

‘How are you feeling?’: a qualitative study examining how cancer survivors frame the quality of their lived experiences.

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Abstract

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Introduction

The likelihood of surviving cancer has steadily increased due to improved diagnostics, surgical and radiotherapy techniques, molecular biology and systemic therapy (Ministry of Health [MOH] 2015b, Malvezzi *et al.* 2014, Maddams *et al.* 2008, Manos *et al.* 2009). For example, testicular, prostate and female breast cancer have a one-year relative survival of greater than 90%, a sustained rate of 80% at five years and 75% at ten years (MOH, 2015a). However, people who survive cancer can experience significant prolonged psychosocial and iatrogenic harms caused by symptoms of the disease, and diagnostic procedures and treatment. These various effects can singularly or collectively be present long after the original cancer is no longer detectable or needing active treatment (Fallowfield & Jenkins, 2015; Berry *et al.* , 2014). As well as dealing with ongoing effects, people who have survived cancer also live with the potential for its recurrence (Hawley *et al.* 2017). Together, these characteristics have led to cancer being viewed as a chronic condition rather than a terminal illness (Tritter & Calnan, 2002; Aziz & Rowland, 2003), with people who are no longer being cared for by oncology specialists and in remission for five years or longer, as still being on the cancer journey (Hewitt, Greenfield, & Stovall, 2006, p. 25; National Cancer Institute, 2014). The terms ‘cancer survivor’ (Institute of Medicine, 2008, p. 23; Richards, Corner, & Maher, 2011) and ‘Living Beyond Cancer’ (Department of Health, 2013; Department of Health 2010) have been coined to express the post treatment stage of the journey.

Background

Not all cancer survivors survive well (Walthert, 2012) often due to the health needs related to their cancer experience not being met (Department of Health, 2013). Various researchers have examined the best ways of

meeting these needs to ensure the long-term health of cancer survivors (Lawn, Fallon-Ferguson, Koczwara, 2017; Mathews & Semper, 2017; Rubin, Berendsen, Crawford, *et al.*, 2015; Department of Health, 2013; Hewitt, Greenfield, & Stovall, 2006; Mols, Vingerhoets, Coebergh, & van de Poll-Franse, 2005) with one of the suggested ways forward being the referral of cancer survivors to cancer survivor support groups, which can include services such as meetings that provide education, sharing of experiences and counselling (Bultz, Speca, Brasher, Geggie, & Page, 2000). However, there has been relatively little research into what types of ‘support’ survivors use and the effectiveness of these strategies in improving their quality of life. The Cancer Society of New Zealand (Canterbury/West Coast Division) had identified a need to understand what support would help survivors to resume life with and after cancer and asked us to examine this on their behalf. The aim of our study was to explore the experiences of long-term (>5 Years) cancer survivors to develop an understanding of what they believed led to a high quality lived experience after having survived cancer.

Design

Because we saw the participants as the experiential experts on the subject (Smith & Osborn, 2008), we used a qualitative, phenomenological hermeneutical approach (Lindseth & Norberg, 2004). A critical realism perspective (Bhaskar & Hartwig, 2016) enabled us to give significance to the participants’ individual experiences (Giorgi & Giorgi, 2008). The Tong, Sainsbury & Craig (2007) consolidated criteria for reporting qualitative research (COREQ) guidelines was used as the framework for developing the study design and the data was examined by both researchers using Lindseth and Norberg’s (2004) phenomenological, hermeneutical method for analysing interview data. Thematic analysis was used to identify patterns within and across the participants’ experiences, views and perspectives (Clarke & Braun, 2017).

Methods

Participants

Our purposive participant sample was recruited from two cancer survivorship support groups run by the Cancer Society, specialist oncologists and a tertiary oncology treatment centre. Health professionals (specialist oncology nurses, volunteers working in oncology services, general practitioners, practice nurses and domiciliary nurses) at the Society and each of these units gave potential participants information sheets about the project that asked them to contact us if they were interested in participating.

Data collection

Over a period of two months, from October-December 2016, we conducted single occasion semi-structured interviews with the cancer survivors that focused on the participants’ experiences of living beyond cancer. The participants could follow their train of thought and include any material they thought was relevant. These interviews took place in their homes and lasted approximately 60 minutes. Interviews were recorded and both researchers kept reflective and descriptive field notes. Interviews were transcribed by a contracted transcriber who had signed a confidentiality agreement.

