Creating the space for spiritual talk: insights from survivors of haematological malignancies

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Abstract

The findings presented in this article are from a recently established research program that aims to make a contribution to health care by using qualitative methodologies to deepen our understanding of the notion of spirituality and to document appropriate ways of responding to the spiritual issues experienced by those coping with serious illness. The discussion focuses predominantly on the insights provided by survivors of haematological malignancies about factors impacting on their need to talk about spiritual issues. The aim of presenting the findings is to highlight the importance of providing the opportunity for patients to talk about spiritual issues and to provide health and allied health professionals with insights on how to deal with this aspect of patient care. The insights provided by the participants go a substantial way in outlining the who, what, where and when of providing supportive communication on spiritual issues.

Introduction

To date, spirituality has been a somewhat neglected area of research in the modern western health care system which relies principally on the bio-psycho-social model of humanity (Chapman 1986; Forbes 1994; Kaye & Robinson 1994; McGrath 1997a; I997b; I999; 2002d; Oldnall 1996; Ross 1994; Soeken & Carson 1986; Stepnick & Perry 1992; Stiles, 1990). The findings presented in this article are from a recently established research program that seeks to address this hiatus in research, and is funded by a major Australian cancer research organisation. The program has a dual focus of exploring the notion of spirituality while documenting appropriate ways to respond to spiritual issues for those coping with serious illness. The findings presented in this paper address communication issues in relation to spirituality for survivors of a haematological malignancy. The discussion focuses predominantly on the insights provided by survivors about factors impacting on their 'need to talk' about spiritual issues, rather than spirituality per se. Thus, it is important before presenting the findings to clarify a number of assumptions about spirituality used in the text.

The academic literature takes 'meaning-making' and 'experience as person' as the starting point for the notion of spirituality (Bradshaw 1997; Cawley I997;Colliton 1981; Hay 1989; Hodder & Turley, 1997; Mauritzen, 1988; Millison & Dudley, 1992; O'Neill & Kenny 1998; Sumner 1998; Taylor & Fertzt 1988; Wald & Bailey 1990). Simply put, 'spirituality is defined as that part of the self where the search for meaning takes place' (Taylor & Ferszt 1988). Preliminary definitions from the literature indicate that spirituality is broader than religion and relates to the universal quest to make sense out of existence (Highfield 1992; Nagai-Jacobson & Burkhardt 1989), a characteristic of human 'being' (Frankl 1973; Saunders 1981). In essence it is 'the organising centre of people's lives', which may or may not be theologically informed (Hodder & Turley 1997).

The preliminary findings emerging from the present research program partly affirm the notion of spirituality as 'meaning making'. Although for some spirituality embraces religiosity (McGrath & Newell 200I), for most it is 'quintessentially of the ordinary' (McGrath 2002a) and refers to the sense they are making out of their life and illness experiences (McGrath 2002ba; 2002c; 2002d; 2003a; 2003b; 2003c; McGrath & Newell 2002). However, the preliminary findings also posit 'connection' as an additional, but essential, dimension of the notion of spirituality. The indications from the research are that individuals need a strong connection with life through family, friends, work and leisure, in order to deal with making sense of the challenge of serious illness. Such a connection can be threatened by a break with the normal or expected relationships and dissatisfaction with life through physical, identity, relational, and existential losses (McGrath, 2003a). When the disconnection is acutely painful (a subjective phenomenon depending on the individual), it is then experienced as 'spiritual pain', creating a void that challenges the individual's ability to make meaning from his or her existence (McGrath 2002b). If the 'spiritual pain' is sufficiently severe, it can lead to suicidal ideation.

Thus, this discussion will be situated in the context of the broader findings from the study about the nature of spirituality and will be predicated on the assumption that for these survivors spirituality is about their connection with, and challenge to make sense of, their everyday experience with life. As reported elsewhere, core dimensions to the survivors' spirituality are their relationships with family, friends and health care professionals, and the way they deal with the challenge of serious illness, treatment and the possibility of death.

The Research

The study, funded by the Queensland Cancer Fund for two years, examines the relevance of the notion of spirituality and spiritual pain for hospice patients (Arm A) and their carers (Arm B), and the health professionals who look after them (Arm C), as well as cancer survivors (Arm D) and patients undergoing curative care in a hospital setting (Arm E). The findings reported in this paper are presented from the arm of the research that explores aspects of spirituality in relation to survivors (Arm D).

The participants in this arm of the study were enrolled through the support worker at the Leukaemia Foundation of Queensland (LFQ). Prospective participants were contacted and told of the study and invited to participate in an interview. All of the participants contacted agreed to participate (n=12), giving a participation rate of 100%. Participants were informed of their ethical rights (such as informed consent, confidentiality, right to withdraw) before agreeing to participate and a written consent was obtained prior to the interview. The university ethics committee approved the study and ratified the project descriptions and consent forms.

