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Using Joint Interviews in a Narrative-Based Study on Illness Experiences

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Abstract

Researchers increasingly recognize the usefulness of using joint interviews in research on illness experiences. However, there is limited discussion of joint interviews as a data collection method and of the factors that influence the choice to conduct individual or joint interviews. Although there are several advantages and disadvantages of both methods, the reasons that underpin the choice to use joint interviews are often not discussed in detail in the literature. Drawing from a narrative-based study on the experiences of living with motor neuron disease, we present joint interviews as a method sensitive both to the shared experience of illness and to the multiple perspectives around illness. Using interview excerpts, we discuss how through the use of joint interviews researchers can explore the intersubjective and heteroglossic nature of illness experiences. We argue that using joint interviews can offer valuable information about how couples co-construct meaning and share experiences.

Keywords

Disability/ disabled persons; epistemology; illness and disease, experiences; interviews; narrative inquiry

The importance of conducting research on illness experiences has been well documented (Frank, 1995; Kleinman, 1988; Mattingly, 1998). Such research is often conducted through interview-based research designs allowing for the exploration of experiences and perspectives on illness. Illness experience is, on par with all human experience, intersubjective (Jackson, 1998; Kleinman, 1988). Rather than being a solely individual experience, illness is lived and understood within the particular social contexts that people inhabit (Kleinman, 1988; Murphy, 1990). Qualitative researchers often acknowledge this and it is common for partners of people living with an illness to be included as research participants in studies on illness experiences (cf. Bolmsjö & Hermerén, 2001; Morris, 2001; Radcliffe, Lowton, & Morgan, 2013). The decision of whether to interview participants separately in individual interviews, or together in a joint interview is an important one because it influences the nature of the data collected.

In this article we focus on the use of joint interviews and discuss the unique contributions of this method in exploring the intersubjective and heteroglossic nature of illness experiences. We achieve this by discussing the use of joint interviews as a data collection method drawing from a narrative-based study on illness experiences of people with motor neuron disease/amyotrophic lateral sclerosis (MND/ALS). Although the use of joint interviews has implications for data collection as well as for data analysis, in this article we focus specifically on the implications for data collection. In the first section of this article we discuss the use of joint interviews in the literature. Following this, we describe the context of our study, before presenting the unique contributions of joint interviews to our understanding of illness experiences.

Background; The Use of Joint Interviews

The term “joint interviews” is used to refer to interviews that include more than two participants (Seymour, Dix, & Eardley, 1995). In this article we use the term to refer to an interview between one researcher and two people who share an experience. Our use of the term is inclusive of joint interviews referred to by other terms, such as “multivocal occasion” (Holstein & Gubrium, 1995, p. 66) or couple interview (Bjørnholt & Farstad, 2012).

In joint interviews the two participants are interviewed at the same time, together. This requirement to interview participants together differentiates joint interviews from multi perspective interviews, because in the latter research participants are not necessarily interviewed together, as Kendall et al. (2010) demonstrated. Joint interviews are sometimes used in family research, but not all interviews used in family research are joint ones (Åsted-Kurki, Paavilainen, & Lehti, 2001). Although co-construction of an experience and interaction between participants are central in joint interviews (Bjørnholt & Farstad, 2012; Morris, 2001; Radcliffe et al., 2013), in family research researchers often use multi perspective interviews with the aim to explore the different perspectives and contrast them (Åsted-Kurki et al., 2001).

Joint interviews have several advantages and disadvantages. Several researchers (cf. Bjørnholt & Farstad, 2012; Holstein & Gubrium, 1995; Radcliffe et al., 2013) have discussed how the use of joint interviews can enable the relational and interactive elements of human experience to be foregrounded through shared storytelling. If people invariably talk about other people (partners, friends, carers and so forth) during one-to-one interviews, then perhaps these voices form part of the

unfolding story and these other people need to be included in the interview (Holstein & Gubrium, 1995).

