

# Moving inwards, moving outwards, moving upwards: the role of spirituality during the early stages of breast cancer

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## **Moving inwards, moving outwards, moving upwards: the role of spirituality during the early stages of breast cancer**

The paper reflects on a study which explored the role of spirituality in the lives of women during the first year after being diagnosed with breast cancer. The study utilised a qualitative method (hermeneutic phenomenology) designed to provide rich and thick understanding of women's experiences of breast cancer and to explore possible ways in which spirituality may, or may not, be beneficial in enabling coping and enhancing quality of life. The paper draws on the thinking of David Hay and Viktor Frankl to develop a model of spirituality that includes, but is not defined by, religion and that has the possibility to facilitate effective empirical enquiry. It outlines a threefold movement – inwards, outwards and upwards – that emerged from in-depth interviews with women who have breast cancer. This framework captures something of the spiritual movement that women went through on their cancer journeys and offers some pointers and possibilities for better and more person-centred caring approaches that include recognition of the spiritual dimension of women's experiences for the management of those with breast cancer.

**Keywords:** spirituality, breast cancer, quality of life, well-being, coping, qualitative research.

## INTRODUCTION

Cancer of the breast is the most common cancer in women worldwide, accounting for approximately 23 per cent of all cancers in women. In the UK there are more than 45 000 women newly diagnosed per year (Cancer

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Research UK, 2010) and almost 4000 of these women are in Scotland (ISD Scotland, 2010). In the Grampian region of Scotland, 420 women were newly diagnosed with breast cancer in the last 12 months. However, while incidence has been increasing substantially over the last 10 years, survival has also been increasing dramatically. Currently, 5 year survival rates are approaching 80%, which is comparable with the best figures reported elsewhere in the world. However, even with improved outcomes, breast cancer remains an important experience within the lives of a substantial number of women, their partners, family and friends, in the UK, and remains a significant source of threat, anxiety and suffering.

With the improvements that have occurred in the diagnosis and treatment of breast cancer, which can be extremely demanding, it is important not to overlook the need for continuing to develop good patient care that seeks to look after the whole person as they go through the experience of breast cancer. Caring for the spiritual needs of women with breast cancer is an important aspect of such a whole-person caring approach and one that requires careful consideration.

To date relatively little work has been done within the UK (Dein *et al.* 2006; Thuné-Boyle *et al.* 2010). The specific context of Scotland has received even less attention. We have only been able to identify one unpublished paper that has looked at the relationship between spirituality and breast cancer within Scotland (Dey *et al.* 2006). This is despite the Scottish government's document *Spiritual Care in NHS Scotland* (Scottish Executive 2002), which states clearly that spirituality is an important dimensions of the care that is to be delivered within the National Health Service. 'NHS Boards are required to develop and implement a spiritual care policy' (Scottish Executive p. 1). Not to know whether or why spirituality is important to women with breast cancer is important if this document is to be anything other than an aspiration. The results of this study aim to contribute to filling this gap in knowledge relating to the UK in general and Scotland in particular. The results presented below relate to the first of a cluster of research projects carried out by the Centre for Spirituality, Health and Disability at the University of Aberdeen (<http://www.abdn.ac.uk/cshad>) in collaboration with the Breast Cancer Unit at the University of Aberdeen and NHS Grampian.

### **Religion and breast cancer**

The study focused on the role of religion and spirituality in the experiences of women during the first year following diagnosis of breast cancer. It is important to note that the two concepts – religion and spirituality – are not the same and that the literature that surrounds both should not be conflated. Nor should one be used to support the significance of the other. Both terms have come to relate to aspects of human experience that are connected but not identical. With that distinction in mind we will begin by looking at the literature surrounding religion and breast cancer before moving on to explore ways in which we might understand and work with the broader concept of spirituality.

It is important to note that, like the term 'spirituality' there is no universally recognised definition of religion. The general tendency within the health-care literature is

to assume that religion is a monolithic term that means the same thing to all people. However, as Pargament (2002) has pointed out it may actually be the particulars of specific religions that have health-bringing capacities rather than the global properties of any particular religious system. For current purposes we will follow Clifford Geertz in defining religion as:

(1) a system of symbols which acts to (2) establish powerful, pervasive, and long-lasting moods and motivations in men [sic] by (3) formulating conceptions of a general order of existence and (4) clothing these conceptions with such an aura of factuality that (5) the moods and motivations seem uniquely realistic (Geertz 1985, p. 4).

Understood in this way religion is perceived as a formal system of beliefs held by groups of people who share certain perspectives on the nature of the world. These perspectives are communicated through shared narratives, practices, beliefs and rituals that, taken together, create particular world views, i.e. ways in which people see and interpret the world around them and make sense of their experiences within that world. Put slightly differently, the structures of belief and systems of practice that form any given religion, shape and form the ways in which those who participate in them see and respond to the world. This shaping and forming aspect of religion impacts on the ways in which illnesses are perceived and responded to by individuals and by communities. As such, religion is a powerful force for shaping a person's understanding of breast cancer and the options they perceive they have to be able to respond to the experience.

### *Religion, meaning making and coping*

The primary ways in which religion seems to impact on the experience of breast cancer are by providing particular ways of making meaning out of the experience and enabling effective coping. Leak *et al.* (2008) found a positive correlation between women's religion and their perceived quality of life (QOL). Religious practices, belief in God or a higher power and a spiritual leader, alongside support from family and friends were viewed as primary sources of spiritual support for African-American women. Interestingly, Purnell *et al.* (2009) found that it was the meaning that women found in their illness rather than particular faith beliefs that made the difference in terms of increasing perceived QOL. It seemed that the women in their study adhered to a particular religious system. However, it was their ability to seek after meaning and purpose, i.e. their cognitive-affective style, that increased

their QOL. This raises the kind of methodological question highlighted by Pargament above with regard to the problems of using religion as a global category. It was the particulars of belief and cognitive style that made the difference for the women in this study.

