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The psychosocial, existential and spiritual needs of people with cancer

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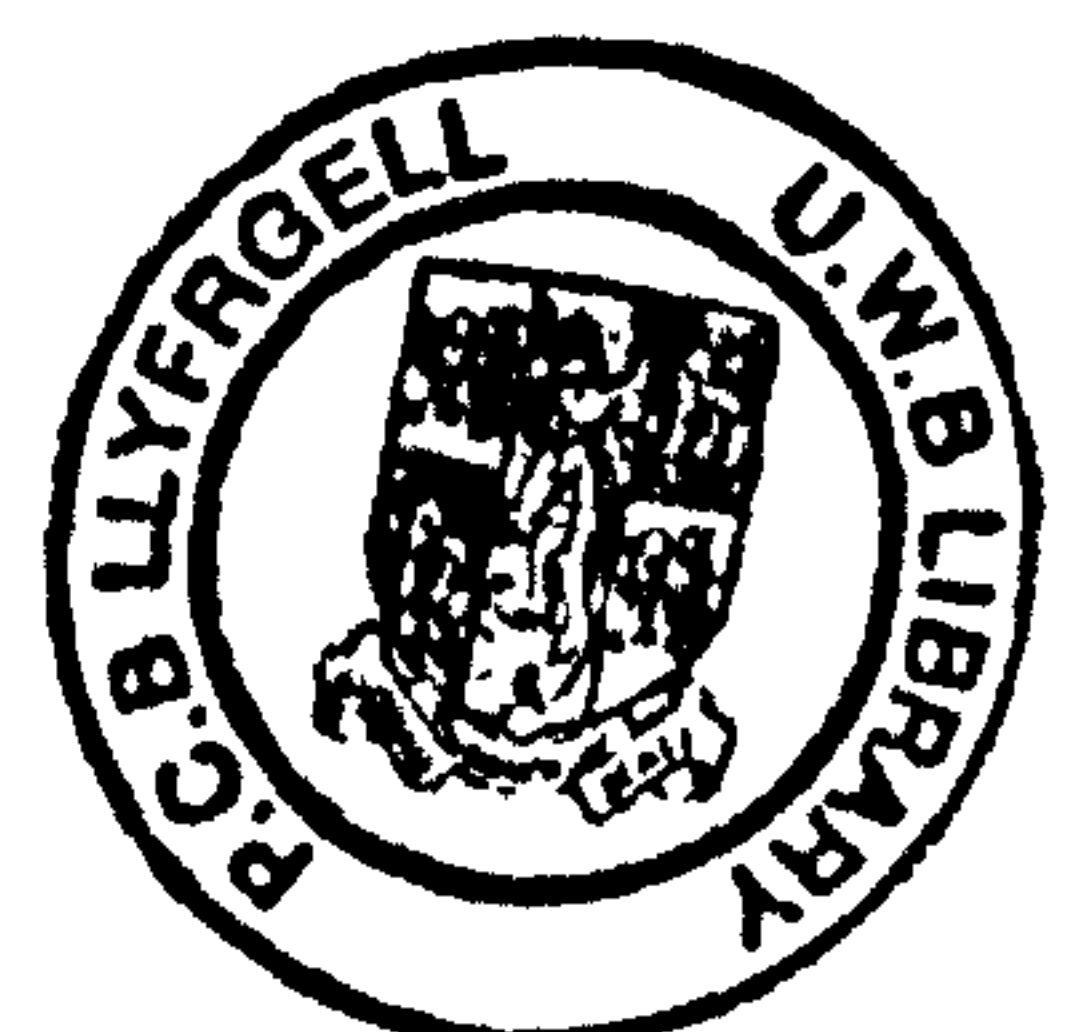
The Psychosocial, Existential and Spiritual Needs of People with Cancer

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[2006]



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- Ethics: Letter of Approval for Amendment Request, 1 page after page 24
- Ethics: Letter from UWB Ethics Committee Providing Approval, 1 page after page 25
- Appendices I – IV, pages 26-34
- Notes for contributors to the *British Journal of Clinical Psychology*, pages 71-73
- Notes for contributors to the *British Journal of Clinical Psychology*, pages 103-105

Readers may consult the original thesis if they wish to see this material.

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I would like to express my sincere gratitude to Dr. Val Morrison for giving me the opportunity to conduct a project in an area of psychology of long-standing personal interest. I would also like to thank Dr. Morrison for her expert reviewing and editorial advice.

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Abstract

A literature review examines needs assessment for people with cancer and identified needs in the domains of medical care, psycho-social support, information, distress amelioration, psychological support, existential and spiritual well-being. The review also considers the emerging literature concerned with the benefits some people describe as resulting from their experience of cancer. The literature reviewed, suggests that non-medical aspects of a person's well-being have a significant role in the person's adjustment to cancer and treatment. The small amount of research in the domains of existential and spiritual well-being suggests the need for these aspects of a person's functioning to be included in any holistic assessment of need. Further, the need for further research of the links between existential and spiritual well-being and adjustment to cancer is highlighted as an important first step in understanding the needs of people with cancer in a holistic way.

The Empirical study was conducted as part of the larger 'CancerCAN' study (see Zinovieff, Morrison, Coles and Cartmel, 2005) that has developed a tool for the assessment of cancer patients' needs'. The present study employed focus groups to explore the existential and spiritual needs of 9 people with cancer. A content analysis identified a wide range of psychosocial needs. An Interpretative Phenomenological Analysis (IPA) identified a master theme labelled as 'positive coping as a priority in dealing with adversity'. Existential and spiritual sub-themes were identified and labelled as 1: the possession of faith; 2: meaning and purpose from cancer; 3: changes in perspective as a result of experiencing cancer; 4: anxieties about the future, and; 5: issues of control. It is concluded that Existential and spiritual aspects of the person

are personally significant for people with cancer and require inclusion in holistic assessment of cancer patients' needs'. Theoretical and clinical implications are considered in a final chapter.

Abstract Word Count = 300

Ethics: Letter Requesting Addition of Paul Priem to the Recognised Research Team of the CancerCAN Project.

**Ethics: Letter of Approval for Amendment Request from the North Wales Central
Research Ethics Committee**

**Ethics: Letter from University of Wales, Bangor Research Ethics Committee
Providing Approval of the CancerCAN Project**

Note: The researcher Paul Priem does not appear in this document as his involvement began at a later date.

Assessment of The Needs of People With Cancer: A Literature Review

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Abstract

Purpose: The research literature that examines the needs of people with cancer is reviewed.

Methods: Research papers published within the 20 year period 1985-current were initially identified using the PsychLit and MedLine electronic data-bases. Papers for final inclusion were selected on the basis of relevance to the topic area. Meta-analytical and review papers were employed when available.

Results: The review examines needs assessment for people with cancer and identified needs in the domains of medical care, psycho-social support, information, distress amelioration, psychological support, existential and spiritual well-being. The review also considers the emerging literature concerned with the benefits some people describe as resulting from their experience of cancer.

Conclusions: The literature reviewed, suggests that non-medical aspects of a person's well-being have a significant role in the person's adjustment to cancer and treatment. The small amount of research in the domains of existential and spiritual well-being suggests the need for these aspects of a person's functioning to be included in any holistic assessment of need. Further, the need for further research of the links between existential and spiritual well-being and adjustment to cancer is highlighted as an important first step in understanding the needs of people with cancer in a holistic way.

Abstract Word Count = 200

Cancer is a major cause of morbidity in the UK. Every year more than two hundred and fifty thousand people receive new diagnoses of cancer (Office for National Statistics, 2001). Overall lifetime prevalence for cancerous illness is estimated at a rate of one-in-three (National Statistics Online, 2004). While there are over two hundred known cancer types and sites, cancers of the bowel, lung, breast and prostate account for more than half of all new cases (Office for National Statistics, 2001). While breast cancer predominantly affects women and prostate cancer is exclusively male cancers of all other types and at different sites affect both sexes in large numbers.

Cancer occurs predominantly in older people with nearly two thirds of cases being diagnosed in people of sixty-five years and over and less than one percent occurring in children up to the age of fourteen years (Office for National Statistics, 2001). These statistics suggest that one third of people with cancer are at ages where they will be working and thus cancer has a national economic impact.

These statistics, in particular those for lifetime prevalence, display the high numbers of people and families living in the UK that are currently, or will be, affected by cancerous illness. The effects of suffering with a cancerous illness are not limited to the physical. People living with cancer will experience effects upon their quality of life in practical, emotional, social and cognitive domains. Understanding the needs of this population must be considered a national concern of great importance if the delivery of health and social care to people and families living with cancer are to be optimized.

This review will describe the recent research that has identified the needs of people with cancer, and will begin with research that has explored the impact of having cancer upon the individual's quality of life. This review utilized PsychINFO and Medline literature search databases to locate current papers and explore recent trends in research of direct relevance to the needs of cancer patients. Search terms employed began with the use of general descriptors ("needs"; "cancer patients") and later were specified more exactly by domain of need ("emotional needs"; "support needs"; "social needs"; "practical needs"; "psychological needs"; "existential needs"; "spiritual needs"; "assessment of needs of cancer patients"). Use of the two databases for the twenty year period 1985-Current generated a total of 722 papers. From this original list papers were selected on the basis of relevance and 79 papers were finally employed.

Quality of Life

Quality of life is defined by the World Health Organization (Szabo, 1996) as an individuals' view of their life position in relation to specific goals, expectations and values. It has been suggested (Cella, 1992) that such a broad overall definition is necessary due to the subjective and multi-dimensional nature of quality of life and in a recent review (Graves, 2003) of the quality of life literature identified a range of definitions containing numerous domains including physical health, psychological health, social relationships, level of independence, spirituality and relationship to the environment.