Data Analysis

Our reading of the transcripts was naive, prolonged, contemplative and empathetic as we wanted to be open to all potentials and possibilities. We read each transcript in its entirety several times to develop an overall impression and then divided the text into units of meaning. After all possible meanings and contextual aspects were identified (Corbin & Strauss, 2008) we grouped the units of meaning into tables under

overarching headings. Each group was then separately examined and arranged into categories. Subthemes were identified, sorted into tables and analysed for themes and overarching themes. This process continued until we understood and could substantiate the emergent themes.

Rigour

Both researchers analysed all the transcripts and cross-checked each other's analysis (Tong, Sainsbury & Craig, 2007). We discussed any differences and then either developed a new theme or allocated the data to an agreed code. Although we reached saturation (where no new data emerged) after analysing ten transcripts, we continued the analysis over the remaining four transcripts to ensure that this was indeed the case. As we are both registered nurses we had to be mindful of not imposing our professional views on the views of the participants so that useful insights were overlooked. We kept reflective logs and involved a lay researcher in the project to challenge our interpretations and assumptions, especially as none of the participants wanted to review their transcripts. (Yardley, 2000). Given that the researchers and participants were of European ethnicity we also involved a researcher of different ethnicity, again to challenge our interpretations and assumptions.

Ethics

Our study was approved the University Human Ethics Committee. Participants were provided with information sheets explaining the study and our expectations should they decide to participate. They were considered a study participant once they had given their written consent indicating their understanding of the study, what was required of them, how their confidentiality would be protected (through the allocation to codes to transcripts and field notes, confidentiality agreements for transcribers, and anonymised publications), and that they could withdraw at any time and have any data removed if they wished. Participants were given the opportunity review their manuscripts. No one chose to do so.

Results

Fourteen cancer survivors participated, these being six men and eight women of European descent, aged 42-75 years, in remission from head and neck, female breast, bowel and prostate cancers. All the survivors had completed a suite of diagnostic and treatment services in their home city, a centre with a population of 400,000 serviced by a full range of primary, secondary and tertiary health services. Our analysis of their experiences exposed a pattern of responses that aligned into positive and negative clusters from which two central themes emerged: 'connectedness' and 'disconnectedness' that were linked with 'living well' and 'suffering'.

'I am living well': connection to self, others and context

The analysis identified that the following attributes were important aspects of enjoying life: being positive, fortunate, accepting, grateful, certain, altruistic, independent, personally evolved, comfortable with self-image and bodily changes, feeling well and strong, being loved and supported personally, well informed and supported in care, and having access to fresh air and outside space. The essence of enjoying life therefore seemed to involve a sense of being connected to self, others and to context (be it the home, social and professional networks, places where care was provided and the people providing care). Being connected to 'self' involved physical and psychological aspects. Physical aspects included feeling comfortable with body changes and self-image and being well or strong.

| My body has changed. It forced me to try new looks that I wouldn't have had the
| courage to do before. It's been a lot of fun. (P3)

Psychological attitudes related to being positive, optimistic, certain, accepting, confident, independent, resilient and looking outwards.

It's the power of positive thinking, and for me it was always there." "All those people that have gone down the road of radiotherapy or... chemo or whatever, some of them have suffered badly along the way... they've lost their hair, they've lost this, they've lost that. They actually have to dig deep. They really have to. And I guess for some of them if it was never in their persona to be like that, they're going to have a very difficult time. (P6)

I had a really, really, really good positive mental attitude, like massively and the fact that there was no point worrying about it. (P11)

I never doubted, I never had any doubt or disbelief in myself. (P4)

I am a coper, absolutely. (P18)

I woke up after my day of operation the next day I thought that's it, that's gone.

And I think I have not deviated off that path ever since. (P4)

Having confidence involved surpassing their own expectations and those of others around them in coping with the challenges of the condition. New strengths and previously unknown resilience and abilities to find support enabled them to withstand the pressures and adversities of the cancer journey.

I felt I had my friends to get together with and talk about it and I did. (P18)

Sometimes it's harder for your partner and your family than it is for you. Because you've got it, you've got to deal with it. You love all of their support but they can't reach in and fix it. (P11)

Looking outward comprised being grateful, fortunate, and lucky.

The more people you tell, the more people know, the more support you've got. Then more chance you've got of succeeding. (P11)

I think it's [cancer] made me a nicer person, a kinder person. Certainly, more compassionate... I will go the extra mile and help somebody... I guess that's my philosophy: I do it because I can. (P6)

I tell people this, if you said, 'I'll give you a million bucks so you don't have to have cancer' I'd say, 'you can keep the million bucks because it's an experience you can't buy'. It's an experience that not everyone gets to go through and it gives you a whole different perspective on the world. (P11).

