



ORIGINAL ARTICLE

Jo's Story: the journey of one woman's experience of having cancer and a 'learning disability'

Melissa Hannah Martean, Department of Learning Disabilities, Highbury Hospital, Nottingham, UK (E-mail: melissa.martean@nottshc.nhs.uk), **Rudi Dallos**, **Jacqui Stedmon** and **Duncan Moss**, Department of Clinical Psychology, Rolle Building, University of Plymouth, Plymouth, PL4 8AA, UK

Accessible summary

- Tells story of a woman with learning disability and cancer.
- Highlights importance of research with people with learning disabilities.
- Promotes people with learning disabilities as reliable research participants.

Summary

With increasing longevity amongst people with learning disabilities, it is not surprising that prevalence and incidence rates of cancer are growing at a significant rate. Much of the research undertaken in the area of psycho-oncology has focused on the 'general population', and over the last decade, there has been increasing interest in using a narrative approach to explore the lived experiences of people who have had cancer. Traditionally, research into cancer amongst people with learning disabilities has focused upon epidemiology or palliative care. However, the present article uses a narrative analysis to explore the lived and told experience of a person with a learning disability, who has been given a diagnosis of cancer. This article highlights the need and provides justification, for more qualitative research to be undertaken in this area.

Keywords *Cancer, levels of analysis, narrative, people with learning disabilities*

Introduction

People with learning disabilities now enjoy increasing longevity owing to many factors (Jancar 1990)¹. However, as people get older, the risk of cancer increases, and although recent evidence suggests incidence amongst people with learning disabilities has increased, it is still lower compared to the general population possible due to the relative rates of cancer screening for people with

¹Improved diet, drugs, genetics and biochemical and biophysical factors.

learning disabilities being significantly lower (Osborn *et al.* 2012). This can be understood in terms of the overall life expectancy in a population with learning disability being generally lower (Carter & Jancar 1983; Cooke 1997; Hogg *et al.* 2000; Jancar 1990; Patja *et al.* 2000; Tuffrey-Wijne 2003). Although there is limited research available to help us make sense of how people with learning disabilities conceptualise cancer, it is encouraging to see that mainstream learning disability journals are promoting the awareness cancer within this client group British Journal of Learning Disabilities Special Edition (Tuffrey-Wijne *et al.* 2008). Existing literature on populations without disability includes the

'self-regulation model' (Diefenbach & Leventhal 1996; Leventhal & Diefenbach 1991; Leventhal *et al.* 1984), health belief model (Rosenstock 1974) and theory of reasoned action (Ajzen & Fishbein 1980) that have attempted to address this issue. The present study focuses on the self-regulation model which proposes that illness representations and conceptualisations are based around five distinct components that determine coping: identity, cause, timeline, controllability and consequences. Whilst these principles are considered distinct, they are not necessarily independent as they come into play as soon as one begins to experience symptoms and can change with illness progression. Furthermore, the emotional responses provoked during this process may vary and can be influenced by the coping mechanisms that are in place for the individual. These representations or conceptualisations can be influenced by the individual's personal, social and cultural context. Previous illnesses shape emotional responses to current episodes of illness. Such recollections can operate automatically by creating experiences of fear and powerful emotional responses without conscious participation, for example phantom limb pain (Leventhal & Everhart 1979).

There have been some studies attempting to locate the point at which we develop our ideas and beliefs about illness, although very little is known about this in connection with people with learning disabilities. In a study undertaken by Bibace & Walsh (1980), a framework was developed to illustrate how a child's concept of illness changes as a function of developmental-cognitive maturity. They identified six stages through which a child's concept of illness passes as it develops: phenominism, contagion, contamination, internalisation, physiological, psychophysiological².

Although this is a useful model, it does not explain how different groups within society might be unable to pass through each of the six stages. For example, the latter stages of the model require one to be able to think in abstract ways, which might preclude a number of people with learning disabilities (March 1991).

To date, there has been little focus on exploring the narratives of people with learning disabilities and their experiences of illness. Exciting areas of research have attempted to locate the individuals' lived illness experience within the context of their lives (Horton-Salway 2001; Riessman 2003; Rozmovits & Ziebland 2004). Autobiographical accounts often bring to life these personal experiences of cancer in a way that enables the reader to connect with their story (Couser 1997; Diamond 1999; Frank 1995).

