodology

The way in which empowerment contributes to patient wellbeing is ambiguous and the characteristics of the patient's ability to regain control in the face of a diagnosis of cancer are difficult to define. In order to clarify the markers for empowerment amongst cancer patients, an in-depth exploration of patient perception of ways in which they empower themselves once treatment is commenced was required. A phenomenological approach was used for this stage of the research. The phenomenological approach explores the "lived experience" of the person whereby the reality is defined by what is "consciously experienced" (Grbich 1999). Furthermore, the lived experience common to all informants meant that all preconceived ideas of the researcher were removed (Grbich 1999). In order to achieve the perspective necessary for this study. The study sampling was purposive (Patton 1990) whereby participants are deliberately selected from a homogenous group of patients in order to obtain a series of 'information rich' interviews. This was particularly relevant for the initial interviews with Shared Care patients as it was necessary to define common themes for empowerment amongst patients actively involved in the treatment and management of their condition (Ward et al. 2000; Bulsara et al. 2002). The themes from the analysis process using the initial dataset from Shared Care patients and the subsequent interviews with the same patients for this study were obtained using a *interpretive phenomenological analysis* (Smith JA 1995; Smith et al 1999).

Subsequently, statements were generated from themes identified from Shared Care patient interviews. The set of statements formed the initial version of the Patient

Empowerment Scale. As previously noted, Triandis considered the operationalising concepts of 'attitude' as the ways in which a person responds to the stimuli (statements) forming the attitude to be measured. Thus, patients were asked to respond to stimuli (statements) to ascertain degree of empowerment because the behaviour (empowerment) could not directly be observed.

2.9 Use of Item Response Theory in developing a Patient Empowerment Scale

Ryan (1983) has described Item Response Theory (IRT) as more sensitive and accurate than traditional test theory when measuring human attributes which are not overtly observable. This is due to the fact that IRT focuses on actual observed scale /test performance amongst respondents. The concept which is relevant and central to the procedure is *unidimensionality*. Unidimensionality implies that the concept of empowerment is measurable as a single construct and in relative isolation from other constructs and human traits which may influence it. As defined by Ryan (1983), "the process of measuring psychological attributes requires us to assume that individual human attributes can be isolated and measured at the one time. We must also assume that measuring instruments are sensitive to a single human attribute."

It may not always be possible to measure concepts such as the level of patient empowerment accurately. As Ryan acknowledges from the field of educational measurement, "behaviour of some (children) during the measurement process distorts the unidimensionality". Although, at times, this may be the case amongst cancer patients, it should be highlighted that levels of empowerment as measured by statements provided in the Patient Empowerment Scale transcend the point in time of a patient during the illness trajectory. The markers (statements) in the Patient Empowerment Scale should remain relevant regardless of patient prognosis. In other words, patients do experience setbacks throughout their illness. However, empowerment through self-efficacy demonstrates how a patient reacts to those setbacks and demonstrates a willingness to adapt to the situation. For example, in regard to relevance of information to the patient, it is the patient's ability to utilise that information to cope with the setback and move forward again which is central to empowerment as a concept.

2.10 The Rasch Model

It has been established that according to psychometric theory, a construct or latent trait such as empowerment cannot be observed directly but has to be observed through manifested behaviours and actions in this case by the test subjects or respondents (Triandis 1971).

Thus scale development involves operationalising a latent trait through a series of statements which respondents may endorse at different levels or by differing degrees along a continuum. This is usually accomplished through the use of a Likert-type rating scale (Likert 1932). It is important also that the statements form an ordered series which increases in intensity. That is, the more intense items should be able to be endorsed by respondents with higher levels of the latent trait. The level of the latent trait (in this case, empowerment) is represented by the total score for each person on the set of items forming the scale.

Other models are used to describe a set of data rather than assessing how accurate the items which make up the scale contribute to providing a measure of the particular characteristic or attitude (Andrich 1988; Andrich 2004). The unidimensionality required by the Rasch Model implies that the construct of interest such as 'empowerment' is unidimensional at a particular level of scale that is useful for the purpose for which the scale is intended (Andrich 1988). If the items that operationalise the construct fit the Rasch model, then that set of items forms a single linear continuum in which the order of items is invariant across all relevant populations. The Rasch model using the RUMM program linearises raw data into an equal interval scale through logarithmic transformations onto a single continuum (Andrich 1982; Wright & Stone 1978).

By examining how well the data fit the model, the validity of the scale as a whole and the items individually can be established. If the data fit the model, then the use of total raw scores to represent respondents' levels of empowerment is justified across the major part of the scale with the exception of the two extremes where the transformations are non-linear. In other words, the addition of the raw scores for items in the PES to provide sound measures of patient empowerment would then be justified.

2.11 Conclusion

The concept of empowerment in relation to cancer patients differs from other related areas such as coping, pain management or specific psychological states such as anxiety

and / or depression. In addition, other scales which define the psychosocial impact of cancer on patients focus on specific aspects of regaining control over the illness such as involvement in decision making, mental adjustment to cancer and physical ways of coping with the illness and side effects of treatment. Empowerment encompasses all of these rather than focusing on one specific element. Furthermore, empowerment requires the patient to proactively seek out support and resource strategies in order to regain and maintain a sense of control. Empowerment is not able to be identified as a directly observable behaviour in itself. It can only be observed through the responses and actions of the patient to certain stimuli. As such, a set of statements (markers) which allude to specific support and resource strategies amongst cancer patients would conceptualise the concept of empowerment. Although the qualitative methodologies used to explore core concepts (support strategies and beliefs) around the experience of cancer would define elements used by patients to regain control and to achieve a sense of empowerment, I was also considered the development of a quantitative measure of the same concept. Thus, the development and administering of a scale using the Rasch Model would provide further tangible evidence for the successful operationalisation of the concept of empowerment which could be measured amongst those with a life limiting illness such as cancer.

Chapter 3 – Results Phase I - Patient in-depth interviews

3.1 Introduction

This chapter details the main themes arising from the original interviews with the former Shared Care patients as they relate to the concept of empowerment and motivation to regain control over their illness. The results section outlined in this chapter will map the patient's journey from the diagnosis through to acceptance and control which results in empowerment. In the final section, the categories which compose empowerment in this setting are summarised. Finally, the way in which the main themes relate to the formulation of statements for the Patient Empowerment Scale will be discussed. Two peer reviewed papers and an invited book chapter were published arising from the findings of the Shared Care patient interviews and they are included in Appendix 4 at the end of the thesis.

The questions used for the in-depth patient interviews were developed from a literature review and from the findings of the original patient interviews during the pilot Shared Care Project (Ward et al 2000) regarding empowerment, support systems and access to resources amongst patients. Through a series of in-depth patient interviews, the main markers for patient empowerment were identified in two ways. Firstly, through distilling main themes of the in-depth interviews of all patients who had been involved in the Shared Care pilot project. Secondly, in theorising about patient empowerment by collating the results of the extensive literature review. The common themes became markers and were operationalised as coping strategies by patients in the day-to-day living with their illness. In conjunction with this, the illness trajectory showed that patients followed a journey of sorts to achieving a level of empowerment. In exploring the themes which are identified along the 'cancer journey' and in referring to the literature review, we were able to formulate the patient empowerment scale (PES) as outlined in the next chapter (refer Chapter 4).

3.2 Methodology

A phenomenological approach using an in depth interviewing technique was employed in order to best identify the complexity of issues amongst informants. Phenomenology is defined by Morse & Field (1995) as seeking to gain what is the essence and core meaning of participants' experiences and, as such, suggests approximately six participants to explore the research topic fully. It was decided to conduct a purposive study (Patton, 1990) whereby participants are deliberately selected in order to obtain a series of 'information rich' interviews. This would provide the researcher with a clearer understanding of strategies employed by Haematology Shared Care cancer patients to cope with their illness. In this case, the Haematology Shared Care patients who had participated in the pilot Shared Care project were re-interviewed. Due to their involvement with the Shared Care project, these patients had specifically demonstrated a consistently strong sense of control and a high level of coping ability in their interactions with clinicians and the health care team. None of those interviewed had another health condition nor were they receiving treatment for an existing mental illness.

Semi-structured questions were constructed for the project using the core findings from the previous Shared Care pilot project in relation to specific themes of coping with the illness and perceived ability to draw on inner strength and outside resources. All informants were asked the same questions in order to understand fully the process of gaining mastery over the illness and maintaining control.

3.2.1 Sample selection

Patients received treatment at a haematology centre which was a tertiary facility and a major cancer centre. The same haematological specialist was treating all patients. The sample was a 'purposive' sample of patients. Diversity of patient demographics by age, gender and prognosis of those attending the haematology centre was intentionally sought in order to establish the characteristics of coping strategies regardless of variations in treatment and prognosis. For this reason it was decided that all 12 patients who had participated in the pilot Haematology Shared Care project would be approached with the knowledge that, for various reasons, it was likely that some would

be unable to participate. One homogenous characteristic demonstrated by the informants was their commitment through the Haematology Shared Care pilot project to take some measure of control over their illness and to work with the health care providers in achieving an open and continuous communication in relation to their treatment and care. Of the original sample of twelve patients, seven patients agreed to participate again in this study. Five patients had been diagnosed and treated for lymphoma and two for multiple myeloma. Five patients were male and two were female. Ages ranged from 39 years to 63 years. Two patients had been diagnosed as terminally ill. Three patients were in remission and one had just relapsed. Of the remaining five Shared Care patients, who did not participate in the interviews, two had since died, one had migrated overseas and two were unable to be contacted.

3.2.2 Data Collection

A letter was mailed to each of the seven patients explaining the aims of the study and inviting them to participate. The researcher then contacted the patient to arrange a suitable time and place for the interview. Questions were designed as a guideline to the research process to obtain an optimum amount of information regarding the empowerment process and to maintain focus. At the sole discretion of the informant, a family member, friend or carer was invited to attend and contribute during the interview to reinforce or provide additional information regarding the illness experience. This was also believed to be important due to the complexity of the relationship that exists between the patient and significant others in their lives. It was further believed that some patients may feel more comfortable during the interview if a supportive family member was present. Duration of the interviews was thirty minutes to one hour. Two interviews were completed by telephone with the two rural informants. Two interviews were conducted at the hospital whilst the patient was attending the Haematology clinic. Both interviews taking place at the hospital were attended by the key informants (the patients) and where requested with their partners. Interviews were taped and then transcribed by the researcher. The remaining three chose to be interviewed by the researcher at the university. Ethical permission for the study was granted through the hospital ethics committee.

3.2.3 Data Analysis

Interviews were analysed using the data management software, QSR NVivo 5.0. Initially, transcripts were read through and analysed manually with codes and major categories being established. Both manual and computer assisted methods of analysis were performed to prevent the researcher from becoming distanced from the data. The Interpretive Phenomenological Analysis (IPA) is concerned with the meanings that are held by participants for events they experience for themselves (Smith JA 1995). Access to these experiences also means that the researcher cannot remain separate from the event or experience but provides their own interpretation of events as described by the participant (Smith JA et al 1999) . Saturation point was achieved in terms of establishing themes from the interviews. Numerous major themes were identified as common to all seven informants in regard to empowerment.

3.3 Overview of stages to regaining control

In order to regain control and achieve a sense of empowerment, all patients progressed through stages of the process. These were identified as firstly, initial reactions to the diagnosis characterised by shock, anger, guilt and denial. The initial stage was then followed by regaining equilibrium and addressing practical approaches to what was and was not within the patient's control. This included aspects such as dealing with financial matters and learning to re-evaluate what was possible or not. In order to maintain balance, most patients had a series of 'critical friends' and family who provided support when necessary whether this is emotional or physical support. This stage was also accompanied by the initial attempts to recalibrate boundaries for well meaning family and friends. Patients acknowledged that initially, there was a 'flurry of activity' from close family and friends in order to try and 'take over' or solve the problem for the patient. For patients, it was important to be able to set boundaries for themselves and to be able to decide and articulate at what point they needed someone's support. This also included the use of resources such as advice of health professionals and relying on the health professional's belief in the patient ability to cope with the management of their condition.

Patients then moved towards acceptance of the illness by willingness to face fears and concerns rather than exhibiting avoidance. The ability to 'face one's fears' was an important step in achieving a sense of empowerment and was accompanied by a scaling back of goals and readjusting to the reality of the situation. In this stage, spirituality and exploration of other ways of managing their illness through use of complementary medicines came to the fore. Adjusting and accepting their situation often went one stage further for empowered patients. That is, empowered patients are defined as those who showed a sense of control over their condition in the ways highlighted above. This final stage in achieving empowerment was the ability and willingness to share their experiences and to help others who were also diagnosed and struggling to find equilibrium. Most patients who were involved with the Shared Care model and who were active participants in the management of their condition regardless of prognosis often spoke of their motivation to advise and comfort other patients. This was either done informally during hospital treatments and visits or more formally through contributing to support groups and similar resources. In addition, patients who showed a sense of empowerment also noted that they still had "bad days" but they differed from other patients in that they recognised that such days were transitory and that any difficulties experienced on those days could be overcome. It is through this willingness or motivation to overcome difficult days that distinguishes the patient's self-efficacy in relation to their cancer. Those who can attribute the 'bad days' as transitory and who believe they can pull through and continue to recover from their illness show a greater degree of self-efficacy than those who remain anxious and anticipatory of the next difficulty.

3.3.1 Relating Patient Goal-Setting (Task, Self and Environment) to empowerment

As will be seen by discussing the findings of the patient interviews in this chapter and supported by relevant literature in Chapter Two, persons with high levels of self-efficacy are able to follow a process which enables them to maintain effort in the most challenging of circumstances. This entails being able to appraise their own capabilities, set realistic

goals, and have a strong commitment to achieving those goals, despite the occasional and inevitable setbacks. The notions of self-efficacy, self regulation and empowerment are, therefore, linked in that high self-efficacy may be seen as necessary for a person to engage in the actions (self-regulation) to achieve personally-selected goals which are epitomised in the idea of empowerment. Table 3.1 shows a matrix of elements of self-efficacy and possible associated strategies in coping with severe illnesses (self-regulation), together with examples of these elements. Two of the elements (Goals and Affect) are psychological processes which Bandura (1994) postulates are ways through which self-efficacy affects human functioning. Namely, Cognitive Processes and Affect. Empowerment is characterised by a high level of control over goal-setting, affect and strategy use in regard to the task in hand (dealing with illness), to the self, and to the environment (the latter being similar to Bandura's (1994) Selection Process). In the sections that follow, the scheme shown in Table 3.1 (Goal-setting, Affect and Strategy Use) is used to examine the responses of patients in the present study in order to understand their reactions and behaviours from the perspectives of self-efficacy, self regulation and empowerment, using quotes from interviews with the participants illustratively. The table (Table 1) below is a schematic representation of the processes important to self-efficacy and associated strategies (self-regulation) that empower patients with a life-limiting illness. The tasks involved in coping with cancer include not only the management of the illness but also the ability to set goals and limits in relation to the self and the environment (health professionals, family and friends, support groups and organizations). The ways in which this impacts upon the patient (affect) cause a patient to employ strategies to control their illness (regulatory). The affects are highlighted from the findings of the Shared Care patient interviews and form the basis for the Patient Empowerment Scale.

Table 1 - Schematic representation of processes important in self-efficacy and associated strategies (self regulation)

<i>Processes</i>		
Cognitive Processes/Goals	Affect	Strategies (regulatory)
<i>Task (dealing with the illness itself)</i> <ul style="list-style-type: none"> • Manage illness • Minimise illness effects • Overcome illness 	<i>Challenge</i> <i>Anxiety</i> <i>Fear</i> <i>Shock</i>	Self regulatory <i>Set short-term goals</i> <i>Physical exercise</i> <i>Take medications</i>
<i>Self</i> <ul style="list-style-type: none"> • Remain positive • Reduce anxiety • Adjust expectation • Nurture the self 	<i>Disbelief</i> <i>Puzzlement</i> <i>Helplessness</i> <i>Anger</i> <i>Empathy</i>	<i>Occasional indulgence</i> <i>Meditation</i> <i>Exploring spirituality</i> Involving others
<i>Environment</i> <i>(Physical and Social, e.g. health professionals, family, friends, organisations)</i> <ul style="list-style-type: none"> • Use resources to achieve task goals • Set limits • Family security • Gather information • Remain in work/ occupied • Emotional support 	<i>Altruism</i> <i>Serenity (acceptance)</i> <i>Optimism</i> <i>Pessimism</i> <i>Depression</i> <i>Confidence</i>	<i>Seek help and support from family and friends</i> <i>Seek information from health care professionals</i> <i>Seek affirmation from health professionals</i> <i>Choose environment that is most supportive</i> <i>Establish boundaries</i>

The results will be discussed in further detail as the patient follows a process (journey) from time of receiving the diagnosis to regaining control using self-regulatory strategies noted above.

3.4 Results of in-depth interviews with Shared Care patients

The Cancer Journey

Once the patient is diagnosed, their individual cancer journey progresses through specific phases whilst relying upon a level of motivation from the patient in order to achieve a sense of empowerment. It is important to acknowledge these phases of the journey in order to identify support and resource mechanisms amongst patients leading to a level of empowerment.

Initially, the patient experiences shock and disbelief on hearing the diagnosis followed by anger and questioning 'why me?' Once this stage has passed the patient tries to establish some equilibrium to their lives. This is usually accomplished once treatment is underway. This stage also involves the re-establishing of boundaries as family and friends rush to provide support for the patient. Patients also utilise this time to evaluate for themselves the types of support that are needed, when they are required and by whom. In following the phases outlined here, the researcher is able to identify, using a qualitative methodology, support and resource strategies along the way which enable the patient to regain a sense of control and empowerment over their illness. The findings in this chapter are presented as qualitative findings which will link into the formulation of the patient empowerment scale in the next chapter.

3.4.1 Reactions to diagnosis

Most respondents were "shocked" or "devastated by the diagnosis and needed to go through this phase before regaining equilibrium. One patient said that the doctor had to keep repeating the news to him in order to make sure that he fully understood the diagnosis.

"When D---- (specialist) told me he went away and came back and gave me the news again. I said to him, "You've already told us that" and he said, "Yes, I know, but you've got to understand... I've got to drum it in to you ". It was the initial shock."

However those who had awaited the result of tests and were "anticipating bad news" felt that the diagnosis did not entirely shock them as they had thought. Two patients also noted that they were not entirely sure what the disease was and said that they had never heard of it before. This meant that the realisation of cancer came to them more slowly.

"I certainly didn't know it was cancer so it never came as a shock. Because I didn't understand what it was in the beginning that is why I slowly came to realise it instead of a huge shock."

Most had clear memories of the diagnosis and the events of the day that cancer was confirmed.

"I remember it like it was yesterday."

said one patient. Some spoke of stoicism needed to begin with in breaking the news to the family. However, this quickly gave way to the realisation of the diagnosis. Although some had begun by feeling stoic, speaking to friends and family brought emotions to the surface very fast.

"I tried to be stoic. But then all my friends started ringing me and telling me how wonderful I was ...that got me down a bit."

For those with families, breaking the news to children was noted by patients as very difficult. Where once, as a parent, they had been in a position of authority, they were now feeling vulnerable and often in need of help in terms of drawing strength from their own children.

Some patients who had believed themselves to be very healthy could not understand why they had been diagnosed with cancer and began searching their past lifestyle to lay blame.

"I suppose the first diagnosis is always the hardest. You would sort of think, well, -why? I lead a healthy lifestyle. You start to think back to earlier years...we were trying to think what we had done and that."

Early days when a full diagnosis was being made was fraught with apprehension for some respondents. The uncertainty about treatment and how they would react was worrying. Fear for the future in terms of treatment and treatment effects was a main concern. However, one respondent noted that once the treatment had begun she found it easier to cope.

"Before you start your treatment it is fairly scary. When it was actually underway, I felt much better and I felt it was a challenge and I was heading somewhere."

Patients said that it took them anything from one day to about a week to come to terms with the diagnosis. Some patients spoke of trying to be stoic for the sake of sparing the feelings of others around them. This was particularly true of family members and children. Many felt that breaking news to children, even though they were adults, was the most difficult task.

"We had been talking to the kids and that was the hardest."

Practical concerns then took place amongst most of the patients. Financial concerns were foremost, especially amongst main breadwinners. Some expressed an unpreparedness to make changes and adapt. Most had mood swings from optimism to depression and fear of what the future might hold.

Informants noted financial concerns in terms of what might happen if they were unable to work and how the family would cope.

"We had just moved house and a mortgage and the week that I was diagnosed we had just moved to a new house. There are a fair few things that go through your mind."

Patients often questioned, "why me" in the early stages.

“People say, ‘why me?’ Well I can honestly say that I did say it that day.”

“I suppose the first diagnosis was the hardest. You would sort of think well, ‘why?’. I lead a healthy lifestyle.”

This was especially true of those who felt that they were living healthy lifestyles in terms of diet, exercise and other positive lifestyle factors. Patients who considered themselves healthy began reviewing past lifestyles in order to try and find a cause for their cancer.

“I didn’t smoke or drink and I lead a healthy life. I am a real ...well, exercise, fresh fruit and veg girl and so I eat healthy.”

“There are questions as to why because you start to think back to what you might have done in earlier years and the fact that I grew up on a farm. Was it chemicals or other things? You just start to question all that.”

Clearly this early stage following diagnosis is filled with many questions and unknowns. It is at this stage that the patient feels that they have lost control. Moving beyond the ‘why me?’ phase is crucial in attempting to regain control through acceptance.

3.4.2 Regaining equilibrium and moving towards acceptance

Realising and recognising the situation

One informant noted that he could cope better with the diagnosis as both parents had died from cancer. Therefore he believed that although coping with the illness was difficult, it was not the worst experience he could go through in life.

“My mum and dad both died of cancer and in hindsight they were not the worst experiences you could go through. They were not pleasant but they were not the worst.

The bottom line is...you have to face up to it.”

All patients interviewed appeared to have moved on from initial shock and fighting against the diagnosis to feelings of acceptance for what had happened to them. Many spoke of 'coming to terms with it' or 'that's life' as part of how they felt about their cancer.

"I saw that there was a reason why I had got this and I just had to get on with it."

Patients spoke of "having to fight it" in terms of developing strategies to cope with the illness and accepting that it was there rather than fighting against it and pretending that it was not present. For most patients however, initial stages of moving towards acceptance was changeable and depended on the stage of diagnosis, reactions to treatment and apprehension about starting treatment. As one patient said,

"You sort of get down and then get back up again..."

As previously mentioned, one patient was extremely apprehensive until her treatment started and then felt that the actual treatment was a challenge in terms of being able to manage cancer and cope with any side effects. Another patient experienced relief when he was diagnosed after months of pain and specialists unable to diagnose his illness.

"I was so relieved when someone had found something wrong so they could try and fix it."

Acceptance of the illness and the next phase of adapting one's lifestyle and scaling back goals are essential to becoming empowered as a patient. Nor does acceptance imply that the patient must give up. It is, rather, that they realistically evaluate what they can and cannot do and then work with their health team and significant others to maintain a good quality of life.

Talking to others and seeking reassurance / support

In the early stages following diagnosis, patients noted that often friends and family would come to them to offer help and support rather than them actively going out to seek help.

“Look – every friend in Perth had the answer to this. I could have started a library with the stuff I got given to me.”

One patient noted that she didn't need to go rushing out to seek help but would deal with things as they happened. Most patients noted that although friends were very willing to help but were uncertain how to help. Most responded as noted by offering books, complimentary medicines and practical ways of assisting the patient in coming to terms with their diagnosis and treatment side effects.

“I used to get given stuff. People would give me internet info and stuff like that. I certainly would read it but I wouldn't go searching.”

Many felt that just having a reassuring presence and closeness of family members following diagnosis and in the early stages was sufficient for them.

“No we didn't seek any outside help. We were going to go to those sorts of things but it was right around Christmas and we thought we would go afterwards. But we had our grandchildren and others which takes your mind off it.”

One patient who didn't have a great deal of family support found that the support centre was very good in helping him come to terms with his diagnosis. Sharing experiences with other patients in the same situation was extremely helpful to this patient. This patient also noted a supportive relationship with his GP from the early stages. Many patients noted that they relied upon the calmness of close family members and partners to help them come to terms with their diagnosis.

“My partner sort of thought that we would wait and see what happens and that. Friends were more emotional.”

One patient spoke of her dependence on her mother for support despite the fact that her mother was elderly. This patient felt that her mother was one person who could truly understand what she was going through.

“I have had thought of suicide but I would not have because of what it would put her through. I told her recently, “If you had not been there I would have done myself in long ago.””

However, the relationship was mutually supportive for this particular patient. In other words, the patient also felt needed by her mother.

Needing the support of family and / or friends is one of the main support strategies used by patients. Although a sense of self reliance is important, the support of significant others is almost equally so.

Keeping the family informed

Some family members were unfamiliar with the terminology of the illness and did not comprehend the seriousness of the diagnosis. Family members and friends were described by patients as ‘emotional’ and ‘devastated’ by the diagnosis.

“At that time they were fairly shocked – I didn’t smoke or drink and I lead a healthy life. They would say, “God! You? How did you get it?” “

Two patients noted that the close family members were “at a loss” as to how to help. For older family members such as a mother or father of the patient a sense of helplessness was apparent. Some parents of patients experienced a period of profound depression following the realisation that they could not influence or remedy the situation. Some parents turned to religion as a means of coping with the situation.

“But for the family, especially T_’s mum who could always sort things out for him growing up...this was something that she couldn’t fix. So it was a kind of helpless feeling – as with other close family members. She couldn’t deal with that very well. She turned to religion to cope.”

It is during this time of settling into the management of the illness that patients often need to remain strong for family members as much as vice versa. The open show from patients to others that they are coping and are mentally positive is important to both the patient in terms of outwardly showing their ability to cope with the illness as much as in establishing boundaries in terms of what they may or may not need from others.

Establishing boundaries

Having lost control temporarily means that patients and their families need to re-establish equilibrium. This involves the patient learning to verbalise what they need and to setting boundaries once more to maintain personal space.

Linked to support was the notion that family and partners would also learn to identify and recognise patient limits. That sometimes a patient just wanted to be alone and it was acceptable to give them their time to themselves. As one partner explained,

“He would come home. Every half hour I would just go in and check and then just leave the room again. So we knew that as soon as he went quiet he just wanted to be alone.”

One patient’s family developed strategies for communicating to family members and friends that the patient needed rest and quiet. They would meet relatives and friends in a lounge but once the patient needed rest he would go to the bedroom and close the door. This created an understanding amongst visitors that he required some time to himself.

Perceived “fussing” on the part of family and friends aggravated some patients. Most preferred to spend time alone to help them come to terms with their situation.

“That was a down side. People would come and they would all ask the same questions. So that was why if I wasn’t up to it my wife would just say, “Look, he’s not up to it.” It was hard but I would just come out of the bedroom and have a chat. That way I had the control.”

The ability to set boundaries is an important aspect of regaining control. Needing the support of family and friends should be counter balanced by an ability to rely on oneself. It was viewed as a positive growth experience. Some found that the illness had helped them to learn to say ‘no’ to others and to prioritise the important aspects of life.

“I lead a more relaxed lifestyle now and have learned to say ‘no’. I was a person who would do anything for anyone. That is the big thing that I have learnt.”

Most patients and their partners expressed the need for family support without interference. For many, it was all about finding a balance with family members and friends in the early stages. One partner of a patient said that the family had experienced the death of another close relative earlier that year and found it difficult not to ‘mother’ her husband in the early days following the diagnosis.

“He has four sisters and all of a sudden they just wanted to ‘mother’ him. I reacted to that with a “hang on a minute! I am still here as well.” They wanted to go to the doctors with him and we had to tell them we could handle it. But they were good then and kept in touch. It is all about finding a balance.”

Patients noted that they appreciated family members learning not to ‘hover’ over them. This was a learning experience for everyone involved. Establishing boundaries can be stressful and difficult to accept both for the patient and for family and friends. Family presence without interference was the preferred relationship for both patient and partner during the illness.

“I am not one to live in other people’s pockets and so they are there if I need them.”
And,

“I’ve had family call in but they don’t interfere.”

However, most patients accepted that family and friends were concerned about their wellbeing. This was regarded as a positive aspect of feeling needed and supported by those most important to them in their lives. However, one patient who had been diagnosed for a second time was distressed that her family regarded her as capable of coping with her illness with minimal support from them due to the fact that she had been through the experience before.

“I really can’t speak for my husband and daughter. Things have changed to a degree. They will say that I have had my treatment and this and that and that I don’t have to talk about it.”

Patients also noted the importance of sympathetic work colleagues who tried to make life easier for the patient. For patients who were in paid employment, the importance of being treated normally in the workplace was often highlighted.

“Work colleagues were very practical in their help. So I had lots of support. I made a point of going to work every day because I thought that if I was sitting at home it can only get worse. In the job I could call my own hours. So there was a pattern.”

All patients noted that they did not speak to health professionals straight away but preferred initially to seek reassurance and security from family and close friends. Many felt that it was important to “touch base” with those who were close to them and to draw support from close ties. The person or persons spoken to were varied and noted as a partner, family members or carer. Religious or church groups were also important to two respondents. The number of people spoken to did not seem as important as identifying with the person for many patients. Some patients only named one person as an important confidante,

“Well the only person is my mother. She is basically the only person that I could identify with and feel comfortable with. So I only spoke to her.”

Others had the support of a large family and relied upon all members extensively to help them through the illness experience.

“I got a lot of support. My wife is very good. We have got nine kids and so that made a big difference to me.”

Three couples noted that they were not comfortable with talking outside the family as they preferred to keep their ‘troubles’ to themselves. They remarked,

“I guess we spoke to a few friends. But we are an old time couple and we believe that our struggles are our own. We deal with it ourselves and it stays with us.”

“It is between my partner and myself. Pretty much just with our family and that.”
“No we didn’t talk to anyone. We didn’t even talk between the two of us. I just wanted to be somewhere secure.”

Friends offered support to most informants but many felt that support offered by friends was not what they needed in the beginning. Patients also noted that friends were unaware of what the patient needed at that time and many resorted to providing the patient with books, articles and information about treating cancer. Patients noted that friends and relatives would try and offer help in terms of providing supplements and books or leaflets. It was as if, as one patient remarked, they “didn’t know what else to do”.

“We know they mean well and they don’t know what other way to help.”

Some were also offered nutritional supplements and advice on complimentary therapies. In other words, offering practical help when offering emotional support was difficult. It is a way of saying, “I am here for you...”

“People also had lots of information for you and we would thank them for that. But they would also bring you supplements and multivits from the health food shops and you could have opened a shop on that! Although we appreciated that it was not what we needed at the time.”

Work colleagues

As noted, some patients said that they needed work colleagues to help them feel more “normal” and create equilibrium when the future seemed uncertain. The following quotes illustrate the value to patients of maintaining understanding work relationships.

“I was able to work part time and have flexible hours. If I had an ordinary job I could not have chosen my hours. This took my mind off things.”

“I made a point of going to work every day because I thought that if I was sitting at home and in the job I can call my own hours. Sitting at home it can only get worse.”

Regardless of whether the significant others are family, friends and / or work colleagues, all patients utilised these forms of support as a means of managing their condition. For many patients, the type of relationship determined the amount of support provided and indeed required by a patient. Usually the relationship went through some changes following a diagnosis of cancer and this was part of a larger evaluation of lifestyle amongst cancer patients. However, the clinician differed from other resources and type of support in that the relationship was related to the illness and required most development on the part of both doctor and patient. For this reason, perhaps, patients who had a long standing relationship with the family doctor or general practitioner (GP) highlighted the reliance that they placed upon the GP for support outside of the hospital setting. For these patients, what characterized their relationship with their GP was the advocacy role that the doctor took on for the patient and the fact that the GP was willing to ‘go the extra mile for the patient’.

3.4.3 Managing relationships with health professionals

Availability of options in treatment and care

For most patients, although they noted that they had valued the options they had where possible been given, most of them trusted the specialist implicitly and were more likely to rely solely on specialist advice.

“I found a couple of options very good and was able to make an informed choice about my treatment.”

One patient indicated that just coping with the illness was a large enough responsibility without having to make decisions about one’s treatment options as well.

“I could have (shared in decision-making) at any time and I was aware of that. But you would not and you just have to have faith in those guiding you. I mean the amount of stuff that people go through is huge.”

And from another patient, explaining the procedures was part of the acceptance of the treatment offered.

“I just felt so confident with D___ that he knew what he was doing. We did talk about these things and he would explain everything about the procedures. This helped you to accept them. If he had just said, “Right...you’re going to have this and that..” I would have said, “Now, hang on a minute!”.”

In fact, one patient felt that she had not been given any treatment options and was resentful of this. Even though she had since gone into remission she believed that she would have felt more reassured by being given reasons for the treatment choice when she had breast cancer. She highlighted the fact that it was empowering to be well informed.

“Yes, I would have liked to have known more. We need to be informed and I think you should have the option to know what is basically going to happen during treatment. Other patients say they would like to have all of their medical results as well.”

None of the interviewed patients initially sought the support of health professionals in coming to terms with their illness. Most believed that the trust necessary to confide in the clinician had to develop over time. In the earlier stages following diagnosis, emotional support was most likely to be sought from close family members and friends with the trust relationship developing with health providers over a period of time. Although for most patients, there was a great deal of satisfaction from the support of health professionals involved in their treatment and care, there were a few concerns. A partner of a patient also noted the difficulty with receiving the right information when someone has been diagnosed with cancer. Missed information and failure to ask important questions is characteristic for many newly diagnosed patients. Learning to manage this plethora of information is one way in which patients and their families learn to regain control over their treatment and care.

“You tend to miss really basic questions whilst in consultation sometimes. We were really relying on the hospital to answer questions. At first you are so shocked and you don’t ask the right questions. What we usually do is absorb the information and go away and digest it. Then ask questions next visit.”

She stressed the importance of hospital staff not assuming that the patient has understood. This patient also suggested providing basic written guidelines in the form of a checklist of questions to ask the specialist during the second visit. She noted that one piece of information in relation to freezing sperm before chemotherapy treatment begins would have been useful to their situation but they were not aware that this was possible.

The role of the general practitioner

When health care providers were eventually sought out in terms of emotional or psychological support, it would most likely be a general practitioner rather than the specialist. This may partly be attributed to the fact that the general practitioner is more easily accessible and also partly to the fact that patients felt that they could ask questions more readily of the general practitioner and that the general practitioner had more time to spend explaining things to patients and develop a close working relationship in terms of managing their illness. One patient explained,

“Our GP is exceptional. He is a wonderful doctor. At the time he gave me his mobile number and told me to phone him any time of the day or night. He was going to drive me home after I got the diagnosis.”

The role of the general practitioner cannot be understated in terms of providing moral support to the patient. One patient had a particularly difficult experience with a general practitioner and went into deep depression. Family members requested a change of general practitioner and the patient’s attitude towards coping with his illness became more positive.

“We were not happy with the GP we had at home. He made me feel very down. One day I went to see him and I was feeling good. So I said to him “Well tell me the good news” and he said, “Well, you are so close to be being in the cemetery it’s not funny.” Then I went back a week later and he said, “Trying to fix you is like trying to push s_t up hill. “ I was devastated. I changed doctors because __ wanted me to. ...he has been fantastic.”

It is vital that the general practitioner is capable of supporting the patient psychologically during the illness trajectory. An example of the impact of general practitioner negativity was explained by one patient. This patient noted that their general practitioner was less than supportive even though the patient was feeling very positive about managing the illness. This patient felt that the impact of the general

practitioners lack of support was to create a sense of hopelessness in the patient which took family members and friends a great deal of time to heal.

One rural patient was away from home at the time of diagnosis but felt that she didn't need any support. She noted that she had accepted that the diagnosis was real and that she "just had to get on with it".

For most patients, the knowledge that the general practitioner and specialist were communicating was extremely important. One patient noted that the general practitioner would be very timely in communicating with the specialist if he were unsure of any aspect of the patient's treatment side effects and care. One patient remarked that he felt so confident that his general practitioner and the hospital were communicating that he would be very happy for the general practitioner to take over some of his treatment if that were possible. This patient also felt that the general practitioner had more time to listen to him and was easier to access. Another patient noted that although the specialists and hospital staff were very attentive, their terminology was often confusing and he relied upon his general practitioner to explain aspects of his treatment and care that the specialist did not have time to explain.

"But the language they (specialists) use is not what we use and some of the terms I had never heard of! In many cases I would take what was written down to see my GP in his rooms. And it gave us a way of really understanding what was happening. It makes you feel that although you don't really have control of the illness, you can at least understand it."

One patient actually preferred to be cared for by her general practitioner as she found the general practitioner honest and straightforward when explaining her treatment and the negative aspects of any side effects.

"My local GP has been fantastic and has been a tremendous support to me. But when I went to see the specialist on my last appointment I went away feeling totally confused. They told me not to worry about it at the moment and we will wait! - But that is not right."

And another patient noted,

“Having a good GP is also important. Any questions he would ensure he answered and also because we felt secure.”

Many patients commended the hospital staff in various ways.

“Even when we first started going we could see – they have a very hard job and the attitude is great. I think it is all about attitude and it is very positive...you can sense it.”

One patient noted the level of professionalism amongst hospital staff.

“It is always good. I have always been impressed with the professionalism amongst staff. They seem to take so much care.”

Nursing staff displaying personal interest in patients and their health and most patients felt that this demonstrated approachability amongst nurses. Feeling sufficiently comfortable in approaching nursing staff with queries was particularly valued by interviewees in relation to knowing that hospital staff were available to support them.

Maintaining a positive attitude and health professionals

Some patients spoke of the importance of maintaining a sense of humour with hospital staff. This provided a more positive outlook for patients and their families in relation to the future. Nursing staff were also important for one patient in helping realise his limitations following treatments and helping him to accept that he should not try and overdo things.

“There needs to be an acceptance that if you are sick then you cannot overdo it. You have to accept that you can no longer push, push, push. It is all trial and error after treatment as to what you are capable of after treatment.”

Being comfortable with the specialists and other health professionals was also regarded as a valuable coping strategy. One partner remarked,

“I think you have to feel comfortable with the doctor. If you don’t feel comfortable with him or her it is a waste of time. Having the support, going through the process and the oneness – I think that is the biggest factor.”

Another patient noted that the hospital staff involved in his treatment had “renewed his faith in humanity”. Staying healthy was believed to be vital to most patients. One patient noted that this was linked to maintaining a positive attitude as depression could make one worse and therefore less likely to be receptive to treatment.

“It is about pulling yourself up. When you are down everything is wrong with you. When I had stress, I had shingles as well.”

Finally, the importance of pleasant surroundings in the hospital setting was also highlighted. Patients commented on the light and bright surroundings at the new Haematology Centre at Sir Charles Gairdner Hospital and were appreciative of the fact that there was no longer “a television blaring” in the waiting room.

“The new surroundings of the Haematology Centre are light and bright and the atmosphere is better. The last thing needed is a TV blaring. It seems to screech when you are ill.”

For some, the choice of hospital and surroundings were almost as important. One patient changed hospitals and explained,

“Conditions are much better here and the hospital surroundings make a difference. Infections are a complication...there are all sorts of infections waiting to pounce.”

Some patients noted the value of supportive health professionals in terms of nursing staff and general practitioners.

Familiarity was another important aspect of the relationship between the patient, a spouse and the nursing staff at the hospital. Awareness of a supportive health professional team provided an inner strength to many patients. Accepting that the patient and family had fears and concerns without belittling those fears was an essential criteria of good nursing staff. Giving honest and open answers was also seen as beneficial.

“I think that familiarity with nursing staff helps you cope in terms of nursing – you feel you are working together and they are with you. The nurse can be spoken to and if you have any fears or concerns this really helps.”

Patients also spoke of the importance of simple and straightforward advice, especially in the early stages of treatment. Patients and their partners spoke of the effects of shock in reducing ability to absorb information from health professionals.