We were lucky it got picked up when it did. (P1)

Being connected to others meant feeling loved, supported, personally evolved, and altruistic. It included acknowledging that those providing support faced their own challenges through the cancer journey and that survivors had a responsibility to support them.

I was going through chemo for six months and I had to drive myself there because he [husband] couldn't. The kids still had all the same things on in the evenings and I had to drive the kids there every night. Even after I'd had chemo. (P18)

It has been just as hard on her to keep her spirits up and try and buoy me up and I'm trying to stay strong for her, so we're trying to stay strong for each other. (P1)

Being connected to context meant feeling comfortable with healthcare settings and the professionals who worked in them. This, in turn, meant feeling supported by those providing professional and lay care, being well informed and able to seek help and experiencing feelings of indebtedness, gratitude, and altruism.

I enjoy the physical aspect of the farming and I need that. I need to do that for my wellness. . . I'd rather be doing positive things and out in the fresh air. (P6)
Our contribution to the support group gives us a sense of gratitude and value. (P1)
I needed to give something back. (P11)
Now if I go along [to the support group] I go to see if I can support somebody. (P4)
That's where we're ok if we can advocate. . . Because, you know, you can guarantee we're not the only ones in this situation. (P1).

It also involved being connected to communities, professional and social groups and the environment. 'Living well' was underpinned by a strong sense of connectedness to self, others and context.

'I am suffering': disconnection from self, others and context

Our analysis found that the essence of suffering meant being disconnected from self (physically and psychologically), others and context. Disconnection with the physical 'self' meant being in pain or uncomfortable, less functional, dependent, and feelings of loss related to self-image.

Every day I still have the pills and aches and pains and I feel like an old nana at the end of the day, I'm an 80-year-old and I can't walk. I'm in so much agony with the stiffness of my joints without having any oestrogen in my body. (P7).
I look at my face and I don't look the way I used to. I lost an enormous amount of face tissue. (P4)

Psychological disconnection from the 'self' meant being frightened, uncertain, insecure, sad, frustrated, angry, dependent, less mentally focused and mentally dull, and stressed.

. . . .lying in wait. . . . It could be a time bomb waiting to go boom. (P14).
Because I didn't want it to come back. And that was another thing for me, because of where I work I was always thinking it was coming back. And I was really paranoid about it. (P3)
I just cried and cried. And yes, that was Sam and my oncologist said oh Sarah are you having a bad day? And I said yes I can't stop crying. (P2)
So my mood's not been good the last three years. . . . (P14)
I was so pee'd off about it and depressed about it and started to get really down about it. (P2)

The idea that positive treatment benefits would not eventuate was prevalent as was the view that the end of cancer treatment did not necessarily signify the end of the cancer journey.

Having that last lot of chemo, it's like where is your life going from here? Are you back in six months because it hasn't worked? Are you gone for good? Are you back in a week because it hasn't worked? You know, where are you? (P3)
I thought hey, ooh, we're fixed. Yeah right. . . It's the legacy of it [cancer], you know, the cancer's that small but the legacy's that big. Problems and the ongoing things. (P2)

Being disconnected from others meant feeling isolated, unsupported, misunderstood, stigmatised and helpless in the face of family suffering and stress. There was little to be gained from sharing their story with others who had not gone through the same experience.

You tell everyone you're fixed, you tell your family and they all sighed with relief and go great and they all move on. So they're not focusing on you either. So it's like . . . mmm, where am I? Am I ok? (P7)

Others you just didn't hear from because they had their own issues about whether you are going to survive or not survive and whether it will affect them and they don't want to know. (P14)

The way I usually deal with them [meltdowns] is to isolate myself. I'll often leave the family down here and go upstairs and move away from them. (P18)

I felt very alone. . . . (P2).

Being disconnected from context meant being 'cut loose', insecure, afraid, inadequately informed, unsupported, being a nuisance, and not trusting a health system that could be self-interested and capricious; for example, being labelled a nuisance by the health system could undermine access to future care.

I thought to myself now they said they'd do . . . follow up, and six months. . . that came and went so I emailed my cancer care nurse. She said you should have been having three monthly blood tests. . . I don't know who was meant to organise that. (P15)

There was no consultation back and there was sort of no follow up process. (P18).