Sunmi-Lee (2001) explored how one cancer survivor, 'Z', integrated unusual life experiences into her life development. From reading 'Z's accounts, one is able to gain a sense of how our society and culture minimises the experience of illness by silencing the sufferers. This has been referred to as

a 'cultural denial of suffering' (Frank 1995) and is thought to arise when society feels uncomfortable with talking about emotive issues. However, recent studies have highlighted the potential benefits of telling one's story (Murray 1997 and Rosenthal 2003).

One or two biographical narrative interviews can trigger the first curative processes of storytelling (Rosenthal 2003) and are being increasingly used in therapy as a way of individuals developing an understanding of their experiences in the wider context of their life, albeit within a population without disability (Rosenthal 2003). However, storytelling should only take place after sufficient time has lapsed to avoid retraumatisation. A considerable balancing act is also required between supporting the narrative accounts and simultaneously holding back so that the storytellers do not become overwhelmed by traumatic experiences (Sachsse 1999). Traditionally, the models for understanding learning disability have been medical, focusing on individual impairments, conditions and medical interventions and which locate the learning disability within the individual (individual model of disability). More recently, there has been move towards to a social model of disability (Chappell *et al.* 2001). However, many argue this model has done little to confront the social oppression, negative societal attitudes and isolation experienced by people with learning disabilities or initiate policies, which have made a significant improvement in the quality of their lives (Oliver 1992). Interest has been developing in use of participatory research owing to organisations such as People First (People First Central England Ltd, U.K.), and studies, which suggest people with learning disabilities, can make good and reliable interviewees (Booth & Booth 1996; Cresswell & Tuffrey-Wijne 2008; Hollins 2000; Hollins & Esterhuyzen 1997).

The rise in participatory and emancipatory research, which was once considered 'taboo' areas, is now being explored (Morris 1992; Oliver 1992; Zarb 1992). Additionally, the government initiatives to improve access to specialist health services and to make existing services more amenable to people with learning disabilities should slowly redress the imbalance. Although steps are being taken to reduce inequality amongst marginalised groups, differentials in status, power, opportunity and integration will always exist (Finlay & Lyons 1998).

Aims and guiding propositions

To date, very little qualitative research has been undertaken with people with learning disabilities in the context of their life experiences, such as the experience of coping with illness. Researching a unique area will increase our understanding of how people with learning disabilities experience cancer. Current research aims to coconstruct the story of one woman's journey of having cancer and a learning disability.

²Refer to Bibace & Walsh 1980 for full description of these stages.

In particular, it explores how her social and cultural contexts have shaped the way she made sense of her lived experience of cancer.

The use of an exemplar

An in-depth analysis of one woman's lived experience of cancer, who had been given a label of learning disability, was chosen as it provides an exemplar of an illness narrative. Despite the uniqueness of her story, there are particular themes that have been integrated into the construction, which have wider social and cultural significance and can be considered at the different levels of analysis (Day Sclater 1998; Doise 1986; Mishler 1986). Jo's narrative is particularly novel as she provides a good account of what it means to be a person with a learning disability, who has been given a diagnosis of cancer. Jo's account also provides insight into how the narrative construction of her experience has been influenced by her social and cultural context (Mishler 1986, 1992; Murray 1997; Paget 1983). It was important to present a thorough depiction of Jo's narrative to be able to give justice to her insightful and revealing account. This supports a tradition of recent research, which has drawn upon single case designs to provide a detailed account of the stories of individuals (Frosh *et al.* 2000; Hogg & Tuffrey-Wijne 2008; Tuffrey-Wijne 2010).

Participant

Jo (pseudonym), aged 63, was recruited through the Oncology Centre. Her consent was obtained using an adapted consent form with pictorial representations. Full ethical approval was gained from the Local Research Ethics Committee, Bristol Royal Infirmary. The first author met with Jo on three occasions, twice to introduce the research and undertake the interview, and once to debrief, where her reflections and feedback were obtained. These interviews were recorded and transcribed in full before the narrative analysis was applied (Wengraf 2001).