Choumanova *et al.* (2006) found that spiritual practices such as prayer, perceived dependence on God to intercede, and guide and social support from faith communities were used effectively by Chilean women to cope with their illness. Thuné-Boyle *et al.* (2010) found that patients perceived belief in God, strength of faith and private religious/spiritual practices increased significantly shortly after undergoing surgery compared with those in the year before surgery. The implication being that the crisis of surgery initiated some mode of cognitive realignment that required the ascription of new meaning to their situation. Harandy *et al.* (2010) in their study of Muslim breast cancer survivors found that almost all of their participants attributed their illness to the will of God. At the same time the women actively engaged with medical treatments. This is in contrast to some of the research emerging from Western cultures in which an external health locus of control diminishes participation in cancer screening, detection and treatment (Gall *et al.* 2011; Gullatte *et al.* 2010). The authors put this difference down to the influence of Islam on Iranian culture and the significance of the idea of 'the will of God' for cultural expectations combined with the increasing exposure to Western ideas of medicine and biological causality. Purnell *et al.* (2009) discovered that religion is a resource used regularly by patients coping with the diagnosis and treatment of breast cancer. However, they discovered that it was spiritual meanings rather than religious practices that was linked to QOL. In other words, the types of meaning ascribed to their illness were determinate of QOL rather than any particular religious practices. Thus we can see that among diverse groups of women and across cultures, religion has the potential to impact positively on the experience of breast cancer.

The precise mechanisms for positive correlations between religion and breast cancer are not clear, but they seem to revolve around two issues. First, religion provides a revised cognitive/conceptual context where experiences can be reframed and new meanings ascribed to them (Zwingmann *et al.* 2006). In this way women are enabled to cope more effectively with their situation. Thus coping and adaptation to traumatic circumstances appear to be significant. Pargament (1997) argues that this association between religious beliefs and coping is unique, i.e. it cannot be subsumed to psychological processes or other bases for coping. This is because religion offers positive

meaning and answers to fundamental existential questions about life and death that other modes of explanation cannot offer.

Second, and connectedly, religion seems to provide a positive sense of meaning and purpose to situations that can easily be perceived as deeply meaningless. The reframing and meaning-making capacities of religion are not always positive. Positive religious coping such as partnering with God or seeking support and guidance from God brings benefits for psychological well-being. However, negative modes of coping such as feeling abandoned by God or angry with God leads to a decrease in mental health, depressive symptoms and lower life satisfaction (Hebert *et al.* 2009). Likewise it is possible to ascribe negative religious meanings to illness. However, while the negative effects require recognition, the overall picture that emerges from the literature provides indications that religion has the potential to be of positive benefit for women experiencing breast cancer.

### Spirituality

When we turn to the literature on spirituality and breast cancer, the first impression is that it is similarly beneficial for the well-being of women with breast cancer. There is a wide range of literature that indicates positive correlations around similar issues to those raised by religion. Spirituality has been positively associated with QOL (Brady *et al.* 1999; King *et al.* 2000; Levine & Targ 2002), self-esteem (Carpenter *et al.* 1999), reduced anxiety (Burgess *et al.* 2005) meaning making (Bauer-Wu & Farran 2005; Coward & Kahn 2005; Sorajjakool and Seyle 2005; Breitbart 2006), hope (Mickley *et al.* 1992), increased ability to cope (Nairn & Merluzzi 2003; Leshner *et al.* 2006) and relationality and social support. (Stanton *et al.* 2002; Meraviglia 2006) Visser *et al.* (2010) in their review of spiritual care and well-being in cancer patients reviewed 27 papers that focused on the relationship between spirituality and well-being. They concluded that, at least for cross-sectional studies, there was a positive correlation between spirituality and well-being. However, a closer analysis of the papers they chose for review reveals that the authors of these studies do not work with any common definition or shared understanding of what spirituality is, other than to state that they are not working with religiosity. So while the general thrust of the literature on spirituality and cancer seems to indicate a positive correlation, what is actually being measured is not always clear.

The problem is one of definition and the practical utility of the concept of spirituality as a focus for research. Spir-

tuality, particularly in the literature emerging from the UK, is generally understood as a generic term that may contain, but is not defined by, religion. People are assumed to be spiritual but not religious. By focusing on 'spirituality' the intention is to draw attention to aspects of patient's experiences that are currently overlooked or underplayed in the way health care is delivered (Swinton & Pattison 2010). Within this frame spirituality is assumed to relate to different combinations of existential and/or religious needs: the search for meaning, purpose, value hope, love and for some God. The assumption is that these aspects of human experience have clinical utility, but that within a secular context religion is not the best vehicle for bringing them to the fore.

However, the particular combination of existential needs that people choose to bring together to form their definitions of spirituality is wide and diverse. The problem is that understandings of spirituality are so broad and varied that claims that 'spirituality aids human well-being' are difficult to substantiate empirically. Without a shared core of meaning it is difficult to assess what is common to the definitions and why it might be appropriate to compare the various findings. So while the various studies may well indicate positive correlations between spirituality and breast cancer, the actual causal factors involved may not be the same across studies.

### The study

It is nonetheless the case that there are certain primary themes that run through the various definitions of spirituality, key among them being the search for meaning and the importance of human relationality at the level of the temporal and the Divine. Our previous discussion on the impact of religion on well-being indicates how these themes might be significant for modes of spirituality that do not include religion. Our study was designed to explore both religion and spirituality. However, the lack of clarity that surrounds the term 'spirituality' posed a significant methodological challenge. In order to deal with the lack of conceptual clarity we decided to construct an understanding of spirituality that in some senses captured the essence and key themes of the broad range of definitions of spirituality available in the literature, but which was evidence based and designed specifically to facilitate practical utility and effective empirical investigation.

In order to achieve this we developed a theoretical framework based on two key theorists whose work on generic forms of spirituality is recognised as significant and well evidenced: David Hay and Viktor Frankl. These two theoretical perspectives offered a way of understand-

ing and conceptualising key aspects of the more generic spirituality as they are outlined in the literature, in ways that were clear, appropriate and observable.

