

Cancer as biographical disruption: constructions of living with cancer

Gill Hubbard · Liz Forbat

Received: 8 January 2011 / Accepted: 1 November 2011 / Published online: 11 November 2011
© Springer-Verlag 2011

Abstract

Purpose From a cancer survivor perspective, the purpose of this paper is to explore what has changed in their lives that they attribute to the disease. The rationale for the study is that evidence of the extent to which cancer disrupts people's lives in the longer term is contradictory.

Methods Written accounts from 40 cancer survivors were analysed using interpretative methods. The researchers drew on the concept of biographical disruption as a framework for analysis.

Results Cancer survivors construct cancer as a biographically disruptive event with ongoing physical and psychosocial impacts. Cancer is constructed as a permanent threat to life which is responsible for increasing their awareness of their own mortality and invoking positive changes to self. These formulations of living with cancer were found across a range of participants, including those who defined themselves as currently free of cancer, those who had recurrence, those who had been diagnosed 5 years ago and those who had been free of cancer for a long time.

Conclusions This study adds to the body of literature exploring how to enhance supportive care for cancer survivors by reflecting on biographical disruption and continuity, and the complexities within individual constructions of changes in life that they attribute to cancer. Cancer survivors should be given opportunities to articulate the impact of cancer, thus giving legitimate space to talk about cancer's ongoing resonance on life so that problems and difficulties are not dismissed or trivialised.

Keywords Cancer survivor · Cancer survivorship · Biographical disruption

Background

More people are living with and beyond cancer due to increased incidence and survival from some cancers [1]. Recent research shows that for most cancers, 10-year survival has improved in UK [2, 3], other European countries [4], Australia [5] and America [6].

Most psychosocial oncology research on cancer survivorship has measured physiological and psychosocial late effects of cancer. Recent research has shown that an increased incidence of cardiac and/or pulmonary dysfunction is observed in cancer survivors [7]. A recent systematic review found that 20–30% of survivors consistently reported problems associated with cancer and its treatment including physical problems, poorer quality of life, psychological distress, sexual problems, problems with social relationships and financial concerns [8]. Numerous studies have shown that cancer survivors have a poorer quality of life compared to that of the general population [9, 10]. More recently, studies have measured fear of recurrence [11, 12].

This literature corpus contributes to the supportive care of cancer survivors by showing which psychosocial domains are affected by cancer and which cancer survivors are most likely to be negatively impacted by the disease. Nevertheless, a weakness of this body of work is that few studies have employed a prospective longitudinal design, which means that knowledge of how the impact of cancer changes over time, from the point of diagnosis to the later periods of cancer survivorship, is limited. Further limitations include the tendency of cancer survivors to underre-

G. Hubbard (✉) · L. Forbat
Cancer Care Research Centre,
Department of Nursing and Midwifery, University of Stirling,
Stirling FK9 4LA, UK
e-mail: gill.hubbard@stir.ac.uk

port problems [13] and the dislocation of psychosocial impacts of the disease from the social context. There is a rich seam of research, however, that has addressed some of these limitations exploring how people make sense of their illness in the context of their lives, which includes studies that have begun to describe living with cancer as biographical disruption.

Theoretical framework: cancer as biographical disruption

Bury's [14–17] research suggests that chronic illnesses create a disruption to one's expected life trajectory and biography. Bury suggests that an event such as the onset of chronic illness brings to the fore pain, suffering and death, which are normally only seen as distant or remote possibilities in ones' life or are perceived as the plight of others. Bury differentiates three concepts to illuminate the process of managing biographical disruption. 'Coping' refers to the methods the ill person uses to manage his or her situation emotionally. 'Strategy' refers to the way in which the ill person tries, through his or her actions, to deal with illness. 'Style' reflects the notion that different people have different attitudes towards illness.

The concept of biographical disruption has traditionally been used to understand experience of chronic illnesses, such as multiple sclerosis [18], stroke [19], chronic pain [20] and HIV and AIDS [21]. Some of this work suggests that living with a chronic illness for some people does not necessarily amount to a fundamental and profound biographical disruption but is experienced as biographical continuity and normality [19, 20, 22–24]. Given the seemingly contradictory findings in the literature, further research on the lived experience of chronic illness is warranted.