Methodology

A narrative life story approach (Wengraf 2001) was chosen as it was seen to lend itself to a more participatory process and to facilitate Jo to engage in the research process. Also it was felt it could encourage a detailed exploration of the subjective experiences of an individual in relation to the personal, social and cultural contexts and allow them to gain a sense of power and ownership through telling their story. The most fundamental social aspects of the narrative are its context, the sources of validation for it and how it allocates power to the narrator and to other people (Parker

et al. 1995). Its major cultural aspects lie in the information, which is shared through it and the values, which are implicit in it.

Analysis Procedure

The process of analysis aims to explore the inter-relation between the lived-through past (lived life) and the present story (told story). The former refers to the chronological sequence of life events that were experienced by the participant. The told story refers to the way in which the story was narrated in terms of the form and content. Four professional colleagues constituted an interpretative panel to generate hypotheses and were used to produce different interpretative responses and to increase validity (Wengraf 2001). This also enabled the first author to reflect on her own researcher and preconceptions. The analysis was undertaken through the following steps:

- A biographical data analysis was undertaken, whereby the life events (or datum) were presented, one by one, to the panel for the generation of predicting counter, tangential and structural hypotheses.
- The told story or the thematic ordering of the narration and text structure was then undertaken and subjected an analysis looking specifically at changes in the form and content of the narrative.
- A thematic field analysis (Rosenthal 2003; Wengraf 2001) was then conducted, whereby the panel were presented with sections of the narrative and asked to generate hypotheses with regard to the meaning of experience for the participant (Wengraf 2001). This then allowed the panel to predict what might happen later in the participant's life. A process of emergent theorising (Glaser & Strauss 1968) was then used. This allowed the prediction of the data that should follow on and then enabled the researcher to check back from such future data to earlier predictions, allowing acceptance or falsification of the hypotheses accordingly. Underlying patterns or structures to the told story were then identified through the principle of gestalt (Wengraf 2001).
- From this a table, outlining Jo's told and lived story was constructed (Table 1) summarising different topics and how they were talked about and how they were linked to the emerging themes within Jo's narrative account. This enabled Jo's story to be developed.

Single question aimed at inducing narrative

This question was: 'Can you tell me about the experiences that have been important to you during your life?' This question allows the participant space to narrate their story in a more liberating way so that unconscious meanings are

Table 1 Jo's Life Phases (BDA) and Text Structure compared alongside one another. BDA refers to the analysis of her chronological lived life as compared to Jo's 'told story'

Biographical data analysis	Thematic field analysis
Phases of Jo's lived life	Structure of Jo's initial account
<ul style="list-style-type: none"> • 2–18 years Jo, given diagnosis of learning disability. Lived with parents and siblings in family home. Looked after by parents. • 18–20 years, attended a local day centre for people with learning disabilities, learned life skills in hope of being able to get a job. • 20–39 years, holiday in France and met 1st boyfriend. Parent's arranged for Jo to have sterilisation without consent. Moved out to live in a shared house with other women and begun work in a laundry dept. • 39–58 years, father died. Mum became depressed and Jo was emotionally strong for mum. Mum diagnosed with cancer, hospitalised and later died. Jo increases contact with siblings. Accepts can't have children. • 58–61 years, had nasal polyps. Bought rabbit and budgie for company. • 61 years, close friend/housemate diagnosed with cancer, hospitalised and later died. Decides to make the most of life. • 62 years, diagnosed with osteoporosis, received treatment. Diagnosed with breast cancer, received radiotherapy and chemotherapy. Met doctor who was 'physically different', identified with him. 	<ol style="list-style-type: none"> 1. <i>Diagnosis of cancer (brief report)</i>. Finds a lump in breast undergoes operation to remove lump and receives treatment. 2. <i>Death (report and some narration)</i>. Links own experience to parent's death, Mum dies of cancer and Dad dies of blood clot. Housemate/friend's death from cancer. Confusion around irreversibility of death. 'Always thought – you get cancer you die'. 3. <i>Own cancer experience (narration, augmentation and some evaluation)</i>. Uses metaphors to describe experience. Fears and anxieties around treatment. 4. <i>Family Context (narration)</i>. Early experiences in family: mother 'strong one', 'dad worked long hours'. 5. <i>Knowledge of cancer (brief report)</i>. Knowledge about cancer gained from media. Felt protected by family about cancer. 6. <i>Family values (narration, some evaluation)</i>. Employment, 'earning money is something to be proud of'. Be strong, move on and do not complain. 7. <i>Identity (narration and evaluation)</i>. Meets doctor with disability. Feels heard and listened to. Turning point for Jo. Changes way she thinks about her cancer. 8. <i>Marriage and children (narration and some report, augmentation and evaluation)</i>. Met first boyfriend. Had sterilisation without consent. Feels parents betrayed her. Believes people with learning disabilities do not get married or have children. 9. <i>A new beginning (narration)</i>. Jo moves out and becomes member of people first. Reflects turning point 2. More independent. 10. <i>Future (Report and some narration)</i>. Accepts not able to have children. Accepts cancer and looks ahead with positive outlook.
<p>Jo's account is presented in chronological order. Difficult life transitions focused around illness, death and dying precipitate positive move towards developing as a person.</p>	<p>Presenting illness narrative, restorying her earlier experiences of bereavements and how she has made sense of own cancer. Is able to become stronger as a person having experienced adversity and by feeling empowered by medic. Emphasis on jumping from report to a narrating style, with some evaluation and augmentation.</p>

