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Living with Cancer Aged 75 and Older: A Biographical Narrative Case-Study

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Abstract

Aging is associated with greater incidence of disease and illness, including cancers. Extensive literature reports incidence, prevalence, and treatment of cancers in older individuals. The subjective perceptions of older individuals undergoing the experience of cancer remain largely unknown. The case-study reported in this article is derived from a larger study whose aim was to investigate the experiences of older people of living with cancer. Data were generated using narrative interviews with 20 individuals aged 76-87 diagnosed with one of four common cancers. Interview data were analysed using the concept of the “illness trajectory” (Corbin & Strauss, 1988). In this article I present a single narrative revealing a detailed and nuanced progression of events and reactions during the experience of cancer. The cancer story reported here is interpreted as a restitution narrative (Frank, 1995) in which the teller reports movement from an altered status (a damaged body) towards recovery and a return to “normal” (a body restored to health). Some features of this story show health care practitioners and services working effectively to provide treatment and care, but other elements of this individual narrative suggest that some outstanding challenges remain to provide the best care for elders with cancer.

Keywords

Cancer, Illness Cancer, Illness Trajectory, Biographical-Narrative Interpretive Method, Restitution, Narrative, Older Adults, Biographical Narrative Case-Study

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Living with Cancer Aged 75 and Older: A Biographical Narrative Case-Study

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Aging is associated with greater incidence of disease and illness, including cancers. Extensive literature reports incidence, prevalence, and treatment of cancers in older individuals. The subjective perceptions of older individuals undergoing the experience of cancer remain largely unknown. The case-study reported in this article is derived from a larger study whose aim was to investigate the experiences of older people of living with cancer. Data were generated using narrative interviews with 20 individuals aged 75-87 diagnosed with one of four common cancers. Interview data were analysed using the concept of the “illness trajectory” (Corbin & Strauss, 1988). In this article I present a single narrative revealing a detailed and nuanced progression of events and reactions during the experience of cancer. The cancer story reported here is interpreted as a restitution narrative (Frank, 1995) in which the teller reports movement from an altered status (a damaged body) towards recovery and a return to “normal” (a body restored to health). Some features of this story show health care practitioners and services working effectively to provide treatment and care, but other elements of this individual narrative suggest that some outstanding challenges remain to provide the best care for elders with cancer. Keywords: Cancer, Illness Trajectory, Biographical-Narrative Interpretive Method, Restitution, Narrative, Older Adults, Biographical Narrative Case-Study

Context

On the morning of Thursday March 24, 2011, I sat in the spring sunshine outside the library of the University of Glasgow, Scotland, preparing for oral examination of my doctoral dissertation. I was already well-prepared but to keep my focus I decided to listen again to my research interview with 76-year old Henry Jameson (not his real name), who had told me in the fall of 2008 about his experience of colorectal cancer. As I listened to Henry one more time I realised that there was a coherence, a wholeness in the way he told his story that I had not been able to capture in the cross-case analysis which I had used in my dissertation. I decided that I wanted at some point to write more fully about this one story, this one person, this one life.

In my dissertation, I used two levels of narrative analysis—one investigating the narrative arc of the cancer journey across interviews with 20 men and women and the second investigating the whole life contexts of the cancer stories told by the participants. In this article I concentrate on the first level of analysis, the narrative arc of the cancer journey, and I want to show in more detail than is possible in a cross-case analysis some of the nuance and subtlety of an individual journey through the experience of cancer in old age. I want to maximise the sound of the participant voice, the co-creator of the data whose voice is usually subsumed under the researcher/analyst voice. This story is particular, it is unique—it has been suggested to me by one cancer care practitioner that Henry’s positive attitude and apparently successful self-management are not typical experiences among older people with

cancer. Nevertheless, I think and hope that health care providers, and narrative analysts, will find this uniquely individual story interesting and illuminating.

Background

Despite increasing longevity and generally improving health in Western populations, the process of aging is associated with greater incidence of disease and illness, in particular of degenerative conditions such as musculoskeletal disorders, ischaemic heart disease, neurological impairments, and cancers. Comorbidity is common in individuals aged 70 and older (Extermann, 2000; Stevenson, Abernethy, Miller, & Currow, 2004) and the incidence of cancer is higher in older populations (Cancer Research UK, 2014). There is extensive literature reporting the incidence and prevalence of cancers in older age groups along with approaches to treatment and the effects and management of comorbidity (Bennahum, Forman, Vellas, & Albaredo, 1997; Extermann, Overcash, Lyman, Parr, & Balducci, 1998; Satariano & Silliman, 2003). There is also a large body of literature on patients' experiences of illness. However, the subjective perceptions of older individuals undergoing the experience of cancer remain largely unknown.

