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Introduction

Advances in cancer diagnosis and treatment have dramatically improved the survivability of those receiving their initial cancer diagnosis (Maddams *et al* 2009). In the UK this population of people is estimated to increase at the rate of one million per decade (Maddams *et al* 2012) and half are expected to survive at least five years (Department of Health *et al* 2010). Despite this optimistic outlook, a cancer diagnosis poses a range of significant challenges to people with cancer and their families. In addition to the financial (Sharp *et al* 2013), social (Baker *et al* 2005), physical and psychological (Armes *et al* 2009) experiences of people with cancer in the post-treatment phase, cancer can also lead to a range of existential concerns, including death anxiety, freedom, isolation, and meaninglessness (Hajdarevic *et al* 2014; Lagerdahl *et al* 2014).

Unsurprisingly, for many people living with and beyond cancer, the prognostic uncertainty following the completion of treatment is linked to concerns about the future, anxieties about recurrence, increased awareness of mortality, and fear of death (Armes *et al* 2009; Lagerdahl *et al* 2014). Those who have completed treatment can also experience a sense of abandonment from services (Macmillan Cancer Support, 2012a) as well as isolation in their personal, caring, and wider social connections (Brennan & Moynihan, 2004). Barriers to communication include patients' acceptance of the socially constructed moral obligation to be positive and cheerful (Wilkinson & Kitzinger, 2000) and ongoing unmet needs to discuss their condition, treatment, and follow-up with hospital staff (Armes *et al* 2009).

In recognition of this, “The National Cancer Survivorship Initiative” (NCSI) was launched in 2008, with the aim of supporting those living with and beyond cancer to lead more healthy and active lives for as long as possible (Department of Health *et al* 2010). To achieve this goal, the NCSI proposed a shift from the traditional medical model towards a more individualised approach, where holistic assessments are emphasised, that facilitate health professionals in identifying the needs of people with cancer and enable the development of joint care plans to meet those needs. Holistic needs assessments and care plans form one of four interventions developed by NCSI, otherwise known as the ‘Recovery package’. The aim of this is to promote and enable individualised follow-up care (NCSI, 2013). However, while the NCSI report recognises spiritual needs, it does not explicitly identify existential experiences, something which may impede some health care professionals’ ability to recognise and support existential concerns that persist following the end of treatment (Westman *et al* 2006).

Research on the existential experiences of people with cancer who have completed treatment is limited but has shown that this is an area of concern for many people with cancer, which can impact on emotional well-being (Halldórsdóttir & Hamrin, 1996; Lagerdahl *et al* 2014) and raise issues encompassing spiritual beliefs, decision-making, concerns about the meaning of life (Hodgkinson *et al* 2007), feelings of isolation, and lack of opportunities to process experiences (Hinnen *et al* 2008). It has been suggested that more support is necessary to manage the transition to life beyond treatment (Lobb *et al* 2009) and that health care professionals can play an important role in helping people with cancer process these experiences (Halldórsdóttir & Hamrin, 1996; Udo,

2014). However, although many cancer practitioners show willingness to address existential concerns, they generally deem these concerns as low priority and primarily applicable to the role of chaplains (Best *et al* 2016; Kristeller *et al* 1999). This is unfortunate, as the resolution of existential concerns can lead to improved quality of life and health outcomes (Bowie *et al* 2004; Levin & Schiller, 1987), whereas unresolved concerns impact negatively on well-being (Hinnen *et al* 2008)

Furthermore, relatively little is known about the views that people with cancer have around support needs in relation to existential concerns. Some studies have examined aspects of this topic but these studied remain relatively few in number and have been carried out in countries where the care models can differ from the UK. Moreover, such studies have often utilised focussed questionnaire surveys (Hodgkinson *et al* 2007), or concentrated on specific cancer types (Adewuyi-Dalton *et al* 1998; Denieffe & Gooney, 2011; Halldórsdóttir & Hamrin, 1996; Lobb *et al* 2009), rather than the shared experiences of people with cancer. How existential well-being can be facilitated in everyday practice has yet to be fully explored (Hench & Danielson, 2009).

The current study seeks to address this gap in the literature by exploring which support needs may be required to help individuals manage their existential concerns following end of treatment. It forms the second part to another study, which explored the existential concerns of the same participants (Lagerdahl *et al* 2014). As outlined previously in this paper, the findings of the first part identified death anxiety, freedom, isolation and meaninglessness as key existential concerns for the participants. More

specifically, the findings showed that, following the end of treatment for cancer, many participants had become more aware of both their mortality and their own authorship in life. This often resulted in a wish to live a more meaningful life but the reality of this proved more difficult for some. Many had experienced a loss of identity and values as part of their diagnosis and treatment, and others felt very isolated in their experience, thereby struggling to create a sense of meaning. By examining the same participant group's support needs around such existential concerns, the second part of this study hopes to increase understanding of how services may better meet existential needs.

Methods

Participant Recruitment

Full regional and local ethical approval was secured. To be eligible, participants had to be in complete remission from their cancer, have finished their first-line treatment within the previous year and be of working age.