The conceptual framework has also been used to describe and explain people's experiences of living with cancer. This work has highlighted that living with cancer is identity altering [25]; loss over body functions has symbolic significance amounting to loss of the 'civilised self' [26]; those who have experienced hardship throughout life do not necessarily experience cancer as biographical disruption [27]. The research that has highlighted that the construct biographical disruption, which was initially conceived by Bury to describe and explain experience of chronic illness, has utility for describing and explaining the acute stage of cancer [28, 29] as well as the terminal stage of the disease [23, 30, 31]. The aim of the study, from which this paper draws, was twofold: add to existing knowledge of cancer survivorship specifically and to living with chronic illnesses more generally and secondly to explore from a cancer survivor perspective, what has changed in their lives that they attribute to the disease.

Methods

Purposive sampling was used to identify men and women living in Scotland with different types of cancer who had been diagnosed with cancer no less than 12 months ago. Invitations were sent to members of patient and carer support groups in Scotland, cancer charities and patient research advisory groups inviting cancer survivors to participate in the study. Those who contacted the researchers were provided with further information about the study, a personal details form (participants were asked to provide demographic and clinical information) and a consent form. The sample included cancer survivors with a range of characteristics that may shape experiences of cancer as biographical disruption [32]. The sample was judged of sufficient size when data saturation [33] had been reached.

Participants were invited to write up to two pages about their experience of living with cancer. They were asked to write about what has changed in their life for the better that they attributed to cancer, what had changed for the worse or stayed the same. The concept 'change' was considered a more neutral term than asking participants to give an account of 'disruption' to life that they attributed to cancer. Data were collected at the end of 2008 and the beginning of 2009.

Despite the preponderance of interview-based qualitative research, written accounts are an established methodology in health research [34], with a wealthy tradition of auto/biographical writing [35, 36]. Latterly, methods using internet data have also proliferated in the health research literature [37, 38]. Analysis often draws on traditional qualitative paradigms, being theory led and theory generating,

In order to move beyond the level of description [39] about people's experiences of living with cancer and explain the changes in life attributed to the disease, the researchers drew on the concept of biographical disruption [15–17]. Data were broadly coded into two subsets: accounts of living with cancer and accounts of diagnosis and treatment. This prepared the way for a much more intensive interrogation of the former, i.e. the account of living with cancer. The coded data were read and reread and collectively discussed by two researchers (the authors) until agreement was reached as to the construction of biographical disruption rendered by a diagnosis of cancer and to the evidence relating to processes of coping with and managing disruption. An initial framework, drawn from Bury's [15–17] concept of biographical disruption guided analysis with a view to identifying patterns and to reaching a consensus about whether cancer survivors were constructing living with cancer as biographical disruption.

The study was approved by the NHS West of Scotland Research Ethics Committee and a university research ethics committee. A summary of the key findings was posted to all participants for purposes of validation. In line with best practice in research, the study was designed and conducted with input from people affected by cancer as collaborators/co-researchers.

Results

Characteristics of participants

Forty cancer survivors were involved in the study. Table 1 summarises the main characteristics of participants.

The majority of participants defined themselves as free of cancer at the time of the study. Thirty reported that they were currently living free of cancer, 4 did not know if they were free of cancer and 6 reported that they still had cancer

at the time of the study, either because they have been given an incurable cancer diagnosis or due to recurrence. Fourteen participants had been diagnosed with a less common type of cancer as well as 15, 5, 3 and 3 participants who had been diagnosed with breast, prostate, lung and colorectal cancer respectively (i.e. the four most common types of cancer). Fifteen participants were aged 50 years or under, and 25 were aged 51 years or over when they were diagnosed with cancer. The study was evenly split between those who had been living with cancer for a long time and those who had been living with the disease for a shorter period of time. Twenty-three cancer survivors had been diagnosed 6 or more years ago, and 17 had been diagnosed between 1 and 5 years ago. Numerical identifiers are used in this paper to protect identities.

Box 1 shows the key constructions of living with cancer by cancer survivors, which are discussed in more detail below.

Box 1: Constructions of living with cancer

Cancer is constructed as:

- disruptive to everyday life many years after diagnosis and treatment,
- a persistent and on-going threat,
- a disease that heightens cancer survivors' sense of their own mortality,
- a disease that invokes a change to self, disrupting anticipated identity.