### *Spirituality as relational consciousness*

On the basis of research on the spiritual life of young children, Hay and Nye (2006) present an interpretation of spirituality as an awareness of one's intimate relationship with all reality whether of God, other people, one's environment or one's self. They argue that this awareness is built into the biology of the species as proposed by Alister Hardy in his Gifford lectures in Aberdeen University (Hardy 1965, 1966) and hence is a human universal. If Hardy and Hay are right, spiritual awareness cannot be confined to the religions or religious people. The ontological commitments of religion may make the spiritual dimension of human experience of great importance to believers, but it must at least be a potential in all human beings, including people who have utterly discarded religion.

Relational consciousness is experienced when one realises one's interconnectivity with others, with God (for the believer) and with the world in which one resides. As Hay puts it: 'A new awareness of the singularity of reality brings with it the realisation that I am much closer to other people, the environment and God than I had originally thought. In relation to other people and the environment I discover in myself an obligation to care for them, even to the point of self-sacrifice . . .' (D. Hay, personal correspondence). Relational consciousness is then a natural desire to reach out and connect with someone or something beyond one's Self. Importantly, it is accompanied by a sense of being obligated to care for other people, even to the point of self-sacrifice: altruism (Hay 2006, 2011).

Some people work out their relational consciousness through religion, which in its most authentic forms focuses on developing loving relationships with God, Self and others; for others it is worked out in different forms of relationship such as family, friends, community, nature and so forth. Most of the time we are not aware of the centrality of our relational nature. Culturally, particularly in the western world, the dominance of individualism (Hay 2011) teaches us that we are self-dependent individuals. However, at certain times, particularly moments of illness and crisis, we are brought to a fresh realisation that we are interdependent and that that interdependence matters for our well-being.

Hay's perspective is not mere speculation. Empirical evidence for his position comes from twin studies

designed to distinguish human characteristics that are inherited from those that are acquired from the environment. There is evidence that spiritual awareness is significantly linked to genetic inheritance across cultures. (Kirk *et al.* 1999, Ando *et al.* 2004) Likewise, studies from neurology indicate similarly that there seems to be a biological basis for the experience of religious and spiritual experiences. (Newberg & D'Aquili 2001; Beauregard & Paquette 2006)

Hay's approach to spirituality as relational consciousness allows us to look beyond the specifically religious manifestations of spirituality and focus in on the nature and significance of human relationships and process of seeking after relationships for the experiences of women with breast cancer.

#### *Spirituality as the search for meaning*

The second theoretical perspective underpinning this study is the meaning-centred approach developed by Austrian psychoanalyst Viktor Frankl. Through his experiences as a holocaust survivor Frankl came to recognise that the primary goal and drive of human beings had to do with a search for meaning, as he puts it: the will to meaning (Frankl 1969). 'Meaning of life refers to what each one makes of a given moment; it is not a general meaning that is revealed to us, but rather the way one chooses to perceive an event or another individual' (Breitbart 2006, p. 336). According to Frankl, meaning can be ultimate or proximate. Ultimate meaning relates to a person's relationship with God or their faith in something beyond normal metaphysical boundaries. Proximate meaning relates to something one sets one's mind to do at a temporal level; a goal to fulfil, to achieve something for a particular cause or person, to care for one's family, friends and so forth. Spirituality in this understanding relates to the human quest for meaning and purpose, which is ever present, but which comes to the fore acutely in times of trauma and existential crisis. The significance of Frankl's perspective for cancer care is evidenced by its use in a variety of contexts, in particular through the pioneering therapeutic work of William Breitbart on spirituality and cancer care (Breitbart & Heller 2003; Breitbart 2006).

#### *A practical perspective on spirituality*

Taken together, Hay and Frankl offer a practical perspective on spirituality that captures the essence of what health-care researchers seem to be trying to communicate when they speak about spirituality. An empirically ori-

ented perspective on spirituality (as opposed to a definition) developed from these two standpoints will enable the recognition and recording of the phenomenon of spirituality in a way that is clear and practical. To that end we might describe the perspective on spirituality adopted in this study as follows:

Spirituality is the quest for meaning, value and relationship with Self, others and, for some, with God. This quest provides an underlying dynamic for all human experience, but comes to the forefront in focused ways under particular circumstances. This quest for meaning, value and relationship may be located in God or religion, but in a secularised context such as the United Kingdom it may reveal itself in varied forms.

#### **Study aims**

The aim of the study was to develop an understanding of the role and function of religion and spirituality in the lives of women within the first year following a diagnosis of breast cancer with a view to facilitating improvements in QOL and spiritual care. Very importantly, it has been noted that the ways in which women adjust to their experience of cancer during their first year following diagnosis has implications for their longer-term mental health (Stanton *et al.* 2002; Hack & Degner 2004). That being so, we were interested in whether or not religion and spirituality functioned in a protective manner at this stage in their cancer journey and if so, how and why.

#### **Design**

The project utilised a qualitative method based on the perspective of hermeneutic phenomenology (Swinton & Mowat 2006). This approach brings together phenomenology and hermeneutics to provide a rich and thick description of the experience being observed and to offer a necessary interpretative perspective on that experience. As a method, hermeneutic phenomenology displays both descriptive and interpretive elements. It is descriptive (phenomenological) in that it seeks to be attentive to how things appear; it wants to let things speak for themselves. It is interpretive (hermeneutic) insofar as it claims that there are no such things as uninterpreted phenomena (Swinton & Mowat 2006).