The eight participants (five female, three male) were all middle-class UK resident Caucasians, with a variety of cancer diagnoses (e.g., prostate, breast, skin, lung, head and neck) and treatment regimens (e.g., surgery, robotic, mixed). Seven were married or involved in long-term relationships. At the time of the semi-structured interviews, participants had an average age of 55 years (range = 43-62) and their treatments had finished about 8 months earlier (range = 2-12 months).

Interview Procedure

Participants were interviewed using semi-structured interviews in a private room on the cancer ward of their local hospital. Participants were given opportunities to ask questions, and told of their right to terminate the interview or withdraw their recorded interview record at any time. None chose to do so. Consent forms were signed before beginning the interview.

As the key interview topic was existential concerns, participants were told that existential experiences are considered as “anything to do with our existence, or ‘being’, and our views of ourselves, the world or the future” and were provided with several examples (Hench & Danielson, 2009). However, it was emphasised that the purpose of these examples was to aid discussion of participants’ own, personally unique and important experiences, since completing treatment. The interviewer employed open-ended questions, designed to encourage open exploration and reflection on participants’ experiences in a safe non-judgemental space. Follow-up questions and prompts were used to explore the issues individual’s raised in more detail. The interviews lasted 60 – 90 minutes.

Inductive Thematic Analysis

Following verbatim transcription of the digitally recorded semi-structured interviews, inductive thematic analysis (Braun & Clark, 2006) was used to systematically organise the participants’ experiences relating to their service needs allowing themes to emerge

both within, and across, participants. Credibility checks were undertaken by an independent verification of the coding framework devised using a 10% sample of data.

Results

The thematic analysis identified four major themes: 'Individualised care', 'Holistic approach', 'Mandatory appointment' and 'Specialised emotional support'. The major narrative appears to be one where participants express a desire for health services to maintain a "continuity of care" where they are treated as a whole person who has needs that extend beyond the physical. All quotes used relate to the existential needs the participants had previously expressed (see Lagerdahl *et al* 2014)

Theme 1: Individualised care

Although many participants talked in positive terms about their experience of cancer and recognised the challenges facing cancer services, many expressed the need to have more individualised care around their existential needs in the period following the end of treatment.

"So I don't feel, I don't want to complain about it, but when you think about it, you feel it could just be a little bit more, em, no a bit more personal" (#7 p.28).

“I felt, how could I put this, there is a certain amount of... conveyer belt, see ya, and away you go” (#6 p.4).

Theme 2: Holistic approach

The common theme expressed was a sense that the health care system placed too much emphasis on participants' physical rather than existential needs.

“... what perhaps needs to happen post-operatively is more of a mixture of dealing with people's emotions as much as dealing with the physical symptoms, and trying to help people understand a little bit more” (#1 p.12).

“If I mention anything that's not the cancer, it doesn't feel like the right environment” (#7 p.26).

Theme 3: Mandatory appointment

All participants expressed wanting a mandatory follow-up appointment with a health care professional.

“Maybe they should have said you know, you need to come back in two weeks or something and talk to somebody again” (#2 p.20).

“When actually, if somebody had... written to me and said come in, I probably would have come in” (#4 p.21).

For some, the wish for a mandatory appointment was related to their own reluctance to access services in relation to their existential needs, judging that these were not important enough.

“And I suppose I also don’t think that I am top of the list, I certainly don’t think I am head of the queue; there are people that need it more than I do” (#8 p.16).

Theme 4: Focused emotional support

Several of the participants believed that the existential challenges of those who have completed treatment are significant enough to warrant focused emotional support.

“There is certainly a need for people to go through ... counselling afterwards” (#1 p.19).

“I mean, arguably, everyone... after treatment needs to be offered some form of counselling or help, emotionally” (#8 p.15).

Discussion

This qualitative study explored the existential support needs of people living with and beyond cancer, in the year following successful treatment with curative intent. This formed the second part of an earlier study exploring the same participants’ existential concerns (Lagerdahl *et al* 2014). Participants’ predominant existential concerns in the first part were identified as ‘death anxiety’, ‘freedom’, ‘isolation’ and ‘meaning making’.

Specifically, participants spoke of an increased awareness around their own mortality, and their own degree of responsibility in relation to how they chose to live their lives. Although many participants expressed a wish to live a more meaningful life, this felt more difficult when coupled with loss of identity and isolation in their experience of cancer. Participants felt there was a lack of awareness that these concerns had not ceased once first line treatment had ended.

In the second, and present, part of the study, participants expressed a desire for a more holistic and individualised approach, which includes emphasis on the existential needs of those living with and beyond cancer, and the impact of these on emotional and psychological well-being. Although many participants expressed very positive experiences of cancer services and an understanding of the challenges that services face, they nevertheless also spoke about their reluctance to access services after treatment had ended, due to the service placing too much emphasis on their medical needs. This is consistent with other work, indicating that individuals have a range of unmet support needs long after treatment has finished (Armes *et al* 2009; Moore *et al* 2014). The present study adds to these findings by indicating that existential concerns is another key area of unmet need for those living with and beyond cancer in the UK, for which they would welcome more input from services.