Construction of cancer as ongoing physical and psychosocial disruption

About half [22] of the participants described ongoing physical and/or psychosocial implications of cancer. As expected, those who defined themselves as still having cancer at the time of the study described ongoing effects;

Table 1 Participant characteristics

Currently free of cancer	
Self-reported 'yes'	30
Self-reported 'no'	6
Self-reported 'do not know'	4
Cancer diagnosis	
Breast	15
Prostate	5
Lung	3
Colorectal	3
Other	14
Age when diagnosed (years of age)	
≤50	15
≥51	25
Number of years since diagnosis	
Between 1 and 5 years	17
≥6 years	23

nevertheless, 14 out of the 30 cancer survivors who reported that they were free of cancer also described ongoing effects of the disease. It may also be expected that those who had been more recently diagnosed would describe ongoing effects. Yet, roughly half (13 out of 22) of those who reported ongoing problems had been diagnosed 6 or more years ago. Thus, constructing cancer as a disease that has long-term and ongoing physical and psychological implications was formulated by cancer survivors who did and did not define themselves as free of cancer and by those who were recently diagnosed as well as those who had been living with the disease for a long time.

The examples below of cancer survivors constructing the disease as one that has long-term and ongoing implications are from those who considered themselves free of cancer and had been diagnosed 6 or more years ago. In drawing on this data, it is highlighted that cancer survivors attribute physical and psychosocial issues that they currently experience directly to the disease that they had been diagnosed and treated for many years ago. As these two examples show, these problems are not constructed as trivial but are formulated as persistent and disruptive to everyday life.

A woman who was diagnosed with myeloma 12 years ago at the age of 44, and defined herself as currently free of cancer, lists eight losses in her life that she directly attributes to the diagnosis and treatment. In the extract below, the final two losses are shown in full as illustration

of ongoing biographical disruption. Cancer is positioned as an illness that disrupts an anticipated life course; she suggests that this is because it impacted on her ability to work thereby curbing her opportunities to achieve the power, status and income that she was anticipating as a woman in her early 40s. She gives the impression that she is socially isolated and out of sync with her peers, feeling so much older than they are. She formulates cancer as a disease that has made her feel abandoned because these losses of income, power and status had happened earlier in her life than expected due to the cancer. She suggests that a cancer diagnosis leaves no opportunity to plan for the subsequent loss of power and status accrued through paid employment. Bouts of anxiety and depression are directly attributed to these losses and presented as a direct consequence of the cancer. The extent of cancer's impact on her psychological well-being is emphasised by the use of the phrase 'intense bouts of anxiety and depression'. What is noticeable is that there is no indication in her account that she has been able to rectify this particular loss. However, she gives the impression that not all losses and changes are permanent. She claims that she defined herself for a very long time as someone who was ill and therefore dependent on others and helpless. Nevertheless, she implies that this illness identity was not permanent and describes resuming control. In her account, she suggests that the impact of cancer on loss of income, power and status was permanent whereas its impact on loss of identity and sexuality was not. This highlights the complexities of disruptions to life, with some disruptions being harder to rectify and manage than others:

However the most overwhelming things to me about cancer and its aftermath was, in short LOSS.

- Loss of control

(...)

- Loss of confidence in my body and how it operates.

(...)

- Loss of energy and spontaneity

(...)

- Loss of purpose

(...)

- Loss of others

(...)

- Loss of layer of skin

(...)

- Loss of income, power, status, particularly if you can no longer work. This is unsettling but needs to be faced by everyone at some point in their lives. If it happened earlier than you planned it can leave you feeling abandoned and isolated from your peer group. Before cancer I felt about 35 after cancer I felt about 85.

- Loss of identity and sexuality

For a very long while I felt that the only significant thing about me was that I was ill.

Being ill means to some extent you can abdicate responsibility and learn to be helpless and dependant.

It is very scary when you then have to resume control and learn to be an adult again who functions in relationship with others.

