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You Have to Make Something of All That Rubbish, Do You?¹ - An Empirical Investigation of the Social Process of Qualitative Research

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In this article, we examine participants' talk about qualitative research. We provide empirical support for post structural theorizations of the interview and propose three distinct but related dimensions of qualitative research: emotional, purposive/relational, and epistemic/ontological. In this study, participants often became upset but constructed participation as enjoyable and cathartic. The purpose of participation was to assist the communities to which one belonged. Participation was an active, reflexive practice that reconstructed the self and changed knowledge about one's self. This latter epistemic/ontological dimension of participation appeared to be the most compelling for participants, but it is also the hardest to observe, with implications for how we consider the costs and benefits of participation. We suggest two practical measures for researchers and institutional review boards to consider in light of our findings: routinely asking questions about the research experience in qualitative studies and reformulating patient information statements to particularize them to qualitative research.

Keywords: emotions; epistemology; ethics; qualitative research, general; research participation

Think back over the qualitative interviews you have conducted and analysed. How often have participants asked about the purpose of a study, questioned your questions, analysed their answers, imagined other participants, or evaluated the potential benefits arising from a project? Such a comment or question is a kind of meta research moment, an instance in which the usual interview procedure—the researcher asking questions and the participant answering—is overturned, drawing attention to the interaction itself. You might remember several meta research moments from your own career, particularly if they involved a potential loss of face for you as interviewer or produced a key insight. You have probably forgotten many others, as these moments are usually treated as peripheral. The synthesis of raw data into powerful ideas and recommendations is difficult. In analysis we strive for focus, for explanatory power, for coherent theorization, and for description layered thickly rather than spread thin so that we can make a convincing case to our readership and enhance the usefulness of our work. In analysis we create succinct publications and presentations by prioritizing and synthesizing data. The meta moments referred to above are usually deprioritized,

even discarded, in analysis and reporting. In this article, however, we experiment with an analysis of these moments to see what insights they can provide for research ethics and practice.

In recent decades, poststructuralist writings have refocused attention on the qualitative research interaction.² This has newly problematized the research interview and its interactional nature (Kvale, 2006; Manderson, Bennett, & Andajani-Sutjahjo, 2006; Nunkoosing, 2005), moving many researchers away from viewing the interview as an opportunity to mine participants for facts or as a window into participants' authentic lives (Silverman, 2001) and toward a notion of the interview as a co-construction, between two complex individuals, of partial, contextual, situated meaning (Cheek, 1996, 1999). Our previous work (Carter & Little, 2007) drew on Kaplan's (1964) important distinction between logic-in-use, the means by which a researcher produces knowledge, and reconstructed logic, a researcher's attempts to explicitly formulate, articulate, analyse, or evaluate his or her logic-in-use. The poststructuralist turn, through its emphasis on reflexivity (Davies et al., 2004; Finlay, 2002; Lather, 1993), has discouraged idealization in the reconstructed logic of qualitative research. It has given researchers permission to attend and admit to previously secret aspects of their logic-in-use, such as how we cope with data in which participants contradict themselves (Power, 2004), how we feel when a participant comments about our bodies (Burns, 2006), how we negotiate multiple roles and relationships with participants (Cartwright & Limandri, 1997), how we deal with unexpected ethical dilemmas (Goodwin, Pope, Mort, & Smith, 2003), or what we do with "useless" interviews (Owens, 2006). This privileging of transparency over idealization in reconstructed logic has provided a new type of insight into the nature of qualitative research and qualitative knowledge.

Because post structuralism fundamentally turned the gaze away from the researched and onto the researcher, these new insights rarely draw on participants' talk about research. We do not wish to diminish the importance of the poststructuralist turn, but we suggest that it could be complemented by also attending qualitatively to research participants' experiences. There is a large body of work that examines participants' experiences in quantitative studies, particularly clinical trials, using quantitative and some qualitative methods but little corresponding work about participation in qualitative research. The few qualitative studies of qualitative research participation that exist often focus on initial reasons for consenting to participate (Peel, Parry, Douglas, & Lawton, 2006) rather than the experience of participating. Qualitative work on the experience of being in a qualitative study (Beck, 2005; Dyregrov, 2004; Exley & Letherby, 2001; Grinyer, 2004; Hynson, Aroni, Bauld, & Sawyer, 2006) has focused on vulnerable participants: recently bereaved parents, parents caring for sick children, people who are dying, or women experiencing posttraumatic stress syndrome after childbirth. The authors of these articles have argued that participating is painful but also beneficially cathartic and empowering, giving participants an opportunity to feel cared for, make sense of their experiences, and affirm their identities. Participants in these studies spoke about participation as altruistic, wanting to connect to and help others. They identified particular aspects of research implementation that they appreciated—for example, the style of initial approach, the research relationship, the openness and responsiveness of a long interview format, or the benefit of writing their stories privately rather than being interviewed. They spoke of the value of talking to an outsider. These articles have also reported a range of participant reactions to seeing results in the public domain, from feelings of vulnerability and guilt to feelings of validation.

The aim of this article is to provide new understandings of the process of research participation by analysing data that are normally deprioritized or discarded in analysis: participants' talk about a qualitative study in which they participated. Our analysis goes to the experience of participating and how participants construct research processes and outcomes.