#### **Sample/participants**

A random sample of 25 women were invited to participate in this study and from this 14 agreed to take part. The

**Table 1.** Participant information

Age	Tumour type	Marital status	Ethnic persuasion	Religious beliefs
60	Invasive ductal	Married	White Scottish	Church of Scotland
47	Invasive ductal	Single	White Scottish	Jehovah Witness
57	Invasive ductal	Married	White other British	Brethren
41	Invasive ductal	Married	White	Church of Scotland
66	Invasive ductal	Married	White Scottish	Other
39	Invasive ductal	Divorced	White	Muslim
52	Invasive ductal	Divorced	White Scottish	None
76	Invasive lobular	Married	White Scottish	Church of Scotland
63	Invasive ductal	Single	White Scottish	Other
42	Invasive ductal	Single	White Scottish	Church of Scotland
55	Invasive ductal	Married	White Scottish	None
42	Invasive lobular	Married	White American	Roman Catholic
54	Invasive lobular	Divorced	White Scottish	Christian
59	Invasive ductal	Married	White Scottish	None

women were approached by the breast care nurses or by the consultant surgeon at the Breast Clinic. The women who agreed to take part had received a diagnosis of breast cancer within the previous 12 months. All had been diagnosed in the Aberdeen Breast Clinic at Aberdeen Royal Infirmary, NHS Grampian. All of the women had undergone potentially curative surgery, and no patients had detectable metastatic disease at their initial presentation. The women were approached after the completion of their surgical, radiotherapy and chemotherapy treatment schedules. A total of 14 patients agreed to participate in the study. Those who declined to participate generally did so because they did not consider themselves to be religious, i.e. not affiliated with any formal religious tradition. This was despite the researchers being very clear that the study was not simply about organised religion and that non-religious people were included in its purpose and intentions. Of those who accepted the invitation to participate, some stated an allegiance to a particular religious tradition and others claimed to be spiritual but not religious. (See Table 1)

The majority of the religious participants were white and most identified themselves as Christian. This reflects the general demographics of the Grampian region of Scotland, which is primarily white and at least nominally Christian.

The small sample size is fully in line with hermeneutic phenomenological methods that focus on richness and depth. The transferability of findings depends on logical rather than statistical inference. It is the internal validity (credibility), as supported by, for example, direct quotations from participants, that enables the reader to assess the potential for generalisation into other settings. Thus the intention was to attain a credible and trustworthy account of the participants' experiences of spirituality and breast cancer.

## Data collection

Data were collected using a series of in-depth interviews that were carried out by breast care nurses, who had been specifically trained in line with the general principles of phenomenological interviewing (Van Manen 1990; Moustakas 1994). The object was to elicit rich and detailed information around the women's experiences. The interviews were recorded and transcribed, thus creating a text that would become the focus for the interpretive process.

## Ethical considerations

Ethical permission was received from the North of Scotland Research Ethics Committee (NOSRES Ref: 06/S0801/122) and The Research Ethics Committee at the University of Aberdeen.

## Data analysis

The analytical framework used in the study was an adaptation of the research frameworks developed in the work of Van Manen (1990) and Swinton (2001). The research process moved through a series of six stages, which can be outlined as follows:

- 1 The researchers immersed themselves in the texts that had been created. This involved reading them over and over in order to get a feel for the content and for the subtle nuances of the interactions with research participants.
- 2 During this process of immersion, and moving between individual phrases, sentences, chunks of narrative and the entire text and context (the hermeneutical circle), themes began to emerge that appeared to incorporate something of the essence of the experience of breast cancer and the role of spirituality in living with it.

- 3 These themes were then collected and organised and representative phrases and statements collected to illustrate and elucidate the various themes and their meanings (Van Manen 1990, p. 30). The various themes were grouped together and the researcher embarked upon a process of dialogical reflection, moving between the extrapolated themes (the parts) and the text as a whole (the hermeneutical circle) in order to check the authenticity of the themes, and to develop a deeper, fuller understanding of the meaning that was being expressed by the research participants.
- 4 The researchers then constructed a thematic analysis of each of the research transcripts. This involved structuring the themes in line with the various emphases within the text and developing an initial interpretation of the lived experience of each of the participants. Relevant extracts were taken from the text and used to illustrate and elucidate the various themes.
- 5 All of these data were collated, and the final process of interpretive reflection and narrative construction was embarked upon. This involved a return to the process of immersion, within which the texts were compared and contrasted in a search for constitutive patterns that unified all of the texts. Writing is fundamental to this form of research. 'Creating a phenomenological text is the object of the research process' (Van Manen 1990, p. 111). Through the process of writing and rewriting, the interpreted accounts were brought together and a final account constructed.
- 6 The research product was fed back to a group of research participants and their thoughts and comments were taken into consideration before the final draft of the account being produced.

## RESULTS

Reflection on the data brought out three key themes that seemed to capture something of the spirituality of the experience of these women within the first year following diagnosis

- Moving inwards: loneliness and reassessment of the Self
- Moving Outwards: relational consciousness
- Moving Outwards and upwards: ultimate meaning

### **Moving inwards: loneliness and the reassessment of the Self**

The first theme related to a turn inwards and a reassessment of who a person was and what their priorities were

in their new situation. Here the uniqueness of the women's experience was key. No one can share your experience of breast cancer.

Because in one sense anything like this is a very personal journey and nobody can actually share it with you, I mean they can become very close but it is a very personal journey and the ups and downs of it can be very personal. It's one of the biggest unknowns physically that I've ever stepped into. And no matter how much information people can give you, written, verbally or whatever . . . you still have to go through it on your own.

The movement inwards meant that, at least initially, the diagnosis of cancer was something that women had to face alone; the movement was from relationship to loneliness.

I remember waiting for the diagnosis in the clinic and I had a jolly good idea as time went on what was going to come and it was a big shock because I'd been very blasé about the whole thing and I don't quite know what I thought, I hadn't really given it much thought that was the thing. I thought well this is something I've got to cope with myself . . . [Crying. Interview suspended]

One woman described this sense of existential aloneness as being like 'walking through a glass tunnel that's got nails on it'. The metaphor of the glass tunnel seemed to signify a narrowing of horizons; a focusing in within which one can see (and be seen by) the outside world but can only move within the confines of the tunnel. The tunnel is a difficult and uncertain place, made worse by the fact that one's emotional pain, while inexpressible in language that will make sense to those outside, is nonetheless difficult to hide from the outside world.