All these losses can engender periods of intense anxiety and depression. (ID 86)

Another woman who was diagnosed 9 years ago with endometrial cancer aged 55 attributes ongoing physical problems to radiotherapy and surgery, and attributes loss of libido and being nervous about travelling to these specific physical effects. The fact that she mentions that 9 years later she is still experiencing problems highlights the ongoing consequences of cancer for her. She indicates that these physical problems are being addressed through medication, although she gives the impression that the medication will help rather than eradicate the disruption to her life that these problems cause. Moreover, the medication to relieve thinning of the skin and dry vagina is associated with loss of libido. Thus, she constructs ongoing physical problems as a permanent consequence of cancer. Of note is how she downplays the disruption to her life; she implies that loss of libido has only caused a bit of sadness:

Physically, 9 years later, I am still having alter effects of the radiotherapy and surgery. The lack of oestrogen following hysterectomy causes thinning of the skin, dry vagina and affects. The ureters causing cystitis. These have been addressed by medication but my loss of libido causes a bit of sadness. I have suffered intermittent abdominal pain and vomiting since the radiation with bouts of diarrhoea which can be unpredictable. This has made me nervous about travelling and I am only now getting treatment which I am hoping is helping. (ID 4).

Constructing cancer as a persistent threat

Just under half (12 out of 30) of the cancer survivors who defined themselves as currently free of cancer formulated living with cancer as living in fear of the disease, particularly worrying about remission or recurrence. Of this group, those who had been living with cancer for 6 or more years (5 out of 12) and those who had been living with cancer for 5 years or less (7 out of 12) gave the impression that they were afraid of recurrence or remission. Of note is that people who were diagnosed with cancer when they were less than 50 years of age (9 out of 12) constructed cancer as invoking worry and fear because of the threat of recurrence. Of the 12 cancer survivors who

reported that they were free of cancer and gave the impression that they were worried or afraid of recurrence, roughly half (5 out of 12) described ongoing physical and psychosocial problems that they attributed to cancer.

Thus, constructing cancer as a disease to be feared is formulated both by cancer survivors who had recently been diagnosed as well as those who had been diagnosed a long time ago. It is also a construction by those who did not necessarily report ongoing and persistent long-term effects of the disease. Formulating cancer as an ongoing threat was more evident among those diagnosed when they were less than 50 years of age. This suggests that fear of and worry about recurrence is not necessarily related to whether or not they attribute current physical and psychosocial problems to the disease or how long they have lived since diagnosis and treatment but may be related to age at diagnosis. The examples in this section are from two people who were diagnosed with cancer more than 6 years ago to highlight how cancer is formulated as a disease where worry and fear are not short-lived but seems to be a consistent feature of life following diagnosis and treatment.

One woman who was diagnosed with melanoma 8 years ago when she was 49 years of age gives the impression that since her diagnosis, she has been striving to achieve a balanced perspective on her risk of recurrence. Aiming for balance and being well-informed is presented as her way of coping with the disruptive influence of living with risk of recurrence. The impression she gives is that coping with risk is a consistent facet of life since diagnosis. She presents her surgeon's perspective of her risk of recurrence which acts as justification for her own perception, which is that there is a chance that the cancer will recur:

Throughout the time since my diagnosis my aim has always been to gain a balanced perspective on m/n and maintain some equanimity about it. Being well-informed is essential to this. As is knowing what the chances of a recurrence (50:50 lifetime risk my surgeon said). (ID 6)

A man who was diagnosed 8 years ago with nasopharyngeal carcinoma when he was 40 years of age formulates cancer as a type of disease that compels him to worry about any change in his body and health since it might be indicative of recurrence. He emphasises that even slight changes to his health make him paranoid. Reference to tests with negative results and to a member of the medical profession suggesting that he is over-worrying gives the impression that fear and worry bear little relation how at risk from a clinical perspective he is of a recurrence of cancer. Thus, cancer is constructed as having a major impact on how he interprets bodily change. He makes reference to tests that have been conducted in the past few years, thus drawing attention to the fact that even 8 years on since diagnosis, he is still worried

about cancer. These tests can be interpreted as his way of coping with the disruption of being diagnosed with this type of illness that poses an ongoing threat:

I feel that I am far more cautious or even paranoid about the smallest changes I notice on my bodies and health. I have had various kinds of tests carried out in the last few years but they were all negative. My GP may have felt that I am over-worrying. (ID 56)

