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**JOURNEYS IN UNDERSTANDING:
FINDING MEANING IN THE
EXPERIENCE OF CANCER**

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fulfilment of the requirements for the degree
of Master of Arts in Psychology
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I mean, in a way, what I'm hoping will come out of your study is that maybe people will realise, - have a much greater understanding of the journey that people with cancer go on, and the stages that they move through, rather than, like, let's just attend to their physical well being and then hopefully, they can just slot back in to the life that they had before. (Kate)

ABSTRACT

Experiencing serious illness holds significance in peoples' lives in ways that go beyond the actual medical condition. Research has found that finding meaning in traumatic life events, such as serious and life threatening illness, is an important part of coping. Having cancer is widely agreed to be the kind of event that would be very traumatic for almost anyone. There may be difficulty in relating to such an event without at the same time experiencing a sense of loss of meaning in life. The focus of the study was on the processes of finding meaning and aspects of the experience that may impact, either positively or negatively, on the ability to find meaning. Five male and six female adults were interviewed about their personal experience of having cancer. An interpretive phenomenological approach was used in order to be open to the structures of meanings in individual lived experience. Findings showed that apart from differences in individual contexts that impacted on the nature of the experience of cancer, the quality of interactions were influential in finding meaning in what had happened. Interconnectedness with others was vital for a sense of self-worth, belonging and commitment to life. The experience of suffering meant that people were brought face to face with the vulnerability of human life. Regaining a sense of life as meaningful was a process involving the integration of the illness implications into perceptions of the self, others and life in general. Through personally experiencing the reality of human vulnerability and the limits of personal control there grew possibilities for a greater acceptance of life as it is, increased tolerance for others and a sense of communality with them, and a growth in self awareness. Personal control was regained through taking responsibility over choices of how to respond to such an event. Regaining control in ways that were achievable signalled an acceptance too of those things that were beyond control. There were re-evaluations about what was important in life. A general change in life focus incorporated the realities of what had happened, thus making them more understandable. A process for finding meaning in the experience of cancer is suggested, and aspects of the experience of illness that are influential in this process are proposed. The search for meaning in serious illness is an ongoing process and participants were at different stages in the journey of understanding. Greater understanding of the lived experience of cancer helps in raising general levels of sensitivity and awareness of the personal crisis that going through such a serious illness means.

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CHAPTER ONE

INTRODUCTION

When people experience stressful events in their life such as the diagnosis of a serious illness, their belief that the world is meaningful or that they have self worth, can sometimes be disrupted. Assumptions about self identity as well as goals and expectations, which were previously taken for granted, may suddenly be challenged. These assumptions may no longer seem meaningful or possible in the context of the new situation. Finding meaning in traumatic and unchangeable life events has been found to be an important part of coping with what has happened and may be a way that people regain a sense of coherence and purpose in their life (Thompson & Janigian, 1988).

The Conceptualisation of Meaning in Illness

Meaning in research on illness has been conceptualised in different ways. Broadly these conceptualisations fall either into the meanings represented by the illness on a cultural level, the implicit meaning that an illness may hold for a particular individual at a particular time, and the search for meaning that may occur as a result of having the illness.

The illness may have meaning in itself, such as what it means to have cancer compared to what it means to have AIDS, or diabetes. Looked at in this way, the illness has meaning through the stigma that it holds. This kind of meaning may impact on the social identity of the sufferer through the cultural representation of the specific illness at the particular time. Illness representations may change over time so that the meaning of an illness evolves. This kind of meaning is related to the seriousness of the illness, perceptions of its causation such as whether it is thought to be contagious, and levels of fear about it (Kleinman, 1988).

As well as representing meanings at a cultural level, illness may hold implicit meaning. As Thompson and Janigian (1988) explain, the implicit meaning of a negative life event refers to the meaning of what has happened for the particular individual. Implicit meaning varies between individuals experiencing the same illness depending on the varying levels of inner resources that they perceive that they have. How prepared a person feels to cope will in turn determine their appraisal of the illness as benign, as a

threat or a challenge. Implicit meaning also varies because illness occurs at different times of life, and in differing personal contexts.

A third kind of meaning comprises the significance that the illness holds in the wider context of life, in terms of personal beliefs about the self and the world in general. Whereas implicit meaning is inherent in the situation, a search for this kind of meaning occurs as a result of what is experienced, and in that way is distinct from implicit meaning or illness representation (Thompson & Janigian, 1988). However, the meaning of the particular illness and how the event is appraised will determine to a certain extent the amount of disruption that is felt and a search for meaning in what has happened derives from a need to understand when a person's world is so disrupted that understanding is lacking.

Thus, this kind of meaning makes sense of what has happened within the wider context of life and allows the person to regain a sense of purpose in living. Meaning serves the functions of providing both order and purpose. These provide a sense of life proceeding in a way that is understandable and predictable, as well as a value for particular ways of living (Thompson & Janigian, 1988). Meaning may be found by drawing from previous experience and beliefs about life that are able to place the event within a wider context that provides meaning. However, sometimes existing understandings are not sufficient to explain the full implications of such an event. Finding meaning then may involve a process of reassessing ways of viewing life in order to find a position where what has happened is congruent with personal beliefs.

Research suggests too that the search for meaning is not something that has an endpoint but is an ongoing process involving constant adjustments as circumstances change (Denne & Thompson, 1991; Fife, 1994; Silver, Boon & Stones, 1983).

Cancer as an Example of a Traumatic Event

Research suggests that the magnitude of stressful events is difficult to measure without taking individual responses to the events into account. It is clear that what is very stressful for some, is less so for others (Lazarus, 1993). Differences in responses may be due to personal or contextual factors. However, there are some situations that are so likely to be traumatic that individual differences are less likely to be a factor in determining peoples' responses (Janoff-Bulman, 1992). In other words, some events would be devastating for almost anyone.

Included in this type of event are things such as violent crime, rape, natural disasters, combat situations, and life threatening illness. A life threatening illness such as cancer is one example which often involves facing the reality of one's mortality, which although known at some level, in daily life tends to be ignored. Fife and Taylor (1995) suggest that both the physical and emotional pain of cancer alter reality and threaten existing meanings.

Filipp (1992) suggests that cancer is prototypical of experiences of loss and crisis in a more general sense. He points out that there are often no ready to hand ways of responding in terms of cultural rituals or customs and that a diagnosis of cancer is likely to result in disruption and disorganisation.

Experiencing a life threatening illness may be an example of what Frankl (1964) refers to as an existential crisis, an experience that leads a person to re-examine their existence in the context of the new, unchangeable circumstances. Previous goals and expectations may suddenly be interrupted and sometimes no longer achievable. Even the word 'cancer' conveys a wealth of meanings associated with pain, suffering and death. Increasing the traumatic nature of the experience is the fact that it is not controllable by the person. That receiving a serious diagnosis of cancer is a life event that would be considered traumatic by almost anyone is widely agreed upon (Filipp, 1992).

Filipp (1992) suggests that there are aspects of time that may make a difference to the nature of the experience of cancer. He claims that "*when* certain events occur in people's lives is often a much more important issue than *whether* these events occur at all." (p. 33) This is for reasons that are understood from both a biological and a social angle. Wortman and Silver (1992) suggest that timeliness of occurrence of a traumatic event may be one of the factors that influence the variability that has been found in coping responses in situations of loss.

Thus, time of life may make a difference either because of age or time of life in terms of the fulfilment of valued roles. Janoff-Bulman (1992) points out that there is research to show that in cases where beliefs have been questioned through previous trauma, or a greater recognition of vulnerability in older people through life experience in general, that difficulty in facing trauma is reduced. The time since diagnosis is perhaps significant as well, as is perceived survival time. These are contextual elements that are likely to vary for each person.

An awareness of the role of time, is also an acknowledgement that the experience of cancer is a process that will undergo change, making the nature of the experience for any individual at a particular moment, part of that process rather than something that is unchanging or static. The issue is not whether having cancer is traumatic or not, but an acknowledgement that contextual factors may impact on how difficult it is to understand.

In attempting to understand how people cope with having a serious illness it is important to look beyond the medical condition to what significance the illness holds for the individual (Kleinman, 1988). Medical expertise often fails to acknowledge personal experience where illness has an impact beyond the physical aspects of suffering. It is important to recognise that a person's view of themselves in relation to their world may be changed. Many medical professionals may see less of their cancer patients once treatment is over and may be unaware of the nature of their adjustment problems (Carter, 1993). As Taylor (1983) points out, most people work through their problems using their own resources and social networks, rather than calling on professional help.

The experience of serious illness can be viewed as a time when sources of meaning may need to be re-evaluated in order to be able to find meaning that incorporates the reality of what has happened. Understanding the processes involved that allow the experience to be more fully understood is important for a better understanding of the experience of people with both terminal and chronic illness. Since treatments for cancer are improving and more people with cancer are living longer, the study of factors that may impact on quality of life is important (Taylor, Lichtman & Wood, 1984).

What is a Sense of Meaning?

Rather than philosophical questions about the meaning *of* life in a more cosmic sense, meaning here refers to meaning *in* life. Battista and Almond (1973) suggest that meaning in life depends on a person having a concept of life that they feel committed to and a feeling of fulfilment in relation to that concept. This view acknowledges that the actual belief system may vary between people, but the important thing is that the person has a framework for viewing life within which they are able to understand life and their place in it. What a concept of life provides is a sense of life as reasonably orderly, predictable and therefore understandable in spite of experiences that at times seem senseless (Thompson & Janigian, 1988).

Finding meaning in the things that happen is the way that humans are able to understand their life (Steeves, 1992). Frameworks for understanding develop from previous experience and are used to make sense of every day occurrences. People interpret events, and feel understanding because of the meanings that these events convey to them. Thus, finding meaning enables people to experience their world as coherent rather than random and chaotic.

Although there are different ways of looking at meaning, it has also been suggested that these different types of meaning all contribute to the ability to find a sense of meaningfulness after a traumatic event. In other words, to be able to find significance in an event which provides a sense of meaning, it is perhaps necessary to have a sense of being able to understand what has happened in a wider sense. This involves the meaning that the particular event holds for a particular person, as well as cultural and social representations of the event that impact on how much of a threat that it is perceived to be. In addition, the ability to relate to what has happened involves attributions of causation and the strength of inner resources in terms of religious or personal beliefs, and previous experience.

Meaning provides a sense that life is worth living because it can be experienced as orderly and purposeful. Even when an event occurs which is beyond personal experience up until that time, attempts are made to make sense of what has happened within the existing framework of inner beliefs about the world. In this way, people try to work out what meaning events hold so that they can understand them and see where they fit within the wider scheme of their life concepts.

Frankl (1967) claims that humans are oriented towards meaning, that they have a "will to meaning" (p. 10). In this way meaning is a motivational aspect of being human which helps in understanding life and the way in which it proceeds. Antonovsky (1987) too suggests that when meaningfulness is felt, there are aspects about life that make sense to the person, that the person cares about, and that they feel are worth being committed to.

In perceiving that one's life and the world is to a certain extent predictable, there is also a sense that things will turn out reasonably well (Antonovsky, 1987). Thus, inherent in feeling a commitment to life as orderly and meaningful, people place value on particular ways of living for themselves, developing goals which they would like to reach. Thompson and Janigian (1988) propose that people who have a sense of life as meaningful not only have goals, but a sense that their goals are important and that they

are able to play a part in reaching them. This sense of meaning, implying a value placed on particular ways of living, is felt too in relatedness which according to Debats, Drost and Hansen (1995) can be experienced through contact with the self, other people and the world. This provides a sense of belonging, of being part of the world. Debats et al. suggest feelings of alienation from the self, others and the world are likely to mean that a sense of meaninglessness is felt.

In these ways, meaning in life provides reasons and purpose for living. Meaningfulness implies that life is understandable, and that people have goals which they value, and feel able to achieve. This confidence is based on assumptions about the ways in which life generally proceeds (Thompson & Janigian, 1988). Thus meaning arises from a sense of being able to understand the things that happen through a lifetime through a sense of order and predictability. It arises too from placing value on particular ways of living that provide purpose. To gain a clearer understanding of how a sense of meaning is felt it is important to understand how frameworks for understanding might develop and provide a basis for building assumptions about the world.

Frameworks for understanding and assumptions about the world

According to Janoff-Bulman (1992), people develop a view of the world and of their own place in it throughout childhood, through being 'looked after', and having their needs met. She suggests that most people assume that the world is in general a benevolent and meaningful place, and that the self is worthy. People tend to be optimistic about themselves and their own lives, and to trust that the world is a just place. Furthermore, they generally view themselves in a favourable light, feeling that mainly good things will happen to them. Usually, since these assumptions are taken for granted and almost beneath the level of awareness, they remain unquestioned.

Although somewhat idealistic and even unrealistic these assumptions are thought to be adaptive as they enable people to experience life as meaningful, predictable and purposeful (Janoff-Bulman, 1992). Research has found too that they are very generalised and do not mean that in specific situations an individual will be lacking in self criticism or unable to learn from experience. However, they can lead a person to assume that they have a certain invulnerability (Weinstein, 1980, cited in Filipp, 1992) which although providing the person with a feeling of confidence, makes a traumatic event come as a shock.

Drawing on research about world and self views, Thompson and Janigian (1988) further propose that people have a life scheme as a way of viewing their life as a whole. This means that their life, past and future, can be viewed by them as a teleological 'story',

with themselves as protagonist. Through the life scheme the person has a concept of themselves and life, based on unspoken assumptions. They have goals which may be conscious and concrete, or vague and unformulated. These goals provide a purpose for living in that they hold value for the person. The life scheme itself is not necessarily explicitly formulated but more in the nature of assumptions about the self in relation to the world which tend to provide feelings of personal control and the ability to achieve goals.

A person may have a view of the world which enables them to understand loss, and negative or traumatic life events (Taylor, 1995). Wortman and Silver (1992) suggest that some people may be less vulnerable to the effects of loss because of learning gained from religious or philosophical views, or some ways of viewing the world. These approaches towards life may in some ways prepare them for situations of loss and suffering. However, as Filipp (1992) points out, traumatic events in general are not something that people are usually socialised for either through formal education, or through role models as there is a cultural focus on remaining optimistic and looking on the bright side of life.

Although beliefs about the world are often unquestioned, because they are very generalised they can fit with most life events with gradual change and adjustments (Janoff-Bulman, 1992). In times of crisis when the reality of death and human vulnerability come much closer, things that are normally not given very much thought such as the fragility of existence, are confronted as personally relevant. The protection that these basic beliefs about the world provide may then be at risk because they may no longer seem feasible or sustainable in the new and usually uncontrollable situation. Gradual adjustments may not be adequate or possible in the situation and changes may need to be made to inner beliefs in order to make sense of what has happened.

Responding to negative life events

Moving from a position of feeling that one is living in a benevolent world to one where that world seems suddenly untrustworthy and where the vulnerability of the self is highlighted, there may be difficulty in rebuilding or reinterpreting the self and the world in a positive way that is authentic with the changed circumstances. Part of the ability to feel a sense of meaning is through the perception of personal control inherent in these kinds of world and self views (Janoff-Bulman, 1992). A sense of having control allows a feeling of personal effectiveness and the ability to make a difference in one's life. Experiencing a life crisis such as a life threatening illness may result in feelings of loss of control and the ability to understand. If pre-existing frameworks for understanding are inadequate for explaining a very negative event there may be a loss of meaning. For a

sense of meaning to be regained there is a need to have a sense of being able to understand what has happened, to fit it meaningfully within the a wider context of life concepts and in doing so, to restore a sense of order in the way that life is perceived.

Taylor (1983) suggests that finding meaning following a traumatic event may depend on the ability to maintain or rebuild adaptive assumptions about the world. Thompson and Janigian (1988) provide a framework within which to conceptualise the ways that finding meaning may take place. As life events occur the life scheme may need to be changed and this is achieved by assimilating the experience through re-evaluating and adapting priorities, self views, world views and goals, that may no longer be feasible. In providing a sense of life as coherent and predictable, this way of re-finding meaning is achieved through the processes of understanding and integrating the wider implications of what has happened into ways of viewing life.

Another aspect of finding meaning proposed by Thompson and Janigian (1988) is changing perceptions of what has happened. This kind of meaning can modify distressing perceptions of the situation. Further, a sense of significance for what has happened may grow in using what has been learnt through the experience to be of benefit to others.

Thus, meaning may be found through adapting the life scheme so that the new circumstances are explainable. Reframing perceptions of the illness experience increases the likelihood of being able to fit it within the life scheme, and means that there is a possibility that the experience may have some positive outcomes, even if these are not directly for the individual concerned. These ways of finding meaning involve an integration of the changed reality into ways of viewing life so that traumatic events that may occur during a lifetime become more understandable. In addition, changed perceptions may provide purpose for the event. Fife (1994) suggests that these two aspects of finding meaning can be viewed as part of the coping process and part of the coping outcome, respectively.

Looking at ways that people respond to negative events in their lives demonstrates the ways in which people make attempts to make sense of the events, and to search for significance for them having occurred. Examining ways in which people view the world and the self in relation to the world, throws light on what is involved in a loss of meaning through experiencing a serious illness such as cancer. The search for meaning may then be viewed as a way of trying to make sense of the situation, to understand the full implications of what has happened, and to find ways to restore a sense that life is worth living.

Ways of finding meaning

Frankl (1964; 1967) describes three ways in which it is possible to find meaning. People find a sense of meaning through their own creativity in ways that they give to the world, by receiving from the world through experiencing and thus encountering aspects of others and the world that are valued. Finally people find meaning through the stand that they take in facing life's adversities, those situations that cannot be changed. Frankl concludes that meaning can never be lost as individuals always have a choice about the ways in which they face adversity. In discussing the search for meaning and purpose in life, Frankl suggests that life is the question, and the answer is in each individual's response to that question; the way in which they choose to live their life. An important dimension to meaning in Frankl's view is that which is gained through self transcendence. Drawing from his own experience he proposes that even at times of extreme suffering, meaning can be found in moments when people experience a broadening of focus beyond self boundaries and concerns, which enables them to reach a heightened appreciation of the value of life and others. These moments foster a sense of belonging, appreciation of life and being part of a greater whole.

In a similar way, Yalom (1980) suggests several ways in general that people achieve a sense of personal meaning in their life. Altruism, dedication to a cause and creativity have in common with the views of Frankl (1964; 1967) that they tend to focus the person outwards beyond themselves leading to self transcendence.

Altruism involves serving others and trying to make the world a better place through the way that one behaves. Dedication to a cause usually has an altruistic element but may include membership of a group, trying to improve things for the oppressed, and being involved with something that will survive beyond personal death. Yalom (1980) suggests that creativity too can provide a sense of meaningfulness, and can be related not only to works of art but to the way that life is lived. Apart from the altruistic meaning that may be derived by discovering and creating beauty that can be shared by others, creativity also leads to moments of self discovery as unconscious understandings are made more explicit.

Other sources of meaning suggested by Yalom (1980) are hedonism and self actualisation. Frankl (1967) on the other hand claims that self actualisation is more a by-product of meaning than a source of meaning. Hedonism involves enjoying life to the full and appreciating it as a gift. Meaningfulness is gained from accepting and making the most of what life has to offer. In striving for self actualisation people are aiming towards reaching their potential, and this provides goals and purpose for life. These are

ways of finding meaning through framing perceptions of life and building meaning by the way that life is lived. In these ways a sense of meaning provides guidelines on how to live, if not always on why we live (Yalom, 1980).

Finding positive meaning through feeling relatively fortunate in some ways, or through finding positive aspects to the experience, has been linked to better coping. In some cases people may respond to the experience in ways that provide new meaning by taking up projects that are linked to the event and that will help others. Even though the event itself may be negative, it will have had a purpose in leading to something worthwhile (Thompson & Janigian, 1988).

Denne and Thompson (1991) also found that meaning was derived from self transcendence when there was a heightened appreciation of just 'being'. In their phenomenological study important aspects of the process of finding meaning were highlighted, although they point out that these were experienced in very different ways. They found that people moved towards an acceptance of personal responsibility for the way that they lived their life, which they approached proactively. Participants confronted and admitted aspects of their personal situation or themselves that they had resisted admitting before. There was a movement towards congruence between experience and personally meaningful concepts, even if this happened over a period of years. In other words, what was felt to be meaningful needed to be backed up through experience, and vice versa. There were decisional turning points involving decision, risk and acceptance of possible outcomes whether positive or negative. And overall, there was progression towards a balanced relationship between the self and the world. This description of the process of finding meaning can be viewed as a proactive movement towards ways of living authentically within particular personal circumstances with an acceptance of the self as well as the world as it is.

The ways that people find a sense of meaning arise out of the way that they respond to events, how they understand them within the broader framework of their life as a whole, and how they manage to live their life in a way that is authentic in terms of their personal circumstances and their wider beliefs.

Recent Research on Finding Meaning in the Experience of Cancer

Research has in general supported the conceptualisations of a sense of meaning and finding meaning outlined above. The main areas of focus have been variations in personal and illness factors associated with a sense of meaning after experiencing

cancer, as well as the processes involved in searching for meaning and how it takes place. Other studies have focused on ways in which it is possible to find meaning.

People may not necessarily identify themselves as searchers of meaning (Dirksen, 1995; Taylor, 1995; Thompson & Pitts, 1993). The reasons suggested for this are that some people are more able to make sense of the situation based on their existing understandings (Taylor, 1983), or that for some people, reasons why the illness occurred and its impact on their life is not a major concern (Dirksen, 1995). Taylor (1995) further points out that at times, the search for meaning has been associated with adjustment problems. Repeated viewing of the situation is unlikely to be adaptive if resolution does not occur (Silver et al., 1983). However, Taylor (1995) found support for an alternative explanation. People may not report a search for meaning because they respond to the need for meaning in different ways that are not necessarily identified as a search for meaning. An unusual finding in Taylor's (1993) study was that whether participants reported that they searched for meaning was not related to whether they felt a sense of meaning.

Studies using a quantitative design have focused on factors that are associated with a sense of meaning, using measures that have been developed for identifying the presence of meaning. The main focus is on contextual factors that might impact on the person's ability to experience a sense of meaning.

In general terms, illness related factors have been found to be associated with sense of meaning but not always strongly. For instance, Thompson and Pitts (1993) found that psychological factors had stronger associations with sense of meaning than levels of physical functioning. Taylor (1993) found too that a strong sense of meaning was associated with less symptom distress, less psychological adjustment problems and less dependency due to illness disability. However, the correlations were modest and most in her sample displayed a clear sense of meaning. An unclear sense of meaning was also linked with difficulties in the ways that health care was provided and disability that impacted on social and domestic activity. Lewis (1989) did not specifically measure illness factors except for length of experience with cancer which showed no relationship to sense of meaning or to psychological factors. Taylor (1993), on the other hand, found that the longer the time spent with recurrent cancer, the more unclear was a sense of meaning.

Focusing specifically on psychological factors Lewis (1989) found that higher degrees of experienced meaning and purpose were associated with higher self-esteem and less anxiety, supporting the claim that finding meaning is helpful for coping with traumatic

events. Thompson and Pitts (1993) similarly found that a clear sense of meaning was associated with the interpretational styles of optimism and a low level of irrational beliefs, as well as a tendency towards internal more than external goals. They also found that participants reported changes in their beliefs and goals since having cancer, and that whereas current reported beliefs and goals predicted a sense of meaning, pre-diagnosis beliefs and goals did not.

These studies demonstrate that physical, psychological and social factors are all associated with a sense of meaning and that variations in these may impact on the person's ability to find meaning in the situation. They lend support to the idea that finding meaning is important for adjustment to illness and that it is important to acknowledge the impact of illness beyond the medical condition. The uncertainty of causal association or direction inherent in correlations is a limitation that makes interpretation of results ambiguous at times (Thompson & Pitts, 1993). Another limitation of quantitative designs in general is the inability to capture the nature of a process that may develop and change over time and may involve changes in causal directions.

Using qualitative designs, some research has attempted to highlight important aspects in the personal search for meaning focusing more on the nature of the process. In a study of people with cancer, Fife (1994) found that the search for meaning occurred in response to loss of control and changes in self-worth and body image, as well as to threats to assumptions about life, disruption of goals and consequences for relationships. She places meaning within the experiencing of a traumatic event such as serious illness, growing out of the experience as it unfolds. She views the search for meaning as a struggle to maintain self-worth, to avoid being overwhelmed by what has happened and to maintain a sense of being able to manage. Meaning is seen as dynamic and it changes over time as well as with changing circumstances.

Fife's (1994) findings support the view that a sense of meaning grows out of the experience of integrating what has happened into ways of viewing the self and life. Steeves (1992) and O'Connor, Wicker and Germino (1990) similarly found that meaning grows out of the processes of attempting to understand and live with the wider implications of having a serious illness, and that changes take place in outlook related to the self, life and others.

Taylor (1995) in a review of studies on illness meaning suggested that a search for meaning is achieved in a variety of ways including looking for causes, asking questions on why this happened to 'me' in particular, questions about responsibility and a search

for significance. Thompson and Janigian (1988) point out that finding a cause is not equivalent to finding meaning as the effect may vary depending on whether they correspond with beliefs and assumptions or not. The effects of attributions are not clear, but in the search for meaning they represent attempts to fit what has happened within an understandable framework (Taylor, 1983).

Several studies have found that sometimes positive meanings grow out of the experience of illness. Fife (1994) found support for previous findings which suggest that the construction of positive meaning for the illness results in better adaptation and the ability to gain or regain pleasure in life. The experience of suffering involved in a serious illness sometimes leads to an overall change in outlook towards the self, others and life. There may be changes in priorities involving the realisation that trivial things are not important compared to relationships with family and others (Dirksen, 1995; O'Connor, et al., 1990; Taylor, 1983). Reappraisals of life may lead to a greater appreciation of life, a living for today, a greater self awareness (Coward, 1990; Dirksen, 1995; Taylor, 1983) and an affirmation of personal strengths (Taylor, 1983). O'Connor et al. (1990) found that a review of life sometimes enabled participants to view their illness within a wider context, perhaps helping in the process of making sense of the changed circumstances.

The consequences of disruption to goals may not always be negative since new goals that are congruent with the new situation may at times be meaningful in themselves (Fife, 1994). Fife points out too that effects on self-worth can sometimes be positive as there is a sense of achievement in having coped. Social comparisons with others may lead to feeling fortunate compared to some, and have been suggested to help in reducing negative perceptions of what has happened (Taylor, 1983). Taylor found that comparison could also occur for hypothetical others who were worse off. Comparisons at times too could lead to a sense of self-worth in having coped better than others at least in some ways.

There has been support for Frankl's (1964; 1967) view that experiences of self transcendence provide a sense of meaning both at the time and on later reflection (Coward, 1990; Steeves, 1992). Coward (1990) concluded that the women with cancer in her study experienced a sense of meaning in the three ways outlined by Frankl. The experience of self transcendence lead to feelings of greater self understanding and broadening of perspective, as well as new purpose in life. Self transcendence arose out of experiences of giving, being open to receiving, and efforts to accept personal circumstances.

In a hermeneutic study of men going through a bone marrow transplant for leukaemia, Steeves (1992) found that some of his participants had experiences of meaningfulness that were sometimes difficult to convey in words but which seemed to indicate moments of insight into life as a whole, providing feelings of well-being and a valuing of life in itself. These moments of self transcendence were important to the people experiencing them and were felt by them to be closely associated with a sense of meaning.

Research has provided support for the contention that meaning is found through active involvement in choices of response to personal circumstances (Denne & Thompson, 1991; Frankl, 1967). Thompson, Sobolew-Shubin, Galbraith, Schwankovsky and Cruzen (1993) found that individuals took an active part in understanding and changing the situation by taking control in ways that were achievable. They found that control was able to be felt mainly over the physical and emotional consequences that came with having cancer. Steeves (1992) too found that the ways in which the men in his sample negotiated a new social position in the changed situation provided a source of meaning. In this way they were able to regain a sense of identity within the illness context. They achieved this by working out who held power, and finding a position for themselves within the illness situation.

Taylor (1983) found that although a loss of control was felt in having a serious illness, a sense of control could be regained in a variety of ways that were still achievable. Taylor et al. (1984) had similar findings on a sense of control and suggested that changed perceptions towards control helped with adjusting to having cancer. They found that perceived control through another, such as a doctor, had analogous benefits to personal control in restoring a sense of predictability and order. Similarly, O'Connor et al. (1990) found that participants took an active part in constructing meaning in their lives through the ways in which they adapted and continued to live with cancer. These were ways of accepting and making the best of personal circumstances and taking a proactive part in regaining a sense of meaning supporting processes of reaching a sense of meaning suggested by Denne & Thompson, (1991). These findings also support Frankl's (1964; 1967) claim that meaning is found through acceptance of what has happened and through choices about how to live. A sense of meaning through ways of returning to living may be felt by regaining a sense of control and self-worth because of ways in which they could make a difference in their lives.