Taylor and de Vocht (2011) described their choice of one-to-one and joint interviews respectively in two separate studies, both of which focused on sexuality and intimacy in couples in which one partner had been diagnosed with a life threatening illness. They stressed the importance of being guided by epistemology in the choice of interview format. For Taylor and de Vocht (2011) both interview formats have certain advantages and certain disadvantages. For example in joint interviews individual perspectives of participants might be harder to discern and some participants might not feel comfortable revealing some aspects of their experience. Conversely, one-to-one interviews might cause anxiety between the couple because participants might believe one is hiding something from the other. There is no format that is universally preferable.

Gysels, Shipman, and Higginson (2008) argued that the choice for joint or one-to-one interviews should be guided by the aims of the study, and the preferences of the participants. In their study they found that several of the participants (couples, in which one partner was either diagnosed with cancer or receiving palliative care) objected to being interviewed separately, and the researcher had to accommodate this. Mattingly (1998) discussed how in the context of joint interviews people can make sense of experiences together, because they get to interpret experiences and convey meaning not only to themselves but also to somebody else with whom they are sharing these experiences. Morris (2001) and Radcliffe et al. (2013) argued that the joint interview is an appropriate method to use when researchers want to explore the shared nature of some experiences.

Context; A Narrative-Based Study on Experiences of Living with

MND/ALS

Seeing all worldviews not as theories of knowledge about the world but as existential means of achieving viable ways of living in and with the world (Jackson, 2012, p. 123).

MND/ALS is an adult onset, incurable, neurodegenerative condition that is characterized by the wasting of voluntary muscles secondary to destruction of motor neurons leading gradually to partial or complete paralysis. Symptoms that can develop in the course of the disease include dysarthria, spasticity, pain, emotional lability, fatigue, constipation, cognitive impairment and depression (Eisen, 2009; Talbot & Marsden, 2008). This methodological article is based on a narrative-based study that focused on perspectives and experiences of daily life of people living with MND/ALS and their partners. The study was approved by the research ethics committee of the School of Healthcare Studies, Cardiff University. The consent form and information sheet specifically sought approval for primary and secondary analysis and related publications. We use pseudonyms to refer to the participants throughout this article.

Through the original study we sought to explore the perspectives and experiences of the participants and how they made sense of their lives. We chose research methods with the aim to create what Dossa (2009, p. 26) called “a paradigm of telling and listening”. In designing the study we were guided by Jackson’s (2012) stipulation that introduces this section, in so far as the focus was not in producing a general theory about the experience of living with MND/ALS, but rather in exploring how specific people live in their local contexts.

Data were collected over a period of approximately 18 months through the use of multiple semistructured interviews with people with MND/ALS and some of their partners. Through the use of open ended questions we aimed to elicit stories about the experience of living with MND/ALS and at the same time we allowed the participants to narrate any stories they perceived as relevant and important for their experience; these stories were created as a result of our interaction in the course of the interview (Holstein & Gubrium, 1995). To accomplish this we had to create the circumstances for extensive narration, as Riessman (2008) suggested. This entailed giving up control of the interview and exercising minimal direction. The interviewer (Sakellariou) asked questions about certain themes but without having a set of answers in mind. Often a question would elicit a long story, intertwining past experiences, reflections on living with MND/ALS and childhood memories.

Following Hydén and Antelius' (2010, p. 590) stipulation that "stories are actually embodied in the gestures, the linguistic, paralinguistic, non-verbal and other physical artefacts that are used as resources in telling and listening to a story", the interviewer paid particular attention to the non verbal elements of the communication, such as gestures, gaze, pointing and blinking and also to paralinguistic elements such as laughing and sighing. The paralinguistic elements were captured through the audio recording and the non verbal elements were recorded in the field notes after the interview.