“The advice may be really basic but for someone who is in shock – that makes all the difference.”

One patient said that he thought it important to keep healthy in case a cure was found in future. This helped him to maintain a positive outlook. The Internet was a great source of comfort in terms of availability of information about treatments and new cures from countries outside of Australia.

“I believe that there will be a cure and coming out the other end of it all. I am going through it and I am healthy and try to keep it that way to fight off illness.”

The use of resources such as the Shared Care diary (Patient Held Record) during treatment

Resources were greatly valued by patients who sought to achieve a sense of empowerment in coping with their illness. One such resource which directly affected the patients in this study was the Patient Held Record and was used as a vital link in the Shared Care Model. The Patient Held Record (PHR) that patients involved in the Haematology Shared Care project had held were seen as a vital tool in providing security and communication between patient and health care providers. One patient pointed out that the PHR had helped him in identifying a problem he was experiencing with depression after he had a chemotherapy treatment. He discussed this with his general practitioner using information regarding the type of chemotherapy and timing of treatment and was able to resolve the problem.

“I was pretty depressed after (chemotherapy) and then he (GP) looked at my notes and he could see this pattern emerging. We found that two days after my chemo I was very depressed. But by writing it I would then know and say, “Well, this is just the chemo”. I could sit down and read it there and see the pattern. So next time I came home and I would say, “Right, I know I will feel depressed but it will pass.” “

Some patients with families also noted that the PHR was useful in that the family could read the notes and understand what was happening with the patient. This also ensured that the patient was not obliged to repeat information to family members on more than one occasion.

“It was good for the kids because with four kids you’d come home after your treatment or your visit and they would keep asking, “Hey dad, what happened today?” So you could then just hand it over and tell them to read the PHR.”

The PHR also served as a prompt for both patient and partner to ask questions during their next medical visit.

“Because before we had the Shared Care PHR we would come out from an appointment and say, “Oh no! We forgot to ask this or that”. So with the PHR we could write anything in if we had any questions for the next visit.”

Another patient added that the PHR served as a back-up of sorts in the early days when the shock of diagnosis and concerns about treatment meant that the patient and / or partner would often forget a great deal of what they were told by hospital staff and specialists.

“Also because it was such a shock at the beginning he (GP) would answer all the questions we had forgotten to ask at the hospital. The PHR was useful as well because you couldn’t rely on your memory.”

3.4.4 Moving towards acceptance

Awareness of and willingness to addressing main fears and concerns for the future

Some patients spoke of initial fears and concerns which had been worked through with family members and solutions reached. Financial worries and ensuring that the family could cope was a foremost concern for most male interviewees in particular. Once these fears were allayed and the families realised that they could cope, many male patients were empowered by this realisation and there was a sense of release. One patient noted,

“I wasn’t given a lot of choice. At that stage I was pretty crook. The first few months I lost my get up and go and it was really hard. Then I saw that the family really were managing the business and as time went on more and more I trusted them and they really didn’t need me anymore! They are coping a bit too well! (laughs). I don’t have any concerns for the future.”

For this patient, worry was more of a financial nature and for him, running a company and employing others was an added responsibility. He initially had felt that he was responsible for ensuring that they had employment and were secure and was afraid that his illness would lead to a loss of jobs for his workers.

For some, treatment choices were a concern. One patient had a dilemma of deciding whether to have a transplant which may not be successful or waiting until he was older and not as fit to cope with the transplant procedure. For this patient and others, the main concern was maintaining good health until a cure or treatment was made available to them. Also, being re-diagnosed was worrying for one patient in remission. Although she tried to maintain a positive outlook she felt that this was something always at the back of her mind.

“Basically I do have a fear of being diagnosed with cancer. It is there all the time at the back of your mind. I am not one of those people who wake up and say, “Hey look, I am alive!” I find it hard to believe that there are people like that.”

Further to this was the concern that drugs intended to treat a patient could aggravate this or other illnesses.

Two patients were concerned that they were not spending enough time with the family and that time was limited.

“You have children and you are just so busy building for the future that no one spends quality time anymore. It is a real evaluation of where you are going in life.”

Some patients noted that they did not worry about money as much as before being diagnosed with cancer. It was a case of re-evaluating life’s priorities. For patients without family support, staying mobile and being able to get around was a very real concern.

“My main concern is that if I want to stay alive I have to stay mobile and that is all.”

The importance of receiving the right information

A greater knowledge of the right questions to ask would have been helpful for many patients initially as many current concerns were a result of not asking the right questions in the early stages of diagnosis. Therefore, resulting fear of the future unknown was common. However, patients qualified this concern during the interview with comments about how they were grateful for the time they have left and commended the health providers caring for them.

“There are up sides and down sides but at the end of the day you just have to be thankful for what you have. We don’t know how much time we have or what lies around the corner. So there are concerns.”

Not being able to plan for the future and not knowing what lies ahead were problematic for all patients whether they were in remission, receiving treatment or had been diagnosed as terminally ill. One patient who had already received chemotherapy treatment spoke of her fear of having to go through it again. Despite fears and concerns for the future, one patient noted that he tried to be thankful for what he had at all times and that he tried to keep worries in perspective.

Informants noted that they were more likely to seek outside help in coming to terms with the diagnosis rather than for practical ways to manage the illness.

Learning to scale back goals

Short term goals were important to the patients and their families. Most did not think too far into the future and had adapted their outlook to living life for the present.

Some patients were reluctant to talk about any concerns that they had for the future. The importance of maintaining a positive outlook was essential to these patients. Amongst other things, faith helped patients maintain a positive outlook. That is, a belief that it will “all work out” was crucial to maintaining peace of mind. Having accepted that they had cancer, most had moved on from the initial shock to accept their illness and set short term goals for themselves in day to day living.

“I still work but fairly casually – I have a very good employer. I arrive at work and if I can’t make it early in the morning I just call in. As long as I do my four hours.”

One patient perceived that the demands of everyday modern living created stress and illness and she had tried to avoid stress in coping with her cancer.

Finding incentives to stay ‘on top’

Patients identified having support from family and close friends as an important incentive.

“I had strength within me but support was a big thing. You need the strength within you to say it is ok. But you also need support to endure.”

Another patient said that being able to see his grandchildren grow up was an incentive to stay fit and healthy. It was also noted that family and friends of cancer patients also found support in talking to each other.

“When I was in hospital my granddaughter used to ring me all the time and of course she was friendly with someone whose father had cancer. He had a daughter and she and my granddaughter are the same age. When she and the girl talked she would go home and tell her father things. Then she phoned to say her father had only got a fortnight to go and we rang up the day her died so they could talk.”

Acceptance and aspects of feeling positive about the future

A realisation amongst patients that they could do nothing to change the situation helped most to cope with the future. One patient noted that she felt that maintaining a positive state of mind was most important. She noted that although the treatment was essential, more important was the patient’s acceptance of their illness and the health professional’s expertise.

“Mental attitude is the only way to cope. You have to be positive because you don’t have any control over the drugs and it is a mind game to a certain degree. Definitely I think you need the drugs but you need the attitude as well.”

There was an acknowledgement by all patients that certain aspects including death in some cases was eventual.

“I realise that I can’t change the situation and that is it. I cope with it and accept that it is there.”

One patient who had seen family members die from cancer felt that he had knowledge about this condition and therefore did not experience fear of the unknown. Most treated the experience as a “wake up call” to the important things in life.

“I have a fair idea of where I am going to. I know I am going to the next life sooner or later. In a way it helped me when my parents got sick. Particularly with my dad. I think that really in a sense it is a wake up call about the priorities in life – “

Other patients said that it helped not to dwell on the future. Most of the patients interviewed felt that worrying was pointless. Most acknowledged that they were limited as to what activities they could do and had made adjustments both physically and mentally to accommodate those limitations. There was definite acceptance of the situation amongst all those interviewed as Shared Care patients. One said,

“I am not living each day as if it is going to come back. I am living each day by looking to tomorrow. I really don’t allow myself to think about it. I am aware that it hinders me but I don’t sit back and think negative about it. I think it is an attitude.”

Letting go of responsibility

Patients with partners highlighted the importance of knowing that the partner could cope without him/her was crucial. Although it was important to feel needed, conversely

some patients felt relieved to see that their families were able to carry on without their input. Indeed, not worrying about the future for close family members was empowering for both patient and partner. As one partner commented when she had taken on the management of the family business,

“I think it has made me stronger. A lot came on me with the family business. That is something I thought I would never be able to do. I think that the biggest part for him is that it will survive and that we can go on.”

Nurturing the self

Another positive aspect of the illness experience is having more time for oneself. Most patients said that they had learned to slow down and evaluate how they would most like to spend their time. For some it included more time with their families and for others it was more about achieving personal growth. Hobbies and interests came to the fore for some patients.

“I do things like yoga which I had never done before. It is as much for peace of mind as for the breathing. I find it enjoyable.”

And,

“The other is that my hobby is writing fiction and I have had a bit of success with that.”

Keeping fit and ‘ahead’ of the illness side effects was identified as important by patients. Most patients actively maintained a healthy diet and an exercise regime. One patient spoke of not being “too hard” on oneself and not to set the sights too high. As he said,

“You mustn’t be too hard on yourself. If there is a goal don’t be too hard. You know you can’t do it this year but you might be able to do it next year.”

However, another patient cautioned that it was unnecessary to be fastidious about diet all the time and that although she mainly ate low fat and low sugar foods that she would allow herself 'treats' from time to time.

"If I do go out and I want a big fat cake then I will have it. Just like a treat."

Some viewed the slowing down process as an opportunity to try new hobbies. This was seen as a way of taking time out for oneself and for using the extra time in a worthwhile way.

Body awareness

Some patients noted that it was difficult to eat well due to loss of appetite after treatments. However, there was an acknowledgement by most patients that drugs necessary to control the side effects could be deleterious to their health. Although dosage was also problematic at times, patients were able to develop the self awareness to know that their body was warning them that something was wrong . As one patient commented,

"I remember once I mucked up the dosage on the medication to build up my blood – steroids – I found myself driving along in the car and if another car would pull out I'd find myself yelling! I realised that I had overdone it on the steroids and a couple of times I could feel myself going!"

Rest was also acknowledged to be important to recovery and to dealing with the effects of treatments.

"The thing that got me with the lymphoma was the tiredness. It affects you something shocking but I used to lie down then."

Gratitude

One patient coped by maintaining the belief that there is always someone worse off than herself. This enabled her to maintain a positive outlook and to resist the temptation 'to feel sorry for herself'. Another patient spoke of the need to avoid worrying and to always be prepared to help others in similar situations. Two patients also stressed the importance of being prepared to talk about the illness and to maintain positivity.

"The best advice is not to let it worry you. I can talk about it and I know that a lot of people can't. Just don't let it get you down. At first I used to think "why did I have to get it?". But I have got it and I can't give it back. A lot of people are asking me how I am and all that. We are happy to talk to anyone not just family. It is better than bottling it up."

Self reliance

Also identified as important by patients was the need to be 'comfortable' with oneself and to try and enjoy time alone for reflection.

"I can amuse myself alone and for me that is a big plus. I don't always need to have social contacts. I can face myself and deal with it. My big thing is mental attitude."

Reducing stress was also seen as an important strategy when coping with treatment and care. In order to produce a stress free environment, maintaining a positive attitude and trying to be less anxious was seen as a means of achieving this. One patient noted that not dwelling on the illness helped him to cope best.

Making adjustments to lifestyle

Patients who had been relatively fit to start with found it less difficult to adjust to taking up exercise as a means of maintaining health. For two, however, the annoyance of not being able to do as much physically and trying to accept that they could not exercise as intensively as before was difficult. One patient spoke of how he found the lowered energy levels problematic.

“My energy levels are lower. If I try doing those things now I would be dragging my feet by ten in the morning. I would close my office door and would put my head in my hands. It was very frustrating.”

Another patient reiterated the sense of frustration.

“Tiredness is really hard to cope with. But basically I don’t think it is right and I need more than a good night’s sleep. I feel tired all the time.”

Another patient spoke of a pattern and how he had learned to build up an exercise regime in keeping with his state of health at the time.

“About three months before I started to mow my lawn again and if I bent down I’d feel unwell. I do a bit of walking about then. Now up in Carnarvon I do about 10 kilometres every morning.”

Some patients had difficulty controlling diet and found it irritating that they could no longer eat the same foods.

“I have really had to behave myself with diet and so on.”

However, most spoke of the awareness that they would have to accept and adjust their lifestyle and expectations accordingly. Another patient regarded coming through a successful treatment as fortunate in that she has been given a second chance. Therefore, she is happy to make whatever adjustments necessary to give herself an optimum quality of life. Having an understanding employer also helped this patient in coping with having to ‘slow down’.

“Coming through the treatment is like getting a second chance. I am lucky to get as far as I have got. But I have just slowed down. I still work fairly casually and I have a good employer.”

Another patient also spoke of the advantage of having a flexible workplace.

“I am in a very flexible workplace and I just reduce the load.”

Being made aware of potential side effects was crucial to patient ability to accept circumstances. One patient also commented on the change in her physical appearance due to lymph oedema as being difficult to adjust to. For this patient, the fact that the change is permanent and that she was not made aware of it before the treatment was very irksome.

“I also have lymph oedema and that is very draining – it is the physical appearance which is really bad. That is permanent and I wasn’t told about it.”

Patients also complained about conflicting lifestyle advice and extremes of advice, which others would offer them to help them cope with their illness.

“When I turned forty I changed to a low fat diet and I don’t have a lot of fat anyway. But when people say I should not eat meat – well, I love my meat and I don’t know what I should be doing there! It is very confusing. Everything in moderation I say!”

Although patients found side effects of illness and treatment frustrating, most preferred being made aware of possible effects so that they could adjust accordingly. Thus, the importance of relevant and timely information was regarded as crucial in managing the illness and therefore empowering themselves to best cope with it.

3.4.5 Moving on– supporting and talking to others with cancer

Feeling useful and being ‘needed’

The concept of being needed and useful to others was extremely important to patients. In fact, this clearly became an important factor in maintaining a sense of control over the illness. Part of this concept of being useful includes a willingness to share the experience with other patients having difficulties. Patients who were living in rural areas

also expressed the regret that they were not closer to the city in order to offer support to other patients.

“Unfortunately I live in the country. But if I lived in the city I would be more than happy to help and speak to other people.”

Talking about the experience was viewed by most as remedial and part of the adjustment and empowering process. This patient also highlighted the importance of being available to help others.

Most patients saw the experience of talking to other cancer patients as a way of helping others through sharing experiences. As one patient had already noted he felt very close to other patients with cancer. It was as if they belonged to a ‘club’ of sorts. He said,

“When you see someone else with cancer especially in the social or work setting it is like being in a real club. It is a bond and you can talk about it.”

Another patient relied upon spirituality and felt that God had given him the experience of coping with cancer in order to help others in similar situations.

“I think it is through our spiritual we are sent to help others through what we have learned. The fact that they know what we have been through and are then automatically open to what we have to say.”

In contrast, one other patient said that although she doesn’t like to attend support meetings she has helped a few friends with chronic illnesses to come to terms with their illness.

“I have another friend who has it and is finding it hard. I am more than happy to talk to anyone with it because I think that the more you know about it the better.”

In other words, the importance of creating a full understanding of the experience of cancer through listening to the stories of others is instrumental in empowering many

patients. This applied to both the counsellor and the 'counselled'. This patient also identified the problems experienced by male patients and carers in particular in "opening up" to talk about their fears and concerns for the future.

"Men are more afraid of this. They also find it hard to deal with the caring thing. My husband struggled a bit in the beginning. He said that the best thing is to make him get out and talk about it instead of bottling it up."

This patient also acknowledged the particular stress placed upon carers of someone with cancer. This was particularly difficult for carers in terms of getting out and having respite from the caring role.

"He was terrific but when he was home caring for me in the winter with him being an outdoors person – staying at home with a sick wife and baby. He got a bit stressed to start with but he also got a bit down."

Two other patients did not feel that talking to other patients in support groups were of any real help to them. Although they were happy to talk to someone on an individual basis, neither actively sought group support.

"I know the support groups are there and I have been offered the contact details but I don't think it would help me very much. I have talked to others and it does help but I wouldn't go out of my way to seek others."

For the other patient, being able to identify with and having a person facilitating the support group who had experienced cancer was essential.

"To me I just thought that what the nurse who took the support group was saying just didn't make sense. I don't know if she ever had cancer. I think if you have a support group then they should be run by someone who has been there."

One patient commented that he felt that the hospital nursing staff was less than supportive of patients talking amongst themselves. Even though he acknowledged that

he felt this was the best way to gain useful information about coping with aspects of the illness such as treatment side effects.

“It does help but the nurses don’t like it. One of the head nurses told me, “You lot get on my nerves. He is telling you what happened to him and you are all thinking, ‘God I hope I don’t have to have it!’ You shouldn’t be discussing it.””

Being useful and needed by others was important to giving patients a sense of self worth and was part of the process of regaining control. Patients spoke to helplessness and powerlessness in the face of their diagnosis. This was followed by an overwhelming feeling of handing over control of their bodies and selves to others, whether they be clinicians, family members and / or friends. However, at this stage in the illness, patients had re-established boundaries and were able to feel that they could help and contribute to assisting others in their earlier phases of the cancer journey.

Spirituality

One patient also noted the importance of finding a balance between the physical or medical strategies and the spiritual side of coping such as prayer and meditation.

“There is a physical and a spiritual side and you can’t have one without the other.”

Another patient also noted the importance of having faith. Not just spiritually but also having faith in the health professionals and their skills. It is important to patients such as this to be able to implicitly trust that the specialist is doing what is best for the patient.

“My faith is very strong and I have no doubt in my mind that he (the specialist) knows exactly what he is doing. Not once did I ever question his judgement. I would grant him anything – it was trust.”

Spirituality featured strongly in helping patients trust in their own judgment as much as in the judgment of others. However, interestingly the practice of faith sometimes

translated into faith and belief in health professionals' abilities to cure them and to rely infallibly on their specialist knowledge.

3.5 Discussion

The Three Categories Of Empowerment

The overarching themes from the interviews conducted with patients indicated that developing a greater sense of empowerment and control was operationalised in three ways by these patients.

Namely,

- 1 **Reliance on strength from others** such as health professionals, religion or spirituality and significant others (e.g. family, close friends). Over the course of the illness trajectory, the patient becomes increasingly adept and knowing which significant others they rely upon for various types of support and how to maintain boundaries.
- 2 An acknowledgment of the disease and **acceptance** that it exists. In other words, an absence of denial. This usually occurred later on into the illness trajectory.
- 3 **Power residing within** the patient to cope. That is, a strong sense of 'self' in relation to one's illness or self-reliance. This includes management of treatment side effects and condition where possible. For example, diet, use of complementary therapies and deciding which sources of information and support were most relevant to the individual.

The three identified categories were not mutually exclusive. However, most patients had each one to a certain degree and indeed, to all patients, one category held priority over another depending on the personality of the patient. Within each of these three categories, a set of resources were used by the patient to exact a measure of control over their illness. These became our markers for empowerment amongst the patients and are identified below as they were conceptualised into a set of statements for patients to respond to. These statements were finalised and confirmed by asking a final

question of patients as to what they regarded as most important to them in managing their cancer.

3.6 Identifying concepts to be included in the patient empowerment scale (PES)

As noted above, patients were finally asked what was most important to them in terms of taking control over their illness and the management thereof. At the end of each interview, patients highlighted the support mechanisms and resources most relevant to them. The following resources were those which corresponded to themes identified in the interviews and in the literature review. These were ultimately used to formulate the pilot Patient Empowerment Scale. Thus to recapitulate on the findings of the literature review and the in depth interviews amongst Shared care patients, the concepts outlined below formed the Patient Empowerment Scale and are discussed as follows.

Regaining control and being involved in managing the illness

Whenever possible, patients preferred to be informed and where possible to be involved in decision making regarding their treatment and management of side effects. Patients also noted that they enjoyed reading about her illness as she felt that she could understand it better and thus feel more in control.

Patients managed practical strategies to control their condition. These were noted as regular exercise, healthy diet, to get plenty of rest and to try to avoid stress. This sometimes included the use of complementary therapies to relieve side effects of treatments and of the illness itself.

Support of family and friends

“For me I think it is the family support, work colleagues and my faith and those are the things I relied on. You know, the books and things...people get stuff off the net but I am not that kind of person.”

Family members and work colleagues were noted as the most important resource for many patients in helping them to cope. This was essential in helping patients manage feelings of insecurity and vulnerability,

“You tend to feel very vulnerable and that week after chemotherapy you don’t feel you are coping and it is a very insecure feeling in your mind.”

Two of the patients interviewed regarded the illness as an opportunity to create a better lifestyle for themselves and their families. For these patients it was a chance to recognise the important people in one’s life and to spend more time with them. Patients relied upon the support of their family and friends.

“You must enjoy your time. Think positive and spend time with the important people. The time had gone forever if you miss the opportunity. We would share time with our son as he is growing and we need to spend that time.”

And another patient said,

“I can’t say that I was really troubled a great deal because I could not have been in a better position. I mean I have a great family and all that.”

For some patients, just knowing that a partner was ‘there’ for the patient without requiring them to actually do anything was important. As the spouse of one patient said,

“I didn’t go to work the week he started chemo as I needed to be there and it was really just a matter of me being there and him knowing I was there if he felt down or something.”

Feeling useful / employment

The literature around empowerment and chronic illness indicated that it was important for patients to feel useful and needed. They needed to have a role to fulfil even though

they were limited in their physical contribution. One patient acknowledged that he had often given supportive advice to other patients and had received good advice in return.

“I told someone to gargle with salt water for mouth ulcers which they didn’t know. It helps them and I do that is how you learn and share. It is a benefit to try out different things.”

For some patients, feeling useful meant continuing with paid employment where possible and in fact patients spoke of their enjoyment in continuing to work despite their cancer. Another way in which patients felt useful was in regard to helping other cancer patients. For some, having a purpose in supporting other patients and their families was empowering. This also indicates an acceptance of the illness and a willingness to demonstrate to others that it is possible to regain control.

Spirituality

“Books and all that stuff is all well and good but I need something more than that.”

Patients who practised a religion also relied strongly upon their faith in the initial months of treatment. These patients relied upon their faith as much as their families to support them. Church clergy, members and friends were also a great source of emotional support. Although most patients had used the Internet and books or leaflets as a resource, most preferred to communicate with others to help them cope with their illness.

One patient and his partner felt willing and able to counsel others in similar situations and have changed their illness experience to a more positive way of viewing it as an opportunity to help others.

“We show others that there is a bright future and that is our strength. It is an extra having it at church. It is more personal and it becomes a close friendship.”

Complementary therapies

Patients also commended specialists who were willing to discuss alternative treatments and complimentary therapies. These patients felt that they were empowered by being encouraged to find out all they could about options and for the clinician to remain open-minded.

“My specialist is very open minded. My sister has a health food contact and she has given me almond kernels. The specialist is very open minded about this and of course the various treatments at the support centre.”

Acceptance and adaptability

“So I know that medicine has really no control over it. They can hold things off but at the end of the day if it is going to take off then it will and there is nothing you can do about it. I think you have got to be happy within yourself and how you achieve that – well, everybody’s different.”

One patient also highlighted the importance of being content with one’s situation in terms of acceptance and positive approach to coping with the illness. This patient believed that drawing strength from within oneself was as important as drawing strength from others. However, one patient also stressed the importance of acknowledging the ‘flat days’ as well as the good days and not to expect a positive outlook all the time.

“I mean you do get your flat days like that and not every day is a positive day.”

Resources and information

“The chat room is absolutely brilliant. I would recommend it to anybody. You dial a message and you would definitely get a response. You know that they have been through the same as you and they know what they are talking about.”

As noted previously, one patient said that she preferred to seek support from the Cancer Foundation chat room rather than talking to other cancer patients and their carers in support group settings. Other patients preferred to either not use the Internet or keep it to a minimum. Some found web based resources overwhelming in terms of amount of information and relevance to the patient's situation. For this patient it was a matter of learning to use the Internet for his own purposes.

"I went on the Internet a couple of times but the information takes you so far and there is so much of it. We worked out what we wanted to use it for and then used it only for that purpose."

Health Professionals

Some patients felt that having an exceptional doctor or specialist was an extremely important resource.

"My specialist was just exceptional and I have so much faith in him."

Reliance on others for support

Those who demonstrated a need to feel supported by other family members and friends and who held strong religious beliefs were more likely to show complete faith in their specialist or consultant despite failures in treatments and uncertainty for the future. One patient expressed it thus,

"My faith in him (the specialist) is very strong. When I met him I had no doubt in my mind that he knew exactly what he was doing. I think having that faith right from the start is important. Not once did I ever question his judgement. Not about anything - it was trust. I would not go through this anywhere else."

Acknowledgement and acceptance of the illness

All patients demonstrated a sense of accepting their illness and viewed this as a means of coping with their illness and possible prognosis. One respondent said that he regarded cancer as his "friend" in that the experience had taught him much about life and to learn to re-evaluate what was important and which aspects took priority.

"You talk about it as if cancer is a friend of yours and someone that you live with and you think, "goodness gracious"! You have to go through any sort of hardship to realise this. It will either make or break you."

Power residing within patient – reliance on self

Patients expressed the importance to them of feeling strong within themselves and that this was the key to them in overcoming difficulties during their treatment and beyond. It was noted during the course of the interviews that respondents who were not married or in a stable relationship often spoke of their own "inner strength" as important to them. However, those who were in stable or long term relationships were more likely to speak of reliance in conjunction with their close family to help them cope.

3.7 Discussion of concepts for inclusion in the PES

The use of a qualitative methodology enabled the concepts around what empowers a patient to regain control over their illness to be verbalized and explored by the patient through in-depth interview techniques. In doing so, the concepts could be used along with the extensive literature review to form the Patient Empowerment Scale. Clearly some of the concepts will be more important than others to a specific patient. As can be demonstrated by the findings of the in-depth interviews discussed in this chapter, some patients will rely on the support of family more than friends, or the use of complementary therapies, working life or spirituality more than another. However, each of the concepts forms a part of what is required by a patient to regain control and to achieve a sense of empowerment. In tandem with the identification of the markers for empowerment, we need to be mindful of the progression of a patient (journey) from

shock and denial on receiving a diagnosis to regaining control over their lives once treatment is underway. The concept of the 'journey will be explored qualitatively at a later stage of this thesis. The next chapter uses the concepts identified and outlined in this chapter to form a Patient Empowerment Scale to be piloted amongst a sample of patients receiving chemotherapy treatment amongst four treatment locations in Perth.

CHAPTER FOUR

The development and validation of the patient empowerment scale (PES)

4.1 Use of the Rasch model and measurement theory

The difficulty in measuring an indistinct attribute such as empowerment cannot be overstated. As I have indicated, empowerment is a nebulous concept which many are aware of but find difficulty in defining. Ryan (1983) said that a “latent trait can never be observed directly; it can only be inferred from observable behaviours”. Thus, in this study, empowerment is measured through a patient’s responses to a set of statements serving as markers for empowering strategies relating to empowerment using resources and support strategies as markers. All statements constructed from patient interviews and the extensive literature review were included in the initial pilot scale with the intention of discarding statements which might prove not to function as clear markers for the levels of empowerment amongst patients.

A peer reviewed paper has been published from this work (see Appendix 5) and was also presented at the 7th International Psycho-Oncology World Congress conference in Copenhagen in 2004 . The abstract of this presentation has been published in abstracts conference edition of the Journal of Psycho-Oncology in 2004 and is included in the Appendix 5.

Evidence regarding the adequacy of the performance of statements was achieved by the use of the Rasch Extended Model with analyses completed using the RUMM program (Andrich D & Luo G, 2003). The purpose of using the Rasch Extended Model to help validate the Patient Empowerment Scale was to establish whether the latent trait or construct of ‘empowerment’ had been successfully operationalised and quantified in terms of a single variable or continuum. If the data collected fit the model then an estimate of a patient’s location on the continuum provides a measure of the degree to which s/he displays the trait or construct (empowerment) represented by the Patient Empowerment Scale (PES). That is, the total raw scores may be used as indications of the levels of the property of interest (empowerment) over most of the operating range

of the variable. (This is not the case only at the two extremes of the continuum – the Rasch transformation of scores “stretches” the scale at these extremes) (Rasch, 1980).

The Rasch model was deemed most appropriate for this study for two reasons. As outlined by Andrich and Styles (2004), when the data fit the Rasch model there are two properties relevant to the development of a scale. Firstly, person (and item) measurements (in this case, level of empowerment) are on a linear scale and secondly, the measurements are invariant across groups for which the fit is verified. This model requires that the data fit the model as opposed to the model fitting the data as is the case in most traditional analyses (Andrich, 1988). This is clearly an important factor in establishing the psychometric properties of a latent trait such as empowerment. That is, the markers which form the Patient Empowerment Scale should remain consistent across groups of patients and circumstances (prognosis and illness trajectory), in order to be able to compare and interpret patient scores.

Scale development involves operationalising the latent trait (in this case empowerment) through a series of statements of varying intensity which respondents may endorse to different degrees. This principle also applies in the health research field whereby in a rating scale such as that used in the Patient Empowerment Scale, patients find it easier to agree to some statements than others. That is, the more intense items should be capable of being endorsed by respondents who have higher levels of the latent trait. The level of the latent trait (in this case, empowerment) is represented by the total score for each person on the set of items forming the scale. By developing a scale specifically relating to empowerment, using resource and support strategies as markers, it is then possible to measure the construct of empowerment for individuals in the sample population. The Rasch measurement model was selected as the most appropriate means of examining the psychometric properties (such as validity and reliability) of the scale as a whole and the items individually, and of investigating how respondents were interacting with (responding to) each statement. The unidimensionality required by the Rasch model implies that the construct of interest such as ‘empowerment’ is unidimensional at a particular level of scale that is useful for the purpose for which the scale is intended (Andrich, 1988).

4.2 Initial Scale Development with Empowerment as a multidimensional construct

Initially, it was believed by the researcher that the concept of empowerment might be a multidimensional construct. As explained below in section 4.2.1. However, initial analyses of questionnaires using the unfolding (multidimensional model) noted that the scale was clumsy and difficult for patients to respond to with respondents taking an average of thirty minutes or more to complete. For this reason, it was decided to re-structure the scale as a Likert type scale for ease of completion by patients. However, the process of developing the Likert, the researcher felt it important to briefly outline in this section the process of developing the Patient Empowerment Scale as an unfolding scale.

4.2.1 Coombs' Classification System

Coombs (1964) highlighted a distinction between measuring people or stimuli alone (single set of entities) and measuring the relationship between the person and the stimulus (multiple sets of entities). Coombs' distinction between single and multiple sets of entities is a basic dichotomy in representational measurement techniques.

Furthermore, a measurement scale will also have two properties of order and proximity. However, some scales may have only one or the other of these two properties. Numbers are assigned to objects (weights) and given an order. Proximity of numbers is also measured and the absolute difference between them is measured to assess this proximity. Dawes (1972) demonstrated these principles in the form shown below.

	ORDER	PROXIMITY
ONE SET	1. Magnitude technique	2. Proximity technique
MULTIPLE SET	3. Interlocking techniques	4. Unfolding techniques

The empowerment pilot scale consists of a multiple set of entities and is establishing proximity rather than order. Therefore, the initial empowerment scale consisted of unfolding techniques prior to the first stage of the pilot. The unfolding scale as developed for the research work consisted of “trade offs” between concepts. In other words we determined whether the concepts were interlinking such as, self efficacy with resources, self efficacy with decision making preferences and so on. Initially we tried to establish whether the trade offs were obvious in the empowerment scale and whether the scale is a continuum such as resource / capacity of the patient. In other words, were trade offs apparent. It was hoped that the analysis of the data from the pilot unfolding empowerment scale would demonstrate this.

The results could be best demonstrated in terms of a contingency table as shown below. Each patient fell into one of the four boxes depending on where he/she placed him/herself on the questionnaire for that particular issue. For example, a person displaying a value of 2 will feel that they have sufficient resources and they are capable of using them.

	RESOURCES	NO RESOURCES
CAPABLE	<i>Value = 2</i>	<i>Value = 1</i>
NOT CAPABLE	<i>Value = 1</i>	<i>Value = 0</i>

The two extreme statements **explain empowerment** and the two other statements explain the **lack of empowerment**. In each of the two statements displaying a value of one there is something lacking either in terms of efficacy or resources. Each patient would have a top score of 28 where each of fourteen sets of statements are assigned a highest score of two and a lowest score of 0.

An article by Michell (1994) served as a basis for the understanding of the process of unfolding statements. The key element is the varying intensity of statements provided.

Michell noted that using the Coombs theory of unidimensional unfolding that attitudes are indeed measurable. The hypothesis is that attitudes are quantitative and measurable on the same dimension. Michell explained Coombs' theory as the measuring of an attitudinal distance between an individual in a set of people (known as *i*) and an attitude (known as *x*). A model to understand the method of unfolding was developed. A set of statements using both the concepts from the Shared Care project and those arising from the literature review and the first set of interviews were developed according to the model outlined in the article by Michell (1994). A set of five statements were produced using the Michell model for each concept. A further exploration of each model revealed that the middle range intensity statements were very similar in each concept and that a smaller set of statements consisting of four statements in each would be as effective in terms of accurately measuring levels of empowerment for each concept. For example, statements which are similar in intensity are shown below.

Statement 4 - ALTHOUGH I KNOW THAT I CAN ASK, I AM GENERALLY IN THE DARK ABOUT MY TREATMENT AND CARE

Statement 5 - I RARELY KNOW HOW TO COPE WITH MY CONDITION

Statements considered to be similar in intensity were removed from the scale. This resulted in a scale consisting of four statements of varying intensity for each pair of concepts (Appendix 1 on Page 244).

For example, the relationship between the dual concepts of patient belief in self and the desire to be involved in decision making process produced a set of statements as seen below.

- I feel capable and **want** to be involved in decisions about my illness.
- Although I feel capable, I **don't want** to be involved in decisions about my illness.
- Although I **don't** feel capable, I would still **like** to be involved in decisions about my illness.
- I **don't** feel capable and I **don't want** to be involved in decisions about my illness.

It was speculated that the unfolding statements would result in a more precise identification of the attitude of the person towards a particular combination of two linked empowerment concepts. The analysis of responses using the RUMMFOLD program for unfolding statements would identify which statements and thus which scale could more accurately locate level of patient empowerment. Main themes were then given a list of statements of varying intensities in order to establish level of empowerment for the patient. Furthermore, each set of statements identifies two concepts which are developed in relation to each other in a set of statements. Statements follow a format of :-

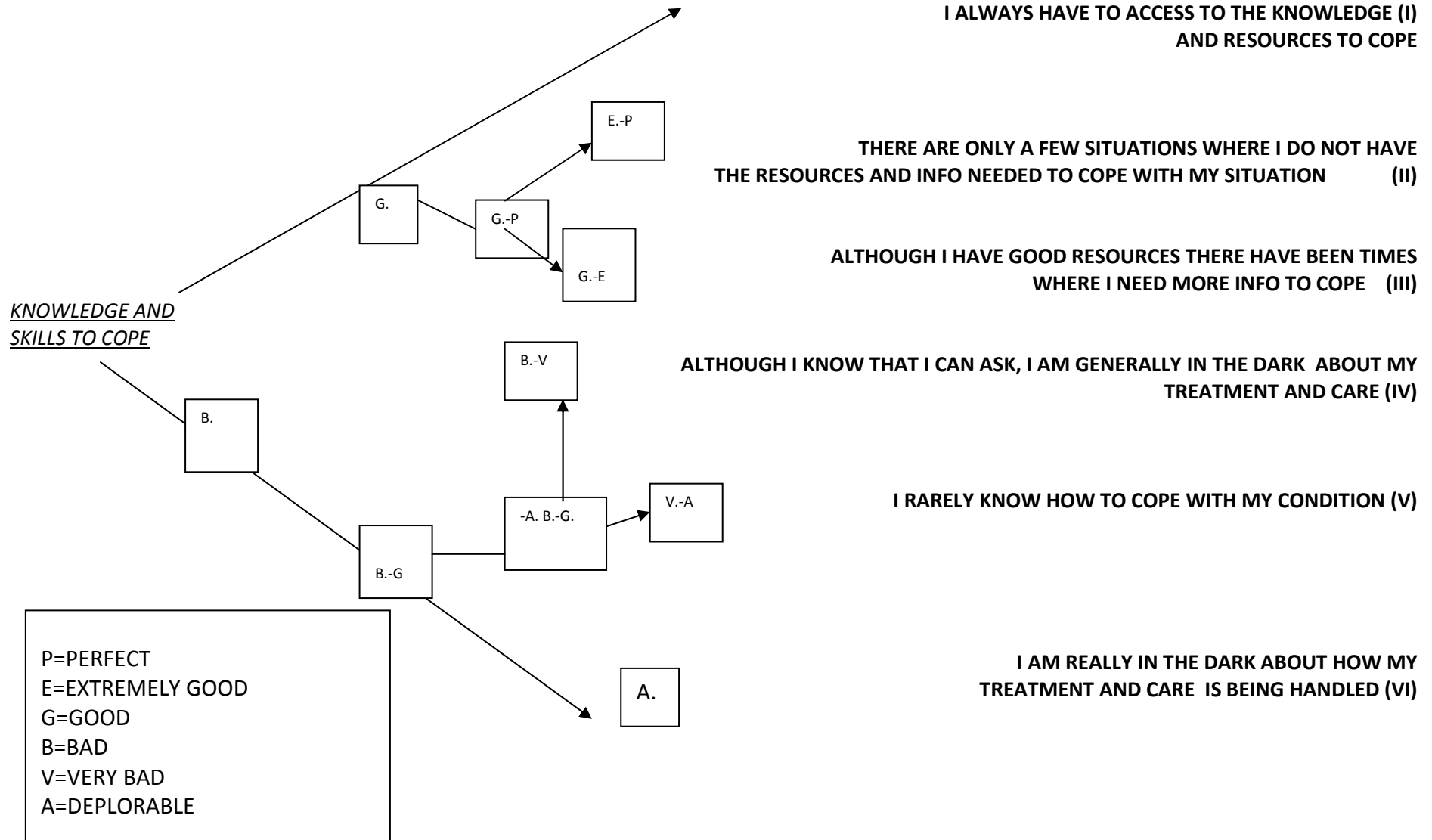
HIGH	HIGH
LOW	LOW

1. high-high
2. high-low
3. low-high
4. low-low

To make up an unfolding scale (Appendix 3). For example a set of statements to examine the relevance of information The sets are as follows.

CONCEPT 1	CONCEPT 2
Self efficacy	Resources
Self efficacy	Involvement in decision making
Self efficacy	Health care provider belief in patient ability
Confidence in GP	Choice of treatment location
Familiarity in GP	Choice of treatment location
Information amount	Information relevance
Support from others	Isolation
Support from others	Usefulness
Acceptance	Adaptability
Self efficacy	Spirituality
Work	Useful
Self efficacy	Complementary therapies

Figure 4.1 SELF EFFICACY – RESOURCES (example of unfolding model)



4.3 Scale Development using Rasch Modelling

Following initial analyses of the construct of empowerment as an unfolding model, the next stage of the Patient Empowerment Scale was developed. As explained previously, the concept of empowerment was deemed to be a unidimensional construct in the formulating of the patient empowerment scale. The assumption of unidimensionality is that individual human attributes can be identified separately (Ryan, J.P 1983). In addition to this, the human trait of empowerment is regarded as a 'latent trait' which implies that it is not directly observable but rather can be identified through a series of patient behaviours, actions and beliefs in regard to their illness. Cella *et al.* (1993) noted that "patient-as-expert" driven scale construction is as important in the development of a scale as clinical expertise and researcher perspectives in helping to ensure validity. Thus it was of immense importance to include the input of patients in the initial development and piloting of the scale. A further consideration, again to help ensure the validity and reliability of the scale, was the use of sound principles of measurement. The literature on measurement of attitudes distinguishes between two different response mechanisms, namely, unfolding and cumulative. In both cases, a scale of items is constructed so that the items become more intense (or more difficult, in the case of achievement scales) as one moves across the continuum of increasing levels of the construct or variable of interest. However, to take a scale measuring empowerment as an example, in the case of the cumulative mechanism, those respondents exhibiting more empowerment would be expected to endorse more intense items as well as all of the less intense ones. Thus, their location on the continuum or the extent to which they feel empowered is represented by their total score on all items to which they respond. In the case of the unfolding mechanism, a person is located, rather, at an *ideal point* on the continuum and is not likely to endorse items that are either above or

below that point in intensity. In this case, the person's total score does not represent that person's location on the continuum.