The case-study reported in this article is derived from my doctoral studies, which investigated the experiences of older people of living with cancer (Hughes, 2011). My specific focus of interest was the experience of people aged 75 and older since this appears to be a hidden population whose experiences are largely undocumented. For example, individuals aged 75 and older are rarely represented in cancer research or policy documents. A rigorously conducted literature search (Hughes, Closs, & Clark, 2009) discovered that from an international sample of 262 papers only two studies focused exclusively on the experience of people aged 75 and older. In the United Kingdom, Department of Health cancer publications since 2000 focus predominantly on the under 75s (Department of Health, 2000, 2005). Moreover there has been continuing concern that older people's specific needs, both physical and psychosocial, are not sufficiently considered, independently of their chronological age, when prescribing treatment and care for cancer (Bailey et al., 2003; Kagan, 2008; National Cancer Intelligence Network, 2013; Porock et al., 2009).

Because older peoples' subjectivity is missing from research on older people and cancer, I chose to use a method which would privilege participants' own accounts of their cancer experiences and their lives, told in the form of a story or series of stories. Frank (1995) argues forcefully that stories of illness are told to be heard, not to be analysed. If the reason for eliciting the story is a therapeutic one then I would agree with this. Where stories are sought for research purposes, though, the story has a wider significance than the celebration of the teller's experience (Atkinson, 1997; Atkinson & Delamont, 2004). Stories generated for research purposes are intended to produce knowledge; therefore, analysis and interpretation of the story are required (Thorne, 2009). Having said this, social research is not conceived and conducted in a moral vacuum and a motive force behind this study was to enable the voices of a hidden population of cancer sufferers to be heard. I assumed, following Vincent (1999) and Asquith (2009), that the current life experience of people over 75 with cancer, and probably with comorbidities as well, would be characterised by suffering. I had a partly moral purpose in seeking to describe this suffering and present it to audiences whose knowledge would thereby be increased and who would be motivated to work towards reducing suffering in this population.

The aspiration to a moral purpose must be approached reflexively, though, given the complexity of social reality and of the limited possibilities for eliciting "truth" through the medium of a face-to-face research interview (Potter, 2006; Seale, 2006). It would be naïve to assume that I can present the "voices of older people" directly and unmediated. Even raw

interview transcripts, sometimes presented in reports of oral history research, represent an artefact that is co-constructed, the output of an interaction between interviewer and informant (Gubrium & Holstein, 2009; Silverman, 1997; Tangaard, 2009) which is then rendered in particular ways by the act of transcription (Riessman, 2008). Interviewing is not an epistemologically neutral act. And it is not morally neutral.

The job of the interviewer, then, is to listen, try to understand, and to “retell it afterwards” (Bourdieu, 1993, p. 61) in a balanced and non-judgemental way. Ultimately the position I take up in this research is that of *story analyst* rather than *storyteller* (Phoenix, Smith, & Sparkes, 2010). As a story analyst I am orientated towards standing back from narrative data, the stories generated in interviews, with the intention of making general and comparative explanatory statements about them. At the same time, though, I hope to achieve some of the storyteller’s goals of evocation and engagement with stories, letting them speak for themselves, and allowing interpretation to be shown as well as told.

Methods

Participants

I conducted narrative interviews with 13 men and seven women aged 75 and older, with one of four common cancers (5 each with breast, bowel, lung or prostate cancer). Participants were recruited from a large cancer treatment centre in the north of England in 2007-2008. Ethical approval for the study was given by a National Health Service (NHS) research ethics committee in May 2007. All participants gave written consent and were interviewed in their homes.

One quarter of the participants (five people) were aged over 80, the oldest (male) being 87 and the youngest (female) 75. Twelve participants were married (two for the second time: one following bereavement, the other divorce); nine were widowed and one (in addition to the remarried divorcee) was divorced. Eight of the participants were living alone at the time of interview, 11 with a spouse or partner and one with an adult child. Of the 13 men interviewed five were widowed (one of them twice); of the seven women participants four were widowed. One man and one woman were divorced. Five men and three women were living alone at the time of interview. None of the participants was in paid work but one man was actively pursuing creative and business interests at the age of 84, undeterred by knowledge of his rapidly advancing prostate cancer. Several others were actively occupied in a variety of way, for example, with hobbies or with family concerns.

Data Collection and Analysis

I elicited accounts of cancer experience using a modified version of the Biographical Narrative Interpretive Method (Wengraf, 2001). This method of interviewing is directed at the facilitation of storytelling. Interviewers begin with a single opening question which invites participants to tell a story which is relevant to the research topic. The interviewer listens, without interrupting, until the participant declares that he/she has nothing else to say. The interviewer asks follow-up questions to deepen stories which the participant has already told rather than to gain new information related to the interviewer’s agenda. Interviewers achieve this by asking “narrative pointed questions,” for example, “What happened then/next/after that?”