In a study of the quality of life among long-term survivors of breast cancer (Dow, Ferrell, Leigh, Ly and Gulasekarem, 1996) it was found that fatigue, pain and sleep problems, often considered as indicators for decreased quality of life, persisted long after treatment had ended. The participants of this study were 294 survivors of breast cancer with ages in the range 27 – 77 years (mean 50.9). Long-standing psychological distress following diagnosis and treatment and fears about a recurrence of the illness were also in evidence. Family distress, the burden of caring and issues of sexuality were also identified as the most significant concerns in the social domain of quality of life. While people surviving with breast cancer expressed a constant fear of future uncertainty related to fears of recurrence of the illness, they also simultaneously expressed having enhanced quality of life in respect of having a life-purpose and hopefulness. These latter aspects of quality of life were positioned within a spiritual well-being sub-scale of the instrument devised to act as a dependant variable for this study. This finding led the author to highlight the need for the inclusion of measures of spiritual well-being in future studies of the quality of life among people with, or surviving, cancer.

Some studies have shown a consistent trend toward links between adequate access to social support networks for women with breast cancer and their psychosocial adjustment following diagnosis (For a review see, Irvine, Brown, Crooks, Roberts and Browne, 1991) More recently a randomized trial of a psycho-social intervention that provided women with social support, showed that women receiving such support had increased survival times when compared to control participants receiving only standard care (Spiegel, Bloom, Kraemer and Gottheil, 1994). The 86 participants were all women with metastatic breast cancer. They were divided into a treatment

group (n=50) and a control group (n=36). While both groups were provided with routine oncological care, the treatment group were also provided with weekly supportive group therapy for one year. At ten year follow up only three of the participants were alive but data from records showed that the survival times (from onset of the intervention) was significantly greater for members of the treatment group. The members of this group survived for a mean of 36.6 months (S.d.= 37.6 months) while the mean survival time for members of the control group was 18.9 months (S.d.= 10.9 months). Such a finding suggests the importance of psycho-social factors for disease related biological mechanisms. Another similar study of 128 newly diagnosed women with breast cancer found no association between the provision of social support and the survival time or time to recurrence of the illness (Cassileth, Lusk, Walsh and Doyle, 1989), although social support was beneficial to other important outcomes such as the development of co-morbid psychopathology, measured using the Brief Symptom Inventory (BSI; Derogatis, 1992). For example, a prospective and naturalistic study of 708 women with breast cancer it was found that at a four year follow-up, that those with good social integration prior to diagnosis, maintained higher levels of quality of life. Further, this study also found that access to social networks accounted for more of the variance in measures of quality of life than both tumor or treatment type (Michael, Berkman, Colditz, Holmes and Kawachi, 2002). This is a very important finding as it suggests a crucial role for psycho-social factors that outweigh clinical and treatment variables.

These papers were included in a recent meta-analysis (Graves, 2003) reviewed the impact of psychosocial interventions upon measures of quality of life. This review divided quality of life into a *physical health domain*, including subjective ratings of

pain and fatigue as well as objective measures of physicians reports of swelling and immune system functioning; an *affective domain*, including anxiety, depression and coping; a *social domain*, including perceived social support, marital satisfaction, communication and sexual activity, and; a *functional domain* that included perception of the domestic environment, hours at work per week, leisure activities, activities of daily living and financial difficulties. Psychosocial interventions were included in the meta-analysis if they could be divided into types according to the self-efficacy, outcome expectations and self-regulation facets of Social Cognitive Theory (SCT: Bandura, 1986; Maddux, 1995).

Interventions including self-efficacy facets of SCT are those that included instruction for coping with cancer by providing information about the individual's illness and treatment, assessment of affective reactions and providing feedback on the use of positive coping strategies, including the identification of negative, unrealistic thoughts and successful cognitive restructuring. Those incorporating outcome expectation elements are identified as those that included teaching patients to recognize and restructure unrealistically negative and pessimistic expectations of their illness and their future. Interventions employing self-regulation components of SCT are described as those that aided people with cancer to plan, monitor and change their coping behaviour to correspond more faithfully with their abilities, environment and desired outcomes, thus enhancing adaptive forms of coping.

It was found that the inclusion of SCT based intervention components had strong positive effects upon measures of global affect, depression, social domain measures and objective physical measures. However, SCT based components were not found to

be related to improvement in anxiety, coping, subjective physical or functional domain measures. It is also worth noting that and individual's existential issues were not addressed by this meta-analysis. Further, while some of the studies included in the meta-analysis had included discussion of spiritual issues as a treatment component they were not considered further in the meta-analysis, as these components did not have the feedback element required for their inclusion in an SCT based intervention program.

Positive Changes in Quality of Life With Cancer

A recent addition to the literature, examining the effects of living with cancer, have stressed the positive changes in outlook that some people experience. Linley and Joseph (2004) reviewed 39 empirical studies and examined the concept of 'adversarial growth'. The authors describe this concept as including personal growth following a diagnosis of cancer, personal changes that are viewed as beneficial and thriving within the context of a cancerous illness. Their review showed that it has been commonly found that people with cancer report positive changes as a result of their illness. Perceived gains included an enhanced appreciation of life and a re-ordering of priorities, greater self-confidence, a more spiritual outlook on life, a greater acceptance of how things work out in life and an increase in motivation and ability to relate to others. 'Benefit finding' has been consistently associated with significantly reduced levels of emotional distress. In a study of 230 breast cancer patients, beginning participation one year after surgery, it was found that that people (n=96) who can find benefits early in their cancer illness, display significantly less distress at four and seven year follow up (Carver and Antoni, 2004). More of the initially

collected data (from Carver and Antoni, 2004) has recently been published and has shown that 'benefit finding' was found to be significantly associated with trait optimism, positive re-framing and religious activity as coping mechanisms. This suggests the possibility that people who find benefits in their cancer may have individual personality differences to those who find no benefit (Urcuyo, Boyers, Carver and Antoni, 2005).

It is clear from the research that the quality of life and overall (medical and non-medical) prognosis of people with cancer, is significantly affected by a variety of psycho-social variables. It therefore seems reasonable to suggest that the assessment of a persons needs, following a diagnosis of cancer, is essential to the complete and effective treatment of people with cancer.

Assessment of Cancer Patients Needs

Early attempts to assess patient needs assumed that care providers possessed sufficient knowledge of patients needs based on awareness of professional experience and an interest in improving their standards of care (Merkouris, Yfantopoulis, Lanara and Lemonidou, 1999). However, care needs are not always adequately or correctly identified by health professionals, for example in a study of 15 patients with advanced cancers of mixed type it was found that medical professionals underestimated the personal significance of anxiety when compared to patient accounts (Krishnasamy, 2000).

It is noted (Boberg, Gustafson, Hawkins, Offord, Koch, Wen, Kreutz and Salner, 2003) that more recent studies have recognized the importance of including the patient in research concerning needs identification, as they are the rightful focus of any patient centered approach to care. Such studies have led to a number of wider patient needs being identified, and these shall now be briefly reviewed.

A study on behalf of the National Health Service Executive (McIllmurray, Thomas, Francis, Morris, Soothill and Al-Hamad, 2001) examined the psycho-social needs of 1000 people suffering lymphoma, lung, breast and colorectal cancers. This study defined psycho-social needs as any patient perceived need, beyond the immediate medical interventions employed in their treatment and achieved a final sample of 402 participants (40.2% response rate). The most prevalent needs identified were for finding valued qualities in the health-care professionals and systems including sensitivity, receptivity, honesty, respectfulness, speedy access and involvement in treatment decisions; being able to obtain full information about what to expect from their disease, treatment time-tables, services and additional sources of information; being able to secure good social support from family, friends and health-care professionals, and; help in locating sources of hope for the future. This study found that many of these most prevalent needs were perceived as being adequately met. However, the study also identified some important patient needs that were not being met. The unmet needs were assistance with financial matters and welfare claims; advice about food and diet; help with housework; advice regarding sexual needs, and; help in dealing with the unpredictability of the future and feelings of sadness. Those at greatest risk for having unmet needs were those at a younger age; having a cancer illness that was long-standing; being socio-economically disadvantaged or

experiencing financial difficulty; not having a religious faith; not having the chance to speak freely about cancer, and; having social activities disrupted by their illness. This study led to a number of recommendations in the areas of training and education for clinicians and also expressed the need for greater research efforts that aimed at the identification of cancer patients needs.

Some studies have constructed and employed standardized quantitative instruments to examine the needs of people with cancer, for example one study (Tamburini, Gangeri, Brunelli, Boeri, Borreani, Bosisio, Karmann, Greco, Miccinessi, Murru and Trimigno, 2003) employed the 23 item Needs Evaluation Questionnaire with a sample of 182 people with cancer. It was found that 40% of the sample expressed an unmet need for information about their diagnosis and associated future conditions, a need for increased dialogue with doctors and economic needs.

In a study of the needs of 230 men diagnosed with a localized prostate cancer (Boberg et al, 2003) it was found that medical care delivery needs were most important. While the medical care delivery needs were being adequately met, the need for support was not being met but this was however rated by the patients as the least important of their needs. This study found that information regarding the possible recurrence of their illness and the side effects of their illness and the treatment was the most important unmet need. A number of studies have examined the information needs of people with cancer and these will now be briefly reviewed.

Information Needs

Information has been shown to increase a person's knowledge of oral cancer (Humphris, Duncalf and Holt, 1999), and skin cancer (Sefton, Glazebrook and Garrud and Zaki, 2000). Information, and thus knowledge, about the person's cancer has been shown to reduce distress and anxiety in a sample of 30 women with breast cancer (Michie, Rosebert, Heaversedge, Madden and Parbhoo, 1996). In a sample of 40 women receiving radiotherapy for breast cancer it was found that a group of 20 women receiving greater information at the start of treatment displayed better coping and than a group of equal size (n=20) offered the same information at a later stage of treatment (Harrison-Woermke and Graydon, 1993). Elevated quantities of information have also been shown to reduce 'decisional conflict' around proposed medical interventions for men diagnosed with prostate cancer (Davison, Kirk, Degner and Hassard, 1999) and increase participation in prostate health screening procedures (Myers, Chodak, Wolf, Burgh, McGrory, Marcus, Diehl and Williams, 1999). Such findings have led to recommendations for enhanced information provision being included in National Health Service strategy documents (Department of Health, 2000).