Initially, because it appeared that the concept of empowerment might operate according to an unfolding response mechanism, a scale was developed using unfolding principles and then piloted on a small sample of fifty respondents. However, this was later discarded because the results of the analysis according to the unfolding model and using the software RUMMFOLD were not satisfactory. Furthermore, the unfolding mechanism does not allow the use of Rasch models. Finally, the use of items constructed according to an unfolding mechanism also resulted in a questionnaire that was rather lengthy and complex for patients to complete. Analysis revealed that patients had difficulty distinguishing between statements relating to similar concepts. For these reasons, the unfolding model was abandoned and items modified instead to form a Likert type scale that is cumulative in nature. Thus this study focused on the analysis of a cumulative scale known as, the Patient Empowerment Scale (PES).

4.3.1 Methods

The development of the scale using a cumulative response model took place in two stages and will be outlined in greater depth in the next section. A number of items was generated from an extensive review of current literature and a series of seven in-depth interviews and a review of main themes from the initial set of twelve Shared Care patient interviews pertaining to control and management of the illness. The literature review and the interviews formed the basis for generating items to form the scale. The initial piloting of the empowerment measure was then conducted with 100 cancer patients (both male and female) recruited from the haematology care centre, the radiation oncology unit and the medical oncology clinic at a major teaching hospital in Perth, Western Australia. Ages ranged between 21 years and 75 years. Patients attending the clinics for treatment were approached and asked whether they would be willing to participate in a study about how they coped with their illness and what was important to them in terms of support in managing their condition. Patients who

agreed to participate were then required to sign a consent form before completing the questionnaire.

Responses from all patients were analysed using the RUMM program for Rasch measurement (Andrich, Sheridan & Luo, 2004). The validity and reliability of the items were investigated using the Extended Rasch Model for measurement. Items were discarded or modified based on several criteria, the first of which was their individual fit to the model. Secondly, if several items were very close in location on the continuum, and, thirdly, were similar in meaning, one or more of them was considered for removal from the scale. On the basis of information regarding all these criteria, certain items were omitted from the scale to form a final version for future use.

A further evaluation of the scale for length and clarity as well as whether certain items were considered distressing by respondents was conducted by using an adaptation of the European Organisation for Research and Treatment of Cancer (EORTC) feedback form - Appendix. Patients completed the form after completing the Patient Empowerment Scale. The results of the feedback form survey will be discussed later in this chapter.

4.3.2 Item generation

As noted in the previous section, items were generated from a total of twenty semi-structured interviews with twelve patients participating in the Shared Care pilot project at the Haematology Centre of Sir Charles Gairdner Hospital in Perth, Western Australia and from an extensive review of the literature in the areas of empowerment, self efficacy and control.

Firstly, an extensive literature review was carried out in the area of motivation and self-efficacy to identify markers for decision-making preferences and patient empowerment to guide the development of interview questions. Secondly, patients willing to be interviewed were identified by their specialist and Haematology Care Centre nursing staff through their involvement in a trial Shared Care program taking place within the Haematology Department. All patients had expressed a strong coping ability in regard to the management of their illness regardless of prognosis. In-depth interviews were initially conducted with twelve of the Shared Care patients regarding their coping strategies and the positive

effects of being more fully included in the management of their illness. A set of these strategies were identified by both patients and the researcher as markers for coping with the illness and whether the strategies also positively contributed to a greater sense of empowerment. All twelve patients were contacted again to request a second interview. This second interview specifically related to issues of empowerment and patients' use of coping strategies in the management of their illness. Seven of the original twelve Shared Care patients completed a second interview. Common themes from all interviews (including the initial pilot project patient interviews with the twelve patients) and the literature relating to coping with cancer were collated. The themes were discussed in the previous chapter (Chapter Three). Fourteen themes thus identified were then operationalised into pairs of statements corresponding to each theme. The statements covered the concepts of access to relevant and timely *information* about their illness, social support *networks*, open and positive *communication* between health professionals themselves and with the patient, *decision-making* involvement, and *adjustment to acceptance* of their illness. Other topics of importance included use of *complementary therapies*, religion and/or *spirituality* and *feeling useful* in terms of paid/unpaid employment. The statements were then reviewed by a number of experts in the field, namely, a haematological cancer specialist, a researcher and breast cancer survivor and three academics with extensive experience in Rasch measurement and scale construction.

4.3.3 Identifying concepts for inclusion in the empowerment scale

Strategies for achieving empowerment amongst patients can be implemented on several levels. However, most importantly, these strategies attempt to provide patients with the knowledge, skills and the "belief in (sense of) self" necessary to take control of their lives once more following the diagnosis of cancer. It is by using these concepts that an empowerment scale measuring various aspects regarding perceived loss of control was developed. The evaluation of the Shared Care project (Ward et al 2000) provided insights into patient attitudes towards empowerment in regard to the Patient Held Record (PHR). Many Shared Care patients felt that they were "in the know" whilst in possession of their own unique Patient Held Record (PHR) and that they no longer felt in the dark about their

treatment and care. Everything regarding these aspects was specified in the PHR. Health professional time and input was also demonstrable to patients and their families from entries in the PHR. Patients spoke of being in control of their illness and care. Most felt more secure through having access to their own record (PHR) at all times. Improved communication appeared to be a key factor in the development of patient empowerment and this theme recurred many times throughout the interviews supporting the concepts highlighted during the Shared Care project. Patients indicated many levels of involvement in their treatment and care.

Areas of control which came to light during the Shared Care pilot study were the importance of access to information, communication with and between health professionals and patients, choice of treatment location and involvement where possible in type of treatment. Items addressing these areas were incorporated into the scale as a means of registering levels of empowerment as perceived by the patient. It was evident from the qualitative component of the study using in depth interviews that employing specific strategies such as support of family and friends, informed involvement in the decision making process and access to relevant resources enables patients to cope better and to feel that they have some measure of control over their illness. Being informed and involved in the process of treating and managing their cancer enables patients to feel more in control. One expressed the importance of the specialist's willingness that he explore other methods of care and management of treatment symptoms even though the patient ultimately relied upon the specialist's opinions regarding what was best for him. A further review of relevant literature regarding decision-making preferences and issues of loss of control and empowerment amongst cancer patients ensured that concepts developed from the Shared Care project concurred with current and previous literature.

It became evident from both the literature review (Cartmell, 2000; Wong, 2000; Friedrichsen, 2000) and the Shared Care project (Ward, A et al 2000) that patient involvement of this sort implied a commitment on the part of the patient to want to be involved in treatment outcomes and to take responsibility for management of their cancer experience. As explained previously, transcripts of the interviews with Shared Care patients were reviewed in order to ascertain aspects of their

own empowerment experience. Themes were then noted and developed into a set of statements which made up the initial Patient Empowerment Scale. Statements were developed from the perspective of the cancer patient in relation to their illness. Main themes initially identified were patient control of illness, patient choice of treatment location (in relation to the Shared Care model), patient information, support from others (non medical), feeling useful, spirituality, use of complementary therapies and acceptance of the illness. Themes are now examined in depth to justify their inclusion in the scale and in relation to the domain of motivation and self-efficacy impacting upon levels of empowerment.

Self-efficacy and resources

Patients established some measure of control over their illness through utilization of resources. Resources included a range of coping strategies such as access to support groups, community organisations and support of family and friends. However, the ability to utilize resources successfully will largely depend upon patient motivation and knowledge of resources available to them. Self-efficacy and the motivation to use those resources will affect the level of success with these and others such as cancer specific chat rooms on the Internet and ad hoc conversations and talking to others affected by cancer.

Self-efficacy and involvement in decision making.

For most newly diagnosed patients, the experience of cancer is frightening and it's outcome unpredictable. In the initial stages of the diagnosis most patients are too shocked to take in all the information given to them. Nor do they feel confident in this new domain to confidently seek the necessary knowledge and participate fully in the decision making process. Nonetheless, those who have or learn to develop an internal locus of control in terms of acquiring knowledge as to how to deal with their condition will express a desire to be involved in making decisions about their treatment options and the management of their condition. Involvement in making decisions is not solely dependent on patient belief in self but is also very much influenced by patient perception of the health professional's belief in their ability as a patient who can be involved in the decision making process. In other words, the patient must believe that the consultant or GP has

faith in their ability and reinforces to the patient that they are willing for him / her to be involved in making decisions. Sharing of information was also noted as crucial in developing trust between the patient and health care professionals. Although patients still noted that they relied on the consultant for the final decision, they did indeed want to be informed as to why treatments were selected and what the side effects and prognosis might be. Most believed that the specialist had their “best interests” at heart and would advise the best option for them. As such, coping is viewed as achievable in terms of a partnership between health care providers and patient.

Confidence in the GP and choice of treatment location

Patient choice of treatment location was particularly pertinent to Shared Care patients. Better communication between GPs, specialists and hospital staff was one expected outcome of the Shared Care project. Therefore, patients generally had a more secure and trusting relationship with their GP. This concept hoped to establish the level of confidence and familiarity with primary health care providers amongst Shared Care patients. Most patients visit their GP alongside hospital treatments either for blood tests or for assistance in managing their condition. Furthermore, many patients valued the role of the GP and were confident in visiting the GP surgery between hospital visits. The necessity of feeling they had some say and the option to have the GP in a more central role in the management of their illness was valued by patients expressing a strong sense of empowerment and control over their illness.

Familiarity with GP and Choice of treatment location

Patients who had a good relationship in terms of trust and willingness to discuss sensitive matters felt better able to cope with managing their illness. The GP’s role was perceived to be important for several reasons. Patients expressed an appreciation for the GP having more time than a rushed consultation at the hospital. This was important for allowing the patient and their spouse or carer to ask questions and clarify any information. Good communication between GP and hospital was also vital to patients in terms of illness management and having one’s GP as an advocate.

Amount of Information and Relevance

A patient may possess copious amounts of information about cancer without it largely being relevant in terms of their specific circumstances. Thus, it was essential for patients to not only have adequate information but for it also to be relevant. Although not crucial to patients who were interviewed, the literature highlights that having access to certain amounts of information regarding cancer treatment and care was important to many patients. Patients noted that information was often provided by family and friends. Although many saw this as a way of close friends and family showing their concern, the information was nonetheless read and noted by many patients. Patients also spoke of information giving them hope for the future in terms of new treatments being made available. This provided an incentive to go on fighting the illness.

Support for others and Isolation

Friends and family were allocated separate statements in the pilot study. The patient relationship to their family is immensely different to their relationship with friends. It was therefore important to measure the amount of support in terms of patient need as separate concepts for family and for friends. Patients with either one source of support or the other fared better in terms of coping with their illness. Although some patients preferred the support to be 'low key', merely having the knowledge that they could assess that support when needed was a source of strength for most patients. Most expressed the importance of having at least one other close family member or friend to share concerns with about their illness and prognosis. This person or persons were perceived as an integral part of 'fighting' cancer for the patient. Many also spoke of the need to have someone who would accept them regardless of their mood and that it was not necessary to always remain positive around this person.

Support from others and Usefulness

Patients expressed a need to be regarded as useful or central to the family in terms of still having a role to play. Patients without family transferred the need to feel useful to their close friends. Patients who needed to be useful to others felt empowered to get better. However, being needed by others is somewhat

different to being useful. Patients who saw their family adapt and move into more responsible roles whilst still having whatever support they as patients could give, were less anxious. One patient spoke of the immense relief he felt in seeing his wife and adult sons take over the family business. Although he was still free to contribute when possible, he felt less burdened by their ability to cope without him.

Acceptance and adaptability

Patients who felt empowered or better able to cope with their illness were willing to accept that they would have to shift the pace and focus of their lives. Although those who were more physically active before being diagnosed with cancer found the transition initially difficult, they learned to accept the changes that the cancer treatment had imposed on their lifestyles. Acceptance of these changes inevitably implied adaptation on the part of the patient and those around them. Arriving at a point where the patient accepted the illness and learned to adapt their lifestyle accordingly was important to most. Most patients perceived this as destructive and having a negative impact by fighting against physical and emotional changes. Many learned positive ways of viewing their ability to adapt.

Self-efficacy and spirituality

Generally, patients who expressed strong spiritual or religious beliefs believed that it helped them cope with the unpredictable nature of cancer. Self-efficacy in coping with the illness was strongly linked to a religious beliefs and acceptance of the illness despite it's changeability. Indeed, spirituality features strongly for many patients as part of their coping mechanism. Those who were empowered through their experience of cancer by means of spiritual resources regarded religion as central to their ability to have power over the effects of cancer. Some spoke of a deeply religious phenomenon whilst experiencing an episode of deep depression or anxiety. None of those who described themselves as religious blamed God for their cancer but rather saw it as an opportunity to become more spiritually aware.

Paid employment and feeling useful

Patients who were still involved in the workforce drew strength from needing to feel useful and contribute to family and society. Some believed that going to work each day enabled them to avoid negativity and to put things in perspective. Although being in paid employment did not always preclude a sense of empowerment, some patients identified it as a means of maintaining a sense of normalcy and usefulness in their daily lives. It was therefore decided to include this concept in the statement list as a means of establishing for those who were still in paid employment whether this affected their lives in a positive sense.

Self-efficacy and complementary therapies

Patients who accessed complementary therapies ranged from those taking herbal and dietary supplements to those who attended sessions in Reiki, massage and other complementary therapies. All those who accessed various complementary therapies stated that the therapies helped them to cope effectively with their illness.

4.3.4 Face validity for the Patient Empowerment Scale

The pilot scale was also reviewed for relevance of content by experts in the field of attitude scale construction and also by health professionals working within the field of cancer. A third academic who was also a breast cancer survivor reviewed the scale for relevance of content and readability.

Using the afore-mentioned concepts, 28 statements (items) were generated to represent the following aspects of empowerment which then formed the Patient Empowerment Scale (PES) as follows (Table 2).

Table 2 Aspects of empowerment defined as markers / strategies

Type of strategy	<u>Definition / marker for presence of strategy</u>
Resources	<ul style="list-style-type: none"> • Capability of using resources to handle illness • Sufficient resources to handle illness
Information	<ul style="list-style-type: none"> • Sufficient information • Relevance of information
Involvement in decision making process	<ul style="list-style-type: none"> • Desire for involvement in decision making process

	<ul style="list-style-type: none"> • Capability to be involved in decision making process
Family support	<ul style="list-style-type: none"> • Availability of a supportive family • Patient need for the support of family
Support of friends	<ul style="list-style-type: none"> • Availability of supportive friends • Patient need for the support of friends
Relationship with GP	<ul style="list-style-type: none"> • Comfortable with GP • Familiarity with GP
Patient perception of GP ability to manage illness	<ul style="list-style-type: none"> • Ability of GP to manage illness outside hospital • Confidence in local GP
Patient perception of health professionals willingness to include them (DMP)	<ul style="list-style-type: none"> • Patient perception of health professionals' willingness to include them in the decision making process • Patient's capability of helping health professionals reach decisions related to the illness.
Complementary therapies	<ul style="list-style-type: none"> • Use of complementary therapies • Complementary therapies help cope with illness
Spiritual beliefs	<ul style="list-style-type: none"> • Presence of spiritual beliefs • Spiritual beliefs help cope with illness •
Acceptance and adaptability to illness	<ul style="list-style-type: none"> • Acceptance of need to change lifestyle • Ability to adapt lifestyle
Patient perceived usefulness to friends	<ul style="list-style-type: none"> • Friends' reliance on patient (usefulness/contribution) • Need by patient for friends' reliance
Patient perceived usefulness to family	<ul style="list-style-type: none"> • Family reliance on patient (usefulness / contribution) • Need by patient for family reliance
Paid employment	<ul style="list-style-type: none"> • Usefulness despite no longer being in paid employment • Usefulness due to paid employment

The items were each given a four-point rating scale of strongly agree (4), agree (3), disagree (2) and strongly disagree (1). Patients were asked to select the response which most closely identified how they felt about each statement. All statements were worded in the positive with no necessity for reverse scoring of any statements. Certain statements did not apply to some patients (e.g. paid employment was not relevant to retired patients) and thus a "not applicable"

option was provided. As the 'not applicable' option provided no information it was treated as a missing value during the Rasch analysis.

Patients completed the Likert-style questionnaire in 10 - 15 minutes. Most statements were responded to and patients were more likely to complete the entire questionnaire. Analysis to establish the psychometric properties of the scale was carried out using the RUMM software program (Andrich, D & Luo, G. 2003). In order to provide enough data to carry out a preliminary analysis to guide selection of items, the initial sample was increased from 25 respondents to 50. Heterogeneity in terms of type of treatment was also an issue (that is, all were receiving treatment through the Haematology Centre) and therefore, a further 51 patients were recruited from the Radiotherapy and Oncology clinics at Sir Charles Gairdner Hospital.

Nonetheless, in order to finalise the PES a larger sample was required. Although originally intended to be administered to Shared Care patients who participated in the Shared Care trial, the number was insufficient to validate the scale. Thus, another sample of adjuvant breast cancer patients were invited to participate by completing the scale whilst receiving chemotherapy treatment. Overall, 101 patients were recruited within three months and the data was merged with the original data and analysed using the Rasch Extended Model (RUMM program).

4.4 Validation of the pilot Patient Empowerment Scale (PES)

4.4.1 Use of the feedback form

Patients were asked to complete a feedback form pertaining to the Likert pilot questionnaire after completing the questionnaire. Overall 26 patients (26%) completed a feedback form.

Feedback regarding the early construction of the Likert scale was obtained from patients in two of three locations (Medical Oncology and Radiation Oncology clinics). The form was developed using the EORTC feedback form as a template and adapted for use with the patient empowerment scale (see Appendix 1). Areas of interest included length of time taken to complete the form, whether the

patient received any help filling out the questionnaire and if so what kind of help. Patients were also asked which questions if any they found difficult to answer and lastly if any of the questions had concerned or upset the respondent. Space was also reserved for any comments that patients would like to provide in addition to the questions about the scale.

Overall, most respondents (77%) took less than 10 minutes to complete the 28 item empowerment questionnaire. Only one patient took more than 15 minutes to complete the form. All responses to the question about length of time to complete the questionnaire are shown below in Table 3.

Table 3 Length of time taken to complete the questionnaire

Response		
(n=26)	<i>n</i>	<i>% respondents</i>
Less than 10 minutes	20	76.9
11-15 minutes	5	19.3
16-20 minutes	1	3.8
Total	26	100.0

Of the 26 patients completing the questionnaire (feedback form), some (27%) had received help in from a person (spouse or relative) who had accompanied them to the clinic. However, this was more usually in the form of some assistance in reading the questions due to poor eyesight or having forgotten reading glasses rather than requiring an explanation of the questions included in the questionnaire.

No respondents reported being concerned or upset by the empowerment statements. This was encouraging in terms of providing some qualitative evidence of reliability, and in terms of the original intention of the researchers which was to produce a concise, self administered scale to measure empowerment.

4.4.2 Results from Rasch analysis of the pilot 28-item PES (January 2004)

An exploratory analysis was carried out on the 28 item scale to give an initial idea of how the scale performed, even though the sample size was not large enough to make overall conclusions. For stable estimates using the Rasch model, a sample size of about 10-15 people per item is ideally needed. However some preliminary conclusions were reached using an initial sample of 100 people.

In addition to establishing whether the items form a single continuum, the researcher also aimed to reduce the number of items to render the questionnaire easier for people with serious illness to complete. Items were omitted from the final scale on the basis of the following criteria:

1. How well they fit the model
2. How close in location they were to each other.
3. How close in meaning they were.
4. Whether residual correlations between pairs of items were high (indicating dependency between pairs of items).

There are four steps to be taken in a basic Rasch analysis of a scale. These are now described and discussed for the results of the analysis of the pilot PES. Following this, a similar presentation for the analysis of the final PES scale is given.

4.4.3 Analysis of thresholds using four or three categories

For a rating scale such as the PES, an ordered series of categories indicates the level at which patients may agree with or disagree with each item/statement provided. There is a threshold between each successive pair of categories and these thresholds, too, should be ordered. Thus Threshold 1 between categories "Strongly Disagree" and "Disagree" should occur lower on the scale continuum than Threshold 2 (between "Disagree" and "Agree") , which, in turn, should be located below Threshold 3 (between "Agree" and "strongly Agree"). Table 4.5 indicates using [*] which items were shown to have disordered or reversed thresholds during the initial analysis, that is, items where the categories were not ordered as expected (Appendix 3).

A subsequent analysis revealed the following (Table 4.6) with threshold locations for each item using three or four response categories as appropriate. This is

shown in Table 4.6 in Appendix3. When the categories for items with reversed thresholds were reduced, the items performed better with three categories. However, data from a larger number of respondents would be needed to ascertain whether the scale should use three or four response categories for all items. The findings of the analysis using a larger sample of patients are discussed later in this chapter.

4.4.4 Item fit to model

Overall, the findings indicated that the data fitted the model well. The overall item-trait interaction test of fit across all items gave a chi square value of $\chi^2 = 96.3$, $p=0.170$ ($df=84$), indicating acceptable fit of items to the model.

The Person Separation Index (the Rasch equivalent of Cronbach’s Alpha) indicated a high degree of reliability at 0.926.

Summary Test Of Fit Statistics Item – Trait Interaction Of Pilot PES Scale

Table 4 Summary Test of Fit

Item-trait interaction		Reliability Indices	
Total item Chi Square	96.268	Separation Index	0.926
Total Degrees Freedom	84.000	Cronbach Alpha	N/A
Total Chi Square Probability	0.169719	Power (test of fit)	Excellent

Individual item Fit Statistics for the 28 Item PES

Table 4.1 below shows the individual fit statistics for each item of the original 28 item PES. The Fit Residual values shown below indicate the presence of either misfitting items or overfitting items.

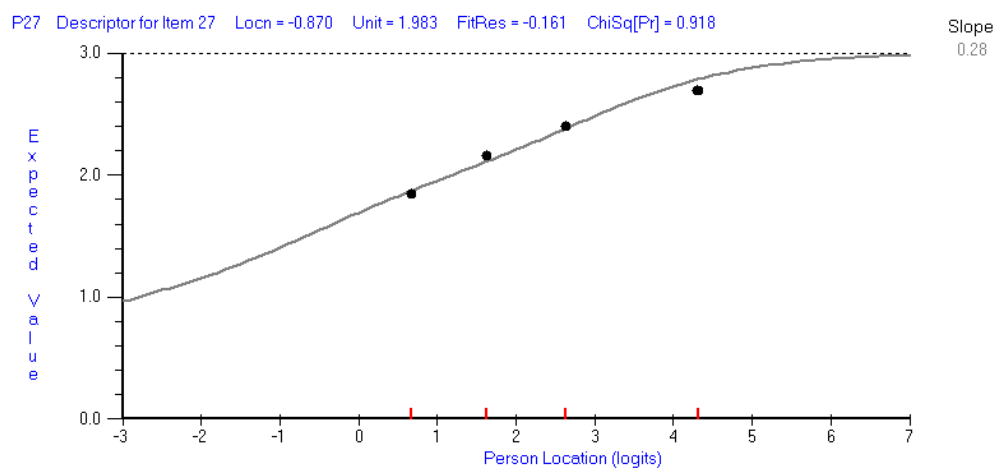
Table 4.1 Individual Item Fit Statistics

Statement (Item)	Location	SE	Residual	Chi sq	Prob
P26 I need the support of my friends	-0.722	0.202	0.569	1.018	0.797
P01 I am capable of handling my illness	-1.076	0.213	-0.689	1.104	0.776
P05 I am capable of helping health professionals reach decisions related to my illness	0.316	0.199	-0.049	1.421	0.701
P16 Health professionals are happy to include me in decisions related to my illness	-0.661	0.218	-0.017	1.8	0.615
P20 I want my friends to continue to rely on me	0.783	0.202	-0.137	1.94	0.585
P11 I need the support of my family	0.542	0.234	1.129	2.12	0.548
P27 I still feel useful although I am no longer in paid employment	-0.91	0.249	-0.035	2.212	0.530
P04 I want to be involved in making decisions related to my illness	0.333	0.184	-1.169	2.262	0.520
P23 My friends still rely on me	0.801	0.211	-0.107	2.624	0.453
P25 I have a lot of confidence in my local GP	-0.927	0.206	-0.862	2.789	0.425
P19 I still feel useful because I am in paid employment	1.394	0.207	1.306	2.837	0.417
P21 My spiritual beliefs help me cope with my illness	1.235	0.159	0.722	2.869	0.412
P17 I want my family to continue to rely on me	0.795	0.190	0.19	3.095	0.377
P13 I think my GP is able to manage my illness outside of hospital	-0.473	0.192	0.274	3.155	0.368
P02 I have sufficient resources to handle my illness	-0.999	0.219	-0.83	3.36	0.339
P15 I can adapt to the changes in my lifestyle	-0.831	0.261	-1.023	3.489	0.322
P10 The information that I have is relevant to managing my illness	0.445	0.221	-0.629	3.911	0.271
P07 I am comfortable with seeing my GP	-1.25	0.197	0.797	4.354	0.226
P18 My friends are always supportive	-2.146	0.238	-1.241	4.68	0.197
P09 I use complementary therapies	0.937	0.193	-0.451	4.965	0.174

P12 I have spiritual beliefs	1.183	0.159	0.981	5.221	0.156
P22 I accept that I have to change my lifestyle	0.888	0.198	0.174	5.318	0.150
P14 My family still rely on me	0.793	0.178	1.789	5.363	0.147
P06 My family are always supportive	-2.399	0.252	0.347	7.747	0.052
P08 I am capable of making decisions related to my illness	-0.99	0.224	-1.903	8.87	0.031
P24 Complementary therapies help me cope with my illness	1.103	0.220	-0.561	9.399	0.024
P28 I know my GP really well	1.13	0.178	2.389	9.715	0.021
P03 I have enough information to manage my illness	1.266	0.153	0.723	11.704	0.009

Figure 4.2 shows the expected and obtained values of responses to Item 27 across the range of person locations. The full range of person scores has been arranged into three step-intervals with increasing mean total scores (or locations). The dots indicate the obtained mean scores for people in each of three step-intervals. As can be seen here with Item 27, the obtained values follow the expected curve very closely. Thus this Item fitted the model well.

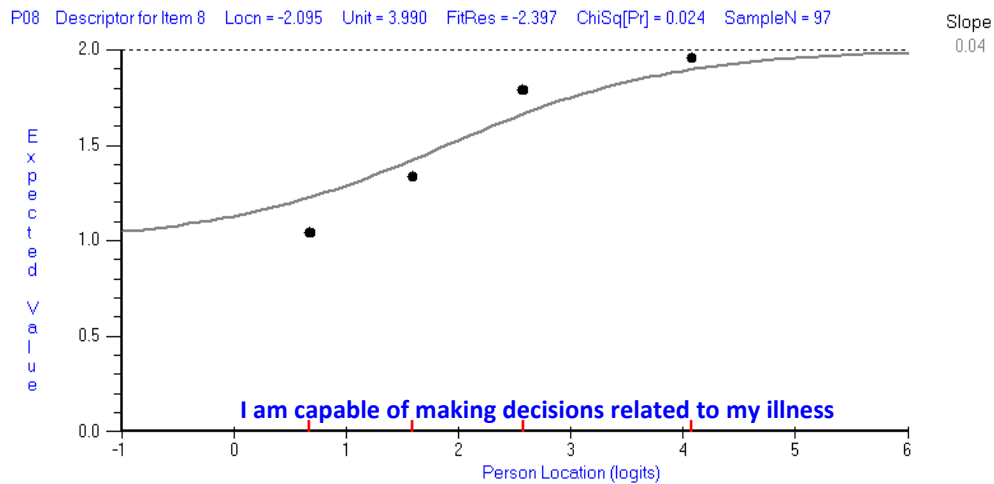
Figure 4.2 Feeling useful in paid employment



I still feel useful although I am no longer in paid employment

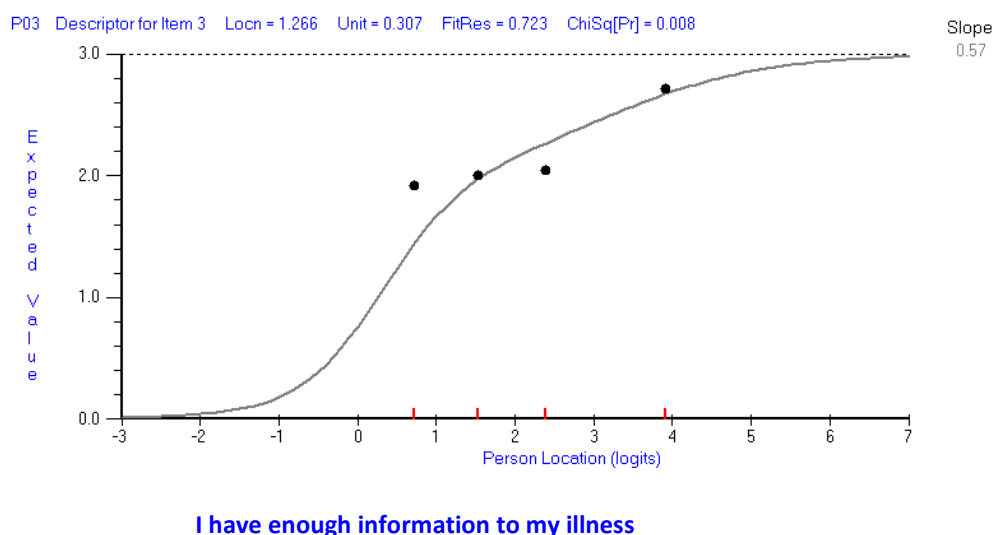
Figure 4.3 shown below shows an item (statement P08), “I am capable of making decisions relating to my illness.” The cause of the misfit (in this case, over-discrimination) for the statement P08, is uncertain (refer Figure 4.3). It is close in meaning to two other similar statements regarding decision making involvement. For these reasons, the statement was discarded in the final scale.

Figure 4.3 Capable of making decisions related to illness



Another item which showed some misfit was Item PES 03: ‘I have enough information to manage my illness’. In Figure 4.4, the graph for this statement shows a tendency to under discriminate between groups of people in the low to middle group of locations. All groups except the highest-scoring group tended to agree to the same extent to this statement regardless of their level of empowerment. This may be due to the fact that the statement is too generic or that patients may differ in their perceptions of exactly how much information is ‘enough’ to manage the illness.

Figure 4.4 Have enough information to manage the illness

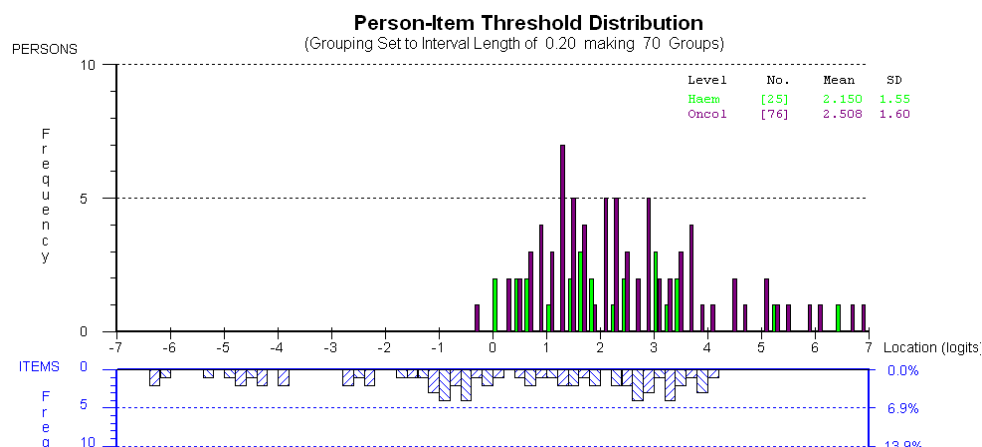


4.4.5 Person locations – distribution of person and item category locations

Residual values were checked for each respondent and seven persons with values exceeding 2.5 were highlighted as shown on Table 4.7 shown in Appendix 3. Analysis of the scale revealed that patients from all hospital sites were located at the reasonably empowered end of the scale. This would need to be reviewed in future as the aim was to develop a scale that could be used amongst patients with greater variation in levels of empowerment. In this sample, most patients seemed to have some sense of empowerment and the use of coping strategies to regain control over certain aspects of their condition. The analysis showed that patients recruited from the Medical Oncology Unit considered themselves slightly more empowered than those in the two other locations (Haematology and Radiology). However, the mean differences were not statistically significant ($p = 0.412$). Figure 4.4 shows the empowerment items evenly distributed along the continuum below the persons. A number of the items were not targeted well for this group of people because some items were targeted below the distribution of people. However, in future studies with a larger sample of patients, this may not always

be the case. Some people with the very highest locations on the continuum are also not well targeted – there is a need to develop more intense items, that is, items indicating even higher levels of empowerment than the present items.

Figure 4.5 Person – Item Threshold Distribution Pilot Scale PES



4.4.6 Coalesced statements

Meaning, location and misfit

Following the completion of the analysis and in order to shorten the final version of the scale, decisions were taken to coalesce some statements and omit others. These decisions were taken by reviewing items to see if they were close in location and also in meaning. For example, of the two statements (PES12) *'I have spiritual beliefs'* and (PES21) *'Spiritual beliefs help me cope with my illness'*, the latter fits the model better and seems to represent the variable better conceptually. Hence PES12 was omitted from the final version.

Table 5a Coalesced statements spiritual beliefs

Statement	Location	SE
I have spiritual beliefs	1.152	0.229
Spiritual beliefs help me cope with my illness	1.265	-0.036

Two further statements (PES09) *'I use complementary therapies'* and the corresponding statement (PES24) *'Complementary therapies help me cope with my illness'* also appeared close in meaning and in location on the continuum. The statement PES09 was discarded in favour of PES 24 (*'Complementary therapies help me cope with my illness'*) which tells us more about the patient's attitude towards complementary therapies.

Table 5b Coalesced statements complementary therapies

Statement	Location	SE
I use complementary therapies	1.086	-0.278
Complementary therapies help me cope with my illness	1.249	-0.333

Further, the statements relating to friends and family are also located close together in the continuum (see below).

Table 5c Coalesced statements need for family reliance

Statement	Location	SE
I want my family to continue to rely on me	0.929	0.189
I want my friends to continue to rely on me.	0.932	0.199

There was some difficulty initially in determining the ways in which patients regard the support of friends and the support of family. Undoubtedly, patients who were interviewed outlined the fact that friends although supportive, had offered support in different ways to family members. However, although qualitative research methods had categorically defined these differences, for the purposes of this brief inventory, the analysis revealed that most respondents regarded the two support mechanisms in the same way. That is, for the purposes

of this short answer (Likert type) questionnaire, it appears that respondents (patients) regard support of friends and family in similar ways.

Due to this, a decision was made to coalesce these statements. Thus, a modified version of the original scale using the coalesced family and friends statements were used for further data collection.

Table 5d Coalesced statements support of family

Statement	Location	SE
I need the support of my family.	0.542	0.234
I need the support of my friends.	0.787	0.2

The remaining two statements which were coalesced related to paid employment and a sense of still feeling useful. The difficulty with these two statements was that a patient was unable to respond to both. In other words, either they were employed or not. Given that the empowerment marker was feeling useful regardless of whether the person was in paid employment or had retired due to ill health or age, it was decided that these two statements could be combined to read, *“I still feel useful in my daily life”*.

Table 5e Coalesced statements feeling useful

Statement	Location	SE
P19 I still feel useful because I am in paid employment	1.425	0.297
P27 I still feel useful although I am no longer in paid employment	-0.87	0.248

4.5 Finalising the Patient Empowerment Scale

In this section the psychometric analyses of the final, modified version of the Patient Empowerment Scale with a smaller number of statements, are presented. The final Patient Empowerment Scale (PES) consisted of 15 items (Appendix1) which included the original items that performed well (that is, fitted the model closely) in the pilot scale analysis as described earlier, as well as a few pairs of items of similar location which were subsequently integrated (coalesced) with each other. The data used for this analysis included all respondents (N=210) from the new sample (110 adjuvant breast cancer patients) as well as the original sample of patients from the pilot analysis (100 patients). This provided a large enough sample to ensure stable estimates of items and person-locations. Once again the RUMM 2020 program was used for the analysis. Respondents from the new sample were receiving chemotherapy treatment at a second hospital location and were breast cancer patients.

4.5.1 Overall results of the analysis

Findings indicated that the fit of items was acceptable and thus that the set of items forms a valid, unidimensional scale. The Person Separation Index of 0.78 indicated an acceptable degree of reliability when data were fitted to the Rasch Model and in examining the Power Test-of-Fit outcome in the Summary Statistics using the RUMM program. This provides a visual statement of the Test-of-Fit as:

- Excellent
- Good
- Reasonable
- Low
- Too low

Whereby 'excellent' or 'good' imply an 'acceptable degree' of reliability.

Summary Test Of Fit Statistics Item – Trait Interaction Of Final PES Scale

Table 6. Summary Test of Fit

Item-trait interaction		Reliability Indices	
Total item Chi Square	70.477	Separation Index	0.787
Total Degrees Freedom	30	Cronbach Alpha	N/A
Total Chi Square Probability	0.000042	Power (test of fit)	Good

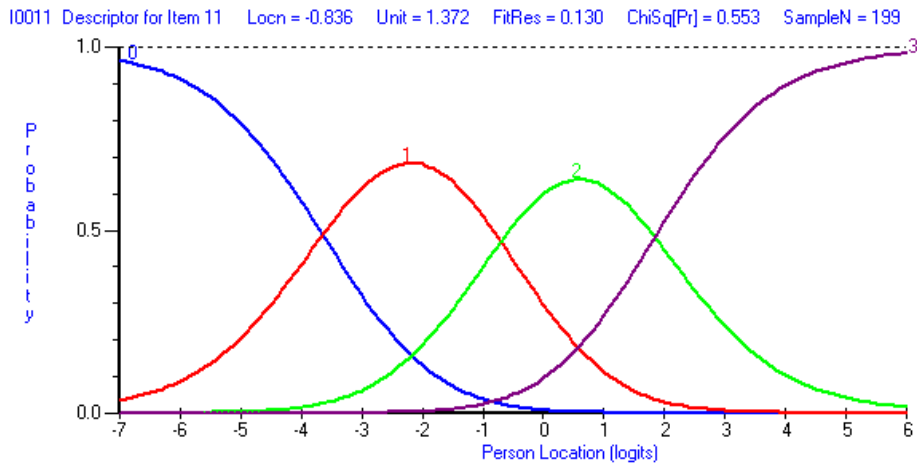
The reliability estimate is based on the same concept as the Cronbach's Alpha which is the 'percentage of observed response variance that is reproducible' (Bond & Fox, 2001). The items each had four ordered response categories in the pilot analysis, however, it was found that for most statements, patients rarely used the 'strongly disagree' option. During subsequent analyses when categories were collapsed to three by omitting the 'strongly disagree' option, the scale showed a higher degree of reliability than was the case with four categories. Unless the scale is to be used with people with a greatly diminished sense of empowerment, it would be better to use 3 rather than 4 response categories.