A heightened sense of one's own mortality

A quarter (10 out of 40) of all participants constructed cancer as a disease that made them aware of their own mortality, including those who defined themselves as free of cancer (6 out of 30) and perhaps to be expected those who did not currently consider that they were free of cancer (4 out of 10). Constructing cancer as a disease that is associated with death and dying was formulated by those who described ongoing physical and psychological effects (5 out of 10) as well as those who did not (5 out of 10). It was also a construction evident by those who had been diagnosed 6 or more years ago (7 out of 10) and those who had been diagnosed with cancer more recently (3 out of 10). Thus, this manifestation of biographical disruption, which is a heightened sense of one's own mortality, was not just present in the accounts of those who had been more recently diagnosed or who considered themselves as still having cancer. The following examples are drawn from the accounts of two cancer survivors who had been living with the impact of cancer for more than 6 years and who did not define themselves as currently still having cancer.

One man who was diagnosed with non-Hodgkin's lymphoma 6 years ago when he was aged 57 who reported that he did not know if he was free of cancer, constructs knowing that he will have a shorter life expectancy as the 'worst' thing about cancer. How much his life expectancy has been shortened is given emphasis by drawing attention to how old his mother is and the use of an exclamation mark. He gives the impression that a family gathering celebrating a birthday is a moment of sadness, acting as a reminder that his life expectancy has been shortened as a consequence of cancer. Cancer is therefore formulated as a disease disrupting his anticipated life expectancy, which in turn has a negative impact on common day events, such as birthdays:

The worse thing about cancer is knowing I have a shortened life expectancy we have just had a big family get together for my mothers' 90th birthday and I feel sad to think that I won't even see 70! (ID 90)

A woman who was diagnosed with myeloma 12 years ago who defined herself as currently free of cancer gives

the impression that cancer led to increasing awareness of her own death. She constructs this shift in awareness of her own mortality in negative terms alluding to holding back from making attachments and commitments to others. This approach to coping with her awareness of her own mortality is considered unproductive. She draws a comparison between her life and other people who do not have a heightened awareness of death, which emphasises that it is cancer which is responsible for this shift in her life:

Thinking that you will die tomorrow or next week concentrates the mind. Most people have to live with an indeterminate death but post-cancer gives you heightened awareness that is not necessarily productive. It is easy to fall into a sense of apathy about your life and a certain holding back from attachments and commitments because you do not want to inflict any greater sense of anticipatory loss on yourself and others. (ID 86)

Constructing cancer as augmenting positive changes to self

The above sections illustrate that cancer survivors construct cancer as having ongoing negative impacts. Biographical disruption is a useful concept for both describing these impacts but also explaining why these impacts are formulated as negative. Nevertheless, a quarter of participants (10 out of 40) formulated cancer as a type of illness that changed the type of person they were, which can be interpreted as an example of disruption to the kind of person they anticipated they were likely to have become in the absence of a cancer diagnosis. In this sense, these changes to self can be considered as disrupting an anticipated identity in the same way that disruptions to income, power and status for instance can be interpreted as disruptions to an anticipated life course.

This construction of cancer as invoking positive changes in identity was evident in those who described living in fear of or were worried about recurrence (4 out of 10) and those who did not (6 out of 10); those who had been recently diagnosed (4 out of 10) as well of those who had been living with cancer for a long time (6 out of 10) as well as those who described ongoing physical and psychosocial effects of cancer (7 out of 10) and those who did not (3 out of 10). Thus, formulating cancer as a type of disease that causes a change to self, which is another manifestation of biographical disruption, is evident amongst different cancer survivors irrespective of how long they have been living with the impact of the diagnosis and treatment.