Method and Methodology

The talk on which this article is based arose from a study of the experience of autologous stem cell transplantation (ASCT) after high-dose chemotherapy. The experience and aftermath of ASCT treatment are the primary areas of interest of the study. We have published information about ASCT elsewhere (Little et al., 2007): It is used to treat some cancers when they relapse or become refractory and is an extreme and lengthy medical ordeal. The study design has also been published (Carter, 2006; Little et al., 2007). The University of Sydney and Sydney West Area Health Service Human Research Ethics Committees approved the study protocol.

The study was longitudinal. Participants were 10 people who had lymphoma that had relapsed or become refractory and was treated with ASCT and the lay carers of 9 of those people. The recruitment setting was a large teaching hospital in Sydney, Australia. All eligible newly admitted inpatients were invited to participate until 10 were recruited. Consenting participants were invited to nominate a carer to participate if they wished; one nominated carer declined to participate. The sample can thus be conceptualized as a consecutive sample of people with lymphoma drawn from a single treatment location and a snowball sample of matched carers. Participants ranged in age from their late 20s to their 60s; their socioeconomic positions ranged from aged pensioner to company director; and they had a variety of cultural and linguistic backgrounds. Patients and carers consented to be interviewed immediately prior to ASCT, 3 months after ASCT, and then every 6 months, up to 6 interviews. If a participant with lymphoma died, his or her carer remained eligible to continue: The choice to continue or withdraw was entirely the carer's. In all, 69 semi structured interviews were completed over the course of 2 years. The number of interviews per participant ranged from 1 to 6. The pattern of interviews and the period of engagement with the study for each participant are detailed in Table 1.

Table 1: Pattern of Interviews and Engagement With the Study

Participant Pseudonym	Interviewer	Interview Number						Total No. of Interviews	Period of Engagement (Months)
		1	2	3	4	5	6		
Abby*	A	I	I	I	I	I	I	6	27
Bronie	B	O	I	I	I	I	I	5	24
Colin*	A	I	I	†	†	†	†	2	4
Delia	B	I	I	I	O	O	I	4	32
Evelyn*	B	I	†	†	†	†	†	1	1 interview
Francis	A	I	I	W	W	W	W	2	3
Grace*	B	I	†	†	†	†	†	1	1 interview
Henry	A	I	I	I	O	O	O	3	7
Ingrid*	B	I	I	I	I	I	I	6	27
Justin	A	I	I	I	I	I	I	6	27
Kevin*	A	I	I	I	†	†	†	3	6
Louise	B	I	I	I	O	I	I	5	30
Norah*	B	I	I	I	I	O	I	5	30

Marvin	A	I	I	I	I	O	I	5	30
Pega*	A	I	O	O	O	†	†	1	1 interview
Quentin*	A	I	I	I	I	W	W	4	15
Ruby	B	I	I	I	I	W	W	4	15
Sigrid	B	I	I	I	O	I	O	4	15
Tony*	A	I	I	†	†	†	†	2	4

Key: * =patient; I =interview; O =participant lost to follow-up or not available; W =withdrew; † =deceased.

There were two interviewers, one male and one female. Generally, they would go together to a location convenient for both the patient and the carer participant in a dyad, and each would interview either the patient or the carer separately and simultaneously. Each participant was interviewed alone and by the same interviewer across the study. At each interview, participants provided a narrative of their experience since the previous interview and answered questions arising from previous data analysis. Most interviews included a question such as “How has it been for you so far participating in this study?”

All interviews were transcribed in full, names were changed to pseudonyms, and data were managed in NVivo 7. ³ Our design did not have all of the features of a grounded theory study: In particular, as discussed above, although analysis iteratively informed the questions asked of participants, selection of participants was not theoretically driven. However, in analysis we used the constant comparative method proposed in Charmaz’s (2006) iteration of grounded theory procedures. In keeping with grounded theory procedures, the talk of all participants was compared throughout the analytic process. This included the talk of patient–carer dyads, which frequently referred to the same events and was compared particularly closely. However, participants were also approached analytically as individuals in a research interaction with their interviewer, as appropriate to the interactionist principles underlying grounded theory methodology. Our aim was to generate a model of the social process of these participants’ illness, treatment, survival, death, and bereavement. A code structure was developed from the data. Guided by Charmaz’s (2006) method, the codes focused on what participants did with their talk, or how their talk constructed their experience. The codes developed included “participating in research,” which tagged all participant talk that evaluated or commented on the research experience or performed an action other than answering or storytelling (for example, challenging or asking questions). This included spontaneous talk and talk in response to direct questions about the research process. As the analysis progressed, it became clear that this talk was extrinsic to our model of the ASCT experience but did provide some important insights into our process of knowledge creation and the ethical principles underlying our research practice, leading us to report it here.

As we have argued elsewhere (Carter, 2006), the longitudinal nature of this study provided an important opportunity for interviewers and interviewees to build a relationship, and this relationship building is an important contextual element in the data. Another important contextual element is previous applied linguistic research done at our centre that examined the structure of interviews (Jordens & Little, 2004). This research formally acknowledged role reversal—the interviewee turning the tables on the interviewer—as an optional phase in any interview interaction. As a result, all interviewers at our centre are encouraged to allow participants to turn the tables in an interview if they so choose.

