

Disrupted lives and threats to identity: The experiences of people with colorectal cancer within the first year following diagnosis

Hubbard G*, Kidd L and Kearney N

* corresponding author

Gill Hubbard, PhD, MSc, PG Cert, BA

Senior Research Fellow

Cancer Care Research Centre

Unit 1 Scion House

Stirling University Innovation Park

Stirling

FK9 4NF

Email: gill.hubbard@stir.ac.uk

Tel: +44(0)1786 849260

Fax: +44(0)1786 460060

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Dr Gill Hubbard is a senior research fellow who leads the ‘Cancer as a long-term condition’ research programme at CCRC. She has a background in sociology and social policy.

Dr Lisa Kidd is a research fellow at CCRC. She has a background in nursing and has recently been awarded a Doctor of Philosophy for a study of perceived control and involvement in self care for people with cancer.

Professor Nora Kearney is Director of CCRC. She has a background in nursing and an extensive track record in cancer care research, in particular, in symptom improvement and patient experiences.

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Abstract

In this paper we focus on the experiences of 18 people with colorectal cancer, involved in a large longitudinal qualitative study to explore people's experiences of cancer within the first year following diagnosis. Three depth interviews over the course of the year were carried out. During analysis, we drew on biographically informed approaches of understanding chronic illness, particularly the work of Bury (1982; 2001; 1991) and Charmaz (1994; 1983; 1995; 2002) to explore the extent to which people within the first year following diagnosis experience cancer as biographically disruptive. We explore the biographical work that individuals carry out in the context of an assault on their identity and discuss the relevance of the concept biographical disruption for people who experience cancer as an acute, chronic and/or life-threatening condition. We also discuss the concept's relevance for people who have lived a hard life and, hence, may anticipate these types of disruptions in their lives and experience their impact differently. We conclude that universal application of the concept biographical disruption to the experience of cancer within the first year of diagnosis is not appropriate. This study has implications for cancer services, in particular, the findings call for the development of interventions to support those people who experience cancer as an assault on their identity.

Key words: colorectal cancer, biographical disruption, identity

Background: Experience of colorectal cancer

Colorectal cancer is the third most common cancer worldwide (Stewart and Kleihues, 2003) and in the UK, where 36,109 new cases were diagnosed in 2004 (Cancer Research UK, 2008). The majority of cases occur in people over the age of 60 years (Cancer Research UK, 2008). As treatments and therapies for cancer improve, the population of survivors with colorectal cancer also grows (Conroy and Blazeby, 2003). There are significant improvements in five-year survival rates for patients with colorectal cancer in the past 30 years (Cancer Research UK, 2008) and as a result, there are an increasing number of survivors living with the consequences of having had the disease (Ganz, 2003).

Numerous studies have found that a colorectal diagnosis leads to significant changes in people lives. People with colorectal cancer are at risk of experiencing poor quality of life following surgery and treatment (Dunn et al., 2006; Engel et al., 2003), continue to experience side effects post surgery and treatment, such as fatigue and altered bowel habits (Camilleri-Brennan and Steele, 2002; Desnoo and Faithful, 2006; Simpson and Whyte, 2006), experience continual fears of recurrence (Northouse, Schafer, Tipton, and Metivier, 1999) and feelings of uncertainty and concerns for the future (Persson and Hellstrom, 2002; Simpson and Whyte, 2006), and often struggle to adapt to living with a stoma and the implications that this has for their physical, emotional, sexual and social functioning (Brown and Randle, 2005; Desnoo and Faithful, 2006; Persson and Hellstrom, 2002; Sprangers, Taal, Aaronson, and te Velde, 1995; Sprangers, te Velde, Aaronson, and Taal, 1993). In the years following diagnosis, people experience difficulties in physical functioning and carrying out daily activities (Marijnen et al., 2005; Ramsey et al., 2000), psychological and social functioning (Ramsey et al., 2000), sexual functioning (Savatta and Temple, 2005), finances

and returning to and managing employment, (Arndt, Merx, Stegmaier, Ziegler, and Brenner, 2004; Sanchez, Richardson, and Mason, 2004) and in adapting to and managing bodily changes, such as a colostomy (Desnoo and Faithful, 2006). Furthermore, many people continue to suffer from longer term side effects including pain, fatigue, and altered bowel habits (Arndt et al., 2004; Desnoo and Faithful, 2006; Ramsey et al., 2000).