I used Corbin and Strauss’s (1988) concept of the illness trajectory as a narrative device to structure analysis of the interview data. The illness trajectory consists of a temporal arc during which a particular series of events typically occur (not as straightforwardly linear

as represented here, obviously, but the general shape holds well): the first noticing of signs or symptoms (of cancer, in this case), subsequent health seeking behaviour (i.e., telling somebody about it; going to the doctor), referral to specialists, investigations, diagnosis, treatment, and increasingly, situating self in living with cancer beyond treatment.

This narrative arc can be revealed as a more detailed and nuanced progression of events and reactions by concentrating on a single narrative. So, in this article I present as much of one particular story as possible, in the participant's own words, along with some interpretive commentary which enables us to "think *with* the story" not just *about* it and "experience it affecting [our] own life" (Frank, 1995, p. 23). Bourdieu (1993) presents a useful model for this extensive quotation from interview transcripts, which permits readers to engage independently with the participant's self-reported experience. I give the participant a pseudonym, "Henry Jameson," and present his cancer story in 12 distinct phases, which I identified by analysing the interview transcript using the temporal arc of the illness trajectory.

I hope to show that in attending to the detail of individual experience and the ways in which it is reported, we can find insights into improving cancer care practice for older people. Some features of this story show health care practitioners and services working effectively to provide treatment and care, but other elements of this individual narrative suggest that there are still some challenges in providing the best care for elders with cancer.

I begin with a biographical summary of the participant and go on to present long extracts from the interview, with interpretive commentary, in which he reports his experience of cancer. "Henry Jameson" is a pseudonym, and all identifying details have been changed.

Biographical Summary

Henry Jameson was born in 1932, in a Lancashire village close to where he still lives. He left school at the age of 14 and worked in a range of agricultural and factory jobs, retiring from work at the age of 66. Henry married in 1960 and together he and his wife had three children. Henry's wife died in 1988 from lung cancer. He enjoyed close relationships with several women over subsequent years but did not want to remarry. At the time of our interview, in November 2008, he was still living contentedly alone, with many friends and an active life. For a number of years Henry had bowel symptoms, attributed by his general practitioner (GP) to irritable bowel syndrome; he did not "feel right," lately noticing blood in his stools which he assumed was due to haemorrhoids. In December 2007, he suddenly started to bleed copiously from the rectum and had to be rushed to the hospital. Initially, Henry was told he had a "burst ulcer" but after further investigations was given a diagnosis of colorectal cancer. He was shocked at this, but said he fairly quickly came to terms with it and developed a very positive and determined attitude towards recovery. He underwent both radiotherapy and chemotherapy to shrink the tumour and then had to have surgery, leaving him with a permanent colostomy. Henry's stories about his illness, and his life, are underpinned by his great appreciation of all the help and support he received from his family, friends, neighbours, doctors, and nurses.

Henry Jameson's Cancer Story

The cancer story which Henry tells is presented here in 12 distinct phases, which I have identified as separate parts of the story for analytic and interpretive purposes—in Henry's storytelling the narrative is sequential and uninterrupted. Henry's cancer story begins with a general reflection on his not "feeling right" for a long time as a result of what his GP diagnosed as irritable bowel syndrome. Subsequent phases tell of more dramatic symptoms, hospitalisation, investigations, diagnosis, treatment, and return to normal life, the progression

and outcome of what Frank (1995) calls “conventional storytelling” (p. 58). In form, as well as content, the narrative told here shares features of everyday storytelling; for example, most of the extracts presented contain linguistic markers which indicate narrative movement: “as time went on. . . it came to a head. . . when I got there. . . next thing” and so on. The quotations are lightly edited to reduce some of the hesitations of speech and the particularities of a regional speech pattern which may not be immediately intelligible to a wider audience or readership. Following Bourdieu (1993) and McCormack (2004), I give the data extracts titles taken from Henry’s own speech.

The First Signs of Illness

Public health information about cancer has long stressed the importance of early detection as one way of maximising the chances of curing the disease. The underlying assumption is that if cancers are identified at an early stage of their development then treatment is likely to be more effective (Department of Health, 2007; Wilkins, Payne, Granville, & Branney, 2008). The problem is that the uncontrolled and unregulated growth of cells which characterises the initiation and development of cancer (McAlister, Horowitz, & Gilden, 1993) takes place beyond awareness of the sensing individual. By the time a person becomes aware of bodily change which may indicate cancer, significant windows of opportunity for effective treatment may have been lost. Consequently, developing the science of pre-symptomatic screening, along with health policies designed to provide screening services and to encourage their uptake, has been a major feature of cancer care and treatment over the last three decades. However, older people are less likely than younger people to take up opportunities for screening and, in any event, most cancers are detected as a result of symptomatic presentation followed by medical investigations (Richards, 2009) rather than by screening. Henry Jameson’s experience fits this latter pattern, and includes at least two instances of misattribution of symptoms to causes other than cancer (Corner, Hopkinson, & Roffe, 2006; Leydon, Bynoe-Sutherland, & Coleman, 2003).