Target Population

All of the participants have been diagnosed with haematological malignancy (cancers of the blood and blood forming tissues such as the leukaemias, lymphomas and myelomas) (McGrath 2001). Patients in these diagnostic groups face a potentially life-threatening condition and undergo risky, aggressive, invasive treatment protocols, including bone marrow transplantation, total body irradiation and high dose chemotherapy, that extend over lengthy periods of time (McGrath 2000). Consequently, this group of survivors would have experienced a confrontation with potential death both at the point of diagnosis of their life-threatening condition and subsequently during their risky high-tech treatments.

Most of the participants were male (n=8), and had experienced a range of haematological malignancies including Chronic Myeloid Leukaemia (n=5), Acute Lymphoblastic Leukaemia (n=2), Acute Myeloid Leukaemia (n=2), Multiple Myeloma (n=1), Non-Hodgkin's Lymphoma (n=1) and Ewings Sarcoma (n=1). The ages of the participants ranged from twenty-five to sixty, (25-29, n=3; 35-39, n=2; 40, n=3; 50-55, n=3; 60, n=1). For most of the participants it had been from three to eight years since they had been diagnosed (3yrs, n=1; 4yrs, n=1; 5yrs, n=3; 7yrs, n=3; 8yrs, n=2), although for two the time since diagnosis was much longer (12yrs, n=1; 15yrs, n=1). The majority have undergone at least one bone marrow transplantation (n=8), and

all have experienced extensive chemotherapy and radiotherapy. More than half of the participants were five years or more post-treatment (5yrs, n=3; 6yrs, n=2; 9yrs, n=1; 10yrs, n=1) an important point in time that signals cure in oncology terms. However, five of the participants were still under five years post-treatment (1yr, n=1; 3yrs, n=2; 4yr, n=2).

Methodology

The meaning survivors are making from their illness experience has been documented through qualitative research using an open-ended interview with each participant. The interviews were conducted by a psychosocial researcher with a counselling background, and many years experience working with families coping with a member with a haematological malignancy. The time and location of the interviews were of the participants' choosing. The participants were encouraged to tell their story from the point of pre-diagnostic symptomatology up to the present with the opening prompt questions: 'Could you tell me of your experience, in your own words and in your own way, from the time you became aware that you were ill? How that has changed how you see the world and what you believe is important?'

The interviews were audio-recorded and transcribed verbatim. The language texts were then entered into the QSR NUD*IST 4 (Qualitative Solutions and Research Pty Ltd) computer program and analysed thematically. A phenomenological approach was taken to the recording and analysis of the data. All of the participants' comments were coded into free nodes, which were then organised under thematic headings. The coding was established by an experienced qualitative researcher. A second investigator for the project reviewed and validated the coding. There was complete agreement on the coding and emergent themes. There were seventy-five free nodes created for the full analysis of the survivors' transcripts, of which those directly related to the topic, 'The Need to Talk about Spiritual Issues', are presented here.

As inductive, phenomenological, qualitative work, the reporting of findings is based on a commitment to the participants' point of view with the researcher playing the role of co-participant in the discovery and understanding of what the realities are of the phenomena studied (Crombie 1996; Greenhalgh & Taylor 1997; Holloway 1997; Streubert & Carpenter 1995). Thus, a narrative account dominates, with a clear separation between the presentation of the exact words of the participants in the findings section and the interpretation in the discussion section (Grbich 1999). For economy of presentation the selected nodes have been organised under categories that, when juxtaposed, build an outline of the issues (Coffey & Atkinson 1996; Marshall & Rossman 1995; O'Connor et al., 1997). Exact quotes are provided in bullet form under the appropriate categories.

Findings

Facing the Challenge

The key factor that impacts on the challenge of creating the discursive practices that allow individuals to talk about spiritual issues is complexity. Anyone seeking to engage in dialogue on this topic with those touched by the experience of serious illness must take a myriad of factors into account, such as the individual's communication and coping style, the timing of the discussion, the place of the discussion, their relationship to the individual, the stage of treatment, gender issues, and support issues. The consequence is that the process can seem daunting and the safer option of doing nothing may appear more attractive, as the following statement reveals:

'I think that is why most people stand off, don't they. Because they understand the complexity of it and they think, Ooooh! No, Too hard! Don't want to do this!'

However, participants reported that there is one important rule of thumb that can simplify the challenge and this is the simple act of asking if the person wants to talk. The response will provide guidance and the offer is a sign of caring, even if not accepted. The simplicity of this message, and the resultant distress when the opportunity to talk is not offered are demonstrated in the following selection of statements from different participants:

'just ask… that is all it came down to, was that you just had to ask. What do I want. And people didn't.'

'my big thing has always been if you don't know what to say just tell the person you don't know what to say and they will take over for you. A lot of people avoided me because they didn't know what to say. And I would have loved to talk … there was a lot that I want to say if they'd just listen, it would have been fantastic. But I understand where they were coming from.'

It Helps to Talk

For many of the participants, the experience of surviving the diagnosis and treatment of cancer left them with a profound need to talk. The opportunity to talk about their experiences was recorded as vital to self expression and an important strategy for coping:

'To me, like communication was just what got me through. The communication, the love and the support and knowing that I was never on my own.'

'I needed to talk and talk and talk and talk and talk.'