Theoretical models that attempt to describe the information-seeking behaviour of cancer patient's suggest that not all people with cancer will benefit from increased information regarding their illness. According to both the monitoring and blunting hypothesis (Miller, 1992) and the monitoring process model (Miller, Shoda and Hurley, 1996) some people are better able to employ their previously developed strategies for coping with threatening situations, by actively distracting themselves

from threat related information (i.e. 'blunting'). It has been suggested (Ford, Fallowfield and Lewis, 1996) that when attempting to assess the information needs of people with cancer, their individual information-seeking style must be considered as 'blunters' are less likely to desire information than 'monitors' and are likely to be distressed by unwanted or excessive information. The ultimate implication of this research focused debate, is that the persons individual coping style must be considered when attempting to assess their needs. However, it is pointed out (Rees, Sheard and Echlin, 2003) that the relationship between these two variables has received scant attention in research of the information needs of cancer patients.

It has also been found (Deridarian, 1987) in a study of men at different stages of treatment for testicular cancer (localized versus metastatic) that men with the more serious metastases described less desire for information. Such a finding implies that stage and site of treatment will also affect the informational needs of the person with cancer.

The quality of life and the needs assessment research, reviewed above, indicates a variety of needs across multiple personal domains and the importance of accurately identifying these. It has been stressed by a number of authors that a holistic assessment of need must take place if clinical practitioners are able to appreciate the context in which such needs arise (Gustafson, Arora, Nelson and Boberg, 2001; Bonevski, Sanson-Fisher, Girgis, Burton, Cook and Boyes, 2000; Huyse, Lyons, Stiefel, Slaets, de Jonge, Fink, Gans, Guex, Herzog, Lobo, Smith and Strack van Schijndel, 1999). Global indicators such as the person's quality of life can be affected by all of the met and unmet needs experienced by the individual. It could be

suggested that some of the most serious signs of unmet need, will be evidenced when an individual experiences deficits in quality of life expressed as serious distress or an emotional disorder. The distress and mental health issues for people with cancer will now be reviewed.

Distress and the Mental Health Needs of People with Cancer

It should perhaps be no surprise that many people with cancer experience considerable distress. Some have stressed the importance of delineating distress so that it is not confused with belonging to the same dimension, and reflecting the relative absence of, a positive quality of life (Carlson and Bultz, 2003). Emotional distress has been defined as “a multi-determined unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation and spiritual crisis” (National Comprehensive Cancer Network, 2002. pg.1).

Recent reviews show that research has consistently revealed a high prevalence of co-morbid mental health problems for people with cancer and have concluded that the most commonly reported point prevalence of major depression amongst people with cancer is 20-25% (Sellick and Crooks, 1999; Massie and Popkin, 1998; Noyes, Holt and Massie, 1998). These reviews also provide evidence that prevalence rates are higher when participants also report raised levels of physical disability, advanced

illness and pain (Sellick and Crooks, 1999). In a similar review the same factors have been found to increase the rates of suicidal ideation in samples of people with cancer (Filiberti and Ripamonti, 2002). However, as in all studies employing cross-sectional data collection methods, it is difficult to know the extent to which links between illness and distress are associative or causal. Further, it is impossible to know in which direction any possible causality might flow. Adjustment disorder, defined as the emergence of reductions in social and occupational domains of behavioural functioning and accompanied by emotional distress, in response to an identifiable stressor, is also very common. From their review it was suggested that between 2.5 and 30% of people with cancer could have reached Diagnostic and Statistical Manual, fourth edition (DSM-IV: American Psychiatric Association, 1994) criteria for diagnosis (Sellick and Crooks, 1999). A recent study that screened three thousand people receiving treatment for a wide range of cancers using the Brief Symptom Inventory (BSI: Derogatis, 1992), found that 37% met criteria for significant distress.

Factors Influencing Distress

One study (Zabora, Blanchard, Smith, Roberts, Glajchen, Sharp, BrintzenhofeSzoc, Lecher, Carr, Best-Castner, Smith, Dozier-Hall, Polinsky and Hedlund, 1997) employed the Symptom Checklist-90-Revised (SCL-90-R: Derogatis, 1994) and identified significant levels of anxious and depressive psychological distress in 35% of 386 participants with cancer. Higher levels of distress were found for those participants in the terminal phase of their illness. Such a finding suggests that the person with cancer may be more likely to experience distress as their illness

progresses and, more significantly, to the point at which no further treatment is available or possible.

Distress can also be partly determined by the site of their cancer. For example, in a study of 4496 people with cancer, Zabora, BrintzenhofeSzoc, Curbow, Hooker and Piantadosi, (2001) found that the highest rates of distress were reported by those with cancers of the lung (43.4%) followed by brain, Hodgkin's disease, pancreas, lymphoma, liver, head and neck, breast, leukemia, melanoma, colon, prostate and finally, gynaecological (29.6%).

Age at time of treatment has also been shown to affect the level of distress. In a study of distress rates amongst women with breast cancer (Wenzel, Fairclough, Brady, Cella, Garrett, Kluhsman, Crane and Marcus, 1999) it was found that significantly higher rates of distress were expressed by women who were younger and premenopausal following cancer treatment. This finding suggests that distress is positively associated with the magnitude of perceived personal losses and future potentialities associated with cancer at younger ages.

It is interesting to observe that this research literature is characterized by a division between that which has explored the potentially wide range of needs, of people with cancer, and that, which has focused upon one particular need. In those studies that have explored a single need domain, those of information and distress related needs predominate.

This review has included a number of studies that highlight the links between having a cancerous illness and subsequently suffering psychological distress. It has been suggested (Brennan, 2004) that the traditional role of the psycho-oncologist has tended toward the assessment and treatment of co-morbid psychopathology in a way that treats both conditions as separable and discrete problems. Based upon his clinical practice and research Brennan (2001) has offered the Socio-Cognitive Transition (SCT) model for understanding the variations that people display in their ability to adjust to living with cancer. The SCT model suggests that it is differences in the way that different people allow themselves to be supported, the support that they receive and who this support is provided by that accounts for variations in adjustment. In turn, support related factors are influenced by characteristics of the individuals providing care, including their backgrounds and attitudes. Brennan suggests a way of approaching the clinical support of people with cancer that he recognizes as a break with traditional psycho-oncological delivery. He suggests (2004) that cancer-care should be holistic and that the psychological distress can and should be addressed by all healthcare professionals. It is suggested that this paradigm shift is best facilitated by refocusing clinical practice upon the 'lived experience' of people with cancer. Brennans' recommendations echo many of the research findings described above and in particular those that emphasise the need for holistic approaches to the assessment of cancer patient needs.

Given the far reaching and highly personal impact of a diagnosis of cancer, the potentially life-threatening consequences and the implied importance of loss of assumed future orientations, established goals, the meaning and purpose thereby derived and the central importance of hope, it is highly surprising that few studies

explicitly consider existential and spiritual well being. While several of the studies of links between cancer illnesses and distress, quality of life and patient needs *do* cite spirituality and existential need as an important element for consideration, very few actually explore this domain of need directly. The literature that describes a more focused exploration of these needs of people with cancer will now be reviewed.

The Existential Needs of People with Cancer

The importance of the individual's ability to discover a satisfying meaning and purpose in life has always been a central tenet of major existential theory (e.g Camus, 1942; Sartre, 1953) and more latterly major psychological theory (e.g. Antonovsky, 1987; Maddi, 1973; Frankl, 1952; 1963; 1978; Jung, 1933; 1940). Beck, (1967) considered hopelessness, the affective quality associated with cognitions about the futility of future action and powerlessness, to be at the heart of the depressed person's experience.

It has been suggested that positive aspects of existential psychological well-being are crucial in areas such as mental health prognosis (Reker, Peacock and Wong, 1987), psychotherapeutic outcome (Debats, 1996), coping style and suicidal ideation (Edwards and Holden, 2001) and quality of life in the presence of chronic pain (Germano, Misjon and Cummins, 2001). However, some have argued that in many such studies, existential well-being has been measured using short term measures of affect such as current mood or level of happiness (Ryff, 1989) and that these are insufficient measures of thoughts and feelings that extend into a person's perceived future.

It has previously been noted, above, that for an individual receiving a diagnosis of and undergoing treatment for cancer will most likely experience existential issues as a very real and pressing concern.

Illustrating this point, a recent case study (Penson, Yusuf, Chabner, Lafrancesca, McElhinny, Axelrad and Lynch, 2001) described the experience of a man diagnosed with Hodgkin's disease and the loss of existential meaning and purpose that he suffered. For this individual this crisis took the form of his feeling that he had 'lost God'. Both secular and religious members of the team involved in his care were able to help him regain his spiritual connection by first acknowledging his anger at God and his fear of death. This case study also highlighted the use of compassion, as a clinical skill, that aided this man to work through his existential crisis and re-establish a more satisfactory existential well-being.

It has also been suggested (Tataryn and Chochinov, 2002) that a person's will-to-live is a crucial existential factor affected by the diagnosis and treatment of cancer. A study of 168 people (51% male) in the age range of 31-89 years, referred for palliative care, employed visual analogue scales to measure will-to-live. It was found that those with the strongest will-to-live expressed less anxiety and tended to be more religious than those with a lower will-to-live. This study also showed that a reduced meaning and purpose in life reduced a person's willingness to participate in, or adhere to, interventions for cancer.

Existential issues are likely to be experienced by the person facing a diagnosis and treatment for cancer. The limited number of studies examining the presence and impact of such issues suggest that they are crucial for the psychological and physical well-being of the person facing cancer. Without exception, authors examining existential issues as an aspect of psycho-oncology comment on the paucity of research and call for more to be conducted.

Traditionally, existential issues, within and without the field of oncology have been the domain of religion and spirituality. Within the field of oncology the hospital chaplain has been the central point of contact for the patient when existential issues arise. In this respect, the links between spirituality, religiosity and existential well-being are tacitly assumed. The spiritual needs of the person facing cancer are then an important consideration and the research that has examined this relationship will now be reviewed.

The Spiritual Needs of People with Cancer

Spirituality and religiosity have often been employed as interchangeable terms. However, more recently religiosity has been divided into the three dimensions of Intrinsic Religiosity (e.g. faith in a God and an afterlife); Extrinsic Religiosity (e.g. church attendance) and Quest Religiosity (a more open questioning position and a desire to live by religious values) (Maltby and Lewis, 1996).