Interconnectedness with others and with life as a way of finding meaning is supported by research. Religious faith and social support were two important aspects appearing throughout the processes of finding meaning in O'Connor et al.'s (1990) study. The

value of relationships with others, and mutual caring were affirmed, and religious faith was strengthened. Steeves (1992) found that in spite of the extreme physical suffering involved in the treatment, participants formed new relationships within the hospital setting which were affectionate and caring. They also made efforts to normalise their social position and their behaviour, perhaps attempting to restore a sense of belonging to the world of the 'healthy'. Feelings of belonging and connectedness to life and to others were felt too at times of self transcendence (Coward, 1990; Steeves, 1992). Other research too has highlighted the importance of relationships in the processes of finding meaning (for examples, Fife, 1994; Taylor, 1983; Taylor, 1993).

Overall, these findings support claims that meaning is found through adjustment of beliefs about life and in reframing perceptions of what has happened (Thompson & Janigian, 1988). The search for meaning seems to lead to reappraisals of life which lead as well to adjustments in priorities, and a general change in outlook towards the self, others and life. Life may become accepted and appreciated as it is with an affirmation of those things that are really important such as relationships, a sense of belonging and feelings of connectedness. There may be an acceptance of those things that cannot be controlled, and efforts to achieve control in different ways. Although the illness process may appear to be beyond control, the individual's response to their situation remains their own choice, and this aspect of personal control seems to be important.

The Present Study

Because meaning can be looked at from many perspectives, it is important to clearly define what is meant by meaning in the present study. The concept of meaning is used in relation to having cancer and refers to the search to make sense of what has happened and to find meaningfulness in the new situation through rebuilding a sense of order and purpose. Meaning is viewed as serving the function of maintaining a sense of life as manageable, understandable and purposeful. Investigating meaning involves understanding what it means for a person to have cancer in ways that go beyond the medical condition, to the impact on the person's sense of themselves in relation to their own life and goals.

The conceptualisation of meaning includes both attempts to make sense of what has happened and a search for significance. The aim of the present study is to locate processes of finding meaning within the experience of cancer and examine more fully ways in which people find meaning in the experience. A primary focus is to identify

aspects within the experiencing of illness that may hinder or facilitate finding meaning. Further, in looking at aspects of the experience that influence a person's ability to regain a sense of meaning, the aim is to throw light on how these may operate within the overall process. There is an acknowledgement throughout the project that variations in personal circumstances naturally have an influence on the nature of the experience of illness, and that each person's experience is unique.

In the present study it was surmised that whereas a search for meaning may consciously be reflected on in some ways, it may be experienced as part of coming to an understanding of the fuller implications of the illness and not necessarily conceptualised in terms of meaning. A search for meaning, and finding meaning was felt to grow out of the process of experiencing illness, and to be inextricably tied up with it. It was decided that if a search for meaning was involved in the process of experiencing a serious illness, then it would emerge from the accounts of what had been of concern to individuals going through the experience. An open approach was considered important in order to avoid assumptions restricting the information that would be offered. Therefore the present study was designed to allow an examination of the lived experience of having cancer in an open way.

CHAPTER TWO

AN INTERPRETIVE PHENOMENOLOGICAL APPROACH

This chapter presents a rationale for using a qualitative approach for the present study. The interpretive phenomenological approach in particular is briefly described as are criteria for judging qualitative research.

Qualitative Research

In deciding what type of research to use, the differences between a quantitative and qualitative approach were looked at both for the techniques used in data collection and analysis, and in terms of the paradigms which inform them. Since each of these approaches derive from different paradigms, they are not just different techniques with the same aim (Henwood & Pidgeon, 1992).

A paradigm is a set of beliefs or basic assumptions that are presupposed in a certain approach. These assumptions comprise a view of the world which automatically defines or sets limits on what can be known, in what way it can become known, and how it is possible to go about finding out (Guba & Lincoln, 1994). These are the ontological, epistemological and methodological questions and they form the basis of the assumptions of the particular approach.

Unlike a quantitative approach, the epistemological position of the qualitative approach arises from the assumption that reality is not so much concrete and 'out there', as a negotiated and agreed 'reality' recognised among people in a particular time and culture. As such, this reality is dynamic and so changes and evolves as the world changes and common perceptions are altered (Benner, 1985). It is in itself both socially constructed and constructing (Fjelland & Gjengedal, 1994). The nature of the reality depends on the perspective of the individual, which in turn depends on the social interactions that have helped define their particular world. Thus, it is claimed that reality cannot be observed and explained as something separable from human activity. In a research situation both the researcher and the researched play a part in negotiating the truth of an agreed upon reality (Guba & Lincoln, 1994).

A qualitative approach focuses on broadening understanding of human experience rather than explaining it and making predictions based on theories (Munhall, 1994). Research done on this basis to a certain extent limits what is examined to what is specifically looked for and measured. A problem then is the part played by that which is not measured.

Benner (1985) suggests that methods for studying objects or biophysiological processes are not always so appropriate for studying everyday understandings, practices and social interactions. Whereas physical phenomena may be examined in a mathematical way, if human activity carries meaning, then the mathematical explanation is not sufficient or complete (Fjelland & Gjengedal, 1994).

By studying human activity quantitatively what may be missed or covered over in the process of objectifying and de-contextualising, are implications of the context within which the activity occurs that may play a part in the construction of human identity and shared realities (Benner, 1994a). Capturing of the essence of the phenomenon as a dynamic process is more difficult with a quantitative approach, but well suited to a qualitative approach (Conrad, 1990).

Individual experiences are not totally private and subjective in that we have shared realities to a certain extent. Looked at in this way, events are situated, occurring within a particular set of social practises and understandings that form a shared background of experience from which the possibilities for our understandings derive (Dreyfus, 1991). Because of this, others' experiences are able to be understood through shared understandings and interactive dialogue.

In studying health and illness, there is the possibility that in examining disease in terms of physical properties only, aspects of healthy functioning can be overlooked. Looking at health in qualitative ways allows a view where health and illness need not be viewed as opposites or as mutually exclusive.

Henwood and Pidgeon (1992) suggest that in assessing the relative merits of quantitative versus qualitative methods of research, the issue is not so much in comparing the validity of the two, but in assessing their suitability to the particular research issues. Phenomenology lends itself to questions about human issues and concerns, but will not be so useful for predictions (Plager, 1994).

For the present study, a qualitative approach was taken as the most suitable for exploring the multiple meanings surrounding aspects of the illness experience. The aim

was to capture experience as it is lived. This meant that individual contexts, beliefs about life and feelings were significant areas of interest and an important part of being able to understand the experience from an insider's point of view. A qualitative design is likely to allow a richer description of the process as a whole. Further, issues may arise which were not anticipated, but which may turn out to be important. A phenomenological approach was felt to be a way of encouraging openness to what was there in the experience, and further, maximising possibilities for making the implicit, explicit (van Manen, 1990).

Interpretive Phenomenology

Interpretive phenomenology is a way of approaching the analysis of qualitative data. There are guidelines and techniques suggested by different researchers who use the approach, but as pointed out by van Manen (1990), these are largely learnt through using them. The individual researcher is encouraged to use what is useful but to use their own creativity as well (Benner, 1994b; Munhall, 1994; van Manen, 1990). Interpretive phenomenology is an approach that situates the researcher in relation to the area of study rather than demanding strict adherence to a method to the detriment of individual creativity. Rather, the researcher learns a way of positioning themselves so that they approach the whole of the research with a phenomenological awareness (Munhall, 1994).

A brief outline of the approach drawn upon for the present study follows in order to show how the researcher was situated in approaching the research project. The phenomenological approach was studied before beginning, but learning took place as well throughout the process of research. Often it was through experiencing the techniques through writing, analysing and reflecting, that they became better understood and used. Working through ethical considerations was an ever present part of the research process as well and was a further encouragement to self reflection.

Munhall (1994) states: "the aim of phenomenology is understanding the meaning of being human" (p. 173). Phenomenological research begins with naturally occurring everyday life as it is lived (van Manen, 1990).

According to van Manen (1990) experiencing is being conscious in the world, whereas reflective consciousness is a recalling and reflecting on that pre-reflective conscious experience. Thus, any attempt to understand that experience is an interpretation. People reflect on and make sense of their own experience making interpretive

phenomenology an interpretation of interpretations. Consciousness cannot be described in itself and the world cannot be described except through consciousness. The aim in phenomenology is to reflectively interact with retrospective accounts or dialogues in order to gain plausible insights about why certain aspects of experience were significant enough to be brought to notice (van Manen, 1990). There is not necessarily direct expression of the phenomenon in the language of the researchers. Ways of knowing are variable and tend to appear through the expression of everyday concerns.

By encouraging participants to talk about the things that have been important to them, the expectation is that the things that have been of concern tend to be the things that are talked about. More direct access to experience is then gained by trying to understand why those things mattered, or what meanings they may have held for the person. What is sought is not so much facts, as what the experience has been like. In the present study the aim was to allow issues of concern to emerge naturally through talking to people about what had been important for them in their own experience with cancer (Benner, 1994).

Spiegelberg (1969) states that; "the genuine will to know calls for the spirit of generosity rather than for that of economy, for reverence rather than for subjugation, for the lens rather than for the hammer" (p. 657). Phenomenology ideally provides a way of expanding our understanding of a phenomenon through practising an openness to the meanings of the experience as it is lived. It is a natural tendency for humans to simplify the world around them in order to make sense of it. To attend to everything equally would be to experience life as chaos. However, although simplification has its uses, when examining a particular phenomenon in order to understand more fully what it is to experience that phenomenon as a human being, simplification risks obscuring complexity that may be necessary for understanding the phenomenon (Spiegelberg, 1969). The aim of phenomenology is not to simplify a phenomenon, but to open it up for clearer viewing and an increased awareness of the possible meanings of that experience for the person living it.

Through turning directly to experience as it is lived by humans engaged in their worlds, the aim is to allow the meaning of ordinary concerns, and the taken for granted, to be revealed (van Manen, 1990). Ways of understanding what it means to be in the world can be accessed not only directly from peoples' accounts of what it means, but indirectly through interpreting the meanings of their concerns and their actions. What is sought is an insider's view and as such it is a move away from quantitative techniques which tend to provide an outsider's view of the phenomenon.

Validity checks

Traditional ways of checking the quality of quantitative research are not applicable to a qualitative approach when it is based on different assumptions. Since the possibility of an objective truth is not an assumption of a qualitative approach, efforts to reduce researcher bias from affecting what is thought of as a 'truth' is not so much of an issue (Henwood & Pidgeon, 1992).

Researchers acknowledge the impossibility of guaranteeing absolute accuracy and generality (Henwood & Pidgeon, 1992; Munhall, 1994) but suggest that there are methods of assessing the quality and validity of qualitative research both throughout the study, and for subsequent evaluation. In the interest of increasing the validity of the account that is given, there are ways of monitoring and evaluating the worth of particular studies. These serve as guidelines for the design and procedures of the study, as well as for retrospective validity checks.

A variety of guidelines for evaluating the quality of research have been proposed. Those suggested by Munhall (1994) are briefly outlined below as examples of some that were referred to during the present study and which can be applied by future readers. The overall aim of validity checks is to maximise the rigour of the research (Munhall, 1994).

Resonancy: The interpretations should sound reasonable, and resonate with aspects of the experience that the reader may have had contact with. Since any account is incomplete, the possibility of capturing any one person's experience fully is unlikely to be an achievable aim, but the participants should be able to recognise parts of their experience. Readers should be able to relate to interpretations and they should clarify puzzles about the phenomenon.

Recognisability: This is similar to resonancy in that the interpretations in the study should ring true. In the case of recognisability even those who have not had a similar experience should recognise aspects of it and become more aware of their own experience as a result.

Reasonableness: This applies both to the method used and to the interpretations made. Interpretations should be convincing in terms of being arrived at appropriately, based on direct evidence of data that is supplied in the write up. They should also be convincing as possible interpretations. Questions about why any aspect or activity of the study was carried out should be easily answerable.

Representativeness: The study should cover the area of concern in a broad enough way to reasonably represent its complexity.

Raised Consciousness: This criterion should result if those above are fulfilled, and is in addition an important aim of phenomenological research. Raised consciousness means that ideally the study should bring to the forefront of readers' minds, aspects of the experience under study that they may have overlooked. Often this is through uncovering the possible meanings of 'taken for granted' parts of everyday experience that for the most part bypass conscious awareness. Thus, issues are raised for conscious consideration that may not have been overtly considered before. In the process, tactfulness and sensitivity in general may increase.

Readability: The aim should be for the writing of the research to be readable, concrete, and interesting.

Relevance: The study should also be relevant beyond the short term aim of completing a thesis. Ideally it should aim at providing guidelines relevant both professionally and personally. The issue of relevance pertains both to the researcher and those who read the study.

Revelations: This criterion as with others, is not separate from the others. In uncovering aspects of an experience that may have been concealed, the study should be revealing so that understanding is deepened.

Responsibility: Ethical considerations should always be at the forefront of the researcher's awareness.

Validity is an ongoing issue that continues to develop beyond the completion of the study by readers evaluating the research and relating it to other research.

Summary

Phenomenological questions are about meaning rather than problem solving. Interpretive phenomenology is an approach that aims to uncover the meanings that are contained in everyday activity, but are not always obvious on the surface because they are taken for granted. An interpretive phenomenological approach was chosen as an appropriate and useful method for gaining an understanding of what it means to have a

serious illness such as cancer, and ways that finding meaning occur within the process of this experience.

CHAPTER THREE

METHOD

Participants

Eleven adults ranging in age from twenty eight years to sixty nine years at the time that they were interviewed, comprised the participants of the present study. Five of the participants were male and six female. Time since diagnosis ranged from ten months to thirteen years. Although all had a diagnosis of cancer in common, and all had undergone treatment involving either radiotherapy, chemotherapy, surgery or a combination of these, there was a variation in types of cancer. Types of cancer included leukaemia (two), breast cancer (three), cancer of the larynx (two), cancer of the tongue (one), melanoma (one), cancer of the cervix (one), and prostate cancer (one). In one case the cancer had developed to a secondary stage.

The participants were a convenience sample who were approached through the Cancer Society in Palmerston North. The only criteria for selection were that they had had a diagnosis for cancer and had undergone some form of treatment, and were willing to talk about their experience.

Overview of participants

Ages given were at the time of the interview and names have been changed for the writing up of the findings.

John (69) was retired when diagnosed with cancer of the throat eighteen months before the interview. He is married with a grown family. He was treated with radiotherapy which was successful. He found the treatment very difficult and became very ill, but since then he has gradually been getting fitter and stronger, although very tired and unable to do very much on some days. Since the time of the interview he has had another diagnosis of primary cancer of the lung. A further treatment of radiotherapy was not as debilitating as it was with the throat cancer and he is once more regaining strength.

Chris (67) was diagnosed with throat cancer thirteen years before the interview. He had a laryngectomy after radiotherapy was unsuccessful. The treatment meant that he lost his voice box, and so has learnt to communicate with an electrolarynx. After

treatment, he was able to return to his job in retailing until retiring five years later. He is married with a grown family of eight.

Justin (53) was diagnosed with prostate cancer eighteen months before the interview. He had radiotherapy and continued to work in his own business, even during the treatment. A work related injury meant that he was already unable to work at his previous profession which was as a butcher. Since then he has continued to run his own business. He has a young stepson and at the time of the interview was separated and single.

Pat (28) was diagnosed with leukaemia five years previously. She was seven months pregnant with her first child when she was diagnosed after a routine blood test. She was given a caesarean, and began chemotherapy a week later. After many months of chemotherapy, she was given a bone marrow transplant using her sister's bone marrow. Recovery from treatment took a long time, and in the year after her treatment she was divorced. At the time of the interview Pat was single, her daughter had recently started school, and she was living in a flat with others.

Sam (47) was diagnosed with cancer of the tongue four years before the interview. After radiotherapy was unsuccessful, he had a total glossectomy, (tongue removal), which also involved using part of his pectoral muscles for the base of his mouth, leaving him weakened on one side of the chest as a result. He has learnt to communicate successfully and has returned to many of his former activities. He was separated before cancer was diagnosed, and now lives alone.

Kate (38) is married and with a young family of four children. She works part time in a library. Her youngest child was six weeks old when she was diagnosed as having melanoma three years before the interview. She had an operation to remove the melanoma and about two years later it was found to have advanced to a secondary stage in the lymph system. She had another operation to have the lymph glands removed from her leg, and shortly after had to return to hospital because of an infection picked up in the hospital.

Michael (28) was diagnosed with leukaemia about ten months before the interview, after he had been feeling exhausted at work and experiencing flu symptoms. His wife had just become pregnant at the time. He was treated with chemotherapy, and during the last phase of treatment, he had a very serious infection. He had his second wedding anniversary in the hospital. He came out of hospital around the time of their baby's

birth, which was ten weeks before I interviewed him, and was gradually building up his strength. Since the time of the interview they are expecting their second child.

Jane (40) was diagnosed with adenocarcinoma of the cervix about two years before. She had surgery to remove her uterus and ovaries. Eight years before diagnosis she had a serious car accident which had left her with many injuries, including head injuries. For her, the accident and the cancer are very much connected parts of an ongoing process of re-evaluating her life focus. At the time of the interview Jane was single, teaching part-time and living in a flatting situation.

Jill (38) discovered a lump in her breast that was found to be malignant, about four years before the interview. She had a mastectomy followed by radiotherapy, and when another lump was found in her other breast some time later, she had another biopsy. The second lump was found to be benign. Jill lives with her husband and her six year old son, and does relief teaching.

Sarah (50) was diagnosed with breast cancer three years before the interview. She had a mastectomy and radiotherapy was found to be unnecessary. She works full time, and lives with her husband. Several years before the diagnosis of cancer, one of her sons died. She has two other grown children.

Emily (59) was diagnosed with breast cancer six years before the interview. Although cancer was found in one breast, she had a double mastectomy for personal reasons. At the same time, she had great trouble with her teeth and jaw, which have been an ongoing problem in terms of debilitating pain. Three years after surgery she separated from her husband and now lives alone. She has three grown sons.

Procedure

The present study was approved by the Massey University Human Ethics Committee after consideration of the proposal. Participants were then recruited through the Cancer Society, Palmerston North after consultation with their Medical Research Advisory Committee. The Cancer Society agreed to help with identifying potential participants, and to make the first contact.

For each potential participant, the Cancer Society was provided with a letter of introduction with a return slip to indicate interest in participating (Appendix A), an information sheet (Appendix B) and a return addressed and stamped envelope. These

were included with a covering letter from the Cancer Society and sent to fifteen people known to have had cancer. From this initial mail out there were ten replies indicating possible interest. A subsequent smaller mail out to three more people resulted in two more replies. Recruitment was planned with the possibility of two phases to ensure that all who responded were able to be accepted into the sample.

Replies from the participants provided permission for the researcher to then contact them directly. Contact was by phone and in one case a subsequent home visit to discuss a time for the interview. At this point, willingness to participate was discussed further and any questions addressed. Out of these replies, one person chose to participate only if there was insufficient response, in which case she was willing to be re-contacted. Since it was important to avoid applying pressure to participate, and eleven participants were felt to be sufficient, this participant was not re-contacted.

The main source of data was interviews in the form of conversations about what the experience of cancer had been like for each person. All of the interviews took place in the homes of the participants. It was felt that this was a natural setting that would minimise any possible discomfort. In most cases people were interviewed alone. In three cases the spouse was in the house and in two of these the spouse was in the room during parts of the interview and joined in briefly. In two cases there was a child present either in the room or in another part of the house. In two cases there were flatmates present in the house but the interview was halted if they entered the room.

The interview took place once a convenient time had been agreed upon. Before proceeding with the interview each participant was asked to sign a consent form (Appendix C) to confirm their agreement in taking part in the study.

The aim was for the interviews to be largely guided by areas of concern to the participants. The information sheet provided a general guide to what was required of the participants. Before commencing with the interview, participants were told that the interview would be conversational, covering their experience of having cancer from their own personal perspective, what it had been like for them, and anything that they could remember that had been difficult, helpful, positive or meaningful. Anecdotes or narrative accounts were encouraged, as a way of keeping in touch with contexts, and providing instances of experience that were meaningful to the individual.

Because what had been meaningful to the individual was being looked for, a 'truthful' picture, covering everything that had happened, was not required. Any account is necessarily selective and can never be complete. Ways of collecting and analysing data

are meant to maximise the possibility of the areas of concern being selected by the participant (Benner, 1994b). Their concerns should shape the interview, rather than those of the interviewer. What people choose to talk about will reveal what has been important for them, thus revealing the meaningfulness of the experience to them in their particular situation.

For these reasons the interview was open and unstructured with the main question being what each participant's personal experience of cancer had been like for them. Areas of interest for the researcher were outlined in the Information Sheet. These very broad questions were raised in the interview unless the participant had already addressed them in the course of conversation.

Talking about the time of diagnosis was often a natural starting point although in some cases, going back further gave a background context to the experience. All interviews were recorded on an audio-tape recorder.

Participants had been informed that they could decline to talk about any specific issue, and to feel free stop the interview at any time. The completion of sides of the tape provided a convenient place to ensure participants felt comfortable about continuing. A time limit was not set for the interview, and length of time varied from 45 minutes to three hours of taped interview. The times of visits were longer as there were periods of talking both before and after the taped conversations. For nine participants there was a single interview. For one there were two interviews because the participant and interviewer agreed that there were further issues to talk about and the initial interview had covered a wider area concerning an earlier car accident. For the other, the tape recorder failed to record at the first interview. As a result, the participant was contacted and given the option of repeating the interview, or withdrawing from the study. Fortunately she agreed to talk with me again, and the second interview was able to be used.

In cases where the participant lived alone, or if it was felt that issues had been raised that possibly could cause distress at a later time, they were encouraged to call the researcher at any time to talk things through. However this did not happen and several participants indicated that they had given thought to the possibility of how the interview would make them feel. In one case, the timing of the interview was planned to come before a counselling session, because of an awareness of the issues that might be raised needing to be discussed further. Two other people said after the interview, that being able to talk about their experience in the interview situation was an indication to them of their progress in the process of coming to terms with what had happened, and

something that they felt that they could not have done at an earlier time. One participant said it was the first time he had been asked to talk about what it had been like from his perspective. Two others indicated that talking was therapeutic, even though for one of these, emotions surfaced during the interview. Several participants affirmed the importance of looking at the experience from the insider's perspective of those going through it, rather than an outsider's view.

Overall, I felt that agreement to take part in the study was a well thought out decision, with participants being aware of and taking responsibility for their own feelings of well-being. Concern over directing the interview or making assumptions was lessened by participants pointing out on occasion when I reflected back their feelings inaccurately.

Each interview was transcribed in full by me, and the transcripts were used for the process of analysis. Although the main source of data was interview transcriptions, in being committed to the area of study and immersed in it, other sources were used in order to become more insightful in interpreting the data. Conversations outside the taped interview, both with the participants and others, were drawn upon. In addition, films, photographs, newspaper articles, paintings, and reading of both research and first hand accounts, provided insights that helped in the interpretation of accounts.

Validity issues were referred to as part of the design and the whole process of researching. After the interview each participant was informed that I would get back in touch with them at a later time to give them an overview of the findings that they could comment on. After analysis of the interviews all but one participant were phoned and informed that I was sending them a letter including the overview (Appendix D). I raised some other issues about confidentiality and consent, and told them that I would ring them shortly after sending the letter to see if they had any comments to make. One participant had moved to another city and was contacted through the Cancer Society.

Before having the thesis printed participants were sent copies of all the extracts that were likely to be used directly in the thesis. This was to confirm their consent and to ensure that there were no concerns about possible identifying factors.

All participants were able to relate to the overview of the findings, although some referred to the fact that not all aspects pertained to them personally. This was a reminder to them that the overall project did not cover any one particular personal story. All participants said that they were satisfied with the overview, and one mentioned that he had highlighted particular parts that had made him recognise things

that had been going on in the back of his mind. Other participants said that reading through the overview had made them realise that they were now in a different space and that it showed them where they had moved from.

In relation to the particular extracts to be used within the write up of the study, there were no concerns expressed about confidentiality. A few small changes were made involving one or two words to increase the clarity of what was meant. Other changes (very few) were grammatical. For most participants there were no changes made, and all agreed to their extracts being used. Other issues arising from this procedure were that some participants appreciated the chance to confirm their consent because of concerns about having talked too freely. However, this did not lead to deletions of any extracts. In another case a word was deleted that the person never uses. This affirmed the importance of going back to the participants as this issue was easily resolved but could have caused concern if it had not been addressed before printing. Finally, for some, reading their own words brought the experience back to the forefront of their minds and in a one or two cases caused some distress. However, this was felt to be part of the process and was not related to a desire to withdraw their accounts.

Analysis

The interpretive phenomenological approach was researched at the beginning of the study and drew from the writings and research of van Manen, (1990) Benner (1995), Munhall (1994) and Spiegelberg (1969). Ways of approaching the area of study, as well as suggested techniques for analysing and interpreting the data, were used.

Guidelines for approaching the data.

Guidelines suggested by van Manen (1990) were used in the present study. Van Manen points out that these guidelines tend to overlap rather than follow in a stepwise fashion. He claims that this approach to research must be learnt through the process of doing it, but his steps are like signposts that help to keep the researcher on track. They served as a way of situating the researcher regarding the phenomenon under study. The six steps are:

- 1) Turning to a phenomenon which seriously interests us and commits us to the world.
- 2) Investigating experience as we live it rather than as we conceptualise it.
- 3) Reflecting on the essential themes which characterise the phenomenon.

- 4) Describing the phenomenon through the art of writing and re writing.
- 5) Maintaining a strong and oriented pedagogical relation to the phenomenon.
- 6) Balancing the research context by balancing the parts and the whole.

(van Manen, 1990, pp. 30-31).

Van Manen (1990) suggests the interpretive phenomenological approach is a writing activity, research and writing being two parts of the same process. In reflecting on pre-reflective activity through writing, there is a growth in insight, and understanding is increased. Van Manen claims that writing is a way of externalising thought enabling us to reflect on it, to see what we know. Writing is also rewriting because through writing it becomes clearer what is lacking and sometimes some of the reasons why. In this sense van Manen refers to writing as “exercising the ability to see” (p. 129). The aim is to uncover layers of meaning, to make explicit what is implicit. The possibilities for responsiveness, tact and compassion are increased. The focus is on the individual, but with an awareness of the importance of ‘other’ in human life, the importance of communality.

These techniques developed by van Manen (1990) helped in the processes of analysis by encouraging openness to the meanings conveyed both directly and indirectly, awareness of layers of meanings that were revealed through the process of writing, and self reflectiveness to raise awareness of the influence of preconceptions, both before analysis begins, and as the process unfolds. This involved a continual moving between the parts and the whole to ensure that uncoverings were consistent with, or grounded in the data.

Process of analysis

Throughout the study I attempted to practise an ongoing reflectiveness on my own approach and the background. This enabled the constant reaffirming of an openness to the voice of the participants, by continually going back to their words.

The recommended techniques and validity checks were used in the present study and referred to in an ongoing way for checking and repositioning myself. When I found myself going forward in understanding, I usually found that I had realised the meaning of some of the techniques at a deeper level.

For example, maintaining a commitment was something that happened through becoming immersed in analysis and searching for understanding, and feeling a responsibility to participants. Reflexivity and moving between the parts and the whole became clearer through attempts to gain a focus on the data both in its detail and the

more general view that incorporated individual experience. Focusing on the view of the whole threw light on the detail, and at other times detail threw light on the whole picture. Moving between the two gave a better perspective and ensured that the variability between individuals was kept in mind.

Reflexivity gradually became more automatic through questioning interpretations, asking questions about other possible explanations, and comparing different texts. In addition, the meanings of words became something that revealed assumptions. In a way, labelling a concept or theme had a tendency to set it in concrete which then could lead to developing a mindset. Therefore it became a habit to question the meanings of words and to try and become aware of the assumptions and connotations contained in words that might change the meaning of what was in the original data. This helped too in avoiding becoming trapped in a mindset in structuring the writing up of the analysis.

No claim is made to be able to have a complete knowledge of the phenomenon through this approach. An acknowledgement is made that interpretations are necessarily selective in what is noticed, and that any understanding or interpretation is situated in a particular place and time. This has implications for what is revealed, noticed and the possibilities for shared understandings between the researcher and the researched. The main aim of the approach is to maximise the possibility that the voices of the participants will be heard (Benner, 1994b).