One woman who had been diagnosed with breast cancer 8 years ago aged 49 associates cancer with making her a more decisive, stronger and outspoken person who now does what she wishes to do. These shifts in what type of person she is and

how she currently lives her life are not presented in vague terms but are punctuated as a three-part list with short, precise sentences which make her claim that cancer has impacted on the type of person she is appear more credible. Cancer is positioned as responsible for these changes to self:

I am more decisive and a stronger person. I live for today and don't delay things until 'I retire.' If I can afford it now—I will. I am also more outspoken than I would have been before my diagnosis. If I think something is wrong or unfair, I am more likely to speak out. I make more time for myself to be on my own and to do what I want to do, rather than being at the beck and call of everyone else. (ID 8)

A man who had been diagnosed with non-Hodgkin's lymphoma 8 years ago, aged 35, relates surviving the illness and keeping up morale during treatment to becoming mentally stronger. His use of parenthesis and exclamation mark draws attention to how de-moralising the treatment of cancer is. Going through this experience of cancer and having survived it is what he attributes to making him mentally stronger:

I feel that surviving what I've been through has made me mentally stronger in some ways. I managed to keep up my morale during my treatment (most of the time anyway)! (ID 40)

Discussion

The study adds to knowledge of the ongoing impact of cancer on people's lives. The conceptualisation of cancer as not an acute, discrete event with a defining end but a disease having repercussions for the rest of life has been reported elsewhere [40, 41]. This construction of cancer as a chronic disease fits Frank's conceptualisation of the remission society where people are effectively well but could never be considered cured. It also fits with the characterisation of cancer survivors as occupying a 'liminal' space, where patients pass through illness but do not return to the space prior to the diagnosis [42]. Other studies have called for representations of cancer survivorship that acknowledge people's fears and the continued presence of cancer in their lives.

The constructions of living with cancer by cancer survivors in this study demonstrated congruence between formulations of changes in life attributable to cancer and the framework of biographical disruption provided initially by Bury [14–16]. The concept is useful for describing and explaining that the impact of cancer threatens one's sense of the taken-for-granted world and one's anticipated future. A biographical trajectory exists from the past (known) to the future (anticipated), which is

integrated into the sense of self and expected life course trajectory. This study illustrates the way in which cancer survivors formulate this biographical trajectory as disrupted by cancer, disrupting an anticipated life expectancy, life course and anticipated identity.

Yet, previous research has suggested that people's incorporation of illness into ongoing life is suggestive of biographical continuity and flow [19, 23] and that the concept does not apply to people who have had a 'hard life' because they do not experience illness as biographically disruptive [19, 20, 22, 24]. There is also rejection of universal application of the term to describe and explain the experience of illness [19, 21]. Charmaz [43] concludes that assaults on identity can be temporary or permanent. This study, however, suggests that cancer survivors cannot be easily categorised as exemplars of biographical disruption or biographical flow; rather, some changes to their lives are constructed as permanent and having a profound impact on their anticipated life course and identity, whereas other disruptions are downplayed or presented as being successfully managed. Supportive care is therefore complex since cancer survivors will simultaneously experience biographical disruption and flow and manage some disruptions more easily than others.

Mathieson and Stam [25] in their study of cancer narratives conclude that cancer moves from the foreground to the background as a person becomes 'well' again but that illness is a constant feature against which biographical narrative was delineated for those with cancer recurrence. Yet, this study suggests that cancer is being constructed by cancer survivors, including those who define themselves as free of cancer and thereby may be considered 'well', as continuing to impact on and disrupt their lives. The study shows that cancer survivors formulate the management of that disruption as an ongoing and continuous part of their life, even by those who consider themselves free of cancer and have been living with the cancer for many years since diagnosis. Given an opportunity (which is what this study did) to articulate changes in life attributable to cancer, cancer survivors are likely to formulate the disease as one that has an ongoing impact on their lives. Of importance to supportive care, the point being made here is whether people are given legitimate opportunities to talk about their experience and the ongoing problems that they face.

Most research that has used biographical disruption as a conceptual framework has focused on negative disruptions to life, such as loss [26]. Other research, however, has illustrated that some people find cancer a life-enhancing and beneficial experience, which is conceptualised as a coping strategy or adaptation to illness [44]. This study shows cancer survivors formulating changes to self, a defining feature of biographical disruption, in positive terms. Of note is that disruption to life is not necessarily perceived by cancer survivors as negative.

Limitations

The study was advertised via cancer support groups and research advisory groups. These individuals have continued to associate with cancer after diagnosis and treatment, and their constructions of cancer as having an ongoing impact on life may differ from those who are not connected to groups. As previously mentioned, a limitation of existing psychosocial oncology literature is the lack of evidence of the ways in which ongoing problems change over time or which cancer survivors are likely to have ongoing problems. This study was not designed to be statistically powered to draw conclusions about the relationship between clinical (for example, length of time since diagnosis) and personal characteristics (for example, age) or relationships between psychosocial domains. Nevertheless, the study suggests that further longitudinal studies would add understanding in this field, exploring the continuing impact of cancer as it changes over time.