I wouldn't say its [support group] actually helped me. . . . (P4)

Support groups aren't great. They don't help much and just load it onto the people who are there. (P14)

I've got too much of my own stuff to deal with to think about others. . . (P3)

There's a lot going through your mind and it's an emotional time so you're not always listening or asking the questions you want to ask because a. you don't want to be embarrassed, b. you don't want to believe you could be sick again. So sometimes you don't ask those questions. (P7)

Disconnection meant 'suffering'. The less connected the person, the more likely their experiences and opportunities would not meet expectations resulting in the absence of a positive lived experience.

Discussion

Much has been made of the idea that cancer survivors need help to 'move on' from the disease and get the necessary help and support to live beyond cancer. Booklets (National Cancer Institute, 2014), support packages (Shaw, *et al.* , 2017), digital applications (Miller *et al.* , 2015; NearSpace Inc., 2014; Schover *et al.* , 2012; Hong, Pena-Purcell & Oy, 2012; Yun *et al.* , 2012), psychological interventions (Malin, Sayers, & Jefford, 2011; Coscarelli *et al.* , 2011), ongoing follow-up (Beaver, Williamson, & Chalmers 2010; Wang *et al.* , 2014) by specialist oncology professionals (Mathews & Semper, 2017), information about long term survival (Jackson, Scheid, & Rolnick, 2013) and coping mechanisms (Rogers, 1983) have been developed to help survivors do this. The United States Institute of Medicine (Hewitt, Greenfield, & Stovall, 2006) researching improving quality of life for cancer survivors notes the following components grounded in the medical model of care as essential to survivorship care: (a) prevention and detection of new cancers and recurrent cancer (including surveillance for cancer spread, recurrence, or second cancers); (b) intervention for consequences of cancer and its treatment; (c) coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met for both cancer and noncancerous conditions, and the care of concurrent conditions; (d) the use of a patient-centred approach defined as including responsiveness to patients' needs, effective communication and information sharing, encouragement of the adoption of healthy lifestyles, and assistance in accessing community support services. Survivorship care plans (SCP) are said to be the key (Hewitt, Greenfield, & Stovall, 2006). Mathews and Semper (2016) have noted that the need for help is possibly greater than what is observed and that therefore, provision should be made for increased and extended support.

These solutions are based in the idea that survivors have ‘problems that can be remediated by intervening with professional solutions. Care is a matter of finding the right solutions for each person and implementing these in the right way. The link between these interventions and an improved quality of life is assumed.

Our findings indicate that the quality of the lived experience of cancer survivors through and after the cancer journey comes about because of ‘meaning-making’ of the experience that is, how their world views, concepts and experiences cause them to interpret their situation. Feeling connected (or not) to self, others and context was not related to the experience per se, but to the interpretation of the experience. What each person had lived through shaped how they saw their future, with concepts of self and community being fluid, dynamic and unique to everyone who entered the cancer journey.

Other researchers have touched on this. For example, Mathews and Semper (2017) note that breast cancer survivors perceive a systemic absence in support from oncology teams and rapid deterioration in support from personal support networks. We interpret this lack of support as disconnectedness. They go on to say survivors can find benefits from the cancer experience, allowing for adjustment and enabling a successful transition from a cancer patient to cancer survivor. We interpret this as finding connectedness.

Interventions that do not meld with the world view of the person for whom they are being recommended (as is often the case with the medical model approach to care) are unlikely to result in improving the quality of life of cancer survivors. For healing to occur there needs to be connectedness between the health professional and the person receiving care and connectedness between the intervention and the person’s framework of meaning because, as this research shows, connectedness itself is essential to a positive lived experience. Shanfield (1980) suggests that cancer survivors make sense of their experiences through their emotions, concerns about mortality, and the sense of vulnerability. Survivors who thrive integrate life and death within their personal life history using their framework of meaning (Leigh, 1992).

The medical model, in being based on the idea that an external observer is better placed to understand the lived experience of the people in need of care than the people themselves, is not designed to facilitate this. The shortcomings of the medical model have been noted by many authors. For example, Chen, Krupa, Lysaght, McCay and Piat (2011) Deegan (2007, 1988) and Swarbrick (2006), have found it to be un-therapeutic, disempowering, and not conducive to healing when used as the basis of care for people with mental illness. The medical model is therefore unlikely to be an appropriate starting point for caring for suffering cancer survivors. If this is indeed the case, nurses may need to rethink their approach to care if they are to contribute to improving the quality of life of cancer survivors as understanding the meaning survivors attach to their experiences is essential to effective care.