BDA, Biographical Data Analysis.

able to surface in relation to the researcher, which would not necessarily be possible or at least as effective if the questions had been more structured. It addresses the power imbalance by handing back power to the participant to narrate what was meaningful for them (Rosenthal 2003; Wengraf 2001). It also allows further questions to be derived from the initial narrative and to hypothesise about theories of interest. In our subsequent session, Jo was asked whether she felt she was different as a person now having had cancer. This was derived from the experiences Jo had talked about in the first session and was also of interest to the researcher.

The following steps were involved in the validation of the results:

- The researcher's reflections were recorded after the interview
- General themes emerging during their narratives were obtained by the researcher and then discussed with the panel.
- The transcripts and the themes emerging within these were then shared with Jo who then gave her feedback

During the analysis, the researcher will bear in mind the way in which Jo's narrative can be understood at different levels of analysis.

Levels of analysis

This paper will consider the character of Jo's illness narrative as a function of the personal/intrasubjective, interpersonal/intersubjective, social/positional and ideological levels of analysis (Doise 1986; Mishler 1986; Murray 2000). At the personal/intrasubjective level, the theories describe how individuals organise their perception, the evaluation of their social milieu and their behaviour within their environment (Doise 1986). Within the interpersonal/ intersubjective level, importance is given to the structure of the narrative account by considering the interpersonal processes that occur within the interview that allows the narrative to be cocreated (Mishler 1986). At the social/positional level, each member in a given social interaction brings certain social characteristics to the interview, such as the differences in social position (Doise 1986). Finally, at an

ideological level, consideration is given to society's own ideologies, beliefs and representations (Doise 1986). This level is also concerned with 'the cultural or dominant narratives' that exist regarding illness or gender.

Results

Jo's story

Jo is a 63-year-old single white female, living in the South West of England, who has a learning disability. Around the time of interview, Jo had been receiving treatment for cancer, a diagnosis that she had received a few months before. For Jo, this was not an entirely new experience as she had known people close to her who had also undergone treatment for cancer, but had died shortly afterwards.

Throughout her life, Jo has experienced a number of significant losses. The way she has learned to cope with these losses emerges during her narrative, as she explains how she has learned to be positive and not dwell on negative or distressing events. This is the message she has taken through her interactions with the people around her, as well as the medical profession. There has been a focus on illness and death in Jo's life, and it is not surprising that early on her story begins to take the form of an 'an illness narrative'. Throughout her narrative, Jo experiences some confusion around her experiences of cancer and uses the interview as a way of attempting to make sense of why the people she loved died from cancer and she survived. If we look at this restorying in the context of the 'self-regulation model' (Leventhal *et al.* 1984), we can see how her initial beliefs around the outcome of her illness are those of expecting to die, as others around her have. However, through reworking her story, Jo is able to reach a point where she believes she is in more control of her illness (controllability principle of Leventhal's model) and will survive her cancer.