Conclusions

This study has added to the understanding of cancer as biographical disruption, developing previous work. The findings in this study add to existing knowledge of supportive care needs for cancer survivors irrespective of whether they have been living free of cancer for a long time or have a recurrence. This study has identified specific and significant unmet supportive care needs. These include ongoing physical and psychosocial problems, including fear and worry of recurrence. This approach adds to the body of literature exploring how to enhance supportive care to cancer survivors by reflecting on biographical disruption and continuity and the complexities within individual constructions of changes in life that they attribute to cancer. We suggest that cancer survivors should be given opportunities to articulate the impact of cancer, thus giving legitimate space to talk about cancer's impact on life so that problems and difficulties are not dismissed or trivialised.

Acknowledgements Macmillan Cancer Support funded the study. Special thanks are given to the cancer survivors who provided their written accounts.

References

1. Maddams J, Brewster D, Gavin A, Steward J, Elliott J, Utley M et al (2009) Cancer prevalence in the United Kingdom: estimates for 2008. *Br J Cancer* 101:541–547
2. Rachet B, Woods L, Mity E, Riga M, Cooper N, Quinn M et al (2008) Cancer survival in England and Wales at the end of the 20th century. *Br J Cancer* 99(1):2–10
3. Information Services Division (2010) Cancer survival in Scotland, National Statistics, Edinburgh