While remaining attentive to these broad guidelines, three main strategies used for analysing the data were paradigm cases, thematic analysis, and exemplars (Benner, 1994b). There was movement between these strategies and they also represent different approaches to the same data that can confirm or question interpretations made through any one of them.

Initially, the data was read and reread as a whole with attempts to be open to all aspects of the data. There are things to be aware of in analysing the participants' accounts that make interpretation easier. What is presented and how the participant is placed is partly an organising, structuring exercise (Riesman, 1990). Insight may be gained by looking at the structure, and being aware of how presentation orients the listener, or carries the action forward, resolves it or evaluates it. How events are told is as important as what is said. It influences how the listener 'hears' and responds. In reading and re-reading the transcripts, I attempted to keep these different aspects in mind. An awareness of uncovering the meaning of taken-for-granted experience was an ongoing part of becoming familiar with the overall approach, as well as the analysis of the data.

As suggested by Benner (1994b) the first step in beginning a dialogue with the data was through a single paradigm case. The first interview was chosen as a starting point. The text was read as a whole several times in order to get a feel for it. The story was then rewritten in its own terms, as much as possible as an insider's account, presenting it as a description allowing access to the participant's voice. Interpretation of this first level of presentation from various vantage points involved examining issues, concerns and events from the text more closely in terms of why they may have been meaningful to the person. As suggested by Benner (1994b) meanings, obstacles, contradictions, options and possibilities that the stories disclose were reflected on in order to clarify and make accessible the meanings in the text. There were attempts to always respect the participant's voice.

The account was rewritten in terms of these possible layers of meaning. Further paradigm cases were analysed in a similar way but using the previous cases as a basis for comparison and contrast. Differences were looked at from the point of view of different contexts, with questioning about whether things would be different if the context was different and whether similar issues would be of concern for different cases (Benner, 1994b). The different texts often threw light on each other and there was an ongoing movement between them.

To begin with this was a lengthy process throwing up assumptions that were unconsciously made. Sometimes through comparing paradigm cases, what was of concern for one threw light on previous cases where the particular concern may have been less noticeable or experienced differently. This was part of the process of being open to all of the data without being restricted by looking only for things that seemed to pertain to finding meaning. Becoming aware of assumptions (even while assumptions had been attempted to be set aside) became part of the process of learning to recognise more quickly when this was happening. In this way, often when parts of texts seemed unclear, they were clarified through learning to be more open to possible meanings that they might hold for the person.

The aim of writing and rewriting paradigm cases is to facilitate understanding and increase perceptual recognition at the start of analysis (Benner, 1994b). The use of writing in these ways was found to be more appropriate personally in the present study, than categorising the data and breaking it away from personal contexts. In the process of writing it was possible to follow the guideline of moving between the parts and the whole all through the process of analysis and the final writing up of the findings.

Paradigm cases were used as an interpretive strategy and a way of heightening awareness, as well as a resource in the final writing of the report.

Thematic analysis occurred alongside the writing of paradigm cases and again, rather than grouping categories, thematic analysis evolved through writing. As each paradigm case was completed, themes were identified in a summary. As subsequent cases were analysed, their summaries involved comparisons with themes that had been evident in previous cases. This allowed the identifying of common themes and also highlighted differences within the common themes. For instance, where loss of control may have been felt by all participants, the meaning of loss of control was different for different individuals.

Direct excerpts from participants' texts serve to provide evidence and to clarify the interpretations that are made, and further, to illustrate different nuances and distinctions involved in the meanings of particular processes for different individuals. Exemplars may be thought of as serving a similar function to 'operational' definitions' (Benner, 1994b). They are a way of demonstrating concerns, and backing up interpretations. Through using extracts directly from the transcripts in the final text, the aim was to ensure that the writing and interpretation were grounded in the data. Readers too, could then more easily make their own judgements on the validity of interpretations.

The interpretation of anecdotes was another interpretive tool that was used at times. Several participants used anecdotes as a way of expressing their experience or a way of conveying the essence of particular moments. Van Manen (1990) suggests that an anecdote may be used to convey something meaningful that is hard to put into words in a more direct way. An anecdote is a small example of personal experience, and a particular occurrence. However, we are usually encouraged to reflect on the meaning implied in the anecdote, which has a relevance beyond the particular instance. In this way, the essence of experience may be conveyed through particular instances.

Several of the transcriptions, together with interpretations in the form of written paradigm cases, and thematic analysis, were read and commented on by my supervisor. The overall integration of the data was also read by him for comment on interpretations. The value of this process was in encouraging me that my approach to the analysis was appropriate and moving in the right direction. In discussing cases, themes and interpretations, as well as the approach and procedures, the process of analysis was kept more focused. Overall, constructively critical comments helped to keep me motivated, focused and on track. Reflexivity was encouraged and I became more aware of what I was doing, and what I was trying to achieve.

The final analysis was drawn together by identifying common underlying themes. The structure of presentation was guided by the focus of finding meaning in the experience of illness. An important consideration was to convey the nature of the experience as a process. Paradigm cases and analysis of themes were referred to in writing up the findings and the original transcripts were constantly referred to. In a similar way to the process of analysis, the process of writing the findings involved a constant moving between the parts and the whole. This helped in identifying broad themes, and yet keeping in awareness the variability of individual experience in terms of the themes. The use of exemplars aided in backing up interpretations and in conveying different aspects of the experience.

Over the course of the present study it became clear that ethical concerns involved far more than gaining consent for the study from the ethics committee, and from the participants for their involvement, input, and issues of confidentiality. Ethical concerns were ongoing in efforts to remain true to the participants' experience. The most difficult time was the time of writing up the findings. As Josselson (1996) notes, as long as the interview transcriptions remain in the drawer, the ethical dilemma can be overlooked. Once writing up the findings begins, the presence of the participants is very strongly felt and making an authentic account becomes of vital importance and yet in many ways impossible to achieve. Josselson points out that it is part of doing research on peoples' lives that anguish is felt in trying to remain true to participants. "To be uncomfortable with this work, I think, protects us from going too far. It is with our anxiety, dread, guilt, and shame that we honour our participants" (p. 70).

Prior Assumptions

In approaching a particular area of study, the researcher inevitably plays a part in the interpretation of data. Personal background and stance may influence what is noticed and understood. There is also inevitably subjectivity in the nature of the researcher's dialogue with the data, the process of analysis and interpretation. While there were ongoing attempts to put aside preconceptions based on personal experience and the reading of literature, I acknowledge that this is possible only in terms of attempting to be aware of the workings of personal assumptions and to be alert to them through ongoing reflexivity.

Cancer is an illness that almost everyone has had some contact with, either personally, or indirectly through friends or relations who have had the illness. In this sense it is an

illness which is part of all of our lives even though we may avoid confronting it personally. My interest came through knowing people who have had cancer, and through studying in the area of health psychology where the implications of illness beyond the strictly medical aspects are a focus of study. I have known people with cancer, and I have seen their strength in facing adversity. I have also seen how they often seem to be involved with helping others to deal with tragedy and illness. Through reading in this area and talking to people, I became aware that sometimes there is still a failure in the medical profession and others to acknowledge or understand the wider impact that serious illness has, and the meanings that it holds for people.

Having not experienced the illness of cancer myself I cannot claim shared understanding through personal experience. This was one of the reasons that I wanted my approach to be open so that I could allow participants to direct what the areas of particular concern were. In this way I tried to be open to their experience and had a genuine curiosity and commitment to understanding their concerns. I believe that there were some aspects of some peoples' experience where I felt an implicit understanding from different but in some ways related personal experience. However, this perhaps also highlights the fact that for areas where I did not have the sense of shared understanding, there were probably aspects that I was less able to be aware of. My aim was to be open and to bear witness to peoples' experience. In retrospect I feel that I did learn in ways that I did not anticipate, my awareness evolved and changed through the process, and some aspects of the findings questioned my previous perceptions and clarified things that were not clear before.

I feel that using an interpretive phenomenological approach helped my awareness of my assumptions as I moved through the process of analysis. Through questioning my interpretations I became aware of sometimes categorising or labelling too quickly. The processes of moving between the parts and the whole and the interpreting of paradigm cases in the light of each other, helped in bringing out ways in which I had a mind set about something that in itself caused a puzzle. By throwing up those puzzles, I believe that the techniques of the approach aid in becoming more self reflective.

Overview of Findings

One of the significant things about going through a serious illness seems to be the need to make sense of what is happening and to find meaning in the situation that enables the person to carry on living with a sense of life being worthwhile. Part of the traumatic nature of the experience comes from the fact that it does not always fall easily within

pre-existing frameworks for understanding. When previous beliefs and assumptions about the world are insufficient for explaining meaningfully what has happened they are brought into question, and this too makes the changed situation harder to make sense of. These inner beliefs about the way that life is or ought to be may need to be re-evaluated and made more congruent with the new situation. The focus of the presentation of findings is on this process of searching for meaning in the experience of cancer. Being able to make sense of what has happened seems to help in acceptance and in coping.

The presentation of the findings is structured into three chapters. The first chapter covers reasons why there is a need to find meaning, the second focuses on processes in the experience of illness that may impact on the ability to find meaning, and the third focuses on ways that meaning is found through living with cancer.

CHAPTER FOUR

THE NEED TO FIND MEANING

Loss of Meaning

In presenting the findings the aim is to demonstrate ways in which meaning may be found as well as processes involved in the experience of serious illness that may impact on the ability to find meaning. It is important to stress that finding meaning is not an end state but a process that arises out of ongoing attempts at understanding, both at a reflective level and at an experiential level. This is true of all the separated phases of the general process of understanding that are discussed in the findings and discussion.

Part of the experience of cancer is a need to understand, because it does not automatically fit within existing frameworks for understanding based on previous experience. Therefore the following section is not strictly part of finding meaning but demonstrates how a sense of meaning was needed; essentially because it had been lost. Finding meaning then comes out of the process of understanding which may lead to a gradual rebuilding and strengthening of adaptive assumptions about the world.

Loss of control: the need to understand

I mean for me, I like to have control over my world. I don't cope well with unexpected things, -¹ or if I go to the doctor and if I've been sick, I'll say, what can I do to make sure this doesn't happen again?so here I was, when I was in hospital, like, the introvert part was being put in a room with four other people and having no privacy and no respect for me. The idealism part was being, - here you are, these are the facts, you deal with them. And I'm saying, but I want better than this, and I want the sense of hope, and I, you know, that's what I need to hold onto. No one was relating to me on the feelings level. I was supposed to accept the facts and not go into the uncertainty and things like that, and I like to be the one who's in control of my world. So here I was at the whim, and the beck and call of every doctor, and not knowing. I had no control over my life at all. (Kate)

¹ When using extracts from transcripts within the written analysis, pauses are signalled with dashes (- -). Occasionally a few words were omitted within the extracts where these did not interrupt the flow or meaning and these are signalled with dots (.....).

Most participants talked specifically about losing control in their life demonstrating the traumatic nature of having cancer, and illustrating the need to understand. Because of feelings of uncertainty, unpredictability and helplessness, there was sometimes a sense of not being able to understand life in the same way any more. The strong presence of feelings of losing control illustrates how inner beliefs and taken for granted assumptions about the world were called into question and were sometimes inadequate for explaining the new circumstances.

Inability to understand: Feelings of losing control started from the time of diagnosis and a sense of control continued to be important throughout the treatment and illness process. The way in which some people conveyed their feelings at the time of diagnosis shows how loss of control was associated with the inability to meaningfully understand, at least initially.

It hit me between the eyes. (John)

It basically just booted me in the guts...(Sam)

Well, I was stunned that it was cancer and not benign, because I was so sure that the lump would be benign. (Emily)

The metaphors used to describe the impact of diagnosis strongly convey feelings of shock and conjure up images of being put out of action, of being unable to respond. There is an awareness that the diagnosis is something to be feared. The suddenness and force of the impact suggest total unpreparedness and a lack of ready resources for meaningfully processing the information.

There is a sense of being jolted from the usual way of being and assumptions of life's predictability in the way that life proceeds, into unfamiliar territory where the person's knowledge about how to respond is limited or even totally absent.

I tried writing about how I was feeling because I couldn't talk to anybody about it. And I can just remember writing, I felt like a train had hit me, and I didn't know how to get up again. (Kate)

If inner beliefs seem no longer congruent or adequate for explaining the situation, it seems as if the ability to move forward in life has to be re-learned. The metaphor of being knocked over and unable to get back up illustrates well the feeling that previous understandings were not sufficient for the new situation. 'Getting up' or existing, was

something that needed to be learned again because everything that was known had changed or been swept away, and so had become unknown. There is the implication that help was needed too, since the way to proceed was also unknown.

Uncertainty and helplessness: One implication of an illness as serious as cancer is that it will not go away, and that it is beyond the individual's power to make it go away. Control over the illness in this way is over having it at all.

A shock is really an understatement in describing it... .. I really didn't have a lot of time to catch my breath, it was very much shock, in the early days of the diagnosis and just sort of the feeling of being, having control taken away. And something sinister having entered my life. We were extremely upset, we cried a lot, my wife and I. I think really everybody was just in shock, and just didn't know exactly what was going to happen. So yeah, it was a pretty crazy time. (Michael)

It's mainly I think the trauma that something fairly serious has happened and it's very sudden, and, I mean there's nothing that's going to stop it. (Sarah)

Losing control was felt as helplessness through the realisation that there was nothing that could personally be done to change the situation, to make things better, or even to know what lay ahead. Often there was a sense of urgency about treatment and this added to the feeling of being swept along with no chance to take in what was happening. In some cases the seriousness of the illness was not fully understood initially, and if the urgency that was shown seemed incongruent then the general sense of things being beyond understanding was emphasised.

Everything seemed to happen so fast, like now I know why they do it, but at the time I didn't have enough information to realise why the urgency. (Kate)

In a sense it was like being swept along helplessly in a current since there was no time for understanding to take place. Not only was the illness beyond the person's control at this point, but so was their life.

Feelings of uncertainty and helplessness were compounded by the realisation of the possible imminence of death.

Certainly you were brought face to face with your mortality. I had to come to the point in hospital there where I had to think, well, I don't know if I'm ever going to leave here. I mean, I could leave here, but it might be in a casket. (Michael)

And the consultant said, I think you should have a mastectomy. Cause it's quite a large lump they removed, and there were pre-cancerous cells around it. And they said well, just to be on the safe side, I think you'd better ... have a mastectomy. Which of course was devastating, and I thought ohhh dear, how awful. And I thought, this is it, this is the end... it was just awful, seemed very bleak... and Christopher was only two and half, so I thought, how awful, you know, leaving a two and a half year old. (Jill)

One of the fears from shared understandings of the word “cancer” is the facing of one’s own death. Becoming seriously ill tends to be something people do not expect to happen to them, at least not yet, and facing the idea of death is usually avoided. Suddenly having to face death personally meant that the limits of personal control were further emphasised.

For some participants there was a feeling of movement forward in time being halted because in facing the reality of death, the future seemed to be suddenly taken away. It was hard to look forward when the future was unknown and unable to be predicted.

And it seems unusual because I haven't been living in the future either, so maybe I've been living in the past for a while, and maybe that's why I haven't moved forward in what I've done. I've never perceived that I was living in the past, but the fact that I had difficulty hanging in there in the present and in the future, suggest that I had to be somewhere I guess. And with that I guess goes the fear of having a shorter life. (Jane)

Coming face to face with death, and confronting the fears that go along with that, was something that was an ongoing issue for many.

That fear that I may not have long to live... and it's a common fear, everybody has that fear I'm sure, but it's dealing with it and working through and deciding what's behind that fear. I guess you revisit that every so often. Yeah, it sharpens.... the fact that you're maybe not going to have a choice about when you die. (Jane)

Feelings of uncertainty were emphasised when there were no assurances that could be given that provided a sense of knowing what to expect.

The last time I saw the surgeon too, I was saying, well, I just have to hold out for five years, and then I'll be all right, wont I? And he said, no, you've got this for the rest of your life. And you'll probably die from it, because of the severity it was when you

first got it. This is what it's gonna mean for you... ..and in some ways I almost think, I'd actually cope better if I knew that I did have, - only three years, or... (Kate)

Uncertainty about the future was one of the most difficult parts of the experience because to the person it felt as if life had suddenly taken an unexpected and sinister turn which they clearly were not able to do anything about. It was not possible to stop the illness from having happened, or to know where it might lead. And it was not connected to anything that they had planned for their life. In many ways, life as it was understood before the diagnosis had suddenly been taken away.

Loss of independence: For most participants, the implications of helplessness impacted on the way that they felt about themselves. For some, loss of control was compounded by needing help since their life roles and responsibilities placed them in the position of being the one who helped others. Often autonomy and self reliance were an important part of identity and being in a position of having to rely on others was not the way they were used to being. Needing help was possibly felt as personal failure and one of the hardest things for some was the idea of not being able to manage without help. Loss of control meant the risk of losing the sense of themselves as an effective and competent person. In this way personal control was closely associated with self worth and self reliance.

I said I cannot, if I can't do anything I'm not going to sit by and watch the place deteriorate and let others do it... ..I couldn't keep up with it, and I couldn't bear not to keep up with it. (John)

I wanted , and I know because I'm an introvert I wanted to actually deal with it myself. I didn't want to have lots of people trying to come in and make a big fuss... ..yeah, I mean I'm not good at asking for help either. A thing that a lot of women struggle with probably. (Kate)

Losing independence through the physical consequences of the treatment of the cancer impacted on the person's sense of identity too. Physical losses were like outward signs of the illness. The more visible and apparent these were, the less able the person was to minimise or deny the implications of the illness, either to themselves or to others. Inner feelings of helplessness were easier to control through remaining private. Outward physical signs of the illness therefore emphasised loss of control through being a public sign of suffering that was less able to be controlled.

The thing that worried me more was that the grand kids would sort of withdraw away from me because I - if I couldn't speak properly...(John)

Oh I felt terrible, and down, and I couldn't even look at it in the mirror, you know, everything was just a raw mess. It felt just absolutely debilitating. (John)

Other aspects of the illness experience seemed to highlight the helplessness that the person was feeling.

And then (the radio-therapist) got me on radiotherapy, and that was probably a pretty hard period then, you know, as I said before, I had this big Chevy ute, and you know I loved the thing. And after eight weeks of radiotherapy, after the first couple of weeks I couldn't drive myself. I lost my independence. (Sam)

The procedures involved in radiotherapy too, seemed to be powerfully symbolic of the extent of the person's helplessness and aloneness in the situation in a wider sense.

*When you were having the radiotherapy, you used to lay down underneath these machines and there were straps around your neck and plastic guards right round you, certain areas of your throat. You know, when they clipped you in there, and they went out of the room, well, it was turned on, and, you were, you know, just **absolutely** helpless. (John)*

They set it all up, this big machine over the top of you, and then they go out, of course, so they don't get any of the radiation. And you're left alone in this room with that big machine, and that's very unnerving. You think, good grief, what's happening to me here? (Jill)

Treatment in general, as well as the unfamiliar hospital environment compounded feelings of helplessness and being set apart, through loss of strength, health and independence, as well as through alienation from former life, other people and the environment. A sense of control is partly felt from known ways of being; familiar daily life that a person is comfortable with and that provides a sense of order. Being taken away from home and into hospital highlighted this kind of loss of control. The hospital setting was potentially alienating, and sometimes made the person feel very alone and set apart from their previous life. In a sense they were doubly in foreign territory.

The leukaemia knocks it out of you, the drugs knock it out of you, and then of course, you're in a strange environment and you've got the stress and trauma of it all to deal with, so yeah, you body's really going through the mill. But still, it's amazing, even

just being able to get out of hospital for an hour, and walk round the gardens or something like that, it can really be - refreshing. It can encourage you, cause at times it can feel sort of claustrophobic and you can, well I felt, - imprisoned at times.
(Michael)

Some participants felt less need to feel so much in control. For some, previous traumatic experiences meant that the limitations of personal control over their life had been emphasised.

I've had a lot of mates killed and all sorts of things, and as I say, I just accept life for what it is. It's just another part of life. (Justin)

For some, personal or religious beliefs about a higher power influenced their inner beliefs about the determining power of the individual. These kinds of beliefs also provided a sense of purpose for what had happened, without the need for completely understanding that purpose.

God's put me here as a Christian, to serve God, and to somehow bring glory to God, if that makes any sense. And yeah, my life's not really my own, it's in God's hands.
(Jill)

I've always felt that things are meant to be, and I don't always see them as coincidences, and maybe it's something not to my advantage, you know, but I would still just say, well, that was meant to be. (Sarah)

Thus, the degree to which a loss of control was felt varied, as did its importance to each individual. Nevertheless it seemed to be important for everyone and a sense of personal control was helpful for feelings of self worth and for being able to make sense of the new situation.

Summary

When a person is diagnosed with cancer, they embark on a journey in unknown territory. The destination is unclear and the course of the journey cannot be predicted. There is much suffering and loss along the way which derives not only from the medical condition itself, but also from the personal crisis that it comprises. Clearly feelings of control were important and losing control was feared. Autonomy, self reliance, confidence in life and independence, which all imply personal control, are closely associated with identity. Consequently, one of the reasons that a loss of control was the source of suffering was because it was a risk to identity.

In western cultures stress is laid on the importance of the individual. On a cultural level the ability to experience life as understandable and predictable is partly based on the assumption that we have a certain amount of personal control, and are able to make a difference in life through choices that are made. Thus, losing a sense of control is risking losing the structure on which self worth and confidence in the world is based and with it losing the basis for understanding.

Overall the realisation of the vulnerability of human life together with the inability to control one's own life can potentially lead to a sense of helplessness, and a lessening of self worth. Loss of control indicates a loss of understanding and as a consequence, loss of meaning in life. The process of understanding then involves the search for meaning in what has happened. For some this was experienced as reaffirming former sources of meaning while for others new sources of meaning needed to be found.

CHAPTER FIVE

ASPECTS OF THE EXPERIENCE OF ILLNESS THAT IMPACT ON THE ABILITY TO FIND MEANING

The nature of the process of understanding, accepting and integrating the reality of having cancer depends in part on the seriousness of the particular cancer, and the success or otherwise of the treatment. There are many situational factors that have a bearing on how difficult it is to make sense of what has happened and differences in individual contexts mean that it is naturally harder for some to make sense of the situation than for others. Other factors though are more part of the process and may vary between each individual, and for each individual, in an ongoing way. A primary goal of the present study was to investigate some of the processes involved in finding meaning that develop out of the experience of illness and to throw light on how these may make it harder for some people than for others to regain a sense of life being worthwhile. However, in looking at aspects of the process that may influence how it is experienced, the intention is not to minimise the suffering of all people going through such a serious illness.

Interconnectedness

Interactions with other people were powerful for either encouraging or hindering meaningful experiences. In some kinds of relationships, usually involving unconditional acceptance, the person was drawn into being involved with others and with life. The connecting quality of relationships worked from both sides; the person giving in the relationship received something from being able to care for others. For the person who is ill, feeling needed or cared about seems to lead to the development of feelings of care. These relationships have the power to draw the suffering person's focus towards life and others. This is important because it is then through living and engagement with life that meaning develops further in a more expansive way.

Having cancer can be alienating and aspects of the experience can compound feelings of being set apart. The findings of the present study suggest that finding meaning in the

experience of cancer is made possible when a person feels a sense of self worth and reconnection with life and living.

Several aspects relating to the importance of the quality of interactions with others emerged from the analysis: acknowledgement of the plight of the sufferer; finding acceptance; needing and being needed; and the use of religious faith.

Acknowledgement

The importance of feeling acknowledged was expressed by all participants. The aim here is to elaborate on what acknowledgement consisted of in the present study, how it was felt, how it was conveyed, and what it meant to participants at different times. The significance of acknowledgement was demonstrated both when it was present, and at times when it was absent.

Acknowledgement seems to facilitate the processes of understanding and finding meaning, but when it is absent these processes are hindered. The role of acknowledgement and of the support of others in a more general sense, is in reconnecting the sufferer to life, living and humanity in general. In this way finding meaning is facilitated through the sufferer feeling a sense of worth and belonging and thus being drawn to feel engaged with life.

Affirmation of the person - recognition of individuality: One aspect of acknowledgement involved a recognition of the individual beyond the medical condition. To begin with this meant the doctor or specialist who gave the diagnosis.

And he said, well it'll be pretty tough and there are no guarantees or anything. And they were very good. The thing I liked about all the people I spoke to, there was the surgeon, and he didn't make anything bright at all. He just - straight facts - bang. Yep, - and I don't know why some other people don't like it - they say he's too abrupt. But to me, you were in no doubt as to where you stood, and I think that helped me a lot. (John)

Recognition was shown through responding to the particular needs and personality of the individual, which required a degree of sensitivity and intuition. For this man, being treated as competent and effective enabled him to retain a sense of preparedness and therefore control, important for his sense of identity. Identity is at risk too by potentially being defined by the illness. Having individuality recognised not only implies that the person's identity is not defined by the illness, but also affirms their individual worth and effectiveness. Conversely, being treated as a medical condition or

a case amounts to an implied disregard and dismissal of the individuality of the person. It is damaging both to feelings of self worth and a sense of identity.

He was really quite callous, he just sort of walked in, and he was so busy looking at his notes, he didn't even look at me, and then looked up and said, yes, well we'll need to take a wider excision of that, and got his pen out and drew this great big huge oval on my leg. Then he said, right, we'll need you in here, I can't do it this week, I'll have you in next week. It was the week of Christmas. And I said, I've got four children and I can't. Can't I leave it till after the school holidays? And he said, if you do that you'll be dead by next Christmas. And he walked out of the room. (Kate)

By not looking at Kate the surgeon implied that the only things of interest or value to him were contained in the file. In addition, a lack of understanding of what she was going through was shown by just focusing on her leg as an object. This extract illustrates how such an attitude conveys the message that the person does not exist beyond the medical condition they represent, which is likely to lead to feelings of being disregarded, and as a result devalued. It is a double setting apart, firstly from finding that your body has 'failed' you, and then from feeling ignored and not worth taking the time to relate to. Loss of self worth is then likely to be compounded.

Initially the response of the diagnosing doctor or specialist is especially significant since one of the reactions from the diagnosis is that the medical experts are looked to for cues about how to respond. This is especially the case if previous experience and inner resources are inadequate for explaining the situation. Cues on how to respond were sometimes not only in regard to the illness, but were felt as well in how the person viewed themselves.

And I suppose that part of me sort of felt like, well the hospital had been so indifferent towards me that maybe that was what I was supposed to be like as well. I was supposed to be acting like it wasn't a big deal. (Kate)

Confusion and incoherence were increased when an attitude of indifference was in contrast with the way the person was feeling themselves. There were many examples of being related to in an offhand way and of the negative effects that this had on the person.

Then he pulled me in there and I went and sat through there, and he said, you've got cancer. And I thought - how nice. And then he said, oh, could you go and sit outside there and wait for the radio-therapist. I don't know whether you know in the hospital

that well, clinic three, sitting out in the corridor with the thirty thousand other people going past, and I was on my own... (Sam)

The implications of being alone and set apart which are sometimes associated with becoming seriously ill, are emphasised in these kinds of interactions. Acknowledgement is more likely to be felt when treated in a way that shows a sensitivity to the particular individual.

Before I had the surgery, the oncology nurse came out to see me, and she was really supportive and helpful and steady. She was like a mother superior really. And she brought out a prosthesis, and I thought well yes, I'm a nurse, I know what it is, - looking at it in her hand. She said, touch it, - hold it... ..well she was there to help me get over it, and I simply got on with it. I can remember her visiting me at home, sitting in our conservatory. And then I had the surgery, and the hospital staff were all really supportive. They were really considerate and kind. (Emily)

(My husband) was very supportive, and I can see that other people might have a problem... ..he came with me every time when I went to the surgeon.(Sarah)

Sometimes where a lack of acknowledgement was felt the intentions of others may have been well meaning but by treating all patients in the same way, there was the assumption that everyone's needs were the same.

These people (hospital volunteers) would come in... ..they used to bring cakes at morning tea every Tuesday... ..and that was a terrific thing....and of course I couldn't eat a bloody thing when I was in there... ..I told them I can't eat them. It bloody well annoyed me, you know. I used to get furious with them... ..they'd chat away about silly things. Well I couldn't, - well maybe it was me, I don't know, but I used to feel so private. Maybe I was always a bit embarrassed about - I think that could have been it, you know, just stupidity... ..I don't know why, but I just got anti because I felt I was being, - manipulated I think, but I wasn't, nobody was trying to do that at all. (John)

The extract above illustrates the frustration of being related to as one of a type and treated in a formulated way, even when from the best of intentions. Ignoring what the person is saying implies that in becoming a 'patient', the right to be heard as an individual is lost. This highlights the risk of becoming defined by the illness. Feeling manipulated perhaps indicates resistance to being treated as one of many and a reaction against presumptions about personal needs. Restoring a sense of individual identity even in small ways, particularly when independence and self reliance are at risk, seems

important for a sense of identity. Privacy and autonomy are also lost in a hospital situation, again accentuating the more general issue of loss of control. This kind of experience illustrates how everyone's needs cannot be met in the same way. The different dimensions and nuances of acknowledgement show how powerful this process is for the way that the person feels about themselves and the situation that they are in.