Two qualitative studies were recently carried out to explore the impact of colorectal cancer on identity (Manderson, 2005; Rozmovits and Ziebland, 2004). Both studies identified that patients' sexual identities were disrupted as a result of their surgery or having to live with a temporary or permanent stoma. Patients' management styles took one of two approaches: i) struggling to preserve or return to a pre-diagnosis identity or ii) acceptance of, and adaptation to, a new post-diagnosis identity. Patients in Rozmovits and Ziebland's (2004) study also spoke of their loss of professional identity. Professional personas were lost, not because of a loss of skills or an inability to carry out work-related tasks, but because of an inability to meet social expectations about professional behaviour within a work context (Rozmovits and Ziebland, 2004).

Theoretical Frameworks: Biographical disruption and identity

Bury (1982; 2001; 1991) and Charmaz (1994; 1983; 1995; 2002) are the forerunners of biographically informed perspectives of chronic illness. The concept of biographical disruption was coined by Bury in the early 1980s (Bury, 1982) as both a descriptor of people's experiences of chronic illness and as an explanatory device to comprehend how people respond and adapt to chronic illness. This paper explores the concept's potential for understanding cancer, traditionally perceived as an acute illness. Tritter and Calman (2002)

argue that although there are common features in the experiences of cancer and chronic illness, the differences are all too significant and cancer should not be defined as a chronic condition. While acknowledging these difficulties, this paper suggests that the concept of biographical disruption has utility for comprehending the experience of cancer. It is a concept used to confer chronic illness as a disruptive event, a major kind of disruptive experience, or critical situation (Bury, 1982). These disruptions arise because illness throws into the air people's taken-for-granted assumptions about their bodies, selves and the social world in which they live (Bury, 1982). Bury (1982) 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. Like Bury (1982), Charmaz (1994) suggests that chronic illness compels people to have an awareness of death. However, she emphasises how this disrupts their identity, particularly if the individual perceives themselves as too young to die or defines themselves as healthy and has had no previous experience of illness. This type of disruption, caused by impending mortality, either through perception or reality, has been raised in studies in patients with cancer (Exley and Letherby, 2001; Shaha and Cox, 2003).

Given this paper's emphasis on identity, Bury's (1991) concept of coping is particularly relevant. It refers to cognitive processes whereby individuals learn to tolerate their illness and '*involves maintaining a sense of value and meaning in life, in spite of symptoms and their effects*' (Bury, 1991:461). Examples of coping include normalisation and bracketing off the impact of illness so that the effects on identity are minimised. According to Bury (2001) there are two processes of normalisation. People normalise in the sense of keeping their pre-illness lifestyle and identity intact by either maintaining as many pre-illness activities as possible and/or by disguising or minimising symptoms. Other people find ways to

incorporate their illness into an altered lifestyle so that normal life is re-designated as containing the illness.

It is the concept of identity and loss of self within the context of illness which has formed the focus of Charmaz's (1994; 1983; 1995; 2002) work. Bury and Charmaz situate their work within the tradition of symbolic interactionism (Blumer, 1969; Cooley, 1902; Mead, 1934), which has a specific definition of identity: '*Personal identity can be defined as the person we think we are. It is the self we know*' (Christiansen, 1999:548). Identity remains a contested concept but for our purposes here, we adopt a symbolic interactionist framework which conceives identity as a means of defining and differentiating self from others and takes into account people's preferred identities and identity goals that they desire, hope and plan for in the future. Identity requires empirical validation in daily life; yet, with the onset of chronic illness, daily life upon which former identities have been built will also have changed. According to Charmaz (1983), 'loss of self' is experienced by people with chronic illness because their former actions, lives and selves are now precluded by illness. She notes that whereas acute illness may cause only temporary disruptions of self, chronic conditions can lead to continued losses of self.

Charmaz (1995) examines how people repair loss of self brought about by chronic illness. Some people 'struggle against illness' and engineer their lives in order to regain, restore and preserve a pre-illness sense of self and identity. Her analysis of men's experience of illness (Charmaz, 1994) for instance, illuminates some of the processes employed to preserve pre-illness identities. Bracketing is a means of removing illness from the general flow of life or confining it to separate place. Viewing illness as an enemy serves to objectify and externalise it, which is another process that men used to preserve a pre-illness identity. Others however,

adapt to illness and establish a new identity in the process: *'Adapting implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways'* (Charmaz, 1995:657). The extent to which adaptation is possible and successful is dependent on context. She suggests that middle class and professional men are better able to alter their paid work to fit around their bodily needs. Hence, they are able to maintain an identity goal, which in this example is paid employment, by altering their daily activities to accommodate the impact of illness. Thus, her understanding of disruption takes cognisance of context.

