

Exposing failures, unsettling accommodations: tensions in interview practice

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ABSTRACT This article aims to augment collective understandings of the ethical complexities of qualitative research, and to encourage more attention to the actual practices of interviewing than has usually been paid in discussions in this area. Drawing on interview transcripts, we offer an analysis of the ways vulnerability may be produced for research participants by the intersection of interview factors (an interview strategy, the interviewer's presence, a line of questioning) with particular discursive and political surrounds. This conceptualization of the conditions of interviewee vulnerability prompts a revisioning of the power that researchers bring to, and exercise in, interviews. In reflecting on interactions with research participants we describe our efforts to use our power wittingly and responsibly.

KEYWORDS: *'active ageing', ethics, 'good death', health system restructuring, home care, informal care, interviewing, qualitative research*

Introduction

Much has been claimed for the qualitative research interview. Interview methods are variously said to offer valid and reliable information, insight about the subjective meanings of social phenomena, and an entree into networks of social relations and institutional power. Claims are made, as well, about what qualitative interviews 'do' to research participants. At one extreme, interviews allegedly empower, generate self-awareness, or offer a kind of therapeutic release for interviewees; at the other, they draw reproach for feigning intimacy with, and then abandoning, the people they engage.

The question of what research interviews do to and for our respondents has been pursued with particular diligence by feminist researchers. Critics of Western and masculinist research practice contend that interview models built on hierarchy and distance tend to exploit research participants. Some

feminists have proposed means to subvert and transform the researcher's power in the interview, suggesting myriad means of establishing collaborative – or at least transparent – relationships (Cotterill, 1992; Finch, 1984; Oakley, 1981).

Others have wondered if collaboration between researcher and respondent is indeed in the research participants' best interests. While noting she is drawing the case starkly, Stacey suggests that feminist ethnography may actually endanger participants: 'precisely because ethnographic research depends on human relationship, engagement, and attachment . . . it places research subjects at grave risk of manipulation and betrayal' (Stacey, 1991: 113). Risk is seen to inhere in the intimacy, the appearance of mutuality, between researcher and researched, rather than in the imbalance of power between them per se. Other writers have drawn the ethical terrain differently, accounting for interviewee vulnerability in terms of the sensitivity of a topic area (Renzetti and Lee, 1993) or the precarious social position of particular research participants (Cotterill, 1992).

Where does risk lie, for interview participants? What conditions produce it? As feminist researchers, we are striving to articulate our responsibility for gauging and minimizing harm to the people whose stories are the wellspring of our work. Institutional ethics review procedures often imply that all manner of harm to research participants can be anticipated, the appropriate salve identified in advance of fieldwork and retrieved at the difficult moment. Critical observers note, however, that ethical research unfolds in the details of its conduct, and call for constant attention and reflection, for revisiting questions of harm along the way (CRIAW, 1996). Yet such revisiting is scant in the literature. Coffey (1999) notes that tensions in qualitative studies are often held in the personal diaries of fieldwork. Raw expressions of worry seldom make their way into fieldnotes that are, typically, 'tidied up' before being shared with others (p. 121).

In this article, heeding the call for reflexivity in research practice, we draw forward some of the worries held in our own research diaries, and bring into text conversations in which we shared our anxiety and perplexity about interviewing. We aim to augment collective understandings of the ethical complexities of qualitative research by describing a particular way in which vulnerability may be produced for research participants: through the intersection of interview factors (an interview strategy, the interviewer's presence, a line of questioning) with political and discursive surrounds. Politically, both the studies that form the basis of this article are set in relation to the erosion of public responsibility for health and social care in Canada; discourses at play include that of 'the good death' and 'active ageing.'

Conceptualizing vulnerability as related in part to discursive and policy contexts prompts a reassessment of the power researchers exercise in interviews. It also encourages more attention to the actual practices of interviewing, the actual detailed engagement with research participants, than has usually been

paid in discussions about research ethics. In reflecting on recent interactions with study participants, we consider a series of strategies for addressing the particular configurations of vulnerability highlighted in this article. Our analysis rests in part on the understanding that 'interviewers are deeply and unavoidably implicated in creating meanings that ostensibly reside within respondents. . . . Meaning . . . is actively and communicatively assembled in the interview encounter' (Holstein and Gubrium, 1997: 114).