In discussing their need to talk and the problems associated with communicating with others, participants couched their responses in a sensitive understanding of the difficulties others face in talking about issues associated with the illness. There was an awareness that others would find talking with them difficult and that, as patients, they would also not always be receptive to talking. Consequently, the important issue was not whether communication was effective but rather whether support was demonstrated by the simple offer to talk. As one participant stated: 'The support is the offering of it, isn't it.'

It Hurts When People Don't Listen

There were many vignettes about hurtful experiences associated with family and friends not being able to talk about the illness and its implications. The survivors related these stories with understanding and insight that indicated that they were aware of the reasons why others had problems with communicating on these significant issues. The understanding of others' avoidance from the fear, confusion and confrontation with mortality associated with such conversations is evident in the following examples:

'I was really disappointed with my family the first time. I think I was looking for an expression of love but they were on one level frightened and on the other level didn't know what to say - it is easier to say nothing.'

'They had enough getting through their life without wanting the burden of an ill person and my husband just tends not to deal with things; he works with the head in the sand approach, if he pretends it is not happening it is not happening.'

'It was really hard with my family. It isn't here, we are imagining it. It took a while for them to actually come to reality.'

All of the participants had painful stories about long term friends or family who disappointed them by not remaining in contact throughout the illness journey. Because there was an established relationship with these friends it was assumed that communication would have been automatically offered unconditionally and that the friends would have had the understanding and commitment to keep the communication open no matter what the obstacles. Although survivors related these stories with understanding about the reasons for lack of communication, there was a great deal of pain evident in their statements:

'because everyone wanted to continue enjoying their lives and they didn't want to have to, I guess, see me in that state I was in. It made them feel bad'

'I don't hold it against them because people deal with things how they do …but their way of coping made it hard for me.'

'And it got down to being able to count them (friends) on one hand.'

Such pain was not only reported during the treatment situation when the patient was very ill with side effects, but more importantly became a significant issue at the end of treatment. The problem is that family and friends perceive the medical drama to be over at a time when many patients are only starting to deal with the emotional and spiritual consequences. Although the full findings on this issues are published elsewhere (McGrath, 2002b; 2003a), an indication of the problem can be seen in the following statement:

'It is like, as you get through it and you're healthy, they turn their back on you… I never had that support, that emotional support later on when I needed it.'

A Caveat - Limits to Talking

Although for many the opportunity to talk is helpful, some would say essential, this does not mean by implication that it is the panacea of all disease or treatment-related concerns. Particularly in haematology where treatments are risky, aggressive, high-tech and invasive, there is a real limit to what preparation through talk can achieve, as one participant explains:

'I don't think anyone can quite prepare you for the physical aspects of it, or the emotional aspects of it, or the mental aspects of it. The total body radiation, to pick up all the bone marrow, so you're totally open to infections and the recovery. So they warn you in that way, but what you're actually going to feel, physically and emotionally and mentally no one can prepare you for. It is something you have got to go through yourself.'

Scary at first

Although supportive conversations are welcome by many, this does not ipso facto mean that all talk about the disease and its treatment is unproblematic. One of the negative factors that operate against discussing such sensitive issues is the emotion of fear. In terms of the patient's meaning-making about the treatment and the possibility of dying, there are many frightening issues that can arise that individuals do seek to avoid, as the following examples demonstrate:

'You hear all sorts of stories. When you're initially in hospital the stories are quite scary because people talk about what they've had and you think I might get that.'

'(talking about dying) it is probably too scary. And certainly health professionals don't want to talk about it. They don't know where to start.'

'oh (sigh) probably a little bit too confronting. If you talk about it (death) maybe you're entertaining the possibility. It is sort of like dabbling with danger.'

Because of the fear involved individuals can rely on an element of denial in processing information about their diagnosis and treatment, as the following example demonstrates:

'I guess I sensed it (diagnosis and treatment) was serious but I didn't say that to myself and I didn't have time … I also delayed it for my birthday.'

'I don't think it really hit me until I went to see the specialist, had the biopsy and was talking to the anaesthetist in the pre-operative room waiting and then I just sort of burst into tears. I think that is probably when it hit me.'

Protecting the Family

Another important issue that can be an obstacle to open communication is the patient's desire to protect family members from worries about the disease and its treatments. There was a concern to protect the family from the anxiety associated with uncertainty, and this is a particularly sensitive issue when family members have a history of dealing with cancer,

'I didn't want to worry my husband and children because for him it meant death and for my children it meant insecurity, not knowing what was going to happen.'

'I couldn't afford to feel down. No, my young son, I was trying to be positive and with my medical situation there was an improvement.'

The desire to protect can extend to any family member, such as partners, children or parents. Special occasions or family events were reported as reasons for not telling difficult news, as the desire was to avoid spoiling the excitement of such times.

There were reports that, where the individual seeks to protect the family, they are able to maintain a high degree of secrecy on the matter of diagnosis, as the following examples describe:

'I didn't tell my family until after I had my biopsy and got the results back.'

'I keep everything to myself, I sort of try not to make my problems other people's problems.'