Results

From the talk gathered into the code “participating in research,” we developed three interconnected domains of qualitative research participation. These domains were inextricably linked. Although we consider them individually for the purposes of clarity, we emphasize that they were dependent and embedded. Participating was an emotional experience. Participating was purposive and relational: Participants located themselves altruistically in their communities and related this community membership to the purpose of participating in the study. Finally, participating was an epistemic and ontological process. Participants demonstrated their own reflexivity about the interview, turned the tables on the interviewer, evaluated their own performance, and analysed the knowledge-creation process of research. We will consider each of these three domains in turn.

The Process of Participating Was Emotional

Being interviewed was clearly an emotional experience for these participants. This is perhaps the least original of our observations. Consistent with existing research, many of these participants said the experience was enjoyable, cathartic, and beneficial. Note that in all quotations, (P) designates a patient participant and (C) a carer participant:

Norah (P): . . . I suppose um talking about it to someone external is, is good just to yeah, yeah just to let it out.

Tony (P): It does good to talk to someone occasionally. ...

Interviewer: I'll give you another call [in 3 months] and see, if you're willing to do another interview.

Colin (P): Yeah, no, by all means, I thoroughly will enjoy that.

Sigrid (C): . . . I've enjoyed taking part in these interviews and if there's ah anything else you need to ask me don't hesitate.

The interview experience could also be upsetting, and many participants needed a break during at least one interview because of this. Consistent with other research, despite the evident sadness experienced, participation was constructed as enjoyable and beneficial overall, and—as will shortly be discussed under the purposive and relational domain—valuable and worthwhile. However, there were some participants for whom ordeal was the dominant experience. Henry, whose wife died shortly after transplant, had great difficulty talking about his experience:

Interviewer: and um how's it, how's it been for you, taking part in these interviews?

Henry (C): [chuckling and upset at once] ah I guess you know

Interviewer: I know it's hard

Henry: rather stressful

Interviewer: yes

Henry: feel silly

Interviewer: oh it's not silly to be upset if someone you love dies, it's happened to some other people in the study too, so.

[Lengthy silent pause]

Henry: [very upset] Oh, if it can help you in any way, it's alright. It's been really hard [tearful, using handkerchief, long pause]. That's about all I can say in that respect. It's been difficult [long pause] but—sort of got there, in a way.

The Process of Participating Was Purposive and Relational

Although being interviewed was an emotional experience, justification for participation or nonparticipation appeared to arise less from these emotional elements and more from the overall usefulness of the project, as illustrated in Henry's talk above. In short, a useful research project was one that helped people in the participants' communities. The interviewer was one legitimate beneficiary; participants constructed their interviews as potentially helpful for their interviewer:

Colin (P): I hope it was informative

Interviewer: It was very informative

Colin (P): I hope it helped you a great deal [italics added]

The relationship built over time between interviewer and interviewee clearly had emotional content and importance. Ingrid made occasional calls to her interviewer just to tell her how things were going, and some participants expressed disappointment when it was time for their interviews to finish:

Bronnie (C): [Speaking about the two interviewers at the end of her last interview] it [was] very nice to meet you both actually

Interviewer: yeah it was great to meet you all

Bronnie: you're sort of got, you're sort of part of the, sort of family, you're just sort of, there, it's gonna be funny actually not having youse come out all the time now.

However, another set of relationships was more strongly present and more striking. Participants located themselves in three communities: a community of patients and carers going through a similar experience, a community of participants in the same study, and a community of patients with whom they had been hospitalized. An emotional bond was constructed with the members of these communities, and participants frequently talked about these invisible others with care and concern. They wondered out loud about the other participants in the study:

Delia (C): How many people have you researched there now?

Interviewer: Oh nine patients

Delia: Nine, nine patients

Interviewer: Nine patients and nine carers

Delia: and have [their transplants] all been successful?

They evoked the somewhat ghostly community of patients who had been hospitalized with them:

Bronnie: [Talking about people who were in hospital at the same time as her daughter, Abby]
Mmm. they don't happen to be on your, books do they? I don't know what their names were, don't know what their names were, there's only [one man], that I know the name of. Abby might know the other people. Mmmm. But they're, you know they're I think [pause] [softly, exhaling] yeah, cause you never know what happens to them.... You never know what happened to everybody else that was there.

Participants also frequently constructed themselves as helping other people with similar illnesses through participating. Sometimes this was a normative hope for a specific transformation. Norah, for example, who was strongly committed to a traditional Chinese medicine paradigm, hoped that her interviews might influence a shift in mainstream medical thinking toward traditional Chinese medicine that would benefit other patients. But more often participants hoped that their interviews would create a general benefit for others:

Quentin (P): . . . if I can help someone else I would love to. Because, it yeah, if, if somebody else can learn, from what I've gone through, I would be rapt.

Ruby (C): . . . I feel like, being through it if we can do anything that can help other people whether it's through an interview or talking to people or doing anything it doesn't bother me at all . . . if it helps others or if it can help you . . . it's fine.