Table 1 outlines seven phases of her lived life alongside the analysis of the text structure. The table illustrates how the structure of Jo's narrative changes (column 2), during the course of her account in relation to specific topics or themes being discussed (column 1). The analysis reflects how Jo begins her story by reporting on the diagnosis she received, with little detail or emotional content. At this point, it is thought Jo's story might be presented in a fairly unintegrated way. However, as the interview progresses, Jo presents her account using different text sorts including 'narrative', 'argumentation' and 'evaluation'. The introduction of argumentation and evaluation, and the increase in the use of narration at this point in her told story might represent the increasing integration of, and reflection on, her life experiences. The development of Jo's case structure, which reflects how her life experiences have shaped her journey and what meaning she ascribes to them, have been

derived from the working document of the lived and told story (Table 1).

Emerging themes (*quotations from transcript in italics*)

Whilst Jo presents herself as a strong, independent woman who has been through and recovered well from adversity, she has not always been this way and throughout life has felt disempowered. At various stages, she provides insight into times during her life where she has felt powerless and has succumbed to the dominant discourses of 'being silenced'. Jo feels that having a learning disability has meant that she has had to work hard 'to feel heard' and her story reflects her desire to take more control of her life. Previously, Jo accepted that this was expected if you had a learning disability, but more recently, through her experience of cancer, has begun to realise that her opinions, thoughts and feelings are important and that she should not settle for being 'silenced'.

Turning point 1

Jo articulated that a turning point for her was when she met a doctor who was physically different, whom she identified with. This led Jo to begin thinking about her life more positively and confidently.

'He was not that different to me...urm, he's different, he is disabled so am I'. 'He was very good and he told me what was going on. Yeah, he talked to me..... to me'. (Page 9)

Jo's identification with the doctor who was physically different was perhaps her first real experience of feeling heard. According to Harvey *et al.* (2000), such turning points are often located within a milieu of transitions. At this point, Jo had already experienced and passed through a number of transitions to reach this point in her life. Her account locates itself within the context of what has been achieved, what is no longer possible and what can still be achieved in her life. Jo's story is also narrated in the context of wider social discourses around learning disabilities, gender, relationships and societal/cultural expectations/attitudes. Identity is therefore the first of three major themes that emerge:

Theme 1

'Identity'

'You get it a lot you know when you're like me. Usually they talk to John and don't talk to me. It's because I have a learning disability. I was bullied at school because of it. People think because I have a learning disability I won't know what there urm going on about'. (Page 9)

Jo being an active member of People First, an organisation promoting people with learning disabilities, had in some way also helped her to develop as a person and to encourage her to begin expressing a 'different self', an outgoing, friendly, independent and confident woman. At various points during her narrative, a 'different self' was beginning to emerge.

Turning point 2

Jo moving out of the family home and joining People First reflects another turning point in her life, 'a new beginning'. These changes enabled Jo to become more independent and seek employment. Her future interactions with others as a result might be more confident, and she may feel better equipped to manage difficult situations. Jo's diagnosis seems to have prompted her to re-evaluate her life and to decide what she wants out of it and has allowed her to see this experience as an opportunity for personal growth. It is likely, prior to this turning point, that Jo responded to situations in a very passive, under-confident way, especially following her dealings with the medical profession around the time of her sterilisation and how she was not asked for consent. There were various passages in her narrative that illustrated this, which seemed to coincide with her talking about times in her life when she had felt 'silenced' or 'marginalised'. The next major theme to emerge was therefore relating to her position in society:

Theme 2

'Positioning in society'

'I called for a doctor and he sent Janice to hospital on the 12th April and I went to visit on the 25th April and she had died. She was not there. They told me she had died of cancer and she was not coming back.....Ever.....Not even to say goodbye. I was very sad and cried. I wished I said goodbye'. (Page 1)

'I can't remember what they told me but I know they didn't tell me she had cancer, I found out afterwards'. (Page 3)