Study contexts, purposes and methods

RELATIVES AND FRIENDS PROVIDING END-OF-LIFE CARE – CHRIS'S STUDY

As trends in cancer mortality continue to intersect with conditions of constraint in the health sector, informal care for people dying of cancer is becoming an increasingly significant feature of social life in Canada. A recent senate committee report defines the territory encountered by dying people, and relatives and friends providing end-of-life care:

Palliative care exists as a patchwork quilt across the country. Access varies from region to region, with significant differences between rural and urban communities. Many people are unable to access palliative care because the closest hospital may be understaffed and overburdened, because there is no home care support, because they have been given the wrong diagnosis, or because death is not imminent.

(Government of Canada, 2000: 20)

Even where palliative care can be accessed, constraints in both tertiary and community-based care services render consistency and responsiveness in formal care less and less available. People providing care for a relative or friend who has a terminal illness also operate in relation to cultural prescriptions about 'the good death'. Someone who dies well at the turn of the millennium in the West dies having availed herself or himself of desired medical and spiritual options (Walter, 1996), dies having acknowledged she or he is dying (Armstrong, 1987) and expressed the feelings this knowledge evokes (Clark and Seymour, 1999); and dies accompanied (Seale, 1995), enmeshed in a network of love and trust, ideally at home. In some representations, the ill person dies peacefully and without pain.

Members of a dying person's immediate social network are strongly implicated in the good death. Relatives and friends, as 'good supporters', enable spiritual and health care choices; they receive (or, if necessary, prompt) and respond to spoken acknowledgements of dying and expressions of feeling; they maintain (or, if necessary, create) intimacy with the dying person. They secure health and social care that eases all manner of pain, and they make the logistical, economic and emotional accommodations a home death requires.

At times, however, the embodied and social realities of dying belie informal carers' best efforts to achieve and participate in a good death. Relatives and

friends encounter a loved one's body as it becomes frail; some encounter a body becoming unbounded (Lawton, 1998), leaking urine, faeces, smells, blood, unfamiliar or incoherent talk, screams. What was possible and forbidden in a relationship before the cared-for person became ill often remains so; when the relationship changes, it is not always in the direction the carer would have wanted. As well, in a policy context where relatives and friends assume considerable responsibility for the health care dying people receive (Sinding, submitted), ensuring a 'good death' is increasingly complex and demanding.

In my research, I set out to explore people's experiences of supporting relatives or friends dying of cancer. My study took as its central question: How do carers' perceptions of formal health services, and their subjective experience of caring for someone who is dying, influence one another? My plan was to explore with study respondents the ways their relationship with their relative or friend changed (and remained the same) over the course of her or his illness and dying, and to ask about their recollections of interactions with health service providers. I wanted to understand the ways informal end-of-life care is shaped by meanings drawn from interactions with health professionals. I was also curious to explore the possibility that an experience of providing end-of-life care would shape the meanings caregivers attached to the health care system and, beyond that, to the welfare state.

In initial interviews, after outlining the study and my position as student/researcher, I asked participants to 'tell the story' of caring for the person who had died. Prompt questions focused on times when the participant found him or herself doing more for the other person and on moments of strain and reward or ease in caring. Second interviews clarified respondents' earlier comments, and further explored their responses to and assessments of interactions with health professionals.

ELDERLY WOMEN RECEIVING HOME CARE – JANE'S STUDY

Elderly women in need of assistance at home confront an increasingly meagre system of community-based long-term care (Armstrong and Armstrong, 1999). Always a poorly resourced portion of Canada's health and social services, home care is subject to no national standards and is not part of publicly insured health care. It comes under provincial jurisdiction and in many provinces, including Ontario (the site of this research), it has been subject to vigorous cost-containment and rationing. With limited resources and increased demand in the home care sector, priority is given to those in need of care deemed 'medically necessary'. People like those in my study are accorded low priority; their needs for low level supportive care (i.e. personal care and household help) are increasingly squeezed out of the public arena or met with only the most minimal of responses (Aronson and Neysmith, 2001).

Needing help at home with activities generally taken-for-granted is not easy in a culture that prizes able bodies and independence (Tulle-Winton, 1999).