Phase 1: I thought it was piles

As time went on, I started with this irritable bowel syndrome. The doctor said it was irritable bowel syndrome. I was taking this stuff and, for years, I didn’t feel right. And then. . . I thought it was piles I was starting with.

Phase 2: Blood was just gushing out of me

And, anyway, it came to a head last Christmas, in December. I had a brandy at my friend’s house. There were seven of us going to this club. We went in this club and I got a pint of bitter. I can remember just having a few drinks and I thought, “Oh, I don’t feel right.” Something in my stomach, which was unusual for me because everything used to work normal— I’d go to the toilet probably twice a day but no less than once a day. But I had been seeing blood and I thought it was piles so I’d been putting suppositories, you know. And then, I went to the toilet at the club. The blood that gushed out of me, I couldn’t tell you what it was like. It took me 10 minutes clearing everything up and washing everything down with a brush in this toilet. And I went back and I said to my neighbour, “I’m going home, I don’t feel so good, but don’t say anything to the others. I’m going home.” Well, I’d to walk about a quarter of a mile from the club, you know. How I got home I’ll never know. I got

inside and straight on the toilet and it [blood] was just gushing out of me. So I rang my daughter up and she rang for the ambulance and it came straight away. And as soon as he saw me he said, "It'll have to be X Hospital for you. I'm not taking you to Y or Z. It'll have to be X," you know. So, it was that bad, I put a big towel between my legs and new pants on, new shirt and everything.

Phase 3: It's an ulcer that's burst. . .it'll mend on its own

When I got there they cut everything off me because I was soaked in blood. I wasn't bothered about that. And then I was in hospital for two or three days, over Christmas. They couldn't do anything on the Christmas Day. And so I'd come round then, I'd stabilized. They didn't give me a blood transfusion; they said I was making blood back. And, they put me on this ward, on Ward 12 and I felt OK again. But they said they couldn't do this telescope thing because there was too much blood. So, I'd to wait till. . .it was the day after, Boxing Day, then they did it. And they said, "Oh, you'll be able to go home tomorrow, it's an ulcer has burst." I watched it on the screen, you know. It looked like a big squashed tomato. They said, "It's an ulcer has burst." "Oh, that's good." They were talking, like, "Oh, it'll mend on its own."

Further Investigations and Definitive Diagnosis

For anyone facing cancer it is important that diagnosis is timely and accurate and that the information is conveyed sympathetically. Henry's provisional diagnosis turned out to be inaccurate and, on further investigation, was confirmed as cancer (Phases 4-5). He reports a shocked reaction to this news in which he almost anticipates imminent death. The manner in which the diagnosis was disclosed, in Henry's report, shows some features of what are deemed to be helpful communicative practices: that is, a signal is given that bad news is coming (though this is fairly oblique, as the reason for asking the identity of a companion may not be readily interpreted as a harbinger of "bad news"), sympathetic expressions are used and he is left with some grounds for hope (Bain & Campbell, 2000; Elliott & Olver, 2002; Thorne et al., 2009).

Phase 4: I came home. . .then back for a scan

So, next thing, I came home. I'd been in hospital about three days, I think. I came home and then I'd to go back for a scan. And this doctor, Dr. S. I was under, Mr. S. a surgeon, [said] I'd to have these scans: a CT scan and an MRI scan.

Phase 5: I've bad news for you, Mr. Jameson, you've got bowel cancer

Next thing, we'd to go and see Mr S., and unfortunately, he was on holiday. So another doctor saw me and he said, "Who's this with you?" I says, "Oh, it's my daughter." He said, "I've bad news for you, Mr. Jameson, you've got bowel cancer." 'Course it knocks you back. And my first words were nearly, "How long have I got?" And he says, "There is things we can do for you," he says. "The worst scenario is, you'll have a bag for the rest of your life, colostomy bag," he said. "Or we may be able to put you back in six months,

depending on how low it is, how much bowel there is left.” So this nurse, K., she was holding my hand. And, I felt really bad, and, she was telling me, you know, how many hundreds there were with it, and all this, and “We’ll try and get you in as soon as possible,” which they did.