Affirmation of feelings - concern for personal crisis: Apart from a recognition of the individual beyond the medical condition, acknowledgement is the genuine understanding and concern for what the person is going through; a recognition of their whole situation, implying a concern as well.

Sometimes others did not realise what the person was going through, or they did not know how to handle the situation. Even friends and family may not always understand the magnitude of the crisis that is being experienced. People around the sufferer may feel helpless too, and for some, real understanding may mean facing the reality of human vulnerability in relation to themselves, leading to fear and sometimes avoidance.

I've found that at times I've felt very isolated and very alienated from the people that I called my friends, because I couldn't really talk to them about what I was going through... ..and I have, there have been people in my life that just aren't here now. You know, they just don't want to have anything to do with me, because they don't know how to talk to me. Or I'll find they'll ask somebody else how I am. Well, what's so terrible about coming and asking me? So I've learnt, there's very few people I talk to now, about what this is doing to me. Yeah, I mean, some have been, some people just don't seem to want to hear, or don't want to deal with it. (Kate)

As one participant pointed out, some of the issues were too much to expect friends to understand, but lack of understanding was sometimes very hurtful.

(When physical healing has been dealt with) then it's the long haul for you, and people start saying things like - it's time you forgot about it, it's time you got on. And it's a phrase you hear quite often - it's time you let go of all that, and moved on. But the person involved can't do that. You know, sometimes it gets stuck and they need help to move on through the grieving, but, you know it's very hurtful for somebody to hear that it's time to move on, and what that's saying is that the friend is sick of hearing you talk about it... ..and you know, like finally, I went through periods of depression, quite significant periods of depression. (Jane)

Feelings of being different, of not belonging and being set apart from others because of what they have been through were accentuated when understanding was lacking. For

some it felt as if there was a distance between them and other people including friends and sometimes family. A sense of being alone was emphasised at these times.

I have had some experiences with people when I tell them what I went through and that, and they don't, don't even want to talk about it... ..it sort of holds you back from telling people. (Pat)

Particularly when the full implications of having a life threatening illness is very hard to relate to or to come to terms with, there is a risk that feelings may be interpreted as somehow having failed at coping, or as something wrong personally. This is one of the ways in which the very experience of illness is threatening to a sense of self worth.

Yeah, I think if I hadn't done anything like that (talking to a counsellor) I would still be, I'd still be really, really sad I think....and to realise that it was all quite okay, and that it was quite normal. Cause I'd started to think I wasn't really - - - yeah. And it was understandable. (Pat)

Recognition of the personal crisis that having cancer involves, means that the person can at least begin understanding the ways that they are feeling, and realise that those feelings are a natural reaction to the situation rather than a manifestation of personal shortcomings.

Often there was a feeling that only those who had been through something similar could really understand the magnitude of the personal crisis that was being experienced. At times when people did understand, feelings were validated both through finding another who had had a similar difficulty, and through sensing a real understanding in the other.

Just something, - you meet some people and they've had something. It might be totally different, but they've had something really go wrong. And you can just start talking to them and can just tell, that they sort of know where you're coming from. (Pat)

There's one man that (my husband) brought home a few months after I had surgery, and he had been diagnosed as having cancer of the small bowel. So he was tuned into my wavelength. (Emily)

My father has got emphysema, so Dad is, - it's funny, since he's had emphysema he's a lot more understanding of what I'm going through. (Kate)

Finding that others had felt the same way normalised what the sufferer was going through, thus counteracting feelings of being set apart by becoming ill. There was reassurance too that their feelings did not signal something wrong with them personally. They were better able to understand, even if this was only an increased understanding of what they were feeling. As with the many aspects of acknowledgement, the value is in reconnecting the person to life, by affirming a sense of belonging.

At times all that was required was a recognition of how frightening the situation was, but without this the person was unsure whether the way they were feeling was normal. Because of this, acknowledgement was sometimes felt as permission to have those feelings.

Well the nurse that stayed with me until I went down to theatre was really good. And he was sort of talking to me about, you know, try not to feel anxious, and it was the first time anyone had mentioned I had feelings, that I was allowed to feel them. (Kate)

Conversely, lack of acknowledgement may be experienced as a sign that the way the person is feeling is inappropriate.

I remember one day I decided I wanted to know what I was up against and what the possibilities were, and things like that. And the surgeon told me - and had his registrar, and the charge nurse, and student nurse and everybody else standing round the bed as well. But no one, - - - like they all heard him say, look, we don't know what sort of a future you've got, we don't know what your life expectancy is, we don't, you know, that's the whole thing, there's just so much uncertainty with cancer and all you can do is be as positive as you can... .. It almost felt that I wasn't being allowed, it wasn't the acceptable thing to actually feel - things you read about in books, to feel anger, and to feel really grieving for being told that I might not be alive to see Sally grow up. I mean, I still have to deal with that all the time. Like that's for me - that is a really big thing. But like other people could just say it as if, - well, it's like - next week you'll get your car looked at. And said with about as much compassion. (Kate)

Lack of acknowledgement of feelings may make the whole experience more difficult by conveying not only a lack of understanding, but also a disregard and dismissal of personal emotions as being of any importance. Clearly, a sense of alienation and being set apart is emphasised in this kind of interaction. Further, the vulnerability of self-worth is compounded. In contrast, true acknowledgement is a recognition of the magnitude of the personal crisis that having a serious illness involves.

How acknowledgement was conveyed: In as much as acknowledgement involves recognition and a respect for individuality and feelings, it was conveyed in different ways. It was always a way of connecting with the unique individuality of the person, but followed no set formula. Whereas some participants enjoyed people openly acknowledging their illness, for others acknowledgement of their needs involved a respect for their preference for privacy. For some there was discomfort in being too public about the illness and talking about the illness was an unwelcome sign of sympathy or pity. The way that acknowledgement was conveyed showed in itself an understanding of individual differences, as illustrated in the examples below.

That was one of the neat things I think about having been in the services and that, and being involved in motor racing, the visitors I had.....the support I got from motor sport people was fantastic... ..yeah, they just heard through the grapevine that I was there.....oh, it just made so much difference, eh. (Sam)

I had a lot of support from all over the country... ..and there was all sorts of people came out of the woodwork and wrote me lovely letters... ..and I think I gained strength too, from the fact that there were so many people that were really concerned for me, and travelled, like there were friends who came, people who I thought were just acquaintances, and then all of a sudden you realised that these acquaintances were actually much deeper friendships than that, and they really were much more sincere. (Sarah)

And then I go over the pub, you know, and next thing everybody's going on about it. I said, for Christ's sake, give it a rest, you know. Jesus. But now, it's good because they all know what I'm like so nobody says a bloody word. (Justin)

Although there were differences in the need for privacy, the similarity when acknowledgement was felt was that compassion was shown and the feelings of the individual were really understood. What was helpful was often conveyed indirectly, not in what was said, but in what may have been implicit in actions, as with practical help.

When I came home from hospital, a neighbour massaged me every day, and that was so helpful... ..She'd learnt a bit about massage, and she was concerned that my husband wasn't caring, - or didn't know how to care, - and she gave me that. (Emily)

Well, by the time I got home, the phone was ringing as I walked in the door. It was really bizarre, and it was horrible actually. Like the grapevine got into action real fast. So it was really horrible because people that I didn't normally have anything to do with were coming round, often not just to give me any support, they actually just

wanted to see how I was coping with it, or hear, what were the details. Some people were really good. And they were the people I knew I could count on to look after the children and things like that. Or they would bring meals round and they actually put into place rosters that could get the children to school and home again for me, and things like that... ..and we couldn't have got through without them. (Kate)

Rather than curiosity, helpful support involved a kind of empathy and commitment. It seemed to show an understanding that while practical help was achievable and useful, the way to help with the more personal crisis was through conveying that they could be counted on, and that they were in a sense standing by. Expecting to be able to help in terms of making things better would perhaps have shown a lack of understanding, since some things are beyond outside help. In providing practical help there may be an implicit acknowledgement of this, while at the same time signalling more personal support indirectly through this understanding.

Acknowledgement was sometimes conveyed indirectly through rapport that was built. These kinds of interactions gave the person a sense of connection with others, allowing intimate contact through an understanding of the individuality of the person. They were interactions where a connection with others was felt. Evidence for this was indirect too, but clear from the obvious regard and affection that was felt from both sides.

You're not supposed to be able to talk, he says, you're not supposed to be able to swallow, - not supposed to be able to taste anything, and he says, - I told you you weren't supposed to be home by Christmas. You might as well bugger off, he says, - you're not doing as you're told. And that was the way he discharged me. (Sam)

They're just such neat people down there, eh. You know, you hear a lot of people with cancer, they tend to have quite an attachment to ward 25 up here, in Palmy. Well, I've got the same thing to ward 32 down there. And no, as I say, they keep in touch with me... ..To give you an idea of what she (one of the nurses) was like, she used to come in in the morning, you'd hear her coming down the corridor, and she'd leap in the doorway and she'd (throwing arms out) Well? And I used to just get my piece of paper out and write, SIT! (laughs) But she, you know, just her enthusiasm and that....if you were sick, she'd give you a hard time until you came right. (Sam)

In many ways acknowledgement was conveyed through the quality of interactions and implicitly shown understanding, rather than more direct kinds of spoken communication. Lack of acknowledgement was something that many participants experienced at times but usually from particular people or at particular times rather

than in a more general way. Nevertheless, either way, the attitude of others had an impact on how the person was feeling.

There was one old night nurse there, - I was bloody sure she used to arrive on a broom.....I've actually still got my notebooks from the time I had to write everything down. And every so often I pull them out and I go through them, and I can tell just by what I've written, - I can tell the mood I was in. Like if this old girl was there, there was big writing eh, you know, - DON'T DO THIS! (Sam)

From participants' descriptions of relationships that were helpful or those which made things more difficult, it was clear that understanding was helped through feelings of acknowledgement because of the implicit meanings that were conveyed. When feelings are recognised by others it is like a validation of the appropriateness of those feelings. Acknowledgement provides affirmation of worth through demonstrating an understanding, rather than an implied judgement of what the person is feeling. Without that understanding the person is set apart further, compounding already existing feelings of being alienated from others through becoming ill. Looked at in this way, acknowledgement is helpful in encouraging a sense of belonging, rather than adding to feelings of rejection.

Summary: What comes with the diagnosis of cancer is the cultural and social representations of the word which have the potential to overwhelm the person's sense of identity. Moreover, the idea of the body having failed brings with it a devaluing of the self too. Being treated as no more than a medical condition means that a sense of self worth and identity, previously taken for granted, are challenged by being disregarded.

Without acknowledgement there is nothing with which to start rebuilding beliefs about the world and one's place within it because a lack of acknowledgement is not simply neutral, but has a strong negative impact. Not having the time spent on you to explain things, not just medically, but in terms of implications for living, is like holding up the learning process of becoming familiar in new territory. In effect, the person is potentially prevented from moving forward in understanding. The risk for identity becoming defined by what has happened is increased by being treated as a 'condition', but counteracted by being treated still as individual and of value. So being treated as being worth taking trouble over, as an individual who is naturally concerned with what the medical condition means for their own life, is providing a starting point for rebuilding a positive sense of identity. When there are no internal cues that fit the situation, cues from others become more salient. The experts are looked to as knowing

more, and meaning is found in the subtle nuances of interactions. The way that specialists, doctors, or nurses relate to the person becomes very powerful for whether the person is able to make sense of the situation or not.

Overall, by connecting with the person and establishing a relationship based on real understanding, feeling acknowledged was important for becoming engaged with living. In many ways this was probably one of the most important things in helping people to understand the new situation. Even when there was a feeling that no one could really help, acknowledgement still helped the person to feel that they were valued, that the way that they were feeling was normal, and that others understood the crisis that they were going through. In a sense, acknowledgement was simply the communication of real understanding and concern from other people. While it was a recognition of difference and an affirmation of individuality, it was at the same time a recognition of similarity and communality with others. Through conveying a real understanding of what the person was going through, the implication was that they were not alone in how they were feeling. In this way, acknowledgement affirms the interconnectedness of all people, allowing a sense of belonging to re-grow.

Finding acceptance

Acceptance includes acknowledgement and yet it implies a commitment as well. Beyond a real understanding of the personal crisis, it was an acceptance of the person with cancer. Thus, acceptance was not only of the person, but of the illness and its implications as well. It came from various sources but at times was perceived by the sufferer as being conditional on fulfilling valued roles. The kind of acceptance that helped the person accept themselves in the new situation was unconditional.

Acceptance, like acknowledgement, provides continuity with the former self, by valuing that part of the person that cannot be changed, that is beyond the boundaries set by physical limitations. It encourages the person to realise that they have not suddenly changed even when stripped of the roles and responsibilities that people take on and perhaps unconsciously assume are a source of their value to others. In other words, true acceptance seems to allow people to feel valued because of what they are, rather than what they do or achieve.

Something my mother in law said to me very early on, she said, well, it looks like this is your time Michael. I think the best thing you can do is just, - you've got to let go of all your inhibitions and just be yourself. You don't have to pretend any more, or put up a front or anything, you just, - just be. And that really helped me a lot because it made me realise that okay, I could get rid of a lot of the normal sort of self protective

mechanisms and sort of dignity, and all that sort of thing that you have, because there's no doubt about it, it was humiliating, and degrading and that, at times. And to actually feel like, okay, this is me, we're all human beings in the flesh. I'm going through this, and people still accept me and love me through that. (Michael)

People who are accepting whatever the case may be, and who are not fearful of confronting issues arising from the illness may provide the kind of support that is helpful. Acceptance of the person within the new situation means that there is no need to make an effort to be, or seem, any other way.

Every day I just - yearned - for her to walk in the room. And when she did, I just felt this, - this calm. ... I think that complete acceptance thing is really important. You know, I could just be myself. I could complain about everything to her and know that she wouldn't get upset, she'd know that was just how I was feeling. (Michael)

Unconditional acceptance from others means the acceptance of the illness and its implications as well and a valuing of the person through that. In this sense, acceptance was valuing that part of the person that is experienced, in consciousness, as separate from the body. When a person becomes ill, suddenly the 'body' part threatens to take over in defining the person and self worth may be at risk. Acceptance conveys an affirmation of the strength and value of the part of the person that cannot change.

I think again it's this connectivity to the outside world. At times when my independence was gone, she became my independence. (Michael)

When I first had melanoma I found, like (my husband) ... he's very much a realist and he likes to deal with facts and logic. And so for me to come in and say, you know, I'm feeling really overwhelmed by all the uncertainty of it all, he just couldn't deal with it. And he was great the second time, like this time when I've been in hospital, he was really good. He looked after me. And, especially like this time I went in, and I had no, - I felt like I had no fight, and I couldn't be assertive. He was being assertive for me. (Kate)

For some, personal strength was sustained by feeling able to implicitly count on others. As with acknowledgement, finding acceptance is associated with the ability to trust and to willingly relinquish control.

When people feel accepted regardless of anything that might happen, there are implications for how they feel about themselves because of what is implicitly conveyed. In the context of having a serious illness, self acceptance becomes easier as well as

coming to terms with having cancer, perhaps through seeing that others can accept them with the illness.

She just said on about the second or third day, she said we'll take the bandages off today. And my husband was there, and he just said ohh, - when she was taking the bandages off - ohh, it looks really good. And I thought - if he says that - and I thought oh yeah, it's not too bad. Looking down, it didn't look too bad, and I thought yeah, I can cope with that... He said to me, he couldn't care if I had no breasts or five breasts, is how he said it. He couldn't care, it wasn't going to affect his love for me, so that was great. You know, I thought oh heck, I'm gonna look so ugly, having this breast off. But he was really good, he couldn't, - and he still says it, he says it's meaningless to him, so that was really supportive. (Jill)

The importance of acceptance was highlighted in cases where it was lacking, especially in those close to the person.

My husband would sort of shoot in, see if there was anything I needed, and vanish again. And of course he was running a small farm as well as a full time job, and I always took second place anyway...the sicker I got, the more he sort of appeared to go into the distance, find other things that he needed to do...I said to him once, - I think you need a woman with breasts. And he said yes, - but I was prepared to put up with you without them. (Emily)

Without acceptance of the person including the implications that the illness has for their identity, it was harder to feel of value and not, in a way, lacking.

For all participants family acceptance was important, but for some there were both positive and negative aspects to family relationships.

Yeah, because, I mean, they're my best and worst things about having cancer. You know, it's weird, but they are(Kate)

Sometimes the sufferer found themselves taking on the role of protecting, which often was a way of transcending their own suffering, through caring for others. It was an achievable way of retaining a sense of control too.

I was very conscious of my wife and the family in as much that if I went in (to the operation) on a low, then I'd take them down with me, but if I went in on a high, it then gave them an even perhaps slightly easier time I think. (Chris)

At other times the role of protecting others was felt as a burden. Suffering was sometimes compounded by worrying about the suffering of others and yet feeling helpless to alleviate it. For some it was as if grieving was not only over personal losses but also on behalf of a partner, parents who faced losing a child, or children who faced losing a parent. For the person going through the illness feelings of guilt may be emphasised through feeling they have failed in valued roles. There may be guilt felt by both the sufferer and other family members, particularly parents.

So straight away that's making Mum feel bad about how she and Dad looked after us. And if anything they did the exact opposite of everybody else. They didn't let us go lying out in the sun. And she always made us wear these revolting hats and long sleeved shirts. But, - so that's hard for her to stop blaming herself... I often end up being the one that's trying to comfort her. I know I'm a lot stronger than she is.
(Kate)

A lack of acceptance was usually not related to the person, but to the reality of the illness. Family members may be going through their own crisis and finding it hard to accept what has happened. However, although unintentional, an inability to accept what has happened can be felt as a judgement of the person as they are. This makes acceptance seem conditional from the perspective of the person who has the illness, creating a barrier against complete openness.

It was a burden with some people because you felt like you had to put on a facade, to put on a front, you know. And unfortunately it turned out to be, - that always was the case for my parents, you know, who I thought would be close enough to me that I wouldn't have to do that. But it, - I don't know whether it was them, or whether it was both of us, but I certainly felt the burden when they were around. (Michael)

The person who is ill may be drawn to others who have accepted the reality and come to terms with it, and who are better able to deal with it.

My parents, they were, - it seemed to me anyway from my perspective, that they really haven't any greater power than themselves to call on, or that they believe in, and they were just struggling so much to deal with it, the grief and the shock of it all, - that I guess I tended to head towards people who had more of a peace in the situation, because of their beliefs. (Michael)

The significance of unconditional acceptance and the implicit meaning that it held, was demonstrated in this dual nature of family connections. Sometimes personal value is perceived as partly dependent on the fulfilment of expectations that come with family

roles and responsibilities. This means that at times the person feels that they have to hide their suffering.

On the other hand, family relationships provided a bond and were often the very thing that reconnected the person to life and gave them something to fight for. Feeling needed provided motivation to return to living and to search for a sense of meaning. Having dependants may have placed demands on the person, but it was seen as very helpful. In one way, it helped in simply getting the person up and experiencing again.

Gives you, - good distraction. Life's got to go on, so it's good, really good. You know, you can't be self pitying when you've got someone to look after. No, it was very healthy I think having a small one. (Jill)

Being needed means being of value to someone, and it also means acting in a way that implies one's own self-worth. The motivating aspect of being needed was evident when the need was from a pet too.

Well, if I didn't have him, you know, well I know that I probably would of just sat there, and done nothing, for the rest of my life. Ah,- and said nothing, but having the pup, I had to train him, - because you can't always reach him with a boot...his lordship makes me do things. (Sam)

For this man who had a total tongue removal, his puppy not only got him moving, but gave him a reason to learn to communicate again, through the need to train him.

Another element of being needed was in urging the person to face the implications of the illness and to look for help, if only for the sake of others.

Certainly there've been a few times I would've just stayed in bed for a week, or two weeks, but you can't, you've got to get up, and you know, get her going and that. Which is good...And being grumpy, which isn't so good, but I think when I was like that, I was getting really grumpy, and I was worried that I would affect her in a bad way. So then I did want to go and see someone, and talk to her (the counsellor), and that really helped. (Pat)

Well I find that at times what I do now is like I'm functioning as the person who's holding the family together and doing all the things. But there's a big part of me that's not really there any more...And the children have said to me, when you hug us, you're not really hugging us properly. And that's when I thought, - - I need to do

something about this. I need to stop feeling so distracted and so withdrawn from them. (Kate)

Implied in a dependent relationship is an attitude of unconditional acceptance, as well as an affirmation of worth. Again, a continuity with the former self is emphasised as the part of the person that is valued, is that part that cannot change through what has happened.

Summary: Overall, acceptance helps to reconnect the person to life, and a sense of belonging is encouraged to grow. Acceptance of the self with cancer is facilitated and self worth is strengthened. Unconditional acceptance conveys to the person who is ill that their value cannot be affected by anything that happens.

Responsibilities and caring about dependants may help through making the person look outwards beyond themselves and their own suffering. In another way, as the extracts above illustrate, it provides motivation to decide that searching for help is worth the effort because of the importance of themselves to others. Being responsible for and caring for someone else may encourage a greater awareness of others' needs in relation to one's effect on them, through seeing oneself reflected by them. Responding to need means acting in a way that implies one is worthwhile. Being depended on means that you are necessary and of value to someone and it seems to urge a person to value their own existence, and the quality of that existence. In this way a purpose for living grows even when there seems to be no personal meaning. Taking the responsibility of fulfilling others' needs leads to a re-engagement with life and living. It is a form of interconnection that provides purpose and leads the person to experiencing in the present. Being needed provides the motivation for taking action to get help, and receiving support may help to make more sense of what is happening. It is as if being needed leads a person back to living and following on from that there is the possibility of life becoming meaningful through learning ways of living it.

Religious faith

Faith in God provided strength for getting through the experience, especially at times when suffering was particularly severe. In a sense, a trust in God was the ultimate trust in that it gave a sense of not being alone, even if death had to be faced.

Gaining strength from a feeling of God standing by was similar to the strength gained from a confidence in people who could be counted on. For some people, their faith in God was strengthened through experiencing the care and support from people around

them. In a way, this was like seeing God in the actions of others. Similarly the power of prayer was a real source of strength for some.

I didn't completely abandon my beliefs and just say, well, I don't believe in God anymore, or he wouldn't put me through this. I always felt the opposite. And I think one of the things that really confirmed that for me was seeing the care that other people were putting in to me, that people were investing. You know, the people from the cancer society, the nurses, the doctors, my wife, our families, and people in the church. Seeing people actually for you and caring about what happened to you in such a situation, made you realise that hey, there probably is a God behind all of this, there must be. (Michael)

For some there was a sense of having only got through because of the strength that they gained from God, and from others praying for them.

I just say it was God gave me strength. I don't think there was anything from me. Humanly I would have been a wreck. I would've gone up to that hospital and having to have a mastectomy, I would have been in tears, and hysterical, you know, I would've been really devastated. But I didn't feel that at all, and I can only say that was God, it wasn't me. (Jill)

Looking back on it I can kind of see how He has been with me, and helped me to cope and brought me through, so I can kind of see that positive aspect to it. (Michael)

Even for one participant who questioned her faith as a result of her illness, the knowledge that there were others praying for her was something that she did not want to turn away from.

I know that there's people at my church that are praying for me as well, and in some ways, yeah, it's quite humbling to know that they care enough to do that for me. (Kate)

Having faith was felt as the lifting of the burden of having to control life, as a complete acceptance that would always be there, and as a source of strength even when all personal strength was lost.

I thought, it's not on me any more. God's taken all this burden away from me. And I just felt, had an amazing peace after that, and I could sleep at night. (Jill)

Letting go of control was facilitated through trust in a higher being. The value of feeling strength from an outer source beyond the self was evident not just at the time, but continued as a source of support in looking back.

A belief in God sometimes provided a purpose and meaning for what had happened. For many this purpose seemed to develop into making a contribution towards making things better for others, to raise awareness about cancer in general and to advocate for the group in which they had gained membership simply by having cancer.

I've had the opportunity to be doing what I've been able to do through patients, and that I hope has given me a better outlook on people, - peoples' sufferings, and their concerns. And I may have been able to (contribute) some small thing to it, to make it a bit better for them. I believe it's done for a reason, - that to me, I should do it because I've been given a chance of doing it. (Chris)

For about half of the participants the importance of a religious faith was discussed. Religious beliefs were not specifically raised in the interviews so that this does not mean that others did not have a religious faith, only that they did not raise it as an issue during the interview.

Gaining strength from a spiritual faith; a feeling of interconnection, belonging, and of not being alone, meant that the benefits of a religious faith resembled those of acknowledgement and acceptance.

Summary

In the present study interconnection grew from relationships and experiences where there was a sense of reconnection because of being drawn to care through being cared about. In this way it was closely tied to, and developed in relationships involving acknowledgement, acceptance and mutual need and caring. It was a feeling of connection to life and to other people. Interactions with others were important for experiencing interconnectedness in as much as they impacted on how the sufferer felt about themselves and their position in relation to others and to life in general.

A sense of being set apart and different may be experienced through becoming ill, and through much of the process of illness, treatment, hospitalisation, and adjusting to losses. When acknowledgement and acceptance from others were lacking, feelings of alienation were compounded. Interconnectedness counteracted feelings of alienation that, to varying degrees, set the person apart from their former ways of living. It seemed to be helpful not only by making the person feel cared about but also in drawing

them towards care and concern for others. It was a two way connection with others, a focus beyond self concerns and a way of transcending suffering.

Feelings of interconnection kept the person involved with life and motivated them in striving to accept and integrate the reality of becoming ill. In being drawn to care about others, and to feel connected to them and to life, a sense of meaningfulness may begin to be regained. In a sense feeling strongly connected to others and to life was a condition for life being able to be experienced as meaningful and for further experiences of meaning to grow.

Overall, other people were important in the process of finding meaning in the experience of illness for a variety of reasons. With other people who were accepting of what had happened, and who related to the person in ways that showed an acknowledgement and affirmation of the essential part of them that was not bounded by physical limitations, there grew a potential for meaningfulness to develop. Feelings of belonging and being connected to life and to others were encouraged. Through feeling connected, and being drawn to caring about others, the person was at times able to transcend their own suffering, if only for a while. Even in looking back at valued relationships, it was possible to feel again the benefit of those encounters or experiences. Caring for others encouraged a widening of focus, and in feeling cared about, there were implications for self worth. In a sense, becoming reconnected to life and living was a drawing outwards of the person's focus, leading them back in to living and experiencing in the present and in the new and unchangeable circumstances.

When feeling engaged with life, it is possible to find meaning in a more expansive way through the ways that life is lived leading to meaningful experiences and some positive outcomes, in spite of the experience of cancer not being positive in itself. Through finding the ability to focus outwards to concerns beyond the self and becoming motivated to be engaged with life the conditions under which life may be experienced as meaningful may be built. Further, through growing self worth as a result of feelings of interconnectedness with others, the benefits of adapting to the illness become significant enough to be worth the effort of striving for. The importance of others is in reconnecting the person, in making them feel once more a part of humanity.

Levels of Understanding

Finding meaning through the way that life is lived with cancer happens gradually while developing deeper levels of understanding of what has happened. Initially attempts were made to relate to having cancer in ways that made sense of what had happened, based on existing experience and beliefs.

The ability to relate meaningfully to what had happened allowed some participants to fit the reality of having a serious illness within their existing frameworks for understanding life. For others though, relating to having cancer was more difficult.

There may be a conscious search for meaning through attempts to make sense of what has happened. Meaning develops too in a less conscious way, from living with the illness, gradually learning new ways of being that incorporate the reality and wider implications of being ill into a sense of self. This sometimes leads to experiences that are valued for themselves and that hold a wider meaning that provides a basis from which to accept the changed self.

Self-worth grew through returning to valued activities, through achievement in spite of changes and limitations, and through sometimes finding value in the new ways of being. Meaning was restored through regaining a sense of worth and identity which was possible as acceptance of the self in the changed situation grew.

The ongoing processes of adaptation and acceptance allowed an integration of the implications of cancer into the person's sense of identity. The process of integration was an ongoing struggle to reach a balance that allowed the person to live life authentically in the changed situation.