The importance of context

Further research that has used the concept of biographical disruption to understand health and illness have highlighted the importance of context. In particular, Williams (Williams, 2000) and Faircloth et al. (2004) infer that those who experience multiple chronic co-morbid conditions may not experience the onset of another illness as biographically disruptive but rather it is experienced as one event in an ongoing life of events. This has been termed 'biographical flow' (Faircloth, Boylstein, Rittman, Young, and Gubrium, 2004). In a similar vein, the concept may not be applicable to those who have always lived with general adversity and material deprivation or who anticipate ill health because of their circumstances, perceived life expectancy or life stage expectation and age. For these individuals, the onset of chronic illness is just another facet of a 'hard life' which may even be biographically anticipated and therefore not amounting to a fundamental and profound biographical disruption but rather one of continuity and normality (Faircloth et al., 2004; Hopkins, 2004; Leveälähti, Tishelman, and Ohlén, 2007; Pound, Gompertz, and Ebrahim, 1998; Richardson, Ong, and Sim, 2006). A study of older women diagnosed with cancer, however, cautions against assuming that those with hard and long lives do not experience cancer as biographical

disruption (Sinding and Wiernikowski, 2008). This is because social forces often obscure and mute their suffering. Stage of life and timing of the illness during the life course has also been found to influence the extent to which an individual experiences illness as biographical disruption (Grinyer, 2007; Wilson, 2007). Thus, these challenges and qualifications suggest that universal prescriptions of chronic illness as biographical disruption cannot be justified.

Methods

The findings discussed in this paper are drawn from a longitudinal qualitative study which aimed to explore the experiences of people with cancer within the first year following their diagnosis (Hubbard et al., 2007). The study received ethical approval from Central Office for Research Ethics Committee and local research governance approval from the Health Trusts where patients were recruited.

Respondents

This paper focuses on the experiences of 18 people with colorectal cancer within the first year following diagnosis with a range of characteristics that may shape experiences of cancer as biographical disruption (Williams, 2000). Fourteen were in the age range 61 to 85 years and four were in the 31 to 60 age bracket, twelve lived in an urban area and six lived in a rural location, three were female and fifteen were male, eight were in paid employment, eight were retired and 2 were unemployed. Sixteen reported under-going surgery, 12 reported undergoing chemotherapy treatment and 8 reported undergoing radiotherapy treatment. Some people received neo-adjuvant treatment (a combination of chemotherapy and radiotherapy) to shrink their tumour prior to surgery whilst others underwent surgery followed by a course of chemotherapy and/or radiotherapy. In relation to an analysis which

focuses on disruptive lives and threats to identity, the small number of women in the sample limits the study's insight to their experiences of cancer and gendered aspects of biographical disruption (Sinding and Wiernikowski, 2008).

The study as a whole included 66 people with cancer recruited through outpatient clinics in Scotland. Recruitment was purposive, designed to ensure a range of characteristics known to shape experiences of cancer. The sampling frame was as follows: i) Cancer: breast, colorectal, lung, prostate, gynaecological; ii) Age: 31-60, 61-85, 86+; iii) Locality: urban, rural; iv) Sex: male, female; v) Occupation; vi) Marital status. People who had been diagnosed with cancer before were excluded because the aim was to understand experiences of those with no previous history. The size of the sample was dictated by sample selection criteria and the research design. The sample had to be sufficiently large to include people diagnosed with each of the most common types of cancers and range of characteristics but small enough for the researchers to analyse the amount of data generated from conducting depth interviews with each patient three times within a year following diagnosis.

Interviews

Semi-structured interviews took place at respondents' homes and were usually between one and two hours duration. Three interviews were conducted with each person, the first around the period of diagnosis, the others at a later stage, during treatment and follow up to gain extensive knowledge of their experiences of cancer within the first year following diagnosis at these three critical periods of the cancer journey (Kendall et al., 2006). An interview guide was developed, and based on a review of UK cancer care policy and advice from patient and carer advisory groups and clinicians. The guide covered experience of diagnosis, surgery and

treatments, cancer and treatment-related symptoms, information, involvement in treatment decision-making, services, and experience of psychosocial issues such as, employment, finances, family, leisure and existential concerns. During the interview, respondents were asked to describe their experiences in each of these domains. Interviews were carried out between January 2006 and January 2007. All interviews, with the respondent's permission, were audio-recorded and transcribed verbatim.