The Experience of Treatment, in Hospital and at Home

Henry reports his first experiences of treatment in three stages: incorporating

- a) the initial treatment prescription and his psychological reactions,
- b) the support he received from his neighbour and friends which sustained a positive state of mind, and
- c) the physical effects on him of undergoing the treatment (Phase 6).

He then goes on to describe in some detail (his characteristic stance as a narrator) further investigations and hospital treatments, together with his continuing care at home (Phases 7-9).

Phase 6: We’re going to make you poorly, to make you better

The first thing I had to have was radiotherapy and chemotherapy. Well, after a couple of days I got my head round it and I was determined I was gonna be OK. My neighbour [. . .] wrote me a thing out, I have it somewhere, and it says, “They’ve found it, it’s treatable. . .,” you know. And she wrote a thing out [that] I could look at every day, you know. . . “and you’re going to be alright.” And I used to look at this every day. And I had chickens [. . .], and I’d rabbits, and I thought, “Well, the first thing is I’d better get rid of these, you know, cos I’ll not be able to look after them.” My neighbours came round, “You’ve not to touch nothing, we’ll look after ‘em. You’ve not to worry [. . .], we’ll look after ‘em.” Because they knew they meant so much to me [. . .] I used to get up in a morning and they were there making a noise, you know, it was lovely. It was like having a little farm, you know. It just used to take my mind off things. It took a lot off my mind. I was planning for a year ahead. I wasn’t thinking about cancer, you know. If you’ve something else in your head. . .if you’re dwelling on cancer you will be down, you know. And I thought, I’m trying to do things that I’ve done, and keep going, you know.

And, they told me, at the hospital, “We’re going to have to make you poorly to make you better.” Which they did. And I went for chemo every day for 5 weeks and radiotherapy every day for five weeks. I’d have chemo twice a day, morning and night, and the radiotherapy sometime during the day [. . .] And I used to come home, and I felt that rotten I used to just kick my shoes off and go and lie on my bed for a couple of hours till I came round. Because I couldn’t describe the feeling. It’s like a sickly. . .you feel. . .it’s like nausea. I couldn’t describe it. And I felt that weak. Radiotherapy seemed to do me worse than ever.

Well, the cancer was only, like, two inches, just inside me. So, first of all, I had to go and have these tattoos put on so that. . .where they’d put this radiotherapy, you know, where they had to go with the rays. I had to lie face down with my head in a, like, a little bucket thing, plast. . .you know, with my head down. They used to measure everything up; you could hear them taking

measurements, you know, and then, when they'd got everything set up, they used to go and leave you.

And I finally got into it. It was no problem. I couldn't feel anything. All I could feel was. . . I was lying on a thing, like a glass top, and all I could feel was. . . I'd a dancing feeling in my feet. . . I used to think my feet were coming off. But I hadn't to move, you know. And that went on for five weeks.

One noticeable feature of the way Henry gives this retrospective account is the extent to which his allusions to the growth of a positive attitude in the face of suffering appear to involve not just the passage of time, but some kind of work on his part. He "got his head round" the treatment process, "looked every day" at a self-help mantra written for him by a neighbour, purposefully thought about things in his life other than cancer and "finally got into" the process of undergoing radiotherapy. This work-like approach is of a piece with the autobiographical account he gave in the interview of a working life spent in hard manual labour.

Like many people with cancer, Henry underwent multiple treatments. His style of reporting discussions with medical staff, and decisions made regarding further investigations and surgical treatment, relies on a form of apparently verbatim conversation in which he presents the relationship between himself and the medical staff as collaborative and unproblematic (Phase 7). Statements reporting potential conflict or dissatisfaction with nursing staff are rendered in less intensely personalised form (Phase 8).

Phase 7: I could operate on you this weekend

Mr. S., he'd come back by then, off his holidays, and he said, "I'd like to do another internal examina. . ." like, "with a telescope," he said. "But I'll have to give you anaesthetic this time cos it'll be a bit more severe than what you had before." So I went in and had this anaesthetic, and I didn't know nothing. I was just talking to this bloke about fishing, you know, salmon fishing, and next thing I woke up in another ward [chuckling] and he'd already done it.

And he came, did Mr. S. and he said, "You know, Mr. Jameson," he said, "the chemo," he said, "and the radiotherapy, it's shrunk it so much there's only scar tissue left," he said. "I could operate on you this weekend if you're agreeable." And I said, "I am," you know, I said, "whenever you want." He said, "Right, I'll see Dr. P." the chemo specialist, he said, "and see if it can be done."

So, Dr. P. said, "You can't do it, because he's another three weeks of chemo working in him yet." So, they delayed it for 3 weeks and then I went in for my operation.