Participants also expressed a desire for a mandatory follow up appointment. The suggestion of a mandatory follow-up appointment after treatment has been completed, in which a more holistic model of approach should be offered, endorses the goals of the

NCSI's 'Recovery package': the promotion of holistic needs assessment and personalised care planning that is responsive to individual needs and provides access to specialist care for all people who have completed cancer treatment (Department of Health *et al* 2010). Participants' suggestions were also in line with the 'Psychological support measures', which form part of the NHS's cancer peer review programme (National Cancer Action Team, 2011). These measures provide a national benchmark of cancer services across the country. They propose that holistic needs assessments should be initiated and carried out regularly by practitioners working at level 2, such as clinical nurse specialists. The measures identify the cancer adapted version of the 'Distress Thermometer' (DT - Brennan *et al* 2012) as a suitable tool for these purposes, as well as the Holistic Needs Assessment (HNA - Macmillan Cancer Support (2012b), also available in an electronic version (eHNA – Macmillan Cancer Support 2012c). Both the cancer specific DT and the HNA/eHNA require the practitioner and person with cancer to co-develop an action plan around the person's highest ranking concerns, from which a care plan can then be developed. This can include providing immediate support, information and signposting; self-management strategies; or referral to specialised services such as clinical psychology, counselling, chaplaincy etc. The present paper supports these initiatives and argues that the consistent use of holistic assessment tools in the period following end of treatment could help services identify unmet needs, such as existential concerns, as well as exploring options for meeting these. This could potentially also have benefits for healthcare services, with less GP appointments and hospital admissions if problems are addressed early and thereby prevented from escalating.

The needs most commonly endorsed by participants in the first part of the present study were those concerning cancer recurrence and uncertainty about the future, both of which have high existential relevance (Denieffe & Gooney, 2011; Lagerdahl *et al* 2014). In order to meet these needs, participants advocated the targeted provision of psychological support. It is important to note that psychological/emotional support has been identified at four different levels within cancer care (National Cancer Action Team, 2011), and existential needs would seem to fit well under this model. Levels 3 and 4 of the model include more specialised psychological support, as provided by a counsellor or clinical psychologist respectively. Although many individuals may require one to one psychological support, it should be noted that a proportion of people may also benefit from other forms of support with existential concerns. One way of targeting existential concerns at an early point would be through the 'Health and Well-being days', also promoted by the 'Recovery package' (NCSI, 2013). By including sessions by clinicians working at Level 3 or 4 at these days, in which existential concerns and ways of managing these are addressed, this may enable some people to work with and find ways of managing such concerns early on, before they intensify. Another alternative to consider may be group therapy. In recent years, increasing support has been found for the efficacy of group therapy in resolving existential concerns (Breitbart *et al* (2015); Lagerdahl *et al* 2014). Where appropriate, this may be considered a more cost effective option at levels 3 and 4.

At Level 2, which is the psychological support typically offered by clinical nurse specialists, the Cancer Manual 'psychological support measures' (National Cancer Action Team, 2011) currently recognises and promotes the implementation of skills training around the assessment of emotional concerns, and the implementation of techniques such as anxiety management. However, it does not address patients' existential needs, and how to work with these. It is the view of the present authors that people with cancer would benefit considerably if more Level 2 training was provided around the assessment of existential concerns as well as ways of supporting people with such concerns.

Conclusion

The expressed views of the present participant sample clearly indicate that continuity of care is important to them and that they felt a sense of abandonment following the unexpected change in service provision that accompanied their successful treatment. Their desire was for services to adopt a holistic model of care, which specifically targets and respond to the existential and emotional needs of those who have completed treatment for cancer. This desire for more personalised care is in line with previous calls for a shift in focus from a predominantly medical model.

The experiences of our participant group dovetail with previous accounts (Macmillan Cancer Support, 2012a; NCSI, 2013) and their narratives outline their needs in terms of a patient centred approach that provides appropriate information and services to meet

evolving existential needs (Daniels & Kissane, 2008; Lindemalm *et al* 2012). This requirement for more personalised care and information is not new; however, the present study is the first to have examined the views of those who have completed treatment specifically in relation to existential needs. The facts that these views largely mirror findings in other areas of survivorship, points to a consistent view on the service provision required.

Limitations

The present study consisted of a relatively small participants sample (N=8), all of which were from a white ethnic background. Any findings should therefore be treated with this in mind, even though themes were generally ubiquitous across the data set. It could also be argued that those who engaged in the study were interested in talking about their experiences. Several participants reported enjoying telling their story with many saying that the interview was the first time they had thought about their experience. Conversely, those that did not want to engage may not have had any existential concerns or find it particularly difficult to talk about their cancer journey. In both cases, their views would add considerably to our understanding of people's post-treatment experiences.

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Finally, we would like to acknowledge our appreciation of the open and honest way in which the people we interviewed shared their experiences of cancer services. They articulated many positive qualities of their experience and clearly recognise the many

pressures that exist for service providers. Further interviews with people with cancer, extending over a period of time, will aid in developing an understanding of how their experiences and needs change, not just for those living with cancer but also those who are living beyond it.

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