We advocate a therapeutic relationship based in a human caring model in caring for cancer survivors as noted in the work of Watson (1999) and Titchen (2001). Watson (1999) makes a case for human caring as being the core of the nursing profession. She advocates a caring-healing model that accommodates the meaning-making of the people nurses care for. She notes that nursing within a caring science context has a worldview in which belonging (connectedness) comes before the separate ontology of being, and before principled, rational-intellectual worldly endeavours. (Levinas, 2000; Watson, 2005a). Titchen (2001) proposes that the presence of the therapeutic relationship lies at the heart of patient-centred nursing and uses several concepts to articulate this:

- *Particularity* ; getting to know the patient within the context of their specific illness and the context of their lives in relation to their responses, physical functioning and body typology and feelings, perceptions, beliefs, imaginings, expectations, memories, attitudes, meanings, self-knowledge, knowledge about and interpretations of health and illness, experience of illness and what is happening, responses to illness, concerns and significant social relationships, life events and experiences

- *Reciprocity* ; an exchange of concern, knowledge and caring that occurs in a close interpersonal nurse-patient relationship
- *Mutuality* ; a genuine relationship between the nurses and the people for whom care is provided
- *Graceful care* ; the nurse using all her physical, humanistic and spiritual abilities to promote the patient's healing and personal growth (Titchen, 2001, p. 71).

Several recovery models being adopted by nurses providing care to people with mental illness lend support for our proposal (Caldwell, Sclafani, Swarbrick, & Piren, 2010; Davidson, *et al .*, 2007; Farkas, 2007; Farkas, Gagne, Anthony, & Chamberlain, 2005; Jacobson & Greenley 2001; Onken, Craig, Ridgway, Ralph, & Cook, 2007). For example, Onken *et al .* (2007) have identified aspects of the human caring model that include relating care to meaning, and purpose in life, and helping those receiving care to re-establish or maintain social roles and meaningful relationships in their communities.

These models sit well with helping cancer survivors attain connectedness by helping them make sense of the experience within their own world view. Within this context surviving cancer is not something that is to be overcome but to be experienced. Healing involves being with the person, accepting their world view and facilitating their accepting and naming the invisible wounds that have been created by the cancer experience so they can connect (or reconnect) with their 'self', 'others' and their 'context'.

Implementing this approach is not without its challenges. In recent decades, linear economic models that have led to the health discourse being conceptualised as a series of financial transactions have dominated health systems. (Grossman, 1972; Wagstaff, 1986; Muir, 2006). In being based in the same assumptions as the medical model (Barker, 2001; Muir, 2006; Delaney & Lynch, 2008; Farley-Toombs, 2011, Chen *et al .*, 2011) they have often worked to undermine the caring aspect of nursing. Governments have 'invested' in health care (for example: Ter-Minassian, 2014) and want people to be processed in the shortest possible time and to receive the least expensive care to reduce health costs. A framework dominated by the medical and economic models (Muir, 2006) may be unable to support a caring-health model of care where connection is required. Watson (2005b) notes that conventional medicalised views of people are unsustainable in the absence of belonging. In other words, belonging is a prerequisite for all the other care that is provided. Paradoxically, if economic and financial models continue to dominate health systems we may find ourselves in situations that resemble hamster wheels whereby we intervene endlessly trying to 'fix' the people we care for, neither reducing costs nor attaining our goals. We believe it is therefore incumbent on nurses to not lose sight of the essence of what it is to care for others and advocate for space in the health system to let this occur.

Limitations

The participant group in this study were all middle-class people of European descent and had experienced a diverse range of cancers, treatment and prognoses. Therefore, the findings may not be directly transferable to other ethnic groups. Having said that, other research we have done with people of diverse ethnicities has identified the idea of 'connectedness' as having a central importance in shaping meaning in these cultures and their communities (Ahuriri-Driscoll *et al .*, 2014; Lee & Reid 2012). Although these findings are likely to be applicable across cultures (Yoon Lee & Goh, 2008; Yoon & Lee, 2010; Yoon, Jung, Lee, & Felix-Mora, 2012; Kurtz, 2013) further evaluation is necessary.

Conclusions

Our findings have identified that the level of connectedness in several spheres is likely to determine the quality of the lived experience for cancer survivors regardless of the number of interventions put in place to help them 'move on' from the cancer experience. The human caring model of nursing care can help

nurses understand how cancer survivors construe ‘quality of life’ so they can provide care that leads to a better lived experience. If nurses are to intervene in meaningful ways they must take the time to engage in relationships with the people in their care to understand the essential meaning of their lived experiences. To be successful interventions should be developed from within this framework of care. This approach is more likely to yield cost effective care than providing interventions per se. Nurses must therefore advocate for a practice environment that enables them to take the time to engage in therapeutic relationships based in human caring.

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