Relating to what has happened

For most participants the diagnosis of cancer came as a shock, but over time some people were able to relate to the idea in a way that made sense and provided meaning for why it had happened. This helped to restore a certain amount of coherence to life. The initial impact of diagnosis seemed to involve shared, cultural understandings of what it means to have cancer; all the fear and uncertainty about pain, suffering and the possibility of death which are conjured up by the word. Relating to what had happened involved attempts to make sense of having cancer in the light of both cultural understandings and personal contexts such as time of life, previous life experience, and religious or personal beliefs. The seriousness of the particular type of cancer naturally influenced how hard it was for each individual to accept and make sense of.

Although cancer is a life threatening illness, and very traumatic for anyone, it seems that some people were able to make sense of the illness having entered their life. For some though relating to what had happened was very difficult without experiencing at the same time a sense of having lost meaning in life.

Time of life: Apart from the seriousness of the particular cancer that varied between people, different personal contexts had a bearing on the amount of disruption that was felt in terms of jobs, family and other life activities. The stage of life and the time of life that the person was in made a difference to whether the person was able to find meaning in the situation.

Well - it was a big shock, but it's a funny thing - I didn't know that it would be like this, but I was just quite - ah - I just accepted it because I was about, what, 68 at the time, and I thought, well, now, they were pretty good innings I've had , so - so be it... ..you know, I'd had a good life so I just - well, that's that. And it is. (John)

People in the later part of life have had the chance to achieve many of their goals and to fulfil valued roles. Perhaps too in looking at life as a whole, an illness occurring at such a time does not seem as unjust as it does for a younger person. In this way it is easier to relate to and fit in with existing beliefs about the world.

When starting out on building a life, there may be difficulty initially in even comprehending the threatening nature of cancer. One reaction may be to downplay the seriousness of what had happened, to appraise the diagnosis as not too serious or as something that could be easily treated.

At that stage I felt quite good. I think I was quite naïve as to how much treatment I was going to have, and I thought that most people,- that they could do a lot for leukaemia now, and that not many people died from it. I don't know whether I was just denying the seriousness of it, but I just thought that it was going to be a piece of cake really, and that I'd be fine, and that everyone else was worried for no reason. Like my family were all really upset, and I was just telling them, no, I was fine. It's going to be all right. (Pat)

I thought this was just something you got cut out and ten minutes later you just walked out of the doctor's surgery. (Kate)

While in the process of starting out on an important stage in life and right in the midst of fulfilling goals, having to turn away from that sort of orientation, and focus on a personal threat may have seemed contradictory. This kind of reaction may have acted as a kind of self protection, and a way of controlling the illness, allowing the main focus to remain on other life concerns. Another possibility is that understanding of the particular type of cancer was limited. In addition, the words 'leukaemia' and 'melanoma' may hold different cultural meanings that the word 'cancer'. For some younger participants, compared to the older participants, it was difficult to relate to what had happened in a way that made any sense to them.

Similarly related to age is the increasing likelihood that many life experiences will have lead to gradual adjustments in world views, so that the personal relevance of hardships, accidents, illness, suffering and other life crises will have been realised. Some people have recognised before the diagnosis that human life is fragile, that things can go wrong at any moment, and that this is personally applicable. Although this may not make having cancer any easier, it may make it easier to make sense of. There were some participants who related to having cancer by accepting it as part of life which was a way of making sense of the situation.

Me, I've seen half a century, so I'm more than chuffed with that. I'm quite chuffed I got that far 'cause I've had a pretty hard life. (Justin)

Related to personal experience but not necessarily chronological age, previous suffering seemed to have prepared some people to face having cancer with a feeling of being strong enough to cope. As well as perhaps learning strategies for coping, previous traumatic experiences seemed to have lead to a greater awareness that life is made up of many hardships, cancer being one of example of these. This was a way of relating that made what had happened at least understandable and at the same time allowed acceptance to grow through an already existing acknowledgement of the limits of personal control. Trust in close others may be well established when the strength of support within the family has been tested before.

We also lost a son who was killed in a road accident when he was sixteen and a half, which was a few years earlier. So that we had become, yeah, as a family, we had become very strong. And my husband and I had become very close and very supportive, so that there already was some inner strength there, I guess. (Sarah)

Previous traumatic events may prepare a person in some ways. There is an understanding of the magnitude of the personal crisis involved. Furthermore, there is

an awareness of the reality that what has happened will not go away; that it must be personally dealt with rather than avoided or put aside. There was sometimes an awareness of having the inner strength to face suffering. One participant who had been in a serious car accident several years previously was determined to respond differently when she found she had cancer.

So yeah, it was like being able to face another trauma if you like, forearmed about what you weren't going to do. Like I wasn't going to hide the anger, I was going to talk a lot more to people, I was going to deal with things differently. So yeah, I had some strategies if you like, to be able to move into looking at the cancer issues a whole lot differently than if I hadn't had the accident... ..I was more aware of my needs when I came to the cancer. I was probably a lot more aware of other peoples' issues too. (Jane)

Trust in inner strength may come from having coped in a previous traumatic situation, even when this had been a long process of learning through trial and error.

Inner beliefs: For some, a belief that God had a plan meant that there was a reason and a purpose for what had happened, facilitating acceptance of the illness.

We're a Catholic family and our religion is fairly strong in our lives, so to me this was just part of living. That the guy up there, I believe this, that he did it for a reason. Simply because I am as I am. I'm an extrovert in a way. And okay, if I was to be used to help somebody else, then to me, that's why it happened... ..I never felt bitter about God or life or anything... ..I never really felt bitter and felt all screwed up about it at all. (Chris)

Sometimes a feeling of strength was gained from faith in God, as well as a confidence and trust that enabled the letting go of control to be experienced as a relief from the burden of worldly cares.

God got me through it. Because I thought humanly, there's nothing doctors can do. If it's through my body, where does that leave me? Well they can't, - I mean medicine's great as far as it goes, but in the end, there is only so much that they can do, they're only human... .. The minister and his wife came round and prayed with us. I felt really sort of bleak and depressed, and everything just seemed so sort of awful. And they came round and prayed and as soon as they prayed with me, I just sensed the whole thing lifting from me. (Jill)

When a person is able to accept becoming seriously ill as a natural part of life and even an opportunity to take new directions in life, a sense of meaning and purpose can grow. Life itself may be viewed as a learning process, so that suffering may have the meaning of developing a greater awareness of others' needs, and a greater valuing of life, so that some positive aspects to the experience are able to develop.

A sort of a value to life and what we can enjoy of what God's given us. But also, with that, a compassion for people who are going through, or who have gone through something similar. (Michael)

While religious faith was for some a source of strength, becoming seriously ill could sometimes lead to a questioning of religious faith, so that the crisis was compounded.

I don't know that I actually believe in it any more. I used to but, I don't believe in it, I don't believe that this came from God, so therefore I don't - like Dad said to me, if you can't credit God with the bad stuff, how can you possibly credit him with the good? And I thought, I haven't got the answer for that any more. So yeah, that's been another crisis to deal with as well. (Kate)

Reframing: Being able to reframe perceptions of the situation, or place it within a wider context, sometimes helped to make sense of what had happened.

I mean I still wondered why was this happening to me. Although I knew the statistics of cancer, and I'm one of a large family... .. there had never been cancer in our family before. But because the statistics at that time out of so many people, there must be, not necessarily one in three, but some people were going to get it, and I just happened to be the unfortunate one who did get it. But then I thought maybe there's some rhyme or reason for that, - and that maybe I was able to cope with it easier, or better, than some of the others. (Sarah)

Comparison with others could lead to a belief in being better equipped than some to face the hardship. Comparison with others who were worse off was another way of reframing perceptions. In this way, some were able to feel relatively fortunate.

I just accepted everything because I realised, you know, when you went to hospital, you realised how many people (were worse off)....(John)

Through feelings of shock, and a feeling that this was something that happened to 'other' people, on reflection most people did not ask 'why me?' for long. Rather, there was an awareness that there was no more reason why it should be anyone else. For

some, this was part of making sense of their own particular situation when they could see that such a thing happening to others would seem more unjust.

The thing that upsets me with cancer is when it's little kids and that. You know, people that haven't seen life. That's the bit that hurts me. (Justin)

There is a realisation of being part of humanity rather than separate and able to be singled out or privileged. This sense of being connected to the rest of the human race, and a small part of the whole picture, allows for sense to be made of such a serious illness that seems so meaningless and unjust in many ways.

For some in the sample, there was great difficulty in relating meaningfully to what had happened, through an inability to make any sense of the situation, or to relate to the fact that what had happened was very serious, at least to begin with.

For some, diagnosis was by chance rather than as a result of seeking help. Since symptoms are signs of illness, a lack of symptoms possibly holds the meaning that whatever is wrong cannot be too serious.

At times too it may be difficult for others to acknowledge or realise the seriousness of the illness, perhaps through a lack of knowledge about the type of cancer.

And all I wanted to do, I just wanted to get in (to the doctor's appointment), and get out of there as fast as I could. I didn't, and in a way I almost shut down, I'd actually started denying the whole experience of cancer at all... ..and in a way it's almost felt like, I was almost getting the attitude that melanoma wasn't really cancer. And that was part of me, I was thinking that too. I was thinking that this was the same as skin cancer, you just go and get it cut out or frozen off or burnt off. But now I realise that's actually really wrong to think like that, but there's still a lot of people that still believe that. And so it meant they didn't have the understanding that I was up against either. (Kate)

For some too there may be less credibility attributed to the seriousness of the illness when the sufferer is young and healthy.

Summary: After initial feelings of shock there is a sense of trying to understand the implications of having cancer on a personal level. Understanding may grow through relating to what has happened in a reflective way, thus finding reasons and purpose for

what has happened. Several participants were able to relate to having been diagnosed with cancer in a meaningful way whereas for others there was more difficulty.

Through the differences in relating to having cancer, there were similarities. Acceptance on the level of relating to the idea of having a serious illness seems to require that what has happened makes sense. How difficult it is to make sense of, and therefore to accept what has happened, depends in part on the degree of seriousness of the cancer, and personal contextual factors such as time and stage of life, ways of viewing life, and religious beliefs.

Those who are able to relate meaningfully to getting cancer are subsequently perhaps less actively involved in a search for meaning because their sense of meaning may not have been completely lost. They may become reconciled to having cancer and accept it based on their existing beliefs and experience.

A fuller understanding is reached through living with the illness, experiencing what it means personally to have faced a life threatening experience which has ongoing implications for living. Understanding occurs not only on a rational level but through the process of experiencing and in this way much of the process of finding meaning grew out of the way that each individual returned to living.

Understanding through experiencing

There was a difference between relating to the idea of having cancer and understanding the fuller implications of living with cancer which was a process that involved learning new ways of being through experiencing. Understanding seemed to occur at these different levels that worked together in the process of moving towards a more complete understanding and acceptance.

The physical suffering of the treatment often meant that the reality was realised at a deeper level. It was as if the physical suffering symbolised the more personal implications of having cancer, the living of it that may not have been fully realised at the more distanced level of relating to illness.

Of course it really hits you then, you know, what it was. (John)

It wasn't until I actually got back in there that it sunk in, what they were gonna do. Oh, you know, sort of then, the whole word fell out, and you know, bloody, I don't mind admitting it, I was bawling my eyes out and all that. (Sam)

What may be understood and accepted initially on a conscious level, may at some deeper level take longer to realise as demonstrated by one participant who had a laryngectomy for throat cancer.

I'd come home from the operation and I would wake up at night. I mean I wasn't frightened about the op, or frightened of dying or anything, but all of a sudden I had no voice, and I didn't have the electro-larynx so I had to - - nothing I could do to talk. People had to lip read or I had to write. I know I did this about three times from memory. I got up during the night. I'd wake and I was dreaming I was talking to somebody. And I thought, that's stupid, you can't damn well talk. I don't know whether I was completely dreaming or away with the fairies or what, but I'd got out of bed, gone down to the bathroom mirror, and looked at myself, and said (mouths). (Chris)

It was possible to have accepted loss on a conscious level while continuing in former ways of being. The difference is between relating to what has happened and making conscious adaptations, and a less conscious bodily understanding that can only be learnt through experiencing the new reality. These two levels of understanding may build on each other working towards a fuller integration where the self with cancer becomes more familiar.

At times when making sense of the reality of having cancer was very difficult, then bodily experience was sometimes in conflict with more conscious understanding.

And not sort of knowing, - getting quite scared really, that I couldn't get up out of it. And thinking, well I've been through all the sickness and that, and I got through it, and now this little thing - this divorce that I want, - is not, you know, is really getting to me. But I think it was everything else. Wasn't just that, it was the build up. (Pat)

For some there was a need to talk about the experience, together with an inability to understand why it was so hard to get back to living as before. At times too, it was difficult to find people who understood.

I just had a few special people I could really talk to. I needed, - I felt that I really needed to talk about it. But I felt that people were getting sick of hearing it. And I didn't want to talk about it too much. Because in a way, they didn't understand. Sort of like, you've got better, - now get on with it. And I was still thinking, shit, - did that all really happen? And I still needed to talk about it. But I felt like they were thinking, you know, you're lucky. And I knew all that, but yeah, I think I just needed more time. Like now, I feel like that. Yep, I got through it and I'm lucky. Well I did

think that then, but now I just feel healthier in my mind that I can, - I don't feel so sad, and I just feel a lot stronger, and want to, yeah, get out and do things more. Which I couldn't understand sort of that year after it, - why I didn't. That's what I wanted to do but I couldn't, kind of... ..and I was angry at myself for not doing that. (Pat)

Talking about the experience may have been repeated attempts to make some sense out of what had happened. The need to express and rework the experience may not have been conscious attempts to find meaning, but they may have been a demonstration of bodily experience or feelings leading the person to consciously confront issues that were not fully in awareness. What was felt was a need to express feelings, to get them out in the open where they could be viewed from another perspective or even viewed by others who might be able to make more sense of the confusing emotions.

The inability to understand the source of suffering may have been partly from general perceptions of illness as something separate from the person. This meant that once it had been treated and physical healing had taken place, the expectation was to continue with life in the same way as before. The effect of the overturning of previous beliefs about life may often remain below levels of awareness until the longer term experiencing brings it to fuller awareness. During the time of treatment the physical suffering of treatment may mean taking each day one at a time and focusing on just getting through so that it is a time that is removed from every day living. It is sometimes not until every day living is returned to that the fuller implications of what has happened are realised. This is possibly one of the reasons why people who have had previous suffering in their life are in some ways prepared when they face serious illness.

For some participants their inability to understand the ways that they were feeling alerted them that there was something wrong, and even to look for help, even if they did not understand initially what was wrong.

And I thought, this is just a stage I'm going through. It's not - I'm cracking up - which was what I was starting to feel like I was. You know, sort of like, there's always real shame - I feel ashamed when someone says - oh you've got depression, - that's what it is. Look, you're not coping... ..but to know that it's just a stage and that you can move through it. (Kate)

In this way, for some participants it was the experiencing of the illness rather than relating to it consciously, that lead them to the realisation of the magnitude of what they were facing.

I've spent all last year trying to make sense of it, and trying to work out at different stages I'd sort of think, what's going on? Why do I feel so down, why do I feel like I'm in this pit? And then sometimes, - like somebody else - I went to listen to this talk, and she described the grieving that she went through when she lost her ideal that she had for her life. And she realised that wasn't going to make sense any more. And it wasn't going to fit, and what she had to do was actually change it and change her direction. And I thought, that's what's wrong! Like I had everything that had made up who I was as a person, had all been taken away from me, or I'd chosen to drop it. You know, all the things that I'd got involved in at school, and playcentre and church, all the things that had meant like if someone said, who are you? - I would have said, well I am a person who does this, this and this. Rather than thinking who I am as a person. And so I had all that stripped away from me and I was left with nothing. I had no answer for who am I? And that was very painful, and that was sort of, yeah, most of last year realising. (Kate)

In these ways the different levels of understanding interact in the process of developing a fuller understanding of what it means to have suffered such a traumatic event.

Summary: There is a deeper level of understanding that seems to grow through physical suffering, as well as the longer term implications of cancer and adaptations that have to be made. When told of the diagnosis, the meaning is in terms of shared cultural understandings about cancer; the meanings contained in the word cancer. Suffering the pain and consequences of treatment, may bring a different dimension of meaning which is more personal, less tied up with the social representation of cancer and more to do with personal vulnerability, helplessness and identity. This is a kind of experiential understanding that comes through living the individual consequences of having cancer and adapting to them. The new ways of being need to become practised before the changes can be more fully integrated into a sense of self.

Integrating changes into a sense of self

Physical pain and loss were the public aspect of suffering and were symbolic of the less visible inner suffering both to others and to the person themselves. Physical changes were sometimes perceived by the person as something that had changed them and that could change the way others would see them.

Like the first fight, it took me ages to actually get out and eat in public. Even now, I tend to be fairly shy, you know, where I go. (Sam)

For me now, it's thinking....do I tell them I've had cancer? At what stage do I tell people. The oncology nurse said, if there's going to be any love making, to show the scars before that time. But the people in the prosthesis shop tell me that what I've got for bosoms is my own business. I wouldn't know when to tell someone, and I'm painfully honest so I feel that I would have to tell them quite soon, - if I found a man. And then, would he sort of feel that he wouldn't want to be involved with someone without breasts? (Emily)

Losses are very often pivotal to the person's sense of identity as demonstrated in the following extracts. There may be an ongoing sense of loss in association with previous ways of being.

To me it comes back to communication, or lack thereof. And it's only at times. As I've said before, I always did talk a lot, and I used to tell stories and jokes and yarns and that sort of thing. You get into a room of people or amongst a group, and invariably somebody would start telling a few yarns, and I had quite a list. And then I found that I can't do it anymore. I can still tell them but everybody's got to be dead quiet, because nobody can hear me. And I think really, I think that's, - so I tend then to drift back into the crowd and not say very much at all. (Chris)

I got a silly sense of humour and that at times. Frustrating now because I used to be very quick, and very fast at putting out, you know, if someone said something, putting in a smart comment. But nowadays I can't sort of do that as well. The comment doesn't come out quite the way I want it to. (Sam)

Voice is central to a person's identity not only for communicating directly but for conveying personality and carrying on social interactions. For these participants, because their loss was so central to their sense of self, it was important enough for them to make the effort so they could communicate as effectively as possible in new ways.

I find now, that when it comes to talking, you can generally see it in someone's face if you're going too fast and they're not understanding. So then I slow down a bit. So I've, oh, its just sort of been trial and error....it was just persistence more than anything. (Sam)

The degree of physical manifestation influences the amount of integration that is necessary. When the person takes trouble in adapting they have at that level accepted the changes as part of themselves. In a sense when losses are an integral part of

identity, adaptation takes place for others as well which helps in the overall integration process.

In some cases, although the physical losses were not publicly visible, the implications for a sense of self were still significant, symbolising lost opportunities. In these cases apart from the loss of future goals, there were changes in sense of self in terms of potential roles.

It was quite hard, you know, the day I went down for a scan, she was there, and suddenly we both realised that by her having her baby there, it highlighted that issue that I was about to lose all that opportunity to... (have a baby)..... and you know, it was very hard to deal with those sorts of things then. (Jane)

The losses that had to be accepted were not just physical but sometimes had wider implications for a sense of identity. Acceptance of the changes were helped by unconditional acceptance from others, as well as the ongoing processes of adaptation. Adaptation helped in terms of getting used to the changes, both for the sufferer and others around them whereas acceptance from others affirmed that the person's value was unaffected by any changes that might happen through illness. Through the processes of interacting levels of understanding, greater acceptance of what has happened both at a conscious and unconscious level may gradually develop.

There may be times when aspects of the illness that have the power to define identity fade and the person's sense of identity is asserted in a more whole way that embraces past and present.

We're practising Catholics, and I used to love singing. I was never a choirist or anything like that but I used to love singing. And we'd go into mass and there was a chap on the door, BillAnyway, then my operation happened and this was some time after, and we were going in to mass and Bill was on the door, and he handed me the hymn book. He told me this later... ..he said, one Sunday you were going into mass and the guy behind you said, - hey, what did you give him a hymn book for, he can't sing. And Bill said - oh yes he can. Yes. And that to me was,- yes, I thought that was great. (Chris)

Here, a valued part of former identity was acknowledged as still part of him. Seeing beyond that which can be shown outwardly signals a connection that is not limited by judgements on outward appearance or abilities. The above extract holds the meaning

that outwardly he may be considered different to what he used to be, but inwardly he is still all that he ever has been.

There's a chap in town who does street cleaningand he'd spot me, and I'd wave to him....what he would do, he would mouth and wave out (hello - how are you?). No, he never made a sound, but I know that meant so much to me. (Chris)

These kinds of experiences may only be of short duration but they are valued for the meaning that they provide in a wider sense. They affirm that the person is still of value the way that they are and that sometimes changes that have come about through the illness can in themselves be a source of moments of value.

Adaptation is also going on for other people and at times changes from the illness become forgotten or transcended. This is illustrated by the experience of one participant who had had a total glossectomy.

Probably the funniest thing that happened when I went back there (for a check up), was old Pete pulled out a tongue depressor to look down my throat. He reached over for one of those, and I started to chuckle. And then he looked at me, - and then realised what he'd done. And he threw it over his shoulder, - (saying) don't you bloody say a word! And, you know, that was the highlight of my day. That really struck my sense of humour. (Sam)

Experiences such as these highlight the fact that identity goes beyond the limitations of the illness. The ongoing physical implications of cancer are a measure of the difference between former and present self but these kinds of moments are valued because the difference fades. Although the illness had very substantial implications for him in terms of loss, there were times when the illness played no part at all. In these ways perceptions of changes grow and fade depending on the situation.

It's sort of like the shadow of cancer hanging over me, at times occupies the whole picture of my life. And other times it will only be a tiny part, a tiny bit of the picture. And that's really hard to try and sort of get other people to understand. (Kate)

I mean I don't even think about it. I just honestly don't think about it. I just box on, doing what I'm doing. (Justin)

Summary

The ways in which participants returned to living after recovery from the treatment of cancer was very individual and reflected the severity of the treatment as well as the

particular type of cancer. Learning new ways of being partly grows out of the process of adapting to the physical losses associated with cancer and its treatment. Acceptance of these losses and an acknowledgement of their reality in everyday living allows the growth of acceptance of the changed self.

Different levels of understanding involve a struggle to reach a balance that feels right. It shows the vigour of the person struggling to survive in an authentic way, not giving up, but incorporating the reality into a way of being that is achievable and yet allows living with hope. In many ways it is like a struggle to accept what has been lost, as well as to accept new ways of being that are feasible.

Through living in general the changed self becomes more familiar and through particular experiences that become meaningful in a wider sense, the changed self may begin to become valued for what it is rather than devalued for what it lacks. In as much as acceptance of the self with cancer means that limitations and changes do not imply a lessening of value, it helps self-worth to strengthen. Meaning grows as acceptance allows gradual integration of changes into self views. Through the process of acknowledging and accounting for what has happened, living becomes more authentic with the changed circumstances.

CHAPTER SIX

FINDING MEANING THROUGH THE WAY LIFE IS LIVED

Accepting the Challenge of Life

There was a strong sense of each individual being proactive in striving to live their life in a way that they could experience as meaningful. For some this was very difficult but however much suffering was involved in the process all participants made efforts to live in ways that acknowledged the reality of what had happened and yet allowed them to live with a sense of hope. For many there was a sense of meaning found in accepting the challenge and making the most of their life in the changed circumstances.

Restoring a sense of control

In the sense that a loss of control was experienced as a loss of meaning, part of trying to make sense of having cancer involved attempts to restore a sense of control. Regaining a sense of control was important for finding meaning in that it gave people a stronger sense of personal effectiveness as well as a return of a certain amount of order and predictability in their life. Meaning grew too out of the process of understanding in that it was difficult to find meaning without having a sense of being able to understand.

An inability to predict or control what will happen explains the strong need that people had to try and make sense of what was happening to them. Clearly, understanding and a sense of control were very closely associated.

Oh, I don't feel angry like thinking, why me? Because I don't think there is any answer to that... ..but yeah, I would like to try and make a lot more sense of it than I do. What can I do about it? And how am I going to cope? - are probably the things I'm asking myself more. (Kate)

Efforts to regain a sense of control, to feel involved and effective, were one way that participants looked for meaning and were a strong feature of their accounts. However, there were variations in the ways in which this was achieved.

When people were able to feel a return of personal control, even in small ways, life regained some order and there were things that they could do that would make a

difference. Sometimes there were attempts to take practical measures to adjust life to fit the new situation where possible. These problem focused responses are like an initial level of understanding and in turning to aspects of the situation that can be controlled, they possibly signal a growing acceptance of those aspects that cannot be controlled.

Everything fell into place, you know, it must have been meant to be that way because, - it must have been destiny because we sold our place fairly quickly, and we bought this, and it was quite suitable for us....I know we loved the other home, loved the garden - but it was a bigger house....I couldn't keep up with it. (John)

The desire to remain self reliant showed as well an unwillingness to become dependent on others and a reluctance to hand over control to others any more than was absolutely necessary.

And of course the doctor said, well you can't run the restaurant and get this treatment. And I said, well you give me the treatment, I'll decide whether I can do the restaurant. Well, I did do the restaurant. (Justin)

Becoming more informed about the illness and treatment was another way that a sense of predictability was restored. It was important to be able to anticipate, plan in advance and feel prepared. Treatment and its effects were easier to endure when they were predictable. Asking questions was a way of feeling more prepared for what lay ahead.

I had a lot of support and good answers from the surgeon. Because we asked questions, ...and because we were asking these questions he even drew pictures, and so I knew exactly where I would be scarred and things. And of course, therefore when I did go into hospital and have it done, there were no big surprises, from that point of view....and so I was fairly well prepared although it had happened very quickly.Once I had made all these decisions (whether to have a lumpectomy or mastectomy) myself, I just moved on to the next step. I think it was probably because I asked lots of questions, and (my husband) asked lots of questions too. And we had things properly (thought out) and then we were able to face it. (Sarah)

Taking an active interest in medical treatment and self care, allowed choice and a way of being able to make a difference over the course and treatment of the illness.

You do trust them to do the surgery because you know, you can't do that yourself, but with that there's a line where they must tell you, or give you the information so that you, or collectively, you make the decisions about what's going to happen, not that they will make the best decision for you. (Jane)

I said, well I don't want (...) anywhere near me. So at least I was strong enough to say I've got choices in this. And I don't think I would still be able to handle his indifference very well. (Kate)

Medical staff also had the power to hinder the person from feeling a sense of control, by not keeping them fully informed of all the options as well as the implications for making particular choices.

She explained the options, but in a way couched things in terms of like, I haven't decided whether to take your ovaries or not, you know, and I challenged her about those sorts of things by saying, you know, they are my ovaries, perhaps it's me who should be making those decisions. And the effect of that for me, which I hadn't picked up on, was that by taking my ovaries, I then had to buy into daily taking of hormone replacement tablets, or deciding whether I wanted to go on hormone replacement or not. And that was an option that wasn't explained all the way through....I'm a great person in wanting to lay out and know all the options ...okay, the odds may be greater if they don't take it out, but the bottom line was that there needed to be more discussion about that in my situation. (Jane)

For one person a sense of control was achieved through taking on a monitoring role.

And so early on I began to take a very intense interest in what was being done to me, and what the drugs were, and in what quantities they were being delivered, what would be expected in the way of side effects, how to deal with those. Basically I wanted to know pretty much everything. That way I could, - I felt happy when I knew the staff were doing what they were supposed to be doing, and if, when little slip ups were made, which after all, we're all human, they do happen, even in serious situations like that, - I could pick up on them. And I did...And I felt that that probably helped a lot because it gave me a little bit of a sense of control back. It felt like, rather than being like a passive recipient of all this care, I was actually a co-worker in my recovery if you like...and made me feel like, okay, I've got to watch out for what these guys are doing as much as they do. And perhaps that got rid of some of my fears that a mistake might be made, and something dreadful might happen. (Michael)

For others focusing on the possibility of a positive outcome restored hope and with it a sense of control in having a goal to aim for.

They couldn't really prepare me. I don't think you could, for the big, - the long haul that it was going to be. I suppose because they didn't really know how it was going to

go because everyone is different with the treatment and that. But, I remember them telling me a lot of statistics which didn't really mean, - I didn't really want to hear. Just sort of cut off from that. All I wanted was to meet someone that had had the same, and got through it. (Pat)

General kinds of information may seem irrelevant to some people in terms of whether they personally are going to make it or not. More personal information that provides some hope to counteract the feelings of helplessness, may be more meaningful. Seeing someone who had got through was like a living example that it was possible and something concrete to aim for.