4. Verdecchia A, Guzzinatib S, Franciscia S, De Angelisa R, Brayc F, Allemanid C et al (2009) Survival trends in European cancer patients diagnosed from 1988 to 1999. *Eur J Cancer* 45:1042–1066
5. Institute of Health and Welfare Cancer Australia, Australasian Association of Cancer Registries. Cancer survival and prevalence in Australia: Cancers diagnosed from 1982 to 2004. Australian Institute of Health and Welfare Canberra Cat. no. CAN 38; 2008
6. U.S. Cancer Statistics Working Group (2010) United States Cancer Statistics: 1999–2007 Incidence and Mortality Web-based Report. Atlanta: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute
7. Carver J, Shapior C, Ng A, Jacobs L, Schwartz C, Virgo K et al (2007) American Society of Clinical Oncology clinical evidence review on the ongoing care of adult cancer survivors: cardiac and pulmonary late effects. *J Clin Oncol* 25(25):3991–4008
8. Foster C, Wright D, Hill H, Hopkinson J, Roffe L (2009) Psychosocial implications of living 5 years or more following a cancer diagnosis: a systematic review of the research evidence. *Eur J Cancer Care* 18:223–247
9. Arndt V, Merx H, Stegmaier C, Ziegler H, Brenner H (2006) Restrictions in quality of life in colorectal cancer patients over three years after diagnosis: a population based study. *Eur J Cancer* 42(12):1848–1857
10. Smith D, King M, Egger S, Berry M, Stricker P, Cozzi P et al (2009) Quality of life three years after diagnosis of localised prostate cancer: population based cohort study. *Br Med J* 340:1057
11. Hart S, Latini D, Cowan J, Carroll P (2008) Fear of recurrence, treatment satisfaction and quality of life after radical prostatectomy for prostate cancer. *Support Care Cancer* 16(2):161–169
12. Rogers S, Scott B, Lowe D, Ozakinci G, Humphris G (2010) Fear of recurrence following head and neck cancer in the outpatient clinic. *Eur Arch Otorhinolaryngol* 2010(267):1943–1949
13. Breetvelt I, Van Dam F (1991) Underreporting by cancer patients: the case of response-shift. *Soc Sci Med* 32(9):981–987
14. Bury M (1997) *Health and illness in a changing society*. Routledge, London
15. Bury M (1982) Chronic illness as biographical disruption. *Sociol Health Illness* 4(2):167–182
16. Bury M (1991) The sociology of chronic illness: a review of research and prospects. *Sociol Health Illness* 13(4):451–468
17. Bury M (2001) Illness narratives: fact or fiction? *Sociol Health Illness* 23(3):263–285
18. Green G, Todd J, Pevalin D (2007) Biographical disruption associated with multiple sclerosis: using propensity scoring to assess the impact. *Soc Sci Med* 65(3):524–535
19. Faircloth CA, Boylstein C, Rittman M, Young ME, Gubrium J (2004) Sudden illness and biographical flow in narratives of stroke recovery. *Sociol Health Illness* 26(2):242–261
20. Richardson J, Ong B, Sim J (2006) Is chronic widespread pain biographically disruptive? *Soc Sci Med* 63:1573–1585
21. Wilson S (2007) ‘When you have children you’re obliged to live’: motherhood, chronic illness and biographical disruption. *Sociol Health Illness* 29(4):610–626
22. Hopkins A (2004) Disrupted lives: investigating coping strategies for non-healing leg ulcers. *Br J Nurs* 13(9):556–563
23. Leveälähti H, Tishelman C, Ohlén J (2007) Framing the onset of lung cancer biographically: narratives of continuity and disruption. *Psychooncology* 16:466–473
24. Pound P, Gompertz P, Ebrahim S (1998) Illness in the context of older age: the case of stroke. *Sociol Health Illness* 20(4):489–506
25. Mathieson C, Stam H (1995) Renegotiating identity: cancer narratives. *Sociol Health Illness* 17(3):283–306
26. Rozmovits L, Ziebland S (2004) Expressions of loss of adulthood in the narratives of people with colorectal cancer. *Qual Health Res* 14(2):187–203
27. Sinding C, Wiernikowski J (2008) Disruption foreclosed: older women’s cancer narratives. *Health* 12(3):389–411
28. Cayless S, Forbat L, Illingworth N, Hubbard G, Kearney N (2010) Men with prostate cancer over the first year of illness: their experiences as biographical disruption. *Support Care Cancer* 18(1):11–19
29. Hubbard G, Kidd L, Kearney N (2010) Disrupted lives and threats to identity: the experiences of people with colorectal cancer within the first year following diagnosis. *Health* 14(2):131–146
30. Exley C, Letherby G (2001) Managing a disrupted lifecourse: issues of identity and emotion work. *Health* 5(1):112–132
31. Reeves MJ, Remington PL, Nashold R, Pete J (1997) Chronic disease mortality among Wisconsin Native American Indians, 1984–1993. *Wis Med J* 96(2):27–32
32. Williams S (2000) Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociol Health Illness* 22(1):40–67
33. Guest G, Bunce A, Johnson L (2006) How many interviews are enough? An experiment with data saturation and variability. *Field Method* 18:59–82
34. Murray M (2009) *Health psychology and writing: an introduction*. *J Health Psychol* 14:158–160
35. Frank A (1995) *The wounded storyteller*. University of Chicago Press, Chicago
36. Willig C (2009) ‘Unlike a rock, a tree, a horse or an angel...’: reflections on the struggle of meaning through writing during the process of cancer diagnosis. *J Health Psychol* 14:181–189
37. Rodgers S, Chen Q (2005) Internet community group participation: psychosocial benefits for women with breast cancer. *J Computer-Mediated Commun* 10(4):5
38. Kivits J (2011) Informed patients and the internvet: a mediated context for consultations with health professionals. *J Health Psychol* 11(2):269–282
39. Ritchie J, Spencer L, O’Connor W (2003) Carrying out qualitative analysis. In: Ritchie J, Lewis J (eds) *Qualitative research practice*. Sage, London
40. Bowman K, Deilming G, Smerglia V, Sage P, Kahan B (2003) Appraisal of the cancer experience by older long-term survivors. *Psychooncology* 12:226–238
41. Zebrack B (2000) Cancer survivor identity and quality of life. *Cancer Pract* 8(5):238–242
42. Navon L, Morag A (2004) Liminality as biographical disruption: unclassifiability following hormonal therapy for advanced prostate cancer. *Soc Sci Med* 58(11):2337–2347
43. Charmaz K (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociol Health Illness* 5(2):168–195
44. Ferrell B, Dow K (1996) Portraits of cancer survivorship. A glimpse through the lens of survivors’ eyes. *Cancer Pract* 4:76–80