Although the motives for not sharing information about the illness with family are protective, the end result of such actions can be painful. Without open communication there is not the sharing and closeness necessary for the patient at such a difficult time and they can be left unable to make sense of the situation:

'I didn't get any family support, not really, because nobody knew that I needed any help … so none was offered.'

'I think I made a mistake in making it taboo.'

As one participant noted about her experience with finally telling the family after protecting them for some time: 'I think I am also disappointed with attitudes. I thought that this would have been a wake-up call for everybody, but it wasn't'.

Autonomy

Another important factor that affected some participants' conversations about their illness was the desire to take control of the situation and handle it by themselves. As can be seen by the following statements, this autonomous desire affects how people access help and information, and can have both positive and negative sequelae:

'it was something I felt …I could do myself. I felt I knew as much as anybody could tell me.'

'I found the first week particularly hard doing it myself, because I was so busy going to so many tests and things and most of it by myself. I would have done it differently, that first week, if I had of thought about it.'

It takes time to be able to talk

One of the consequences of fear, the desire to protect the family, and the autonomous wish to be in control, is that considerations about the need to talk have to be situated in an understanding of timing. It is of interest that mostly male participants made reference to the fact that they needed time to process their own thoughts about their disease and its implications before they were able to share their ideas with others. Whereas most women reported the process as working through their concerns with others, the predominant (but not exclusive) male response was that of working out what they thought before they shared it with others, as can be seen by the following examples:

'I was sort of shut down. I didn't really say much. Because what I was thinking, it was all pretty dark stuff really. But I don't have a problem now, talking about it.'

'And it might take months until people get their head around what is going on and express themselves. It takes a lot of work. Some people might need to go through a trauma before they realise, or they might need time out to, to think about things.'

It was clearly stated, particularly for men, that pressure to share feelings or insights about their experience when they were not ready was negatively received. The opportunity to deal with their own feelings in their own time was more important than the offer to talk. The transgression of personal boundaries, particularly if combined with the perception that the other lacked confidence in the survivor's ability to handle the situation, was not appreciated. The negativity and need for solitude and autonomy is seen in the following statements:

'And I said, I don't need nobody to talk to. I can handle that. I wasn't prepared for all the sooky stuff.'

'my wife was really good during the second transplant coping with the relapse. Because like we never talked about it really. I mean she'd always known that I need to, you know, well I need her, but I don't need her yapping in my ear telling me how I should be feeling or anything. And she never has. I mean that is not what I need. Maybe some people need it but I didn't. If she had ever said anything I would have only had to say, look you know just leave me roll with it. And she would have.'

As one male participant revealed, part of the resistance to talking about the experience is the fear that such discussion could undermine the individual's ability to cope by drawing attention to his vulnerability: 'I just shut people out that I thought brought the weakness out in me… '

As stated by one male participant, the exception to the resistance to talking is if the survivor thought that they could help others: ' I thought it would help somebody then I wouldn't mind doing it. But for the sake of (ruminating), yeah, it is not value adding at all.'

For those seeking to know when it is appropriate to open up conversation, the participants' advice was to ask if such talk is needed, or otherwise to rely on intuition: 'It is where people are at… I guess you just have to be intuitive to know when people are wanting to talk.'

One very important factor with regards to timing in talking to survivors is the fact that many concerns do not surface until after treatment is completed. The fast pace and demands of coping with treatment force both the survivors and their families to focus on the sheer practicalities of surviving the day. It is not until the patient is off treatment that many or most of the issues interfering with the meaning they are making from life surface and need to be dealt with. Unfortunately, this corresponds to a time when others perceive that all is over and the survivor should be feeling happy and satisfied with the outcome, so the delayed reaction can come at a time when support is being withdrawn: 'And I got to five years post transplant and I hit a brick wall and I just thought, I should be happy that I've survived. And all these other issues that I hadn't even thought about have all come up.'

The Healing Power of Talking to Others Who Have Had Similar Experiences

Participants indicated that timing was only one of the important factors impacting on the usefulness and significance of the opportunity to talk about the meaning they were making from their illness experience. Of utmost importance is the experiential background of the person to whom they are talking. In the area of cancer survivorship, academic or clinical training per se is not perceived as important as evidence of a shared existential experience that flags to the survivor that the person they are talking to has some ability to enter their world with an appropriate degree of life knowledge. As the experience of serious illness can be life altering and often forces the individual to face significant new challenges that lead to a completely new perspective on life, there can be a strong sense of needing to talk to others who have had to face the same existential crises.

Consequently, statements by others who have not been through similar experience but who presume they know what the survivor is feeling are perceived negatively, for example:

'Someone trying to tell you how you should feel or someone saying they know how you feel. For example, statements such as 'when I had a cold' … you know and as though the two were the same. Like be real! As though a cold is going to take your life!'

The participants reported on their struggles with trying to talk to others who did not have life experiences to help them understand the challenges they face, and their conclusion that there was an 'existential understanding-gap' that blocks communication:

'I get a bit exasperated with people like that. Not that I expect them to get out there, I wouldn't wish it on anybody, to see what reality is about, but you just think, god, you've got no idea. And it is not their fault.'