Right at the very middle of it really, I was really quite unwell, and em, after the first three chemos my tumour had actually grown. I had three tumours, but the bigger tumour had actually got bigger and I did find that really difficult. I was trying not to let my husband see that I was upset; we've always tried to be really honest with one another as well.

The tunnel contains the pain, but those looking through its glass sides can only see aspects of it. The woman inside sees, feels and experiences things that cannot be spoken, only observed from a distance.

The turn inwards enabled women to frame and to reframe their experience and to explore what resources

they may have to cope with the situation. The primary resources that all of our participants turned to were in the realm of the relational. Initially breast cancer was seen as a death sentence: 'When you are diagnosed with breast cancer you feel like it is a death sentence . . . not just for me but for all the people who depend on me'. The threat that breast cancer brings opens up questions of mortality for the women. It marks the end of hopes, plans and expectations and is perceived as a personal and a communal event. It is communal insofar as it brings with it the potential for a multitude of smaller deaths that relate to the hopes, dreams, expectations and possibilities that affect both the woman and her circles of relationship. The woman might die, but so, in multiple ways, will aspects of those who love her.

At this stage women are faced with a choice: to allow the diagnosis to leave them lonely and fearfully under the shadow of death, or, to explore other possibilities. Either is a option. However, for our participants, the turn to relationships was in all cases apparent.

The diagnosis was devastating but once my inner strength kicked in I began to see it as possibly a positive . . . Having children and a reason to keep going has really helped.

Here Frankl's idea of seeking after proximate meaning begins to come to the fore. In the face of the trauma and uncertainty of the diagnosis of breast cancer this woman discovers a goal to fulfil and an achievement to be made, in this case caring well for her family.

Your family go through the pain and shock just like you do. My son (he's 5) got really angry to start with, but in time he has coped with it quite well. My daughter (she's 7) has struggled . . . she can't really let go of it and move on I feel I need to be strong for her. But that is a good challenge for me! It forces me to think about how I can face things positively.

Thus, by recognising and exploring the importance of proximate meaning for the process of coping, the turn inwards began to enable a turn outwards; a turn towards recovering meaning through relationships with others; a turn towards spirituality.

### **Moving outwards: relational consciousness**

As women began to come to terms with their experiences of cancer, they started to notice things they had not previously been aware of, in particular the significance of their embeddedness in a complex mesh of relationships that were potentially healing. These relationships were

fundamental to their ability to positively frame and cope effectively with their illness experiences.

I have got some really true friends and that's something you do find out when you have cancer: who your friends are . . . I think we always know there's people out there but I think sometimes you don't realise just how many people care for you . . . I think I've always been a person that's appreciated it, but it certainly does highlight it and I've gotten much closer to people. I'm a person who, if I make a relationship, I make them for life and I would be really close with them but this has even made it closer. I think I've allowed them to come into this with me . . .

Relationships had always been central to the lives of this woman. Now the implicit becomes explicit. The experience of turning inwards, slowing down and taking stock opened up a conduit for the recognition and expression of relational consciousness.

I think I've realised how important I am to a lot of people and how much support I have from so many sources, how important I am to my parents, sisters and brother has been a real eye opener. It's given me a chance to discover that which is a nice thing really. Being needed, being important in other people's lives, being a good friend, a good mum, a good wife, yeah those things. I think having children and a reason for going on, my husband, lots of friends around keeping me going has really helped.

What we see here is a coming together of Frankl's search for proximate meaning and Hay's emergence of relational consciousness, to relocate the women in the midst of a vital relational network that reshapes and reforms the meaning of the cancer event. These relationships had of course always been there, but their presence and significance came sharply to the fore in the face of the experience of breast cancer. In a real sense, the presence of the illness and its implications enabled the women to access their relational consciousness and appreciate and participate in the interconnectedness of proximate spirituality. One woman summed this up quite movingly:

I'm not sure I believe in God as such, but I believe in people and people's kindness to each other . . . so that's what spirituality means to me, the fact that we are spiritual, we will help each other and we do care about each other in a more meaningful way than just looking after each other when we're well.

The important thing to notice within this dimension of the women's experience is the implicit spirituality that

came to the fore and that became profoundly important for the ways in which they perceived and dealt with their illness experience. Religion was not necessary; but spirituality was central to their experiences.

### Moving outwards and upwards: ultimate meaning

While proximate relationships and the spirituality that emerged from them were important for the women in our study, for some, their search for meaning and the focus of their emerging relational consciousness stretched beyond the human and into the realms of ultimate meaning. For those women the primary meaning of the term 'spirituality' had to do with a person's relationship with God and the various consequences of engaging in such a relationship.

... well spirituality to me is really just my relationship with Jesus Christ, that's my spirituality and that is what you know... gives me my peace... inside and freedom; it's my relationship with Christ. That's what spirituality means to me.

A relationship with God was always available to these women through prayer and through the prayers of others:

Sometimes when I have been, you know, really down... in the pits and thinking how am I going to claw myself back out of here... the power of prayer has carried me... at times when I have been at my lowest I have discovered that some people have been praying for me.

While non-religious women discovered they were enmeshed in a temporal web of proximate relationships that was deeply healing, those with a religious commitment had a similar experience at the level of the Divine.

Yes, I did take more time out to pray, and it was very important to me, you know I do pray often and ask for help with this, and also to thank God for all the people, all the different ways that people were helping me and supporting me. For example lots of people were saying that they'd added me to their prayers. At the church where I grew up, other people were saying they were praying for me. It was very important to me to have that support, but also for me to go directly to God... I'm Catholic and believe that Mary is also a good intercessor, so I was asking her as well... throughout my treatment I wore some sort of religious medallion, a cross or I've got... a medal with Mary on it.

Not only were these women drawn more deeply into their relationship with God, they also came to realise the sig-

nificance of their spiritual connections with other believers and, interestingly, with religious figures and icons. In this way their relational network was deepened and thickened and their options for developing a sense of meaning and relational connection increased.