Spirituality has recently been divided into the dimensions of: Cognitive Orientation Towards Spirituality; Experiential/ Phenomenological Dimension of Spirituality;

Existential Well-Being; Paranormal Beliefs, and; Religiousness (MacDonald, 2000). While these definitions of religiosity and spirituality clearly overlap the latter is broad enough to encompass the former. It has been suggested that in contemporary western culture, where traditional forms of religiosity are in decline, such a definition of spirituality has much greater utility for the purposes of health related research (Bussing, Ostermann and Matthiessen, 2005).

Some of the limited research in this field has concentrated on the personal benefits of spirituality in coping with the terminal stages of living with cancer. In a qualitative study of 28 patients with a variety of cancers and their caregivers, seven categories of spiritual needs were identified as present in patients. These were the needs to relate to an Ultimate Other, have hope and gratitude, give and receive love, review beliefs, have meaning, and have needs met related to religiosity and preparation for death (Taylor, 2003). However, other research has highlighted the significant role that spirituality can play in enhancing coping with disease. Cotton, Levine, Fitzpatrick, Dold and Targ (1999) have shown that spiritual well-being is positively associated with quality of life, fighting spirit, and reduces feelings of hopelessness, anxious preoccupation and cognitive avoidance of cancer related information. A recent review (Seeman, Dubin and Seeman, 2003) has also highlighted positive associations between a person's Christian faith and a range of physiological mechanisms that are crucial in fighting disease and maintaining health. A recent review (Koenig, Larson and Larson, 2001) offers support to the suggestion that spirituality is often employed by the individual to help retain a sense of control, hope and their sense of a meaning and purpose for their life. Reductions in perceived control, hope, personal meaning and purpose are strongly implicated in the etiology of hopelessness. It has also been

suggested that spirituality serves the role of *meaning-making* through providing a connection with life that allows the individual to deal with the demands, challenges and losses associated with diagnosis of, and treatment for cancer (McGrath, 2002).

It could be suggested that spiritual perspectives are only as important for consideration in the field of psycho-oncology as in any other domain of life and health. However, some research examining the coping styles of individuals experiencing chronic pain suggests that those with cancer, as opposed to other chronic illnesses are more likely to employ spirituality for coping with their illness (Dom, 1999).

Psychotherapeutic interventions that focus upon existential well-being have been found to provide reductions in ratings of perceived pain, anxiety and depression (Greenstein and Breibart, 2000; Breibart, Gibson, Poppito and Berg, 2004). However, these authors concede that their suggestions are largely theoretical due to the paucity of empirical data. Given the potential for cancer services to provide services offering effective amelioration of existentially based problems, which have such wide ranging significance and impact, it appears essential that any assessment of the needs of the person with cancer, should incorporate assessment of existential need.

Spiritual perspectives, broadly defined for their use in increasingly secularized societies, appear to be readily employed by the individual for coping with the existential challenges resulting from the cancer journey. While not every person with cancer will require or adopt a spiritual perspective, it is essential that those who employ such, are facilitated wherever possible. It has been suggested that oncology

nurses, at the front line of treatment should be particularly aware of the person's potential need for spirituality (Taylor, 2003; Musgrave and McFarlane, 2003).

Conclusions

The needs of people with cancer are medical, psycho-social, psychological, existential and spiritual. Assessment of the needs of people with cancer has developed from research examining the impact of different elements of their experience upon their quality of life and more recently has directly focused upon the range of potential needs each person may have. This range of needs may comprise those for specific qualities to their interaction with medical staff, information about diagnosis, prognosis, effects (and side effects) of treatment, support with disablement resulting from disease, help in facing existential challenges and facilitation in methods employed in approaching such challenges. Existential challenges have been shown to affect physical health, psychological health and ability to cope with the treatments offered. Spirituality has been shown to be commonly and powerfully employed by the person with cancer for approaching the existential challenges they commonly face. Therefore, the assessment of these aspects of the person must be incorporated into any holistic assessment of the persons' needs.

Word Count 5509

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References word count = 1892

Appendix: Note on the exclusivity of papers included in the review

Throughout the review paper all review papers included are identified as such in the main body of the text. Where the discussion has subsequently reviewed a paper or papers that have been included in a previously cited review paper, this is also clearly indicated in the main body of the text.

A Qualitative Examination of the Existential and Spiritual Needs of People with Cancer

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Abstract

Objectives: The larger CancerCAN study (see Zinovieff, Morrison, Coles and Cartmel, 2005) identified the needs of people with cancer and has developed a tool for inclusion in a quantitative assessment of cancer patients' needs'. The present study explored possible existential and spiritual needs in the lives of people with cancer.

Design: Focus groups were held and discussions of the participant's experience of having and being treated for cancer were facilitated.

Methods: A total of 9 participants were recruited via a regional cancer treatment centre and attended the three focus groups.

Results: A content analysis identified a wide range of psychosocial needs. An Interpretative Phenomenological Analysis (IPA) identified a master theme labeled as 'positive coping as a priority in dealing with adversity'. Existential and spiritual sub-themes were identified and labeled as 1: the possession of faith; 2: meaning and purpose from cancer; 3: changes in perspective as a result of experiencing cancer; 4: anxieties about the future, and; 5: issues of control.

Conclusions: Existential and spiritual aspects of the person were identified as personally significant for people with cancer. Existential and spiritual well-being are areas of potential need that require inclusion in holistic assessment of cancer patients' needs'.

Abstract Word Count = 198

People with cancer have their quality of life affected by factors across a variety of psychosocial domains additional to their immediate physical illness and medical interventions employed in their treatment. A recent emphasis on identifying the self-perceived needs of this population have consistently located needs in terms of information concerning the individual's diagnosis, course of treatment and what to expect from their disease (e.g. Michie, Rosebert, Heaversedge, Madden and Parbhoo, 1996) support from family, friends and medical professionals (McIllmurray, Thomas, Francis, Morris, Soothill and Al-Hamad, 2001), and help for coping with the distress that often accompanies diagnosis and treatment for cancer (Carlson and Bultz, 2003).

Given the personal impact and potentially life threatening consequences of cancer and the significance of personal losses in life areas such as an assumed future, the goals that are positioned there and the meaning and purpose that are subsequently derived from them, it is likely that existential issues comprise a significant part of the individual's distress. It is therefore surprising that potential needs within these aspects of the person's existence have not routinely or directly been explored.

Existential and spiritual aspects of a person's quality of life have begun to receive attention and results suggest that they have important roles in mediating the person's adjustment to their illness (Penson, Yusuf, Chabner, Lafrancesca, McElhinny, Axelrad and Lynch, 2001), adherence to treatment (Breitbart, Gibson, Poppito and Berg, 2004) and distress (Tataryn and Chochinov, 2002).

It has also been shown that those people who adjusted most positively to having cancer tend to be those who found benefits in having experienced cancer and

survived. The benefits described have included an enhanced appreciation of life, a greater acceptance of what happens in life and increased motivation to relate to others (for a review see; Linley & Joseph, 2004). In a recent study of long-term survivors of breast cancer (Urcuyo, Boyers, Carver & Antoni, 2005) it was found that those most likely to find these benefits were high in trait optimism, engaged in positive cognitive re-framing of their experience and engaged in religious activity. The well-being of people with cancer in existential and spiritual domains of their life is beginning to be shown as likely serving a crucial role for a significant number of people coping with cancer.

Previous calls for an holistic assessment of the needs of people with cancer (Bonevski, Sanson-Fisher, Girgis, Burton, Cook and Boyes, 2000; Gustafson, Arora, Nelson and Boberg, 2001) further support the inclusion of assessment for a persons' needs' with respect to existential and spiritual aspects of their lives. This information about the person with cancer is important throughout oncology services and has been suggested to be particularly so for oncology nurses at the front line of treatment (Taylor, 2003; Musgrave & McFarlane, 2003) who have the highest rates of contact with the patient.

A recent research initiative identified the needs of people with cancer and developed a new needs assessment tool to be included in a quantitative assessment of cancer patients' needs' (see Zinovieff, Morrison, Coles and Cartmel, 2005).

The present study, which was facilitated and hosted by this larger (CancerCAN) project, set out to explore the existential and spiritual needs of a small sample of

people with cancer and place these within the context of other domains of needs that can be drawn from the literature including need for practical support, information needs, social support and emotional support.

Method

Recruitment: Individuals receiving treatment at a regional Cancer Treatment Centre were approached by one member of the research team (FZ) and offered the opportunity to participate in the first (questionnaire survey) stage of the CancerCAN project. Of the 147 people who took part, in the survey, 56 people offered to participate in later stages of the research. These 56 people were approached in writing and provided with information about participation in focus group discussions. Upon obtaining informed consent, a total of 9 people were invited to attend one of three focus groups and self-selected which group to attend on the basis of their availability. In the following descriptions of members of each group names have been substituted to maintain participant's confidentiality.

The Participants

Group 1 was attended by Karen, Brenda, Inga and Angela. Karen was a 50 year old married woman with a son who had left home. She was diagnosed with breast cancer two years prior to her participation. She had been treated with surgery and chemotherapy and was currently in remission.

Brenda was a 68 year old woman who lived with a partner and had no children. She had been diagnosed with breast and secondary ovarian cancer 9 months prior to her participation and was receiving check-ups but was not aware of plans for further treatment at that time.

Inga was a 54 year old woman who lived with her partner and had no children. She had been diagnosed with a malignant ovarian cyst 30 months prior to her participation for which she had been successfully treated. She was currently attending check ups but was not undergoing any treatment at that time.

Angela was a 63 year old single woman with no children. She had been diagnosed with breast cancer 42 months prior to her participation and had been successfully treated with surgery, chemotherapy and radiotherapy. She was also attending for check ups only.

Group 2 was attended by Simon, Fred and Paul. Simon was a 43 year old man who lived with his partner and her children. He had been diagnosed with Hodgkin's lymphoma 2 years prior to his participation. He had been successfully treated with chemotherapy and although he was in remission at the time, it had been suggested to him that he might require radiotherapy in the future.