Participants

Recruitment for the study was carried out through the local regional care adviser of the Motor Neuron Disease Association (MNDA). In this article we focus on three couples who were interviewed together. We use the term "participants" to refer to

these six people and the interviewer. Some of the participants spoke with “broken and vicarious voices” (Hydén, 2008, p. 36), because of speech impairment. Although they were able to make sense of their life and create meaning, communicating that meaning was not always easy. The three participants who had MND/ALS presented with dysarthria and used different communication techniques. One participant used a lightwriter, which is a portable machine looking like a keyboard that turns text into speech. The other two participants with dysarthria did not use any augmentative communication devices; their speech was intelligible but sometimes laborious and slow.

Carrying out Joint Interviews

Carrying out joint interviews presented several benefits. Often the partners would expand on short answers given by the person with MND/ALS, and then the person with MND/ALS would signal approval or disapproval of the new, expanded story. Sometimes it was a joint story that the couple had discussed and agreed on and it was relayed during the interview process. In many instances either of the partners would remind the other about experiences and occurrences and by rekindling each other’s memory they would offer a richer story. So, the data collected were richer as has also been previously observed by King (2005) and Philpin, Jordan, and Warring (2005).

The decision to carry out joint interviews was also an epistemological one. We use the term epistemology to refer to how researchers view knowledge and what they consider to be valid knowledge (Lyotard, 1984). In our study we viewed knowledge as relational and dynamic. All stories shared by the participants were equally valid within the context they were produced in. Following Eco (1989), we viewed narratives in our study as “opera aperta” (open works), open to multiple

interpretations and constructed by different narrators for different readers. All

interpretations were “true”, to the extent that they were meaningful for a narrator and/or a reader. Borrowing from the Personal Narrative Group cited in Riessman (2001), it was “truths” rather than “the truth” that we sought to explore through the use of narratives in our study.

The production of narratives is an intersubjective experience, happening between a narrator and his or her audience, and its value lies in that relationship rather than on accurate reproduction of events (Jackson, 1998). Narrators transform an experience and construct new experiences through telling a story and audiences give their own interpretations to the events narrated and draw their own conclusions. Frank (1995) and Mattingly (1998) argued that storytelling can lead to shared meaning making between people and Chase (2005) described narratives as interactive performances. Through narratives people make sense of their experiences and how they are positioned in the context of their life. Narratives do not offer a general representation of reality but instead reveal how people make sense of their own specific reality (Mattingly, 1998). Through the use of joint interviews in our study we foregrounded the intersubjective and heteroglossic nature of illness experience.

Illness as an Intersubjective Experience

Human experience, Jackson (1998, 2012) reminds us, is intersubjective.

Intersubjectivity refers to how humans share experiences and how they depend on each other to construct and to make sense of these experiences (Jackson, 1998, 2012).

In essence intersubjectivity is about a sharing of individuals’ lifeworlds, which is a prerequisite for human interaction (Husserl, 1922/2002). Rather than being

independent, autonomous subjects with total control over their lives, people are linked

to other people with emotional, biological, social, financial and a multitude of other ties (Arendt, 1999). This network of human interconnections provides the foundations for human experience (Husserl, 1922/2002).

For the three couples who participated in our study the experience of being in a relationship lasting more than 30 years was a vital part of who they were, and how they experienced MND/ALS. Seeking an individual perspective from these participants would be contrary to the aims of the study, removing participants from the actual context within which they made sense of life with MND/ALS. Their experience was essentially intersubjective and data collection had to be sensitive to this and appreciate and respect this.

Often the participants would complement each other and even sometimes prompt each other to share information. In the following excerpt Marion prompted Dave to tell the interviewer more about their new profile bed supplied by social services. Although Marion started off the story by saying that they got a new bed, she then invited Dave into the conversation with her suggestion to “tell Dikaios”.