The underlying gestalt

Jo has responded to her diagnosis and treatment in a very positive way. She has learned through her previous experience and interactions with others, 'how to respond' in difficult situations. This shaping forms the basis of the underlying gestalt for her entire narrative. Jo's previous experience of growing up in a family that prided itself on being positive might have influenced the way she

conceptualised, lived and storied her cancer experience. In our culture, we also have a tendency to put on a 'brave face' to prevent causing discomfort to others around us ('Cultural Denial of Suffering' in Frank 1995), so we become socialised from an early age that talking about emotive issues is 'taboo'. This seems to be even more prevalent amongst people with learning disabilities (Sinason 1992). Being positive therefore reflects the next theme to emerge:-

Theme 3

'Being positive'

'I was a bit sad and shocked to start with but then I focused on the treatment and getting better. I was told I was very positive and good about the news. The doctors liked me because I didn't make a fuss. John told me that sometimes the doctors think that people like us cause trouble in the hospital so the nurses and doctors don't like us being there'. (Page 1)

We can see how this sends out a powerful message to people with learning disabilities, as to how they are expected to behave by others; if they do not conform, they will not be liked.

Sinason (1992) suggested that the families and carers of people with learning disabilities, who are close to grief and find it difficult to bear, will encourage happiness amongst people with learning disabilities. She terms this 'the handicapped smile', where people learn early on to 'mask' their true distress through the responses received from the external world during times of distress.

From the analysis, we are able to see how Jo begins her narrative by jumping from 'reporting', her story in little detail to 'narrating' it. This is a pattern that continues for a while until Jo becomes more comfortable with the experience of telling her story. One could hypothesise that the use of reporting and narrating intertwined in the earlier stages of her account could be a reflection of Jo's uncertainty of what is to be expected from her in the interview. This is reflected by Jo's uncertainty with regard to whether she should talk about her father's death:

'I used to like my dad singing to me. He couldn't really sing very well but it used to make me smile. Shall I urm tell you urm about when he urm died?' (Page 6)

This illustrates Jo's uncertainty about what and how much to reveal to the researcher. As the interview progressed, Jo used a narrating style more frequently to tell her story. These sections of narrative were based on Jo's subjective experiences of the losses encountered, and she uses these accounts as a way of making sense of her early life experiences.

Jo's narrative in the context of different levels of analysis

Personal/Intrasubjective

Jo reflects on her illness experiences as changing her into a more determined person who wants to enjoy and make the most of life. Her social milieu had previously prevented her from 'being who she wanted to be', and her story allows her to think through these issues and reconstruct her story. Jo also began to reconstruct her identity following her encounter with the 'doctor who was physically different'. This was another important turning point for Jo as it enabled her to make some life changes in terms of the way she wanted to live life and how she wanted to be perceived by others. It was not long after this experience, where she became a member and more recently, an organiser of People First.

Interpersonal/Intersubjective

As a researcher, I was able to view the interview as a coconstructed process, where specific stories and themes emerged in relation to my 'self'. These might have varied according to whether I had been male or an older woman or indeed from an ethnic minority background. Jo's life story, which was developed in the context of this particular relationship, also contains examples of cultural themes and connections, which can be generalised to the experience of others.

Social/Positional

Throughout the interview, we were both aware of our different positions within society. Jo came to the interview from a socially marginalised position, being a single woman in her 60's who has a learning disability, who had been sterilised, whereas the researcher was coming from a completely different position, being a middle-class, married, educated, pregnant woman. Although power imbalances were discussed in our initial introduction, they were difficult to eradicate as Jo had been used to taking the lead from others.

Jo's acceptance with not being able to have children could be indirectly attributed to her having a learning disability, which reflected her position and subconscious conforming to the potential dominant and cultural discourses around people with learning disabilities and parenthood:

'I have accepted that I will not meet anyone that I will marry and I won't have children of my own. I have a learning disability so that makes it difficult for me to meet boyfriends and as you know urm I can't have children'. (Page 12)

Ideological

Whilst Jo seemed unaware of the cultural or dominant discourses existing around illness, gender and learning disability, these began to emerge indirectly in her narrative in how she talked about experiences or the experiences she chose not to talk or elaborate on. Again this highlights how Jo has learned to present herself in the context of such dominant discourses that talking about difficult experiences is 'taboo'. This was particularly evident at various stages in her account where she commented on her discomfort at talking about difficult or painful experiences:

'I'm sorry I'm talking about sad things. You don't want to hear about those do you?' (Page 10)

'I shouldn't have said urm anything. I'm sorry'. (Page 12)

By narrating her experiences of cancer and death in the way she has, a unified context has been constructed and coherence has been established (Hyden 1997). Even though coherence is fragile, her positioning in the final narrative account reveals the identity of an independent, confident woman who looks forward with hope to the future. One could argue that Jo's experience of cancer and her restorying of these experiences have allowed her identity to unfold and a 'different self' to emerge (Hyden 1997).