Francis (C): . . . if something can helping to, can be helping the patient have similar problem like my wife, we don't mind to share the experience with those people.

These relationships, and the degree to which they could be served by participation, were not constructed uniformly. This is particularly well illustrated by differences in the talk of Kevin and his wife, Louise. Kevin positioned himself as completely informed and supportive of the study as a direct result of the participant information process:

Kevin (P): . . . I have read the information sheets, and I understand the intents, and the value of it, and ah I'm happy to be part of it, it seems to me thoroughly worthwhile.

He spoke strongly throughout the study in support of the idea of progress and the importance of research. His altruism had a notably technical edge: He was helping others by contributing to a larger scientific project. Louise, his wife, who also received patient information statements, had them explained, and had consented in writing to participate, had different priorities than Kevin:

Louise (C): . . . the last few days I've said, I said to Kevin a few days ago "I really I don't want to bother with this [research] you know, I don't feel like I'm getting anywhere with" . . . I feel it is [more] important to speak [with someone] that's gone through this same thing as Kevin.

Kevin constructed Louise's expressed desire to meet other patients and carers who had undergone ASCT, rather than to participate in the study, as "strange":

Kevin: She obviously . . . seems to expect, to get some comfort from that. Ah, whereas, aaah being involved in the study, she has, sees no value in that for her. [pause] And I'm, the opposite, um, other people's experience to me, ah, is, is not going to, alter my, outlook, I don't think. I don't expect it to. I'd participate, ah, for the sake of doing it, because you know you never know what ah, you're going to get out of something, but I really have no expectation, of, ah gaining anything from that

Interviewer: right Kevin: aaaah, but this study, I see as valuable

Interviewer: right

Kevin: just, we're, chalk and cheese like that.

Both Kevin and Louise located themselves in a community of patients and carers. For Kevin this community was best served through research participation and knowledge accumulation, whereas Louise prioritized direct personal contact with fellow community members and their stories.

The Process of Participating Was Epistemic and Ontological

Consistent with poststructuralist conceptions of the interview, these 19 people participated actively in joint performances between themselves and their interviewers. The epistemic/ontological domain of participating reflects that active, reflexive positioning and addresses the epistemic and ontological work of participation. It was constructed from four kinds of talk: talk that turned the tables on the interviewer, examples of participants interrogating their own performance and inviting critique, talk in which participants noted the importance of context, and talk that constructed participation as epistemically and ontologically reconstitutive. We will discuss each of these in turn.

Participants frequently turned the tables on their interviewer. The tables were turned in different ways, depending on the personal relational and communicative style of the interviewee, but always exposed the interview dynamic by interrupting it. The interruption of the normal flow and power balance—the interviewer asking questions and the interviewee answering— foregrounded the "interviewiness" of the interaction. Participants quizzed their interviewers, seriously or jokingly, about their credentials or their work:

Kevin (P): Is this voluntary work that you do?

Interviewer: No this is my job, it's part of my job

Kevin: I am just wondering how many questions you ask, and what rate of pay, I think you asked me three questions [laughs].

Ingrid repeatedly shaped the conversation using a characteristic type of talk that closed the current conversational topic and either provided or requested a new one:

Ingrid (P): . . . so any more questions for me? No more like that one.

Ingrid: . . . so but that's it. So what else can I answer for you?

She also provided instructions about interpretation:

Ingrid: . . . I'm doing alright . . . so don't say bad things about me because I'm doing alright at the moment!

Bronnie and her daughter, Abby, did substantial conversational work to connect themselves with the interviewers. Abby cheerily questioned her interviewers about their lives and their own illness experience:

Abby (P): [At the end of Interview 4] Other than that. What else can we talk about? [long pause] Can't think of anything else. I've just about talked myself out I think [chuckle]. Yeah. What about you? What have you got to talk about?

Bronnie raised the issue of the potential emotional impact of the interviews on the interviewer:

Bronnie: . . . Do you talk to anybody um that, that, hasn't gone into remission?

Interviewer: yeah [pause] Yeah we start off, with a group of people and we just follow them, you know, whatever happens.

Bronnie: that must be hard for you.

The degree of table-turning changed for some participants across the study. These changes over time made clear the significance of a long research relationship in the construction of an interview. Delia, for example, was relatively reserved in her earlier interviews, but during her final interview she asked detailed questions about the interviewer's own illness experience and beliefs about alternative medicine and instructed the interviewer to turn off the recording device at one point so that she could share a scandalous story "off the record."

Table-turning—participants' interrogation of their interviewers—provided one basis for arguing for participation as an active, epistemically sophisticated performance. The second basis for this argument was talk in which participants interrogated themselves and their own performance, demonstrating a reciprocal reflexivity. At the outset, some participants articulated nervousness, expressed a preference for structured questions instead of the open space of narrative interviewing, worried out loud about their ability to perform, or wondered whether they would have anything to say. At the end of interviews, participants frequently reflected on the adequacy of their performances and often worried that they had talked too much! Sometimes participants explicitly asked the interviewer to provide them with feedback, but more commonly they evaluated or questioned their own performance, thereby creating an opportunity for the interviewer to be supportive. A good example, used as our title, was Ingrid's question in summing up her third interview: "You have to make something of all that rubbish, do you?" Other comments had a similar theme:

Evelyn (P): What else. I have been talking too much.