Analysis

The analysis for this paper involved two distinct procedures. First, drawing on the constant comparative method (Glaser and Strauss, 1967), a descriptive and thematic approach to data analysis was adopted. This process of descriptive analysis about people's experiences of diagnosis, surgery and treatments, cancer and treatment-related symptoms, information, involvement in treatment decision-making, services, and experience of psychosocial issues such as, employment, finances, family, leisure and existential concerns, evidenced that cancer caused disruption to people's lives (Hubbard et al., 2007).

In order to move beyond the level of description (Ritchie, Spencer, and O'Connor, 2003) about people's experiences of cancer within the first year following diagnosis and begin to explain this disruption, we drew on the concept of biographical disruption (Bury, 1982; 1991; 2001) for the second stage of analysis. That is, our descriptions of people's experiences of being diagnosed and living with cancer in the first year following diagnosis were analysed further to determine whether cancer represented biographical disruption. The 18 respondent interview transcripts were divided between two researchers (GH and LK) and were individually scrutinised to interpret the extent to which cancer represents biographical

disruption. We used an initial thematic framework, drawn from Bury's (1982; 1991; 2001) concept of biographical disruption and Charmaz's (1994; 1983; 1995; 2002) concept of identity to guide the explanatory stage of analysis. Each researcher searched for evidence of physical, emotional and social disruption and evidence of threats to identity. This evidence was then collectively discussed by the two researchers with a view to identifying themes and patterns and to reaching a consensus about whether individuals experienced cancer as biographical disruption.

Findings

Disrupted biographies

Using Bury's (1991) definition of biographical disruption and Charmaz's (1983) concept of 'loss of self', several of the people in this study appeared to experience cancer as biographical disruption because it represented a threat to their identity. Individuals respond by engaging in biographical work to manage this threat. The experience of threats to identity manifest as ruptures in the taken-for-granted assumptions that comprise an individuals' social world. This includes bringing to the fore pain, suffering and death which in turn are experienced as threats to identity. An example is when the onset of illness brings to the fore one's own mortality and acute awareness of the ageing process. This is evident when individuals perceive that their illness has affected their appearance and self image:

'I hate myself at the moment. I really hate going out because I look...oh my skin at the moment...my face, I'm coming out in spots and I don't like the way I look. I look like a little old lady and I don't feel like one usually...I've never classed myself as old...I look at that

photo [before cancer diagnosis] and think now that's me...this [talking about the present] is not me.' (P6, I2, unemployed, female)

Looking older threatened P6's previous identity and made her think that she was no longer the same person as she was prior to her diagnosis. She referred to a photograph of her former self which served to re-enforce her perception that she was no longer the same person. Her negative perception of her self image was re-enforced by her GP who had written on a form that she had read that she was a *'frail, underweight female who now looks older than her years.'* With reference to Bury's (Bury, 1991) concept of biographical disruption, cancer took on symbolic significance for P6 because it affected how she saw herself and how others saw her. Further, her experience demonstrates the ways in which others, in this instance, health professionals, can influence the ways in which an individual perceives their identity.

A cancer diagnosis can lead individuals to perceive that they are no longer the same person as they were before. This can be due to changes in their physical and emotional dispositions. Some people saw themselves as different to who they once were, suggesting that a disruption to their sense of self had occurred:

'... one of the questions is that the thing is, do you look in the mirror and think that you look different or something? Well I do feel some days I'm the same person as I was. In some respects I'm stronger; in other respects I'm weaker. I think I'm stronger mentally and physically weaker but I mean you look in the mirror and sometimes and you think it isn't me sort of thing but its, can be strange. But the other day I was getting a contact lens thing and

the woman says, "Go and put your contact lenses for me son." I was at this big mirror right in front of me and it was like looking at a stranger, it was incredible because you're right up the mirror like that. ' (P28, I3, employed, male)