Marion (M): You are okay at the moment, but, sort of, more symptoms, and knowing the best way to treat everything really . . . he had a profile bed, one of those with the air mattresses, but that was okay for a while. But Dave finds it a bit more uncomfortable now, because you sleep on your side, don't you? Tell Dikaios how you get out. You were hoping it would be a bit better to get out.

Dave (D): Well, I was, it doesn't go to 90 degrees, it's a bit sort of. I can get up so far but it's this last little bit, they have to pull me to get me upright.

M: They don't do an attachment they have on a normal mattress . . . and the cot sides, which Dave finds good to pull on, but they don't go right down, so they dig in your knees.

D: So, when I sit at the side of the bed they dig in in the back of the leg.

M: But I think the ones in the hospital would go straight down. I think they see what they can do, you know, but we'll see . . . we had the district nurses and they gave us some slip sheets which are quite smooth . . .

D: To move, when I get in the bed to get in the right position.

After the excerpt above had been transcribed we noticed how well Dave and Marion were coordinating their contributions to the story, filling in the gaps and prompting each other to share more information. During the course of the interview they would negotiate between them who would say what by directly asking each other, as in the excerpt above, or by introducing a subject and then looking at each other to decide who would tell the story.

People living with an illness and their partners might feel angry, embarrassed, tired, confused, content, or any other of an endless list of emotions and feelings. Rather than being individual, these experiences are often co-constructed and shared between people. These experiences would be something else, something different if they were individual (Husserl, 1922/2002). This does not mean that people experience the same thing and interpret it in the same way, but that they have access to each other's lifeworld and they can perhaps understand it (Husserl, 1922/2002). In the following excerpt it is evident that Dave and Marion were not only talking about a shared experience in terms of a shared activity but in terms of feelings as well. They

both shared their frustration having to pay for their newly ordered, specially adapted car, without having actually received it.

Dave (D): You sign for it electronically, they've given me a code to type in to say that I accept the car, that's the time when you start paying for it.

Interviewer (I): And they collect money already?

D and Marion (M): They collect money already.

M: Already four weeks they've taken. But they give it to you back. I don't see why they do it.

D: I don't see why they don't wait until it comes in.

M: It's strange. All these things mean chasing chasing chasing, it's.

D: It's annoying.

M: It is frustrating, yes.

Disease can lead people to alter the way they relate to each other and to the world around them. In the case of a couple, disease can lead to changes in the relationship when for example one partner has to take additional responsibilities as a carer (Kleinman, 2009), or it can lead to new ways of structuring and sharing experiences when a person develops physical disability or speech impairment. People with MND/ALS might lose speech altogether and need to use augmentative communication devices, adopting a new voice. They might also develop paralysis leading to them needing assistance with many daily activities, such as going out. Social activities such as cooking, or sharing meals with a partner can be affected (Sakellariou, Boniface, & Brown, 2013). In the following excerpt, Dafydd described how Siobhan, his wife, started eating again after receiving nutrition exclusively through percutaneous endoscopic gastrostomy (PEG) for several years.

Now she started to eat again. She can't eat meat, but she can eat almost anything else. I am having dinner, she wants a bit of it all the time, you know. So, she eats pasta. I was doing a poached egg with cheese in it, mash it up, she eats that. Mashed potatoes, she would eat that. Anything, like. Yesterday we had cream cake, she had that [Siobhan laughs] and then she had my half of it [more laughter].

The story above was narrated by Dafydd, but Siobhan actively participated in it by nodding acceptance and by laughing, sharing emotion and confirmation of the story relayed by her husband, while she was taking a rest from typing on her lightwriter. This narration by Dafydd, enriched by Siobhan's participation, offered a glimpse of a daily experience shared between the couple. What could have been a story about Siobhan's PEG is seen under a new light through the joint interview; Siobhan and Dafydd had not been able to share a meal for a long time, during which she was fed exclusively through a PEG.