Louise (C): I am just wondering if what I say is important enough to you, to um work with.

Marvin (C): . . . how do you find, do I actually answer your question point to point or do I actually go sideways sometimes?

Ruby (C): . . . as long as I answered all the questions, I got a bit off the track.

Participants talked about their interviews not just as performances, but as steps in a longitudinal knowledge-creation process:

Norah (P): . . . I don't mind doing [the interviews] because you know I know it's for research and something that um, you know something that yeah you can look at and, and sort of get ideas from I suppose. Yeah so.

Interviewer: when you say you don't mind, do you mean that you're not really that keen or

Norah: oh like I'm doing it more sort of, yeah for your research than yeah my yeah. I'm happy to do it for the research.

Kevin (P): [Clinicians] are only able to help [patients when they are ill] because, somebody has gone before, and provided information, and there's been an accumulation of wisdom that uh, that gives them the, the ability to study that information and come to conclusions and provide, ah, a result to ah to the people who come after, I mean it is just logical to me.

We have already seen that participation was justified partly through personal benefit and benefit to the interviewer but made sense mostly because it might help the participants' communities of experience. The mechanism by which those communities might be served was the construction of useful knowledge. It is thus understandable that participants would request reassurance about the suitability of their contributions for the creation of this knowledge ("You have to make something of all that rubbish, do you?").

A third kind of talk underpinning the epistemic/ ontological domain openly evaluated the nature of the knowledge that was being constructed and the importance of appreciating that knowledge in the context in which it was created. The timing, the place, the circumstances, and the interviewer influenced the finished product:

Interviewer: . . . how do you feel about the future?

Ingrid (P): yeah I'm okay at the moment . . . we'll work out, after [my check-up] tomorrow, you should talk to me after tomorrow

Louise (C): Once we get that remission you know that we are after, then I will probably have another, a different sort of, I will have more to talk about and, and ah, you know, I will be more positive.

Justin (C): [About his mother] [The interviewer might be able to bring out] some of the thought processes and things that worried [her] that may be . . . somebody who is an outside observer might be able to ah pick it up a bit more [than a member of the family].

Sigrid (C): Yeah I only wish that I had of spoke to you probably that, within that first month of losing my husband because it would have been my real true feelings, even though I was babbling on for the first couple of weeks, I was talking in puzzles and jigsaws, um because my mind was racing, but um, that was, would have been my true feelings of how I felt if it was going to help you with your research.

The final basis on which we argue for an epistemic/ontological domain of participation is participants' talk about the relationship between their retellings and their experiences. Sometimes this was about the stability or elusiveness of memory, but in an important sense, being an interviewee was frequently not simply a retelling, but also a reconstruction of experience. The act of participation had an epistemic dimension—it reconstructed one's knowledge about one's own experience—and an ontological dimension— it reconstructed the self. Participants talked about interviews not simply as the creation of knowledge for a research project but as instrumental in their recollections of their lives and constructions of themselves, their identities, and their realities:

Marvin (C): . . . I guess when, when you ask questions that ah, that I've, I might of, um, briefly looked at and um and not really deeply think about . . . I think it's good, I um, I guess it's, it helps in a way sometimes that um, that things I I generally overlook in a way, um I don't think too much of it, but when, when the question is asked it makes you think another level. Um. Probably one of the ways to understand myself maybe a little bit better, what I really am about, yeah....

Norah (P): Um, I think it's good yeah because it's sort of lets me evaluate how things have progressed.

Bronnie (C): . . . If anything [participating in the study] probably helps[me], uh, in a way . . . [because you asked me questions such as] "did anybody ever ask you how you were feeling?" And I'd never really thought about it. And I said—well no! not really! not really because, you don't think about that because, every-everybody's focus is on, onnnn, the person who is sick, ummmm, and you don't think about, y-your own self or you don't think about anybody, you know?

Justin (C): . . . I don't particularly mind [taking part in the interviews]. It's sort of interesting to go back and sort of rethink all of the issues myself as I am going along and ah how that's affected things and, what things I might change, or what I would like to see changed, um whether I made the right decision at the time....

Quentin (P): . . . I suppose I was talking today, um, I suppose it reminds me of, how far I've come? Which is a good thing?

Tony (P): Yeah well [in the interview] you go back over what you've done and you just y'know recall what the goals were and what we've achieved and what we haven't achieved . . . it stimulates the mind as to, y'know yeah I've still got to do that I've still got to do that.... I reflect back on it because when you rang up and said about coming in I thought "Well what are we going to talk about that we didn't talk about last time" and I sat down and reflected on it and it was good.

This constitutive effect of interviewing was not always a good thing. The interview process could interrupt participants' necessary efforts to live in the present or to move on from their illness experience:

Interviewer: And how have you found it taking part in these interviews?

Ingrid (P): . . . Oh it's just not easy, because it sort of brings it all back

Interviewer: oh yeah

Ingrid: that's all nothing else, it's just that it brings it all back and you've got to try and remember, you ask questions and you've got to try and remember . . . as I said because you go on and on and on and on, and I don't go too far ahead looking at things and I try not to look back.