Fred was 53 year old married man with no children. He had been diagnosed with mantel cell non-Hodgkin's lymphoma 26 months prior to his participation and had received 6 chemotherapy treatments and a stem-cell transplant. He was due to receive a further stem-cell transplant.

Paul was a 49 year old married man whose children also lived at home. He had been diagnosed with non-Hodgkin's lymphoma 30 months prior to his participation and had received chemotherapy and a stem-cell transplant. He was currently attending for check-ups only.

Group 3 was attended by Ellen and Antonia. Ellen was a 32 year old married woman with no children. She had been diagnosed with breast cancer 22 months prior to her participation and had been successfully treated with surgery, chemotherapy and radiotherapy. She was attending check-ups and was not aware of the need for future treatments at that time.

Antonia was a 63 year old married woman with no children. She had received a diagnosis of breast cancer in 1980 and had more recently been treated for secondary ovarian cancer. In total she had received 7 surgical interventions, radiotherapy and chemotherapy. She was currently attending for check-ups.

Conducting the Focus Groups

The focus group took place in a seminar room at a local cancer treatment centre where all of the participants had received their individual treatments. A nurse showed each participant to the room upon arrival. The researchers (PP and FZ) greeted each participant and offered refreshments. When all participants had arrived, the group was introduced and subsequently facilitated by one of the researchers (PP). The general focus of the discussion was described as within the area of the needs of cancer patients. It was also pointed out how valuable each of their experiences was, to us, for the purposes of the research. The facilitator then described how the discussion

would explore the many different needs that might arise for the participants, explained the need for tape recording and also that any participant could ask for information given to be removed from the recordings at any time. The discussion was tape recorded from this point. The facilitator asked the group to introduce themselves using a name they would be happy to use for the discussion and then tell a little of their cancer journey. This part of the discussion provided the valuable participant information presented above. Following this introduction the facilitator employed general prompts to move through the areas of practical, social, informational, emotional, existential and spiritual needs (a copy of the focus group protocol and the prompts employed is available from the first author upon request).

The typical prompt employed for the purposes of eliciting discussion of existential and spiritual issues was; “of an interest to increasing numbers of people involved in providing care for people with cancer, and a personal interest of mine, are those big questions about meaning and purpose in life and the big questions of ‘what is my place in the universe?’ Did anyone experience asking those big questions? Did anyone have any needs in that kind of area? If so, how did you deal with those needs?”

Qualitative Analysis

The tape-recorded focus group discussions were transcribed verbatim. The transcripts were then analysed using Interpretative Phenomenological Analysis (IPA: Smith, 1996; 1999; 2004). This method has at its centre the features recommended for ensuring the validity and credibility of a qualitative analysis (Elliot, Fischer and Rennie, 1999). Each transcript was read and an initial coding for each interpretable

utterance was written in the margin. Following the coding phase the codes were grouped according to the emergence of interpretable themes that allowed a coherent sense to be made of the codes. Once a theme had been identified and named, evidence for this theme was sought across the data generated by all three focus groups. Successive iterations of this process led to the identification of a series of themes that made best sense of the data under examination. Central to the conception and practice of IPA is the inclusion of the researchers' preconceptions', initial understanding and any hypotheses that explicitly or implicitly employed in approaching the analysis. These are considered essential to the process of interpretation and it is recommended (Smith, 1996) that, as far as possible, a statement of these should comprise the initial phase of the analytic process. A statement of the researchers personal position will thus comprise the first part of the results of the analysis described in this paper, below.

Following the facilitator's (PP) analysis, a second researcher (FZ) independently coded 2 of the focus group transcripts. The second researcher was then supplied with the interpretative themes identified by the original analysis (PP) and on the basis of her own coding was able to confirm the existence and coherence of these themes within the transcripts of the focus group discussions.

While the foci of the present study were the existential and spiritual issues being explored, a content analysis of other needs expressed by the participants was also conducted. This analysis generated a simple frequency count of the needs experienced in the areas of practical, social, informational and emotional needs. This

analysis allowed the subsequent existential and spiritual issues to be described within the holistic context of other needs.

Results

The Researchers Perspective (PP): The transcriptions were coded and analyzed thematically by the first author (PP) who has no personal experience of cancer either first hand or amongst family members. The author has a broadly spiritual perspective on the process of living, but this is not formalized in any way and certainly stops short of having a religious faith. A long-standing interest in the relationship between existential issues, psychological distress and the role of spirituality had led to two previous studies of these links. These prior studies had not however examined this relationship in connection with the needs of people with cancer.

Psycho-social Needs: Prior to the exploration of existential and spiritual needs, a content analysis was conducted to examine the wider needs of people with cancer. The results of this analysis allow the exploration of existential and spiritual needs to be viewed in a holistic context. The transcripts were coded according to statements of need (that had reportedly been met or otherwise). In part due to the small numbers of participants the constellation of needs described were highly individual. This made categorization into domains of need (e.g. practical, informational and support needs) a strategy borne of practical necessity. The observed individuality of the expressed needs is an important feature and indicates the

need for those assessing needs to tailor psycho-social interventions, wherever possible around the individual. Table 1, below, describes the needs expressed by participants of the focus groups, and do not include those of an existential and spiritual character and these are explored in greater detail later.

- Insert Table 1. About Here -

Existential and Spiritual Needs: The IPA was informed primarily by the theories of Viktor Frankl (1952; 1963; 1978) and data were approached from this existential perspective. A (super-ordinate) master-theme emerged, upon which other sub-themes appeared largely dependent. This was given the interpretative label of 'positive coping as a priority in dealing with adversity'. This super-ordinate theme can be distilled from, and also appears to link each of the five sub-themes. It is characterized by the high motivation expressed by some members of the focus groups to cope as well as possible and find benefits to their adverse change in life circumstances brought about by cancer. Angela says, "I was prepared to face it like I would do with any situation that comes before me" and later goes on to say "it is your determination and it is mind over matter and trying to make the best of it that helps you carry on isn't it. Keep going!" Ellen agreed and described how she felt that she must "just get on with things really".

Brenda perceived luck in one cancer related situation and said, "I was very fortunate that the general surgeon was on holiday and there was a locum from Christie's who was the best man". Brenda also described benefits as a result of having had cancer and specifically stated that she enjoyed socializing more after she had been treated for

her cancer and says “It gives confidence as well strangely enough”. Karen agreed and said that “at one time I would never go anywhere by myself and now you know I go to aqua-aerobics by myself, that has given me more confidence”.

Paul described encouraging his own sense of mission and struggle and how he had “immersed himself in kind of survival story books like Lance Armstrong which every cancer patient I think reads, and how he had a ten per-cent survival or something and now he has won the Tour de France several times. And his second book every second counts and all sorts of expedition books to the Antarctic and all stuff like that. And I found that very motivational”. Paul also described having found a new lease of life and that “my whole life has changed thanks to cancer”.

This master-theme echoed throughout each of the sub-themes identified. These sub-themes were 1: the possession of faith; 2: meaning and purpose from cancer; 3: changes in perspective as a result of experiencing cancer; 4: future anxieties, and; 5: issues of control.

Theme 1: The Possession of Faith: The prompt offered during the focus group to provoke discussion of any potentially existential issues, most immediately generated discussion of spirituality. In all three groups people very quickly stated whether they had an existing faith. Paul, Antonia and Angela described a religious faith that pre-dated their diagnosis. Angela described that for her “coming into a situation that is difficult to face, your faith and your belief in God helps you”. Fred described discovering faith and stated that “I had no idea what faith was until I got cancer”. Similarly, Inga described, “wishing to speak with a minister” soon after

diagnosis. Brenda described, “not having a religious faith” but believed “in a supreme being that looks after us all”. Similarly, Ellen described “having a faith in a particular way, but not like in a religious way”.

In their respective groups Karen, and Simon described not having a spiritual or religious perspective. In response to this issue, Karen described herself as “being a very practical person, “I just don’t have any truck for all of that”. Simon responded by stating that he had “got my support from my very, very close family”.

The issue of spirituality/ religiosity was immediately provoked, in the context of potential existential need, and suggests that for many of the participants a pre-existing spiritual or religious perspective served an important function for them. For two of the sample the experience of having cancer quickly led to a *new* consideration of spirituality. Three of the participants described benefiting from their contact with inpatient pastoral services.

Faith also appeared to have a wider meaning for many, and was something that they transferred to the medical teams and consultants involved in their care. Fred described his faith as “faith in myself that I had my own faith in everybody around me who has tried to help me get better”. Conversely, Karen who described herself “as a very practical person” and not having employed faith, also appeared to feel the loss of control more keenly and viewed cancer as “one of the few things that you have got absolutely no control over”. Brenda also mentioned the lack of control and described, the “lack of control...you are in other peoples hands aren’t you”. One possible interpretation of this is that having faith, whether this is invested in a religious figure

or medical staff, is a constructive way of actively relinquishing control. This active relinquishing may result in the attenuation of anxieties associated with the individual feeling that they have lost personal control, or that it has been taken from them.

Theme 2: Meaning and Purpose From Cancer: Fred described a series of detailed projects aimed at inventing products that would facilitate the care of cancer patients. At the invitation of medical staff he had given presentations to nurses about quality of cancer care. He also described having a personal “mission” to advance human understanding of cancer aetiology. While he was surprised at the invitations to talk to cancer professionals he described having previously felt that he “knew somebody was going to ask me to do something”. Angela described feeling that fate had intervened in such a way that her going into hospital for treatments was timed, so that she was present to help other people attending at the same time. She described her interaction with a distressed patient and that “after we had had a talk she was fine and I thought, well this was my reason for coming in now”. Paul described praying with a pastor in his hospital room and feeling great emotion when the pastor asked God to help “as we need Paul back in the community to help with this (charity) work”. These participants all described deriving their purpose from the fact they were fighting cancer. In the case of Paul the pastor appears to have facilitated drawing upon his greater purpose (beyond his fighting cancer) and placing it in his more immediate context. Paul also described getting a great deal of inspiration from reading about “adventurers and stories of survival”. For Fred, he derived a great motivation and formally presented his experiences and invented treatment related aides. Angela attributed a meaning and purpose to her inpatient treatment via her helping others. For these participants the meaning and purpose derived from their

cancer experience, appeared closely linked with their spiritual faith and charitable work.