Toward the end of the excerpt Dafydd teases Siobhan by saying "she had my half of it" and Siobhan laughs, thus communicating their joy at this newly reestablished joint experience. Rather than merely the actual fact that Siobhan is reducing her dependency on the PEG and is able to eat some foods, what is communicated on this occasion is a couple's joy at being able to share a meal. The use of joint interviews in our study foregrounded the various ways the participants were approaching their shared experience of living with a progressive, incurable condition. Using joint interviews enabled us to access an emotion, joy, which might have been hard to capture through a different data collection method.

Heteroglossia refers to the presence of “another’s speech in another’s language” (Bakhtin, 1995). In the case of illness for example, the presence of multiple perspectives constitute a heteroglossic world comprising the voices of people living with an illness and the voices of the health care providers, but also those of family, friends, work colleagues and other social actors. These multiple discourses are interconnected and are grounded in the diverse cultural discourses operative in every society. In an analogy with the textual construction of a novel in which heroes are situated in interactions initiated by the author and act within preset boundaries, social actors operate within an inescapable dominant cultural discourse. These multiple “languages”, the diverse perspectives of the various actors together with the scripts, beliefs and attitudes present in society comprise the social whole that is the setting of human action. The different ways people talk and thereby represent the world around them, express their realities and the way they live in the world (Bakhtin, 1995; Good, 1994).

In the context of illness multiple discourses exist; official and vernacular, explicit and implicit, scientific and narrative and so forth. It is important to listen to the voices of people living with illness and their partners because people experience living with illness in different ways (Hunt & Mattingly, 1998). The standpoint and perspectives of people living with an illness and their partners do not always coincide. Sometimes they experience illness in different ways because their roles are different. The use of joint interviews allows for the different perspectives and voices to be heard (Bjørnholt & Farstad, 2012). We illustrate this point through the following excerpt.

Agnes (A): But the storytelling group, I think you are coming to a stage where it is harder and harder for you to go to the storytelling group, haven't you.

Gareth (G): No. I enjoy going to it, I just have to be careful. Can't go to any venues where there are steps.

A: Yes, it's getting more difficult. There will come a stage when you won't be able to go to the storytelling group.

G: As far as there are no steps.

A: Yes, I know that, but there will come a stage when you can't walk at all.

G: Yes, but I can sit in a chair, so I don't have to.

A: Yes, but I will still have to get you in and out of the car, Gareth.

G: Alright, yes.

A: It isn't going to be that straightforward, is it?

G: I don't know, I can't tell.

A: So, we don't know, but he does enjoy it.

G: Yes.

In the interview in which the discussion above was recorded, Agnes and Gareth were discussing Gareth's involvement in a storytelling group. Agnes anticipated future difficulties and was reluctant to make any plans, but Gareth focused more on his present experiences. They both expressed the different ways they made sense of living with an illness but at the end they arrived at a shared understanding that they did not really know how the disease would progress and whether Gareth would be able to still participate in the storytelling group in the future.

Toward developing an understanding of the experience of living with an illness

The foregrounding of the intersubjective and heteroglossic nature of illness

experiences through the use of joint interviews highlights the contextual nature of care practices. Letiche (2008) referred to care as being in-between or being-two because it cannot be defined by a single process but it is always situation-bound and depends on who delivers it and who receives it; in effect the meaning of care is co-constructed by the people who are involved in it. Participants in our study who were also carers sometimes had to accept loss of control, and the people with MND/ALS sometimes had to exercise control. Although Gareth appeared to be in control by not projecting into an unknown future, Agnes anticipated difficulties to come and did not know how they would cope with these new, but yet unknown, challenges.

The way people make sense of their life influences their needs, their choice of services and the way they negotiate their illness. Individuals, their families and friends and health care professionals have their own ideas of how life is to be lived, what needs to be done, how and why. They create what Kleinman (1988) called the different personal and interpersonal meanings of the disease and of life with it. These different perspectives are in constant negotiation in the context of daily life with everybody involved in a dynamic dialogue, trying to establish a common ground for understanding of what is good and what has to be avoided (Letiche, 2008). This is important both for care practices as these are performed at home, often by a partner, but also for health care practices performed by professionals (Mol, 2008).