We go to church, central Baptist church, and they were fantastic at that time. I had to wait ten days before I had the operation. And a woman came round to see me, and she was a real tower of strength. She was someone who'd had breast cancer about my age, about twenty years ago. And there was someone that had lived through it. She was great. She came round and just talked really openly about it, what had happened to her. She had the same, she had little children and she just went through it all. She showed me what her scar looked like, she showed me what a prosthesis looked like, and she was wonderful. (Jill)

These responses show too a strong desire to look beyond the illness as something that sets them apart, and to regain a sense of belonging and normality through finding that this was something that had happened to others. However, at times, seeing others who had got through was too far removed to relate to personally.

It's almost like there's a gulf there. Because they're on the other side of what you're going through, you think, great, it's possible, but it's like, - - they're over there, and I'm still over here. (Michael)

Some participants were able to relieve their own sense of helplessness by helping to lessen the suffering of their family. Although there was no way of controlling what had happened, there was a sense of control in being able to help others. In a way the meaning of a valued part of identity, that of carer and provider, could be maintained by focusing on relieving the suffering of others.

You feel so helpless. I know for me it was like that. They could do nothing for me. But it was me that had it. What I was saying to them is - hey guys, you know its not that bad. And hopefully it worked....If I knew that they were really down to it then it would not have helped me one bit. (Chris)

By keeping his own spirits up he was able to help both himself and others close to him since their well-being was connected to his own. While helpless to change the situation, he was still able to have an influence on the suffering of those that he cared for. For another participant protecting his mother meant not telling her.

See my mother doesn't even know I've got cancer, - it'd kill her. (Justin)

For some participants, at least at times, control was maintained by keeping feelings private and taking measures to ensure that the illness was not acknowledged in a public way. This perhaps provided a way of at least controlling the amount of disruption that was felt as a consequence of the illness.

It's something I can't stand (pity or sympathy). It's just my bloody hurt, nobody else's. Nobody else's problem, just mine. (Justin)

Another aspect of wanting to be private was to try and minimise the seriousness of what had happened and in that way protect others from having to suffer as well. A mixture of wanting to protect others from suffering, and a need to remain in control is illustrated in the following example from one participant at a time when she developed secondary stage melanoma.

I thought, - but I can't tell Mum and Dad. So we didn't go home that day. We made some excuse and went home the next day. And even that, when we got home, and I rang up the doctor, and the nurse said, no, I'm sorry, he's busy, and is it urgent? And I said, oh no, not really. It was just, I just thought, if I start saying it out loud, it will be really bad. But while I'm just the one who's worrying, maybe I can minimise it.... I didn't want to worry them, and I didn't want to worry anybody else. And I wanted, and I know because I'm an introvert, I wanted to actually deal with it myself. I didn't want to have lots of people trying to come in and make a big fuss. (Kate)

There was a fear of losing control of things that became public, whereas private worries are to a certain extent controllable. Carrying on outwardly as if everything is all right means that awareness is held inside where it is possible to control and will not have the same power as when outwardly acknowledged as requiring attention. This way of controlling the illness sometimes required not outwardly acknowledging the seriousness of the illness.

Control was also sometimes maintained by talking about what was happening only on a rational and somewhat distanced level.

But I was able to talk about it quite factually. And I could say to people, you know, it appears that I'm going to have to have, you know, a mastectomy, next week, sort of thing. And whilst I could talk factually it didn't upset me, and I was able to ask lots of questions. It was when I knew, either you saw tears in peoples' eyes who you were talking to, or could get it in their voice coming through the phone, and then I would tend to get, - a bit more upset. (Sarah)

It is as if having the emotional aspects out in the open is what is feared because this is where the suffering is being felt. If emotions could be kept inside then the person was able to maintain a feeling of control.

At certain times control was willingly handed over to others and in a sense this meant that the meaning of control changed and it was retained through trusting others to be in control.

But it got to be a bit like home. Even though you'd hate it in a way, I also really loved it cause it was so, - it was just like home. And when you did feel really sick, say if you'd gone home and you got all, - got sick, you know, you'd just look forward to going back to that bed and being comfortable. (Pat)

The strong need to be self reliant lessened when trustworthiness was found in others and letting go of control was experienced as a relief.

Suicide was mentioned by very few participants. One man discussed the option of taking his own life if things became too painful. It possibly provided a sense of security since his only fear was prospect of not being able to bear the pain, or of a long drawn out death.

You can bet your life on it, if it does spread either side, I won't be hanging around this man's territory and dying like a dog, I bet you any money you like. I'll make bloody sure of it. My oath, it's my right, it's my body, my life. I'm a great believer in it. (Justin)

A sense of control was maintained through fighting against the illness controlling him, through making the most of life while that was possible, but allowing himself the choice of when to end his life if quality of life became impossible. In a sense allowing himself the choice about when he would die was the ultimate form of control over his life.

Summary: Overall, the ways that feelings of control were restored varied between people, and also for the same people at any one time, and as circumstances changed. For instance, control gained through minimising the seriousness of the illness was sometimes unable to be maintained over time when it was incongruent with inner suffering. There were some things that could not be controlled, and the acceptance of the loss of control in these areas involved an acceptance of what had happened, an acknowledgement that it was beyond control. Sometimes this realisation took a long time. The degree to which loss of control had to be accepted varied depending on the type of cancer and treatment, and in some ways, how much it was outwardly apparent on an ongoing basis. When control could be regained, even in limited ways, it helped to rebuild a sense of meaning through the process of restoring predictability, choice and effectiveness.

Learning to relinquish control was very much part of the experience of illness as well, and was the flip side to the meaning that was restored through being able to gain control in ways that were still possible. In this sense, there were changes in the meaning of personal control through learning what had to be accepted, or let go of, and what should be strived for.

Over time, regaining a sense of control provided meaning as well because it showed that the individual was making choices about their own response to serious illness. Making efforts to regain control restored feelings of confidence and effectiveness through taking an active part in the illness experience. It signalled as well an engagement with living. There was a sense of achievement in choosing to live in a way that acknowledged the reality of the changed situation and yet still provided a sense of meaning. In attempting to regain control over the way they lived their life, the person was taking responsibility for themselves, their life and way of living, striving for their own personal potential within the limits of the situation.

Taking responsibility for the self

Permanent changes had to be accepted and got used to, and possibilities for living with the changes tested and learnt. For all participants there were losses that had to be adapted to and in adapting people sought to minimise the possibility of changes causing problems. Each individual influenced how they found meaning through the choices that they made about how to live.

The thing I'm looking at at the moment is integration. It goes on all the time... .. integrating the big parts of what you were, to the new parts, and becoming that me that I'm happy with, you know, that I can live with I guess. (Jane)

I guess I tend to be proactive rather than reactive. But I think that was probably part of my make up anyway. And this may have enhanced it but it hasn't actually changed it as such. But I would far rather get out there and try and make something happen, than wait and see what happened when it did. (Sarah)

What should be accepted and what should be struggled against was always a matter of judgement. There was a desire by most participants to integrate the reality of what had happened into ways of viewing life.

You have to go through, you can't go round. It's got to be dealt with. I have worked on that myself, with support from the right people. But I'm ready, I feel I'm ready to move on. I've been going to a Christian support group on a Saturday night, once a month. But I just feel now, you know, - sounds selfish, but I want to do something more positive with my Saturday night. (Emily)

I feel like, - that with cancer, I've got to somehow find a place that I can face up to what I'm dealing with, but not go into it so deeply and be so overwhelmed by the uncertainty that I have no hope. But not go so far towards being so positive and hopeful that I don't actually recognise what I'm dealing with and actually start denying it, and start trying to pretend I'm a person who's - - - I notice sometimes like, somebody in the cancer support group said, - you never hear about the ones who survive cancer. And it's almost like, they almost put that part of their life behind them, and don't ever want to think about it ever again. (Kate)

I mean I've got to accept. You know the serenity prayer. Accept the things you can't change, and you're encouraged to change what you can. And I sort of pray that, all the time. And then I'm able to, - it's like a change in gear from what you want, - to what is, and getting on with it. (Emily)

Self care was a way of controlling the illness and of taking responsibility for the self. One benefit of self care was to minimise the problems that could be caused by the long term effects of the illness. The more the losses were acknowledged and accounted for, the less they encroached on life and the less they needed to be carefully thought about all the time. As a result the person allowed themselves the best chance for a good quality of life in the new circumstances.

I should be doing exercises more regularly than I am, but it's just been circumstances, and I'll be doing those again every day. And my husband has also learnt the massage to stimulate the lymph system, and so that if we do that, - even if it does swell, if we

can control it, that's the main thing. And I haven't let that stand in the way of doing things that I want to do. (Sarah)

I think it's a matter of accepting it, knowing that if you fight against it, you could drive yourself and everybody else mad. So okay, - I'm like this, - you get on with life. Okay, you've got to watch things like cold air and dust, and I'm a bit of an asthmatic, - but yeah, it's just part of me. I don't really think anything about it. (Chris)

I think the key is that because of reading a lot about it, and having gone through the experience personally, I'm more aware of things. And so I tend to be more aware of the fact that I'm handling something the way I always used to, and I think, - now why am I doing this? And I start to process and think about it a bit more. But the process of actually changing how I do deal with things overall, is quite a slow one. It's taking time. (Michael)

Though I feel that surgery was the right thing, and they got the cancer, I think that it's up to me now, to develop a balanced lifestyle, so that I don't allow myself to become run down, my immune system to get weak. And to get back into that possibility that the cancer will take hold again somewhere else. And so that's been a real change for me. That's my goal if you like. (Jane)

There was a purpose in taking responsibility for personal well-being, placing a value on quality of life, and at the same time it involved taking an active part in the process of living life in the best way possible in the circumstances. By acknowledging and 'owning' body changes that had come through the illness, their negative effects were minimised.

In a similar way to the power of others to draw the sufferer towards an engagement with living, former valued activities and ways of being could also draw the person's focus outward.

I was looking in this rock pool....and I could see these feelers down there eh, and I thought, oh yeah, - and I said to (my friends), I'm just going to have a float in there and sort of see what it's like. So I went and got my wet suit, put it on, and I'm just lying in the water with a snorkel. And with no teeth and (no tongue) the snorkel wasn't sealing properly. So I got used to it, and I thought, I must go down and have a look at those feelers, eh. So I said, - I'm going to try going down. So I went down, put my hand in and grabbed this crayfish out, and I came back up, and I was spluttering and carrying on and they says, - oh, are you all right? And I says, course I'm bloody all right, - hold on to this bloody thing! And I threw it up on the

beach... ..So a mate of mine was up from Christchurch for the Grand Prix and that. And I said, - look, can you take a box of crayfish back for me, to ward 32 for me. And he said, yeah, yeah, no sweat. So I gave him a couple to make sure the others got there, - and I wrote on top of, - in the top of the box I put, - this one for Dr ---! And when they opened that there was a note inside which said - who says I can't use a snorkel? (Sam)

The attraction of a familiar activity can draw the person to involvement so that for a while the illness fades to a background issue. The extract above demonstrates how the process of learning new ways of being involves testing the limits and striving for potential which becomes possible when the person is fully involved in the process of living in the present. There is also a sense of achievement in living successfully with limitations.

Testing the possibilities for living often meant returning to former activities, sometimes in modified ways, making the most of what could be done within the new circumstances. It also involved finding new ways of approaching life that were not limited by the new realities. Just as physical manifestations may have been an outward symbol of the illness, a return to former activities provided an outward symbol of normality.

I know my limitations. That garden out the front there, I built that myself. Took me about four days, and a hell of a lot of pain. And no, I did that myself and I'm quite proud of that. I mean, I don't try and do things, you know, - I know my limitations, like reaching up and out that way (with weakened arm). Well, - I know at Manfield, when they had a major accident, you wouldn't think there was anything wrong with me.....while the adrenaline's going, you know, you don't feel a thing, but a couple of days later, ohhh, all hell breaks loose. But I do it because it's there to be done. (Sam)

The extract above illustrates the ongoing judgements involved in the struggle between acceptance and engaging in living in a meaningful way. There is a balance between being aware of things that are no longer possible, and yet being able to become involved in the present enough to disregard those limitations for a time. In becoming involved the suffering of the illness is transcended for a while. There is this kind of balance and ongoing struggle involved in not giving in to limitations, in fact struggling with them and testing the limits, while at the same time accepting them.

Finding inner strengths: The increased need to be more focused on personal needs than before becoming ill, seemed to lead not only to a growth in self awareness but also lead to the ability to give more to others.

Unless I can square myself away and be happy with the way I am, then I'm only able to give a very limited amount. Yeah, and I'm finding because of my experience, and I guess the way I am now, - then I am able to give more to people, and to take time, and maybe I'm listening better. (Jane)

In the process of learning about and acknowledging personal limits, ways of giving to others became more effective too.

Rather than saying yes, she was my friend, and going to her funeral, I'm still able to, though she's getting quite ill, still able to go...and genuinely talk with her. And so it's something that I probably wouldn't have been able to do before, and I can do that now. And I feel happy about putting the limits on.....It means that I can give to her what I can, and I don't promise things that I can't deliver, I guess. (Jane)

Becoming ill was a powerful learning experience and through it people became more aware of their own inner qualities. Self-worth was strengthened by an awareness of personal qualities that became highlighted through the experience.

Skills that are applicable to every day life but sometimes we don't learn them as we go through. Like learning to put boundaries in, learning to say no, letting go. Those are the three that are quite important to me that I've been working on. And particularly since the cancer stuff. (Jane)

Focusing on the self sometimes strengthened feelings of personal control through feeling the ability to make a difference through choices about how to live. For many there grew the realisation that rebuilding a meaningful way of living was up to them.

Some things that were actually really hard at the time, now I can actually see that they were of some help, because, say for example this nurse that I was really relying on to give me some help, or give me some answers. And her sort of indifference, or inability to be proactive, at the time, - I found just so frustrating, and I found it was one more person who'd let me down. But it was actually something that was really good, - it helped. It made me do something about it, you know, it made me take some responsibility for myself. (Kate)

One participant spoke of a feeling of strength that still provided reassurance in looking back.

One thing that happened, when at one stage I got really, really sick, and I thought maybe I wasn't going to make it. I just remember a feeling of really, - of feeling physically really weak, but feeling really strong. And it's really hard to explain, but that sort of gives me strength, and that if something ever happened like that again, that would, whatever it was, that energy or whatever, would come.... And I think that that helps me when I'm in situations when I feel threatened for some reason, or I feel low self-esteem, I think that I'm not, I tell myself that no, - I'm really strong. And that helps, yeah. (Pat)

A strengthening of personal qualities seemed to grow out of the experience of suffering, but this was not something that the person had a choice about.

I wouldn't wish it on anyone, but I think having been through it, I've grown as a person through it. But if I look back, I would rather've not grown, if that's what it took to grow as a person. No, I'd rather stay how I was. But I think you can't help but grow through it. (Jill)

For some, being able to perceive anything about the experience as positive took a very long time but grew gradually out of the process of understanding over a period of years.

But now, I can say quite clearly, that I have learnt skills that I would probably never, never have learnt, had I not been through that thing. It's only recently, very recently I've been able to say that. The losses have been considered far greater than the gains. But as I bring together the different parts, - of how I've had to operate, to what I was, and feel more comfortable with who I am now, it's become a lot easier. (Jane)

Although participants could see that there had been some positive things that came out of the experience of illness, this did not mean that the experience in itself was in any way positive.

Summary

What is no longer possible and what needs to be modified is learnt through trying out. In re-engaging with life and starting to rebuild life in which the new situation can be incorporated in a meaningful way, former concerns and activities were often returned to but in different ways. Self care lead to a sense of achievement through becoming more aware of personal strengths such as the ability to cope.

Feelings of personal control continued to be important and achieved in ways that were possible. Meaning was also gained through the achievement felt in overcoming and facing the challenges involved in the experience. However, the emphasis of personal control was changed through the experience so that there was a letting go of control over things that had to be accepted. Personal control was maintained most strongly in the choices that were made about how to live in the unchangeable situation. There was an awareness that nothing and no-one could take what had happened away, or to change it, and that it was up to the individual to find a way of living that felt right.

Changed Focus Towards Life

While previous assumptions about life may have been challenged for some, out of the experience there was the possibility for strengthening beliefs that were more congruent with the unchangeable situation. A changed focus for life evolved out of the experience of serious illness and sometimes provided sources of meaning. How much of a change there was depended partly on the seriousness of the illness and treatment and on the values that the person held before.

Although the extent to which former beliefs about life and the self were called into question varied, for most participants there was a change of focus. A re-evaluation of priorities lead to an affirmation of the value of those things that cannot be affected by traumatic events that occur through a life time. New ways of looking at life were closely related to changes in perceptions of control that seemed to evolve out of the experience. In these ways, the changed focus towards life integrated the reality of what had happened into the way that the person viewed the world.

For many participants there was a strong sense of having changed in ways that made it impossible to go back to living the way they were before. It seemed that their way of viewing life and themselves was such that former ways of being were no longer appropriate.

I'm not the person I was three years ago. (Kate)

I think that part of this for me is that I am changing, or that I have changed. And the person that I have become, yeah, or the person that I've grown towards, or want to grow towards, is not the person that I was a while ago. And with that support

systems, or your friendships, your family supports and those sorts of things undergo changes too. (Jane)

Sometimes I feel like I'm different - to everyone. And it's sort of - because it has affected me....I don't know, I do feel a bit different. (Pat)

Re-evaluation of priorities

A strong feature of participants' experience in the present sample was a re-evaluation of priorities. There was a letting go of concerns that were seen to be unimportant in the wider scheme of things. There was also less importance placed on material things.

And you know, then you just continue on with your life, but you've changed direction slightly....I think you're priorities change a lot after this type of illness. Little things don't matter so much any more. You know, I used to make sure my windows were cleaned every few months, and now I wouldn't know when they were cleaned last. And that doesn't matter. And in fact that was quite important before if I was having people to come to stay or anything, you know, make sure the windows were clean and what have you. And now that doesn't matter any more, it's more the contact with people. And it doesn't matter if there is only a bought biscuit in the tin, it's much more important to have that time with people, than to do those sort of mundane things. (Sarah)

Things that are enduring, and that cannot change through events that happen in life, were evaluated as of the most importance. For most people there seemed to be a reaffirmation of the value of people, highlighting the part that they play in life being experienced as meaningful.

And so, I dunno, I keep asking myself now, do we have to have a crisis to be able to come to those sorts of understandings, that quality of life is important, and that family and being with people, and sharing time with people is as important? And if you're trading off between whether you're going to make the next million dollars or be with your family, then to me the family wins out every time. (Jane)

At times other people, and in some cases God, were seen as more dependable than life itself and in a way provided the feeling of confidence that was lost through coming face to face with human vulnerability.

And there's no doubt about it, when I came to difficult points in the treatment, like having to accept my death if that was to be the case, or when I was very very sick towards the end, I just had to really let go, of a lot of things, and it just helped me to

have a belief in someone greater than me, who loved me, who would take care of me whatever the case would be. (Michael)

Through facing what was in many cases a life threatening illness, the vulnerability of human life was highlighted in a very personal way. Bringing to the foreground an understanding of personal powerlessness to control life, meant there was a realisation that traumatic things can happen, and not only to others but to the self.

I think that the only thing that I've learnt out of it is that it can happen to any of us. I mean I've always been as fit as a fiddle, even my doctor, she said I was remarkably fit for my age. But it doesn't matter how fit you are, how physically fit, how healthy you are, it can still, the lurgy can still get you. It doesn't matter who you are. That's the learning you get out of it. (Justin)

And it gave me a shock to think yes, something could happen. Your life is not, you know, there's nothing, - you can't control your own life, because we could walk out and have a heart attack, and get run over, today. But you never think like that when you're younger....but it happened to me, and so it gave me a shock, - a big shock.-Oh Gosh, my life could actually end today or tomorrow, and what's life all about? Is there a hereafter, what's the purpose in life? It made me re-evaluate everything, and it strengthened my faith realising that God's in control of my life. (Jill)

When the idea that such things can happen to anyone is integrated into the person's view of the world, the self is not set apart from anyone else as having a privileged position of invulnerability and this has implications for the way people in the world are viewed. It is a more communally based view, where the individual feels a part of a greater whole. The ability to view life in this wider context helped in making sense of what had happened.

The world doesn't revolve around one person, you know. What's the point of sitting at home and moping away to your bloody self? While you can enjoy life, enjoy it. (Justin)

Looked at in this way, there seemed no more reason why terrible things should happen to others than to the self.

Very early on I saw a young girl who was about 20. And she came in, and she looked in about the same condition as me. She had a slightly different form of cancer. And ah, I basically saw her condition continue to deteriorate and deteriorate, and until,

basically she was on her death bed, - and then she was just gone. And I thought, well, - what's the difference between her and me really? (Michael)

Implicit in the realisation of human vulnerability and thus the limits of personal control, is an awareness that people are not responsible for things that happen to them. Through the experience of getting cancer, the power of circumstances over individual power is emphasised. This is learnt in relation to the self, but generalises to attitudes towards others. In seeing the situation as more powerful, there is a tendency to be less judgmental and to look beyond outward appearances to the common humanity within each individual.

I used to be a very arrogant person, I know that. I've probably been spoilt. I really enjoyed life, but, I couldn't abide fools. Changed all that now, so I realise that everybody's got a niche in life, you know. (John)

It's made me more open minded and not so judging of other people....and that some people put on a real front and that, and you can be taken with it. But really they, - I think I can see people more clearly now, you know, that they're no more together, you know, no one's really any more together. (Pat)

Many participants had the attitude that after such a life threatening experience, each day of living was a bonus to be appreciated as a gift. With the appreciation of life came a determination to make the most of it and to enjoy it.

When you come out, having been through something like that, sort of a life and death type situation, you think, you do appreciate everything a little bit more. You take it, you tend to take things for granted. And when you think, gosh, I might not be here in a few months time, - when you've been through all that, you think the things that used to worry me or get me uptight, - how trivial. And it makes you really appreciate people, and, just every day really. You know, I should be thankful that I'm here, and makes you, put everything in perspective really. (Jill)

I catch my breath every now and then, saying, hey, slow down, enjoy your meal, and enjoy the weather, the day, you know, - there was a time when you didn't know you were going to have another day. (Michael)

Well, I learnt working in ward 25 that you really need to live each day. You live now, because you may not have tomorrow....yes I knew that, but one doesn't always practise it as well as one should. But that's why I go dancing. (Emily)

Similarly, for some there was a determination to enjoy what was available in the present rather than putting things off for the future. There was a realisation too of how former ways of living often took the value of the process of living for granted.

I believe you have to take any opportunities that are there, you know, when they offer. And even if it's perhaps, - if you'd rather do something next year or whatever, but the opportunity is there to do it now, - that you should do it. Take that opportunity while it's there, because it just may not present itself again. (Sarah)

I was very ambitious, and was wanting to make a lot of money and have a really, I guess a luxurious lifestyle eventually. But I can see now that really, in doing that and in chasing after those kinds of goals, you make sacrifices along the way. You can't help it even when you think you aren't..... and I guess, coming through this, because now I look at life differently, I can see that it's better to live life and enjoy it as you go along. And to enjoy life in the circumstances you find yourself, rather than always to be aspiring to something better and better. (Michael)

For some, comparison with others could sharpen appreciation of life through feeling relatively fortunate. This provided meaning through viewing the situation within a wider context where the situation was not perceived in such a negative light.

As I say, I'm one of the lucky ones. That's because quite a few there I suppose about 40, 50% of the ones, some of the ones you got to know, some of them quite friendly, you know. They didn't all die straight away. Some did. Some there they just, ah, didn't appear for treatment.... I thought, - now, look how lucky you are. (John)

On the other hand, comparison with others could make the person feel guilty for being the one to survive.

I would go and talk to a lot of people going down for transplants and they'd get me to talk to them. Which I really didn't mind and quite liked doing. But, - and then I'd want to know how they were getting on and actually most of them died. Yeah, and I was sort of thinking, well, I don't know, I might be a bad omen. But I mean, I didn't mind doing that, but I started to think, well, why, why am I still alive, and they're, they didn't make it. And I'd look at my life and think shit, I should be doing something more than I'm doing now. And then I'd get really down thinking I wasn't doing anything - - important enough... ..and still in a way (I'm) in a dilemma as to what I'm supposed to be doing. You know, I feel like, being given another chance, I've got to do something really important. (Pat)

The extract above demonstrates how guilt may be felt for surviving where others did not and even feeling somehow to blame. These are attempts to find some kind of meaning in the situation, even if in a way that involves self blame.

The way that life was lived had the potential to provide a sense of meaning. Although things were not as planned before becoming ill, meaning was still found at times through experiences which were of value in themselves.

I decided originally I wanted to keep living for my stepdaughter, but I thought, well, if I'm going to keep living, I'm going to enjoy myself. So I decided, well, that's the way it was going to be, and if I happened to kill myself in the process, well stiff pips, I was on borrowed time anyway. (Sam)

The focus was often on appreciating life for what it is rather than on the need to be achieving more, or determining how life should be. Inherent in this attitude is the acceptance of life as it is.

If I'm going to get it, a tumour, well, you know, mind you it doesn't worry me because, that's it, but its been made quite clear that I may be revisited, and I accept that too now. So every day you live is a bonus....I just accept things as they are now. (John)

The whole thing is a refocus I guess, and that doesn't hurt. I think illness, and accident and that, - well particularly with cancer I think, maybe more than some other illnesses, - but you refocus on what's there, what's the value of, - of where we're going, what you want to do. (Jane)

For some there was a new value placed on simple pleasures that were not appreciated in the same way before becoming ill.

I used to go up for my treatment every morning and I used to come home, here, and sit in that chair and go to sleep with a book. You know, before this happened I used to get low every time. I used to feel guilty if I sat down in the middle of the day to read a book. I shouldn't be doing that, you know, - got to be working, doing other things. (John)

Affirming the value of the present and life as it is, allows the person to accept and appreciate the process of living, rather than focusing on future possibilities at the expense of the present.

I recognise that the journey is probably just as important in some ways, particularly with the creative side. The journey is just as important as the product....rather than just striving for that perfect me, or that ideal me, - or that I've got it sorted out, - it's like a reality, it's like an ongoing thing. You make adjustments all the time. (Jane)

The need for control over life diminished in importance. It seems too that sometimes a consequence is that the person takes themselves, and their control in their life less seriously which can lead to a greater enjoyment of the present in ways that are different from before.

I find that playing golf and other things, you're prepared to fight for anything, but if you don't win it doesn't matter, you know. Whereas I used to love to win before...I'm still competitive but a bit more relaxed about it...I can laugh at myself a little more now I think, no really I can. (John)

Through the re-evaluation of priorities there sometimes grew an acceptance of life as it is with a greater appreciation of the process of life. As with all aspects of the experience of illness, connectedness with others and with life provided meaning through strengthening the value placed on relationships and a greater awareness of their enduring quality.

Overall, changing priorities meant adjustments in the ways in which life and others were viewed. In the affirmation of the value of aspects of life which are enduring in spite of changing life circumstances, a sense of meaning grew.

Learning to trust

Feelings of interconnectedness encouraged a broadening of focus towards care for others. Sometimes this connecting quality of others and life grew through the experience of suffering. Interconnectedness seemed to arise out of a growth in the ability to trust, an affinity with others who had suffered, and in a broader sense, a more empathic view of human frailty in general.

Learning to trust was important in the way people viewed others and themselves, and provided the possibility of finding meaning through strengthening human connections. When trustworthiness was found there was a changed perspective on the need for help. Finding care and acceptance of the self while in a dependent state seemed to bring the realisation that self-worth was not dependent on being self reliant and independent.

It didn't feel so bad because when I was in the hospital, - and they're marvellous in the ward there, you're just, - yeah, you were just accepted, and no argument, you know... the way they sort of retained your dignity in there was terrific. (John)

For some, learning to trust came through having to depend on others. Relinquishing control was often felt as a risk because it was facing the fear of losing control. Some people were more able to relinquish control perhaps because they placed less value on total self reliance. For them, the experience of needing help and finding help was an affirmation and strengthening of that focus. For others self reliance was highly valued and needing help was devaluing to those in the position of need. Needing help was often seen by the person as bothering others, highlighting as well the importance of contributing, for a sense of meaning.

They didn't have to feel that they had to look after you, you know - so you didn't feel like you were a bother to anyone. (Pat)

For some, suffering had to be very severe before they could willingly let go of control. When there was no choice, for instance when a person found themselves in a position of helplessness, there was the possibility of learning that letting go was not as they had expected. This was usually because they found that others could be depended upon and also that others continued to value them in spite of their helplessness. Finding the ability to be able to willingly trust others seemed to strengthen feelings of self-worth because of the implications of self value in finding trustworthiness in others. In some ways, investing trust in others was like handing over control and in this way it could be seen as retaining a kind of control through consent in the process.