Proposing Relative Weight of the Three Domains: Using Patterns of Withdrawal From the Study

It is our contention that the epistemic/ontological dimension of participation was the most compelling in this data, for two reasons. First, this domain seemed richer and more complex. However, the stronger evidence, for us, was the pattern of participant withdrawal from this longitudinal study. Because we approached this study via a constructivist epistemology, we did not presuppose that "real" reasons for participants' continuing or withdrawing existed or could be observed. Rather, we observed what was done in discursive interaction and drew conclusions from this as to how participation was constructed.

We have already seen that Henry became extremely upset when talking about his experience. He appeared to have every reason to withdraw on the grounds of emotional risk, but did not. The obvious suffering Henry experienced during the two interviews after his wife's death was a source of great unrest for the research team. However, equally, we felt ethically bound to honour the commitment we had made to Henry at the outset of the project to continue to interview him throughout the study if he wished. We felt it was important to respect Henry by allowing him to make his own decisions about continuing participation, while repeatedly emphasizing non-obligation and the ability to discontinue at any time. This interaction occurred close to the end of Henry's second interview:

Interviewer: With this study when we um enrol people in the study we follow them up for 2 years, would you be interested in doing a follow-up interview in say in 3 or 6 months.

Henry (C): [nods head]

Interviewer: I will give you a phone call closer to the time to see if you are still interested

Henry: perfect

And his final interview concluded as follows:

Interviewer: Would you like to go ahead with another interview or would you like to stop, it's entirely up to you.

Henry: what would the next interview be for?

Interviewer: just to see how you're going in 6 months' time [Henry: mm] but if it's ah

Henry: well you can give me a call and see how, how I am

Henry himself became unwell after this final interview. In ensuing correspondence, the possibility of continuing interviews remained, but meetings were unable to be scheduled because of Henry's illness. He never formally withdrew from the study.

We have already seen that Louise wanted to connect to her communities of experience through direct meetings with other patients and carers. Consistent with this, she expressed concern that the study lacked purpose across her interviews:

Interview 3

Louise (C): [Before this interview] I was just thinking "what's the point? Why do you need to know these things?" and I didn't really understand why, and that's probably um, I mean that's certainly what made me, you know I just didn't understand.

Interview 6, first question

Interviewer: [Could you] bring me up to date [with your circumstances] . . . if that's alright with you.

Louise: [This is a little skeptical] Mmm. Okay, but, can I ask you first

Interviewer: Sure, sure? Yep?

Louise: I-I'd like to ask you exactly [Interviewer: yeah] what, what, [inhalation] uh this is, what the whole thing the interviews, lead up to, what's the end result of that and why, why do you do them?

However, despite Louise's expressed distrust in the purpose of the interviews and repeated assurances by the researchers that she could withdraw at any time, she continued to the end of the project, even after Kevin's death.

The three participants who withdrew explained that participation was changing their sense of self and their knowledge about their experience in undesirable ways.⁴ Quentin and Ruby said that the process undermined their efforts to get back to normal after Quentin's recovery. Francis, whose wife died suddenly after transplant, withdrew from the study after his second interview because

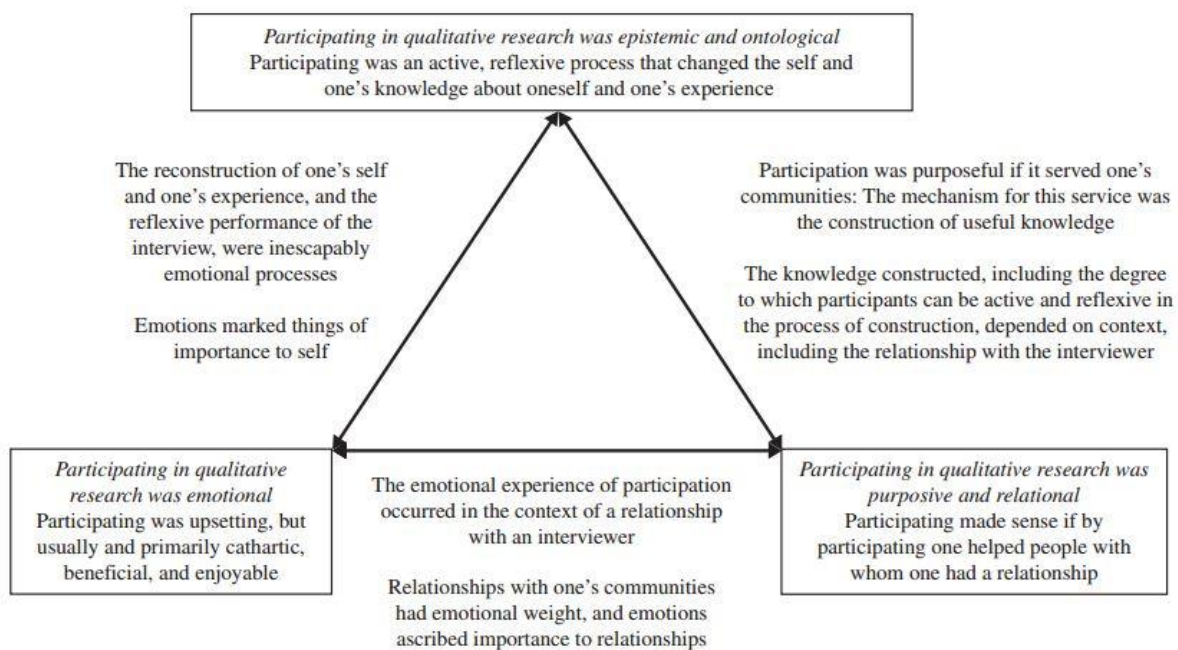
. . . I just try to, go on my life. I will carry the good memory of my wife, and just go on, keep living, *writing another chapter again myself*, you know. So um. . . I would prefer not to [continue with the interviews] because um um, I just need a celebration [of] my wife . . . my wife's life, you know, I think she have a wonderful life . . . *I don't want to um, you know, be, you know, remembering about hospital I don't want to be memorizing those kinds of things.* [italics added]