The process of health care is not about always finding solutions. After all there might not be any solutions available. The process of health care is about understanding and negotiating the positions of everybody involved (Mol, 2008). This understanding is achieved little by little, through synthesizing the different voices and making sense of the intersubjective and heteroglossic world of illness (Good, 1994).

The use of joint interviews allows researchers to capture these different voices and explore how they resonate with each other.

Methodological Weaknesses of Joint Interviews

In joint interviews the individual perspectives of the couple might not be as clearly communicated as they would be in individual interviews (Kendall et al., 2010). This was a considerable concern especially during the first interviews in our study.

Individual perspectives were still expressed through the joint interviews, but sometimes they were not easy to discern. Often when partners of people with MND/ALS would animate the story they would at the same time include their own interpretation of it, thus leading to intertwined stories, one entering into the other. In such cases we had to be careful to establish whose perspective was being shared, or whether it was actually a shared perspective.

It is acknowledged that interviewing the participants separately might have offered a different understanding and produced alternative storylines. However, the aim of this study was not to offer a definitive storyline, but to explore how people make sense of life with MND/ALS, in their own contexts and in their own ways.

Ethical Considerations

Researchers need to be aware that the use of joint interviews might cause tensions in the relationship between the couple, especially if there is a discordance of opinion, or if partners share information in front of each other for the first time (Bottorff, Kalaw, Johnson, Stewart, & Greaves, 2005; Gysels et al., 2008). Participants in our study seemed to be within their comfort zone during the interviews and even though discordances occurred several times, this did not appear to cause tension. Although it

is not possible to know if tension arose after the end of the interview and the departure of the interviewer, the relatively long term nature of the study gave participants some opportunities to discuss such tensions. Furthermore, the interviewer would frequently remind participants of their right to take a break, discontinue an interview at any time or discontinue their participation in the study. It is important that researchers remind participants that they are in control of their participation, especially when the data collection methods are potentially emotionally challenging, like joint interviews.

Some of the participants in our study were people who lived with serious impairments; some could not speak without the use of communication aids, several could not walk or use their upper limbs and most used wheelchairs. Also, some participants needed their partner, who was also their carer, next to them at most times to help with saliva management or body repositioning. In that context, it was recognized that it could be stressful to separate the couple. Gysels et al. (2008) encountered similar issues in their study with people who had cancer, and people in palliative care.

Furthermore, because of the speech difficulties experienced by some of the participants, their partners often acted as the animators of the story narrated by the persons with MND/ALS assisting them in telling their story. This has also been observed by King (2005) and Philpin et al. (2005). The use of joint interviews enabled these participants to share their stories. Not offering joint interviews might sometimes silence people who rely on somebody else for communication.

It is important that researchers are aware whether the use of joint interviews increases the vulnerability of some of the participants, because of gender dynamics or

caregiving relationships, among other reasons. When it is likely that the safety or wellbeing of the participants might be compromised as a result of their participation in joint interviews, then the use of this method is contraindicated (cf. Bottorff et al., 2005).

Conclusion

In considering whether to use joint interviews, researchers need to take two issues into account; the wishes of the participants and the aims of their study. Joint interviews are not appropriate in all situations and sometimes participants might wish to be interviewed individually. Furthermore, some research designs might require multi perspective, but separately conducted, interviews, if the focus is for example on individual perspectives about illness experiences, coping or caring.

The use of joint interviews with couples in studies based on a narrative design can offer rich data, leading to more detailed stories that foreground shared experiences and intersubjectivity. This is especially useful in research on illness experiences where parts of the experience are shared despite the two partners often having different perspectives on the illness and how it affects their shared life.

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