You just put yourself at that stage, you know, I just accepted the fact that I was in other people's hands. Completely. And I never realised what it was like to be so helpless. I didn't think I'd ever be helpless...but it made me - - - also realise how many good people there were around. And you know, the fact that these people, you could see them doing these things, - dealing with other people. You realised - that you were quite prepared to put yourself in their hands. (John)

She was the one, I swear by her. At least she didn't bugger me around. She was good, she just explained everything to me. And I said, well okay, you're the doctor, I'm just a butcher, so you go for it. (Justin)

Developing trust seems to change the meaning of control, so that rather than being lost it is consciously handed over. Letting go of control then had the potential to be

experienced as the relief from a burden of responsibility. A trust in God provided the same kind of relief.

When trustworthiness was found in others who were in a position of care or close to the sufferer, letting go became easier. A more tolerant and understanding attitude towards others was also emphasised when the person found that they were still valued in spite of being in a position of need. The perception that needing help was personal failure, was overturned since the self in need of help had been validated, and this transferred to judgements of others needing help.

I'm a lot more conscious of other people. And faith in other people. (John)

In this process there are implications for self views and world views. The need to control becomes less of an issue with a move away from the value of independence at all costs, and towards the valuing of humanity as a source of trustworthiness, and predictability.

Trust was important for finding meaning through affirming the value of others. Trustworthiness implied the person was valued and grew out of relationships involving interconnectedness. In terms of changes to life focus, the growth of trust and faith in others enabled people to feel a commitment to others, where they had felt this commitment towards themselves.

Meaning through receiving and giving

There was a bond felt between the sufferer and others in the same position. For some participants who spent time in hospital in the cancer ward, contact with others who were going through similar suffering lead to experiences of mutual support that were helpful.

I felt, - closely connected to them. And I really felt for them a lot, and their families, and seeing what they were going through, particularly if some of them were in much worse situations than I was. It helped put things in perspective. It was very helpful then. Yeah, I guess it was a way of, getting my mind off myself a bit as well. We were able to help each other. There were some people I made very good friendships with, and, we were able to help and encourage each other a little bit. (Michael)

You almost feel a bond between people who have been through it all. (John)

Often the care shown by others going through the same experience provided examples of caring and great strength. Just knowing that others were going through the same thing, that they cared, and had had the same feelings of fear and uncertainty, provided people with a feeling of not being alone in what they were going through. Having care shown, strengthened feelings of caring.

I met a lot of people that were so brave and especially in that ward.....maybe it's because it was, - people knew how serious things were, they just didn't tend to talk about themselves so much, and it was more a caring, you know, how are you, sort of thing. And looking out for each other. Just people's strength, just seeing other people's strength is amazing.....But just that real scariness too, that you know someone else has felt it at some stage too. (Pat)

The care of others in the same position encouraged a broadening of focus towards others, and those people in themselves became representations of possibilities for ways of being that are worthwhile.

Just as participants found other people who had been through something traumatic understood in a way that could be sensed, they found that they themselves developed this understanding and sensitivity.

One of the other things I notice is, I often pick up things from people. Even if they haven't quite said that, you know, I will pick up something that's just there. A bit more sensitive and a real empathy with people. And I'm sure that's part of the process. Perhaps they will just, they won't really say it, but there will just be something there, you know, there's a comment and I'll often pick that up. And then I'll say to (my husband) about so and so, and he won't have noticed, but then quite often, we'll find out later that yeah, that's exactly.... and I think your dealings with people, and listening to people, - they just tend to tell you more than they would otherwise. (Sarah)

An affinity with others going through a similar experience came partly from the understanding and compassion for what they were going through. Personal experience gave them credibility in terms of real understanding.

One benefit is with another laryngectomy patient, that I can say I know how they feel. You know, probably a number of times you haven't been well and someone says - I know how you feel there. They really haven't got a bloody clue how you feel. But I can say it to a laryngectomee that I know how you feel at any stage of their operation

or their problem, - I know how they feel, and they know that I know, and that's a bonus. (Chris)

I have quite enjoyed helping out at the hospice. Mopping floors, in the ward, vacuuming, doing tasks around the place. Because it's something I can do....you get to be quite friendly with them I find, both male and female, you know, whereas I was never an outgoing person before. But it's something that I've learnt, and that I feel quite pleased about because people always up there, they seem quite pleased to see you and they chat, - and they won't chat with others, you know. Cause,- like I know how they feel.....and you sense whether they want somebody to sit up, and you sit down and might have a yarn... I can also sense it if they don't. (John)

The growth in awareness enabled communication on a deeper level. Out of the experience of illness participants gained a sensitivity and an ability to really understand what others were going through. This sensitivity was sensed by others and they confided more than they might otherwise. The ways in which most participants felt that they were now able to give to others involved receiving as well. The giver felt enriched by their ability to communicate and connect with people more effectively. In addition, this sensitivity and real understanding was a way of making a contribution, thus providing a new source of meaning. Having suffered, the suffering of others is understood implicitly through personal experience.

Whether because of help that they had found in their own experience, or because they had not had help but had felt the need for it, all participants wanted to be able to give something back or to help others. They found too that they could help in a more effective way because of their experience. In a sense participants often found themselves helping simply because there was the opportunity to help.

Where people had received help there was an acknowledgement of the hope and sense of belonging that it had allowed. Motivation seemed to come both from an awareness of how important and helpful others had been to them, and from an awareness of how things had been more difficult at times when there was a lack of understanding or help from others.

When I had mine done, there was no one really I could talk to about it. (Sam)

And we try and see other patients who are in a similar position to us, or to what we've been through. And it's hard, because it brings a lot of it back, but you also feel a kind of connection there, and a responsibility, to encourage and to help them. Because

there's no doubt about it, I had patients who had been through it, who came and saw me. (Michael)

Most participants found that they were involved in helping others with cancer as well as raising awareness about different kinds of cancer and of ways of preventing cancer. This provided a purpose for what had happened, even when the experience itself was very difficult to make sense of.

Yeah, I mean I am trying to find some good things to come out of it. And one of them was going to the board of trustees where the children go to school and, sort of talk to them about it so that now, there's in place, - there's a 'shady school' policy. And after the talk that I gave them, I was co-opted onto the policy committee, so that I actually helped write it. So I mean, if nothing else, if I can do something to stop other people having to cope with this, then I feel like well, that's one good thing that's come out of it. (Kate)

The ways in which people chose to give back were varied and were dependent on what felt right for the individual person.

When they said they've got this volunteer visiting training day, I thought yeah, that's me. So I went along to that, and I've been part of this action group, for this lymphedema treatment, because I could see women suffering from it...I thought well, you don't want to have your whole life dominated by it, by your illness, but it's good to think of positive things that you can do since you've been through it. How can you actually perhaps try and help others who are going through it as well. (Jill)

I've been able to come in touch with a lot of people, patients, and family, in so many ways. And I'd say what I've done, I do this of my own accord. And if I can help somebody, to show them what it's like, - what it's like after, - then that's great. I think it's great in as much as I've been given the chance to be able to do it. (Chris)

Being able to make things a little easier for others and knowing how helpful it can be talking to someone else who has been through the same sort of experience, creates positive meaning out of the experience of suffering.

Some participants found that doctors looked to them for help and expertise in order to help others going through the same experience.

So when they have a patient that is going to have a laryngectomy they ring me. In most cases it's personally, and say, hey, we've got somebody going in. And I just go

in and I talk with them. Because it's sort of an unknown thing. You're gonna lose your voice, - well yeah, so what? How is it going to effect you? (Chris)

Having personal experience brings with it a credibility that more theoretical advice might lack. Participants were often turned to as a resource for helping others. Satisfaction is gained in providing hope by representing a future possibility for achieving a quality of life, and by realising that they may be able to alleviate another person's suffering, even if only for a while. Through the experience of illness, the person gained the ability to contribute towards others in ways that could make a difference to their experience.

For some, the opportunities to give came through friends who were going through a similar experience. For one woman an awareness of seizing the moment and not putting off reaching out to another was balanced carefully with an awareness of her own needs as well.

I rang her and said, I sure as hang would want to be at home, you know, if that was the case for me, and would she let me come and look after her. So I spent two months with her, nursing her I guess. So it was quite a challenge for me to deal with that, and trying to focus on her issues, rather than mine, or keep mine separate from hers, and still be able to work through for me. Because my grieving goes alongside hers I guess. So it was quite a challenge... ..and it was a very valuable experience for me, but it was hard. (Jane)

For others, the opportunity to give was through raising general awareness about the illness so that it became better known.

Probably the biggest thing that's given me the most confidence I think, is talking to the kids, eh... ..that's my number one project...going round to schools...It's mainly telling the kids what I've been through. (Sam)

I keep in mind that people don't basically know what a laryngectomy is... ..some of the amazed looks I get on peoples' face, which is natural. But when anyone makes fun of me or laughs, then my immediate thought, my aim is then to go to that person and say, hey, you don't laugh at a spastic, you don't laugh at someone with multiple sclerosis, so why laugh at me? And there are other people out there who won't stand up for themselves and say, hey, that's not on. So that's the other thing that I try and do... ..and I've had a few phone calls back and letters, somebody came to see me and apologised, so at least I've got through to some people (Chris)

Through living with cancer, part of helping others is to have an impact on how people living with cancer are viewed in society. It is like a kind of advocacy for others who are suffering in a similar way. There is a sense of responsibility and purpose in raising public awareness about the particular type of cancer, where others might be less willing to do so through being less outgoing.

For others, there was a desire to put things in order and to provide for loved ones. This provided a goal that gave meaning to life.

What I'm interested is getting this business off the ground. Once I get it off the ground then I don't give a bugger. Doesn't worry me. I'd just like to get it off the ground, and just put my boy in it, you know. Just something for my boy. (Justin)

There was an awareness that life could suddenly end without the chance to give or to express care to those one wanted to. Some found the determination to make ways of living meaningful and authentic with what was found through the experience to be of real value. This gave an urgency to take action on the basis of beliefs rather than to hold them in a more theoretical way.

Yeah, it sharpens the fact that you're maybe not ever going to have a choice about when you die.....I guess one of the spin-offs from that for me is that Iattend to squaring things away a little bit more. Like making sure that you do say thank you to somebody, - immediately or very soon after, because you may not get that chance later on. That's always true. It's brought that closer, and so that if you don't get the chance to do it (later) then you have completed what it was that you needed to do. To say thank you, to say good bye, to visit somebody, to acknowledge, or yeah, to enjoy something. (Jane)

In this way, meaning was found through striving to live in ways that were true to beliefs that were strengthened and perhaps highlighted through the experience of suffering.

Several participants had taken part in other research studies, or been interviewed for newspaper articles. By volunteering to take part in the present study, all participants were aiming to help raise awareness of the things that are important for people going through the experience of cancer.

Giving back is part of the change in focus that people seem to gain through the experience of serious illness. Through the experience it is clear that people gain a real

understanding of others going through the same experience. Understanding seems to be automatically learnt and is something that people were aware of not only because they were wanting to give back, but because it was revealed in a less conscious way through others sensing an understanding in them and talking freely to them. It was also felt through finding the ability to understand people more clearly and to see beyond surface appearances, which lead to a more tolerant attitude in general. In this way, giving to others is a source of enrichment to the giver. There is the sense of contributing in having the opportunity to help, and strengthening self esteem through being valued. There is also a transcendence of personal suffering in feeling concern for others. The giving may at times only be in bearing witness to another's suffering but this in itself provides the acknowledgement that is so important.

Summary

A sense of belonging and being a part of the whole of humanity is emphasised more than material achievement or the ability to control life and one's place within it. The process of life is appreciated in itself and so is the ability to connect with others in a way that places value on their humanity. The growth of awareness and the ability to be of value to others provides a source of meaning through contributing to others. Meaning also grows out of receiving from others in terms of appreciation of others and the ability to look beyond outward appearances and achievements. In valuing others and feeling more a part of humanity as a whole, there is a widening of focus beyond the self to others and life.

Thus, a change of focus provides meaning through integrating the reality of what has happened into ways of viewing the world. Ways of living then become more authentic with the changed circumstances. Positive outcomes of the experience evolve from the changed focus and alterations in outlook make what has happened more explainable and understandable.

CHAPTER SEVEN

DISCUSSION

The present study supports previous research into the ways in which people find meaning following serious illness. In a broad sense meaning was found through the processes of integrating the reality of what had happened into self and world views. This was achieved through the overall and ongoing process of understanding the wider implications of what had happened. The gradual movement towards a greater sense of understanding and meaningfulness involved ongoing changes in the ways that people perceived the situation and their position in relation to others and the world. The ways in which people returned to living, having re-evaluated the things that were of importance to them, allowed a sense of meaning to rebuild.

A primary aim of the present study was to investigate aspects of the experience of illness that had been meaningful in either a positive or negative way, to question what it was that had made those aspects of particular concern. This approach allowed access to processes within the experience that might hinder or facilitate the finding of meaning.

The findings throw light on why and how particular aspects of the experience of illness are important in the ability to find meaning. They also suggest that changes in outlook sometimes arise from the processes of suffering in illness in ways that allow a sense of meaningfulness to be restored. In talking to people about their experience there was a strong sense of the process of understanding as ongoing, and unfolding over time.

This chapter discusses how the experience of cancer can involve a loss of meaning, and the ways in which rebuilding a sense of meaning comes through understanding and integrating the wider implications of having cancer for the particular individual. There is a gradual movement towards understanding both from reflecting on what has happened, and from the experiencing of illness. Processes for finding meaning, arising from the learning that is involved in the experience of suffering and illness are suggested. Within the process of regaining a sense of meaning the person may be helped or hindered by the quality of their interactions and relationships with others, both in the medical profession and in their social network of family and friends. The meanings that different kinds of relating hold are highlighted, as are contextual issues that naturally impact on the suffering person's ability to make sense of the situation, and to find meaning in what has happened.

The Processes of Losing and Finding Meaning in the Experience of Serious Illness

Even for those who were able to accept having cancer on a rational level, the initial impact illustrated the traumatic nature of the diagnosis. To begin with the implications on a personal level were hard to take in.

Becoming ill has implications for a sense of belonging in a culture where health is seen as the norm (Frank, 1993). When the illness is life threatening as well, there are implications for facing the imminence of one's own death and realising human vulnerability in general. There are many aspects of the experience that make it hard to fully comprehend within previous frameworks of understanding. For many in the present sample, the experience of illness resembled an existential crisis (Frankl, 1964; 1967).

Because previous experience may not be sufficient to explain satisfactorily the unchangeable situation the person finds themselves in, there may be a sense of losing control and of things going out of control. There is a strong sense of needing to understand, to make sense of what has happened in terms of the unique position of the individual. Losses, both physical and psychological, may have an impact on the person's sense of self, and sense of the world as just, orderly and meaningful (Janoff-Bulman, 1992). Losses can disrupt the person's view of their preferred identity, and initially their body may seem different, and no longer known in taken-for-granted ways (Charmaz, 1995). The disruption of the body is felt at times as the disruption of the self. Loss of meaning is felt in the inability to understand the fuller implications of what has happened.

To varying degrees, the former ways of existing in the world have been lost and the illness experience is a journey of discovery because the person has to learn new ways of being that incorporate the implications of what has happened. For the person to be able to reach a position where they can live with hope and a feeling of life as coherent and meaningful, the ability to make sense of what has happened is vital.

This is a process that is experienced as a struggle to live with the implications of cancer in a way that integrates the experience with inner conceptions of the self and of the world. There is a continuity with the former self, but the self has also changed. A change of focus towards life may be necessary in order to be able to incorporate the new reality into inner beliefs. In the present study, participants were involved in this process although they were at different places on the journey. When people are able to

find a sense of meaningfulness, it grows out of the experience of suffering involved in becoming seriously ill.

In order to reach a better understanding of the experience of having cancer it is important to acknowledge that apart from being a bodily experience, serious illness is a personal crisis (Kleinman, 1988). It is a journey of suffering and loss, which involves the gradual realisation and acceptance of what living with cancer means for a sense of identity and a sense of self in relation to the world. This is a process which is ongoing and perhaps has no end point.

In the present study, the search for meaning was located within the processes of understanding the wider implications of having a serious illness, supporting the findings of previous research (Coward, 1990; Fife, 1994; O'Connor et al., 1990; Steeves, 1992). This search involved attempts to relate meaningfully to what had happened, to adapt and to accept both the illness and the self with the illness.

Moving towards an understanding of the wider implications of being seriously ill

Understanding and acceptance of what had happened seemed to be reached through experiencing as well as relating in a more conscious way and this was a process that was ongoing. Another way to understand the different kinds of understanding and acceptance is to recognise the paradox of both having and being a body which Kleinman (1988) suggests. Human consciousness allows reflection on experience so that there is an awareness of 'having' an illness, which is a slightly distanced way of experiencing compared to the 'being' of the illness which is a more direct living of the illness.

These two levels of experiencing imply different dimensions of understanding. Relating to 'having' the illness includes cultural and social understandings of what it means to have cancer. The 'being' of an illness is associated with the more personal implications of illness such as vulnerability and helplessness (Kleinman, 1988). It requires too a kind of embodied understanding, which involves learning a new way of being that incorporates the reality of what has happened. Embodied understanding tends to be unconscious in as much as it largely comprises taken for granted ways of being that we become skilled at and carry out automatically.

The processes of experiencing and reflecting on the implications of having cancer are not isolated from each other but interact in ways that facilitate understanding in a more complete way. As Janoff-Bulman (1992) suggests, even experiences of seemingly sudden understanding are usually the end result of complex processing involving interacting conscious and unconscious input.

When a person is able to relate to having the illness in a meaningful way, embodiment of the illness helps to deepen understanding even though this may be experienced as a struggle. Conversely, when there is great difficulty in relating to what has happened in a meaningful way, then sometimes the only way to relate to the illness is to minimise it or fight against it, at least initially. When this happens, it seems that the embodiment of the illness creates feelings of conflict and suffering that have the potential to push people towards gradually reaching a fuller understanding on a conscious level so that they are able to better understand the ways that they are feeling.

Initially the feelings of conflict and suffering may not be understood, but they often seem to alert the person that something is wrong, leading them to seek help, or at least engage in ongoing attempts to understand the source of suffering. Even understanding some of the reasons for those feelings, and realising that they are a natural and understandable part of the process, provides a sense of coherence on which to start building. Self-worth becomes less vulnerable when the person discovers that what they are feeling is part of an understandable process and not a result of personal shortcomings.

The conscious and the unconscious seem to work together to allow greater levels of understanding and an integration of what has happened into a more whole sense of self. In other words, there is an inclination to incorporate the implications of what has happened into ways of viewing the self and the world so that living can be authentic and true to each person's individual circumstances.

The levels of understanding that were illustrated in the experiences of some participants can be viewed as part of the process of struggling to find a way of living with cancer and viewing what has happened so that it is congruent with inner beliefs about the world. In this sense the findings of the present study support previous research which locates the search for meaning in the processes of responding to changes in sense of self, others and the world (Fife, 1994; O'Connor, et al., 1990; Steeves, 1992; Thompson & Janigian, 1988), but extends them in suggesting how some aspects of those processes occur. The different levels of understanding demonstrate how both through living the illness and reflecting on the implications of the illness for themselves, people actively work towards incorporating the illness experience into their life perspectives.

As people move through the processes of understanding, they respond to the changing circumstances in their lives. Benner (1985) points out that humans are self interpreting

and because they care about the way that they are, they take an active part in their being and influence as well how others see them. Loss of control is motivating in that everyone wants to be able to understand what is happening and to feel, even in limited ways, that they can predict and influence aspects of their life. The person is usually active in their struggle to make sense of what has happened, so that their conscious understanding may work towards becoming congruent with their bodily experience.

Meaning in the present study was located within these attempts to restore a sense of control and further, to take a proactive part in choosing ways to respond to the unchangeable circumstances. Taking responsibility for approaches to living often lead to ways of living that were valued and therefore meaningful to the individual. There was a determination to act on beliefs that were strengthened and highlighted through the experience of suffering.

The ways in which meaning develops out of suffering

A change of focus towards life seemed to grow out of the suffering involved in the experience of illness. What was learnt through the experience of suffering became the basis for rebuilding a sense of meaning. In becoming seriously ill, people confront their own mortality as well as the fragility of human existence in general. In learning the limits to the control that they have in their life, and their own personal helplessness, they learn to accept what has to be accepted. They learn too that it is up to them to choose how to respond to the unchangeable situation. This leads to re-evaluations and affirmations of what is important in life. There is the potential for meaning to grow from the values that may become strengthened through the overall process of illness.

The learning that occurs through personally confronting human vulnerability has wider implications for the ways in which life, the self and others are viewed. The affirmation of the value of things in life that are enduring, form the basis of the rebuilding of assumptions about life that are adaptive for meaningful living. This provides support for Thompson and Janigian's (1988) framework for finding meaning in terms of adjusting self and world views and re-prioritising what is of value.

"I never thought I would be so helpless": One of the harder aspects of the experience is losing a sense of self reliance and realising that personal control is in reality very limited. Part of being able to make sense of what has happened involves trying to regain a sense of personal control in ways that are achievable, so that uncertainty is reduced and a sense of the world as orderly and predictable can be regained, even if within acknowledged limitations.

Thus, paradoxically, within the process of finding ways to restore a sense of control is the acceptance of those things that cannot be controlled. The experience of cancer involves learning to relinquish control to a greater or lesser degree. Letting go of control is often something that is very much avoided, depending both on how much value the person places on being self reliant and autonomous, and on the other hand, the extent of helplessness that is reached. Coming to terms with the possibility of dying involves an acceptance of the possibility of having to let go of everything.

The prospect of becoming entirely helpless is usually feared because it means facing the risk of losing control. However, in facing this risk there is the possibility of discovering that letting go is not entirely as expected and sometimes leads to the strengthening of meaning in areas not acknowledged before.

If acceptance and trustworthiness are found in others, then there is the possibility of strengthening feelings of trust, and finding that it is not only possible to relinquish control but that at times it can be done willingly. Bierhoff (1992) suggests that trust grows from relationships that imply a high positive regard, warmth and an accepting attitude. The growth of this kind of trust was evident at times for some participants in the present sample. When this happens, the need to be in control and the fear of losing control lessen. In a sense, control is retained through willingly handing it over to others who are trusted. A sense of the trustworthiness of others, which is highlighted when treated as still of value in times of need, implies that the person is valued in ways that cannot alter through things that happen to them. If the person is able to feel valued in spite of being in a position of helplessness, this seems to generalise to the way that they view others in a position of need.

“It can happen to anyone”: In experiencing a serious and often life threatening illness there is the realisation that these things happen, and that they can happen at any time and to anyone. This leads to the realisation of human vulnerability in general, through personal experience. Through the process of learning that becoming dependent on others does not mean becoming less worthwhile as a person, people may gain a greater tolerance for the human frailty of others. As the situation that people find themselves in becomes perceived as more powerful, individual characteristics are less likely to be seen as causal. In the process, differences between the self and others are reduced too, and as a result a bond with humankind in general grows. Rather than feeling so much a separable individual, there is a feeling of being part of a greater whole.

There is often a growth in acceptance and understanding of human frailty through personal experience. In the awareness of the vulnerability of the self, the similarity between all humans in their vulnerability is realised. Thus, a greater sensitivity to others, and a sense of communality with them, seems to grow out of the experience of suffering. This too leads to an openness to experiences of giving and receiving that provide new sources of meaning.

"I could die today or tomorrow": The realisation of human vulnerability that comes with having a life threatening illness means that independence and self reliance sometimes become perceived in a different way. In a similar sense Arnold Beisser (1989), who was paralysed from polio, discovered through his experience of illness the real source of feelings of independence.

Every living being depends on others of its kind and the environment for nourishment and support. So a feeling of independence is not based on a belief that one is self-sufficient, but on a confidence that what one needs is available from the outside. The wider the circle that we can rely upon, the more we can feel and behave independently. We confuse this feeling of independence with self-sufficiency, and interpret it to mean that we have done everything on our own. The belief that we are "self-made" men and women is a belief in a biological impossibility. (p. 42-43)

There is an affirmation of the value of people and an implicit acknowledgement of the importance of interconnectedness between people for feelings of independence, autonomy and confidence in life.

The experience of personally confronting the fragility of human existence has implications too, for the way people see themselves placed in their world, and their ability to accept their life as it is. There is a realisation that seeking after a better life for the future and striving for achievement, is often at the expense of appreciating the present. A determination to enjoy the process of living, to accept life as it is, rather than always looking forward to the prospect of finally reaching some ideal position, grows out of the experience of illness.

"I just accept life as it is now": In accepting life as it is, there is a letting go of the need to determine how life should be, with further implications for what is valued in life and different ways of living in general. This contributes to a change where the focus moves away from a need to feel in control of one's life, the need to be entirely self reliant, and moves towards a greater awareness of the importance of others. Further, a connectivity with others is strengthened when viewing the unchangeable situation

within the wider context of life. There is the realisation of being a part of humanity rather than separable from others, as is the tendency when autonomy and self reliance are highly valued.

Thus, the letting go of control that is an element of the experiencing of illness, and the source of suffering for many, sometimes develops into a change in outlook which involves more tolerance of people as they are, and a greater appreciation of life as it is. In letting go of control over life and over the illness there seem to be possibilities for new ways of rebuilding a sense of meaning. The world may be found to be less trustworthy and predictable than it seemed before, but feelings of trust for people may grow. There is an affirmation of the value of things that are enduring.

Inherent in this change of focus is the possibility of rebuilding assumptions about the world that are still adaptive in providing a sense of order and predictability. Self-worth and confidence in the world, previously provided by a sense of personal control and self reliance, have the potential to develop again from a different source, demonstrating the positive side of the risk of losing control. While personal autonomy and control are seen as less powerful, the value of being part of humanity is reaffirmed. There is a connection with life, as part of life, but not so much a need to feel personally in control of it. The reality of personal suffering and hardship becomes more explainable within this framework.

"I feel that it's up to me now": Out of the general change in life focus come possibilities for finding meaning in the way that people then live their lives.

Self care was a way that people minimised the problems that their physical losses caused, and in this sense, focusing on the self lead to a greater ability to focus outwards and to become involved in life. Charmaz (1995) suggests that looking after the self is a sign of integrating the illness implications into a sense of self, looking after yourself rather than objectifying the body. She suggests too that movement from measuring the changed body against past 'perfection' towards living with it as it is, means the possibility of experiencing one's body as more predictable and manageable again. In taking account of the illness, and looking after the self, the limiting effects of losses on the processes of living are kept to a minimum.

For each individual there are ongoing judgements about what should be accepted and what should be struggled against. This involves testing the limits of individual possibilities, constantly evaluating what can be achieved and what limitations must be accepted. Thus, the process of integration involves the ongoing testing of possibilities

for the self. In this way, acceptance is not giving up, and nor is struggling with the illness a lack of acceptance. It is more the finding and re-finding of a balance between acceptance and testing the limits of possibilities, as circumstances may alter, allowing an integration of the illness into the sense of self while still striving to reach for personal potential. The process of integration develops towards a realisation of a new life balance that is re-evaluated in an ongoing way. Acceptance is a process and is related not only to what has been lost, but also to acceptance of the new ways of being (Beisser, 1989). In this way, meaning is found in reaching towards valuing ways of living in the present, striving for quality of life in the unchangeable circumstances (O'Connor et al. 1990).

Adaptation, self care, acceptance and proactive living are related to meaning because they show an integration of the present with the past, as well as an active engagement with living. They show the individual accepting the challenge of living in a way that acknowledges and accounts for what has happened, while still striving for ways of living that are meaningful. This may be connected to Frankl's (1967) reference to life as the question, and the answer to meaning in life deriving from each individual's response to that question. There is a similarity to Steeves' (1992) finding that men in his sample found meaning through their individual efforts to negotiate a social position for themselves in their changed circumstances.

Learning that the situation is unchangeable and that no one can make it go away is often a long and painful process. What seems to be gradually learnt is that human life is beyond personal control, but the way that it is lived, in whatever circumstances the person finds themselves, is within personal control. Frankl (1967) suggests that a source of meaning is found in personal attitudes and responses towards life's adversities. These include an acceptance of those things that cannot be changed, as well as retaining personal control through choices about how to respond to life. Further sources of meaning are found from being open to receiving from the world and giving to the world. O'Connor et al. (1990) found that people built meaning in their lives through the ways that they adapted and lived with cancer. There is support too for the views of Thompson et al. (1993) that people are active in understanding and changing the situation and Denne and Thompson (1991) who found that people regained a sense of meaning when they moved to a position of accepting and acting on their felt responsibility for the way that they approached their life.