Phase 8: I couldn't have been looked after better (in hospital)

I went in on the 16th of June, I had my operation on the 17th of June and I woke up in intensive care. They were absolutely marvellous with me [. . .] I woke up in intensive care and Mr. S. came and he said, "Well, Mr. Jameson," he said, "I'm afraid you'll have to have a bag for the rest of your life," he said. "It was so near to the bottom of your bowel," he said, "we couldn't join it on. I've had to take everything out." I was stitched up. I'm cut

from here to here [gestures thorax to lower abdomen]. My backside's at the front now [. . .] but nothing at the front ever bothered me.

I was in hospital a month and a day and I couldn't have been looked after better. But there were different ones that were a bit off, you know, like, didn't have much time for you, but most of the time I mean the. . . I think she was the matron on there, M, she was absolutely marvellous with me. And a lot of them were, you know, most of them were. There were only odd ones that were, you know, they couldn't be bothered if you shouted [for assistance] or rang your bell, you know. I was full of morphine. And this thing at the back, where I was stitched at the back, I had this big dressing on. When I used to go for a shower, it all used to come out and, ohhh! It used to make me sick nearly, you know. And the pain, I couldn't describe it. I was taking pain killers, you know, I had pain killers. Everything was alright as far as that goes. They wouldn't let you have pain, you know.

Phase 9: District Nurses come every day and put this dressing on

I was in hospital for a month and a day. They finally [with indwelling urinary catheter following urinary retention] let me home. And the [district] nurses, they've looked after me. I couldn't have had. . .you know. They come every day and put this dressing on and one of these nurses said to me, she said, "You know Mr. Jameson, I'm going to tell you now," she said, "when you first came home," she said, "your backside, it was five inches deep," the hole that they were putting this pack in. So, what it was like when it was newly done, I don't know. Well, I know they used to put all this packing in with a sterilized metal rod, you know. They used to pack it in and I used to be over the bed and I used to. . .I used to nearly pull my eyes out with trying to shut. . .because it used to hurt that much when they put these things in [. . .] But it's taken it from. . .it's only this last week or two [November 2008], and that's from June, for it to heal up. I still get pain and I'm still sore at the front. But they tell me it's this radiotherapy that's still in my skin. Now, when I had this radiotherapy it burned right through, from my back to my front [. . .] everything was swollen up. All the hair went off me here round. . .'round my private area it was just like I'd been scalded. My skin, it was tacky [sticky] and I said, "Is it normal?" He said, "It's normal." All I could do, they give me this, some sort of Aquafoam to put on it [. . .] just. . .just to soothe it, at the front. And, anyway, it gradually. . .when I stopped with the radiotherapy, it gradually went better. Well, I still get this tightness and he said, "It'll be in you for another eight month," you know. Well, I mean, I'm not bothered about things like that.

Continuing Life with Cancer

Bringing his story up to the time of our interview (November 2008, nearly a year since the sudden onset of rectal bleeding which signalled the presence of colorectal cancer) Henry emphasizes the many positive aspects of his experience (Phases 10-12). Post-surgical chemotherapy leaves him tired and nauseated but he has no symptom burden from the cancer itself and he refers, repeatedly, to the positive frame of mind which he has been able to sustain, through his own determination not to "dwell on" having cancer and through the support of his family, neighbours, and friends.

Phase 10: *Everybody's helped me*

I can get about, I can do things. My daughters, they come and one does my shopping and cleaning. And, you know, everybody's helped me. And this is the way I've carried on. But, I've had things to occupy my mind. My mate takes me fishing [then] my mind's on what I'm doing, it's not dwelling on cancer. And I think this is the main thing, you know. I described it to one bloke. He said, "Well, how do you go so positive?" I said, "Well," I said, "the only way I can describe it to you," I said, "if you were having sex," I said, "you wouldn't be thinking about cancer would you?" He said, "No." I said, "Well, when I'm dwelling on [other] things," I said, "I'm not thinking about it neither" [chuckles].

And this is why I've kept the animals. And I've gone to shows with them. I've had help taking me. There's a bloke, he does a lot of shows and he picks me up and takes me to C. and wherever. And my mate takes me fishing and my mind's not on. . . I don't sit at home dwelling, I'm out. I've had to wait for the nurses coming in a morning to put this dressing on and as soon as they've been, I'm out, you know. They know that they come before 10 o'clock, you know. Well, I'm out. And I like to be doing things because I'm not dwelling on what I've got, you know.

Phase 11: *The main thing for me is this, they've done marvellous with me*

I'm on chemo now. After I'd had my operation they told me, this Dr. P. I went to see him, he said, "Well," he said, "we've done trials and," he said, "we've found out that if you have this dose of chemo after. . . you know, it'll be a lot stronger than what you had before, but," he said, "we do it after your operation," he said, "we've found out it's better than waiting six months and having a blood test and if there's anything wrong we've lost six month if we wait," he said. "So, you don't need to have it, if you don't want. But if you want to have it you'll have to sign," you know.