We are not arguing that these participants' withdrawals from the study were in no way emotional or relational. However, we would argue that by emphasizing that participation led to "memorizing those kinds of things" and prevented "getting back to normal" and "writ[ing] another chapter again myself," rather than, for example, saying "it is too upsetting" or "I don't see the point," these participants foregrounded the epistemic/ontological domain over other domains in their construction of the research process.

Theorizing Qualitative Research Participation

Based on our analysis, we have theorized participating in qualitative research as illustrated in Figure 1.

Figure 1: Three Interconnected Domains of Participating in Qualitative Research



As discussed, we propose participation as consisting of three interconnected domains: emotional, purposive/ relational, and epistemic/ontological. In the emotional domain, most participants said the interviews were enjoyable and cathartic, and we also observed that many participants became upset at least once during their participation. For a majority of participants, the enjoyment and catharsis outweighed the upset; when the reverse occurred, participation became an ordeal. However, enjoyment or ordeal did not appear to be central to the meaning of participation. In the purposive/relational domain, participation made sense because it strengthened an altruistic connection— a purposive relationship—to a community of people with a common experience of illness and treatment. In the epistemic/ontological domain, which seemed to us to be the richest and most compelling, participation was an active, reflexive, and reconstitutive practice. Participants in this study—and we suspect, based on our experience, in most studies—were not passive subjects but active and critical co-creators of knowledge. They turned the tables, invited critique of their own performances, commented on the limitations of the knowledge that was being created, and talked about participation as changing their selves and their knowledge about their experience.

Critically, these dimensions were interrelated. Participating epistemically/ontologically—engaging in a self-critical performance of one’s extreme experiences and reconstructing one’s self and one’s experience—was inescapably emotional. Participating purposively/ relationally—making sense of participation as assisting related others—also had emotional weight. This was demonstrated in the care and concern expressed in the interviews for people, mostly strangers, who were undergoing similar experiences. This embedding of the emotional domain in other domains is consistent with pre-existing theorization of emotions as inherently relational, cognitive, and to do with the self, as “appraisals or value judgments which ascribe to things and persons outside the person’s own control great importance for that person’s own flourishing” (Nussbaum, 2001). The emotional and purposive/ relational domains were also interconnected in that the emotional experience of participation, particularly the enjoyment and benefit, occurred in the context of a continuous and supportive relationship with a particular interviewer. Finally, the epistemic/ontological domain was inextricably caught up with the purposive/relational domain in two ways. First, the degree to which people could be active participants was determined in part by the relationship with the interviewer. Second, the mechanism by which participation served others and thus became meaningful was the creation of useful knowledge: It was this mechanism that was interrogated when Ingrid asked, “You have to make something of all that rubbish, do you?”

Discussion

What Lessons Are in This Study for Qualitative Research Practice?

This analysis suggests that it is useful to ask participants about the experience of participating in interview research and to attend to spontaneous talk about the experience. By doing this, we have been able to argue empirically for constructs that are generally justified theoretically, providing discursive evidence to support the claim that interviews are active co-constructions, between two complex individuals, of partial, contextual, situated meaning (Cheek, 1996, 1999). These participants constructed their interviews as performances in particular places, times, and relationships and reminded their interviewers that if they had participated in different places, times, and relationships the interviews would have been different. This reinforces the proper centrality of context in, and the inescapably partial nature of, qualitative analysis.

The distinctions that we have developed in this study between emotional, purposive/relational, and epistemic/ontological aspects of participation have implications for our developing understanding of the ethics of qualitative research. Guillemin and Gillam (2004) have distinguished between procedural ethics, the ethics enshrined in institutional review board (IRB) procedures, and “ethics in practice” or micro ethics, the small but significant everyday ethical dilemmas that are part of the conduct of qualitative research. Empirical work on qualitative research participation tends to emphasize that participants benefit emotionally from participating, perhaps because IRBs frequently deny this possibility. Conversely, IRBs tend to focus on whether participants will experience emotional harm in qualitative research and on the relational constructs of coercion and confidentiality. Of course, harm to participants, voluntariness, and privacy are of utmost importance in ethics review and must remain central in IRB considerations. However, this study, which contributes to the micro ethics of qualitative research, suggests a reprioritization of concerns.