Other participants described having a practical focus. Simon described “having bleak moments and then thinking, “I can do this””. Karen described, “just focusing on getting through the chemo”. It seems that the participants all derived a personal purpose from their cancer. These personal purposes appeared to be derived from their *fight* against cancer.

Theme 3: Changes in Perspective: Ellen described not having any “spiritual revelations or anything” but she felt that she had “a better balance in my life” following her treatment. Karen described having “a better sense of perspective” and felt she had benefited by this so much that “you could almost describe it as a good thing”. Paul, Fred and Simon agreed that their experience of having cancer had taught them that, “money means nothing” and that the most important things are “your health and your family”. Paul also described how he placed a greater emphasis upon the quality of present life and “not needing to go into the office every day”. In a similar vein Ellen, Angela and Brenda described taking more holidays and spending more money for themselves and on family members than they would have done previously, and living more for the moment.

Many of the participants expressed a similar change in perspective, whereby following their experience of cancer, relationships assumed a greater meaning. The temporal context became more present focused and the quality of those proximal moments took on a greater importance. The participants implied that the changes to

their perspective were imposed and that their experience of cancer had “taught” them and “made them realize”. However, the changes in perspective were welcomed. It is possible that not all people adapt to the experience of cancer in this way. While none of the current data provide evidence for the implied dimension, it is easy to envisage individuals for whom shifts in temporal focus and other aspects of their perspective are more difficult to make or are resented. Anxiety and anger directed towards cancer may lead to an avoidance of cancer related topics and may subsequently find adaptation to their life with cancer more distressing. It is possible that those experiencing most distress were less likely to attend focus groups dealing with topics around cancer.

Theme 4: Anxieties about the Future: Fears of death and dying were perhaps surprisingly under reported as an explicitly experienced feeling at any point of the participants’ cancer journeys. Ellen reported that she “was really scared of dying” at the point of diagnosis and Karen reported how references to cancer in the media provoked expression of her worry “that, you know, I am going to die”. Brenda reported the complete absence of fears related directly to death, as “there is absolutely nothing to fear”, similar to Angela who stated that, “I firmly believe you go to a better life”.

Many more of the participants reported fears more directly related to the presence of cancer in their body rather than the ultimate possibility of dying. It appears that the focus of anxieties was the rather more concrete one of the presence of cancer, than the more abstract notions of death, dying and non-existence. Fears of the cancer were

most often reported to have occurred during remission, or during the watching-and-waiting phases, of the participants' cancer journeys'.

Paul described his having "a practical focus of surviving the chemotherapy" and how this stopped him worrying "about all of the emotional issues". The vast majority described their families as having greater concerns about their death than they themselves did.

Ellen, the youngest participant described the most specific fears about the future. These fears centred on whether she would be able to have children following her chemotherapy, dying and leaving her husband after only a short time together.

Those with a spiritual faith had the greatest absence of fears about dying. The future anxieties of the participants were more concerned with the loss of relationships and these fears were described as belonging more to the families than the people with cancer. Faith and the more practical focus of surviving the treatment appeared to be related to the absence of fears around death and future losses.

Theme 5: Issues of Control: A number of participants described issues of control relating to their cancer. Ellen described how she felt that life choices regarding having children were taken away from her, due to infertility that may have resulted from her treatment. She stated that, "I am very in control of my life, the way that I work and everything else, and suddenly I felt that these decisions were being taken away from me". Karen also described how cancer "is not the only big thing that kills people, but is one of the few that you have got absolutely no control over".

Statements such as these indicate that the perceived absence of control caused these participants some distress and contributed to a sense of loss and helplessness. The possible links between themes of control and faith have been discussed above in relation to the latter.

Discussion

The initial content analysis provided a context of psycho-social needs experienced during participant's individual cancer journeys. The identified themes were grouped into five domains that represented an experience of needs in areas of emotional support, information, support for family members and carers, practical and social support and the qualities of staff and treatment systems. These findings support recent research that has identified similar needs for this population (McIllmurray, Thomas, Francis, Morris, Soothill and Al-Hamad, 2001; Michie, Rosebert, Heaversedge, Madden and Parbhoo, 1996; Carlson and Bultz, 2003). Within this holistic context the primary focus of the current paper was the qualitative exploration of existential and spiritual themes that emerged from analysis of focus group data.

A master-theme given the interpretative label of 'positive coping as a priority in dealing with adversity' was identified. This super-ordinate theme has many of the characteristics previously found in those people with cancer who are able to find benefits from their experience of having cancer (for a review see; Linley and Joseph, 2004).

The identification of sub-themes was guided by an awareness of a broadly existential framework. Existential issues of meaning and purpose, control and anxieties about the future, were all identified. Also identified were changes in life perspective that were perceived as beneficial and, an important role for the spiritual and religious perspectives that individuals employed in adapting to the demands of cancer and treatment.

The presence and easy consideration of existential issues, arising with the use of general prompts, indicates the potentially important need for including specific assessment of these aspects of personal need, amongst cancer patients.

Further, psychotherapeutic interventions that focus upon existential aspects of the person's distress have been found to alleviate psychological and physical symptoms associated with their illness including perceived pain, anxiety and depression (Greenstein and Breibart, 2000; Breibart, Gibson, Poppito and Berg, 2004). Given the potential for cancer services to provide services offering effective amelioration of existentially based problems, which have such wide ranging significance and impact, it appears essential that any assessment of the needs of the person with cancer, should incorporate assessment of existential need.

Issues in the existential, spiritual and religious domains, appear to be highly inter-related. Specifically, expressions of faith and how in many cases this was invested in the people providing medical care and personal relationships appeared to have strong links with issues of control. It has been previously suggested that people who adjusted best to having cancer tend to find advantages in their situation that they had

not previously appreciated, and accentuated positive aspects of their lives in creative ways (Affleck and Tennen, 1996; Updegraff and Taylor, 2000). It has also been shown that perceived control is an important feature in allowing people with cancer to maintain the optimism necessary for finding positive aspects of their cancer experience (Collins, Taylor, and Skokan, 1990). The present findings support the previous suggestion that faith, as an aspect of spirituality/ religiosity, may comprise a cognitive strategy for pro-actively relinquishing personal control in a way that allows perceived estimates of control, albeit external, to be enhanced (Koenig, Larson and Larson, 2001).

Group Composition and Data Issues: The participants, both within and across the three focus groups, displayed homogeneity on several dimensions. Firstly, the groups were composed of people who had successfully negotiated between one and four stages of treatment. The majority of the participants were waiting on the results of tests, which would give them the 'all clear'. One male participant (Group 2) was waiting to begin a further stage of treatment. Secondly, all of the men had suffered from a lymphoma and all of the women from breast cancer, with one of the women also suffering a secondary cancer at the site of her womb.

While participants at this stage of treatment were able to draw retrospectively upon their experiences at the time of diagnosis and while undergoing treatment, no data from those in end stage or palliative stages of treatment were available. It has been suggested that existential and spiritual issues become more important for individuals during the palliative stages of cancer (Tataryn and Chochinov, 2002). The absence of participants in this stage may have affected the findings of the study. It also needs to

be acknowledged that a limited number of cancer sites were represented by the focus group participants, and this has also shown to affect the needs expressed by people with cancer in the domains of information (Deridarian, 1987) and distress (Zabora, BrintzenhofeSzoc, Curbow, Hooker and Piantadosi, 2001).

All of the participants were in middle age, or early old age. Ellen was the one member of the sample who was atypically young (31 years) in comparison to the rest of the group. It is therefore the case that the current sample did not fully represent the large diversity of the cancer population. Further, and more importantly, the participants in this study displayed many characteristics associated with people who find benefits in their adverse (cancer) experience and who have been shown to adapt best to the life changes that such experience can bring (Linley and Joseph, 2004). As previously stated this group characteristic is evident in the emergent master-theme of 'positive coping as a priority in dealing with adversity'. It has been suggested that people with cancer displaying these characteristics and an enhanced ability to adapt and cope comprise only a proportion of the population of people with cancer (Urcuyo, Boyers, Carver and Antoni, 2005). It is highly likely that these characteristics comprise the largest source of bias within the current sample. Patients displaying better adjustment through the relative absence of distress and psychopathology tend to display an increased motivation to relate to other people (Linley and Joseph, 2004). Given the degree of self-selection inherent to the recruitment method it is perhaps no surprise that the participants would display homogeneity on this dimension. It might be further suggested that future studies seeking to gain access to participants who are coping less well with their cancer should employ interviews with individuals. Interviews may be easier for those participants who are not coping and feel less

inclined to participate in focus groups, which are an inherently social activity. This group of people with cancer could be identified by their relatively higher amounts of distress, psychopathology and the absence of access to supportive relationships and social networks.

Conclusions

In spite of some sample limitations interesting conclusions can still be drawn from our findings. Existential and spiritual concerns comprise a significant domain of potential need for people with cancer. Although deeply embedded within the daily experience of living with the illness and its treatment, these aspects of people's lives are often expressed in a distinct way. For these reasons it appears important that any assessment of needs incorporates specific items that target potential needs in these psycho-social domains.

Word count (excluding table) = 5178

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References Word Count = 643

Appendix: Table 1.

Table 1. Psycho-social needs expressed by focus group participants (excluding those within existential and spiritual domains).

Domain of Psychosocial Need	Needs Expressed Within Domain
Emotional Support	<p>Counseling to be offered</p> <p>Use of music</p> <p>Speaking with survivors of cancer</p> <p>A non-medical person to speak with openly about feelings</p> <p>Side effects and changes in physical appearance</p>
Information and Advice	<p>About sources of financial support</p> <p>About meeting the cost of prescriptions</p> <p>About balancing working and treatment</p> <p>Honest prognostic information</p> <p>Thorough illness specific information – upon demand</p> <p>Thorough treatment specific information – upon demand</p> <p>Thorough information about side effects and implications for future health</p> <p>Illness and treatment specific information in a written format</p>

Qualities of Staff and Treatment System	Privacy during treatment Staff sensitivity to patients emotional state Clean and cheerful surroundings for treatment Good bedside manner of consultants A single point of contact for enquiries Continuity of staff contacts throughout treatment Availability of contact for longer following treatment
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Table Word Count = 197

Appendix: Note Concerning Data Availability

Raw data could not be included as an appendix to the preceding research paper. This was due to the large size of the transcriptions that would have far exceeded the word limit for LSRP thesis appendices. If examiners require a copy of the raw, transcribed data these are available upon request.