So, I signed for this chemo and I'm in the midst of it now. I think I've had about three months now, is it, or something like that. I think it'll be March when I finish. I have it twice a day, you know, which is a fair lot. And it knocks me sick, but I'm getting used to it, I think. I have 14 days on with it and seven days off. And I look forward to them. Not so long and I'll be off again. And there's always somebody coming, like my grandchildren. They come round and while they're here I'm not. . . sometimes I feel nauseated and feel sick and I feel depressed and when they come, it goes, you know. I'm dwelling on something else.

It's altered me a lot in some ways. I used to bother about money, would I have enough for this or that? But now I don't. There's other things. Life's more important than anything, you know, money's nothing. There's a lot of things I used to bother about going wrong I don't bother about one iota, now, because they can be put right, you know. It doesn't matter what it cost they can be put right. The main thing for me is this: they've done marvellous with me, what they've done, you know. When you think, you've been changed round from front. . . from back to front, like this. And I'm happy enough. I feel strong enough. As soon as I get off this chemo I can feel different, you know. And I know I'm gonna be a lot stronger when I've finished with it. But

they told me that. Mr. S's assistant told me, when I went to see them, he said, "You've no cancer in you whatsoever," he said. "It's gone. It's all been taken out," he said. "What they've done, why you're having this chemo," he says, "it's because they want to do. . .they've done tests on what's come out of you, what I've taken out and," he says, "out of five tests they found one cancer cell," you know. "That's all it is," he said, "that's why they want, you know, it's just like a precaution." So, I felt really good about that, you know.

Phase 12: *It's amazing, what you can do.*

So, this is the stage I'm at now. And, you know, there was a bloke in there when I was having radiotherapy and I knew his sister and her husband, they used to go to the same club as I went to, and he couldn't do with this radiotherapy. He had a mask on because it was in his throat, you know, and he'd taken everything off and screamed and they had to fetch him out. And she said, "Will you have a talk to him?" I said, "Well, I don't see what I can do." She said, "Just have a talk to him, Henry." So, I had a talk to him. And I said, "You know, I said, "I felt like you feel when. . .I didn't know I was going in for it, I felt like screaming and jumping out," I said. "You've to think about your grandchildren and getting better and they're doing it to make you better," and all this. And I tried to explain. He went back in and had it done, and he's never looked back since. And he rings me up at least once a week, you know, and I ring him up, you know, "How're you going on?" "Oh, I'm doing alright." It's amazing what you can do. A lot of it's in your mind isn't it? You can make yourself bad with dwelling on things if you've nothing to take it off your mind. I feel sorry for folk that live on their own and never see anybody. I live on my own, but I've plenty of backup round here. My neighbour across the road, she comes in every day, you know, to see me.

Discussion

Narratively, this is a coherent, but as it must always be, a partial and selective account. Some details are skipped over in the interests of progressing with the main story; for example, Henry says nothing about the experience of irritable bowel syndrome and he telescopes the time interval between first discharge from the hospital, return for scans as an outpatient and further return for results and diagnosis.

More significantly, some whole stories that we might expect to hear are absent. Henry refers in Phase 5 to the possibility that he might have a colostomy and in Phase 8 to the formation of the stoma as part of his surgery. He says nothing else about it beyond, "My backside's at the front now. But nothing at the front ever bothered me." When invited to tell a story, it appears that we tell what is significant to us, what looms large in our memory as pleasurable or challenging or interesting, and what is consistent with how we choose to present ourselves to the world at any given moment. Henry tells illness stories of symptoms, investigations, treatments, side-effects, and recovery. But he is silent on the subject of continuing to live with a colostomy, beyond the post-surgical adaptation which he reports as being straightforward.

The overarching plot of Henry's story concerns the central foci of an illness trajectory—first symptoms -investigations-diagnosis-treatment—and follows a chronological sequence covering a period of approximately 11 months, reported here as comprising 12 phases. A network of actors, including family members, friends, neighbours, and health

professionals play their expected roles, mostly, in the perception of this narrator and the lead actor (Henry) to his great satisfaction. He singles out for particular appreciation nurse K., matron M., the friend who looks after his animals and, above all, the neighbour who provided him with a written, positive thinking mantra. A few, unnamed, nurses did not live up to expectations of their role, in his reported experience.