4.5.2 Analysis of thresholds using four categories

In principle, the use of 4 categories may provide greater precision of measurement than, say, a dichotomous (yes / no) response from patients. However, this will only be the case if the categories can be shown to be operating as expected, that is, with each successive category indicating more of the property or variable of interest; in this case 'empowerment'. Table 4.8 shown in Appendix 3 shows the threshold estimates or locations for each item. As can be seen, the items marked * did not perform as well as expected because the thresholds are disordered or reversed.

The Category Probability Curves show the probabilities of responding in each category across the range of person locations and indicate graphically whether the ordering of the categories is as intended. Figure 4.6 shows an item where this is the case.

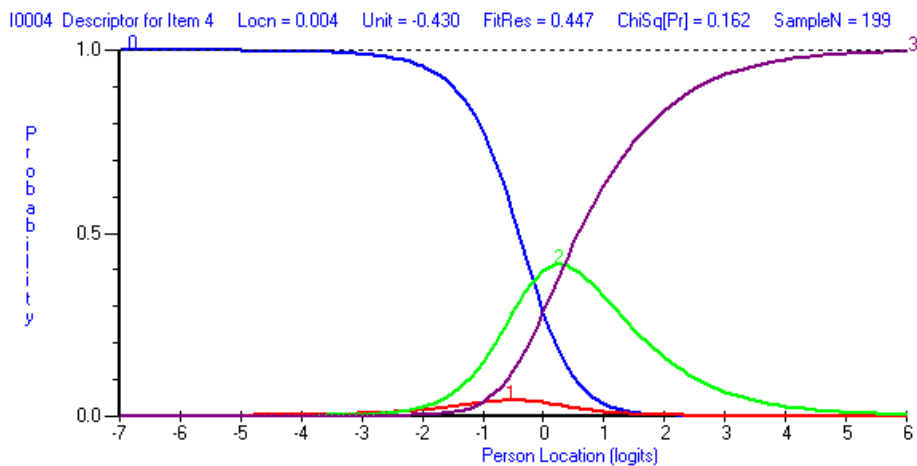
Figure 4.6 Item with correctly ordered thresholds.



Item 11 - I still feel useful in my daily life

However, Figure 4.7 shows the Characteristic Probability Curve for another item (Item 4 “My family are very supportive”) where the categories were not ordered as they should be.

Figure 4.7 Category characteristic curve for Item 4



Item 4 – My family are very supportive

4.5.3 Analysis of thresholds using three categories for all items

By adding response categories from two adjacent categories - thus reducing the number of from four to three for all items - the threshold locations improved.

Although it is strictly necessary to consider reducing the number of categories only for those items that show reversed thresholds, in practice, having different number of response categories for different items in one scale would be clumsy and likely to present problems for respondents. Hence a decision was taken to reduce the number of categories for all items, post hoc, to investigate whether this would eliminate the problem without causing a large reduction in reliability.

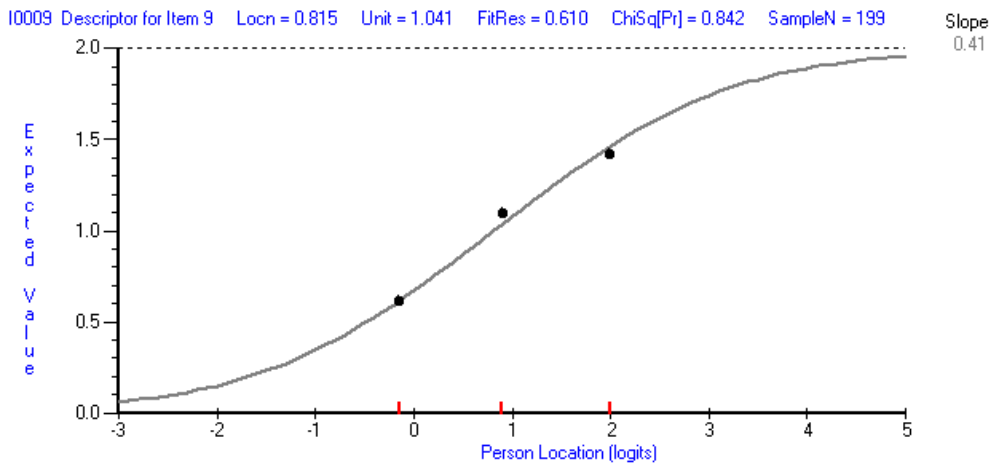
Table 4.9 (shown in Appendix 3) shows the thresholds are now all performing as expected. The Person Separation Index for this analysis was 0.787. Since this is slightly better compared with the PSI from the analysis with 4 categories, it is accepted that reducing the categories has not impacted on the reliability of the scale, in fact, it has improved it slightly, giving added support to the decision to reduce the numbers of categories.

In summary, very few respondents used the 'strongly disagree option' across all items. The only items where this option was used were Item 14 '*Complementary therapies help me cope with my illness*' and Item 15 '*I have a lot of confidence in my local GP*'. It was speculated that items in a future version of the PES should perhaps have only three categories and this possibility is discussed later in this chapter. However, more data from a broader sample of patients would be required to decide whether three or four categories for these items should be used. Another option would be to retain four categories, but with altered labels such as 'disagree', 'agree slightly', 'agree', 'strongly agree' in order to target the categories more appropriately to the people, but this assumes that any future respondents would be at least as empowered as the people who participated in this study. It is likely that such a change would distinguish better between patients who are moderately empowered and those who are highly empowered. More data would need to be collected to assess how well these new categories performed.

4.5.4 Fit of items and persons to the model

Table 4.9 shows the overall individual item fit for the final PES (Appendix 3). Items such as Item 9 (Item characteristic curve (ICC) shown in Figure 4.8) fitted the model well, '*I want my family and friends to continue to rely on me*'

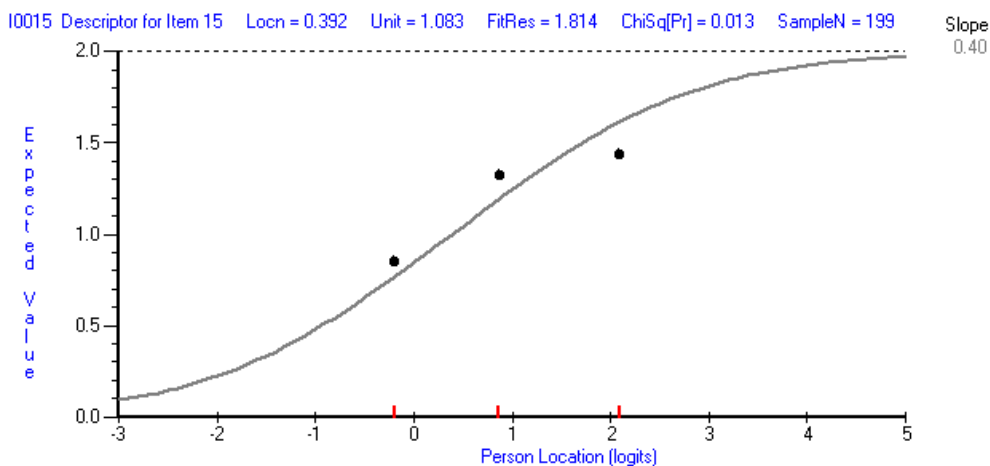
Figure 4.8 ICC family and friends continued reliance



Item 9 – I want my family and friends to continue to rely on me

Some items fitted the model less well. This was the case with one such item (Item 15) stating, “I have a lot of confidence in my local GP”. The ICC for this item shown in Figure 4.9 indicates that the item tends to under-discriminate amongst the middle and high person-location groups, but it is within the bounds of acceptability. It is noted here that no single test of fit is sufficient on which to base a decision about fit to the model, rather, it is the picture that emerges from several sources of information, including inspection of the ICCs.

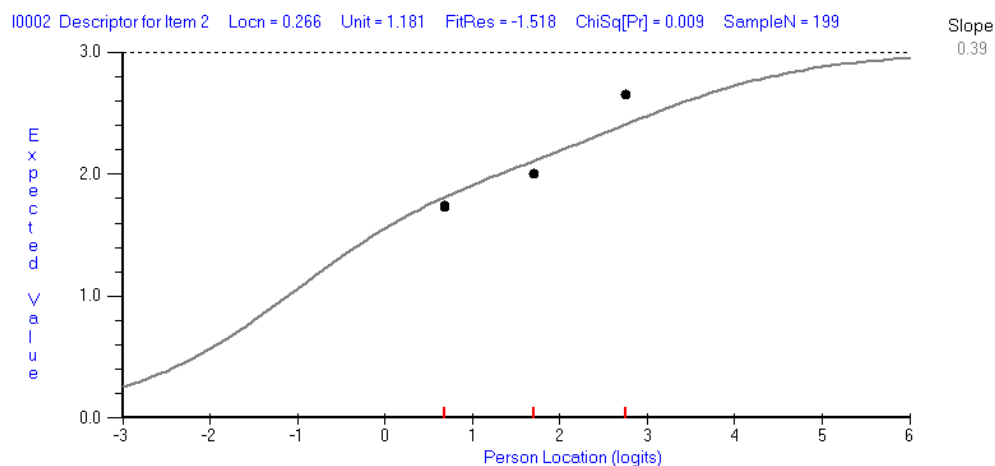
Figure 4.9 ICC Confidence in local GP



Item 15 – I have a lot of confidence in my local GP

The worst fitting item from the second analysis was Item 2, “I have all the information I need to manage my illness” shown in Figure 4.10 below. It tends to over-discriminate between the middle and top scoring groups of people. Again, however, it is considered acceptable given the small sample of patients used for this second set of analyses.

Figure 4.10 ICC Information to manage illness



Item 8 – I have all the information I need to manage my illness

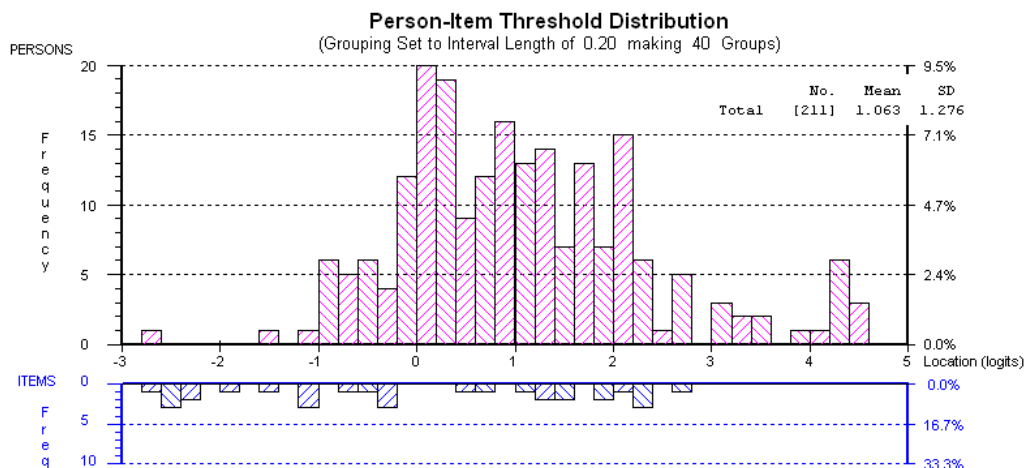
Based on a consideration of the tests of fit and examination of the ICCs of all items, it is accepted that, on the whole, the 15 items form a single scale. That is, all items are contributing to the measurement of a similar variable. Even if we accept that Item 15 does not fit very well, because up to 5 percent of items may misfit purely by chance, all 15 items are accepted and retained in the scale for the purposes of this study.

4.5.5 Item / Person Distribution Location

Although the graph of person and item distributions presented in Figure 4.11 below for the 15-item scale still shows the person distribution to be skewed to the high end of the continuum as it was for the pilot study, there is, nevertheless, a comparatively wider spread of person scores (locations) when compared to the

Person-Item Threshold Distribution for the 28-item scale presented earlier in this chapter. Three persons had residuals outside of the acceptable range (>2.5).

Figure 4.11 Person-Item Threshold Distribution



From an inspection of the Figure 4.11 above, it is also apparent that more intense items are needed to more adequately measure people who have a high level of empowerment. This step could be considered in the future development of the PES.

4.5.6 Order and location of items

The location of items shown below in Table 6 demonstrates that concepts such as the support of family and significant others and the involvement in management of the illness were those which patients were most likely to agree with, and thus are those indicating the lowest levels of empowerment.

Complementary therapies and the desire to be relied upon by significant others were least likely to be agreed to: respondents would have to perceive themselves as highly empowered to agree with items at this high end of the scale.

Table 7 Final PES 15 Items Individual Fit Statistics

Item/ statement	Location	SE	Residual	Chi Sq	Prob
P01 I am capable of handling my illness.	-0.594	0.146	-1.533	7.747	0.020
P02 I have all the information I need to manage my illness.	0.6	0.186	-1.551	11.267	0.003
P03 I am capable of helping health professionals reach decisions about my illness.	-0.612	0.147	-1.04	9.224	0.009
P04 My family are very supportive.	0.5	0.186	0.637	3.146	0.207
P05 I need the support of my family and friends.	-1.184	0.206	-0.010	0.360	0.835
P06 My family and friends still rely on me.	-1.349	0.154	1.007	5.415	0.006
P07 I can adapt to changes in my lifestyle.	0.05	0.177	-1.273	7.157	0.028
P08 Health professionals are happy to include me in decisions about my	-0.3	0.162	-0.818	3.129	0.209
P09 I want my family and friends to continue to rely on me.	0.815	0.166	0.610	0.344	0.842
P10 My friends are always supportive	-0.708	0.143	0.203	6.884	0.032
P11 I still feel useful in my daily life.	-0.158	0.181	0.135	0.344	0.842
P12 My spiritual beliefs help me cope with my illness.	0.592	0.131	1.134	2.353	0.308
P13 I accept that I have to change my lifestyle.	0.531	0.141	-0.231	4.867	0.087
P14 Complementary therapies help me cope with my illness.	1.425	0.146	1.159	5.42	0.066
P15 I have a lot of confidence in my local GP.	0.392	0.125	1.814	8.759	0.012

4.5.7 Discussion

The analysis of the 15-item scale indicates it is a valid and reliable scale to use with the type of respondents who participated in this study.

The analysis of data using the 15-item version of the PES and a larger number of patients indicated there was more variability in the levels of patient empowerment than was the case with the pilot sample. Patients were more heterogeneous on a number of levels such as difference in hospital location, treatment regimens and type of cancer and this may explain the increase in variability of scores. However, we have not tested for Differential Item Functioning between groups. It is intended that further plans to validate the scale will include tests to assess the suitability of the scale across groups (eg gender, disease type). The PES benefited from a reduction in categories from four to three, possibly due to the fact that respondents were not discriminating between the “Strongly Disagree” and “Disagree” categories for most items. The exceptions

to this being items such as, *'I can adapt to changes in my lifestyle'* and *'spiritual beliefs help me cope with my illness'*. It may be that a future version of the PES should use three categories. Namely, 'Strongly agree', 'Agree' and 'Disagree' or four, namely, SA, Slightly Agree and Disagree although the researcher has not reached a final decision regarding wording changes.

The fit of the PES to the Rasch model justifies the addition of raw scores by health professionals to create a total patient empowerment score. In such contexts, it would not be necessary to use the linearised Rasch logit scores for scores along most of the continuum. The logit scores do, however, provide more information than the raw scores at the two extremes of the continuum.

The main intention of the PES was that it be used in a clinical setting by health professionals. It is intended that the self-complete questionnaire could be given to the patient for completion without the assistance of a health professional. The clinician could then add the patient responses to obtain a raw score to provide an indicator of the level of empowerment for a particular patient. Given that a patient's positive attitude towards use of relevant support systems and resources impacts on their ability and motivation to regain a measure of control over the illness (empowerment), it is useful for clinicians to be aware of level of perceived empowerment amongst patients.

CHAPTER FIVE

5.1 Exploring role of empowerment using PES concepts

As previously stated, this study not only sought to develop a quantitative measure of patient empowerment which would demonstrate that empowerment was a separate and measurable human attribute. The study also explored the role of empowerment in the wellbeing of cancer patients. It was decided that the in-depth nature of the enquiry into the role of empowerment in the wellbeing of cancer patients would be best explored through the use of qualitative research methodology. An invited book chapter and a peer reviewed paper (in press) have arisen from this area of the research (see Appendix 6). The concept of empowerment, as understood from the previous work of identifying and constructing the markers which making up the final Patient Empowerment Scale (PES), highlighted a number of core concepts which are central to patient empowerment and wellbeing. To recapitulate from the findings of the PES, the core strategies demonstrated in varying degrees of empowerment by individual patients in accessing resources and support systems are as follows:

- Information and resources usefulness
- Seeking advice and having a trusting relationship with health professionals
- Involvement in the decision making process
- Acceptance and adaptability
- Reliance on self and using self-efficacy mechanisms in the face of difficulties
- Family and friends support
- Spiritual beliefs
- Use of complementary therapies (e.g. herbal remedies, meditation and massage)
 - Feeling useful (encompasses other areas such as friends and family)

This part of the study was also interested in exploring further the concept of a cancer 'journey' as spoken of by some Shared Care patients previously

interviewed. It was the intention that reviewing the stages of the illness trajectory from diagnosis through to final treatment would clarify how patients regain control over the illness and learn to accept what they can and cannot control about their cancer. In addition, the concepts / markers for empowerment are elements that patients learn to use along the way in order to regain control over their lives both physically and emotionally. Thus by accepting their ability to manage the illness, being able to adapt to a new set of life circumstances in a positive way. This chapter will not only explore further the core concepts of empowerment within this group of breast cancer patients but also the structure of the cancer 'journey' taken by patients as a means of identifying ways in which they regain control over their lives.

A series of eighteen semi-structured in-depth interviews with breast cancer patients were completed to investigate further the concept of empowerment and the role it plays in the wellbeing of cancer patients. Previously, patients were interviewed and had participated in the Shared Care Model pilot project. This may have presented a degree of bias regarding ability to regain control not least because all patients reported a reasonably good relationship with the clinicians and nursing staff and a pro-active approach to managing their illness. Furthermore, through opting to be part of a shared model of care they had actively sought to be included and involved in their overall care. Nonetheless for the initial stage of formulating key components to enabling patient empowerment this was justified on the theoretical basis of using a purposive sample to obtain the richest source of information possible regarding the topic. Namely, the ability to regain control in the face of a life limiting illness, patient empowerment and motivation. The justification of choosing a further subgroup of patients was so that a broader perspective would be obtained regarding motivation and empowerment. That is, not all patients would be as pro-active in seeking involvement in their treatment and having a strong belief in their ability to manage aspects of their illness. In contrast to the initial sample of Shared Care patients, patients who completed the breast cancer interviews did not have access to the support of the Shared Care program. Thus they largely relied upon their own abilities and motivation to regain control and identify which resources and support strategies were most useful to them. The results were, nonetheless,

strikingly similar to the patients interviewed as part of the Shared Care program in terms of use of resources and support mechanisms. This chapter will present the results of eighteen in-depth interviews with breast cancer patients as it relates to the area of patient empowerment. The questions used for the in-depth interviews are noted in Appendix 2.

5.2 Methodology

A purposive study deliberately selects participants in order to obtain a series of 'information rich' interviews. We recruited a purposive sample of 18 breast cancer patients who were receiving adjuvant chemotherapy treatment at a specialist hospital and who had already completed at least one round of chemotherapy. This group represented women at a similar stage of disease, all in good health without other co-morbidities (except for one patient with diabetes Type 2) and who were uniformly receiving chemotherapy for the first time. Twenty-two patients were invited to participate in the study of which 18 agreed to be interviewed when followed up by the researcher. The two who declined both cited difficulties in coping with treatment side effects as the reason for refusal. The remaining two were unavailable for the timing of the interviews.

Method

The oncologist asked if the patient would be willing to be contacted by a researcher to participate in a phone interview. If they agreed, they were provided with an information sheet and required to sign a consent form by the oncologist. The researcher contacted each participating patient one week after their last chemotherapy treatment. This was identified as the best time to contact patients because it was anticipated that symptoms would have subsided and the patients would be more comfortable talking about their experiences retrospectively. They would also be less likely to be affected by any physical and psychological side effects from their chemotherapy regime. It was also believed that each patient would have also had time to reflect on their experiences and gain perspective on their approach to managing their illness.

A series of questions were developed by the researcher following on from previous work from this study focusing on the areas of motivation and empowerment amongst cancer patients. The questions focused on exploring the support strategies patients used in order to motivate themselves to regain control over managing certain aspects of their illness. The process also required an acceptance and acknowledgement that certain aspects were outside of their control.

The interviews were recorded and transcribed . The data were then analysed using QSR NVivo Version 4.0.

Ethics was obtained to conduct the study from the Mount Hospital Ethics committee in accordance with requirements.

5.3 Results

The interviews explored the theme of regaining control following a diagnosis of cancer and the 'journey' spoken of by some patients which ultimately leads to a sense of empowerment and control over some of the physical and emotional illness symptoms and side effects. A number of areas have been highlighted in this series of breast cancer patient interviews in relation to the stages of the cancer journey to achieve empowerment. Each are discussed below and highlighted through the findings of the in depth interviews conducted with the sample population of breast cancer patients.

5.3.1 Stage One – Losing control

Stage 1 is characterised by shock, denial and fear of the future. There is a perceived loss of control by the patient.

Most patients speak of the early days following diagnosis as characterised by shock, anger and disbelief. This stage occurs before or at the beginning of chemotherapy treatment which remains largely an unknown. For those who have experienced it before, patients are anxious in regard to what lies ahead and their ability to manage the effects of the treatment. There is a fear for the future and the unknown outcome of any proposed treatment regimens. A loss of control over

their bodies and their lives in general is a common perception amongst newly diagnosed patients. The confusion that embodies this early post diagnostic period has a number of outcomes for patients. Firstly, they are confronted with a frightening situation in regard to their health and future and an overwhelming worry that they may not survive. If they are a first time patient they usually have never been faced with a potentially life threatening situation such as this. Secondly, they are in need of understanding from a team of health professionals, most of whom they will never have met previously, They will seek guidance as to how they can be helped to navigate their way through the treatment regimen in order to regain a sense of control over their lives with the ultimately aim of remission from their cancer.

The early days following a diagnosis of cancer are described by most patients as a time when they are grasping at any information and support that becomes available. This is often a period when they feel completely disempowered. Unfamiliar medical terminology, uncertain outcomes and anxiety for family and significant others in relation to the patient all come to the fore. In addition and from the patient's perspective, health care professionals, support groups and family and friends are all providing a plethora of advice and information that they feel may help the patient.

Fear of acknowledging the diagnosis

The stage following diagnosis of cancer is commonly a stage when the patient is at their most disempowered. Patients highlighted the experience of vulnerability which comes with the diagnosis of cancer and the fact that it did not discriminate amongst those with healthier lifestyles.

"I have a very healthy lifestyle and exercise so the doctor was very surprised. I just didn't think it would happen to me and I was a bit smug. Well, that has changed!"

Some patients also engaged in "doctor shopping" in the early days following diagnosis. For some, it was a reaction during the denial phase of the illness. In other words the patient is seeking someone who would actually tell them that

everything would be all right and the outcome positive regardless of diagnosis. The same patient explains further,

“My doctor at that time was very thorough but I have actually moved on since and I got this new doctor because I didn’t want her - she was a fear monger. I got actually scared by this doctor. She did say, “Look if you are going to get cancer, the best one to get is breast cancer”, but I could see in her face that she was already worried. So I said, don’t tell me any more. So I haven’t gone back to her at all. My husband and I decided to take charge there and then and pick doctors and see people that we are comfortable with that I am not feeling anxious with.”

Focus elsewhere

Some patients were not ready to accept their diagnosis and were in a stage of denial or unwillingness to face the future and determined to only focus on the positives and the normalcy of life. One said,

“Oh no, I am positive...I am going to be here for a long time. My daughter in law is expecting a baby and so I am looking forward to that you know, I focus on the positives.”

For another patient, it was important to concentrate on the treatment before thinking about the future. She said,

“Not right now, I just want to get it over and done with.”

CONFUSION IN THE EARLY DAYS (POST – DIAGNOSIS)

Information seeking

In the early days, patients and their families may seek out information. However, it is rarely strategic in terms of what is needed but rather a grasping at any information that becomes available. Patients strongly rely on advice and information from clinicians in this early stage. Although the early stages are

characterised by a sense of helplessness, patients seeking to be empowered will learn to seek information strategically whilst relying on the advice of their clinician.

Timing of information and patient readiness

Clearly, the ability of a clinician to gauge the appropriate timing to provide information to patients is crucial. It is important that health professionals and those involved in the early stages of the cancer patient's diagnosis are aware of readiness in terms of amount and type of information that patients want to receive. One patient explained it thus,

"I only took on board what I could cope with. I think there is just so much. The shock at the beginning means that you kind of don't really take everything on board."

Another added,

"I think that we were quite overwhelmed with the information for breast cancer. I didn't read it all. I don't want to smother myself."

In the early stages the sense of being overwhelmed is foremost in the patient's mind. As it is, they are already faced with an unknown illness and perceived threat to their wellbeing. It is important that they are not burdened with more information that is unnecessary in the early stages. One patient said in relation to timing of information,

"Although the information was important I think that they possibly gave it out earlier than they should have done."

Denial in the early stages following diagnosis impacts upon the patient's ability to receive and act upon information. One patient highlighted it as follows,

"I just felt that I didn't want to hear too much. It scared me and obviously you get told different things along the way. I feel that I was in denial but what could I do? I pretended that nothing is wrong and got on with my life as best I can because I didn't want to dwell on it and I wanted to be as happy as I could be."

Another patient said that even hearing the word 'cancer' and accepting that this was the diagnosis was difficult in the early stages.

Patients who are coping with feelings of shock and denial and are unlikely to absorb most of the information provided to them. One patient said,

"The doctor I think gave me too much information at that time. I was given all the results and because my cousin had ovarian cancer he started talking about genetics. I couldn't take it all in at the beginning. It is good to know in hindsight but I was not sure how much I needed to know and how much I didn't."

Often patients find that the initial fear and shock of the illness diagnosis means they will be offered conflicting advice by significant others outside of the medical profession. This is usually done with the intention of demonstrating that they care at a time when both patient and family feel they are not in control of the situation. At this point, more than ever, patients will rely on the advice of their clinician.

"I was in two minds as to whether to have chemo or not. I had my family on one side there was me on the other side saying I didn't want to have it done. I was very concerned that it would affect my vital organs. So talking to the specialist was very helpful. She went through everything and advised me to agree with my family to have it done but at one stage I was saying "Oh no. I don't want it done."

Difficulties in accepting advice are common in the early stages as the decisions regarding treatment need to be made fairly quickly. This can lead to a greater sense of losing of control for the patient at a time when they may not fully have accepted the diagnosis or had time to review a proposed treatment regimen.

Another patient highlighted the problem of timing in relation to the initial

specialist visit and the fact that the patient is unable to ask questions about the diagnosis. She suggested the following,

“Advice from health professionals is crucial to you. The specialist was telling you at the time but you are in shock when you are receiving information and it is delivered in a matter of fact way. So I guess it would be useful at this point just a few weeks or a month down the track to be able to go back to the specialist and to say, “Well, what did you mean? And can you explain it at a different level. What is involved here”. That would be useful because the first time that you are hearing you are just floored...you know...taken aback by what you are hearing.”

In making decisions another patient said that part of feeling they were included was being given time to digest information and not feeling rushed. She explained that she wanted to be informed and then, most importantly, being given time to ‘think about it’ afterwards before a decision is reached

Internet

Although many patients acknowledged that the Internet is a valuable source of information there was a clear understanding of it’s limitations as well. In the early stages of treatment, many patients preferred guidance from clinicians regarding which information they ought to access rather than expecting the patients to decide for themselves. Although many patients had accessed the Internet at some stage early on during their diagnosis, most said that they had relied more on face to face contact with a clinician. As one patient said,

“I still believe that information at a written level is good but I also believe that face to face contact is important as well. It’s a combination – I am not really one much for Internet searching. I had enough happening already.”

Some said that they had searched the Internet for clarification following a specialist appointment to enable them to make a decision regarding treatment options. Another found that this made her more emotional and that she decided not to access the Internet whilst feeling emotionally unstable.

"I didn't particularly want to go onto the Internet because at that stage I was a bit emotional and I wasn't really ready for it and I haven't gone back. I don't think I need it."

In addition, some patients had a more guarded approach to use of the Internet. In fact one patient said that she found it "quite frightening" due to the amount and sometimes conflicting types of information. For patients in the early stages of their illness, guidance from experts and trusted significant others seemed to be more important. Pamphlets recommended and provided by health professionals were also valued. Some patients highlighted the importance of timing in regard to seeking information on the Internet. That is, the early anxiety that encouraged random Internet information seeking was overcome once targeted advice and information was provided by the clinicians and health care team. One patient explained,

"Initially when I was first diagnosed we went to the Internet a lot to find out what it was all about. But then I started the treatment and I got info on cancer and how it would all be treated, you know? So I found it useful in that initial stage."

Ways of accessing information

Patients also believed that the way in which information was provided by the health care team was important. One patient said that it was not sufficient to provide names and contact numbers but rather that this needed to be accompanied by a recommendation or an explanation of why it would be of benefit.

"I think just get information with names. I think that there has to be some recommendation with that. You can't just say 'go to the Cancer Foundation', you've got to say 'look, there's or that's really good and I highly recommend you to go. You've got to make some links. You've got to get a little bit of insight into what they can get from those, so it's just a bit overwhelming and I will ring up but

I don't really know what I'm ringing up for. It's very difficult to do that for yourself and you really need."

This was endorsed by another patient who said that the leaflets she was provided with were useful only in as far as the support nurse went through them with her and explained the information further.

"But another young lass that gave me those leaflets and she actually went through everything with me and told me that, you know, that there's a point where you peak and then you go right down and move right down to a low point and she explained about the hair and the nails and that and really, a lot of information. I thought she was very good. Yes, she gave me like a little folder with all the information in. She also booked me into a class where they showed you how to do your make-up and how to take care of your skin, it dries out a lot and all that sort of thing."

Both of these patients viewed obtaining relevant information as a means of regaining control over their condition and that it was vital to have guidance through the early stages of treatment. Other important sources of information for patients were counselling lines, particularly with counsellors who had experienced cancer themselves. Complementary therapies, information and informal talks with friends and family were also useful to some patients. One patient reiterated the immense importance of providing information to newly diagnosed patients,

"I don't know how other [people cope] because I think that you really fall in a hole and if you don't have people around to help you then you wouldn't know where to turn. I found that just speaking to other ladies whilst having my chemotherapy, they don't even know that the hospital Support Centre exists."

Knowing which questions to ask

Patients were initially uncertain of which questions to ask. It was evident that a period of time was needed by the patient following the shock of diagnosis in order to absorb the information needed to generate useful questions. A patient explained it thus,

“Maybe when you have had more than one [chemo] you can cope with it better. Initially, it is a shock. I have put everything on hold for the last six months. Initially it is a shock. I don’t know but it [treatment options] is in the air and at the back of my mind.”

Due to the difficulty that patients experience in communicating concerns when initially diagnosed it is important for health professionals to try to provide timely advice without overloading the patient. As one patient said,

“I think it is very important. I am given all the advice from there [the hospital]. At first I didn’t ask a lot of questions. I think that a lot of things were pretty much discussed for me.”

5.3.2 Stage two – Attempting to regain control

The second stage of the cancer ‘journey’ is characterised by learning to regain control through information seeking, getting to know the health care team and reliance on the support of significant others. A developing reliance on self is demonstrated by patients who seek to be empowered, as can be seen from the results of this study.

LEARNING TO IDENTIFY WHAT IS RELEVANT

Learning to re-evaluate

Being able to prioritize what is important and necessary amongst the plethora of support and advice was a challenge for most cancer patients. Once treatment has commenced, this stage is distinguishable as one where a patient who seeks to be empowered, learns to formulate and express opinions in relation to their illness rather than solely being led by others around them. In other words, the patient begins to actively seek some involvement in managing the outcomes of their illness and treatment regimen.

Processing information

Learning to decide what information is relevant and useful to an individual is an essential component of regaining control over the management of the condition for patients. Information was useful to all patients interviewed but with specific criteria attached. Part of the process of acceptance and adapting to the illness was to acknowledge preferred sources of information. In other words, as one patient said, “to take on board” information which was relevant and useful and to learn to disregard the rest. This was explained as follows,

“Yes it (written information) is important. You have a written back up. But then you reach a point where you have to process the information that is relevant to you and to discard what you don’t need. You look at the questions that you need to ask of yourself and others. When I reach that point I ask myself, “What do I need”?”

Furthermore, as the patient and their family progress through the illness trajectory there is a capacity to utilise further information and in doing so to most often seek information of practical nature.

“I think it is very important and I think we could probably have done with more information as we went on. Just sort of how things can affect you to do with the drugs that you’re taking and the effects of the drugs and how you can cope better with the drugs and the effects that they have on your body.”

For some patients who valued reading and researching the illness themselves, written material was very useful. Some patients said that information given to them was used a resource to refer back to whenever they were concerned about something. One patient felt written information was an essential back up to the advice given by health professionals.

However, for others who had not fully come to terms with the illness, it still remained a potential source of worry.

“The surgeon gave me a booklet on breast cancer but I could not read all of it because there was only so much that I could cope with. My husband actually read it for me and there are tiny bits and pieces that are useful. ”

Patients became adept at evaluating information that was useful to them. Some patients said that it could be difficult to assess quality of written information due to the fact that one is unable to directly clarify meaning and advice provided in a pamphlet or booklet. She gave an example,

“I don’t think that it clarified everything. One of the reasons is that they [those writing the booklet] have not clarified how you are meant to do the exercises. After the surgery all I got from them was a pamphlet that said, “You need to do these as soon as possible.” I started as soon as I got home - I had a bit of trouble with my wound. My wound opened up a bit. So I don’t know if I was meant to start straight away or after a few weeks. I also wasn’t actually shown how to do them.”

It was observed that patients regulated the need for information depending upon what stage of their illness they were at in terms of acceptance. Patients eventually learned to discard the information that was not needed and also any information that might be irrelevant and cause unnecessary concern. One patient said,

“My approach is to seek the information that I needed it but not too much. I found that it was just a process.”

There is also a stage when patients realize and accept their prognosis and are ready to ‘confront’ the reality of their situation through information provided.

“I put it in a suitcase and nearly threw it away! It wasn’t until much later that I read it and thought, “Oh, I have a much better prognosis than I thought.” You get so much in the beginning and you’re in shock.”

Another patient said that although she was aware that the Cancer Foundation could help her she was also aware that there was a time when she would be ready to access that help.

RELEVANCE AND USEFULNESS OF INFORMATION

Patient character and how information is received

For patients who are attempting to regain control over their illness and the management of their treatment and side effects, information can be extremely useful and is certainly valued by most patients. However, it is also dependant on the type of personality of those receiving the information. One patient said that the more information she had the worse she felt because she was a “worrier” to begin with. This patient did not welcome information and saw it as a threat.

“I don’t like people to give me information because I might have to take it ‘on board’.”

However, those with receptivity in regard to handling the situation welcomed advice and information and viewed it in a more positive light. For patients such as these, the frank approach was preferred. One patient noted,

“I wanted to know the good and the bad. I wanted factual information and I wanted it delivered in a way that they were not beating around the bush. To just give it to me straight up – yeah.”

One patient had witnessed her mother pass away from cancer some years previous and felt initially that it was a “death sentence” when she was diagnosed. However, access to information creating the realisation that treatments had progressed since then enabled her to “completely turn around my way of thinking”.

DEVELOPING A RELATIONSHIP WITH THE HEALTH CARE TEAM

Relationships with health professionals

One patient recognized the difference in relationships between the clinicians who are there for advice and information and other types of support from breast nurses and informal groups. She explained it in this way,

"I guess that I trust the doctors that I go to. I think they're experts in their field. But I don't expect a lot else from them because I know that you go for an appointment and there's only a specific time for your appointment and that appointment is directed to what the surgery is, or what the chemotherapy is that you're going to have. There's not a lot of time to ask anything else. If I mentioned anything else the doctor would say 'oh, that's very good.' But I don't think they really interested. Probably because they've got limited time as well and are limited to their field and that's where they get their expertise and nothing else."

In relation to this, knowing whom to rely on emotionally was also important for patients. One patient said that she relied on her psychologist because she was neither friend nor family but someone she could trust to be open and honest with her.

"If I am in distress I ring her and we just talk over the 'phone, so I know I have her to count on and she is purely there for me and I can say anything and everything to her because I know she is mine. I don't have family influencing her, I don't have friends influencing her, she doesn't know anyone else except me."

DESIRE TO BE A PART OF THE PROCESS

Opportunity to discuss

Being included in the decision making process does not imply making a decision alone but it does entail the patient being included in discussions with the doctor as to treatment intentions and advice on how to best manage the illness and any treatment side effects. Having the opportunity to discuss options was

overwhelmingly important for patients. This was the case even when few options remained. Most patients would ultimately abide by the specialist's advice but it was still important for them to go through the process of being included in treatment and management decisions. When this did not happen, patients indicated that they felt resentful. One patient complained,

"Now I am thinking well, "Do I need this operation? Are there other options? Are there variations and options?" It is just that this is how it was delivered to me and that this was what was going to happen and I don't feel there was any decision making involved."

It is important for the clinician to be aware that providing time to discuss treatment decisions and options is vital in managing the individual needs of the patient. Patients become anxious and frustrated when questions are not fully answered and there is no time provided for them to seek clarification. Furthermore, the occasional unwillingness or inability of the doctor to discuss options with the patient does not preclude the patient from "going and doing my own research". Furthermore, it is vital to developing a relationship of trust that this occurs. Some patients said that they felt agitated when not given the opportunity to collect all the information needed to make an informed choice. One patient sought information from a different source,

"The receptionist at the desk [specialist rooms] was fantastic. She gave me more information than the doctor. I became less aggro for every time I went because of that receptionist."

Nonetheless, as with the patient above, other patients had times when they just wanted someone with medical knowledge to talk to and to allay fears or address concerns. Another patient said,

"I know that I have another big operation coming up. I really want to know what it is all about. It would be nice but the specialists are not always available."

Sifting through medical information

Some patients felt that they received the most useful information from the specialist. However, for others the perception that specialists are too busy to answer queries is evident.

“Then I saw the specialist. She is lovely but she is so busy. I actually feel like I am a number....she is so busy.”

There are also accessibility issues for some patients which affect the ability to ask questions for patients. One said,

“Sometimes, you get there and you may have waited a long time. Your symptoms might have diminished a bit and so you just want to get it over and one with. She is lovely, I know that. But sometimes you just want someone to spend a bit more time.”

However, there were other patients who preferred only the core information from a specialist. Two other patients noted that it was important to them that the specialist was willing to simply provide the necessary information rather than giving them too much information which may not be relevant and could cause anxiety and fretfulness. One of those patients explained it in this way,

“I didn’t want to know too much about it. I thought that I just had to put my faith and trust in the doctor pretty much and then after that I just needed to know how to cope with it.”

Presenting information to the patient

However, it is also important that the doctor maintains a positive outlook in order for the patient to place her trust in that doctor. It was important to patients that they attend an appointment and leave feeling more positive about their ability to cope with their illness. Regardless of prognosis, it is important to patients that the doctor provides information in a straightforward way.

“She [doctor] was very positive. Straight down the line and just made me feel that it wasn’t such a drama.”

In other words, it is important that the doctor engenders a feeling of confidence in the patient to manage their illness outside of the hospital or clinic visit.

“She is a terrific doctor. Every time I would leave her office and I would be feeling confident. I’d go in there feeling hopeless and I’d come out feeling that this is ok. She is very positive.”

It is also important to patients that doctors take the time to explain and give patients ‘breathing space’ to make decisions based upon the information that they provide. One patient highlighted a particularly valued encounter with the specialist. She said,

“He actually rang back himself and really took the time to explain it to me. There are lots of question marks regarding this treatment – ok, you have got to make decisions within a certain timeframe. These are very important decisions.”