'they were work people, I guess I was trying to build some sort of a relationship with them. They know that I've been sick. They can't even begin to understand my losses, I just thought that would be nice to try to communicate.'

As one participant succinctly summed up the situation: 'I tried and it didn't work. Because they don't understand.

Further findings from this study demonstrate that survivors experience distress over such issues as their perceived greater intolerance to minor illnesses in others, their perceived more serious outlook on life, and their perceived inability to take seriously the more superficial aspects of life and conversation (for example discussions on hair styles, clothes). The changes to the survivors sense of identity because of their altered meaning-making directly impacts on the content, and with whom, they now choose to communicate. There is a sense in which they find that their satisfaction with communication is more restricted both in what they want to talk about and who they find sensitive and responsive to their need to talk.

In contrast to this, there were strong positive statements about the benefit of talking to others undergoing a similar life journey, such as at the treatment accommodation centre or groups run especially for survivors. There were reports from survivors that others who had 'been there done that' had useful insights that helped them during their illness journey, for example:

'I had a conversation with someone who had been through cancer before and they said to me …[tips] Those little tips helped me because I'd never asked for help, I never felt comfortable in doing it. And when they said that to me it was sort of like, okay I will do that.'

Although the participants indicated benefits in talking to other survivors, such relationship were not always available either because the individual had lost contact with others who had left the hospital or others where bonds had existed had since died. Also, there is a down-side for those who do have contact with other people who have the same experience. When survivors are talking to others undergoing treatment there is always the down-side of fear of hearing about others in a similar position who have died: 'I went to (a support group) for a while. But they were too depressing. Like they had actually known people who had passed away and I'd think to myself, well I am still here. I don't want to be knowing about people who have passed away, seeing as though I am still in that vulnerable position where I myself could pass away. So I found it quite morbid and frustrating.'

Also, there is the complication of the differences between diagnostic groups and the variation of treatment/outcome experiences within the same group: 'But, ..there is a lot of variance between the same disease as well. Some people have good experiences and an easy road and some have a lot of complications or what not.'

Need to Talk About Things Other Than Illness

Participants differentiated between talk about the meaning they were making from their illness and talk about other things to do with life in general. For some, the opportunity to digress, if only momentarily, from their illness and explore life away from treatment was highly valued:

'there were a lot of people who would sort of really dwell on it (treatment), and sort to speak about it all the time. There wasn't anything else - I suppose a lot of the time there isn't anything else - but I sort of tried to look outside the picture and sort of discuss things that were happening in the world and our lives and whatever else.'

'Even during the treatment time people used to say 'oh how are you going? (said in a soft voice). I wasn't interested. I mean, I was getting on with life..'

It was noted that survivors would vary their conversation depending on their perception of the person to whom they were talking: 'But I've sort of, it all depends on the person, as to what sort of conversation I would give.'

Need to Close the Door on the Treatment Experience

The survivors, in contrast to hospice patients interviewed, are able to bring closure, if only temporarily, to their treatment experience. For some, at this point in their journey with the illness, it is important to talk about issues other than the implications of the disease and its treatment. The desire to 'move on' from treatment is reflected in the topics they choose to talk about and the people to whom they seek to talk. The desire to move on is clearly explained by the following statements:

'I've gone from three monthly check ups to six monthly checkups. I was anxious to get there because that meant that I was less likely to relapse. Though they say it can relapse up to ten years later or so it is still in the back of my mind, but I know I am well and I have dismissed it now. I am sort of at the point now where that was something that happened, it is over, it is done with. If it comes back it will be, for me anyway like getting a new cancer. And I will deal with it as that I think. But I'm just at the point now where I feel it is fair enough to just forget it'

'We've moved on from cancer. It was a stage in life. We don't dwell on the fact that I might only live to 75 instead of 85 or 93 like dad did or something. All we want to do is make sure we are physically able to do what we want to do and look at doing that for as long as possible.'

The resistance to talking about the illness during the stage of moving on is seen clearly in the following statement: 'you know a lot of people dwell on their sicknesses and sort of discuss them. I've sort of moved well away from that now, and people say you try to broach the subject and I'm like, nah, that was in the past and I don't want to talk about that.'

For some of the participants, it was noted that they decided to cease attending the survivor support group that they have previously found very satisfying in order to bring closure to the constant exposure to talk about their illness experience, as explained in the following text: 'I stopped going to (survivor support group) because every time you go to a (survivor support group) function everyone talks about negative things. I'd rather talk about stuff you're going to be doing like holidays and the future.'

For many the support group was an important but transitory stage of their survivorship recovery. The group was seen as important during the time that they came off treatment and were left with no one to talk to who understood what they had gone through. However, many later came to the stage that they wanted to bring closure to the experience and move on and that is the point when they left the support group. The key point is that the need to talk and the content of that talk changes over time.

A caveat to this conclusion is that although the survivors reported that they wanted to move on, this was not always possible or ultimately desirable. The survivors report that their reality had changed permanently and that efforts to put the illness experience behind them would only be partially successful as it was not seen as something that could be viewed as separate from their life journey: 'It's there in the past and it's not something I'm going to forget or want to forget or put behind. I mean, what's happened has been part of my life.'