Antonovsky (1987) suggests: "We are all terminal cases. And we all are, so long as there is a breath of life in us, in some measure healthy." (p. 3) There were many

instances in the present study which showed the health and vigour of individual responses within the experiencing of illness.

The present study throws light on the ways in which a sense of control is restored and how the meanings of control may change in the experience of serious illness. As Taylor (1983), Taylor et al. (1984) and Thompson et al. (1993) suggest, people will often actively find ways to restore a sense of control in areas where this is achievable, and they will tend to accept their inability to control those things which are beyond control. Thompson et al. (1993) found that perceptions of control were important for adjustment to illness and that although the illness may have been beyond control, other aspects such as some of the emotional and physical consequences of illness, were not. As with the present findings, this suggests that in regaining a sense of control where possible, there is an acceptance of aspects in the situation that are beyond control. An acceptance of the changed life circumstances and of new ways of being is important and is at the same time something that is revisited on an ongoing basis as circumstances change and relentless uncertainty is faced.

Taylor et al.'s (1984) finding that a sense of control could be felt vicariously is related to findings in the present study that suggest that the meaning of control may change, and that if trustworthiness is found, then handing over control willingly is a way of retaining a sense of control. Similarly, Taylor (1983) suggests that in searching for meaning people are attempting to regain a sense of control in ways that are possible in the circumstances, such as in taking measures to prevent a recurrence, and taking an active part in their response to having the illness.

In terms of being a crisis, the experience of illness has the potential to be a turning point. What is learnt in the experience contributes to a change in life focus that subsequently may provide meaning. The change of focus integrates the changed and uncontrollable situation into beliefs and assumptions about life. The value of being part of humanity as a whole is affirmed and no longer taken for granted. In these ways it is possible for new sources of meaning to arise out of the experience of suffering in illness, through the learning about life and others that are inextricably part of the process.

Processes that Impact on the Ability to Find Meaning

There were aspects of the experience of cancer that seemed to impact strongly on the nature of the person's experience and which had the power to help or hinder their ability to rebuild a sense of life as meaningful. Interactions with other people were very

important because of the implicit meanings they held that impacted on feelings of self worth and belonging. Social interactions had a strong impact on the way that the person felt about themselves. When interactions with others were felt as supportive, the process of finding meaning was facilitated. Conversely, when support was lacking, the alienating aspects of illness were compounded, and self-worth became more vulnerable. Individual differences in personal circumstances and in personal beliefs about life, impacted too on the meanings that the illness held for each person.

Interpersonal issues

Throughout the whole process of the experience of illness, feelings of interconnectedness with others and with life, were important. This might be through children and other family members who needed or were dependent on the sufferer, or it might even be through a pet that needed looking after. It might be through relationships with doctors and nursing staff, or through people who were going through a similar experience and who extended a caring attitude. At times the environment too can act as a solicitation towards living (Doolittle, 1994), providing a reconnection to life and a sense of belonging. Interconnectedness provides a source of meaning through affirming to the sufferer the value of others as well as the value of life itself. By drawing the suffering person towards experiencing in the present interconnectedness is important for facilitating the move towards a sense of meaning even at times when understanding of the situation is lacking.

By making explicit the implicit meanings contained in interactions with others, the findings of the present study throw light on some of the reasons why they constitute such a powerful influence on the nature of the illness experience.

When a person finds that they have cancer there may be feelings of alienation due to being set apart from the healthy community, with added implications of the body having failed. Body changes tend to highlight the separation from the previously known self (Charmaz, 1995). In as much as health is seen as something that people strive for, becoming ill may also be experienced as failure. Health and illness are often viewed as mutually exclusive so that becoming ill means losing health. In a culture where health is seen as partly under personal control, health can be held up as a virtue, so that becoming ill carries implications of failure in some ways. Illness is not consciously looked at in this way, but it becomes clear that part of the experience of being ill involves the need to prove the self as worthy (Charmaz, 1995). Sometimes it is almost as if the ill person has to validate their worth to others in order to prove it to themselves. Unless a person is able to relate to the illness in a meaningful way, self-worth may be difficult to maintain. Perceptions reflected by others become especially

powerful for self judgements at times when self-worth is vulnerable (Janoff-Bulman, 1992), which is sometimes the case when experiencing illness. Further, without self-worth it is difficult to maintain the motivation to preserve an engagement with life.

As Brallier (1992) points out, the suffering person may feel alienated from the ill self that they are experiencing, and these feelings may be increased by being treated as a case. Gaining a feeling of being valued in a way that cannot be altered is very affirming to the person who is going through so many changes. Acceptance of the self with the illness becomes easier, implying an acceptance of the reality of the illness as well.

Aspects within the process of experiencing illness that allow a person to feel valued are perhaps the most important things that enable a person to begin rebuilding their life in a way that can be experienced as meaningful. The growth in trust which allows a sense of meaning to re-grow, is dependent on the quality of interactions with others. In the processes of changes in perceptions of the self, others and the world, interactions with others are important in allowing a sense of meaning that is positive.

A feeling of being acknowledged and accepted seems to have the power to counter feelings of alienation that may be felt in becoming ill, and to reconnect the person with feeling part of humanity again. The significance of feelings of interconnectedness for a sense of belonging and engagement with life, are illustrated in the experience of Arnold Beisser (1989), referring to the time, over a period of years, that he spent in hospital and to the care he received from particular people.

Just thinking about them now I become warm and relaxed. These people helped willingly, with interest and compassion. They seemed to receive something valuable from the act of giving. My comfort was their goal. When one of them would appear on a ward of patients, it was as though the room would suddenly light up. Fear and tension would recede. These willing helpers were among the most appealing people I have ever met. They seemed happy, generous, open, and compassionate. They were nurtured by their relationships with people who needed them. They usually had a remarkable sensitivity to the needs of people as well, often seeming to understand without words. With them I felt restored to the human community. (p. 37)

The above extract illustrates the healing element of interconnectedness and the continuing source of well-being that is provided in looking back. The two way nature of interconnectedness is demonstrated as well, showing that in giving something is received as well. A way of implicitly showing positive regard and understanding, and finally the connecting quality of such relationships are conveyed. All these aspects of interconnectedness were found in the present sample in descriptions of moments that

were helpful for coming to terms with the changed personal circumstances. The connecting quality of helpful social interactions enables people to broaden their focus as they are drawn to care about and to feel committed to others and to life. Participants felt a need to reach out to help others in need in a similar way, demonstrating the two-way nature of interconnectedness.

In situations where acknowledgement and unconditional acceptance are lacking the process of relating to and understanding the implications of cancer may be held up because of the implicit meanings conveyed. In social interactions where acceptance seems conditional, and where there is a disregard for the individuality of the person and their predicament, the person's self-worth is likely to become more vulnerable. The feeling of being set apart and the devaluation of the self, that are often felt in the experience of illness, are compounded. In contrast, the connecting qualities of others are a source from which to start rebuilding positive assumptions about the world that can provide a sense of meaning.

Relationships which have an element of interconnectedness, draw the person towards feeling a bond with others. In this way feelings of interconnectedness are perhaps what reconnect people to life, which is then able to be experienced as meaningful. The motivation to experience life looking out at the world and others is provided. A sense of belonging encourages the feeling of being part of the world and in this sense feelings of connectivity are experienced as self transcendence. When participants felt a strong connection to others, when they felt the need to reach out and care for others, or became totally involved in experiencing in the present, they were able to transcend their suffering and for a while the significance of their illness faded into the background. At these times, continuity between past and present is affirmed too. These moments provide meaning too in looking back on them as suggested by Coward (1990). They seem to allow a sense of meaningfulness to be experienced and to grow through a sense of belonging. The findings on interconnectedness as both a source of meaning and a facilitator for meaning, support Frankl's (1967) claims that meaning is found through experiences involving self transcendence.

Attempts to make sense of, and find meaning in the experience of serious illness are helped when people feel reconnected to life, so that those things that help a person to feel connected are an important contributing factor in the ability to find meaning in the experience. Interconnectedness provides a source of meaning, as well as facilitates the finding of meaning, through soliciting a broadening of focus towards others and the feeling of commitment to aspects of living that become valued. There is support for research that suggests that meaning is found through reappraisals of life involving the

affirmation of the value of relationships, a growth in awareness and sensitivity, attempts to relieve the suffering of others and reaching beyond the self to help others (Coward, 1990; Dirksen, 1995; Fife, 1994; O'Connor et al. 1990; Taylor, 1983; Thompson & Janigian, 1988).

Contextual issues

The nature of the process of understanding, accepting and integrating the reality of having cancer depends in part on each individual's beliefs, previous experience, and circumstances. These are unique for each individual and naturally impact on the nature of the illness experience. The seriousness of the particular cancer also has a bearing on how hard it is to make sense of.

Although a diagnosis of cancer is widely agreed to be the kind of experience that is traumatic for anyone, there were differences in the degree to which beliefs about the world had been disrupted. Attempts were made to make sense of the situation on the basis of existing understandings about life supporting suggestions by Janoff-Bulman (1992) and Thompson and Janigian (1988) that people attempt to understand negative things that happen to them based on pre-existing assumptions and beliefs.

When people were able to maintain their religious faith throughout the illness, this provided a sense of belonging, and trust in being able to count on a power greater than the self. Having faith means that a sense of purpose can be maintained, and that control can be let go of more willingly. Religious teachings too, emphasise the values that seem to be highlighted through the experience of suffering. The sense of placing individual life within a wider context, of suffering being part of life, and of having someone to count on who is standing by, all help in finding meaning in the experience of illness. As Wortman and Silver (1992) suggest, some religious teaching may provide an orientation to life that prepares people for facing situations of adversity. These orientations, which may be lacking in more general cultural understandings, may mean that when adversity is faced there are meanings already in place that help in making sense of what is happening.

Differences between people in their beliefs about life, their previous experiences and other illnesses, and their responsibilities and goals, had an impact on how hard it was to make sense of having cancer. Findings supported suggestions by Janoff-Bulman (1992) that previous traumatic experience may prepare people to face further trauma in some ways. Their beliefs have already been challenged and possibly adjusted to become more congruent with the reality of personal suffering. Differences in the seriousness of the particular type of cancer, the type of treatment, and whether there had been a

recurrence, meant that it was more difficult for some than others to make sense of what had happened. Some participants were able to make sense of what had happened and this meant that they could maintain a sense of meaning through the experience. For others there was much more difficulty. Either way, the journey of understanding involved much suffering.

However, greater severity of illness did not necessarily mean that the person was unable to find meaning, a finding that supports previous research. Rather, it impacted on the amount of life disruption that was felt, and the nature of the journey to find meaning in what had happened. A greater disruption to life can sometimes lead to a more pressing search for meaning in the need to understand the wider implications of the illness for the person's life. At times, new sources of meaning grow through the suffering leading to transitional experiences.

Taylor (1993) found that the severity of illness related factors was associated with strength of felt meaning, although most of her sample did have a clear sense of meaning. Conversely, Lewis (1989) found that length of time since time of diagnosis showed no relationship to sense of meaning. As suggested by Lewis (1989) the measure he used may have been too simplified to capture the effects of the severity of the illness.

The findings of the present study suggest that the impact of contextual factors are too complex to be predicted by measuring length of time living with cancer. They suggest that someone who has found a sense of meaning in the changed circumstances may have gone through a long process of understanding to reach that point, whereas someone who is struggling with a sense of meaninglessness, may be in the process of working towards a sense of understanding. Further, a sense of meaning is unlikely to steadily grow along a continuum, but rather is something that is revisited as circumstances alter or feelings change. One of the most difficult aspects to accept and learn to live with in an ongoing way, is a sense of uncertainty about the future.

Future Directions

The present study was carried out at one particular time and in this sense could be viewed as cross sectional. However, because all participants were at different stages both in terms of time since diagnosis and where they were in the process of understanding, the analysis did provide a strong sense of moving through a process over time. This was aided by the fact that participants looked back over their experience and were aware of how their own understanding had changed over time. In

several cases there were things that were incomprehensible initially which gradually became more clear and therefore more meaningful, through the process of understanding the wider situation more clearly. Even the observation made by three participants about feeling a sense of achievement in the ability to talk about their experience in an interview situation which they felt they could not have done earlier in the illness experience, points to the processural nature of coming to terms with serious illness.

Further research could expand on understandings of the processes of finding meaning using a longitudinal design, following the same people through their experience over a period of time. The present study highlighted the way in which the experience of illness is a journey which involves changes in understanding which evolve out of the experience over time. A longitudinal design could confirm whether these processes unfold in a sequence over the course of time.

Although the interview data was gained from single interviews with each participant, except in one case where there were two interviews, this did provide good depth of information. There was a redundancy of ideas both within and across interviews. However, future research could use multiple interviews to confirm the validity of interpretations through confirmation. Van Manen (1990) suggests too that gathering and reflecting on lived-experience data can be two different stages of a project, carried out at different interviews. When this is the case the participants have a greater role as collaborator. In the present study, the dialogue with and reflection on the interview material was carried out by the researcher and the role of the participants was their response to the overview of the findings, and other conversations related to the study. Further research, and resonance with readers, can confirm the validity of interpretations made here.

Although the sample in the present study cannot be claimed to be representative since it relies on self selection, it did include people from different walks of life, and at different times of life. Although those who volunteer could be viewed as those who have coped well, there was evidence of people being at very different stages of the journey both in terms of time since diagnosis, and the ways in which they were feeling in terms of their illness. The experiences of individuals within the present study varied widely. Ways of talking about their experience were different, as were their responses to their unique circumstances. However, although ways of experiencing varied, there were underlying common concerns that have a more general relevance in terms of understanding the experience of serious illness. Validation of the findings is possible by carrying out similar studies using different samples.

Concluding Comments

Since experiencing and interactions with others are ongoing, the process of finding meaning is evolving and has no end point where it is finally achieved. Further, it is something that continually needs to be re-evaluated as circumstances alter. This is something that is true for all people as they try to make sense of the things that happen to them, a uniquely human activity, but is perhaps clearer and more intense during the facing of very traumatic events such as serious illness (Hall, 1994).

When assumptions that were adaptive for coping are called into question, people become vulnerable to a loss of self-worth and life purpose. Finding meaning can be viewed in terms of trying to make sense of a traumatic situation through adjusting those ways of viewing the world so that the event is explainable (Thompson & Janigian, 1988). When people are able to regain a sense of meaning, the ways in which they do so evolve out of the learning that takes place when facing personally the vulnerability of human life, and learning the limits of personal control.

The findings of the present study add to research in the area by expanding on some of the processes that have been found to be involved in finding meaning and how these work in relation to experiencing a serious illness. A process for finding meaning in the experience of cancer is suggested. It is hoped that the findings will increase understanding of the lived experience of illness, of the meanings that are implicit in different kinds of social interactions, and of the wider implications of the experience for viewing the self, others and life in general. This will help to raise awareness of the journey that people who are diagnosed with cancer embark upon. An important implication of the present findings is that a greater acknowledgement and understanding of the magnitude of the 'existential crisis' that people experience through such a traumatic event, is in itself something that could help alleviate their suffering at times.

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APPENDIX A

I am in the process of looking for people who will help me by participating in my study on the experience of illness. An information sheet is enclosed which tells you about the study and what it will involve for people who take part.

If you are interested in finding out more, please fill out the slip below and return it to me in the stamped and addressed envelope provided. Remember that you are in no way committing yourself by returning the slip. If you do reply, I will contact you and we can talk in more detail about the study and its procedures, and discuss any questions that you may have about it. At that point, if you agree to participate, we can arrange to meet and talk at a time and place that suits you.

Thank you for taking the time to read about the study. I look forward to hearing from you.

Yours sincerely

Bridget Rowsell

I am considering participating in your study and would like you to contact me to discuss it further.

Name:

Contact phone number/address:

APPENDIX B

EXPERIENCES OF ILLNESS

INFORMATION SHEET

My name is Bridget Rowsell and I am completing an MA in Psychology. My supervisor is Kerry Chamberlain, a lecturer in Psychology at Massey University. The project I am conducting has the approval of the Massey Human Ethics Committee.

The aim of our study is to understand better what the illness experience means from the perspective of those living through it. To do this I would like to informally interview some people so that they can tell me what being ill has meant to them. I will ask some questions during the interview but will also be guided by what have been important issues for you. I am interested in hearing about personal experiences of illness and anything that may have helped in coping or coming to terms with what has happened. Examples of issues we want to cover are whether there have been any positive aspects to your experience of the illness, whether your life has changed since you had cancer, what the most difficult aspects have been and whether it has changed the way you see yourself.

The interviews will take about 40 minutes and may be done over one or two sessions depending on individual wishes. The interviews will be audio-taped and transcribed by me for later analysis. The tapes will be stored in a secure place and will only be accessible to my supervisor and me. No names will be used on any of the materials. This is to ensure anonymity as well as confidentiality. All tapes and transcripts will be destroyed at the end of the project, but you can have your tape returned to you if you wish.

You are invited to take part in this study but participation is entirely voluntary. If you choose to take part, you have the right to refuse to answer any questions. You have the right to ask for the tape to be switched off at any time during the interview and to withdraw from the study at any time. You are encouraged to ask questions about the study. Any information that you provide is with the assurance that your name will not be used in the report without your permission. You will be provided with a summary interpretation of your answers to ensure that your experience has been interpreted in a way that you agree with. If you agree to take part, it will be under the conditions set out in this information sheet.

Please contact me or alternatively my supervisor if you have any questions. If you leave a message with your phone number at the Psychology Office, phone 3569099 (ask for the Psychology Office), I will return your call as soon as possible. My supervisor may be contacted at the same number.

Thank you

Bridget Rowsell

APPENDIX C

EXPERIENCES OF ILLNESS

CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

If I agree to participate, I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researchers on the understanding that my name will not be used. *(The information will be used only for this research and publications arising from this research project).*

I agree to the interview being audio taped.

I also understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signed:

Name:

Date:

APPENDIX D

c/o Psychology Department
Massey University
Private Bag
Palmerston North
November 27th

Dear

I am sending a brief outline of my interpretation of the series of interviews about having cancer, in which you took part. This is partly to keep you informed of how I am going and partly to give you an idea of my focus. The completed thesis will be much fuller, with an expansion of these ideas, and examples from your individual experiences. My plan is to use your words directly from the transcribed interviews in order to provide examples and back up for what I am saying. Because I am looking at different experiences, some of the things that I suggest may not apply directly to you, but you should be able to relate to what I am saying. My interpretation is of necessity generalised.

Another issue which has arisen again is that of confidentiality. I have decided that before I complete the final draft I will send you a list of the quotations from your particular transcript that I would like to use. This would be to confirm with you that I have your permission for that and to give you the chance to withdraw anything in particular if you wish. My main concern is that often I have not wanted to take a particular comment completely out of the context and therefore some may be quite long (by that I mean about the length of the paragraph above). I feel that this gives more of a feeling for individual contexts and gives specific instances of experience that prevent the analysis from becoming too generalised. On the other hand, in some cases it may make recognition of a particular individual a possibility, especially in such a small community. In all cases I have used different names, however I will leave it up to you to decide whether the possibility of recognition is likely, and whether it is a problem for you or not. So far I have only changed names, and changing personal details is something further that can be done to make recognition less likely. I will also provide you with the personal profiles that I will use (brief introductory sentence or two for

each participant) for similar reasons, and to check that I have details such as age correct.

OVERVIEW

Implications beyond the medical condition

In talking to a number of people I was attempting to look in an open way at what the experience of having cancer had been like from individual perspectives. The aim was to try and understand an insider's rather than an outsider's view, and to gain insight into aspects that might impact on the nature of the process and make it more or less difficult for the person to understand and to regain a sense of meaningfulness in life.

It seems that the experience of having cancer is an unfolding process that is in many ways a journey of suffering and loss, involving the gradual realisation and acceptance of what living with cancer means for a sense of identity and a sense of self in relation to the world. The suffering derives not only from the medical condition itself, but also from the personal crisis that it comprises. When the illness is life threatening as well, there are implications for facing the imminence of one's own death and realising human vulnerability in general. The overall process seems to involve attempts at gaining an understanding of the implications of having cancer, and adapting and learning ways to live meaningfully with the new reality. It seems as if the medical aspects of the illness were mainly dealt with satisfactorily, but most of you were well aware that there were implications that went beyond the medical condition, and its treatment. For some of you, getting back to living was just as much, if not more of a problem than the treatment and physical suffering involved in the illness.

Different personal contexts and inner beliefs

Differences between people in terms of their beliefs about life, as well as differences in their individual contexts such as time of life, previous experiences and other illnesses, responsibilities and goals, had an impact on how hard it was to make sense of the experience of having cancer. Further, differences in the seriousness of the particular type of cancer, the type of treatment, and whether there had been a recurrence, meant that it was more difficult for some than others to make sense of what had happened.

Trying to find meaning in what has happened

One of the significant things about going through such an experience seems to be the need to make sense of what is happening and to find meaning in the situation that

enables the person to carry on living with a sense of life being worthwhile. Part of the traumatic nature of the experience comes from the fact that it does not always fall easily within pre existing frameworks for understanding. When previous beliefs and assumptions about the world are insufficient for explaining meaningfully what has happened they are brought into question, and this too makes the changed situation harder to make sense of. These inner beliefs about the way that life is or ought to be may need to be re-evaluated and made more congruent with the new situation. The focus of my study is on this process of searching for meaning in the experience of cancer. Being able to make sense of what has happened seems to help in acceptance and in coping.

Processes of understanding

Understanding may grow through relating to what has happened in a reflective way, finding reasons and purpose for what has happened. Understanding and meaning may also develop through the process of living with cancer, regaining a sense of control, adapting and testing the limits of personal possibilities.

For some of you, previous experiences and views on life in general may have helped in finding some meaning in the experience. A belief in God or a power beyond the self, or a sense of being a part of a greater whole, may provide a purpose for having become ill. For some, the suffering may develop meaning as a powerful learning process leading to personal growth and greater awareness.

For others though, in order to make sense of the new and uncontrollable situation it was necessary to re-evaluate and adjust ways of viewing the world before the new situation could start to be made sense of. This is a very difficult process and involves much suffering.

In adapting to having cancer and in learning to live with it, the experience sometimes develops meaning through the ways that people live their life, leading to positive outcomes from what has happened. These positive outcomes provide meaning in spite of the fact that the illness experience itself is not positive. Sometimes the insight and sensitivity gained through the experience, often without necessarily realising it, provides opportunities for helping others and being able to provide a real kind of understanding for others going through similar experiences. This increased awareness relates to others in general, many of you seeming to find, over time, a greater tolerance for others and an ability to see beyond surface appearances and therefore be less judging. These kinds of things too can provide meaning in the experience. Living life to the full, taking each

day as a bonus, testing the limits of personal possibilities in an ongoing way, and searching for a way to live authentically in the changed situation, are other ways that people seem to rebuild a sense of meaning.

The importance of others in remaining engaged with life

Apart from differences in personal contexts perhaps the most important thing in being able to make sense of what had happened was the support of other people. The importance of others in such an experience is evident from the moment of diagnosis. When feelings of self worth are at risk as can happen when experiencing illness, perceptions reflected by others become especially powerful for self judgements. Feeling understood and acknowledged as an individual seems to be important for keeping a strong sense of identity and self worth. Conversely, being treated with indifference or as a case, a medical condition, is like disregarding and devaluing the individual. Without a feeling of self worth it is difficult to maintain the motivation to preserve an engagement with life. When real understanding is hard to find the effect is not simply neutral, but compounds feelings of alienation, uncertainty and lessening self worth that seem to be a part of the experience of becoming ill. For most of you, over the whole process of the experience of having cancer there seemed to be a mixture of both helpful and unhelpful interactions with others.

Beyond the support or lack of support of the medical profession, the support of friends and family is not always all positive even when the people care very much. Role expectations and responsibilities, felt from both sides, may sometimes create a barrier so that the sufferer feels the burden of having to protect others from how they are feeling. The flip side of this is that these same feelings keep the person connected to life, through their care for others, mutual need, and feelings of communality.

People close to the person who has cancer may have difficulty in understanding and accepting what has happened, and this too may mean the sufferer feels responsibility that sometimes prevents openness and may be experienced as a feeling that personal worth is conditional on fulfilling valued roles.

A feeling of being acknowledged, and a sense of being accepted regardless of anything that might happen, is felt in different ways by different people but always demonstrates a real recognition of what the person is going through, an affirmation of the person's value beyond the medical condition or any role expectations, and an understanding of the needs of that particular individual. Some people are a lot more private than others,

and in these cases acknowledgement involves an understanding and a respect for that privacy.

A feeling of being acknowledged, of being accepted and valued, may also come from more spiritual sources and where this is felt there is a feeling of strength being gained from the strength of God, others who are praying for you or who care about you, or even from a more indefinable inner source. For some of you though, your religious faith was shaken and this was another source of suffering which made the search for some kind of meaning in what had happened more difficult.

At times when a person is physically very weak, feelings of interconnectedness that grow out of acknowledgement and acceptance, provide a feeling of strength beyond personal weakness. The feeling of having others who you implicitly know are standing by you, and who you can count on, is important both as a source of personal strength and for feeling worthwhile. It allows a focus beyond self concerns towards life and to others to develop, and this allows the person to feel connected with humanity even when their own life has become less certain. Interconnectedness implies a two way relationship, and it seems that when such relationships are present, or develop, it is this feeling of connection from both sides that sometimes reconnects the person to life and others. The value of pets too should be mentioned, as well as the life connecting qualities of the environment in general.

Interconnectedness may develop between the sufferer and medical staff, or may be found in existing relationships with children, spouses, other family members or friends and even those who were previously thought of as acquaintances. A feeling of being acknowledged and accepted seems to have the power to counter feelings of alienation and of being alone that may be felt in becoming ill, and to reconnect the person with feeling part of humanity again. Overall, interconnectedness is a way of becoming engaged with living, and it is a way through which further sources of meaningfulness may be found through finding new goals, purpose, abilities and sources of valuing life. In this way, interconnectedness can be seen as a way of becoming engaged with living, and in the process of living and feeling connected with living, sources of meaning are able to grow.

Change of life focus

Sometimes a change of focus in life is developed through the experience and this has the potential of providing a sense of meaning. This is likely through things like finding the ability to give and to receive without judging the need for help as a sign of being

deficient, valuing of life as it is with a lessening need to control it, affirming the value of other people above material things, a determination not to sacrifice the present for the future and to enjoy life today more fully, attempting to improve things for others who have cancer, or others who may get it in the future, and many other sources of meaning.

Concluding comments

Attempts at making sense, and finding meaning in the experience of serious illness seem to be helped when people feel reconnected to life so that those things that help a person to feel connected are an important contributing factor in the ability to find meaning in the experience. In the present sample what seemed to encourage connection with life was acknowledgement, acceptance and interconnection with other people, and for several of you these were provided by a religious faith. It was clear that at times when there was a lack of these things it made the process of understanding more difficult. A strong feeling of connection with life meant an engagement with living and the motivation to search for a way of living that provided a quality of life in spite of having a serious and often life threatening illness. From this position, the way that a person lives their life may then provide experiences that build further meaning for having had the illness through a sense of purpose, and sometimes outcomes that grow out of the experience that are meaningful and worthwhile. This is a process that tends to be ongoing, and evolving through experiencing. The search to make sense of what has happened grows out of the process of understanding, and involves continuous re-evaluating as circumstances alter over time. It is a process that involves much suffering and often a re-focusing of the way in which life and the self is viewed.

The focus I have taken is one out of many possible ways to integrate the findings from several very different experiences. My thesis will present my interpretation of experiences of having cancer from looking across and within the experiences of eleven very different individuals, with very different experiences. Inevitably the interpretation will be incomplete as I tried to understand those parts that you shared with me. And inevitably, my interpretation is made from the standpoint of my own personal background, my educational background in psychology, and from the focus I have chosen to take within the area of health psychology.

The aim was to examine whether within the unique aspects of individual experiences there may be some common concerns that could throw light on the experience of having cancer and other kinds of serious illness in a more general sense. I feel that this has been achieved through what you have told me of your personal experiences. I believe gaining a fuller understanding of your particular experiences has a more general

relevance that could help the understanding of others going through a similar kind of experience. Further, I feel the understanding of people in general for others going through such a traumatic event may be increased through learning more about what it is like for the person going through it.

Finally, I would like to thank you for agreeing to take part in my study and helping my attempts at understanding your experiences. It is true that I could not have done my study without you, and for nearly a year I have been immersed in the process of analysing your interviews. Along the way I have learnt so much and feel privileged to be doing such a study.

I will ring you in about a week to check whether you would like to make any further comments. Apart from that, I will also check with you about the quotations I propose to use, before my final draft, as well as other confidentiality issues.

Yours sincerely