Another “plot” is evident, too, in Henry’s reports of his inner reactions to his experiences. His reports of his emotional and psychological responses show a progression over time from shock and fear (“it knocks you back. . .how long have I got?”) to determination (“I was determined I was gonna be OK”). This determination for recovery and survival seems to come partly from his inner resilience, which may be borne of and fostered by a lifetime of hard work, a strong network of family and community relationships, and experience of loss (Hughes, 2011; Hughes et al., 2009), but is also fostered by others’ apparent determination to help him (“they’ve done marvellous with me; everybody’s helped me, you know”).

The extent to which Henry’s expressions of a positive attitude are a feature of performance in an interview setting (Gubrium & Holstein, 2009; Silverman, 1997) is difficult to gauge. The language he uses sometimes reveals a contradictory quality whereby he states something in unequivocally positive terms which is undermined to a degree by another comment. For example, “I couldn’t have been looked after better” (Phase 8) is followed immediately by, “There were different [nurses] who didn’t have much time for you,” thus indicating that he **could** have been looked after better. Henry describes post-surgical pain which nearly made him vomit, but said that the nurses “wouldn’t let you have pain.” These apparent contradictions could be a tacit way of indicating that, as might be expected, not all his experiences had been positive but that his chosen orientation is to look on the positive side as much as possible. He achieves this partly, as he says repeatedly, by “not dwelling on it.” His positive frame of mind is so evident to others that he is asked to support a fellow patient undergoing radiotherapy (Phase 12).

Both of these plot lines, reflecting parallel and interwoven experiences of a changed body, emotional and psychological reactions to the potentially mortal threat of cancer, and the life-enhancing nature of relationships, permit an interpretation of Henry’s story as a “restitution narrative” (Frank, 1995)—that is, a story which the teller both experiences and reports as progressing from an altered status (a damaged body) towards recovery and a return to “normal” (a body restored to health). Return to normal, though, does not mean taking up life exactly as it was before. Unexpected emotional and psychological benefits are reported from undergoing the whole experience and while continuing to hope for a final cure for his cancer from the post-surgical chemotherapy, Henry proclaims himself “altered” (Phase 11) in respect of his attitude to problems and his anxiety about money.

Implications for Health Care Providers

When I look at Henry’s story through the lens of my professional background as a nurse and teacher, I see some elements of his reported experience which reflect well on health service provision. I also see some outstanding challenges. While it is not generalizable from the experience of one individual, I think health care providers can be proud of the speed and efficiency of a healthcare system which admitted Henry to hospital urgently, stabilised his sudden blood loss and went on quickly to investigate and treat his condition, irrespective of his chronological age. I think it is good to hear that nurses (K. and M.) offer comforting as well as technically proficient care. I also think it is heartening to know that some of the older people cared for in the health system are also cared for by many others (family, friends,

neighbours). It is encouraging to know that it is possible to have flexible care systems (district nurse visits) that fit services to how people want to live their lives.

At the same time, there is a continuing challenge to encourage older people to seek medical advice at an earlier stage of experiencing symptoms. The dramatic onset of rectal bleeding which took Henry into hospital was not the first appearance of blood in his stools (“I had been seeing blood. . .I thought it was piles so I’d been putting suppositories”). This misattribution of symptoms appears to be not uncommon (Corner et al., 2006; Leydon et al., 2003). It is to be hoped that the work of the National Awareness and Early Diagnosis and Initiative in England (Department of Health, 2005) will prompt more people to respond sooner to symptoms. It might also help, if initial results show the programme to be effective, if the National Bowel Cancer Screening Programme (Department of Health, 2005) could be extended to include those over 75.

Practitioners might also reflect on the likely emotional and psychological effects on patients of receiving a provisional diagnosis expressed as though it were definitive. They should consider carefully what it might be like for a person to receive a diagnosis which might not seem to be unduly alarming (“it’s an ulcer [that] has burst”), to be then informed that they have a life-threatening illness (“I’ve bad news for you, you’ve got bowel cancer”). In addition, professional carers might take up a challenge to give their best attention at all times to patients (“some of the nurses were a bit ‘off’ with me at times”) and to think more about how to minimise the pain of wound care procedures.

Conclusion

In my local hospital, a poster inviting patients to take part in a review of the hospital services proclaims, “Your Experience is Important to Us.” This biographical narrative case-study provided the opportunity to hear extensive and in-depth experience from an older person with cancer. I chose to present a single case-study in the hope that readers might gain insight from engagement with a detailed, evocative, well-structured story and that, in reflecting on the interpretations offered here, readers will also be able to contribute their own analytical and interpretive thinking to the large amount of narrative data offered for consideration.

Note

Ethical approval for this study was given by a UK National Health Service (NHS) Local Research Ethics Committee (LREC) in May 2007. Details of the ethical principles underpinning the design of the study and the ethical practice governing its conduct are reported in detail in my doctoral dissertation (Hughes, 2011), which is accessible at <http://theses.gla.ac.uk/2651>

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