The Talk That Did Help

Friends who remained in contact and open to talking about the survivor's illness were of great importance as can be seen by the following examples:

'It was the friends that network, that kept us going.'

'I've had some good friends that have stuck by me … they're not put off by the fact of 'oh I don't know if I can continue this relationship because you might die' sort of thing. They stuck by me.'

Open communication in the partner relationship was considered essential for some. Where the individual was able to access strong communication throughout their informal network of family and friends there appeared to be less need to attend support groups as can be seen by the following statement: 'The support I got from family and friends I mean I got support anywhere. So I didn't go to any of the leukaemia support groups because I had my own network and being a positive person I didn't think I needed that.'

Some found the need for professional or counselling talk: '(Grief counsellor) actually has given me enormous support when I hit that wall. Gave me enormous… great ideas and some wonderful counselling and really helped me move. Although she says you did it all by yourself.'

'The support worker… a shoulder to cry on. She is about the only one that does that for me. Helps very much.'

Many found talking to others who had been through similar experiences at the survivor support group very helpful. It was noted that this was especially important during the time at the end of treatment when the survivor had to deal with the loss of previously close relationships with hospital staff, with a dramatic withdrawal of attention and with family and friends who believed that as treatment had ended there was nothing more to deal with. As one participant explained: 'Not quite 12 months later and I found that (survivor group) a real blessing, because I could talk about everything that I hadn't been able to talk about. And nothing was taboo. You didn't have to protect people. (Survivor support group) was really good, it was excellent for the period of time when I wasn't ready to give up being (the patient). Whereas everybody else wanted to forget about it and not talk about it.'

Discussion

The insights provided by survivors of haematological malignancies are offered as one contribution to fostering innovative discursive practices that are inclusive of the spiritual dimension of health care. The findings resonate with the literature calling for inclusion of spirituality in clinical practice (Hemingway 2000; Kendrick & Robinson 2000; Kirsh et al., 2001;Narayanasamy 1996; Rolph 2001; Schaub & Schaub 1999; Trieschmann 2001; Sheldon 2000; Ziegler 1998) and extend the idea by describing insights from survivors on the who, what, where and when, to inform the development of such inclusive practices.
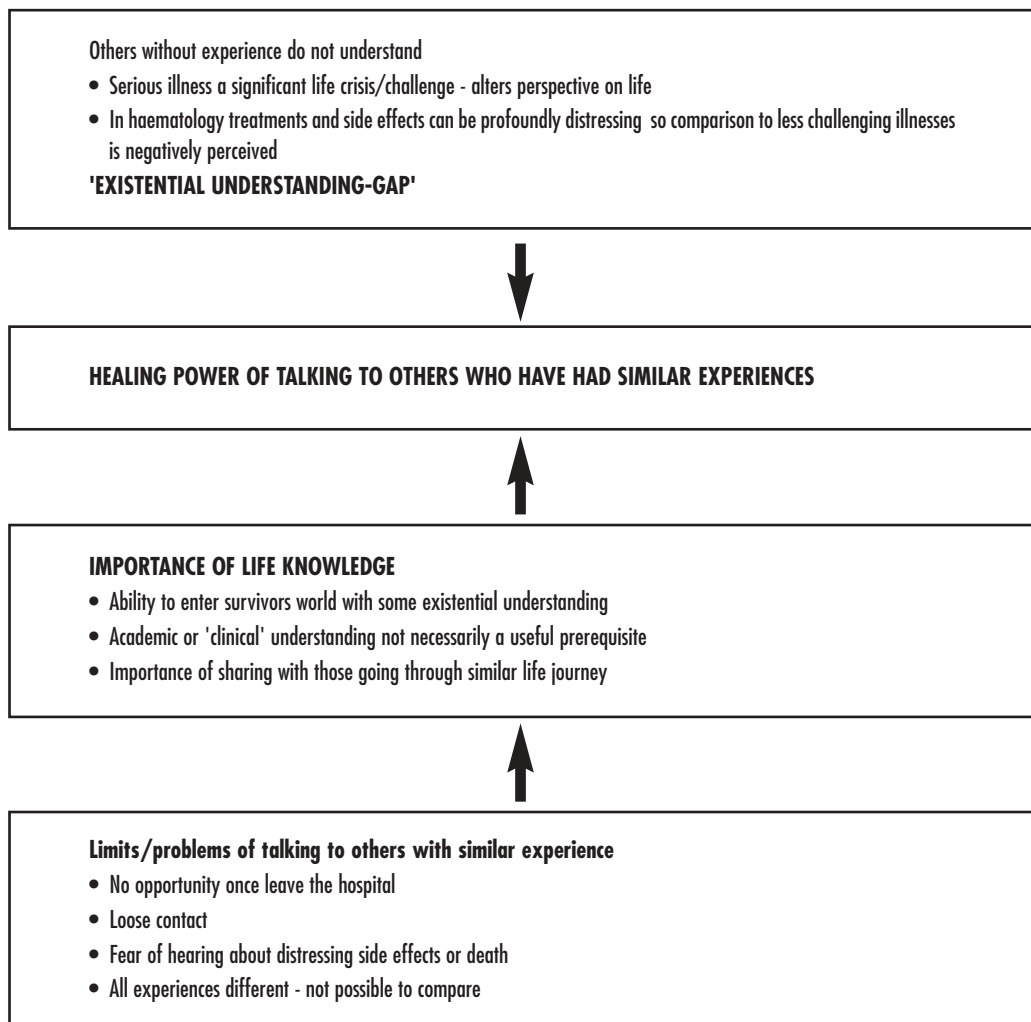
Indications are that there is presently a widening search for spirituality, as distinct from organised religion, particularly as it relates to the meaning individuals are making from their experience with illness and health care (Chandler, 1999; Chiu 1999; Howell 1998). However, the findings indicate that there are a myriad of factors that operate to block the opportunity for others within the intimate network of friends and family to provide patients/survivors with the opportunity to talk about the experience and meaning of serious illness. The lack of opportunity is perceived as hurtful and distressing. The lack of opportunity to talk is recorded as quite problematic during the time of considerable need brought about by the illness, treatment and survivorship experience.