Contributions to Theory, Clinical Practice and Learning

Implications for Future Research and Theory Development

Existential Issues

It has been suggested that positive aspects of existential psychological well-being are crucial in areas such as mental health prognosis (Reker, peacock and Wong, 1987), psychotherapeutic outcome (Debats, 1996), coping style and suicidal ideation (Edwards and Holden, 2001) and quality of life in the presence of chronic pain (Germano, Misajon and Cummins, 2001). It has also been found, in studies more specifically concerned with cancer, that a reduced meaning and purpose in life can reduce a person's willingness to participate in, or adhere to, interventions for cancer (Tataryn and Chochinov, 2002). The current study explored the presence of existential issues amongst a group of people with cancer and found that existential issues could be discerned as a theme emerging from the groups' discussions'. The existential themes identified within the data arose from focus group discussions in response to only general prompts. The discernment of existential themes that appear to have been appropriately considered and spoken about in a way coherent with existential theory (e.g. Frankl, 1952; 1963; 1978) suggests that existential issues are of personal significance for, and can be accessed and verbalised by people with cancer. Given the well recognised paucity of research that has focussed upon this aspect of well-being in people with cancer, this finding can be considered significant. In response to the prompts employed to initiate discussion of the presence of existential issues, many of the participants immediately referred to spiritual

perspectives and whether or not they possessed one. This finding suggests an inherent link between existential and spiritual issues and provides support to previous studies that have also found that a person's spirituality may serve to reduce feelings of hopelessness, feelings of a loss of control and enhance quality of life and having a sense of a meaning and purpose for life (Cotton, Levine, Fitzpatrick, Dold and Targ, 1999; Koenig, Larson and Larson, 2001). These findings will now be examined in greater depth in connection with the present findings concerning spiritual issues.

Spiritual Issues: Definitions

The first theoretical issue that must be noted concerns the definition of spirituality. Spirituality and religiosity have often been employed as interchangeable terms, however, more recently, religiosity has been divided into the three dimensions of Intrinsic Religiosity (e.g. faith in a God and an afterlife); Extrinsic Religiosity (e.g. church attendance) and Quest Religiosity (a more open questioning position and a desire to live by religious values) (Maltby and Lewis, 1996).

Spirituality has recently been divided into the dimensions of: Cognitive Orientation Towards Spirituality; Experiential/ Phenomenological Dimension of Spirituality; Existential Well-Being; Paranormal Beliefs, and; Religiousness (MacDonald, 2000). These different definitions also highlight that while spirituality and religiosity may overlap, they are not the same thing.

The findings of the present study suggest that the broader definition of spirituality was of greater utility during the focus group discussions and also during interpretative

analysis of the transcribed data. The more broadly defined definition allowed more personally relevant perspectives to be included. The finding that spiritual perspectives, whether more narrowly religious or not, appeared to serve the same function as more conventional forms of faith (e.g. Christian) also suggests that for the purposes of the current study this definition of spirituality has the better criterion validity.

It has been suggested that in contemporary western culture, where traditional forms of religiosity are in decline, the broader definition of spirituality has much greater utility for the purposes of health related research (Bussing, Ostermann and Matthiessen, 2005). This suggestion is supported by the findings of the present study.

Spiritual Issues: Well-being and 'Meaning-Making'

A recently emerging literature has suggested the significance of existential and spiritual issues for the well-being of people with cancer, for example, recent research has highlighted associations between religious faith and physiological health functions such as endocrine-immune productivity (Seeman, Dubin and Seeman, 2003). The present study did not employ direct measurement of physiological variables or address such questions and so definitive statements about this association are not made.

Cotton et al (1999) have shown that spiritual well-being is positively associated with quality of life, fighting spirit, and reduced feelings of hopelessness, anxious preoccupation and cognitive avoidance of cancer related information. It has also been

shown (Koenig, Larson and Larson, 2001) that spirituality is often employed by the individual to help them retain a sense of control, hope and a sense of a meaning and purpose for their life. The present study identified themes relating to 'possession of faith', 'meaning and purpose from cancer' and 'anxieties about the future' and data suggested clear links between each theme. Those participants who most clearly expressed finding a meaning and purpose from their experience of having cancer did so in connection with their pre-existing spiritual perspective. Further, the emergent master-theme, 'positive coping as a priority in dealing with adversity' was identified within the data. This super-ordinate master-theme was taken to reflect the aspects of fighting spirit, having a meaning and purpose for life, retention of a sense of control and hope in the presence of their cancer expressed by the participants. These findings offer strong support to those of previous studies.

It has also been suggested that spirituality serves the role of *meaning-making* through providing a connection with life that allows the individual to deal with the demands, challenges and losses associated with diagnosis of, and treatment for cancer (McGrath, 2002). This theoretical hypothesis is offered clear support by the findings of the present study. It should be further noted that even when described as occurring in a spiritual context, for many of the sample this 'meaning making' process is also described as taking place in the context of relationships with family members, friends, other people suffering with cancer and communities to which the individual feels a part. Furthermore, this aspect of the 'meaning-making' process is described by participants of the present study, as taking place within the context of relationships, even in the absence of a spiritual faith. On the basis of the present study data personal

spirituality may serve a facilitative role for a more important and underlying process of 'meaning-making'.

It could be cautiously suggested that the person's ability to make a meaning for their life, within the context of relationships, could comprise the function that distinguishes those who display 'positive coping as a priority in dealing with adversity' and those who might not. Several recent studies have found evidence for this suggestion. For example, access to social networks has been related to enhanced quality of life for women who have survived breast cancer (Irvine, Brown, Crooks and Brown, 1991; Carlson and Butz, 2003) and a recent prospective study found that personal history of pre-morbid access to social networks increased survival time and quality of life for women surviving breast cancer. In fact, these variables accounted for more variance in survival and Quality of Life outcomes than did tumor and treatment type (Michael, Berkman, Colditz, Holmes and Kawachi, 2002).

On this model a spiritual perspective, either via a religiously conceived relationship with God or a spiritual relationship with a wider or unified reality could be viewed as a form of special, private and relatively internalised relationship. Of course this is not the first time that relationships and religiosity have been viewed as sharing a common foundation. Freud, (for example, 1927) conceived of religion as a neurotic internalisation of relationships from early stages of psychosexual development. Freud viewed possession of a religious faith as a compulsive clinging to a father-God for the purposes of protection. On the basis of the current discussion however, while the ability to 'meaning-make' within the context of relationships may have foundations in early developmental processes, possession of a religious or a broader spiritual faith

could just as well be viewed as facilitative and part of a wider ability of the person to adapt to adverse changes to life circumstances.

The evidence for a more general 'benefit finding' through the experience of cancer has been recently reviewed. Linley and Joseph (2004) reviewed 39 empirical studies and examined the concept of 'adversarial growth'. The authors describe this concept as including personal growth following a diagnosis of cancer, personal changes that are viewed as beneficial and thriving within the context of a cancerous illness. Their review showed that it has been commonly found that people with cancer report positive changes as a result of their illness. Perceived gains included an enhanced appreciation of life and a re-ordering of priorities, greater self-confidence, a more spiritual outlook on life, a greater acceptance of how things work out in life and an increase in motivation and ability to relate to others. 'Benefit finding' has been consistently associated with significantly reduced levels of emotional distress. It has been suggested (Carver and Antoni, 2004) that people who can find benefits in their cancer illness are those with a trait predisposition for making positive cognitive appraisals of personal situations. This suggests the possibility that people who find benefits in their cancer are likely to have individual personality differences to those who find no benefit. Most recently, in a study of 230 survivors of breast cancer, 'benefit finding' was found to be significantly associated with trait optimism, positive re-framing and religious activity as coping mechanisms (Urcuyo, Boyers, Carver and Antoni, 2005). This possibility is also implied by Ho, Chan and Ho (2004) who describe similar findings but point out that the people participating had all been previously identified as 'high-functioning' survivors of cancer.

Benefit finding literature is supported by the findings of the present study and in particular the identification of the master-theme labelled as 'positive coping as a priority in dealing with adversity'. Themes identified within the data contributed by the study's participants were skewed towards that typically found amongst people capable of 'benefit finding' from their having cancer. Similar to the study conducted by Ho et al (2004) it must be suspected that the participants of the present study would fall into a category of high functioning survivors of cancer. This has some very real methodological implications for future research in this area.

Methodological Issues

The themes identified within the participants' discussions' tended toward accounts of how existential needs had been met or ameliorated. In many cases this had been achieved by a pre-existing religious or spiritual perspective. An even more inclusive method of meeting these needs appeared to be the ability to 'meaning-make' within a context of relationships. The five existential and spiritually oriented themes identified were linked by a super-ordinate master theme of 'positive coping as a priority in dealing with adversity'. While these findings offer support to the literature concerned with benefit finding in people with cancer it must also be considered a limitation of the present study. The nine participants who took part in the focus group discussions may not have adequately represented the population of people with cancer. In their meta-analytical review, Linley and Joseph (2004), found that the gains perceived by people finding benefits from their experience of cancer or displaying 'adversarial growth' included an enhanced appreciation of life and a re-ordering of priorities, greater self-confidence, a more spiritual outlook on life, a greater acceptance of how

things work out in life and an increase in motivation and ability to relate to others. These qualities were found amongst the master and sub-themes identified within the discussions of the present studies participants' and some of them may offer an explanation for the apparent bias toward 'high functioning' identified. Enhanced self-confidence and an increased social motivation may have been significant factors determining the uptake of the offer to participate in the present study. The effect of these factors may have been further magnified by the employment of a focus group procedure. The other qualities identified by Linley and Joseph's review, including the high proportion of participants with a spiritual outlook may have thus been more prevalent as a secondary consequence of the focus group method employed.