P28 saw himself as simultaneously the same person and changed, suggesting that the experience of cancer heightened his awareness of his evolving self. He recognised that he had changed yet his biographical work predominantly entailed attempts to retain a pre-diagnosis identity, thus, reducing the threat to his sense of self. One of the main strategies that he used to retain a pre-diagnosis identity was to remain in his paid job. His job gave a sense of value and meaning in life which Bury (1982; 1991) identifies as becoming threatened with the onset of chronic illness. P28 describes his place of work as, '*kind of my extended family,*' and that he felt, '*responsible for the livelihoods of other people that work for me.*' He said that he was the only individual in the company that knew every job and every financial implication, thus, giving the impression that he was vital to the operation of the company, which augments his sense of value and meaning in life. As Bury (1991) points out, with the onset of chronic illness, one's sense of value and meaning in life can come under threat. Within the context of biographical disruption, Bury (1991) suggests that those experiencing chronic illness mobilise a range of resources to manage the disruption. P28 was able to remain at work during treatment, thus fulfilling his ambition to retain his former pre-diagnosis identity, which was to remain indispensable. Thus, remaining in employment following a diagnosis of cancer for P28 can be construed as a coping technique to manage biographical disruption (Bury, 1991:461).

Once back at work full-time, however, respondent P28 acknowledged that he was not able to perform his job in the same way as he had before the onset of cancer. He could not concentrate for the same length of time and he did not have adequate energy to do as much work as he had before his diagnosis. Bury (1982; 1991) suggests that the dislodging of taken-for-granted assumptions is further evidence of biographical disruption, and not being able to do the same job as usual fits this category. Additionally, P28 may be said to be displaying elements of coping through '*active denial*' strategies (Bury, 1991), where he engaged heavily in everyday activities like going to work, explicitly positioning himself in opposition to someone who is consumed by illness. After treatment had stopped, work continued to remain an important modality of distraction: '*From the minute I go in, in the morning until the time I come away, it [cancer] doesn't even come into my mind.*' This resonates with Bury's (1991) notion of 'bracketing off' cancer because, whilst being at work, cancer is forgotten. For P28, being able to return to employment also represented normality, another example of coping with biographical disruption (Bury, 1991): '*I was concentrating on getting myself back to normality. Eh, back to work even and that was my aim, was to get back to work*' Yet, despite returning to work full-time, which was P28's way of restoring his pre-cancer identity, restoration was not complete or absolute because he was unable to carry out the same tasks that he had in the past. Thus, despite his determination to minimise biographical disruption, the impact of cancer was too great to avoid it altogether.

Both Bury (2001) and Charmaz (1994) describe biographical work to engineer lives in order to regain, restore and preserve a pre-illness sense of self or to adapt to illness and establish a new identity and a new sense of normal in the process. According to Bury (2001) people normalise by keeping their pre-illness lifestyle and identity intact through the maintenance of pre-illness activities. Whereas P28's biographical work primarily involved returning to

employment, others were attempting to retain normality through the maintenance of daily activities:

'I just find it hard with being so independent. I mean it's like [name of daughter], she's trying to let me do things...I mean I've been pulling out a few weeds out of the garden but when I do want something doing and I can't do it myself, I get frustrated if they [family] don't come down and do it. I've had all my curtains down, I've washed them all and I mean I'm trying to clear up and that and I do get very tired...I've just got to keep going, it's the only way I'm getting through it, it's the only way I'm getting through it is to keep going.' (P6, I2, unemployed, female)

P6 experienced the disruption of cancer as a threat to her independence as well as an assault on her physical self. She found it difficult to carry out daily activities such as, housework and gardening but tried to maintain her independence by '*keeping going*' which facilitated her attempts at retaining pre-diagnosis normality. Similarly, P28 strove to get back to normality as soon as possible. He expressed his wish to lead a normal life which entailed: '*getting up, getting mobile, keep walking about, kept driving my car.*' Immediately after surgery he took an unassisted shower, which was his way of retaining his independence and as described above, returning to work enabled him to present himself as independent and indispensable, both of which were key and valued components of his identity.

Further evidence of biographical disruption is that a diagnosis of cancer can bring to the fore people's own sense of mortality and death: '*I keeping thinking well all them [other people*

she knows who have died of cancer] are going. When is it my turn?’ (P6, I3, unemployed, female)

Death is obviously the ultimate biographical disruption and individuals who do not deny the possibility that they may die engage in biographical work to manage it. One individual who was given a poor prognosis explained that she was aware that she was going to die but tried not to dwell on it:

‘I still have the numbness here [points to head]. You know that’s the only thing that bothers me. My only concern is that gets worse, which would probably indicate that the disease is getting worse, which might mean that, “oh no the time” [death] might be getting closer. I tend not to dwell on it.’ (P50, I2, employed, female).