The opportunity to discuss their experience with others is seen as a significant coping strategy. Thus, as reported elsewhere (Cole & Pargment 1999; Howell, 1988; O'Neill & Kenny, 1998; Schnoll et al., 2000), the indications are that increased attention needs to be given to creating the discursive opportunity for spiritual talk. The findings provide extensive detail on factors that need to be taken into consideration. The basic 'rule of thumb' is, if in doubt simply offer to talk.

Although the findings indicate that the discursive opportunity to talk about the illness experience is highly valued and appreciated, it is noted that individuals also require the respect for their need for solitude. For as O'Connor and associates (1997) note, spirituality is private and involves judgment which is personal and often private. Of equal importance is the opportunity to talk about issues other than their illness. Examples of helpful communication were also offered, including friendships that remained in touch, open communication with partners, counselling, helpful health professionals, and survivor group support.

The findings highlighted the importance to survivors of talking to others who have similar life experiences. An 'existential understanding gap', as represented diagrammatically in Figure I, exists between survivors and those who do not share a similar life experience. Such a gap in communication is experienced as distressing and an obstacle to effective communication. The findings indicate that life knowledge is a significant factor impacting on communication between survivors and others. However, although communication with those with similar experiences is seen as positive, this may be problematic because such individuals are often not available and there is the fear of hearing about distressing side effects and death.

Figure 1: The 'Existential Understanding-Gap'

Others without experience do not understand
- Serious illness a significant life crisis/challenge - alters perspective on life
- In haematology treatments and side effects can be profoundly distressing so comparison to less challenging illnesses is negatively perceived

'EXISTENTIAL UNDERSTANDING-GAP'

HEALING POWER OF TALKING TO OTHERS WHO HAVE HAD SIMILAR EXPERIENCES

IMPORTANCE OF LIFE KNOWLEDGE
- Ability to enter survivors world with some existential understanding
- Academic or 'clinical' understanding not necessarily a useful prerequisite
- Importance of sharing with those going through similar life journey