Discussion

The analysis reflects the aims of this study, which were to present the journey of one woman's experience of having cancer and a learning disability in the context of her social and cultural background and to facilitate her to feel empowered to tell and own her story. Although her story is unique, it has wider social and cultural relevance, which will be discussed. The following discussion will also consider the aims, before highlighting the limitations and strengths to the design. Reference will also be made to the wider clinical relevance of this study before drawing on some useful conclusions.

The main findings of this study illustrate how wider social and cultural influences have impacted on the way Jo has conceptualised, represented, lived and told her experience of cancer. Jo draws on her previous experiences of cancer and the interactions she had with people around her at the time, to make sense of her own current illness experience. From this, she has learned how she should respond in similar situations. At various turning points in her life, Jo felt empowered to reassess her past and present experiences in a way that enabled her to feel more in control and own them. These turning points have given Jo the opportunity to feel empowered to share her lived experiences.

The context of the interview allows the reworking and restorying of one's life experiences, which can also be perceived as a transformatory process in which one is actively renegotiating subjectivity, thereby allowing for self-reflection (Day Sclater 1998). For example, whilst Jo begins her narrative by briefly mentioning her own cancer experience, she does not present her lived experience until much later on at which point there appears to be a reworking of these themes. From Jo's narrative accounts, we are able to draw upon Bibace & Walsh's (1980) model to understand how she might begin to conceptualise cancer. At various points during her story, Jo talks about cancer within the 'contagion stage' of the model, whereby cause is located within the individual. Jo is able to make sense of the fact that in certain circumstances, cancer might be attributable to external events (phenominism) such as smoking but struggles with attributing cause to events that are less concrete. Jo is then able to move on to locating her experience within the contamination stage of the model, whereby cause is attributed to a body or object that is 'bad', 'I suppose I just have a bad boob'.

Jo's representation of cancer

In the context of Leventhal's self-regulation model (1984), Jo's lived experience can be thought of as being focused around five main principles: identity, cause, timeline, controllability and consequences. For Jo, identity refers to her having constructed an idea of what cancer is 'supposed to look and feel like' based upon previous experiences. Jo reflected on both her Mum and friend losing hair and weight during chemotherapy and being sick. Jo's representation of her own cancer and the way she talked about this experience was much more optimistic, perhaps due to her cancer being less noticeable, as she had retained her hair and was not experiencing sickness. Being optimistic also links in with her 'family values' of being positive and how she has learned to present herself in a society that is uncomfortable with human suffering (Frank 1995). The principle of 'cause' reflects Jo's ideas about her cancer being attributable to the self, whereas Jo's representation of the 'timeline' principle is that of expecting to die, as others before her have.

However, whilst Jo has experience of people dying from cancer around her, she has developed a wider knowledge base and recognises that not everyone dies from cancer. Cancer serves to threaten self-identity, and individuals often use strategies that have been successful in dealing with other life events, to manage their cancer experience (Van Der Molen 2000). For Jo, her identity as a 'person with a learning disability' meant that she relied on external information-seeking behaviour as a way of coping with the fear and anxiety that usually accompanies life-threatening illnesses such as cancer. Jo's need for information was

interwoven throughout her narrative not only in terms of attempting to use her narrative to make sense of her experience but also to seek information on 'how she was doing in the interview'. Her narrative included sources she had drawn upon to make sense of her cancer. These included relying on family, friends and the medical profession and watching documentaries to provide her with the information needed. This enabled her to represent her own cancer as an illness she could have died from, but survived. Jo's controllability over her symptoms prior to her encounter with the doctor who was physically different might have been left up to others. However, this turning point allowed Jo to take more control over her illness and own her experience, which has enabled her to maintain a positive outlook. Finally, the consequences Jo describes when representing her cancer are linked mainly to her social network and everyday activities. This reflects the way in which the cancer has perhaps affected Jo the most.