P50 planned for her funeral, which enabled her to express her identity after her death and how she wished to be remembered. For instance, she planned for a humanist funeral in accordance with her beliefs. Furthermore, prior to her death she maintained her pre-illness identity through a continuation of participating in social activities that she had always enjoyed:

‘I try not to let it bother my social life too much. I was still trying to go out for meals and I still try to go to concerts.’ (P50, I3, employed, female)

Bracketing off the disease (Bury, 1991) can be perceived as a method of managing biographical disruption. It can also be conceived as a means of even preventing threats to identity. For some individuals, being diagnosed and treated for cancer is perceived as a brief moment in time in their life. It will be endured but eventually overcome, with life resuming as before. Thus, any disruption, biographical or otherwise, is episodic and limited:

'No I never asked [about prognosis]. I deliberately didn't ask. As far as I was concerned, I have always had a positive attitude and as far as I am concerned, I will come through the other end. I will have a little bit of hardship for the dip in the middle, but I say I will be there at the other end because it will not be for the lack of not wanting to be' (P2, I1, employed, male).

By bracketing off the disease, P2 maintained his pre-cancer identity because he did not let the experience fundamentally change his life; for P2, the experience of cancer was time-limited, no more than a 'dip.' He continued to work during his treatment, which symbolised continuity with a pre-diagnosis identity, and he changed his time of appointment for treatment to early morning so that his work pattern was less disrupted. He kept up with DIY around the house and garden and also began to make preparations for a vacation abroad, which had initially been put on hold due to his diagnosis. Thus, by bracketing off cancer, he minimised its impact on his life and thereby the self he knew.

Disrupted lives without a threat to identity

Not all individuals experienced cancer as a threat to identity. Our findings suggest that people with cancer can experience illness as a physical and emotional assault which disrupts their daily lives but without it being an assault on their identity. Thus, for some individuals, cancer does not represent biographical disruption in the same way and to the same extent as with the individuals who perceived that cancer threatened their identity. Whilst their daily lives were disrupted, there was no indication that this disruption led them to question their identity or to carry out biographical work in order to retain a pre-diagnosis identity or to develop a new post-diagnosis identity. The biographical work that they engaged in was thus, a continuation of the biographical work that they had always done irrespective of the onset of illness. They, therefore, did not speak of strategies that they had developed in order to manage a threat to their identity. They did not bracket off the illness, as a means of protecting their identity, nor did they use strategies to retain a pre-diagnosis identity or develop a new post-diagnosis identity.

Those who experienced cancer as disruptive but not a threat to identity can experience it as an assault on their physical self because of symptoms related to cancer and treatment:

'Some days I am very sore but I think it's just the diarrhoea you know... it just wears me out some days. There's some days I feel totally drained but its very weakening when you have diarrhoea like that all the time.' (P13, I3, retired, female)

The physical disruption is a major kind of disruptive experience, yet, the interviews with P13 did not suggest that this disruption made him question the taken-for-granted assumptions

about his body, self and the social world in which he lives (Bury, 1982). Cancer can also be experienced as an assault on emotional self:

'I'm normally quite a calm guy but now I'm on a short fuse all the time... it's just bang... the tension.' (P15, 11, retired, male)

P15 highlights the emotional change he has experienced since his diagnosis. However, the interviews do not suggest that this experience led to loss of self as defined by Charmaz (1983). The individuals who experienced cancer as disruption but not biographically so can also experience change in their daily lives and social activities:

'I used to go down to the village and things like that. I used to play golf but I packed it in because it was a waste of money because I wasn't playing too long. I suppose it has [impacted on my life] I'm not going anywhere.' (P37, 11, retired, male)

Like the other individuals (P13, P15), P37 experienced disruption in his life, in the context of social activities and as a consequence of a cancer diagnosis but he did not relate this change in social activities to identity and thus, it did not appear to threaten his sense of self.