Once again, getting to know ways in which the health professional team provide varying forms of support is important to a patient’s journey. It is also another means of regaining control and achieving empowerment in acknowledging what forms of support were most needed at any given time and using those support systems to the patient’s advantage. Most patients felt that advice received from health professionals was useful and ensured that they became more in control of the overall comprehension of the treatment trajectory. Different health professional roles implied that advice and its usefulness to patients would vary. One said,

“I have often felt that I am in a bit of a tunnel and I am just being pushed from one thing to another. But still I don’t know any better.”

Regardless, of whether the clinician is a GP or a specialist / surgeon, it is important for the patient to find someone who is prepared to 'go the extra mile'. This includes not "fobbing off" patients with availability of the doctor and providing timely and relevant advice regarding any side effects and management problems. Patients learn to gauge who is most able to provide them with the necessary support.

"Pretty much one of my top priorities are – are they [clinician] good? Are they prepared to go the extra mile and are they accessible? You know that maybe in twelve months time you won't be behaving like that. You are not expecting a handout."

Nursing staff

Oncology and breast cancer nurses, although generally perceived as being more accessible, were also a valued means of support only in so far as they had time to spend with the patient. This included the ability to answer questions and have time to provide advice to the patient. One patient said that she felt that the nurses were 'pretty much hand picked for that kind of role' meaning that they had to be a very unique type of person to provide consistent support needed by patients and their families. However, conversely, two patients said that because their nurse appeared rushed and busy that the support issues were not fully addressed. They were only provided with a support group number to contact.

Overall, most patients perceived nurses to be invaluable in that they were usually more accessible for patients and easily approachable. Nurses were also more likely to develop a closer relationship with the patient by using physical gestures such as hugging and reassuring both them and also accompanying family and friends.

"It is about establishing a relationship. You know we give each other a big hug and I am really just a patient for her. Just seeing her....it is an emotional thing as well as physical."

Nurses who were more inclined to provide individualized and personal advice and support were particularly valued.

“The nurses were fantastic. They would fill in the puzzle, they would give me the picture, they would tell me what was happening to my body.”

One patient commended the fact that the nurse had provided her with personal contact details. Another said that she relied greatly upon advice from the nurses regardless of which nurse it might be.

“It was the nurse with all the information she gave me. She is...She’s just wonderful. Yeah, she was very helpful, very helpful, and I’m so glad that I took the time out to go and see her. She just told me so much more about it and so much literature she gave me, so it just really did help me”

One patient also noted that it was an important role of the nurse to explain what was happening to the patient whilst receiving treatment so that the patient felt they had some measure of control. She explained it as follows,

“The staff in the chemo room are very helpful. Because you’ve lost control over what’s going on it is at least important if you know what is going on. You feel like you can manage it better.”

Role of the General Practitioner

Some patients still sought out the GP who would be suitable for them. In assessing suitability, patients spoke to a doctor who would be supportive, frank regarding illness trajectory and prognosis and prepared to ‘go the extra mile;’ in terms of additional and lengthier appointments. This was in contrast to the perception from patients that specialists were “very busy” and were there specifically to provide medical advice and treatment regimens for patients.

Nonetheless, patient reliance on the GP was variable. It was usually dependant upon two factors. Firstly, the length of relationship and thus the degree of familiarity with the GP. Secondly, the ability and the willingness of the GP to be

involved in the management of the patient's condition outside of the hospital setting. Rural patients interviewed for this study were more likely to have a positive longer term relationship with their GP. One rural patient said,

"My GP is very supportive and I have had him for fourteen years. Yes, we are in a unique situation as we live in a country town so we have this country style which means that we get more than just the 'walk in and walk out'."

For some older patients there was a sense that the role of the GP had changed in recent years and that they were no longer able to provide the support which they may have given in previous years.

"I don't think that GPs are like they used to be. You know, they would come home and home visit and sit by your bedside."

Some patients were unfamiliar with their GP until they had been diagnosed with cancer. Not having a relationship already in place made it difficult for some to see how the GP could be involved in their care within the community setting. For some patients, the GP was regarded as important for reassurance in knowing that he or she was available should the patient need their support. One patient remarked,

"My GP was absolutely wonderful. He told me and told me that he was there any time for me. I haven't been back to him, because I have had lots of family and friends' support. I have been back to him once. But at the moment I am travelling OK, so"

Another patient felt that she was not getting the answers she needed in relation to her diagnosis from the specialists and sought advocate support from her GP. The GP was able to facilitate a speedier result for the patient and called the patient at home to explain the results to her.

Again, another patient reiterated the importance of a GP who is prepared to 'go the extra mile' for their patients. She particularly valued the fact that her GP was

always willing to 'fit me in' regardless of when she had called. However, she did also acknowledge that this often meant looking for the 'right person' in terms of the GP. Another patient felt similarly about the need to 'seek out' the right GP. This patient said,

"Since then I have done some canvassing with friends and I have now got a good GP. So I now have a GP whom I feel comfortable with...she went through my notes ... she went through them all. I said that these are my current concerns and health problems at the moment. I feel like I am working with her and not against her...which is what you want and it makes a difference."

One patient reiterated the importance of seeing a GP who maintains a positive attitude towards the patient. She said,

"I went to my GP, I've got a couple, both are in the one practice. A male who is great and I am on the same wavelength with him. The other lady doctor and she's been lovely but she's all doom and gloom. When I first went to her regarding something else she said 'Oh, chemo, you'll be so ill'. And I came away thinking 'oh, why don't I shoot myself now?'"

As with the patient just quoted above, not all patients had positive reports regarding GP input. One patient felt that her GP was apathetic about her situation and thus could not see the point in continuing to see him regarding managing of her illness. She explained,

"Well, you need to gain support initially, what between booking yourself in and having surgery. I went to the GP and he sat there and said, 'Oh, what are you here for?' So that's the last time I saw him."

Although most patients received the diagnosis from the GP they also felt that the GP was not really part of the process of receiving and digesting information.

“So when I first got the news from my GP. I felt that she didn’t really help. I mean she gave me the referral but she wasn’t really a part of the process.”

Patients who desired to take control were more likely to rely on the doctor for support and to help the patient maintain a positive attitude towards their illness.

Communication issues

Two aspects of good communication were extremely important to patients. One was the ability of the clinician to communicate relevant information to the patient. The second was the ability of the health care team and in particular clinicians to communicate with each other. Patients felt more positive about their treatment regimen when clinicians were perceived to be communicating effectively and in a timely way about the patient and that the illness was being managed appropriately by the health care team. One patient said that she felt secure that her ‘team’ (patients own word) were communicating. Other patients felt that time is often an issue for both specialists and GPs alike in relation to communication. This can cause issues between the GP and the specialist in terms of patient management and continuity of care. Another also said,

“What is worrying me most at the moment? I suppose the doctors haven’t sort of said anything definite between each of the doctors, I am not criticising any of them, but it is not gelling. I would like the whole thing discussed and that they should communicate better. You are feeling confused and they sort of set you straight and then you come away and then think well ok...it is hard when you are feeling that way.”

The Shared Care pilot project showed that patients feel more secure when they know that health care providers are communicating with each other as well as the patient. The findings from this set of interviews showed that it was also an important factor in making sure that they were “in good hands”. Patients soon became aware when clinicians were not communicating. One patient said that her GP did not even know that she was receiving treatment for breast cancer.

“They seem to be doing their own little unique part - I wish they would all communicate a bit better with each other. I ask the GP because my bones would ache and I know I will have arthritic changes with my treatment.”

Another patient could not confirm team work amongst doctors but felt sure that they were communicating due to their overall knowledge about how each was managing individual aspects of her cancer treatment. She said,

“I am not sure if they work in collusion or not. However, it meant that they were a team and that they worked together and were in consultation with each other. And they were communicating, they were varied specialists and they could give you the best advice.”

It was also important to one patient that the main specialist / oncologist was supportive and approved of the other doctors being involved in the patient’s treatment and in the management of the condition. One patient said that it was due to the specialist’s belief in her ongoing ability to manage her illness and be involved in the process that she kept herself motivated.

Clinicians were highly regarded who showed willingness for patients to seek second or other opinions. This was associated with need for clinicians to demonstrate their confidence in the patient’s ability to be involved in managing the illness with the aim of instilling a sense of control amongst patients. Furthermore, patients re-established their self confidence by being aware that the clinician was receptive them managing their own care collaboratively with medical / specialist care. As previously highlighted, patients also sought out clinicians who provided straightforward advice even if the advice or information was unpleasant.

“My breast specialist was up front from the day dot. We didn’t have to ask, he gave us literature to read and take home. I found that very helpful and I think he was very open to anything we wanted to talk about. He was forthcoming when we asked questions. Even though it is bad news you still want to know.”

This was also important when decisions were to be made about treatment and illness management. Patients respected the opinion of the clinician who considered how all aspects of the illness impact upon patients. For some women, it was also important to access doctors who are female. Patients sometimes perceived them to have greater empathy and sensitivity. One patient said about male doctors,

“I know I shouldn’t generalize but they don’t have the same communication skills and empathy.”

SEEKING NON-MEDICAL ADVICE

Valuing information from others with experience

One patient was also offered a contact number for someone to talk to who had been through the breast cancer experience herself. This approach was felt to be beneficial and relevant for patients who could then ask questions of someone more easily accessible than the medical professionals. Another patient has a nursing background and was familiar with cancer trajectory and treatments already. She said,

“You know chemotherapy is not new to me. I spent hours talking to patients about it.”

Other persons were able to provide personal information that patients could not otherwise access. This had a particular relevance to them in the early days following diagnosis. One patient went to see a friend who is also a health professional to gain information regarding breast reconstruction surgery. As she explains,

“I didn’t feel like going anywhere else like the organizations but I felt that I had someone that I could go to and discuss things. I had that and it was great. I was able to see her and she was open to discussion and to show me her surgery. That

was something that really helped me to make up my mind about the surgery and the reconstruction.”

Being able to discuss and even make light of the situation with peers is often vital for patients to move to the next stage of acceptance leading to empowerment. For some, there is an awareness that one has reached the stage of acceptance and that they are ready to talk to others about strategies to help them cope.

“I am actually just starting to go to those things now. I am actually ready to talk to women who have had it and then they could actually tell you that it was not as scary as it seems.”

Although breast cancer patients may be aware of losing hair and other visible side effects, many feel that seeing others in the same position helps them accept the situation and move onwards. This stage of acceptance was highlighted by one patient thus,

“Basically, all the women, you know they are in your position and you’re going to be like them further down the track. That was very helpful. I mean, just looking at the girls that have actually lost their hair and they come in with wigs and like there’s one little lass, she was younger than me, she sat next to me, and I mean, I thought it was her own hair, and she took her wig off, you could have knocked me off the chair, I mean, I didn’t want to stare but I was just so amazed at how different, you know, the wig just looks so real.”

Another patient also expressed the emotions which accompany the sense of regaining control thus,

“I didn’t want to know how bad it was, I wanted to know what strategies they had for making it easier or making it better or that sort of stuff. And that’s what I needed from people that have been through it and that sort of stuff.”

Balancing advice with the help of other survivors

Obtaining advice and support from others who had experienced cancer was important to patients in order for them to realise that one could go through the experience and survive. This gave patients a renewed sense of optimism and helped put everything into perspective.

"[Survivors] can say, "look it is terrible but you can come out the other side." To be able to talk to someone who has had surgery and looks well and is happy in life. You say, "I can look to the future and it is not a death sentence." I think that is a really important thing to do."

There are times when patient is able to choose to go against a doctor's advice when they feel supported by a friend / colleague who is a survivor. Another patient explained her experience,

"I was wondering which way to go because I was not comfortable about the Lapdorsy and having back muscles removed. It just seemed too much and too hard. It didn't seem right for me at the time but the plastic surgeon said that it is the industry standard at the time. It really didn't sit well with me."

Patients benefited from the experience of talking to individuals whose opinion they valued whether they were health professionals or significant others. Although perceived as overwhelming at times, it was believed that the information could be useful to them at some point.

"Having people contact you from all over the place to offer their stories and bits of advice. So it kind of comes at you from all directions and it is too much initially with the Internet as well. I guess I have sort of kept it at arms length and just keep what I see as appropriate at the time."

Balancing information from books and pamphlets was something that patients who had learned to adapt and accept were able to use more effectively. One patient said,

"I take each day as it comes. I don't expect problems. I don't read through the book and think 'I should get that, I should get that, and I should get that.'

Patients ultimately use the information they feel is relevant to make decisions about their future. For most this is an individual journey which takes into account family, friends and lifestyle within the context of the enormous amount of information that is available to breast cancer patients in particular.

"You are looking for something and although you don't want to unpick the past you want something that is going to be right for you. You have to take into account your husband, you and your lifestyle. So in that respect I was very lucky that I had this person who had opted for one treatment and not the other. The plastic surgeon had only touched on the differences very lightly."

Learning to seek out and assess the information that is useful is an integral part of regaining control and achieving a sense of empowerment for patients and their families.

Readiness to attend support groups

Early diagnosis of cancer and the unwillingness of the patient to accept it presents difficulties in seeking out support outside of immediate family. In relation to this, opinions varied regarding the usefulness of support groups. Most of those who expressed negativity were newly diagnosed patients who had not yet attended a group and were sceptical of the benefits. Furthermore, some were concerned that being reminded by others of the illness would create unnecessarily negative feelings and focus attention on the worrying aspects of the illness. This was even more difficult if the patient was not already experiencing side effects of others within the group at the time. Some women were fearful that attending a support group with other women would bring the realities of the illness home. One woman explained in thus,

"I didn't want to go to a support group...I didn't want to go there and face people that were sick because that was just too confronting for me....please don't take this the wrong way but I am not one of those women."

This patient also found the chemotherapy wards confronting for the same reason. This is a stage of denial which is common amongst those who have not reached acceptance stage of their illness. Another patient felt that the group interaction would be depressing and she preferred to keep company which would "uplift" her. To be with "normal people" as one put it.

"I have thought about it a lot. Maybe I should and maybe I shouldn't. I want to be uplifted. I don't want to go down that track. I want to be with normal people."

Although for some it was an aspect of denial for others it went outside of their personal preference to attend a group with others. For another patient who was further along the process of acceptance she attributed the lack of willingness to attend as something she would face in any similar situation. She said,

"I haven't gone to those support groups. I couldn't face them. I am an older mum and I'm not.... I was never one to go to playgroups or anything like that. I am fairly self sufficient. I have had a lot of flak about it but it was my choice and maybe it was wrong in some ways because if I had joined up I would have had a lot of support. But, maybe it would have worked the other way...I may not. I wasn't going to go anyhow."

Being aware of the reality of the situation could be discouraging for some. One patient said,

"You are confronted with your mortality possibly for the first time and you don't know how long you've got so you don't know if it is long term. It always sort of hangs over you like a large cloud all the time."

Resetting goals can sometimes be limiting for patients in terms of financial commitment. The costs of treatment offsets the ability to purchase anything which requires a long term commitment to payment. For example, a house or a new car is often too daunting a prospect for patients. For other patients, goals are scaled back to 'just get through the day' whilst coping with treatment and the illness in general. As one said,

"Just getting through the day is my goal at present."

GAUGING THE SUPPORT OF FAMILY AND FRIENDS

Relying on others for support

One patient maintained that her optimism was achieved through the support of significant others such as family and friends in her life. Patients learned to rely on significant others and to determine their own individual support needs. That is, to identify what it is that they need emotionally and physically from others.

"This [optimism] I believe to be a very prime factor. I have got a lot to live for and a lot of support. There is absolutely no reason why I should throw in the towel. I can't even think about the alternatives."

Another patient said that although she relied upon her own strength she also needed her family to support her.

"I rely on myself to sort of set my own goals and deciding what I'm going to do but then I need all my family and friends as well."

Relying on others also meant having a need for friends, family and often a health professional to 'encourage one to be positive' at certain times. Dependency on the ability of the family to support the patient could have a negative effect for some patients. For example, one patient felt that the capacity of the family to dwell on the negative aspects of the illness was harmful for her and something which impacted upon her sense of optimism whilst receiving treatment. One the

other hand, another patient felt that it was also up to her as a patient to maintain and to show others that she was optimistic in the face of her diagnosis and prognosis.

“And if you’re positive around other people, then they tend to think that’s the same thing and they don’t drag you down. “

For another patient, she noted the importance of showing her strength in supporting others and not appearing helpless or making them uncomfortable. She remarks,

“I see myself as setting the standards. I have talked a lot about it to friends and family. I have three sons. My younger son has said, “Good on you mum. You’re a little trooper!” That is a boy’s way of saying that they look up to me. But I think that it has to set the standard. When you say you are having chemotherapy they gasp...It isn’t pleasant but it is ok. So I defined that I am the one who has to go to them and say something which makes them relax.”

The same patient goes on to further explain that she finds reaching out to others and showing them that she has accepted the illness helps her also to better accept the situation and to have a sense of control over her illness. She said,

“I mean everybody sort of says to me, you know, I’ve coped really well but I think I’ve sort of been expected to.”

Relying on family support – changing family dynamics

The cancer journey implies that roles amongst family members and close friends will change as priorities change. In the early weeks as treatment gets underway there are a certain number of adjustments to be made in accepting and adapting to the illness. Once the cancer diagnosis is received, family dynamics change as does the patient’s ability to maintain their perceived usefulness and contribution to the family. The following are key themes arising from the concept of family support both from the patient’s perspective but also from the family’s point of

view as perceived by the patient. Patients indicated that there was an unspoken acceptance amongst family members that each had a role to play in supporting the patient. The early priority of defining and establishing that role was discussed in most of the interviews. Patients with younger children felt that they wanted children to help maintain a sense of normalcy through 'just being themselves'. For spouses and partners it was a supporting role which primarily gave the patient space to find personal strength in coming to terms with the illness. Patients usually resented being "smothered" by a partner or spouse. In regard to other family members such as mothers and mother-in-laws, a more supportive role in practical ways was valued such as looking after children, preparing meals and looking after the family whilst the patient was unable to do this themselves. Each family member went through a period of weighing up just where they fitted in, in terms of providing support to the patient.

Spousal adjustment

The diagnosis and treatment of cancer had created many insecurities for some spouses and partners. There were identified difficulties in coping with the fact that a partner had become ill and some expressed anger and anxiety for the future. For some spouses it was difficult to know how to help and many had a sense that they were unable to "fix things" as they had before. One patient said,

"It probably has changed a little bit. I have always had a very caring family, and it is probably very hard on my husband to accept and know what to do, what to say and when to do it."

Knowing when to take time to relax and recover and acknowledge moments of tiredness was very important to patients with the ability to read the signals from their bodies. This often also acknowledges and welcomes the help of others in being able to "take a back seat". One patient said,

"I would say receive a lot of strength from my family and my husband and my Mum. Yes, she stayed with me for two months when I did my first three chemos and now my husband takes time off during the chemo weeks so that I can rest and

he helps for me, and cook for me, he is good. He'll cook and he'll do everything so that I can just relax. "

Patients viewed the strength drawn from a caring partner as invaluable in terms of providing support. One patient said that the support of her husband who was 'understanding, insightful and sensitive' had helped her cope. Another felt that seeing her partner cope had also helped her cope too. One patient valued the closeness that the illness had brought between her and her partner. She remarked,

"My husband and I were close and we are even closer now. He is just there and has been amazing and has been there all the way."

For some patients the illness had meant that they openly discussed topics in a positive way which they had not discussed before. This was brought about by a new found awareness of the relationship in the face of a life threatening illness.

Changing and strengthening relationships

Sometimes, the diagnosis could improve relations between family members in bringing them close together during the upheaval. One patient found that the illness has brought her and an estranged brother closer again and that he had provided her with unforeseen strength whilst coping with her treatment. As she said,

"It was as if the door had been flung open and he wanted to come back into the fold."

Impact on children

The impact of cancer and having to examine relationships in the face of life limiting illness had actually improved relationships and brought family members closer. Children who were old enough to understand the impact of cancer on the

patient were most often deeply affected by the impact of the illness on their mother.

"I have got two boys and a girl. If I have a tearful moment or day they understand."

Another also commented,

"Although having said that my son he has hardly gone out. He is very soft hearted. They [children] have been really good."

For some patients the illness had enabled other members in the family to learn to nurture. Whereas previously the patient had been the nurturer with spouse and children this role had since changed and the nurturing was now shared between family members. One patient said that the illness and greater amount of time spent with children had helped her understand "what makes them tick" for each child and this had helped her 'manoeuvre' her way around relationships with them. For another, she felt that the experience had made her more aware of herself and others around her. It is all part of what is important and what is not. One patient said,

"I used to get uptight about my daughter and tidying her room, you know. So now if she doesn't do it, so what?"

However, younger children are unaware of the impact apart from physical and palpable symptoms and this was a comfort to many patients. It is a part of retaining normalcy and as two patients put it,

"But I suppose that just the main physical thing that they tell you is the [losing of] hair. So other than that, and they see me sitting around a bit more..."

"As for my family they are still as normal. My kids - they haven't really changed. I think everything has pretty much stayed the same."

It was also noted that even the more difficult aspects of family relationships were welcomed as part of maintaining that sense of normalcy.

“You know, now, we’ve sort of, you know when things go back to normal when you start arguing and we start yelling at the children [laughs]!”

One patient spoke of her teenage children thus,

“But then otherwise my kids have been wonderful you know. And fortunately they are at the age they are because teenagers are a little bit selfish. In a way I am hoping that being like that is helping them not worrying about this too much.”

For another patient the illness had created awareness amongst the family of how important relationships were with each other. Another explained it thus,

“Yes, the kids, I think, just don’t sort of get it. Yes, yes, it is good, you don’t want them being worried. They are completely unaware. Sometimes you wish they’d be quiet. Other than the fact that they face an adjustment for all of us, they sort of look at me in the face as mum which is all very good.”

Older children were also able to offer support to the patient and to “come up with positive suggestions whenever spoken to”. Good family relationships with teenage siblings also mean that they were more aware of the importance of learning to nurture. One patient said,

“Certainly I have noticed that I have two teenage daughters and they are at the stage where they didn’t care all that much. It is very much ships in the night but after the diagnosis they are just so close they spend time together and they go off shopping together. It has really had a huge impact on them as well.”

Even when older children were not located in Perth it was important to both themselves and the patient that they maintained contact at significant points in the patient's treatment phase in particular.

"My family all live in Melbourne and Sydney but they stay in touch all the time so, you know, they sort of make sure one's around at some time or when I've had my operations and that sort of thing."

Support from parents

A family's lack of or inability to provide support was sometimes difficult for patients to accept. One patient said that the fact that her ageing mother was unable to cope with her diagnosis of cancer made it difficult as she wished she could share her thoughts and feelings but felt that this would not be welcomed. Other parents were unable to talk to the patient but still provided support in ways that they were most comfortable with and often reverted back to childhood nurturing years. For example, one patient said that her mother kept cooking for her beyond her needs as a way of showing that she was offering support.

"My mother's way of worrying and coping is cooking. Yeah, she'll cook, you know, she'll cook and cook and cook and cook. Yeah, and that's her way of showing her love and concern and everything. It's really hard not to judge because you know, how would I react if that was the other way around?"

Support from friends

Support from family and support from friends was a concept that differed greatly over the course of the illness trajectory. Whereas most family members felt the necessity to adjust and provide support to the patient this was not always the case with friends. One patient explained it thus,

"You find out who your staunchest supporters are and who are the ones who will back away. You are aware of all that and a couple of people who know and would not make any contact at all. You take that on board and you think "Oh,

well...that's their issue and that's their problem in dealing with this." But it is real sorting out process."

Most patients acknowledged the support of friends whilst taking into account that the relationship and types of support were somewhat different from that of family. As one patient explained,

"I think that family will come first. I rely on my friends in practical ways you know, if it is a lift or shopping...even just to talk over things."

For patients who did not have close family however, the support of friends became more crucial. One patient said that she regarded her friends as 'her family' and that they had increased their support of her during her illness at times when they were most needed. Another patient explained that her friends were people she 'felt safe with'. Nonetheless, the support of family was seen as more important for those who had family and this was due to the fact that most patients felt that they could be themselves with family regardless of their mood.

"Family is the one that is there for me and my Mum, when she came down here. With family, you know, they see you in all situations and are there to help."

Another patient reiterated this by saying that she tended to let her family know more about her health and her concerns than friends. As she puts it,

"I tend to do more of the blustering thing with my friends."

Usually help from friends was of a more practical nature and they were relied upon by patients to provide practical support as a mean of showing that they cared for the person without being intrusive. One patient explained it thus,

"Anything from a phone call to a gift to a casserole....you have friends ringing on the doorbell who say, you know, I want to give you a hug...and just continuing to walk on their way. It can be anything. You know, I have even had somebody (I don't know who it is) sending me cards on a regular basis anonymously."

Others had friends who would come and do the dishes regularly or the gardening. Other patients sought company from friends and would go for walks or have coffees with friends to spend time with them. Over time the support lessened but was still there from close friends. One patient said that she was initially “inundated with food from friends” but that this had slowed down to one couple who still provided regular meals. For other patients it was important to be listened to however in terms of types of support that they wanted. One patient noted that some friends were just not good at listening to what the patient needed. Another had the opposite difficulty in actually asking for help and that good friends would pre-empt this difficulty and offer assistance anyway.

Many patients were astute at working out which friends would provide support throughout the illness regardless of the patient’s state of mind and what stage their illness was at. One patient, in the early stage of her illness was experiencing the phase of constant attention from concerned others and said,

“Oh, wonderful support. Have had constant phone calls! I don’t return the call and they understand it if I don’t ring back and I’ll come home and there’ll be so many calls on the ‘phone it’s not funny.”

Rural communities

Rural patients were more likely to speak of community support rather than the support of a few close friends. Patients regarded the entire community as a circle of friends and relied heavily upon their support in the early days and when receiving chemotherapy treatment. One patient said,

“So we have had tremendous support from the community as well. We are in K_____ up. I have often wondered about how this would have been for me if I had been in Perth and I don’t know. I spent my childhood in Perth, and the rest of my time down here so I just don’t know whether you have that same network or not, I don’t know.”

Another rural patient spoke of the gratitude towards the community and said that this motivated her to recover so that she might repay the community when it was needed.

“You spoke about goals before, I think what this has made me more conscious of is my contribution to the community as well and how to return the millions of favours that people have done for us and we’ve had some friends come and work in the sheep yards. When we were in Perth for my treatment there was a time there were people coming in to do our work for us, it’s almost overwhelming, in a way. I’ve tried to remember what it’s like and how important it’s been to me to have that, so hopefully I’ll be a better person for it.”

Often rural communities would show support even though they did not know the patient or their family well. One patient said that she had received cards from those who were not close friends but who wanted to show their support anyhow. Another patient also highlighted the support of close friends which was balanced with the awareness of not intruding on the patient’s need for privacy in dealing with the illness.

“No, really it is just close friends and they are good because they might phone and although one might come around, they will say, “I am not staying but here’s a meal...” That is lovely because it is not intrusive.”

Yet another patient spoke of the support in the workplace in helping her maintain her independence. During treatment times it was accepted that she would not be at work for a few days whilst recovering her equilibrium.

Using complementary therapies

Most patients were aware of the benefit in using complementary therapies whilst receiving chemotherapy treatment with only a few expressing negative opinions about such therapies. The most often practiced therapy was meditation and even those who had not tried to meditate before were willing to try it when they became ill. Some spoke of the sense of peace and relaxation that they

experienced in practicing meditation. Many saw the extra time spent at home as an opportunity to try things they had never tried before.

Patients who were unwilling to try complementary therapies had often had negative influences or experiences previously. However, there was some confusion between complementary therapies and alternative therapies for some patients. One patient explained,

“I’m scared to do complementary therapy because my mother is Chinese and she’s absolutely dying to fill me up with all herbal potions, and I stopped her in her tracks and said to her ‘you know Mum, Dr ___ is a Chinese woman and she said I can’t take any of this herbal stuff.’ And because Dr ___ is Chinese, my Mum can’t argue with that. Because she’s a woman, Mum can’t argue, If she was a man she would say, “He’s a man, he doesn’t understand!” We know completely how to handle it, so we have a good laugh about it.”

Not all patients relied on or had faith in herbal remedies. Another patient spoke of their mistrust thus,

“You know, well-meaning friends say ‘have you heard about apricot kernels?’ I’ve heard everything from apricot kernels to cranberry juice. I said to my friend, I said ‘if the multi-million vitamin company and they are multi-million dollar companies ...if they firmly believe in the treatment, why haven’t they put it out there? Why haven’t they put their money where their mouth is?’ Make it available and make it acceptable like a tablet, like a drug, against all the other anti-hormonal treatments or whatever. You know, why don’t they do that? “

Another patient also spoke of her mistrust and termed it ‘preying on the vulnerable’ and patients accepting the cost because they were ‘forever hopeful of finding a cure’. Others were less vehement but still sceptical of many of the claims of complementary therapies.

Nonetheless, a number of complementary therapies were valued by a great many patients. One patient said that she valued the support of her acupuncturist and

although she spent a great deal of time there that she was never charged the full fee for the visit. She said,

“My acupuncturist. She spends probably an hour or more on me and that is a long time. She does her needles and she massages the bits that are sore and she cares about me.”

Some patients valued massage therapy and also noted that it provide them with a designated time to relax and remain still. One patient said that she regarded her massage therapist as a support person whom she could rely on. Another said that despite the fact that she valued the relaxing nature of a massage, it did not help her resolve her anxieties and that she needed other avenues to do so. One also added her naturopath as a support person.

Medical professional approval

Some patients also noted that they were aware that medical professionals sometimes did not approve of complementary therapies and this often precluded them from using complementary therapies and medicines more often. One patient said,

“What I also found was my particular doctor wasn’t interested in doing supplements, so they weren’t supportive of that.”

Thus, making a decision to continue to use them was a means of asserting control over the management of their condition for some patients. One said,

“So yes, I have been to the vitamins and the alternative things and I know some doctors don’t like it but it’s working for me and I’m doing it That was probably what my husband found hard to accept. You know, ‘why aren’t you doing things their [doctors] way?’”

Another patient reiterated this by noting that she was aware the some doctors had a 'very blinkered view of things' and that she was going to use the therapies anyway.

Other medical professionals however were more supportive and often patients needed this affirmation from doctors that they could make some of their own choices regarding managing some of the more unpleasant side effects of their condition in this way.

However, for some patients the cost factor of complementary therapies were a barrier to their use and furthermore the confusing array of therapies was a deterrent to some patients.

"It's very confusing. The more you read the more confused you get."

One patient said that it was important for doctors to be aware of the therapies and medicines that the patient was accessing in case they had negative side effects or interfered with treatments.

Timing for use of therapies

Patients who were newly diagnosed were unlikely to rely on the use of complementary therapies to manage their symptoms until they had re-established some equilibrium and sense of control. One patient said of massage therapy,

"I said to my husband 'I'm just going to wait until everything's finished and I'm on this sort of track, you know, this right treatment, and then when I'm feeling well enough and I've got the time, I'll go and do it. But I'll do it slowly and my own pace."

For others the time needed to access therapies on top of treatments and other commitments meant that it was too difficult. Also, rural patients noted that there were neither the facilities nor the time to travel and have a massage or other complementary therapy of similar nature.

"I would have done it but you know, being isolated up here, we don't have a lot of that available and because I work in town and my girls are going to school, I didn't really have the opportunity to do that."

THE ROLE OF SPIRITUAL BELIEFS

Return to spiritual beliefs

Some patients noted that although they no longer practiced their religious beliefs that the onset of the illness had meant that they sought solace in spirituality once more. Patients began to practise religious beliefs again such as prayer and attending a church or other place of worship.

"I was brought up Catholic and let it lapse. But the first thing that I have started doing is praying. It has possibly helped me a bit...if we get something from that well, why not?"

For others, the support of a religious or spiritual community was vital in maintaining their inner strength. One patient felt supported by others who were praying for her through her church although she did not know them personally.

Balancing religion with other values

One patient acknowledged the importance of religious or spiritual beliefs but also added that one had to have "faith in oneself" first.

"I do have my belief but I also have a very strong belief in myself. I would put that before religion."

Furthermore, patients who acknowledged the uncertainty about their prospects of recovery expressed calm and accepting feelings about their futures. One patient saw this as 'letting God take care of you' and said that she found this belief 'quite comforting'. Other patients took it a stage further to a heightened

awareness of the spiritual in all other beings. One patient spoke of the sense of the 'eternal' that she was aware of in all beings. She explained it thus,

"It's huge. I do believe that we are spiritual beings but I am not as dogmatic about any particular religion but I certainly believe. I have a feeling that we're eternal and that there's a consciousness in us. I think that there are forces out there that are helping me along."

Another patient spoke of the sense of 'someone or something looking out for me' since she had been ill. For some patients they had discovered 'other ways' of connecting with the spiritual. One patient described how she loved gardening and that this was her way of connecting with God. She also expanded upon this,

"You see gardening is very important to me and we have a house on a hill and we look out over the sea. I think that "there is God". It is not in the church but out there. I think that's spring is starting and all the little gardens come alive. To me that is God and that is a miracle...Also the goodness of people that is part of it. People who are so nice and kind. That is just my idea."

Learning to balance new found spiritual beliefs with religion was common amongst those who spoke of religion in relation to their cancer. Some patients highlighted the fact that they had become increasingly aware of the 'possibilities' in regard to spiritual help and guidance, as one patient put it. Another explained,

"I guess that I have got an increased awareness of what possibilities there are. I am just thinking more deeply about things you know life death, etc. What else there is and why we are here. What is this all about and so on."

One patient said that she believed it was 'more than coincidence' that a girlfriend had given her a book which related directly to her situation and had truly helped her understand herself at the time. Another noted that she felt comforted by her sister's Reiki practices even though she has been sceptical originally.

"It really makes you feel good, it makes you feel really tingly inside and warm and because I am having a bit of a breast pain after I got this tissue expander in at the moment and she did that [Reiki] on it and it was amazing, sort of like it just felt like all these tingly sensations going through. It is, it's sort of ... onto that way of believing."

Other patients regarded their heightened awareness of the spiritual in a broader sense than religion. One patient explained it thus,

"Spirituality I suppose comes into it. You are going through some profound changes in your life. You tend to go with the flow of life. I think that what I am learning is that I am taking an enormous amount of pressure off in life. You know, when your body can't clean to house, then it can't clean the house. I guess in the spiritual sense it is learning to get in touch with my body and letting that get into my life as in priorities."

Two other patients also spoke of renewed receptivity. One commented,

"I guess I am not a strong 'mainstream religious believer', as it were. So I am not with an established church or whatever. But, I am questioning more my spirituality and I am being more open to possibilities. I am just very receptive and open probably more so than before."

5.3.3 Stage Three – Coping with hurdles and setbacks

Stage three is arrived at after a period of treatment has transpired and can occur when patients feel that they have begun to manage and control aspects of their illness when the first setback occurs. This is a period where difficulties are manifest and the patient relies on themselves and others to work through hurdles and regain equilibrium. This stage is characterised by the realisation that temporary hurdles and setbacks will occur and is important to recognise their transient nature and overcome these in order to regain control.

CHANGES IN RELATIONSHIPS

Keeping up an appearance

Patients found that maintaining a sense of normalcy in relation to every day life was important to maintaining positivity. Although this was easier with family and friends, many found the reactions of strangers difficult to cope with. It heightened the awareness of the cancer and their 'different-ness' in terms of the illness. One patient said that she was hugely resentful of the attitudes of strangers to her illness. She noted,

"It makes my hackles rise a bit when you're walking around in the shops and people look at you when you're wearing a hat."

In terms of maintaining an appearance of coping, most patients felt that others who recognized them as 'strong' before their illness would expect that they would remain so. This could be disadvantageous initially for those who had been perceived as the main strength for the family but nonetheless something that they ultimately came to appreciate. Some patients with families also perceived themselves as "the fixer" (as one patient puts it) and that this assessment was necessary to retain normalcy throughout the illness. One said,

"My husband has always classed me as a strong person. I have never really thought about it in that way. I just deal with things I suppose."

However there were others for whom, "putting on a bluff" helped them maintain a brave face in the face of the illness. She noted,

"And it's quite surprising what you can find, I suppose, and some of it's bluff as well, you sort of tend to put on a brave face for other people but it kind of helps keep you bolstered that, you know, you've got this image that you've got to follow it through."

Some patients who have always taken on the role of family 'fixer' and support needed to be made aware that they should slow down to allow their bodies to adjust to the treatments. Furthermore, that they would not be able to 'take everything on' and carry on as normal. One patient said that it was her sister who reminded her to slow down and learn to adapt.

"She said, "I don't know how you are doing it with those young kids". And I thought, "Gee, I suppose it is a bit tough". The more I thought about it, the more I thought, "You know it's hugely tough...""

Another patient did not view the appearance of strength in an entirely positive light and wanted others to be aware of her changed health status. This patient also noted that if she were not looking sick physically to family members then they did not realize how worried and anxious she still was. She explained,

"It's that bizarre sort of situation where you have to put on a well, healthy, coping-well-type front when the family comes over and it's to reassure them that you are actually not that bad, or that you're not dying yet. She [mother] sees me running around after the children, doing things for them, and you know, she says 'oh well, she's all right she can still do all that, she must be OK.' And I'm not sick enough for her."

To compound this problem, some patients also spoke of a sense of guilt which was difficult to handle in terms of the family having to cope with a mother / spouse who was no longer well. One patient said that she felt "guilty in bringing the sadness into the family" and she added that "I want them to be normal instead of worrying about me". Another patient tried hard to show that she was coping in front of family and especially children so that it would be "easier for people around me".

Overprotective family

At the other end of the spectrum, some patients found it difficult to cope with a family members and partners who had become overprotective. Two patients

noted that husbands had become much more caring towards them through the illness and although the attention was welcome, some patients felt guilty that the partner was finding it hard to cope.

"I'd say it's harder on him because I think if you're lying down feeling sick all the time, you know, they understand more. But they don't like you to think that you can do things. He is very supportive but...he is finding it hard to accept."

For one of these patients, a recurrence had rendered her husband much more insecure regarding their future. She noted,

"He really has fallen apart the second time."

One patient said that she was unhappy with the fact that her husband was 'hanging around all the time' and that this reminded her that she was at present unable to reciprocate and re-establish her need to feel useful. Another patient said,

"It hasn't changed me but it has probably changed my husband. He is probably more hanging around and more worrying about leaving me alone. He was going to Perth for business at the moment and he wanted me to come with him. I thought..."well, I am capable of looking after myself."

Further to this, another patient added,

"Anything that happens, you know, anything small that happens to me now, it's sort of like, all panicking, you know?"

This can place additional strain on patients as they try to bolster others as well as trying to cope with their own emotions. Patients also acknowledged the great deal of pressure on children that the illness had caused. It was sometimes difficult for smaller children to understand and adapt to circumstances and limitations of the illness.

“She [daughter] asks, “Can you put my hair in a ponytail?” Some mornings after chemo to lift my hands up, I could cry just with the tiredness, the pain. But I think that these poor little kids, we sent them on a holiday on the last chemo just to take the pressure off. My husband who knows how I feel, I think that it’s a huge thing, the whole family went through chemo.”

Setting boundaries with the family

Clearly, for many patients the diagnosis and treatment of cancer brought about a change in relationships with family and thus a re-establishing of boundaries and limits. The establishment of limits for patients was necessary following an extreme phase of over-nurturing by family members as a means of demonstrating their concern for the patient. For some patients, this could be stifling and negated the ability to maintain a sense of normalcy which so many need. For one patient it was difficult to make a spouse aware that she was ill at times when she was not visibly ill but was still lacking in energy and unable to maintain the normal pace of life. One patient said that she found it tiring to be constantly cheerful and for this reason would tend to “hold people at arms length” because she needed space,

“I know I don’t really like it but I do need to have a little bit of space around me.”