Jo's narrative represented her recent experience of being diagnosed and treated for cancer. What made this illness narrative interesting was the way Jo had begun to make sense of her own cancer experience, which had arisen from her cancer journey beginning around 20 years ago, when her mother died of cancer. This was Jo's first experience of cancer, which set the precedent for the way she managed later experiences. Jo was able to reflect on the process of telling her story and how this had enabled her to begin to make sense of her cancer experience (Rosenthal 2003). During her narrative, Jo presented some confusion around why she survived the cancer and others around her did not. Re-evaluating her experiences through storytelling has enabled us to gain insight into how she begins to make sense of why her cancer was different.

Until her recent diagnosis and meeting with the doctor who was physically different, Jo had not talked about these experiences. Instead, Jo had suppressed them and presented herself in the way she had learned to through her interaction with others. Through her own personal journey of cancer and with the telling of this experience, Jo has begun to find a 'different self' (Lowen 1997). Since Jo told her story, she has made contact with the local community centre, has enquired about dancing lessons and feels she is beginning to enjoy life and wants to make the most of it. She reflected on feeling more confident and empowered to talk to others about her experiences, to try to promote cancer awareness amongst a population with 'learning disability'. Narrating one's story enables reinterpretations of events to take place, which can often lead to positive changes in the individual's view of their past, present and future life amongst populations without disability (Rosenthal 2003).

Wengraf (2001) argues that a life story presentation is likely to contain less than 10% of the original raw data. Although it is necessary to apply data reduction to the data (Miles & Huberman 1994), one is able to ensure that it

remains as true as possible to its complexities and that the data are represented as well as possible. However, the most likely limitation of using a narrative analysis is that of losing significant indications of detail. A 'bad summary' may just provide a broad generality and neglect more theoretically based themes or ideas (Wengraf 2001). A participatory framework in undertaking clinical research with people with learning disabilities can offer sensitive ways of representing the views of individuals from 'marginalised groups' (Cameron *et al.* 1992). Authors suggest that this type of ethical life story research is a way of documenting an individual's experiences, which represent political and historical documents in their own right. Life story accounts are also available to be drawn on as cultural resources, which reveal that it is possible for therapeutic benefits to take place.

Clinical implications

Jo's account is exemplary and highlights the richness of undertaking qualitative, in-depth research with people with learning disabilities. By listening to people tell their story, we allow them time and space to communicate about their illness and the opportunity for them to feel empowered in a way that might help them to make decisions about treatment. It also highlights the importance of the medical profession being open and honest with people with learning disabilities about diagnosis and treatment, as this may empower individuals to take control over their illness and make decisions that feel right for them. One could also argue that by talking openly and honestly about difficult and emotive experiences with people with learning disabilities might in some way begin to reduce the fear society holds about communicating with people with learning disabilities about such experiences.

Conclusions

It is not possible to isolate cancer from other events in an individual's life, regardless of whether that person has a disability or not. Themes emerged during Jo's narrative, which shows how cancer impacts on different levels within a personal, social and cultural context. Cancer can also impact on specific issues relating to self-identity, relationships and future aspirations. These themes, whilst unique to Jo, have provided theoretical insights, which has allowed for generality to other contexts. According to Bloom *et al.* (1998), life is viewed by individuals in terms of 'their current lifestyle, past experiences, hopes for the future, dreams and ambitions'. This is certainly true of people with or without a disability. This was true for Jo, as her past experience of cancer was a powerful influence on how she managed her recent illness. Jo chose not tell her story in a chronological sequence of medical events. Rather, what emerged was a

sequence of chronological issues that were important for her. However, for Jo, it was not until specific turning points in her life and her engagement in the interview process that she was able to find a 'different self' and tell her story. Jo's account provides arguably a coherent exemplar of an illness narrative and suggests a counter-argument to the long-held beliefs that people with learning disabilities do not make good research participants (Hollins 2000; Hollins & Esterhuyzen 1997).

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