The importance of context

A number of possibly inter-related factors may have influenced why some individuals experienced cancer as disruptive but not biographically so. Williams (Williams, 2000) for instance, suggests that those experiencing a 'hard life' may not necessarily experience chronic illness as biographical disruption. An element of a 'hard life' may be previous experience of a life-threatening illness either personally or in the family. Although what constitutes a 'hard life' is not easy to define and should be understood in the person's wider life context and experiences and how they make sense of the other pressures on them, our findings confirm the suggestion that a 'hard life' may lessen the extent to which cancer represents a threat to identity. Some of the people in the study who did not appear to experience cancer as a threat to identity had previous experience of a life-threatening illness:

'All my life it seems to be one thing after another and then some people go through life and nothing happens to them, you know... its just one of those things, that's the way of the world.'
(P13, I3, retired, female)

'I thought that [heart attack] would finish me not this daft thing [cancer]. They say when you get to my age you just accept everything that life gives you. There's nothing I can do about it.' (P33, I1, retired, male)

These individuals (P13, P33) perceived that they had had a 'hard life'. P13 had had a previous hysterectomy and double mastectomy and P33 had had a heart attack and three of his sisters and his mother had previously died of cancer. Neither of these individuals appeared to experience cancer as biographical disruption as defined by Bury (1982, 1991).

Age could also be a factor; P33 appeared to anticipate that at his age illness is inevitable. Others, however, who equally perceived their lives as ‘hard’ did appear to show evidence of cancer representing biographical disruption. P6, who is described in the previous section, described her life as ‘hard’:

‘You see if you know my background and my family, this [cancer] to me is just another thing in my life. I mean I lost my parents when they were young. I’ve had two problem marriages, and I’ve been through a lot. So this [cancer] is just another obstacle to me and that I seem to manage to, scrape through each time, you know. That’s why I think I’m so strong willed. I’ve more or less been on my own since I was 15 you know, I’ve looked after myself since I was 15.’ (P6, I2, unemployed, female)

Thus, having a ‘hard life’ does not necessarily negate the experience of an illness, such as cancer, as representing biographical disruption or minimise the amount of biographical work rendered by the onset of illness.

Discussion

Cancer as an acute and chronic condition representing biographical disruption

The concept biographical disruption has traditionally been used as a descriptor of people’s experiences of chronic illness and as an explanatory device to comprehend how people respond and adapt to chronic illness. It is not always clear when the acute phase of an illness ends and when chronicity begins but chronic illness is usually defined as a type of condition

that has enduring effects and long-term implications for people's lives (Bury, 1991). Cancer has traditionally been conceptualised as an acute illness (Tritter and Calnan, 2002), however, with improvement in cancer survivorship (Cancer Research UK, 2008) more people are living longer with the consequences of a cancer diagnosis and treatment and thus, it is a disease which may increasingly fall within the category of a chronic condition. Hence, the concept biographical disruption may be a useful description of people's experiences of living with cancer and it may also be a useful explanatory device to comprehend these experiences. This study, however, did not explore people's experiences of living with cancer beyond a year and, therefore, focused on the acute phase of cancer when people were diagnosed, received treatment (curative or palliative) and during the early stages of follow up. The study suggests that during this acute phase, some individuals experienced cancer as biographical disruption. Thus, whilst the concept biographical disruption has not usually been applied to understand acute illness it is a relevant concept for describing and explaining people's experience of cancer within the first year and, hence, during the acute phase of a potentially chronic condition. The concept also has relevance for understanding and explaining the experience of individuals who would not experience cancer as a chronic condition because they later died. Thus, this study suggests that irrespective of whether an individual will experience cancer as acute or chronic or the length of time that they lived with illness, some of them will experience it as biographical disruption. This implies that it is not the acute or chronic nature of an illness or its duration which determines whether it will be experienced as biographical disruption but other factors, including its impact on a person's identity.

Biographical disruption is a relevant concept for describing and explaining the experience of cancer for some individuals primarily because a diagnosis of cancer represents a threat to identity. Whilst we acknowledge that 'battle' metaphors for cancer are contested, the terms