In these participants' accounts, emotional aspects of participation were less troublesome, relational aspects more complex, and epistemic/ontological aspects more central than in common procedural formulations of ethics. These different aspects of participation were also differently accessible. It was relatively easy to infer participants' emotional states from their verbal and nonverbal behaviour; accordingly, it was comparatively easy to make a judgment about the harms or benefits of the emotional dimension of research experience. Evidence of epistemological or ontological harm or benefit was less accessible. Whether someone's knowledge about their own experience, or their sense of self, had been altered by participation in a study like this one could be known only retrospectively by asking the interviewee or closely analysing the interview data.

We suggest that procedural formulations of ethics could be particularized to better match our micro ethical analysis of participants' constructions of qualitative research participation. Indeed, it seems from this study that participating in qualitative research might be a substantially different experience than participating in experimental or survey research. There are two ways in which procedural ethics might change to better respond to qualitative research participation. First, participant information sheets could be revised so as to better inform each potential research participant about what she or he is likely to experience in a qualitative study. Second, participants, particularly in longitudinal qualitative studies, could be routinely asked to reflect on their experience of the research process. We shall elaborate on each of these suggestions in turn.

Revising Participant Information Statements

In our experience, current participant information statements, and presumably the conversations that should go with them, do little to prepare participants for the likely experience of participation. Our interpretation of these data suggests that at least for a study like this one involving repeated interviews with patients and their carers, participants would be better prepared by wording such as this:

In this study, you and an interviewer will talk at length several times about your experience of illness and caring. This will not be a simple matter of the interviewer asking questions and you answering. You will also shape the conversation and will have opportunities to tell the interviewers what you think they need to know. We know from previous studies that most people will get upset sometimes in these interviews. However, on balance the experience is a good one for most people. Participants generally get to know their interviewer over time, enjoy talking to them, look forward to their interviews, and say it is good to have an opportunity to tell their stories. We also know that interviews give people an opportunity to reflect, remember, and reinterpret their experiences. Being a part of this study will probably change your experience of illness and caring and might change the way you think about yourself.

In every study like this one, some people decide not to participate or to stop participating after a while. There is absolutely no obligation for you to participate or continue in the study. You can withdraw at any time with no penalty, and for any reason, and you don't have to tell us why. You might want to move on and stop talking about illness; you might feel as though there is no point to participating or that it's too upsetting. You don't have to explain this to us; you can simply stop participating.

If you decide to participate, your story will help the research team to understand your experience of illness and caring. Your story will be used to help other people going through similar experiences.

People are often unsure about the usefulness of what they have to say, but we know from experience that anything you tell us will be of great benefit. If you decide to share your story with the research team, they will work hard to ensure your contribution is used to assist as many people as possible.

Inviting Participants to Talk About Their Experience of Research

In addition to reformulating patient information statements, we suggest that participants, particularly in longitudinal qualitative studies, could be routinely asked to reflect on their experience of the research process. The balance of benefits and harms for any individual research participant cannot be known in advance, and IRBs might be reassured by research protocols that include a checking mechanism of this kind. When studies focus on particularly sensitive issues or vulnerable populations, researchers might agree to provide IRBs with a regular report based on participants' reflections on the experience of participation, a practice that could facilitate bold research while safeguarding research participants. However, we also emphasize that the final decision to participate does rest with competent participants. In this study, participants made their own choices about costs and benefits and weighed emotional, purposive/relational, and epistemic/ontological costs and benefits differently. Participants who apparently carried significant emotional costs chose to remain involved, participants needed to have purposive/relational benefits explained, and participants withdrew when the epistemic or ontological costs became too high.

This study supports and extends previous work about the experience, ethics, and epistemology of qualitative research. It occurred in a particular context: repeated interviews with 10 patients and carers of 9 of those patients, all critically ill, all experiencing a serious and life-threatening medical ordeal. It involved the experience of surviving serious illness and the experience of bereavement. It is likely that talk about participation in different types of qualitative studies—such as those focused on non-life-threatening illness, illness for which treatment is less extreme, or people who are not ill—might produce different talk about research participation, and it would be useful to be able to make such comparisons. To pay attention to participant talk in this way would greatly enrich our collective reflexivity. Much excellent theoretical and contemplative work has been done about the process of qualitative research. Our primary intention in this study was to bring the voices of participants back into that ongoing conversation.

Endnotes

1. This question was asked by Ingrid when reflecting and summing up at the end of her third interview.
2. Post structuralism was not the first intellectual movement to do so: Symbolic interaction, in particular, has underpinned a strong tradition of attention to interaction for many decades. However, it seems to us that the problematisation of the qualitative research interview in the literature has been more clearly attributable to post structuralism of late.
3. The transcription style used here is designed to evoke the spoken language of participants without using technical symbols. We have used commas to mark pauses or drawn breath, question marks to indicate rising tone at the end of phrases, ellipses to show where talk has been omitted, underlining to signify vocal emphasis, square brackets to include any words we have changed for clarification, and italics to designate interpretative emphasis.

4. Of course, participants can withdraw from research without reason or penalty, but people tend to explain themselves, and these participants did so spontaneously.

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