Future research in this area should attempt to gain a more representative spectrum of people coping well and those not coping so well with their having cancer. Individuals not coping well with having cancer may express higher levels of distress, hopelessness. Only in this way could the full significance of existential issues for people with cancer be comprehensively understood. This may necessitate the employment of a less 'social' method (i.e. focus groups) that may have deterred people who do not have the qualities typically found in people capable of 'benefit finding' from participating in the present study. The use of individual interviews may more successfully facilitate access to people who might be deterred by the thought of participating in a group discussion. Further, conducting such interviews at the person's home might facilitate participation by people who have less motivation for arbitrary social interaction.

The participants of the present study tended toward homogeneity in respect of stage of their illness, i.e. they were nearly all attending for check-ups only. It has been found that at later metastatic stages of cancerous illness people display increased suicidality (Filiberti and Ripamonti, 2002), depression (Sellick and Crooks, 1999) and reduced desire for illness and treatment related information (Deridarian, 1987). It is also therefore likely that existential and spiritual issues may also be affected similarly by the stage of a person's illness. In order that the existential needs of people with cancer be more comprehensively examined it will be necessary for future research to make efforts at including participants from more varied stages of illness, , from diagnosis, through treatment, possible relapse, remission, palliative care etc.

The participants of the present study are small in number and do not adequately reflect the large number of other possible cancer sites found in the population of people with cancer. It has been found that the highest rates of distress were reported by those with cancers of the lung (43.4%) followed by brain, Hodgkin's disease, pancreas, lymphoma, liver, head and neck, breast, leukemia, melanoma, colon, prostate and finally, gynaecological (29.6%) (Zabora, BrintzenhofeSzoc, Curbow, Hooker and Piantadosi, 2001). It is also possible that existential and spiritual needs might be influenced by cancer site and future research must make efforts to include participants from a more representative range of cancer sites.

Summary

Further exploration of the findings of the present study and the opportunity to speculate upon the theoretical implications has identified a number of significant

findings and recommendations for future research. Both existential and spiritual issues have been found to be salient for people with cancer. This finding is facilitated particularly by use of a definition of spirituality that is broader and more inclusive than more traditional and narrow definitions of religiousness. The findings of the present study suggest that existential issues and spiritual issues are strongly connected. Further, the findings also suggest that existential and spiritual issues may be related to a process of 'meaning-making' within the context of relationships. While these possible relationships are deserving of greater research attention it must also be noted that the current study's focus group method may have attracted participants more socially motivated and more likely to have a spiritual perspective. The participants of the current study did not fully represent the population of people with cancer, in respect of stage of illness or site of cancer. However the paucity of research examining the potential existential and spiritual needs of people with cancer make the findings of the current study, discussion of, and recommendations arising from them, a valuable contribution. Many facets of the discussion of the findings of the present study, in the context of the research literature, have direct clinical implications and it is to these that this discussion will now turn.

Clinical Implications

Assessment

A number of authors have suggested the necessity of assessing the needs of people with cancer within an holistic context as assessment conducted in this way allows the relative import of each need to be viewed in the context of the persons' whole needs'

(Gustafson, Arora, Nelson and Boberg, 2001; Bonevski, Sanson-Fisher, Girgis, Burton, Cook and Boyes, 2000; Huyse, Lyons, Stiefel, Slaets, de Jonge and Fink, 1999). The present study presented examination of existential and spiritual needs within the context of other needs described by the participants (see table 1 of the empirical paper). Examining the potential areas of need for people with cancer in this holistic way allowed it to be shown that existential and spiritual needs, however well met for the participants of the present study, occupy a distinct domain of need. The foremost clinical implication is therefore that potential existential and spiritual needs be incorporated into assessment of the needs of people with cancer. If such an assessment includes the use of questionnaires, items designed to assess these areas of potential need must be included. This implication is particularly relevant due to the current study comprising one element of the encompassing CancerCAN project (Zinovieff, Morrison, Coles and Cartmel, 2005), which aims to develop an instrument for the assessment of the needs of people with cancer and their carer's.

The findings of the present study suggest an important, adaptive, and health promoting role for processes of 'meaning-making' in the context of relationships. Access to adequate social networks and supportive personal relationships is therefore an important health determining factor. Needs in this domain of the person's life must be incorporated into any needs assessment, for example, by the inclusion of specific items designed to assess support needs where questionnaires are to be employed, or through the use of specific prompts if semi-structured interviews are to be carried out.

Discussion of the present study's findings also suggest that people who are least able to 'meaning-make' and 'benefit find' during their cancer journey may be less optimistic by nature and less motivated to access and engage in services designed to address psycho-social needs. This may be particularly so when such services are socially oriented and require personal interaction. Assessment of these aspects of a person's motivation for treatment, perspective on possible outcomes and beliefs concerning the ability of services to meet their needs may reveal valuable early indicators of those most likely to experience difficulty in adapting to their illness or accessing services appropriately. Therefore assessment of these aspects should also be incorporated into any needs assessment, whatever the methodology employed.

The areas suggested as necessary inclusions for assessment of the needs of the person with cancer are highly sensitive, personal and potentially difficult to access through use of self-report questionnaire items. For this reason it might also be suggested that the use of semi-structured interview rather than self-completion of a needs questionnaire by the person with cancer may be more appropriate and more illuminating.

Intervention

Some research has suggested that interventions based upon Social Cognitive Theory (SCT: Bandura, 1986; Maddux, 1995) might offer strategies to address the needs of people with cancer. It has been found that the inclusion of SCT based intervention components had strong positive effects upon measures of global affect, depression, social domain measures and objective physical measures. However, SCT based

components were not found to be related to improvement in anxiety, coping, subjective physical or functional domain measures.

The findings of the present study suggest an important role for spirituality in addressing the existential needs of the participants. However, a spiritual perspective can only be developed by the individual for his or herself. For people who possess a spiritual perspective this should be identified during a holistic needs assessment and this should then be fostered by the provision of opportunities to spend time with a person or people offering support from a broadly spiritual perspective. The traditional employment of clergy or persons from any well-defined spiritual perspective may be too narrow and potentially exclusive. Clinical and counselling psychologists working from an existential and humanistic framework may be better placed to offer such a service to the diverse perspectives that may be encountered. However, should a person themselves have a well defined religious faith, access to people or a person with the same faith should be facilitated wherever possible.

The findings of the present study also suggest an important role for processes of 'meaning-making' in the context of relationships. The current discussion has also considered the possibility that those people most likely to be experiencing elevated levels of distress and potentially unmet existential needs, are those least likely to have a spiritual perspective or access to the kinds of relationships necessary for facilitation of the 'meaning-making' process. This is not to suggest that pro-actively encouraging new considerations of spirituality, for people who have never done so or who are not spontaneously doing so, is a necessary intervention component. Rather, interventions should aim to provide a supportive, therapeutic relationship that focuses upon finding

a personal context for the person's cancer experience and employs the therapeutic space for facilitation of a 'meaning-making' process.

It is further possible that this group of people with cancer may be more difficult to engage in services aimed to address needs in this domain. Accurate identification of these people with the greatest potential distress and existential needs is of paramount importance. Further, it is possible for the reasons described above that people with the greatest existential need might be the first to reject offers of appointments with a counsellor of any description. This may be combated by having the needs assessment by a member of the multi-disciplinary treatment team with the sensitivity to process issues, and specifically those of engagement and rapport building necessary. The ultimate implication for clinical practice and service provision is that provision of a supportive relationship that provides the context for an individually tailored 'meaning-making' process should be the rule rather than the exception. Process issues have been discussed in the context of implications for clinical practice. A number of process issues were also encountered while conducting the present study and these shall now be discussed.

Process Issues

The present study employed a focus group method to facilitate discussions across broad domains of potential need. The conducting of these groups presented little in the way of problems and this may have been partly due to the relatively high functioning character of the participants. Notwithstanding the absence of explicitly held, personal perspectives throughout the month that the groups were conducted the first author experienced a series of dreams on the theme of cancer. These dreams

were characterised by stereotypically negative views of cancer and feelings of fear, pessimism and panic. This disparity between explicitly recognised cognition and that more pre-consciously influenced would suggest the implicit presence of cancer related fears. The presence of such fears however implicit or pre-conscious in nature could potentially have affected the facilitation of the focus groups and subsequent interpretative analysis of the data.

Facilitation of focus group discussions requires the 'facilitator' to include all members of the group and to direct the discussion toward those relatively less inclined to contribute under such conditions. While this was not difficult for the focus groups employed for the present study it may have been more difficult if the groups had been less homogenous. Should the groups have been attended by more people in terminal stages of the illness or experiencing higher levels of distress it is not inconceivable that implicit cancer related fears, held by a facilitator, might bias the direction of discussion. Under such conditions group discussions might be anxiety-avoidance biased in favour of those speaking positively about, or 'benefit finding' in their experience of cancer. This possibility was attenuated by the attendance at each focus group of the third author (FZ).

In a similar way, the same anxiety-avoidance bias could potentially influence interpretation of the qualitative data generated by the focus groups. The influence of implicitly held beliefs and assumptions is always a possibility when conducting an interpretative analysis. It is for this reason that the data are independently scrutinised as an inherent part of the method to ensure the validity of the analysis and findings.

Summary and Conclusions

Existential and spiritual issues have been shown to be significant domains of need for people with cancer. Holistic assessment of the needs of people with cancer is required which should necessarily incorporate elements designed to assess the persons' existential and spiritual needs'. This assessment might be best conducted by members of the multi-disciplinary healthcare treatment team who are appropriately sensitive to the indicators of potential needs across these domains and further, to the issues of engagement and rapport that might also come to bare upon the assessment context.

Interventions should be individually tailored and facilitate the provision of appropriate relationships for the purposes of developing a 'meaning-making' process. In following such recommendations we can ensure that the most effective treatment is offered to the person as well as their cancer.

Word Count = 4114

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References Word Count = 794

Appendix – Statement of Thesis Word Count

Thesis Abstract = 300

Ethics Proposal = 5300

Literature Review = 5509

Research Paper = 5178

Discussion Chapter = 4114

THESIS TOTAL = 20301

APPENDIX TOTAL = 5475