‘assault’ and ‘threat’ are used here specifically in relation to the context of biographical disruption. As this study shows, cancer engenders physical, emotional and social change to the extent that an individual can become a stranger unto themselves. Biographical work involves re-thinking of the historical as well as one’s future biography. This revision of past identities is possible due to history’s plasticity, which allows for never completely finished readings and facilitates re-interpretation. It also involves future biographical projections and identification of personal goals. What the onset of chronic illness and a diagnosis of a life-threatening condition, such as cancer does, is disrupt biographical work. Charmaz (1983) notes that whereas acute illness may cause only temporary disruptions of self, chronic conditions can lead to continued losses of self. This study suggests that some individuals within the first year following a diagnosis of cancer experienced biographical disruption as episodic, with a beginning and end point, and a key strategy used to achieve a time-limited biographical disruption is through the bracketing off (Bury, 1982; Charmaz, 1994) of cancer. Thus, we agree with Charmaz (1983) that assaults on identity can be temporary. Others, however, appeared to continue to experience cancer as a threat to their identity throughout the 12 months of the study. Although the study did not explore experiences further than 12 months following diagnosis and, therefore, only examined the early stages of cancer chronicity, some individuals appeared to experience a permanent loss of their pre-diagnosis sense of self. They no longer saw themselves as the same person that they were prior to their cancer diagnosis. However, a limitation of the study is that we were unable to evaluate whether or not this was indeed a permanent loss of their pre-diagnosis identity. Even with this proviso, the study suggests that it is not necessarily the acuteness or chronic nature of a condition that determines the extent to which an illness represents biographical disruption but the extent to which it assaults identity and the biographical work that ensues.

The importance of context

The study confirms Bury's (1982; 1991) identification of the strategies and resources that individuals use to manage biographical disruption, primarily their pre-diagnosis identities, but in the context of cancer. These include bracketing off illness, and doing things such as going to work, doing household tasks and participating in the social activities that they had done prior to diagnosis to achieve normalisation and maintain a pre-diagnosis sense of self. Thus, cancer is not dissimilar to other illnesses, which have been found to represent biographical disruption including stroke (Faircloth et al., 2004) and multiple sclerosis (Green, Todd, and Pevalin, 2007). The study also adds weight to the body of evidence suggesting that biographical disruption is context specific (Faircloth et al., 2004; Pound et al., 1998; Sinding and Wiernikowski, 2008; Williams, 2000).

In particular, the study supports the argument that some people who have had a 'hard life' may be less likely to experience a life-threatening condition, including cancer, as biographical disruption, although this is not applicable to all who have had a hard life. A facet of a hard life may be experience of previous serious illness either personally or within the family. Some individuals who had co-morbidities for instance, did not express the disruption rendered by cancer as a threat to their identity. Thus, the study supports others (Faircloth et al., 2004; Wilson, 2007) who reject universal application of the concept biographical disruption to describe and explain the experience of illness. Further research, however, is necessary to be able to verify the proposition that previous experience of serious illness lessens the likelihood that a diagnosis of cancer is experienced as biographical disruption.

Further evidence rejects universal application of the concept. The study suggests that some individuals experienced disruption to their lives as a consequence of cancer whereas others also experienced cancer as a threat to their identity. It is possible that the people who did not speak of the impact of cancer in the context of their identity simply did not speak of this in the interviews. Whilst acknowledging this limitation, the difference is significant both conceptually and in relation to providing care and support. The study highlights the significance of identity, suggesting that unless illness threatens identity then the illness may be disruptive but not biographically so. Thus, we support the definition of biographical disruption brought about through illness – chronic or acute - that has identity as an explicit and integral characteristic. Those who experience illness as biographical disruption engage in biographical work to retain a pre-diagnosis identity and normality and/or to develop a new identity and sense of normal. In contrast, those who experience the onset of illness as disruption but not an assault on their identity engage in the same biographical work that they have been doing irrespective of their change in circumstances. Their biographical work has not changed because there has been no threat to identity as a consequence of their diagnosis.

The study has relevance for care and support because those who experience cancer as a threat to identity may benefit from interventions that support them to do effective biographical work in the context of an assault on their identity. Biographically informed care for those with acute or chronic illness would support people who experience illness as a threat to their identity. Practitioners would support these people to retain pre-diagnosis identities and also to develop new identities in the context of their change in circumstances. Greater efforts would be made to supporting people to remain in paid work, continue with daily household tasks and participate in social activities if this is what they wanted to do to retain their pre-diagnosis identity and to develop new post-diagnosis identities. In the context of a diagnosis

of a life-threatening condition, such as cancer this approach would also support people to retain their identities through the process of dying for instance, by planning their funeral so that the funeral itself reflects their identity as P47 managed to do in preparation for her death. Biographically informed approaches supplement the medical model of illness, which considers only the character of the disease in isolation of personal biographies, and transcends foci on managing the practical consequences of symptoms arising from the unfolding character of the disease. As such, it may become a useful approach for supporting people to manage the psychosocial consequences of their diagnosis.

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