Another patient echoed this sentiment and said,

“I do welcome people and so on. But I do notice that I do have a bit of a space.”

However, for others the attempt to maintain hope could be difficult and one patient said that her husband had found it ‘hard to accept’ and was relying on statistics to keep hope alive. For another the fact that she had been diagnosed for a second time was more difficult than the first time in terms of maintain a positive attitude.

Setting boundaries with friends

For some patients the initial support of friends could be overpowering and not always welcome. Some patients felt that they were rendered helpless with overwhelming support of friends and were determined to remain in control and useful. One patient said,

“Sometimes they try to do too much instead of letting me drive myself to chemo and things like that. You know, I can do that and everybody is panicking and I’m saying, ‘No, I can do it.’ and I then drive home. People have got to let me do things that I want to do.”

Other patients were uncertain of the intentions of acquaintances and believed that some were being ‘nosey’ in overly involving themselves in the patient’s life. Most patients preferred the company of closer friends who were supportive without being overbearing. This was also true in terms of providing emotional support from friends,

“There are just some [friends] who are different who just have the depth or the understanding who know where you are at and who know how to help you.”

One patient spoke negatively of her friend’s perceived ‘fussing’ and referred to her relationship with this particular friend as ‘being treated like a ‘pet project’’. Setting boundaries with friends was important to patients in order to retain a measure of control. This patient continued,

“She made it out like that one day and I put her back in her box. I told her,” It is my situation and I will deal with it.” That is the thing we were talking about earlier and it is about setting boundaries.”

Another patient termed it ‘sorting out your real friends’. Friends who were not supportive were acknowledged by the patient as those who have not come to

accept the illness and were still uncomfortable around the patient. One patient said,

“There are just some friends who don’t know how. Just because of their own life experiences or whatever. They feel a little bit helpless or whatever. Feel a little bit uncomfortable or whatever about ringing. Even bumping into you when you are out. And that is just the way they are.”

However, this is part of the acceptance process for patients as well. As one noted, it sorts out who remained the most reliable and supportive friends. Patients liked to stay in control regarding the type of support and the degree of support that was being offered. One example was a patient who said,

“I’ve got a girlfriend... And just being there, you know, phoning me all the time and I don’t know, just being really good friends.”

Decline in support as treatment progresses

However, beyond the initial few weeks the support is provided by a few core friends. This phase is another period of adjustment for many patients. One patient spoke of this phase beyond the initial intensity of support as “being abandoned”. However, there were the friends that patients continually relied on more than others. One patient said,

“I guess I don’t rely on it...but I have been staggered by the consistency of the support over a period of time and that it really highlights the old saying, “It sorts out your friends.”

For others, the support of friends was seen to dwindle over the months. Many acknowledge that this is part of the process of recovery and of others “getting on with their own lives”.

“And they start to dwindle down. And there’s not a lot of them left to see the whole thing through with you right to the end.”

Some patients found this difficult to accept and adjust to. For others, when the initial overwhelming support from everyone dwindled it was hard to readjust. One said,

"I mean, flowers, you know, to the hospital, I could easily have run the florist's shop. Everyone was very sincere with their concern and worry but it's funny how as time gets on, it sort of dwindles. I was thinking 'OK, chemo's nearly finishing, what happens to me now?'"

Patients would also worry about being left to cope without the medical team involved in their treatment once they had almost finished their cycle of chemotherapy. One said,

"I went back to my GP and because I was worried, I said 'what happens to me now? Am I left on my own? Who's going to look after me and what's happening?'"

Insecurities such as those mentioned above were common amongst patients once chemotherapy was well underway or almost completed. Some patients would mention jokingly that support had waned. However, for others it was a source of anxiety and loneliness as the degree of support diminished. Later on into the treatment and towards remission, patients found that they went through another period of adjustment as the threat of the illness subsided. This was characterised by many as a return to normal life which often saw family members reverting back to their usual behaviours and the realisation from the patient that they and their illness were no longer the focal point. One patient put it thus,

"So my role had to change. You become the centre of the universe for a little while, don't you?"

Yet another said that this was not an altogether 'pleasing' experience for her.

“That’s what I say to my husband, how are you going to get back because I am so spoilt now, you know? Because I get my meals get cooked for me and that.”

For another it was the realisation that family members are not ‘perfect’ and that relationships are not always trouble-free.

“And I get on better with my Mum. I’m not so guarded with her and with my ... I’ve got three other sisters. I think now we get on better. But whether that will stay for the next five years or ten years, I don’t know. Things usually as with normally families go along and slowly revert to the way it was before.”

LOCATION AND DISADVANTAGE

Rural perspective

Rural location of patient sometimes increased difficulties in access to timely advice from health professionals. In fact one patient also felt that being a public patient rather than a private one was preferable as there were more systems in place for rural public patients. She noted,

“But I think that being rural you do miss out on a bit... Their [public rural patients] referrals are different and their support group is different too. I found that a lady from K_ which is the next town on, she got opportunities to go to Narrogin and she knows of a breast cancer nurse there that rings her up to find out how she is going. I don’t have that.”

Another rural patient also reinforced the necessity for medical professionals to weigh up beyond providing medical advice and to look at the person’s circumstances in terms of what is feasible. If rural patients cannot access the services advised by the doctor then this can create further anxiety.

“I often thought that they are quick to say ‘go see a counsellor’ but for example, it’s not that easy for me to go and see a counsellor in Perth when I live in Kojonup. It wasn’t a really practical solution. I think that perhaps doctors should make more of an effort to not just give you the medical advice.”

Acknowledging the boundaries to self reliance

Patients who spoke optimistically about their ability to manage the side effects of their illness were much more open in acknowledging the help of others. Most were also aware of their limitations and welcomed the help of friends. One patient said,

“The cancer has been a very enlightening experience. We love to get home and it is better to be in your own home. I have some soup that someone has left and bread. I need it. “

Other patients acknowledge the support of significant others so that they can use all their energies in recovery and “not letting the illness beat me”. However, this was tempered with an awareness that the person had to take control of their own recovery as well as relying on others. One patient spoke of the strategies she used as such,

“I found the best thing for me has been walking every day, sometimes with someone, sometimes by myself, and yoga and meditation. And that has been, I think, it helps me as one of the major coping things is that if I’m feeling a bit uptight or whatever but it helps me get to sleep.”

Some patients although acknowledging the work of others in terms of raising funds and providing support to cancer patients felt that she was “not quite there yet’ in terms of helping with fund raising and similar events. This patient noted that it ‘brought it home to her in a way that she was not yet ready for’.

ASKING 'DIFFICULT' QUESTIONS

Facing mortality

One major question which patients found most difficult to ask was the question around prognosis and survival. One patient spoke of her reluctance to ask the most pressing question thus,

“Yes, I can ask things but the only thing I didn’t ask the surgeon was, “How long have I got to live?” But thinking of that, I went to RPH first and the doctor said there that cancer is not death sentence. That was very positive for me. It is all part of survivorship.”

For breast cancer patients, appearance was also a concern, particularly, for younger patients. One main worry for some was losing their hair during chemotherapy treatment. The ability to ask questions and seek advice regarding appearance alongside how best to manage those physical changes was immensely important in maintaining positivity. Being afraid to ask questions, as the patient quote below demonstrates, indicates that the person may not have fully accepted the illness and are still feeling not entirely in control of managing the illness.

“I don’t know too whether this headache business is normal and I don’t know who to ask. Part of me is just a little bit scared to ask the questions. I want to know if it is a good answer but if it is a little bit bad I don’t want to know!”

Patients spoke of the importance of health professionals being frank and then allowing the patient time to organize the necessary requirements such as wigs and booking classes to manage make up to improve one’s appearance. Although challenging to deal with, patients preferred an honest and straightforward approach from doctors,

“One other little thing was that when the doctor said, “You will lose your hair” and she was very matter of fact. Then I started thinking well, my mother didn’t but that was different because she had different cancer.”

Health professionals who were unwilling to provide forthright information to patients were perceived as less supportive and more difficult to collaborate with than those who were frank about prognoses, conflicting medical advice and any difficulties along the way. This patient said,

“The other thing is also about the CT scan. There has been some controversy about them. I feel that I have to do it but it is good to ask. I was being positive and I was going to take everything but then you get a scare about how it causes cancer. The doctor said, “Well, I haven’t seen that but I have heard about it”. You go to them for help but then they don’t get back although Dr ___ did ring me.”

However, despite facing their mortality often for the first time, patients were aware from the early stages of treatment that it was necessary to avoid others expressing negativity. One patient did not see the need to frighten herself by asking others about their bad experiences which may or may not happen to her. Another said that the fear expressed by significant others could make the patient’s acceptance of their diagnosis very difficult.

Age of patient also impacted upon sharing experiences with others. Two younger patients said that they found it difficult to attend groups and treatments with a majority of women who were older than them.

“I was noticeably the youngest one there and the other women were a lot older. I think it doesn’t help when they are all so much older because it’s not relevant to my situation.”

Another younger patient said that she found it ‘disappointing’ that she was not able to ‘touch base’ with someone her own age.

Receiving conflicting advice

However, one problem which should be highlighted is the difficulty in managing patients with complex care needs and cancer. One patient found it distressing that she was also diabetic and that although one specialist had prescribed treatment

that this was problematic when also mapping out a treatment regimen for cancer. She felt that the specialists did not seem able to communicate to each other and agree upon the best treatment regimen for her.

“The biggest thing I find is each specialist is really only concerned with their specialty. When you’ve got more than one medical condition ... I unfortunately have diabetes insipidus. I’ve got diabetes mellitus as well but having the three conditions and trying to balance ... that was what really came to a head. After the second chemo I was trying to balance all three conditions. The chemo demands you drink more. The diabetes insipidus treatment says you can’t. So I just ... I do feel at times that I’m the only person who’s balancing three conditions.”

As mentioned previously, patients needed to feel that clinicians were communicating with them and keeping them informed. It was important for them to feel ‘included’ in the process of treating and managing their illness. Absence of this was extremely disempowering. One patient complained that the clinician / breast surgeon had a very poor ‘bedside manner’. Although trying to reason with this behaviour, the patient still felt largely excluded from the management of the illness. She also felt that the surgeon and other doctors were not really concerned with her as a person. This made seeking advice problematic.

“My breast surgeon and the health professionals had a very poor bedside manner. He is a medical professional I suppose by the nature of what he does every day you know, cuts women open and cancerous tissue and you think, “Heck, what a job!”. But I think that his bedside manner was very clinical. And as a result of that at times I felt outside of the loop. I knew that I needed to approach him but that he was not terribly approachable.”

One other patient reiterated the absence of dialogue and time spent in preparing the patient and family for what lies ahead. One patient termed this as the ‘roll in, roll out basis’ on which doctors see their patients when they don’t have time to spend. Furthermore, there are often difficulties with language and explaining treatments to patients in a language they can follow as lay persons.

“So I was hit with ‘well, there’s a new drug out and this will lower your chances of recurrence. And I thought now hang on... maybe I’ve got to be hit between the eyes with information to absorb but I don’t know. I’ve often said to A_____ that because I am just a lay person, I’m not an academic. I found a lot of the information is above my head. The specialist is friendly, but it’s information that I can’t understand and I would say to her, I haven’t got a clue what you are talking about.”

Two patients with a medical backgrounds found communication much easier with her doctors due to the fact that they were aware of her background and communicated more effectively.

One patient described her difficulties in finding the “right GP”.

“I have a pretty good relationship with my current GP. But you see he didn’t even know about my treatment. I would love to just be able to talk to somebody because I am really scared. And I haven’t found that person yet. Your fears are not always scheduled and you could be feeling at your worst at night but you feel that you shouldn’t bother anybody.”

Further to this, there are times when the patient is aware that there are changes to their body. It is important that clinicians consider that the patient is usually extremely aware of what is happening to their body and when they seek advice that this is usually from genuine concern. One patient explained her experience in sensing a new lump under her arm which she could not seem to convey to the clinicians.

“I went back to the surgeon and said, “Look please ease my mind and just re-examine me and tell me if you think that any changes have occurred”. He did a quick sort of physical and in a very dismissive sort of way. “I have drawn a picture of the size of the lump. I have got it in my file and it hasn’t changed.” That is pretty much what he said. It was all that he offered. I didn’t feel too good about that. I felt quite angry actually at the time. That was the experience that I had and I can

honestly say, it wasn't pleasant but all I could do was say, "Alright, I have to sit it out.""

COPING WITH THE "BAD DAYS"

Transcience

All patients who spoke of the ability to control aspects of their illness were aware that 'bad days' occurred. What was evident amongst those who were learning to regain control and manage their illness was the awareness that such days were transient. Empowered patients were able to surrender on certain difficult days and accept that such days would happen and that they would ultimately be able to move forward again. Release of emotions was commonplace and patients said that part of coping was 'having a good cry and then I can get on' and 'having a little talk to feel so much better'. One patient also said,

"I usually get grumpy and stroppy and then I have a good cry."

And another younger patient said,

"Lots of times I think it's just hard at my age. I think that I do have bad days and then I do go into a 'oh poor me' for a little while."

All patients had mechanisms for coping with such days. Another aspect of 'bad days' was the sense of 'why me' and a degree of self pity. Others wanted to be 'left alone' to cope with the difficult days and others learned to respect this.

"I'm just one of those if I'm sick, I'm sick, I just want to crawl up in the corner. I don't really want to go visiting or anything like that and obviously the children can understand that because when they ring me, they can tell a different tone in my voice. Which is good and that's fine and they're always happy when I'm back on track again."

However, beyond the self pity, patients who were successful in regaining control over their cancer treatment and management were able to move forward. One patient explained this as,

"I suppose it's just a case of there's no going back, there's no choice, there's no stopping, I've just got to keep going."

The ability of support persons to carry on with the day to day tasks is also important in helping the patient transition through this phase. One patient explained,

"I end up a bit depressed but luckily my husband is at home and he does the tea."

Another said that although she could not "even be bothered to talk" on bad days her husband was accepting of this and was able to take over her usual routine.

Most patients highlighted the importance of having personal space to deal with the emotions and sensations that are associated with 'having a bad day' and for most (though not all) this necessitated removing oneself from the world to have 'time out'. Some patients acknowledged that they did not even want to talk to others at times like these. One patient also stressed the necessity of realizing that this stage would eventually come to an end and not become too preoccupied with negative thoughts,

"I have to shake myself and think...well, it's going to be over."

Another said,

"I watch a bit of TV and wait."

Yet another patient approached this by looking forward to the future for something significantly positive in her life. This helped her focus on the future rather than the present.

Retreating into self

Most patients also had a need to retreat into themselves for a time. This is usually self imposed and yet was acknowledged as important to recovery and regaining emotional equilibrium. One patient said,

"I just suppose that I stay home and if it is a cold day then I sit by the fire. And I just tend to sit in the chair. I don't want to read and don't want to interact with people."

One patient spoke of family as the only contact she needed or desired at this time. This relates to the interaction with friends and family in different ways and the awareness for many that family are there at all times to "accept them for what they are and how they are feeling" regardless of mood.

"When I have a bad day I withdraw and I don't want to see anyone, I don't want to talk to anyone...I just want my family. I just want my kids."

For some patients, removing themselves completely is essential to recovering from these phases. One patient said that she just retreated into her room for the day and another patient said that this was also important to her in preventing significant others from worrying about her. She also said,

"I can accept my misery better than when I have got others worrying about me."

Using short term goals

Another part of coping with bad days was the use of short term goals in coping with difficult symptoms and emotions. One patient said that she acknowledged that this was challenging but that she had to remind herself to think 'short term'. She also noted that people with cancer needed more support in this area. Another patient said that friends were also instrumental in helping one through the transition phase and provide the patient with small gains and something to look forward to.

“I’ve just been amazed how often, if I was feeling a bit slack, that suddenly someone would ring me up and one of my friends would say ‘how about next such-and-such a day, we do such-and-such’?”

5.3.4 Stage Four – Acceptance and adaptability

Patients who reached stage four in achieving a empowerment, move towards acceptance of their cancer and a belief in their ability to control and manage what is within their control. This stage is characterised by an acceptance of the illness and adaptability to manage what it is possible to control (e.g. diet, exercise, setting boundaries and maintaining positive thought patterns). It also highlights the patient’s greater ability to trust others such as clinicians to manage other aspects such as treatment and side effects.

ADAPTING TO CHANGED CIRCUMSTANCES

Acknowledging physical limitations

Patients who showed signs of feeling empowered were those who also were able to accept their physical limitations whilst receiving treatment. Nonetheless there was also an acknowledgement that there is pain and discomfort to manage before the body recovers from treatment and it is how patients deal with these problems that indicates how likely they are to regain control of the impact that cancer has had upon them. Nurturing the body and allowing it time to heal is essential. At such times, less strenuous activities for patients which provided enjoyment or quiet were drawn on. For one patient, she said that she just ‘sleeps through it’. Another patient explained it thus,

“I cope by relaxing and knowing that this has hit my body and I do need to relax a little bit here today and just sort of ... my sister and I just got a heap of movies out! We sat and watched kids’ movies like Dr Doolittle and they make me laugh. I think that’s the thing, to get in things that are going to make you laugh, are going to make you happy. You know, even silly little movies like that, you know.”

Another patient valued maintaining her sense of humour in regard to her limitations was essential. She noted,

“Just have to go with the flow. A friend rang me yesterday and wanted me to go on a dog walk. And I just said to her, “Hang on, I’ll just check with my body first!” That is more or less the way it works.”

One patient also reiterated the importance in “listening to one’s body” and said,

“I think I just listen to my body that day, a couple of people have told me to, you know, I probably have a couple of days when I need to sleep.”

Another patient also said that she actively ‘planned to do nothing for the week after treatment’. Garnering the support of significant others was highlighted by some patients. One patient said that her husband ‘keeps me buoyed up’ and another that her spouse is, ‘very supportive and understanding, very nurturing’.

In regard to adaptation, having to change core values was problematic for some patients. One patient was reluctant to have chemotherapy due to her aversion to taking medications and said,

“I mean I think that one of the hardest things about the treatment. I don’t take any medication at all. You would find it hard to find Panadol in our house. Normally when I get up, I have an enormous sense of wellbeing. I am not a crank but I eat good food. My aim is to get that feeling of wellbeing but I find it very irksome when they put that chemo into you and I feel that all those chemicals are going in to your body. That is the hardest.”

For this patient, the main issue was one of control over her body and the difficulties she had in having to hand over that control to the health professionals. She also added, ‘I would like to be back in control of myself’.

Learning to accept illness and death

A central part of the process of accepting the illness is the process of thinking about death. As one patient said,

“But you know, it often goes through your head...how you are going to die.”

However, beyond the fighting stage during the illness trajectory, the patient will come to terms with such thoughts. The same patient explained further,

“Up to the time I had the biopsy I thought about death. But now I sort of think, “Ah, so this is how it happens. This is how it will be.” I was very calm about it, and it was a like a peaceful feeling that came over me.”

Moving away from religion

Another patient felt that a person who has not always followed their religious beliefs would get very little long term comfort when ill from resuming religious practices. For those whose beliefs were not strongly practised before their illness, some patients felt that it was very difficult to ‘hang on’ to those beliefs when very ill. She said that she had almost given up her faith and said, “.....but we hang on”. Some other patients became quite confused whilst seeking spiritual comfort when returning to religious beliefs during their illness. For one patient the problem arose from trying to reconcile mainstream church / religious beliefs with other healing and spiritual practices such as Reiki. Nonetheless, this patient also felt that the illness had made her ‘more open’ to other spiritual /religious practices which she previously would not have explored in the belief that ‘whatever can help is good’.

For some patients, religion and spirituality played no great part. For some of these patients, there was a lack of acceptance and a great deal of resentment. One said,

“No, it doesn’t help [comfort from religion]. Not for me. I find it very hard to believe actually, that ... I’ve been through a lot in my life, you know, and especially after my Mum died.”

Fate and control

A significant part of acceptance for the patient was establishing what it was possible to control and what was outside of the person’s control in relation to the illness. One patient said,

“You know, you want to control everything but ultimately, you don’t have that control. Somebody else higher has that control. Whether it be God, or whether it be fate or whatever. That’s out of my control.”

5.3.5 Stage five – Empowerment: engaging in the future post - treatment

The fifth and final stage of empowerment moves beyond the acceptance stage of the illness trajectory. Patients, having accepted their state of ill health begin to adapt to circumstances using self-efficacy to re-examine a situation and also to be willing to persist when obstacles present. This stage necessitates the patient knowing their own strengths and utilising their ability to tap into support structures when necessary. The patient will also become pro-active in achieving a sense of wellbeing and optimism during their illness and beyond. Thus, empowerment and taking a proactive approach to the illness was essential in maintaining a sense of control. Reaffirmation was essential to many patients in order to move forward with their lives,

“I just see this as a hiccup because it is just something that I have to do.”

ACCEPTING REALITY

Realism

Nonetheless, patients were more willing to be realistic about their prognosis and to what extent they could make future plans. One patient had this most strongly

brought home to her whilst attending a work evaluation with a supervisor. She explains,

“Yeah...I had an assessment done at work. It came to the stage where we asked ourselves what we would like to achieve, etc. had to tell my director that, “Look I don’t think I have a direction at the moment and I don’t really want to be looking at that path at the moment. I suppose I am just really taking everything step by step. I am not fussed with furthering my education at the moment. I want to get through this first” ”.

Looking for answers was a part of adapting to a new life post diagnosis and treatment. One patient believed that life circumstances had brought her to this stage and that it was grounded not so much in the physical but the emotional difficulties in her life. This was a realisation that had enabled her to begin to re-evaluate her life and priorities in a positive way.

Scaling back goals (adaptability)

Scaling back goals and plans is an essential part of acceptance. One patient felt that acceptance was about “re-evaluating your life” and learning to re-set goals. For others, short term goals were seen in terms of surviving to the next life event such as getting through to Christmas or a family birthday. For others, even the process of evaluating one’s goals and priorities was a new experience and some valued it for the benefit it brought to the patient’s life.

“I’ve spent a bit of time thinking about goals and things in life that I haven’t before. I’ve certainly done a lot of reading about decisions and lifestyle and things that we can do to make life better for us all.”

And another said in relation to priority and goal setting,

“Well, certainly you are never the same person after a cancer diagnosis as what you were before. It impacts on you at all levels I have found. It affects your

priorities, it affects your relationships and goals, what is achievable and what is not."

Many patients recognized the necessity of living "in the present" and appreciating life on a day to day basis. This was an important component of the ability to adjust goals and long term future plans in order to maintain a degree of control. For one patient she had struggled to move beyond making no plans in the early stages of treatment to more recently readjusting to a shorter term future. This patient outlined it specifically,

"Definitely it has changed my perspective and goals. I mean, I went through a stage of I didn't want to plan anything because I might die tomorrow and everything was on hold."

Another patient viewed this in a broader context as life in general and for living in the present regardless of health status.

"Now my stage is that I'm living for today but you know with or without this breast cancer you don't know what's around the corner. So my attitude was like, if it's within our means, you know, if we want to do it, we're just going to go ahead and do it, whether that be holiday or buying another house or whatever I'm not going to sit and wait for D Day as such."

For other patients, the reality of the prognosis meant greater awareness of the importance of making the most of life in the present day to day living. This patient termed it, "wanting to make more of what you are doing with your life" which also encompassed, "changing your perspective on what's important".

MAKING LIFE EASIER

Maintaining control and setting limits

Losing control through diagnosis of cancer and then having an 'influx' of friends and family to offer support can be confronting for patients and spouses / partners.

Often part of acceptance and adaptability is to regain some of that control where possible and to set boundaries with family and friends. This is essential for patients and is about feeling that they are able to make changes within themselves to allow for some control over their illness. One rural patient said,

“But we also have so many friends in Perth who invite us to come and stay. But we prefer to book into Crawford Lodge and then visit friends for dinner or coffee. We just feel that we don’t want to rely on people or impose. Then we come back and we feel that we have visited and seen people.”

Patients also focus on adapting diet and lifestyle as a means of establishing control over their illness. One patient took this a stage further and highlighted the fact that controlling her diet since her illness had in fact improved her skin beyond how it was before she became ill. This is seen as one area where in learning to adapt, the person is also learning to regain control.

“I always have been pretty conscious of nutrition and exercises in any way that We are focused more on that, I suppose and having a little bit of control. I think that’s it. You’ve got to minimise the risk of having it again and other than your lifestyle, your diet, your exercise, watch your weight so they are the kinds of things that you just do.”

Taking control where possible was important to patient’s maintaining self esteem and also to developing a sense of empowerment. One patient explained this in terms of losing her hair due to chemotherapy treatment. She took the pro-active approach ahead of the anticipated loss of hair.

“My hair started to fall out and I went to the hairdresser and got it all shaved off. It was too depressing with all of this hair all over you. I felt quite empowered. I had always loved silk and I had all these old scarves. And this was my first point of the day. What to wear on my head. Every day I dress I always put my make up on and I always put a nice scarf on because I feel that that is empowering and I feel that I am in control.”

Changing perspectives

Learning to accept and adapt is crucial to empowerment of patients. For many it is the shedding of old patterns and beliefs. For a few it is also called a “life changing experience” for many more reasons than dealing with the physical effects of cancer. One patient explained,

“I’d say it has been a revolution. You are different and people treat you different. I won’t do things the same anymore. I think that I realised pretty early on in the piece that this is a serious situation and I wasn’t going to dice with it I was just going to be honest here and whatever is not working has to go. Also to be completely open and up front about yourself and ask yourself what you are holding on to and what you need to let go of.”

Other patients also highlighted the fact that one changes as a person through the experience and that part of conquering the illness and learning to adapt in learning to accept the new. One patient said,

“There is no doubt that it is life changing. No doubt. I don’t think that anyone goes through this and thinks that they can carry on the same old way afterwards.”

For some this can be a positive experience once they have learned to accept their illness. One patient said that she has learned to not to ‘stress out’ so often and for another she had learned to think more about her own wellbeing.

“I think I sort of, before this breast cancer, I think I put everybody before myself.”

For the persons who participated in this study, part of learning about oneself through the experience of cancer, was to ‘Learn to say no’ which for some in relation to family and friends was a first time experience. However, all saw this in a positive light and one noted,

“So yeah, I’ve learnt a lot as far as that is concerned about myself and doing things for myself and learning how to say ‘no’ when I don’t want to do something. I think I’ve learnt a lot because I really used to stress a lot.”

Some patients also expressed gratitude in that they perceived themselves as not as “badly off” as other patients or that they were further towards finishing their treatment. One patient said,

“No, they are a lovely bunch of people (hospital and patients) but you’ve been going for a long time you see somebody for the first time that is always worse off than yourself. So at the moment I am staying positive that this is my treatment and I am halfway there and I am thinking I am just looking down the line.”

HELPING OTHERS ALONG THE JOURNEY

Helping friends cope

Interestingly, some patients were more concerned about the worrisome effects that the illness was having on others around them. Some patients reiterated that they felt it important to set friends’ minds at rest and to provide reassurance and stability in the face of their cancer experience. For some patients, this was an essential part of needing to feel useful and was due to the fact that they realised that they were still needed by friends. One patient felt that she could be useful to other patients and explained,

“Some people are very fearful but you say, “Look I have been through it and I am in a Reiki group and then you give them a hug and I find that very important.”

Another reiterated the sense of usefulness that one experiences by reassuring others; both other patients and those feeling uncomfortable with the illness. One patient explained it thus,

“I find that if you can make people relax then all of a sudden they smile...you have to be the one to release it from them and then they will come and give you a hug afterwards.”

Another patient accepted that some people were fearful of approaching her and felt it was her duty to put them at their ease. She said,

“My girlfriends from school, right from the very beginning, when they found out, I mean, I was very up-front about it. I never hid it, I never pretended, I never made it secretive. And I did it mainly to stop the gossip, and I didn’t want it to filter down to the kids. And I just thought, you know, I thought breast cancer doesn’t discriminate. It can happen so easily to any one of us, to any one of those mums at school.”

Some patients spoke of the initial problem with friends feeling useless in the face of someone they cared about having a life-limiting illness and being uncertain of how to help. For one patient it was important for her to enable friends who wanted to feel useful by helping out. She said,

“And I just think they feel very, very useless and when they can make a meal or I have a friend come and help me clean my house and things like that, I just think it’s their way of making them feel like they are actually doing something.”

Some patients also drew support from other patients and highlighted the ‘bond’ that they had with others who had shared the same experience. The giving and receiving of support from other patients was significant for many. One patient said that the other patients were ‘a delightful group of people’ and another explained how they had helped her,

“I think it’s good, you know, sort of like having people that have been through it too, that people can talk to. For example, a friend of mine, her sister-in-law went through it and I’ve been speaking to her a couple of times and she says ‘yeah, well, this happened to me and that happened to me’ and having the injection, she said ‘oh yeah, it will really make you feel yuck’. So I was prepared.”

The support and advice of others in which shared experiences are a validation of symptoms and feelings are essential in helped in the patient maintain security that what they are experiencing is normal and to be expected.

ADAPTING TO CIRCUMSTANCES

Focusing on the positive

Some patients said that they would actively seek out positive experiences when going through difficult days. In relation to this, the same patient found that a greater awareness of cancer information around her was difficult to avoid and she preferred not to take notice. One example of this was the television focus on cancer prevention and cures which seemed more obvious to her since being diagnosed. This was not a denial of the illness, but rather a means of staying strong and managing the experience whilst remaining in control. That is, not focusing on anxieties regarding potential negative side effects of treatment that may not occur. Many hoped for a cure but it was not something which many patients dwelt on whilst receiving chemotherapy treatment. Instead, it was more important to patients that they empower themselves by facing up to their cancer diagnosis and coping with the effects of treatment.

Gratitude also played an important role for many patients. Although they were ill, some spoke of the importance of looking at the positives in their lives. This requires strength from the patient and is shown as an inner strength rather than the effects of others around them. One patient said that when she feels depressed,

"...I don't stay there for too long. I think 'come on, pick up and ...' there is no one else that I really want to swap places with anyway, even if I think 'God, that person has been so lucky, That has gone really well for her', I think 'I don't really want to be her, I want to be me'."

For some patients, they preferred to have others around the talk to.

"If someone comes I don't say "go away" but it is often that when you have a little chat that you feel much better."

Other patients also acknowledged that they preferred some other contact with people whilst going through a difficult phase. One patient said that she found this instrumental in bringing herself out of a state of depression,

"It is just that contact with other people, that family, my brother would ring me or something and we'd have a laugh or ... I think that was amazing how often that happened when I'd just be feeling a bit flat and then someone would make some gesture of friendship that brought me out of it."

Some patients regarded this time positively because they were able to contemplate and spend time in reflection rather than, as one patient put it, "getting up and doing things". She also noted,

"If I just want to laze around, I can laze around. It's just time to focus on different things as well and not focus on myself feeling sick. Just trying to do, or read, or do something to take my mind off it a little bit, rather than actually sitting around and feeling sorry for myself."

Changing perspectives was a major focus for many cancer patients and many spoke of an "epiphany" once the initial shock of diagnosis had passed. Spending time with family and children in particular was highlighted by many patients. Goals to aim for in overcoming the illness were often structured around significant events in one's life involving family and close friends. One patient said,

"And I really, really think about my kids' futures a lot, you know what I mean, like I really want to be there to ... like I think about them having boyfriends and girlfriends, getting married and having their own kids and I really, you know I think about ... I never thought about that before. I think well, I really want to be here to see that."

Another patient said that she found dealing with the future in relation to children and other family members much more difficult than decisions regarding future financial challenges. She also noted,

“That probably, you know, when you’ve got young kids, I think that’s probably the hardest.”

Adapting one’s working life

Many patients were in employment when diagnosed with cancer and for some this required re-scaling workloads and learning to adapt. Many patients had positive experiences with employers who were willing to assist them in creating new roles and scaling back duties whilst receiving treatment. For others it required an assessment of the need to work particularly those in more stressful roles.

“As soon as I was diagnosed I didn’t want to be at work. I work as a medical receptionist and it was really stressful.”

Another patient also decided not to work but to focus more on the ability to get well without the stresses of working life. Furthermore, for this patient it was also seen as the opportunity to review one’s career. This patient said,

“I thought, ‘No, I’m not going to go to work.’ I could push myself and I could go to work but then I’m just doing the same thing that I’ve always done... I wanted to stop work and thought, “I’m doing chemo. I’m going to review my life and see what I want to do in the future.”

For some patients, focusing on the illness and the necessity to regain control without the added complications of a stressful job was essential. Furthermore, adjusting to the diagnosis of cancer was a difficult enough task in itself for many patients. Another patient explained it thus,

"I got quite well and I thought 'oh, can I just not go to work?' But I thought it's not just about my physical wellbeing, it's about a whole lot of other things so I'm going to take this time for myself."

Another aspect of learning to adapt and accept the illness for patients was the need to have a degree of normalcy in their lives. Often this was achieved by continuing in paid employment. For another patient, the need for life to continue and maintain normalcy including paid employment was important to her,

"So I guess that when people say well just wait and see or just wait for such and such... just wait...it is like a red rag to a bull (laughs). I can't wait! I guess you just see how it goes and living for the moment just kind of creeps into your way of thinking. My life is important and there is no accommodating or compromising."

Emotional support from friends

As previously highlighted, one core strategy for achieving empowerment was by tapping into the support of significant others. Many were supported in psychological and emotional ways by friends depending on the previous relationship status between patient and friend. One patient noted,

"My friends support is practical and emotional. I have friends who think in this way and it just solidified your friendship as well."

For other patients, it was a more perceptive emotional support that was provided. This would often entail minimal or brief contact from a friend which would imply that, "I am here for you if you need me". One patient explained this in the following way,

"Some friends, for whatever reason, have this immense insight into where you are at and they give me support. A lot of it is just that someone will ring up for two minutes. They ring you up and say, 'How are you going? Alright? Ok I have gotta go...' And that is enough...You don't need this long drawn out conversation. "

For another patient, keeping in touch with a friend who has a similar life limiting illness was important to her because this person was able to identify with the patient and provide the emotional support needed. As this patient said, ‘...they can tell if I want to talk about it or not’.

Other patients sought support from friends who could provide humour and light relief. These patients did not seek practical support as much as helping them maintain a sense of normalcy by providing humour or stories from their own lives. One patient said,

“And so you know, the girls were fantastic and initially, you know, they did a party for me before I went into hospital, it was fabulous, and they had been cooking for me, they had been coming over for cups of tea, just keeping me company.”

LEARNING TO MOVE ONWARDS

Problem solving

Part of learning to “move onwards” (as one patient described this final stage of acceptance) was to discover how to pinpoint problems and then problem solve. Learning to identify and confront patterns and old ways which were not working was crucial to adaptability.

“Yeah...just get to the middle of it and get to the centre of it. And identify what some of the problems are and to then say “ok now we let it go”.

One patient pointed out that it was important to be able to slow down in the phase following diagnosis and treatment to be able to do this. For one patient it became an opportunity to review aspects of her life that were not working for her and to make changes. She noted,

“Ask yourself what you’re still hanging on to that’s not working for you? You know, are you happy, all those sorts of things. That gave me a real sort of hope for the future, I thought that I’m going to work on all these things.”

For some patients being able to adapt was linked to the “right time of life” whether this was age related or situational. One patient said,

“Had it happened to me before then, oh boy! But because it happened now, where I am with the husband that I am with and have the support network that I have with friends and you know, just to keep my body on track and help me bounce back. That sort of thing has made a big difference.”

However, for some there were difficulties in learning to move onwards when cancer had already caused the loss of other family members and this created a certain loss of faith in the medical profession for a few patients. One patient explained,

“My sister died of breast cancer in 1997, three months after she had a check up that said she was OK. So I find that every time they tell me consoling things, I think yes, they told my sister that. So I have to get my head around that but I will ... I will definitely keep going. I am trying to keep on with the breast cancer counselling later on to get my head around that.”

These situations require a much greater effort on the part of patients to maintain a positive attitude and highlight the importance for many patients and their families in sustaining a frank and honest relationship with health professionals.

FACILITATING THE JOURNEY

Main source of strength in achieving empowerment

It was often difficult for patients to name one main source of strength and in fact most had several strategies in being pro-active and in control. This may be due to

the fact that dependent on the circumstances patients rely on different means of support for different things. It is essential in exploring the role of empowerment in the wellbeing of cancer patients that focusing on whom and what is important to the patient in terms of support is identified and acknowledged. Support persons for patients provided them with some essential support mechanisms. These included validation of their feelings, a sense of normalcy and remaining positive.

"I have a very positive husband. One that is annoyingly positive, you know? (laughs). We are not allowed to say in our house phrases such as 'I wish I had' or 'if only'... that is barred."

Patients were asked what they saw as their main source of strength as a means of identifying what was most important to them. Most patients saw their families as their main strength although there was an acknowledgement of the realities of difficulties in relationships during a time of crisis. One patient said in relation to her main source of strength,

"Obviously, my family and my husband and kids. I try to be normal for them as I can. They don't deal with it as well. For the most part they are young and don't realize so it is not too difficult."

This same principle also applied to friends. Another patient said,

"They will come in and have a chat although they don't impose."

Although patients generally acknowledged the support of family it was important that the family were not too overwhelming in their willingness to provide support. This made the patient focus on their illness too intensely and was in fact detrimental to maintaining a positive outlook. One patient said,

"My husband...he is just a very quiet person but he is always there and he doesn't push anything. He is just available."

Children were often unknowingly perceived as a great source of strength in helping patients maintain a degree of normalcy. Patients also valued the sense of being needed by the children as a mother regardless of the impact of the illness. Many patients need this normalcy from their children in order to cope.

"I look at my kids and they are my driving force. I look at them and I know that I was going to lose my breast and go through five months of chemo and everything else on top of it, I know why I'm doing it. I'm doing it because I want to be around for my children and they are my driving force."

Another patient reiterated this,

"Yes, because most of the time it actually pushes you around and it's probably a good thing. You tend to focus less on your own things, you know."

Children also provide the incentive to "get better" for some patients. Whereas a spouse or partner is needed for emotional and physical support, children are an incentive to conquer the illness. This is due to the perception by mothers who are also breast cancer patients that they are and will continue to be needed by their children. One patient clarified it thus,

"It can be heartbreaking but at the same time empowering. You know, you look at them and think "gee, you know, I'm really going to do whatever it takes to make sure I'm here to watch my boys grow up to be fine young men".

And another patient put it more simply,

"Basically because I want to be here to see my children as adults."

Work colleagues were seen as another source of strength for some patients. One patient spoke of her employers as a community and that all staff drew strength from being part of that community. Another found the humour in the workplace to be beneficial. One patient said that she job shared and if she had a "bad night"

before that her colleague would take on her workload to help her through the day.

Rural patients also commended the support within the community as crucial to their positive attitude. There is a strong sense of support from others in a community which is often not mentioned amongst those living in Perth. This extended to the workplace or farming communities where workloads were very often shared.

“The other good thing about being rural is that you have very good community support. I class my work that I do there with others as really like family members. There are only 300 in our community itself and you don’t realise that until something happens. I have had a lot of people who have expressed shock at my situation. It affects them as well.”

Religion was also highlighted by some patients as crucial. This patient said,

“The first thing we [husband] did was go away together. We spent that weekend just praying and meditating that God is in control regardless of what we are going through and no matter what trials you are going through there is God.”

Religion would also provide support in the knowledge that other church / religious community members were also providing spiritual support for patients. This could take the form of practical support such as providing meals for the family or more emotional in terms of ‘praying’ for the patient and their family. Often the support consisted of both. For others it was more about finding religion again once diagnosed with cancer. For some, it was about revisiting old religious practices that had not been touched upon for many years.

For some patients, other health care team members provided a consistent source of strength. One patient named her psychologist as her main source of strength along with an acupuncturist to ease the physical symptoms. Another patient found a supportive GP her main source of strength in that she provided sound advice on other aspects of managing the illness day to day such as diet and

nutrition. Sometimes this support also included affirmation and positive attitude for a patient.