The perceived presence of God, Mary, Jesus, the prophet Mohamed, Buddha and so forth, combined with the prayers that people offered on the women's behalf, seemed to function both as an extension of their social support and as a stabilising force. The stabilisation seemed, at least in part, to come from the fact that specifically religious beliefs offered answers to significant existential questions that were not available elsewhere. For example, rather than breast cancer being perceived as a random event in a meaningless universe, religiously oriented women grafted it into a different explanatory framework.

I would say your life's probably mapped out for you and each day is a new day and each day you find different things come along and how you handle them and I believe at times there is help out there to be got and there is somebody who helps you to be strong.

Even the negative experience of breast cancer could be understood as in some sense providential, that is, relating to a wider Divine plan. God has a plan for everyone's life and even breast cancer has meaning and purpose within this bigger plan. In this way women seemed able to gain a degree of control over their situation and find a sense of meaning and hope even in the midst of the profound challenges that the diagnosis of breast cancer brought to them.

### Who is to blame for the cancer? From Theodicy to Anthropodicy

The question of how women perceived the causes of their breast cancer was an interesting one. One might have expected that those with a religious spirituality would engage in some kind of theodicy: an explanation of how an all powerful loving God could allow such a thing to happen. In fact what we found was that women were more likely to offer an anthropodicy: an explanation of the cause of their illness that blamed it on human beings, including themselves.

He's [God] always there for me. I think that was the most wonderful thing... when I had the cancer because when the professor came and gave that talk, you know that evening I thought, my goodness I am a candidate! My weight and drinking... I thought, you know, have I caused this cancer; but then because I

know who I am and I know that He [God] loves me so much He would never ever have chose this for me.

There is an interesting tension here. On the one hand God is perceived to be in control and has a plan for everybody; but on the other hand the woman is convinced that God had not directly brought her cancer upon her. It is particularly interesting to note the way in which the talk from the professor, presumably on the nature and cause of the illness, had raised issues with regard to self-blame and that these issues were clearly of some concern. However, the concerns raised by the medical explanation seemed to be eased and overcome by the spiritual beliefs that the cancer was not caused by God and that no matter what the cause of the cancer was, it is here now and she has not been left on her own. She has found a source of relational support, comfort and hope that transcends the boundaries of medical possibility and explanation and opens up the future in new ways.

## DISCUSSION

The three movements of the breast cancer experience – inwards, outwards and upwards – trace a complicated relational dynamic within which women seek to cope with and make sense of living with a diagnosis of breast cancer. A key finding is the observation that, in terms of the inward movement, it is clear that woman need to be given time to discover the meaning of the inner existential loneliness that is created by the diagnosis and ongoing experience of breast cancer. Women need time and inner and outer space to begin to work through what the diagnosis means for the way in which they perceive themselves in the world. It may be that at this stage, facilitating and creating space and time for reflection, including religious and spiritual reflection, are as important as medication and medical intervention.

With regard to the outward movement towards proximate relationships, it is important to note that while breast cancer is obviously a biological condition, it is also and equally a social and relational experience. Breast cancer always belongs to and deeply impacts upon an individual *and* a community. That broader set of relationships is a powerful source for hopeful meaning making that is fundamental for the women's well-being. Recognising and facilitating proximate relationships is a spiritual task that takes seriously the emergence of relational consciousness and the impact that this has on coping and the maintenance of well-being. In order to care well for the individual one needs to recognise the social nature of breast cancer and care well for individuals and their communities.

Our research worked on the premise that spirituality is a relational concept that comes particularly to the fore during the journey of breast cancer. That being so, supporting and encouraging relationships is a primary task of spiritual care. For the women in our study, their relationships primarily came from their natural social circle. All of our participants had strong social networks and were able to work out their proximate spiritual needs without any real difficulty.

However, consideration needs to be taken of people who have small or even non-existent social networks. For example, social networks tend to shrink as people get older. Precisely how can health-care workers help to facilitate the fulfilment of relational consciousness in elderly women who have weakened social networks? Questions such as this warrant serious consideration and require to be earnestly and creatively addressed.

With regard to the upward movement, for some of the women in our study, religion played a significant role, offering a different way of explaining, framing and coping with breast cancer. In line with the general findings within the literature, religion offered ways of cognitively realigning the experience of breast cancer, thus enabling more effective coping. It also offered an external dimension of social support that often goes unnoticed. The religious women in our study clearly seemed to draw religious figures into their social network and to act towards them according to how they were perceived. The religious figures that they related to may be perceived by an outsider as 'imaginary' and therefore inconsequential to the clinical process. However, in terms of social support and positive psychological impact, these figures were very real indeed. God became a powerful dialogue partner to whom they turned in times of need.

Religion, therefore, cannot be understood if it is assumed to be a global term that means the same thing to all people in all contexts. Rather, religion is a framework of ideas and concepts that while sharing some common ground with all believers, is often worked out and interpreted in ways that are deeply personal and that relate in deep but often hidden ways to the complexities of the individual's experience. Learning to understand the complicated ways in which religion functions as a system of explanation and coping on an individual level is crucial for understanding how women are actually experiencing their illness.

The study has two weaknesses that are worth highlighting. First, there is an issue with self-selection. The women who took part did so because they had a stated interest in spirituality. In other words the participants did not come from a neutral position. That being so, the findings may

not necessarily represent the views of the more general population. However, this weakness is not unique to the study of spirituality. Any study that asks participants if they are interested in the subject matter will have a similar issue with self-selecting participants. The fact that the results of this study resonate strongly with the wider literature indicates that while self-selection is an issue, either it is an issue for all studies that have looked at spirituality and breast cancer, or our study has captured the dynamic it was intended to.

Second, it focused on a relatively small group of people thus reducing the options for generalisability. However, as has been shown, this approach is methodologically sound and does not reduce the practical application of the findings. The intention was to present the experience and enable people to discover resonances with their own situations; resonances that have the potential to lead to positive changes in perspective and practice.