Limits/problems of talking to others with similar experience
- No opportunity once leave the hospital
- Loose contact
- Fear of hearing about distressing side effects or death
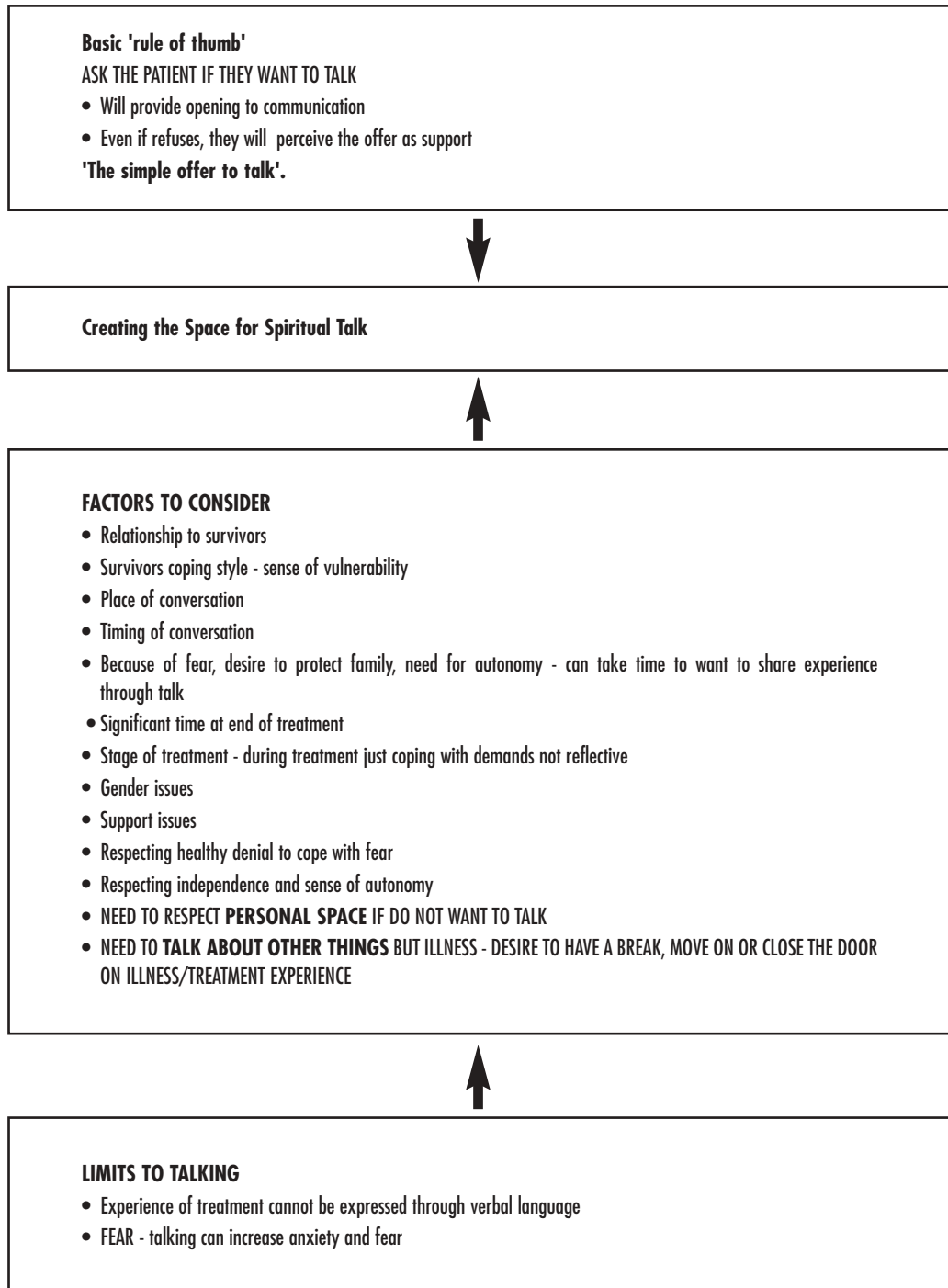- All experiences different - not possible to compare

Clinical Implications

The findings indicate that serious attention should be given to creating the discursive opportunity for survivors to talk about their experience and the meaning they are making from the changes to their lives brought about by the confrontation with serious illness. As Figure 2 outlines, the insights provided by the participants go a substantial way in outlining the who, what, where and when of providing such a supportive discursive opportunity for 'spiritual talk'. From those insights the following summary of recommendations is drawn:

1. There should be an increased appreciation of the need to provide survivors with the opportunity to talk about their experience.

2. There should be increased public awareness of the block to communication and effective strategies for overcoming such obstacles. Such information needs to be circulated in the popular press as well as in the health care literature. The principal message should be an affirmation of the basic rule of thumb - If in doubt, simply offer to talk.

3. Those involved in the support and care of survivors should be provided with information about the factors that are important in facilitating communication. Such factors include consideration of issues of relationships, coping style, place, timing, treatment stage, gender, support, fear and autonomy. Appreciation should also be given to the importance of respecting the need for solitude and the significance of talking about issues other than the illness.

Most importantly, our collective understanding of the importance of 'life knowledge' as a factor in effective communication needs to be given increasing priority. The difficulties created by the 'existential understanding gap' need to be appreciated and, as a consequence, emphasis should be place on building person-to-person support and support groups in response to serious illness. Such information affirms the importance of volunteers. This is an area that needs further research.

Figure 2: Factors that are important to take into consideration in creating the space for spiritual talk

Basic 'rule of thumb'
ASK THE PATIENT IF THEY WANT TO TALK
- Will provide opening to communication
- Even if refuses, they will perceive the offer as support
'The simple offer to talk'.

Creating the Space for Spiritual Talk

FACTORS TO CONSIDER
- Relationship to survivors
- Survivors coping style - sense of vulnerability
- Place of conversation
- Timing of conversation
- Because of fear, desire to protect family, need for autonomy - can take time to want to share experience through talk
- Significant time at end of treatment
- Stage of treatment - during treatment just coping with demands not reflective
- Gender issues
- Support issues
- Respecting healthy denial to cope with fear
- Respecting independence and sense of autonomy
- NEED TO RESPECT **PERSONAL SPACE** IF DO NOT WANT TO TALK
- NEED TO **TALK ABOUT OTHER THINGS** BUT ILLNESS - DESIRE TO HAVE A BREAK, MOVE ON OR CLOSE THE DOOR ON ILLNESS/TREATMENT EXPERIENCE

LIMITS TO TALKING
- Experience of treatment cannot be expressed through verbal language
- FEAR - talking can increase anxiety and fear

Conclusion

The hope and expectation is that the insights provided by this group of survivors about their journey with a life-threatening condition will go someway to deepening our collective understanding about how best to respond to the human experience of serious illness.

Acknowledgment

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