“So she has given me strength. She gives me the belief that anything can be cured given the right attitude.”

Some believed that the main source of strength was themselves. This was achieved by maintaining a positive attitude and the awareness that despite the support of others it was essentially down to one’s own mental attitude and the belief in self. One patient explained it thus,

“I think myself probably. I actually think that I know that I have a tremendous amount of support. That gives me strength but I am just so utterly alone. Those people cannot be in your shoes with you. You are taking this journey on your own and so you have to find the strength within you. You may call on people or your faith or whatever but it is largely what you have got inside you that is important.”

Maintaining health and looking after oneself and one’s own interests is perceived as part of self reliance. This empowered cancer patients by giving them the sense that they are in control of their illness. One patient said that it had enabled her to have a career change. For another patient it was about remaining strong despite the knowledge that others in the family had lost a battle with cancer in previous years. This was part of fighting spirit with often was seen to accompany those expressing positive attitude to “beating cancer”.

“I mean my father died at my age and I really don’t want to die. There are things I still want to do in my life. I want to go around Australia when I retire ... I sort of strive for those sorts of things, I look forward to being able to do things like that and I don’t sort of like, think, I don’t look at it as if I’m going to die, I look as if I’m going to beat this and I’m going to do things that I want to do. Won’t let it get on top of me sort of thing. Yeah, yeah, I have regained control.”

Awareness amongst patients that times when they have negative thoughts are temporary is important in maintaining inner strength. One patient referred to the passing negative times as “having a little switch inside of me”. This created an ability to be aware of negative thoughts and to try to overcome them as part of a process of recovery and regaining control. Some mentioned having negative thoughts and fears but were quick to dispel these again.

“No I just think that I can’t change it. I must admit when I feel sick I think “what am I doing?” but that passes and I have a much more positive attitude.”

Another added,

“I just refuse to believe that the outcome will be any different to me being ok.”

Regaining control over negative thoughts and changing one’s perspective was crucial and could only be achieved by the patient themselves. This provided evidence of the importance for patients to rely on self in addition to receiving the support of others. Sometimes, this required more effort,

“Just one instance the other morning when I was going to work, I did feel sorry for myself. I just turned around to myself and said, ‘Get up and go to work!’ I can imagine that would be so easy, to sit down and feel really sorry for myself and say, ‘I’m not going to work, I don’t feel very well.’” But once I got there and I started doing, because I do love my job, I found that I just got better as the day went on ... the sickness went away, my mind was on other things, not thinking about how sick I felt or things like that.”

OPTIMISM AND SELF-EFFICACY

Recovering from setbacks

Despite the fact that the diagnosis of breast cancer can create feelings of shock and anxiety, persons with an optimistic outlook will eventually regain a sense of control. Most patients who identified themselves as optimistic acknowledged that

they had periods of self-doubt and transient jolts to their belief in their own abilities (self-efficacy). Patients spoke of “getting back in the saddle again” and “back on balance again” in regaining their sense of optimism. One patient said that although she viewed herself as positive, she was aware of temporary moments of self doubt as a normal part of adjusting to the illness. Another patient noted,

“I am very optimistic. I don’t think the experience has changed that. I just think that you have to transfer your optimism to the new situation.”

Other patients were more cautious in their optimism and noted that they also tempered this with a sense of realism about their prognosis. Another patient said that she could not yet decide whether she was or not but that generally she was able to maintain a sense of buoyancy that she would regain her health. One patient who was still in a denial phase said that she was still struggling with changes that had come upon her through her treatment and that she had put her life ‘on hold’ until she was feeling better.

There were times when some patients also acknowledged that despite optimism there were issues that had not yet been addressed for them and that recognising this was the “first step” in confronting those issues. For one patient, confronting one’s self was difficult and required assessing personality and characteristics in a new light.

“Yes, because that’s the thing, it does make you think. Like I said before, you just suddenly feel that you are going around with a mask in life and then [when diagnosed] you realise more than before.”

For some it was confronting to have to look at the realities of their illness and the possibilities of what may happen.

“They work in the back of your mind - the realistic possibilities rather than sticking your head in the sand and hoping for the best, like some.”

Patients spoke of an awareness of the relationship between optimism and realism. However, patients displaying optimism and good self-efficacy believed that despite setbacks they could move forward and try again. One patient put it thus,

“There has been quite a few blows in the last ten years or so, so I think it’s probably a little bit more of a struggle to be optimistic, which I think I still basically am. I feel myself coming through it and getting on with life. It’s the difference between blind optimism and informed optimism, I think.”

NURTURING THE SELF

Absolving blame and thinking positively

Patients were unable to achieve a positive outlook initially as many spoke of their experience with cancer as a ‘journey’ which included the necessity of experiencing anxiety, fear, anger before regaining control and developing a more positive outlook for the future. One patient explained the end stage of the journey thus,

“I look at things as positive. I think about it (cancer) as “well, I’ve got it...There is no blame or anything like that.” I just have to try and get better from it.”

Another patient acknowledged similar feelings of accepting the situation and coming to terms with it.

“You can’t blame anyone or anything like that. I would prefer to continue as normal. I am not different and I haven’t changed, I haven’t changed as a person.”

For others, the illness provided an opportunity to test one’s strengths and take control of one’s life and relationships. One patient described the experience as “the best time in my life to get cancer because a couple of years ago I would have been lost.”

Several patients said that the illness required them to become even stronger and more optimistic in regard to the future. For one patient she regarded optimism as an 'ally' in her fight against the illness. She said,

"Yes, I think that was probably one of the key things at the beginning that helped me that I was going to overcome it and get through it at the other side."

Another also noted the importance of focusing on the positive and that this was strongly linked to the willingness of medical professionals to provide information and a sense of frank realism in regard to outcomes for the patient. This helped the patient prepare for future consequences.

"It was good to know. You think 'OK, well, this is going to happen and I'm going to get on top of it, you know.' You know it's going to happen."

And further to this,

"What you can do for yourself to make it easier. That's the key to it, I think. It is a conscious decision."

Patients also felt that their optimism was fuelled by a "strong desire to survive". One of those put it thus,

"It's made me more like that, more determined to get on top of things and not let things get me down so much."

And another said,

"It just gives you that sort of strength to say 'no, I'm going to do this' "

For another patient, the ability to think positively also impacted upon her caring relationship with her sister and the fact that she acknowledged her strengths in coping with the illness.

“Yeah, I suspect that I can cope better than they can. Yes, I think that I’m coping better with my cancer than if my sister got cancer. It would be much harder to cope with because I can deal with my own pain easier than I can deal with other people’s. If it is me I think well, it’s OK, I can do it.”

Another dimension to this final stage in the journey is also learning to trust one’s own opinions once more and re-establishing a relationship with oneself sufficiently to seek involvement in managing the illness.

Re-establishing a relationship with oneself

“I have heard it said to just take one day at a time.”

Patients spoke of the importance of being “at peace with oneself”. This is a major component of accepting the situation in order to adapt. One patient explained it thus,

“No I am pretty good with myself. I am pretty comfortable with who I am. I have had two sisters with cancer and it was not a shock....I suppose I am aware.”

Another spoke of other challenging life experiences creating the stoicism necessary to cope with the illness,

“I am a strong person anyway. My background with my life has been, you know, if you read it in a textbook you sort of wonder ‘gee, how come she didn’t go off the rails?’”

One other patient agreed that, “you have to rely on yourself a lot” and another added in regard to reliance on self that “it’s got to come from inside before you can get it from anyone else”. In fact only one patient who expressed a great deal of anxiety and frustration over her illness also said that she felt least empowered.

Instead she placed all her reliance on her health care team and members of her church to ensure her recovery.

Another aspect was the value of life experience for one patient. She noted that seeing “how others struggle” in the past is a life lesson which helps one put everything ‘into perspective’ with the illness.

Putting things in perspective

The diagnosis and reality of cancer mean that many patients were able to review life events in a different perspective. This was all part of the adjusting process and facing reality. Indeed, for some this was a “revelation” in terms of assessing what was and was not important to them.

“As I said, I don’t worry so much about silly things, which I was worrying about before.”

Although negative thoughts were a part of the process, these were seen as part of a larger whole for patients who had accepted the illness. Mention of negative thoughts and periods of time were accompanied with words and language such as “fleeting” and “temporary” in recognition of their transitory nature.

“On the whole I’m about 75%, 80% optimistic. I get down days where everything is, like, “Oh my God, am I a sitting time bomb waiting for a recurrence?” I get fleeting thoughts like that.”

Recognition and awareness of negative periods of time and negative thoughts was clearly important in helping women adjust to their illness. As one patient said,
“I try and bury the negatives in my life a little bit. I try not to be overwhelmed by the negatives.”

Some patients highlighted that they were aware of others who were worse off than them or who had greater problems than themselves.

Strong will to survive

Optimism and reliance on self were related strongly to a firm will to survive. Reasons for “beating the illness” were varied and related to identifying what was important to the patient. For many breast cancer patients, this was the need to there for one’s family and in particular for one’s children. For one patient, this also required the acknowledgement of the present circumstances.

“Like.....to imagine that you would actually want to cross over because it was so bad in the present. I love the present. I have a strong desire to live.”

It is important to be aware of the need for the patient to still feel useful in regard to significant others. As one patient puts it,

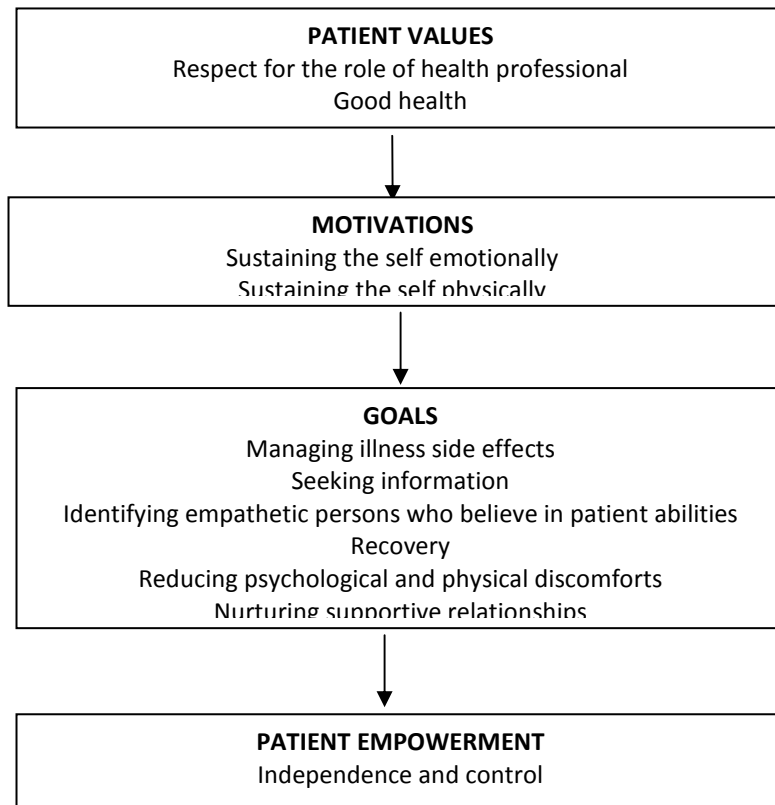
“It gives me goals.”

5.4 Relating empowerment to motivation and goal setting process

Motivation, realistic goal-setting and a willingness to succeed (empowerment) were evident amongst many of the patients interviewed. Patients are likely to acknowledge their set of circumstances in terms of whether or not they regarded each component as controllable or not. Furthermore, internal circumstances (how a person feels about a circumstance or event) will be perceived by the patient as either stable (patient ability to cope and what they expect the outcome of their efforts to be) or unstable (dependent on their mood and the immediate effort they are willing to exert to exact control). Finally, external circumstances may be categorized as stable factors such as task difficulty and relationship with health care providers and unstable factors such as changes to the illness trajectory or treatment side effects that are unforeseen. A meta-analysis of relations between causal attributions, coping and psychological adjustment in chronically ill individuals noted in the literature review (Roesch and Weiner, 2001) showed that the ability of a person to handle his / her illness is correlated with a range of positively motivated cognitions and behaviours. Furthermore, as was discussed,

Roesch and Weiner noted that attributions linked to their illness were linked by individuals to coping strategies that helped them gain a measure of control. Figure 5.1 demonstrates the process of empowerment relating to this study that enabled positively motivated patients to achieve their goal of regaining a measure of control over their illness.

Figure 5.1 The process of empowerment relating to motivation



5.5 Discussion

The in-depth interviews explored more widely the stages that patients go through to regain control and sense of empowerment following a diagnosis of cancer.

The stages that patients went through following their diagnosis were likened to a 'journey' through from the early stages of shock to regaining control where possible over the illness and management of the condition. The journey towards empowerment also moves a stage beyond the ability to regain control in order that patients feel that they have learned something positive about themselves and to have made some life changes for the better. There was a sense that time is crucial and many patients spoke of re-evaluating their lives and relationships in

relation to possible limited time both now and in the future. Once treatment commences and patients explore their experience with cancer, all are able to identify a number of support and resource strategies which are personally important to them. This study identified that there are a number of core strategies common to all patients who seek to regain control over the illness.

This series of interviews explored the set of core support and resource strategies specified in the PES which a motivated patient will learn to utilize and adapt to when faced with a life limiting illness such as cancer. The main aims are to regain control of their health and thus achieve a sense of empowerment. Central to this is a reliance on self which patients with a marked sense of self-efficacy will display. The ability to assess what is useful or not in managing their illness is a skill which patients with strong motivation to succeed use to their best advantage. This is accompanied by a sense of transience during 'bad days' and the knowledge that through a strong belief in self reliance and social support structures they will overcome difficulties.

In addition, the role of the health professional is central to successfully motivating the patient through providing support and information related goals which are relevant to helping them cope with their illness. In the face of chronic illness such as cancer, patients need to be included in goal setting in regard to issues such as the management of the disease and where possible the type of treatment to be provided. The health professional (clinician or breast cancer nurse) can help to provide the patient with goal structures which are achievable and thus can encourage the patient to attempt 'goal achievable tasks'. In relation to this, patients who participated in this study showed motivation in overcoming the limitations of the illness by interacting with health professionals in two main ways. Firstly, they expressed the desire to be included in decision making process. This included the peripheral involvement of being kept informed and advised by the doctor and being given the opportunity to ask questions. Secondly, the patient maintained that the clinician demonstrated a positive attitude towards the patient's capacity to make a meaningful contribution to the decision making process and to developing a 'partnership' in the management of their illness.

The interviews focused on exploring the ability of the breast cancer patients to empower themselves by being motivated to develop a set of support systems and resources core coping strategies. Empowered patients maintain control throughout an often adverse and uncertain prognosis and overall illness trajectory. Strategies which primarily motivate patients to play an active role in managing their cancer are information seeking and the desire to be part of the process of treating and managing their condition. A strong belief in one's own ability to cope with the illness and side effects of treatment are also central to the ability of the patient to overcome any adverse conditions. When the strongly defined sense of self is lacking the patient is unlikely to achieve a high level of empowerment as they are solely reliant on external resources such as health professionals and members of a community (e.g. church) to define their ability to overcome any difficulties they may face. The strategies are there to help the patient complete the journey. The arrival is a state of empowerment characterized by a set of resource and support strategies which are enablers to the state of empowerment.

Chapter Six - Discussion and Limitations

6.1 Limitations

A paper by Perkins & Zimmerman (1995) referred to empowerment as,

“...a construct that links individual strengths and competencies, natural helping systems and proactive behaviours.”

In this study, patients combined their strengths with a proactive approach to maintaining control over their treatment by accessing support mechanisms, systems and utilising resources. In addition Perkins & Zimmerman (1995) also noted that empowerment research is more focussed upon identifying strengths, capabilities and enablers to optimal wellbeing rather than identifying risks, weaknesses and negative approaches to a problem or hurdle. Shared Care patients who were initially interviewed were highly motivated to develop coping mechanisms through use of support and resource networks. Thus, regardless of prognosis, such resources enabled them to have some measure of control over their illness and engendered a heightened sense of empowerment. The purposeful sample employed for the initial in-depth interviews with Shared Care Model patients was appropriate for the exploration of the topic of empowerment. However, the validation of the scale required a more diverse sample of patients in order to demonstrate a wider distribution in terms of level of empowerment across a continuum. A complete validation of a scale such as the PES usually requires a sample population of between 600 and 1000 persons. Given that our sample was smaller than usually required for the complete validation of the scale using the Rasch Model further validation would require more diverse and larger samples of patients. However, the results from our sample indicated a good level of reliability at this initial stage of validation. Another consideration for later versions of the PES is the fact that some people with the very highest locations on the continuum did not appear to be well targeted using the current statements. There is a potential to develop more intense items, that is, items indicating even

higher levels of empowerment than the present items making up the PES. Finally, the Rasch analyses showed that there was some difficulty amongst respondents in distinguishing between 'strongly disagree' and 'disagree' for some statements. It is speculated that the condensing of categories from four to three would be beneficial without compromising the reliability of the scale. However, this process will require a future and possibly larger study by re-wording the three remaining categories [from 'strongly disagree', 'agree' and 'strongly agree'] for clarity and balance.

In addition, the Shared Care patients who completed the original interviews were diagnosed with haematological cancers and agreed to participate in the Shared Care Model. Thus, treatment regimens, management of the condition and side effects may be different in ways to those of other cancers. At this early stage there was no opportunity to seek input from patients with other cancers to ascertain approaches to support mechanisms and this may have influenced the statements to a degree. However, the larger sample of patients and the breast cancer patient in-depth interviews may have negated this bias to a certain extent. Core issues identified in the initial data collection stages seemed to have been commonly identified in later patient interviews and the scale validation.

In support of the common themes identified, it should be noted that important support structures marked as statements in the original 28 item PES which did not fit the model closely (such as familiarity with general practitioner) were in fact also identified as not important in later interviews with breast cancer patients. This is possibly due to the fact that the Shared Care Model requires patients to develop a closer relationship with their GP outside of hospital and the GP is in fact nominated by the patient for participation in the disease management. Otherwise, it is usual, although not ideal, for patients to see little of their general practitioner once they are receiving treatment within a hospital setting. Similarly, waiting to be involved in making decisions about one's treatment per se was less important to patients than being involved in the process alongside the clinician.

Overall, further studies in this area would recommend a larger sample of patients from a greater diversity of cancers. In addition, accessing patients at different points during their illness trajectory to ascertain whether empowerment markers

remain consistent would be useful before during and after chemotherapy treatments.

6.2 Discussion

The study sought to meet three main objectives. Firstly, to explore the concept that empowerment can be measured separately from other quality of life indicators. This is based upon the principle that achieving empowerment requires a more proactive approach on behalf of the patient to take greater responsibility and to have greater involvement in their treatment and management of cancer. It differs from related concepts such as coping due to the fact that it requires the patient to move beyond the role of passive participant during and after their cancer treatment to be more fully involved in the decision making and information seeking process. In order to understand the process of patient empowerment, we were required to explore the ways in which cancer patients act upon their prognosis and attempt to optimize the outcomes of their treatment.

The second objective sought to explore ways in which patients who actively seek to access tailored resources and support structures to manage their illness achieve a greater sense of empowerment than those who follow the advice of health professionals and significant others in their lives without seeking to fully understand or question the recommendations or options provided.

Finally, the concept that empowerment improves the psychological outcome in patients was investigated using a qualitative methodology of the 'lived experience' of participants. Although no psychometric measures were used to assess anxiety and depression, the qualitative work explores, from the patient's perspective, the effect upon them from initial shock, anger and depression moving towards acceptance, a greater perceived control and empowerment. Increased empowerment is achieved through the active use of resources and support systems and strategies in order that patients can regain a measure of control over their illness.

6.2.1 Empowerment as a quality of life indicator is a uniquely identifiable concept

It was believed that empowerment takes into account the way in which patients act upon their prognosis and are able to optimize the outcomes of treatment. It may not always be possible to measure concepts such as specific level of patient empowerment accurately. Ryan (1983) acknowledges from the field of educational measurement that, "...behaviour of some (children) during the measurement process distorts the unidimensionality". Although, at times, this may also be the case amongst cancer patients, it should be highlighted that levels of empowerment as measured by the statements provided in the Patient Empowerment Scale transcend specific points in time during the illness trajectory. Furthermore, research established that there are some core strategies when a patient is seeking access to support and resources for which their ability remains constant regardless of prognoses. That is, most will develop an understanding of what is required to achieve a level of control and empowerment such as learning to accept and adapt lifestyles and what types and amounts of information are relevant to their individual circumstances. Once the initial shock of diagnosis has passed and the patient begins treatment, this study revealed that patients usually begin to ascertain the support and resources required to help them regain control over their illness. Although there may be times during the illness trajectory when patients become anxious about the treatment outcome, they will have developed an understanding of what is needed to remain in control of the management of their treatment and illness side effects. Thus, the markers (statements) in the Patient Empowerment Scale should remain relevant regardless of patient prognosis or point in time during their illness trajectory. Patients do experience setbacks throughout their illness. However, empowerment through self-efficacy demonstrates how a patient reacts to those setbacks and demonstrates a willingness to adapt to the situation. For example, in regard to relevance of information to the patient, it is the patient's ability to utilise that information to cope with the setback and move forward again which is central to empowerment as a concept.

The development of the Patient Empowerment Scale required the utilisation of Rasch analysis to assess the psychometric properties of the scale. In other words,

the Rasch Extended model represents the structure which the data should exhibit (Schumaker & Smith 2007) in order to obtain the correct measurements of the trait (empowerment). Thus, Rasch analysis was the methodology best suited to scale development of this kind because it assessed the robustness of each scale item by fitting the data to the model. The first analysis of the data using the RUMM program (Andrich et al. 1988) enabled the researcher to identify how closely each item fitted the model. In this way, items (statements) which did not fit the model well were discarded from the final PES. The results of the analysis revealed some unanticipated results. For example, from the qualitative data analysis it was originally believed that the support gained by patients from family and close friends would differ extensively and that patients would reflect this in their responses to the statements about support from family and friends. This was not the case, with the findings revealing that the statements regarding support from family and friends were close together in location on the continuum. Therefore, for the purposes of brief responses to a questionnaire such as the PES, patients regarded support from significant others similarly. To clarify, responses from patients which are obtained briefly through the completion of a questionnaire may account for grouping into the same concept the support of family and friends. Conversely, when talking to patients in-depth about the types of support offered by family and friends the support mechanisms obtained are usually very different. Thus, the grouping of family and friends support in a single coalesced statement is relevant for a brief quality of life measure such as the PES. Nonetheless, it is not necessarily relevant for a more in-depth exploration of the support provided by family and friends to patients.

Similarly, the degree of involvement of the general practitioner was believed to be closely linked to the level of patient empowerment within the Shared Care model. However, the initial Rasch analysis showed that overall the reliance that patients had on their GP was dependant on the patient's level of confidence in that particular GP. Nonetheless, being aware and included in the decision making process was clearly of immense importance. Equally important was the patient's belief that the health professional had faith in his / her ability to be involved in the management of their condition.

Another enabler to achieving a greater sense of empowerment was identified as whether the patient still felt useful in their daily life. In addition, a sense of usefulness was relevant to feeling empowered regardless of whether the patient was in paid employment or not. The statement which required a response on whether feeling useful was important was one which fitted the Rasch model most closely thus validating how important the patient's ability to feel useful and needed by significant others in their lives was to those responding to our questionnaire. Certainly, other studies maintain the importance of the concept to chronically ill patients of preserving a life purpose and sense of usefulness (Carlsson et al. 2006; Do Rozario 1997; Wilson 2007).

Overall, the scale has been shortened through use of the Rasch Model from an initial 28 items to the final 15 items making up the PES. Although the final version of the PES requires a larger sample of patients to be further validated, the Rasch Model and use of the RUMM program for the initial and subsequent analyses showed that the scale has a good degree of reliability.

Although the Patient Empowerment Scale was partially validated and showed good reliability in the initial analyses, a larger sample of patients is required to fully validate the scale. Future research is seeking funding to explore the psychometric properties of the PES as follows. The initial results show that informal and social support markers indicate that social support structures and access to resources are as important as more formalised treatment advice and support resources. However, given the liminality of the illness experience amongst cancer patients, patient perceived levels of empowerment may potentially change at different points throughout the active treatment phase. Thus, future directions for research will seek to recruit cancer patients to follow up with the PES at initial, midpoint and at the end of the active treatment phase.

It is important to explore the ability of the PES to remain stable across the active treatment phase of the cancer trajectory and across all domains. In regard to convergent validity, this was not tested for this research with other scales. However, the PES is currently being tested for convergent validity in a separate NHMRC funded trial of the Shared Care Model using the PES, the HADS, FACT-G and the mini MAC.

In addition, future research should evaluate construct validity further by comparing the PES with other similar scales such as the COPE (Carver et al 1989) as a comparison scale. The COPE is a multidimensional coping inventory to assess different ways in which people respond to stressors. The COPE consists of 13 subscales used to measure the following areas: problem focussed coping, emotional focussed coping and coping responses which are less useful to the patient. Although the preliminary results are encouraging, the comparison of the two scales along with the current study of the PES and other validated measures will seek to fully establish that the PES shows 'empowerment' as a uniquely identifiable concept.

However, the results from the PES development and partial validation also posed further in-depth questions regarding the types of support and resources that patients valued most. That is, as noted above, some of the strategies and resources which were used by patients to achieve a level of empowerment appeared to be less valuable when solely focusing on the findings of the Rasch analyses and the PES. Some examples of this were the perceived importance of patient relationship with their general practitioner whereby closeness of relationship was dependent on a number of variables such as rural locality and length of time that the patient had known their GP. Thus, despite initial in-depth interviews with Shared Care patients highlighting the high value that patients placed on a close and ongoing relationship with their GP, the scale revealed that across three of four areas (statements) these requirements were not valued by a larger sample of patients, many of whom were not participants in a Shared Care Model. The three areas were confidence in GP ability to manage the illness outside of hospital, comfort and trust. The item which fitted the PES most closely and thus remained in the final scale referred to having confidence in the local GP. Another example of seeking further clarification through qualitative methods was the role of friends and family in supporting the patient and the reasons behind a widespread use of complementary medicines. Although in-depth interviews established that friends and family were relied upon for very different kinds of support, the PES showed that in a brief measure of empowerment, patients tended to regard the two forms of support in the same way. Similarly, although

the scale established that many patients relied upon complementary medicines, the scale was unable to provide depth of information as to what forms of complementary medicines and why the patients relied on these so heavily.

These concepts required a qualitative methodology using in-depth interviews completed with cancer patients in order to explore the anomalies obtained from the findings. Thus, the second and third concepts were best explored using a qualitative approach.

One other potential area for future research is the actual use of the PES from a clinician's perspective. It is important that the researcher investigates at a later stage how the PES can be used by clinicians to explore potential level of patient empowerment. This may best be investigated both qualitatively by interviewing clinicians about the markers for empowerment as defined in the scale. In addition, a more rigorous RCT intervention may demonstrate the use of the PES for clinicians and cancer nurses within the clinical setting. In so doing, it is hoped to demonstrate that awareness of areas in which a patient may be lacking such as social support, decision making preferences and adaptability could inform the health care team about possible required areas of support for that patient.

6.2.2 The Benefits of Patient Accessing Tailored Resources And Support Structures In Achieving Empowerment.

Patient ability to cope with a life limiting illness highlights the fact that desire for support increases with patient perception of their prognosis (Rose 1990). Certainly the need for support is common to all cancer patients although the level is variable depending on stage and severity of prognosis (Peters–Golden 1982). There are also distinguishable types of support which are valued by patients in diverse ways (Gass et al. 2007). These include tangible forms of support such as transport, help with household tasks and similar practical or physical needs. There are however, other desired forms of emotional and psychological support such as reassurance, ability to express one's emotions in relation to the illness and rebuilding self esteem which are equally valued by patients (Gonzalez & Lengacher 2007). For those offering support such as close friends, psychological support can be harder to maintain over the longer term.

Studies within the area of chronic illness indicate that both the ability and the willingness of the patient to pro-actively access support structures and resources is crucial in enabling them to regain mastery over their condition (Kyngas & Rissanen 2001). This research highlighted through qualitative methodologies that those who are more actively involved in their treatment and management of their illness are also most likely to achieve a sense of control and greater level of empowerment. Nonetheless, it was perceived as equally important for patients to receive clear guidance in the early stages of their cancer following diagnosis as to what specific information would be relevant to their needs and which other support resources were available (Campbell 2006; Owen et al. 2005). The provision of guided or targeted information regarding resources and support systems ensured that patients were better able to organize their individual needs and to recognize what may or may not be useful to them on a personal level (Ciambrone 2006). It was evident from the findings that if this type of guidance in regard to support and resources did not occur, difficulties for patients occurred at either end of the spectrum. That is, either they received too much information or that the information was neither clear nor relevant in the earliest stages following diagnosis. Some patients spoke of their confusion and anxiety on receiving huge amounts of information and in contrast, those who felt they were not given enough guidance were prone to access the Internet and any other available resource, thus causing further panic and confusion. It was clear that patients who were provided with specific information without being given 'information overload' were also those who were better able to regain a sense of control over their condition.

In regard to tailored support, it should be noted that there is a growing emphasis on the Internet for the provision of web-based information and support such as online discussion boards (Delmar et al. 2006; Mayer et al. 2007; Gooden & Winefield 2007; Hoybe et al. 2005). Certain studies maintain that they empower the patient to a degree not possible previously due to easier access to medical and related information specific to their condition (Ziebland 2004). Nonetheless, the Internet and web based support can only achieve a degree of success in addressing the needs of all cancer patients and indeed, some studies maintain

that the degree and ability of Internet useage is closely linked to socio-economic status and educational level (Fogel et al. 2002; Mayer et al. 2007).

In addition to this, patients who had access to the support of other cancer survivors, greatly valued this as a means of reassuring and validating their own experiences (Ussher et al. 2006; Larsson et al. 2007). It was an indication of enhanced level of empowerment for the patients interviewed in this study to be willing to share their experiences with others in need of support. In fact, breast cancer patients interviewed who were in the earlier stages of their illness were much less willing to access support groups and to discuss the illness with others. There was a clear avoidance accompanied by the desire for patient-perceived normalcy whereby patients in the early stages of their treatment said they would prefer to 'steer clear' of such encounters with other cancer patients and survivors. Support requirements also encompassed the need for patients both in this and other studies to re-affirm their understanding of a number of illness related issues. They clearly value the opportunity to talk and clarify issues with a health professional or other person with experience of cancer on a regular basis (Hardyman et al. 2005). Support and re-affirmation of their capabilities was utilized by patients to regain control and build empowerment. This approach by health care teams would enable patients to be well on the way to self management as a goal of empowerment (Kralik et al. 2004).

Ability to provide support and re-affirmation are necessary to building a positive relationship between patient and health professional. This research has shown that patients not only value frankness and clarity amongst health professionals but also that the clinician demonstrates that they have faith in sharing information and decision-making with the patient. Certainly the patient values the willingness of the clinician to share information with them regarding their treatment and care (Adams et al. 2001; Blanchard et al. 1988). The willingness to be involved in shared decision-making remains a contentious area of research. Studies have contradicted each other in this regard (Say et al. 2005). In this study, we found that the opportunity for patients to be involved in decision-making was accepted as important. However, more important to most patients interviewed was the ability of the clinician to communicate frankly and openly about the patient's progress during and after treatment and further to this, to provide

relevant and targeted information. This kind of openness also enabled the patient to freely discuss options in regard to the management of their treatment side effects such as use of complementary therapies.

Most patients still accepted that they would rely on the clinician's advice regarding which treatment would be best and to provide treatment options whenever these were possible. However, even though patients accepted that the clinician's decision was final, they also hoped that the clinician would share relevant information and provide time for patients to consider their options before reaching a shared decision.

Overall, the need for patients to have access to tailored resources and support systems is largely dependent on the point in time of their illness trajectory. It does, however, appear vital that patients in the early stages of their illness following diagnosis are provided with guided support and access to resources in order to avoid anxiety and confusion given the plethora of information provided by clinicians and other health professionals. The opportunity to be informed and to be able to ask questions was acknowledged by patients in both the Shared Care study and the breast cancer patient interviews as imperative to regaining a sense of control over the treatment and the illness itself. Formal support systems such as those valuable to breast cancer patients did not necessarily enable patients to regain control and feel empowered. In fact some felt that having an excess of information with very little guidance was more worrisome than having too little information at hand in the early days.

In contrast, patients felt that the Shared Care model provided more opportunity to enable empowerment to occur. This is because each Patient Held Record was individualized for the patient. Information and resources were therefore relevant for each patient specifically.

Undoubtedly, most patients were eventually able to assess which support structures and resources were most useful to them as individuals. They also learned which information and types of support they could discard. However, this took some time and for some patients the adjustment was fraught with anxiety. The Shared Care Model was a support and resource arrangement which patients felt empowered by for a number of reasons. Namely, open communication, terminology explained and hospital and GP visits documented clearly for patient

and family. Certainly, a tailored resource and support structure is valuable for patients but with two provisos. Firstly, that it is tailored in such a way as to avoid “one size fits all” in providing support. Patients in this study highlighted the importance of relevant as well as timely support and information. Secondly, the patient needs to show willingness to be involved in his or her care. It is vital in facilitating a sense of empowerment that the patient has a sense of control over the management of their care and open communication with health professionals and significant others.

One prospective future direction for this research would be to explore what direction patients as survivors might take once they have achieved a substantial level of empowerment in the remission or post treatment phases. Patients who are resilient may be those who are not just empowered but also open to benefit finding and growth (emotional) through the post treatment phase. These are potential confounders for the concept of empowerment as understood by the researcher and need to be explored more fully in future research.

6.2.3 Empowerment improves the psychological outcome in patients

This study explored the potential for empowerment to improve the psychological outcome for patients. However, this was approached from a qualitative perspective. As such, no measures of psychological distress were measured for this study. However, there are a number of identifiable concepts which point to level of wellbeing for patients. These are discussed as follows in this section of the discussion.

As has been outlined in the previous section, the development of a greater level of empowerment amongst patients appears to be reliant on timing for the provision of support and information following the diagnosis. Those interviewed for this research spoke of the initial shock following diagnosis and the ensuing confusion and anxiety before treatment was underway. Patients **need time to adjust** to both their diagnosis and prognosis (Saino et al. 2001) in order to be able to regain a measure of control. Further to this, they need to have an understanding of what is possible and how to determine reasonable and achievable goals in being involved with their treatment and care. Participants in the Shared Care Model and also those who were interviewed whilst receiving

chemotherapy treatment for breast cancer pointed out that they needed time to “take on board” their diagnosis and to have an opportunity to experience the early stages of their treatment so that they would know what to expect. Thus, the allowance for a period of adjustment is crucial to most patients given the often short timeframe between diagnosis and commencement of treatment. Patients initially feel they have lost control over their bodies and their lives for a time. Optimally, this period should provide support to enable the patient to establish which areas they can have control over (eg dietary and lifestyle) and which areas they need to develop a relationship of trust in order to hand over control to another person (e.g. the clinician). However, at all times whether they are in control or not, patients prefer to remain informed (Salkeld et al. 2004) about their treatment and the management of their illness.

The importance of maintaining overall **optimism** despite the occasional setback was highlighted in this study. Another study by Marshall & Brown (2004) showed that the combination of low expectancy and resulting negative event experienced by the patient has greater impact upon subsequent psychological action than a patient’s high expectancy of success and positivity. In other words, the Marshall & Brown study showed that a negative experience can exert a greater influence upon a person than positive. By taking this into account, it is important in order to remain positive, that the patient is able to assess, accept and ultimately adapt within their own levels of coping rather than being driven by external influences which may lead to failure fuelled by unreasonable expectations. In addition, a person uses their self-efficacy mechanisms such as willingness to exert the required effort by engaging with available support mechanisms around them in order to adapt irrespective of prognosis. Clearly, it is central to the empowerment process for the patient to be able to assess whether the level of effort required will be sufficient to control aspects of their treatment options and overall care.

This study further noted that during qualitative interviews with patients they spoke positively about their ability to cope with their illness by setting themselves short term goals. Furthermore, they expressed **acceptance of their limitations** regarding the illness despite their prognosis if they were able to re-establish shorter term goals such as learning a new skills such as yoga, travelling that coming weekend to visit a grandchild or attend a family event. This once more

emphasises the need for patients to be allowed to develop an understanding of which areas they have control of and similarly, any areas where they may need to hand over control to a health professional or significant other. It is the acceptance by the patient of this altered status that leads to a heightened sense of empowerment. Goal setting enables the patient to focus on the positive aspects of coping with cancer thereby empowering them to regain control where possible over aspects of their illness (Schulman-Green et al. 2006).

Another important factor in improving patient psychological wellbeing and increasing level of empowerment was the ability to maintain a sense of purpose or **usefulness**. This study revealed as with other current research that those who remained in paid employment this was the ability to contribute to the company and in general to society through their work (Nachreiner et al. 2007). For those no longer in paid employment, this meant still feeling useful within their family or circle of friends. Clearly for patients who are proactively involved in their treatment, being able to offer support to others, to feel needed and to contribute to the family (significant others) is vital to achieve an enhanced sense of empowerment (Lundman & Jansson 2007; Ringdal et al. 2007; Mitchell 2006).

The willingness to be involved in learning how to best cope with all aspects of the illness enables patients to feel psychologically and sometimes physically better (Golant 2003). This includes an initial acceptance of the fact that cancer is present followed by concordance with the treatment regimen decided upon, accompanied by a positive outlook in regard to managing the effects of the illness. Patients who are solution focused are likely to better manage the illness and to look for remedies to setbacks and hurdles than those who are focused on the origins of their cancer (Taylor et al. 1984). In searching for solutions, many patients perceive a number of areas as a means by which they feel they are **in control during and after treatment**. Complementary therapies is one such area which the literature has shown to be a domain where patients can establish control over their recovery or at very least the diminishing of their symptoms and side effects (Shumay et al. 2001; Thorne et al. 2002). Similarly, research has also shown that exercise was perceived as a means of controlling wellbeing and general health (Courneya & Friedenreich 1999). More recently, a modest survival benefit has also been demonstrated in current and post treatment cancer patients who participate

in physical activity (Midtgaard et al. 2007; Fairey et al. 2002) although much research needs to be completed yet in this area. Patients interviewed for this research were generally motivated to take control where possible over areas of their daily living by refining or **learning a new skill** such as meditation, yoga or other gentle exercise. Some patients also used their renewed physical ability (for example mowing a lawn, participating in a yoga class or completing a run / marathon) to gauge an improvement in health status by noting that they felt better physically by participating in something which demonstrated a sense of wellbeing and improved physical health. Patients sometimes noted that it was important to keep healthy in case it would help their recovery or have a positive effect on the outcome of their treatment. Similarly with diet, many made healthy changes to dietary habits and regarded this as a positive step in aiding their recovery.

Contributing to others' knowledge in a similar situation is a significant component of psychological wellbeing. Golant et al (2003) emphasised this in a study whereby patients were empowered through group intervention and positive reinforcement to manage the side effects of their treatment using the Patient Active Empowerment Model. The model mentored patients in managing treatment side effects and the result was a decrease in depressive symptoms by empowering them to cope more effectively and proactively with their illness. In fact, one of the patients interviewed for this study spoke positively of this type of interaction with other patients as a 'club' whereby each patient provided support, empathy and encouragement for another. **Willingness to participate** in support groups and other similar strategies such as online discussion boards was also reliant on stage of illness for patients. This needs to be taken into account in future development of tailored support structures and resources for patients. Many patients valued the support not only of that provided to them but also, as already highlighted, the opportunity in later stages of their treatment and post treatment stages to give support to others. Initially, patients in earlier stages of their illness and treatment regimen were reluctant to accept that they had a potentially life limiting illness and found it confronting to attend support groups and acknowledge their situation. However, many found that with time and treatments out of the way they were able to provide support to other patients commencing treatment.