### **Implications for practice**

The study has important implications for research and practice in the following ways:

- 1 The observations surrounding the inner movement that is initiated by a diagnosis of breast cancer is important and indicates a need for carers to learn how to initiate clear, meaning-centred conversations around the impact of diagnosis. If, as our results suggest, this is a time of reassessment and reconstruction of the self, then it will be beneficial for health-care professionals along with family and friends, to recognise the need for the creation of physical and emotional spaces to enable such reflection and for all parties to recognise that withdrawal and angst may have healing possibilities rather than simply being seen as depression or avoidance. Our study offers information and perspective that could facilitate therapeutic understanding and effective clinical empathy.
- 2 The observation that spirituality is a relational concept is important. Cancer belongs to communities as well as individuals and these communities are vital for women's well-being. All of the women in our study had strong relational networks. They therefore had adequate resources for working out their proximate spiritual issues. However, for many women with weakened or non-existent relational networks, dealing with the emergence of their relational consciousness will be difficult and perhaps impossible. This may have an impact on well-being and mental health in the short and the long term. Health-care providers should be sensitive to women's relational networks and seek to recognise people who are relationally vulnerable. Incorporating and focusing on questions around spirituality and relational connectedness within standard approaches to caring has real potential in helping to recognise spiritually vulnerable patients and preparing to meet their needs.
- 3 Sensitivity to the spiritual in its religious and non-religious form is a key aspect of the caring process that needs to permeate and guide all of our practices of care and out tasks of understanding. In particular the complexities of what religion means and how that meaning impacts upon a person's understanding of what is happening to them is vital. It is not enough simply to note that a person has a religious belief. These beliefs may be central to the way in which she understands and reacts to the process of treatment and care. To misunderstand or misrepresent a woman's beliefs may be to misinterpret the very essence of what she perceives to be happening to her. Recognising and working with the meaning dimensions of religion is an important clinical task and responsibility. Breitbart's (2006) work on meaning-centred therapy groups is a good example of what this might look like in practice.
- 4 The observation that good and accurate information about breast cancer can lead to self-blame and guilt is worthy of consideration. In a social context where people look to medicine for explanation and meaning in the ways that at one time they may have looked to religion, great care and sensitivity is required by those who have responsibility for information giving. Doctors are in a position of great power. The information they provide will shape and form the ways in which women understand their illness and the range of options that they may have to deal with it. A focus on spirituality and the meanings that can be ascribed to information given enables the therapeutic implications of meaning construction to be held at the forefront of the thinking of health-care professionals.
- 5 Finally in terms of research, the model and approach that was developed in our study provides a working model of spirituality, which is designed specifically to facilitate empirical enquiry. This model has the potential to be transferred into other research contexts.

Our study then enables carers to recognise and respond to the hidden dimensions of the experiences of women with breast cancer. In recognising and responding to the depth and complexity of women's spiritual experience, new possibilities for effective and deeply empathetic care are opened up. Our study has contributed to the beginning of an important conversation.