Furthermore, some patients noted that they found it easier to identify with another cancer survivor providing advice rather than a nurse or other health professional that had not been through the experience regardless of how credible that information might be.

Resilience in the face of setbacks was a fundamental component for our model of empowerment amongst patients who positively expressed acceptance and adaptability. Clearly, almost every patient said that they were aware that there were and still would be 'bad days' during and after their illness treatment phase. For some this was more of a challenge to accept than others. However, all acknowledged such feelings as being transient and had ways of coping with such days whilst reminding themselves that it would pass. Patients also had the ability to retreat and nurture the self on such days instead of denying the reality of 'having a bad day'. Not dwelling on such times but still acknowledging their existence was crucial to the success of being able to 'move forward'.

6.3 Conclusion

Overall, the findings of both the quantitative and the qualitative study components revealed that empowerment improved the psychological wellbeing of cancer patients. This was achieved through active uptake and use of support strategies and tailored resources. However, such resources are external to the patient and although useful do not provide a patient with an enhanced sense of wellbeing and empowerment in themselves.

The development of an enhanced sense of empowerment was dependent rather on a number of psychological markers common to all of the patients interviewed both for the development of the Patient Empowerment Scale and also in exploring the role of empowerment in the wellbeing of patients with cancer. Having time to adjust and adapt to altered circumstances following a diagnosis of cancer also proved to be a crucial factor in regaining control and feeling empowered. This was accompanied by personal beliefs about one's ability to regain some control over certain areas of treatment and self-managing side effects throughout day to day living. Resilience and 'fighting spirit' ensured that setbacks and hurdles were transient and could be overcome. The diagnosis and experience of cancer

treatment was also a time of focusing clearly on what was important and for many involved major re-thinking over their priorities and life goals.

The development of the scale and validation thereof would have been strengthened if a greater number of patients were available to complete the questionnaire. Nonetheless, the Rasch Model analyses showed that the PES had a good level of reliability and it is anticipated that with a larger sample of patients that the reliability of the scale would be finalised with positive results. In addition, the PES could be applied in future research to other populations such as those with diabetes or other chronic illness in order to provide further evidence of validity and reliability. The statements which make up the PES provide generic markers for empowerment which are potentially relevant to a number of chronic illnesses such as support of family and friends, relationship with health care professionals and acceptance and adaptation to living with a longer term illness.

Certainly, as postulated, the use of the Rasch Model has shown that the concept of empowerment is a uniquely identifiable concept. In addition, the role of the PES as an outcome measure for future trials of interventions relating to patient empowerment is clear. The PES was developed to assess level of empowerment amongst patients. Although the PES will be useful for clinicians and researchers in future in assessing level of empowerment it is important to acknowledge the complexity of information provided by the qualitative component of the study. The role that empowerment plays in the wellbeing of cancer patients was explored extensively using in-depth interviewing amongst diverse individuals receiving chemotherapy treatment for cancer. This provided a greater understanding of the mechanisms by which individuals achieve a heightened sense of empowerment using both tailored support and also relevant, timely resources. Empowerment is achieved through developing their own understanding of what 'works best' for themselves as patients within their unique situation.

The reliability of the PES as defined by the Rasch Model indicates that there are a number of core strategies and skills adopted by patients to empower them to cope with their illness. These strategies were further highlighted as relevant during in-depth interviews with a diverse group of patients receiving chemotherapy treatment for cancer. It would be vital for future research to

explore types of structured support and tailored resources that patients proactively use in order to regain control and hence empower themselves in playing an active role in managing their cancer.

Appendix 1 Patient Questionnaires

Example of unfolding statements in Unfolding Model PES.

PATIENT EMPOWERMENT SCALE - INSTRUCTIONS TO PATIENT

Please indicate by marking with a tick (✓) whether you strongly agree, agree, disagree or strongly disagree with the following statements

For each issue, there is a set of four statements. Please read them carefully and tick your response to ALL of them. Your responses to each of the four are likely to be different.

Note that family is distinguished separately from friends for the purposes of this questionnaire.

<i>Your use of resources (support groups, talking to others for advice outside of the medical profession)</i>						
	Strongly agree	Agree	Disagree	Strongly disagree		Not applicable
I am capable of using the sufficient resources that I have to handle my illness.						
Although I am capable of handling my illness I don't have sufficient resources to do so as well as I would like.						
I am not really capable and I don't have sufficient resources to handle my illness.						
I am not always capable of handling my illness even though I have sufficient resources.						

<i>Your willingness and ability to be involved in decision making about your illness (eg treatment options, treatment location, etc)</i>						
	Strongly agree	Agree	Disagree	Strongly disagree		Not applicable
Although I don't feel capable of making decisions about my illness, I still want to be involved.						
Although I feel capable of doing so, I don't want to be involved in decisions about my illness.						
I don't feel capable of making decisions about my illness and I don't want to be involved.						
I want to be involved in decisions about my illness and I feel capable of doing so.						

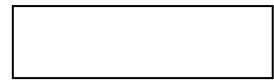
**PATIENT SUPPORT STRATEGIES PILOT QUESTIONNAIRE
INSTRUCTIONS TO PATIENT**

Please indicate by marking with a tick (✓) whether you strongly agree, agree, disagree or strongly disagree with the following statements. Please read the statements carefully and tick your responses to ALL of them.

Note that family is distinguished separately from **friends** for the purposes of this questionnaire.

	Strongly agree	Agree	Disagree	Strongly disagree		Doesn't Apply
I am capable of handling my illness						
I have sufficient resources to handle my illness (<i>e.g. support groups, talking to others outside of the medical profession</i>)						
I have enough information to manage my illness.						
I want to be involved in making decisions related to my illness.						
I am capable of helping health professionals reach decisions related to my illness.						
My family are always supportive.						
I am comfortable with seeing my GP.						
I am capable of making decisions related to my illness.						
I use complementary therapies.						
The information that I have is relevant to managing my illness.						
I need the support of my family.						
I have spiritual beliefs.						
I think my GP is able to manage my illness outside of hospital.						
My family still rely on me.						
I can adapt to the changes in my lifestyle.						

	Strongly agree	Agree	Disagree	Strongly disagree		Doesn't Apply
Health professionals are happy to include me in decisions related to my illness.						
I want my family to continue to rely on me.						
My friends are always supportive.						
I still feel useful because I am in paid employment.						
I want my friends to continue to rely on me.						
My spiritual beliefs help me cope with my illness.						
I accept that I have to change my lifestyle.						
My friends still rely on me.						
Complementary therapies help me cope with my illness.						
I have a lot of confidence in my local GP.						
I need the support of my friends.						
I feel still useful although I am no longer in paid employment.						
I know my GP really well.						



DEBRIEFING / FEEDBACK QUESTIONNAIRE

Empowerment pilot study – Likert scale 2004.

Please tick the box th the response / number that best applies to you.

Q1.How long did it take you to complete the questionnaire?

- Less than 10 minutes 11 – 15 mins 16 – 20 mins
- 21 – 30 mins More than 30 mins

Q2.Did anyone help you to complete the questionnaire?

- No (go to Q4.) Yes

If yes, who helped you?

Q3. If yes to Q2, what kind of help did you have?

- Read questions to me Explained questions to me
- Explain answers to me

Other help – please specify below.

Q4.Were any of the questions difficult to answer?

- No Yes

If yes, which questions? _____
(please indicate to interviewer)

Q5. Did any of these questions upset / concern you?

No Yes

If yes, which questions upset you?
(please indicate to interviewer) _____

Q6. Do you have any other comments on the questionnaire?

Your birthdate (Day,month,year)____/____/____

PATIENT SUPPORT STRATEGIES QUESTIONNAIRE

Please indicate by marking with a tick (✓) whether you strongly agree, agree, disagree or strongly disagree with the following statements. Please read the statements carefully and tick your responses to them. **If a question does not apply to you please leave it blank.**

	Strongly agree	Agree	Disagree	Strongly disagree
1. I am capable of handling my illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I have all the information I need to manage my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I am capable of helping health professionals reach decisions related to my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. My family are very supportive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I need the support of my family and friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My family and friends still rely on me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I can adapt to the changes in my lifestyle.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Health professionals are happy to include me in decisions related to my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I want my family and friends to continue to rely on me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My friends are always supportive.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I still feel useful in my daily life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My spiritual beliefs help me cope with my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I accept that I have to change my lifestyle.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Complementary therapies help me cope with my illness.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I have a lot of confidence in my local GP.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix 2 Breast cancer patient interview questions

BREAST CANCER PATIENT INTERVIEW QUESTIONS 2005

QUESTIONS FOR INTERVIEWS (red italics provide the rationale for asking each question)

1. Explain what focus of interview is to be. *(Explaining that we are most interested in seeing how the person views their ability to cope with the treatment and the management of their condition. What helps them to get through and how they cope in specific ways).*

I would like to explore some of the types of support and also your own ways of coping with the illness. So firstly,....

2. Having now received treatment for your cancer - how important would you say that information about the condition was to you in helping you to manage your situation? Was there any particular type of information that you preferred? *(probing for preferred ways of receiving info – some patients for example like to attend support groups and others prefer to access the internet)*
3. How important is the advice that you receive from health professionals – such as doctors and nursing staff? Explore specialist and GP differences in supportive roles. Why / why not is this advice important to you? *(Most patients with a sense of empowerment and good self-efficacy are comfortable with listening to advice of health pros but can also rely on their own judgement. They are aware of the roles that HPs will play in providing support).*
4. *(If not discussed in previous ask...)* Have you been able to have a say / input into any decisions regarding your illness when meeting with your specialist / GP?
5. How do you see the future beyond your treatment etc? *(probing for ways in which future plans and goals are visualised and readjusted to allow for the illness. Learning to adjust and set realistic goals is an important part of the empowerment process).*
6. What keeps you going? Your main source of strength? *(Finalising type of coping strategies preferred by patient).*
7. Do you think of yourself as an optimistic person? Has the experience changed this in any way? *(Patients will who have accepted their illness will usually lean to scale back goals and expectations and this is a major factor in self-efficacy – i.e. realistic goal setting).*

8. How much do you rely on yourself to get through your treatment? *(Do patients have their own boundaries and mechanisms for coping? Also how much do they rely on their own inner strengths as well as family / friends support).*
9. Has this experience changed your relations in any way with your children / spouse / partner? *(Ability to work through the experience with family in a positive way).*
10. What about support from friends? Do you regard the support of friends any differently than family? *(Does the patient regard the support that they receive from friends any differently than family? Explore the differences.)*
11. When you are faced with a really bad day in relation to your cancer – how do you cope with it? What really helps you? *(Establishing main factors relating to patient coping strategies and ability to adjust and motivational strategies to cope).*
12. How do you regard religion / spirituality in terms of your cancer? *(Use only if the patient has not mentioned religion / spirituality previously)*
13. Complementary therapies? *(Use only if the patient has not mentioned complementary therapies previously)*
14. Any other issues relating to coping and management of the illness not addressed during our interview?

Appendix 3 Rasch Analysis Output and Tables for Patient Empowerment Scale

Table 4.5 Locations and item threshold estimates

In logits for pilot version PES using four categories for all items (reversed thresholds shown)*

Item	Location	Threshold 1	Threshold 2	Threshold 3
P01 I am capable of handling my illness	-1.076	-3.030	-0.272	3.302
P02 I have sufficient resources to handle my illness	-0.999	-3.146	-0.356	3.502
P03 I have enough information to handle my illness	1.266	0.680	-2.588	1.909*
P04 I want to be involved in making decisions related to my illness	0.333	5.381	-6.811	1.430*
P05 I am capable of helping health professionals reach decisions related to my illness.	0.316	-0.213	-1.959	2.173*
P06 My family are always supportive.	-2.399	0.893	-4.163	3.270*
P07 I am comfortable with seeing my GP.	-1.250	-3.516	0.656	2.860
P08 I am capable of making decisions related to my illness.	-0.990	-1.016	-1.783	2.799*
P09 I use complementary therapies.	0.937	-2.051	0.523	1.528
P10 The information that I have is relevant to managing my illness.	0.445	-0.848	-1.958	2.806*
P11 I need the support of my family.	-0.014	0.003	-1.440	1.438*
P12 I have spiritual beliefs.	1.183	-0.179	-1.134	1.313*
P13 I think my GP is able to manage my illness outside of hospital.	-0.473	-6.004	1.701	4.303
P14 My family still rely on me.	0.793	-1.989	-0.192	2.181
P15 I can adapt to the changes in my lifestyle.	-0.831	-3.766	-0.863	4.629

P16 Health professionals are happy to include me in decisions related to my illness.	-0.661	-4.472	0.340	4.132
P17 I want my family to continue to rely on me.	0.795	-2.223	-0.238	2.461
P18 My friends are always supportive.	-2.146	0.810	-5.239	4.429*
P19 I still feel useful because I am in paid employment.	1.394	-1.205	0.744	0.461
P20 I want my friends to continue to rely on me.	0.783	-1.892	-0.749	2.641
P21 My spiritual beliefs help me cope with my illness.	1.235	-0.236	-0.947	1.183*
P22 I accept that I have to change my lifestyle.	0.888	-1.161	-1.570	2.731*
P23 My friends still rely on me.	0.801	-2.803	-0.454	3.257
P24 Complementary therapies help me cope with my illness.	1.103	-2.067	0.045	2.022
P25 I have a lot of confidence in my local GP.	-0.927	-4.122	0.431	3.690
P26 I need the support of my friends.	-0.722	-3.063	-0.005	3.067
P27 I feel still useful although I am no longer in paid employment.	-0.910	-3.945	0.166	3.779
P28 I know my GP really well.	1.130	-2.251	-0.185	2.436

Table 4.6 Item locations and item threshold estimates pilot PES*In logits for pilot version PES using three or four categories as determined by initial analysis*

Item	Location	Threshold1	Threshold 2	Threshold 3
P01 I am capable of handling my illness	-0.868	-2.936	-0.252	3.188
P02 I have sufficient resources to handle my illness	-0.836	-3.087	-0.35	3.437
P03 I have enough information to handle my illness	1.168	-2.192	2.192	
P04 I want to be involved in making decisions related to my illness	-0.206	-2.048	2.048	
P05 I am capable of helping health professionals reach decisions related to my illness.	0.121	-2.487	2.487	
P06 My family are always supportive.	-2.184	-3.13	3.13	
P07 I am comfortable with seeing my GP.	-1.082	-3.436	0.645	2.792
P08 I am capable of making decisions related to my illness.	-2.095	-3.99	3.99	
P09 I use complementary therapies.	1.086	-1.933	0.458	1.475
P10 The information that I have is relevant to managing my illness.	0.373	-3.003	3.003	
P11 I need the support of my family.	-0.542	-2.122	2.122	
P12 I have spiritual beliefs.	1.152	-1.636	1.636	
P13 I think my GP is able to manage my illness outside of hospital.	-0.367	-6.02	1.697	4.323
P14 My family still rely on me.	0.993	-1.835	-0.284	2.119
P15 I can adapt to the changes in my lifestyle.	-0.655	-3.664	-0.9	4.565
P16 Health professionals are happy to include me in decisions related to my illness.	-0.436	-4.237	0.21	4.027

P17 I want my family to continue to rely on me.	0.929	-2.207	-0.247	2.454
P18 My friends are always supportive.	-1.908	-4.299	4.299	
P19 I still feel useful because I am in paid employment.	1.425	-1.492	1.492	
P20 I want my friends to continue to rely on me.	0.932	-1.844	-0.762	2.606
P21 My spiritual beliefs help me cope with my illness.	1.265	-1.454	1.454	
P22 I accept that I have to change my lifestyle.	0.648	-3.203	3.203	
P23 My friends still rely on me.	0.96	-2.717	-0.498	3.215
P24 Complementary therapies help me cope with my illness.	1.249	-1.957	-0.034	1.99
P25 I have a lot of confidence in my local GP.	-0.733	-3.909	0.288	3.621
P26 I need the support of my friends.	-0.787	-3.518	0.282	3.236
P27 I feel still useful although I am no longer in paid employment.	-0.87	-4.087	0.24	3.847
P28 I know my GP really well.	1.267	-2.241	-0.19	2.431

Table 4.7 Person residual values indicating misfitting persons (Values exceeding 2.5 [])

ld	location	stderr	residual fit
28	0.707	0.299	-0.329
27	3.386	0.428	0.657
29	0.707	0.299	-0.329
30	0.903	0.301	2.624
31	1.629	0.333	-3.952
32	1.856	0.339	-3.004
33	1.69	0.324	-0.458
34	3.185	0.395	-0.175
35	0.814	0.299	-2.269
36	5.157	0.699	0.929
37	3.261	0.408	0.419
38	2.092	0.369	1.75
39	0.391	0.334	-1.47
40	1.328	0.386	0.489
41	1.45	0.379	2.267
42	1.49	0.332	-1.316
43	2.172	0.414	-0.556
44 extm	6.428	1.218...	
45	2.421	0.386	-0.726
46	2.878	0.434	1.469
47	2.889	0.378	-1.822
48	0.169	0.336	-2.608
49	2.926	0.461	0.852
50	1.64	0.372	-1.678
51	0.994	0.359	-3.149
52	1.046	0.344	-3.112
53	3.641	0.469	2.107
54	2.613	0.371	-1.445
55	2.223	0.357	0.199
56	1.961	0.352	0.279
57	1.957	0.365	-1.505

58	1.552	0.386	-0.63
59	2.659	0.348	3.132
60	0.666	0.368	-2.089
61	2.741	0.396	-1.088
62	1.279	0.36	-1.54
63	1.312	0.334	0.287
64	0.484	0.297	-3.974
65	1.319	0.319	-3.624
66	2.861	0.372	0.083
67	3.029	0.379	1.2
68	4.944	0.706	-0.293
69	5.157	0.699	0.182
70	0.725	0.296	-0.92
71	1.117	0.333	-3.766
72	2.897	0.453	-1.859
73	2.23	0.373	-0.706
74	0.994	0.303	0.969
75	1.961	0.352	-0.002
76	1.586	0.343	0.392
77	3.565	0.452	-1.284
78	0.333	0.374	0.114
79	3.56	0.408	1.274
80	0.273	0.294	-1.038
81	3.108	0.376	2.239
82	1.652	0.329	-1.036
83	1.374	0.312	1.146
84	2.189	0.476	0.524
85	2.426	0.436	3.478
86	1.717	0.345	-1.194
87	2.31	0.37	-0.22
88	2	0.349	-1.166
89	1.935	0.365	0.246
90	2.313	0.336	0.282
91	4.552	0.729	0.071
92	4.853	0.597	0.505

93	3.667	0.43	3.278
94	4.268	0.716	0.535
95	1.884	0.4	1.021
96	1.173	0.373	-3.166
97	1.515	0.339	-1.686
98 extm	6.588	1.222...	
99	1.044	0.324	-3.485
100	2.129	0.384	3.187
101	0.523	0.345	-1.029
102	3.321	0.401	0.568
103	3.377	0.465	-0.568
104	1.184	0.312	1.528
105	3.402	0.396	0.116
106	0.587	0.328	-3.083
107	3.471	0.448	1.104
108	2.501	0.391	-0.225
109	1.277	0.31	-4.134
110	1.304	0.323	-3.975
111	2.32	0.345	4.029
112	1.327	0.365	-2.684
113	2.189	0.48	0.021
114	2.248	0.365	1.281
115	-0.063	0.29	0.116
116	5.428	0.891	-0.72
117	2.777	0.514	-1.968
118	1.304	0.323	-3.975
119	4.239	0.503	-0.355
120	5.873	0.866	-0.694
121	1.092	0.334	-0.955
122 extm	6.687	1.217...	
123 extm	5.839	1.262...	
124	0.553	0.293	0.195
125	0.916	0.408	-3.267
126	1.2	0.32	0.015
127	3.473	0.433	-0.272

Table 4.8 Item locations and item threshold estimates (four categories) for final PES

Item / statement	Item location	Threshold 1	Threshold 2	Threshold 3
1 I am capable of handling my illness	-1.185	-2.759	-0.488	3.248
2. I have all the information I need to manage my illness.	0.368	-1.86	-0.8	2.66
3. I am capable of helping health professionals reach decisions about my illness.*	-0.425	-0.996	-1.531	2.527*
4. My family are very supportive.*	0.004	2.058	-2.397	0.339*
5. I need the support of my family and friends *	0.254	5.572	-5.528	-0.044*
6. My family and friends still rely on me.*	0.772	-0.636	-1.383	2.019*
7. I can adapt to changes in my lifestyle.	-0.948	-3.555	-0.774	4.329
8. Health professionals are happy to include me in decisions about my illness	-0.862	-2.621	-0.928	3.549
9. I want my family and friends to continue to rely on me.	0.825	-1.219	-0.506	1.725
10. My friends are always supportive.	-1.119	-2.293	-0.327	2.619
11. I still feel useful in my daily life.	-0.835	-2.812	0.135	2.677
12. My spiritual beliefs help me cope with my illness.*	0.872	-0.565	-0.81	1.375*
13. I accept that I have to change my lifestyle.*	0.630	-1.086	-1.209	2.295*
14. Complementary therapies help me cope with my illness.	1.224	-1.612	-0.207	1.819
15. I have a lot of confidence in my local GP.	0.424	-1.25	-0.5	1.75

In logits for PES using four categories for all items

Table 4.9 Item threshold estimates for PES using three categories for all items

Item / statement	Item location	Threshold 1	Threshold 2
1 I am capable of handling my illness.	-0.594	-1.955	1.955
2. I have all the information I need to manage my illness.	0.601	-1.726	1.726
3. I am capable of helping health professionals reach decisions about my illness.	-0.612	-2.002	2.002
4. My family are very supportive.	-1.349	-0.988	0.988
5. I need the support of my family and friends	-1.184	-0.665	0.665
6. My family and friends still rely on me.	0.500	-1.598	1.598
7. I can adapt to changes in my lifestyle.	0.050	-2.631	2.631
8. Health professionals are happy to include me in decisions about my illness	-0.300	-2.292	2.292
9. I want my family and friends to continue to rely on me.	0.816	-1.041	1.041
10. My friends are always supportive.	-0.708	-1.500	1.500
11. I still feel useful in my daily life.	-0.158	-1.304	1.304
12. My spiritual beliefs help me cope with my illness.	0.592	-0.957	0.957
13. I accept that I have to change my lifestyle.	0.531	-1.689	1.689
14. Complementary therapies help me cope with my illness.	1.425	-0.918	0.918
15. I have a lot of confidence in my local GP.	0.392	-1.083	1.083

Table 4.10 Chi Square tests of individual item fit (using reduced categories)

Item (statement)	Location	SE	Chi Sq	Probability
9. I want my family and friends to continue to rely on me.	0.815	0.166	0.344	0.842
11. I still feel useful in my daily life.	-0.158	0.181	0.344	0.842
5. I need the support of my family and friends *	-1.184	0.206	0.36	0.835
12. My spiritual beliefs help me cope with my illness.*	0.592	0.131	2.353	0.308
8. Health professionals are happy to include me in decisions about my illness	-0.3	0.162	3.129	0.209
6. My family and friends still rely on me.*	0.5	0.186	3.146	0.207
13. I accept that I have to change my lifestyle.*	0.531	0.141	4.867	0.088
4. My family are very supportive.*	-1.349	0.154	5.42	0.067
14. Complementary therapies help me cope with my illness.	1.425	0.146	5.42	0.067
10. My friends are always supportive.	-0.708	0.143	6.884	0.032
7. I can adapt to changes in my lifestyle.	0.05	0.177	7.157	0.028
1. I am capable of handling my illness.	-0.594	0.146	7.747	0.021
15. I have a lot of confidence in my local GP.	0.392	0.125	8.759	0.013
3. I am capable of helping health professionals reach decisions about my illness.*	-0.612	0.147	9.224	0.010
2. I have all the information I need to manage my illness.	0.6	0.186	11.267	0.004

Appendix 4 Publications arising from the Shared Care patient interviews

PATIENT INVOLVEMENT IN CLINICAL NURSING

Haematological cancer patients: achieving a sense of empowerment by use of strategies to control illness

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Haematological cancer patients: achieving a sense of empowerment by use of strategies to control illness

Background. The role that empowerment plays through involving haematological cancer patients and their families in their treatment and care is undeniable. It encompasses the implementation of various strategies to achieve a sense of empowerment. **Aims and objectives.** This phenomenological study sought to identify core strategies used by cancer patients regardless of their illness stage and prognosis who exhibited a strong sense of empowerment in coping with their condition.

Design. A phenomenological approach using an in depth interviewing technique was used to identify the common factors which patients and spouses believed could enable them to achieve a measure of control in managing their illness. These measures were referred to as coping strategies.

Methods. It was decided to conduct a purposive study and re-interview seven of 12 patients who had previously participated in a pilot Haematology Shared Care project and who had developed a high level of ability in coping with their illness. At the patient's discretion, spouses were invited to participate and to contribute to the interview. Three spouses participated in the interviewing process.

Results. Common strategies emerged regardless of the patient's stage of illness and prognosis. Informants identified the determination to remain in control of the illness and treatment side effects, having the support of family and significant others, illness acceptance and maintaining hope as crucial to their sense of empowerment.

Relevance to clinical practice. It is hoped that clinicians will gain a deeper understanding of the varied and numerous strategies used by cancer patients in coping with their illness. This understanding will ensure that by encouraging these strategies, patients and their families will be supported by health professionals to achieve a greater sense of empowerment. As this and other studies have shown, working alongside health professionals contributes to empowerment for both the cancer patient and significant others in their lives.



Patient perceptions of the GP role in cancer management



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BACKGROUND

During the course of their cancer treatment, patients have to deal with a number of health professionals. We investigated patients' perceptions of the role of the general practitioner, with particular reference to GPs' ability to manage patients' cancer outside of the hospital setting.

METHOD

We took a phenomenological approach, focussing on empowerment, and any central role of the GP. In depth interviews were conducted on the same haematological cancer patients over a 2 year period. Results were analysed for main themes regarding support and management of illness.

RESULTS

Many patients had a long term relationship with an individual GP. They perceived GPs as providing a primarily supportive rather than treatment role outside of the hospital setting, and relied on them for clarification and reassurance.

DISCUSSION

The personal, confiding relationship between the GP and cancer patient might be better exploited by specialists. Patients could feel more empowered in relation to their condition if provided with information by their GP that is more relevant and explicit. For this to occur, specialists must first provide GPs with timely and pertinent information about their cancer management.

Cancer patients are seen by a number of health care professionals during their management. However, patients perceive many of these – particularly specialists and general practitioners – as filling diverse roles, serving very different purposes.^{1,2} The importance of GPs' ability to positively support cancer patients cannot be overstated,³⁻⁵ especially outside the hospital environment.^{6,7} We examined this particular role of the GP in a study exploring patient empowerment, and how this assists haematological cancer patients develop coping mechanisms in relation to their illness. Crucial to this role is the quality of communication between specialist and GP.⁸

Method

We used qualitative phenomenological methods, investigating the experience of subjects through in depth interviews. The reality of an illness was defined by what was consciously experienced by the patient.⁹ In depth semistructured interviews were conducted on a sample of 13 patients with haematological cancer participating in a pilot intervention project based on shared care. Patients assessed their control over the management of their condition and their communication needs. A second set of interviews was conducted with seven of the patients to further investigate patient coping strategies (the remaining six patients could

not be re-interviewed because of ill health, death or relocation).

Ethics approval was granted by the Human Research Ethics Committee at the Sir Charles Gairdner Hospital where patients were receiving treatment.

Transcripts of patient interviews were analysed using QSR Nvivo.¹⁰ Themes and subsequent categories were distilled. The specific role of GPs in the management of their condition was examined from the patients' point of view.

Results

Although patients commented on the roles of different health professionals, here we only report on the role of the GP. Three main themes emerged: patients valued the close relationship, based on trust, with their GP; they relied upon their GP for clarification of information and treatment options provided by the hospital; and they preferred the familiarity of both the surroundings and the trusted relationship with their local GP, ie. they preferred continuity of care with the GP.

Establishing a relationship of trust

Most patients interviewed believed they had a good relationship with their GP in terms of communication and familiarity (Table 1). The GP was seen by one as an advocate who could intervene when the patient was unclear or concerned about the result of a hospital visit. However, most preferred

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Empowerment of cancer patients in terms of taking greater control of their treatment and care has been noted in recent research (Clark, 1996; Davison and Degner, 1997; Eddleman, 1994). Nonetheless, research into how empowerment may be characterised in patients with severe illnesses and how they might seek to maintain control over their lives under such burdensome circumstances, is still in its infancy. Some studies suggest that participating in and having some say in their own treatment and care is beneficial to many patients (Cartmell, 2000; Davison and Degner 1997). It is, also, believed that being informed about their condition and prognosis is empowering and ultimately contributes to the wellbeing of many patients and their families (Morris and Royle, 1988). Further, the strategies which people diagnosed with cancer use to cope with their illness are varied, individualistic and governed largely by the liminality of their experience of the illness (Little, 1998). The research presented in this chapter sought to identify how patients with cancer seek to empower themselves given the initial perceived loss of control over their physical and mental health, and what strategies and resources they recruit to aid themselves in regaining some sense of control. Twenty patients diagnosed with different types of cancers during the period 2002 to 2003, participated in a series of in-depth interviews regarding their illness and their concerns thereof, their perceptions of the roles and reactions of family, friends, and health professionals, and their use of strategies to deal with their circumstances.

Two theoretical formulations which were initially developed in the field of psychology, may be generalised to provide a framework within which to understand the most pertinent elements of empowerment in coping with life-threatening illnesses such as cancer. These two theories are, firstly, Bowlby's theory of grieving (Bowlby, 1980) and, secondly, Bandura's concept of self-efficacy (Bandura, 1994). Bowlby's theory of a grieving process enables us understand the emotional reactions of people to a diagnosis of cancer and their progress in trying to attain a sense of control over and acceptance of - though not resignation to - the situation.

Self-efficacy refers to the beliefs people have about their competence in being able to achieve certain goals. High self-efficacy is characterised by awareness of all pertinent aspects of a situation, personal goal-setting, perseverance, and confidence in one's ability to reach valued goals. These characteristics can empower people to use a range of differing but appropriate strategies to achieve goals, and to use all pertinent resources to make decisions about how best to proceed. Further to this, in operationalising such goals through coping strategies, the patient engages in a self-regulatory process which ultimately leads them to achieve a sense of empowerment about their condition. Zimmerman (2002) noted that self-regulatory learning does not solely rely upon the person themselves to succeed but also includes the instruction, modelling and encouragement of others including peers. In this study, the role of significant others is shown to be crucial to patients in achieving this sense of empowerment through self-efficacy and self-regulation. The notions of self-efficacy, self regulation and empowerment are, therefore, linked in that high self-efficacy may be seen as necessary for a person to engage in the actions (self-regulation) to achieve personally-selected goals which are epitomised in the idea of empowerment.

Appendix 5 Publications arising from the development of the Patient Empowerment Scale

The Psychometrics of Developing the Patient Empowerment Scale

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ABSTRACT. Although patient empowerment is widely acknowledged as important by health professionals it remains a somewhat nebulous concept. An initial empowerment measure has been developed through an extensive review of literature combined with a series of in-depth interviews of cancer patients concerning their use of coping strategies. The results were analysed for major themes in relation to sense of control over the illness. A set of twenty-eight statements were formulated from themes into a

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Likert-type scale for self-completion by 100 cancer patients. The scale could be used in assessing level of empowerment amongst cancer patients thereby establishing through this information, the patient's ability to make decisions about coping with their illness. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2006 by The Haworth Press, Inc. All rights reserved.]

KEYWORDS. Coping strategies, measurement, patient empowerment, patient support, Rasch Model

INTRODUCTION

Undoubtedly, empowerment of patients with a chronic illness such as cancer is of vital importance in helping them address and cope with their illness and reduce psychological distress (Anderson, 1996; Link, Robbins, Mancuso, & Charlson, 2002). The loss of control experienced by most patients can only be addressed by ensuring that patients are involved more fully not only in the management of their condition but also in decisions regarding treatment options (Auerbach, 2000; Brundage et al., 2001). Regardless of prognosis, empowerment manifests itself in patients who have successfully regained a measure of control over their condition (Bulsara, Ward, & Joske, 2004). Nonetheless, empowerment remains a concept which is difficult to define in a measurable and relatively objective way. Furthermore, there is a need for the understanding of patient empowerment to progress from an abstract conceptual idea to a valid, practical measure for use by health professionals. Such a measure will assist them in acquiring an indication of the level of a patient's coping ability and self-efficacy in terms of managing their illness and consequently aid in making decisions about support strategies. The empowerment scale focuses on both coping strategies and self-efficacy because only those patients who achieve both can be empowered, that is, because it is possible for a patient to feel that they are coping with their condition but have little control over how they manage their treatment and side effects. It is an intrinsic sense of self-efficacy which facilitates the use of coping strategies to achieve the patient's sense of empowerment. Some existing scales identify psychosocial aspects of a patient's ability to deal with their condition and incorporate markers for anxiety, depression and mental adjustment to cancer (Watson, Greer, & Young 1994; Akechi, Okamura, Yamawaki, & Uchitomi 1998; Zigmond & Snaith, 1983).

QUALITY OF LIFE

distress and physical functioning shown in the initial study is confirmed, but again does not explain the whole picture. Patients will be followed up for 2 years, the baseline and follow-up results may inform the implementation of routine psychosocial and QL assessment in oncology practice.

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Women with Breast Cancer: The Relationship of Anxiety, Depression, Age, Stage of Cancer and Cancer Treatment to the Quality of Life

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PURPOSE: The aims of this study was to evaluate the dependency of quality of life of breast cancer patients upon the level of anxiety and depression, the age of the patients, the stage of cancer and cancer treatment. **MATERIALS AND METHODS:** The study cohort comprised 63 women with breast cancer treated in the Department of Breast Surgery of Institute of Oncology. EORTC QLQ-C30 questionnaire and Hospital Anxiety and Depression Scale (HADS) were used for the study. **RESULTS:** The study revealed that borderline and abnormal results in HAD scale correlates with worse results of General quality of life, Emotional and Cognitive functioning. Higher depression level correlates with worse results in Insomnia and Financial difficulties. The results in Physical functioning, Insomnia and Constipation were statistically reliably worse in women 60 years and elder than in younger ones, but the results in Social functioning were worse in younger patients. For the patients with I–II stages of breast cancer results of Role and Cognitive functioning scales were statistically reliably better than those of the patients with III–IV stage. There was no statistically reliable difference found in Quality of life of women treated for breast cancer for the first time and those treated repeatedly. **CONCLUSIONS:** Worse results in Quality of life of breast cancer patients depends upon higher level of anxiety and depression, elder age, higher stage of disease, but does not depend upon cancer treatment.

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Measuring a Sense of Empowerment in Cancer Patients

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The concept of empowerment and the degree to which it exists amongst cancer patients is often overlooked within the clinical setting in hospitals and amongst health professionals. Although in theory, many doctors acknowledge the importance to patients of regaining some measure of control over their illness, in reality empowering patients proves problematic. Given the liminality of the cancer experience many patients struggle to maintain a sense of empowerment whilst coping with their condition. Nonetheless, it is evident that management of the illness in terms of understanding, acceptance and adapting one's lifestyle is beneficial to most patients. Trying to identify markers for empowerment in terms of coping strategies employed by cancer patients is possible. Following a qualitative phase of the research, a preliminary scale has been developed which seeks to identify and name these markers to measure the degree of empowerment present in cancer patients. A Pilot Scale was developed and implemented amongst patients attending the Haematology Care Centre of a teaching hospital in Perth, Western Australia. The findings, analysed using Rasch analysis, identifies which markers have most relevance to cancer patients' ability to cope with the management of their illness. A further refined scale is currently being administered to a wider group of cancer patients attending Medical Oncology and Radiation Oncology clinics. It is hoped that health professionals will use the scale to assist in establishing areas of strength and weakness in the cancer patient's ability to adjust to and manage their condition.

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Native American Cancer Education for Survivors (NACES)

Burhansstipanov L¹, Krebs LU², Hariton J¹, Dignan MB³, Gamito E²

Appendix 6 Publications arising from the breast cancer patient interviews

Austral-Asian Journal of Cancer Volume 7 (3) July 2008: pp 145-150.

Abstract

This study adds to previous body of knowledge regarding self reliance amongst patients in the face of life limiting illness such as cancer. A phenomenological approach using an in-depth interviewing technique was used for this study. A consecutive group of women receiving adjuvant chemotherapy for early breast cancer were selected. Those who consented to participate were interviewed by telephone. The overarching theme amongst patients reinforces the significance of self reliance amongst cancer patients in maintaining control over their illness. Although acknowledging the merit in accessing various mechanisms of support, all patients also highlighted the importance of being aware that they largely must rely on themselves. Furthermore, in order to overcome treatment side effects, a patient needs the self determination to succeed. The initial shock and anxiety experienced by many cancer patients following diagnosis is often accompanied patients being overwhelmed with a plethora of information about their condition and it's management. As the treatment regimen proceeds, patients become aware that although they value the support given from various sources, they also need time and space to self-reflect and draw on inner strength in managing their illness. Health professionals need to allow patients the time to work through the advice given and to trust in the patient ability identify and build upon their inner strength.



Book chapter Nova Publishers

**MOTIVATING WOMEN WITH BREAST CANCER TO ACHIEVE
EMPOWERMENT BY THE USE OF SUPPORT STRATEGIES**

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Abstract

Breast cancer patients often experience shock when receiving a diagnosis of cancer and are at a loss as to how to convey the information to family and close friends. The process of adjustment is likely to take some weeks as patients learn how to adapt their lifestyle once treatment begins and to regain some control over their situation. For some patients this process will be easier than for others. Clearly there are some patients who cope better with the adjustment. However, the particular circumstances which seem to help with the coping process are not clearly understood. This study sought to identify one of many support strategies which patients utilize to take control over their illness. Specifically, the positive interaction with health professionals that enables patients to navigate their way through the management of their illness and side effects of treatment in order to attain a measure of control.



MP/mab/Ethics2002-128a
Ext 2999
12 February 2003



Dr Caroline Bulsara
School of Population Health
1st Floor, 45 Stirling Highway
UNIVERSITY OF WESTERN AUSTRALIA

Dear Dr Bulsara

HUMAN RESEARCH ETHICS COMMITTEE – Trial 2002-128: The Role of Empowerment in the Wellbeing of Cancer Patients

Thank you for your letter dated 10 February 2003 responding to the concerns of the Committee. Please be advised that ethical approval of the project has been granted by the Human Research Ethics Committee. The approval is for the proposal dated 9 December 2002, the participant questionnaire, and the Patient Information and Consent Form dated 28 January 2003. Approval is granted on the understanding that the project will commence within twelve months of the date of this letter or a new application may have to be submitted. Equally if the project is discontinued before the expected date of completion the Committee must be informed and the reasons provided for the cessation.

Whilst the Committee is satisfied that the protocol as submitted has adequate safeguards to protect the rights of individual participants it is the responsibility of the researcher to advise the Committee of any departure from the original protocol which could impact on this ethical approval.

Please be advised that this committee complies with the National Statement on Ethical Conduct Involving Humans. Thus, we are bound by National Health and Medical Research Council (NH&MRC) guidelines to monitor the progress of all approved projects until completion to ensure that they continue to conform to approved ethical standards. Therefore you are required to submit annual reports on the human rights aspects of your study and immediate reports of any serious adverse events. You are also requested to submit for approval copies of advertisements to be used to recruit subjects (if applicable). An annual report is due each year on the anniversary of the project's approval date. A reminder will be posted to you several weeks in advance.

As the responsibility for the conduct of the trial lies with you as the investigator, all correspondence to the committee should be signed by you. Please quote Ethics 2002-128 on all communications associated with this study.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'M Platell'.

**DR M PLATELL
DEPUTY CHAIR
HUMAN RESEARCH ETHICS COMMITTEE**

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