## REFERENCES

- Ando J., Suzuki A., Yamagata S., Kijima N., Maekawa H., Ono Y. & Jang K.L. (2004) Genetic and environmental structure of cloninger's temperament and character dimensions. *Journal of Personality Disorders* **18**, 379–393.
- Bauer-Wu S. & Farran C.J. (2005) Meaning in life and psycho-spiritual functioning: a comparison of breast cancer survivors and healthy women. *Journal of Holistic Nursing* **23**, 172–190.
- Beauregard M. & Paquette V. (2006) Neural correlates of a mystical experience in Carmelite nuns. *Neuroscience Letters* **405**, 186–190.
- Brady M.J., Peterman A.H., Fitchett G., Mo M. & Cella D. (1999) A case for including spirituality in quality of life measurement in oncology. *Psychooncology* **8**, 417–428.
- Breitbart W. (2006) Enhancing meaning in palliative care practice: a meaning-centered intervention to promote job satisfaction. *Palliative and Supportive Care* **4**, 333–344.
- Breitbart W. & Heller K.S. (2003) Reframing hope: meaning-centered care for patients near the end of life. An interview with William Breitbart. *Innovations in End-of-Life Care* **4**, Available at: <http://www2.edc.org/lastacts/> (accessed 17 June 2011).
- Burgess C., Cornelius V., Love S., Graham J., Richards M. & Ramirez M. (2005) Depression and anxiety in women with early breast cancer: five year observational cohort study. *British Medical Journal* **330**, 702–705. doi:10.1136/bmj.38343.670868.D3 (published 4 February 2005).
- Cancer Research UK (2010) *Breast Cancer Statistics – Key Facts*. Available at: <http://info.cancerresearchuk.org/cancerstats/types/breast/index.htm?script=true> Accessed 1800. 4/03/10.
- Carpenter J.S., Brockopp D.Y. & Andrykowski M.A. (1999) Self-transformation as a factor in the self-esteem of breast cancer survivors. *Journal of Advanced Nursing* **29**, 1402–1411.
- Choumanova I., Wanat S., Barrett R. & Koopman C. (2006) Religion and spirituality in coping with breast cancer: perspectives of Chilean women. *The Breast Journal* **12**, 349–352.
- Coward D.D. & Kahn D.L. (2005) Transcending breast cancer: making meaning from diagnosis and treatment. *Journal of Holistic Nursing* **23**, 264–283.
- Dein S., Stygal J. & Martin P. (2006) The use and expectations of prayer among women with breast cancer. *Healing Ministry* **13**, 23–31.
- Dey L., Chouliara Z. & Tiliopoulos N. (2006) Experiences of spirituality and breast cancer. Published Abstract, The BPS Scotland Annual Conference, November 2006, Perth.
- Frankl V. (1969) *The Will to Meaning. Foundations and Applications of Logotherapy*. New American Library, New York, USA.
- Gall T.L., Charbonneau C. & Florack P. (2011) The relationship between religious/spiritual factors and perceived growth following a diagnosis of breast cancer. *Psychology and Health* **26**, 287–305.
- Geertz C. (1985) *Religion As A Cultural System. Anthropological Approaches to the Study of Religion*. M. Banton, Tavistock Press, London, UK.
- Gullatte M.M., Brawley O., Kinney A., Powe B. & Mooney K. (2010) Religiosity, spirituality, and cancer fatalism beliefs on delay in breast cancer diagnosis in African American women. *Journal of Religion and Health* **49**, 62–72.
- Hack T.F. & Degner L.F. (2004) Coping responses following breast cancer diagnosis predict psychological adjustment three years later. *Psychooncology* **13**, 235–247.
- Harandy T.F., Ghofranipour F., Montazeri A., Anoosheh M., Bazargan M., Mohammadi E., Ahmadi F. & Niknami S. (2010) Muslim breast cancer survivor spirituality: coping strategy or health seeking behavior hindrance? *Health Care for Women International* **31**, 88–98.
- Hardy A.C. (1965) *The Living Stream*. Collins, London, UK.
- Hardy A.C. (1966) *The Divine Flame*. Collins, London, UK.
- Hay D. (2006) *Something There: The Biology of the Human Spirit*. Darton, Longman & Todd, London, UK.
- Hay D. (2011) Altruism and spirituality as forms of relational consciousness and how culture inhibits them. In: *The Origins and Nature of Cooperation and Altruism in Non-Human and Human Primates* (eds Sussman R.W. & Cloninger C.R.). Springer, New York, USA (forthcoming).
- Hay D. & Nye R. (2006) *The Spirit of the Child*, 2nd edn. Jessica Kingsley Publishers, London, UK.
- Hebert R., Zdaniuk B., Schulz R. & Scheier M. (2009) Positive and negative religious coping and well-being in women with breast cancer. *Journal of Palliative Medicine* **12**, 537–545.
- ISD Scotland. (2010) *Breast Cancer*. Available at: <http://www.isdscotland.org/isd/1420.html#Summary%20statistics%20for%20breast%20cancer> Accessed 1800. 4/3/10.
- King M.T., Kenny P., Shiell A., Hall J. & Boyages J. (2000) Quality of life three months and one year after first treatment for early stage breast cancer: influence of treatment and patient characteristics. *Quality of Life Research* **9**, 789–800.
- Kirk K.M., Eaves L.J. & Martin N.G. (1999) Self-transcendence as a measure of spirituality in a sample of older Australian twins. *Twin Research* **2**, 81–87.
- Leak A., Hu J. & King C.R. (2008) Symptom distress, spirituality, and quality of life in African American breast cancer survivors. *Cancer Nursing* **31**, E15–E21.
- Leshner G., Cheng I.-H., Song H.J., Choi Y. & Frisby C. (2006) The role of spiritual health locus of control in breast cancer information processing between African American and Caucasian Women. *Integrative Medicine Insights* **2**, 35–44.
- Levine E.G. & Targ E. (2002) Spiritual correlates of functional well-being in women with breast cancer. *Integrative Cancer Therapies* **1**, 166–174.
- Meraviglia M. (2006) Effects of spirituality in breast cancer survivors. *Oncology Nursing Forum* **33**, E1–E7.
- Mickley J.R., Soeken K. & Belcher A. (1992) Spiritual well-being, religiousness and hope among women with breast cancer. *Image—the Journal of Nursing Scholarship* **24**, 267–272.
- Moustakas C. (1994) *Phenomenological Research Methods*. Sage Publications, London, UK.
- Nairn R.C. & Merluzzi T.V. (2003) The role of religious coping in adjustment to cancer. *Psychooncology* **12**, 428–441.
- Newberg A. & D'Aquili E.G. (2001) *Why God Won't Go Away: Brain Science and the Biology of Belief*. Ballantine Books, New York, USA.
- Pargament K.I. (2002) The bitter and the sweet: an evaluation of the costs and benefits of religiousness. *Psychological Inquiry* **13**, 168–181.
- Pargament K.I. (1997) *The Psychology of Religion and Coping: Theory, Research, Practice*. Guilford Press, New York, USA.
- Purnell J.Q., Andersen B.L. & Wilmot J.P. (2009) Religious practice and spirituality in the psychological adjustment of survivors of breast cancer. *Counseling and Values* **53**, 165–185.
- Scottish Executive (2002) *Spiritual Care in NHS Scotland*. NHS HDL (2002) 76. Available at: [http://www.sehd.scot.nhs.uk/mels/hdl2002\\_76.pdf](http://www.sehd.scot.nhs.uk/mels/hdl2002_76.pdf) Accessed 1342 17/01/11.
- Sorajakool S. & Seydel B. (2005) Theological strategies, constructing meaning, and coping with breast cancer: a qualitative study. *Pastoral Psychology* **54**, 173–186.
- Stanton A.L., Danoff-Burg S. & Huggins M.E. (2002) The first year after breast cancer diagnosis: hope and coping strate-

- gies as predictors of adjustment. *Psychooncology* **11**, 93–102.
- Swinton J. (2001) *Spirituality in Mental Health Care: Rediscovering a 'forgotten' dimension*. Jessica Kingsley Publishers, London, UK.
- Swinton J. & Mowat H. (2006) *Practical Theology and Qualitative Research*. SCM Press, London, UK.
- Swinton J. & Pattison S. (2010) Moving beyond clarity: towards a thin, vague, and useful understanding of spirituality in nursing care. *Nursing Philosophy* **11**, 226–237.
- Thuné-Boyle I.C., Stygall J., Keshtgar M.R., Davidson T.I. & Newman S.P. (2010) The impact of a breast cancer diagnosis on religious/spiritual beliefs and practices in the UK. *Journal of Religion and Health* Early View, Article first published online: 26 MAY 2010. <http://www.interscience.wiley.com>.
- Van Manen M. (1990) *Researching Lived Experience: Human Science for An Action Sensitive Pedagogy*. State University of New York Press, New York, USA.
- Visser A., Garssen B. & Vingerhoets A. (2010) Spirituality and well-being in cancer patients: a review. *Psychooncology* **19**, 565–572.
- Zwingmann C., Wirtz M., Müller C., Körber J. & Murken S. (2006) Positive and negative religious coping in German breast cancer patients. *Journal of Behavioral Medicine* **29**, 533–547.