For elderly people, it can signal the slippage of dearly held reputations for self-sufficiency. It means that an external gaze is directed to areas of life generally deemed personal and private: homes and the most self-defining and intimate areas within them, and bodies. The entry of home care into these social and physical spaces holds the contradictory promise of both enabling people to live at home and imperilling their senses of competence and of self (Twigg, 2000). For home care recipients, the challenge in these complex circumstances is to sustain a sense of control and continuity. By impressing themselves and their particularities on their encounters with home care personnel, they endeavour to stay in charge of their territories and themselves. These endeavours are, of course, made more daunting when increasingly care is rationed and depersonalized as a result of the time constraints and regulations that its providers are pressed to observe (Aronson, 2002).

To explore how elderly people accommodate themselves to needing and receiving care at home under these conditions, I undertook a longitudinal study of elderly women. I was interested in understanding how they navigated and made sense of both changes in their own health and social circumstances and changes in the home care environment that surrounded them. Often, elderly service users are pictured in quite static terms, as if their situations and needs are fixed and unchanging and as if they are passive beings. The opposite tends to be true. Health conditions and practical impairments change and develop over time and biographies and identities unfold lifelong. I was also eager to understand how the unfolding personal circumstances of these service users intersected with wider social forces, especially with shifts and retreats in public service provision.

Accordingly, I interviewed study participants every six to eight months over three years. In initial interviews, I explained the purpose of the research and my own interest in it, and asked broadly how they came to need assistance at home, how it was organized and actually delivered and how they felt about it. In successive interviews, participants updated me on these broad dimensions of their situations and, as greater rapport was established, I invited them to elaborate on the daily details of their lives and on how they saw their present situations in the context of their lifetimes and their expectations, worries or aspirations about the future.

Results: exposing failures, unsettling accommodations

The people in both our studies live in relation to discourses that prize certain forms of their experience: certain kinds of dying (and, thus, certain ways of caring for someone dying), and certain kinds of ageing. The 'good death/ good caregiver' and 'active ageing' discourses also set minimum standards; falling below these standards marks failure. In Chris's study, failures of intimacy and commitment emerged. In Jane's work, respondents' talk revealed failures as social beings and as worthy, independent citizens. Jane's interviews also

exposed research participants' failures in a more material sense, as she became witness to respondents' difficulties in managing daily affairs.

In each of the areas of experience our studies explore, accommodations are vitally important. For the people taking part in Chris's research blunders or omissions in caring cannot be redressed. With increasing frailty and shrinking care services, the women in Jane's study have few opportunities to organize home care around their own routines and preferences. The people we spoke with have accommodated, both materially and emotionally, their losses. In interviews, accommodation strategies varied: participants in Chris's study employed 'consoling refrains' ('she didn't suffer'/'everything possible was done'); the women in Jane's study committed themselves to 'making do' and refraining from complaint.

In this section, we consider how our interviews, unfolding in particular discursive and policy contexts, expose research participants' failures; we also explore ways interviews may unsettle or provoke questions about the accommodations participants have made to the change and loss in their lives.

RELATIVES AND FRIENDS PROVIDING END-OF-LIFE CARE – CHRIS'S STUDY

Failures of intimacy Over the course of interviews and analysis, I came to understand that many of the people I interviewed perceived themselves as having been chosen by the dying person to accompany her. Closeness to the dying person was often set forth as both a requirement and a reward for informal end-of-life caregiving. Yet in some instances, relatives or friends suggested that they had been excluded from, or barred access to, certain aspects of the dying person's life or care. 'It wasn't possible for her to sit and talk with me . . . in fact she would do everything to avoid that happening,' said Ms N. 'It was very clear to me that while she couldn't talk to me or couldn't talk to R or would keep us very firmly at a distance she would talk to [the nurse] (Ms C).'

Early in our interview Ms N described a decision to give her sister a manicure and pedicure. 'I kept putting [the nailpolish] on, never properly, but it was something that we could do and it felt nice to be able to do those kinds of things.' She told me that she kept the nailpolish after her sister died and, though painting her nails was not generally a part of her life, used the bottle until it was finished.

Over the course of the interview Ms N's unhappiness about her relationship with her sister unfolded. She recounted several instances in which her sister sent her on futile errands and foreclosed possibilities for meaningful conversation. In the context of this talk, she commented again – in quite a different way – on her attention to her sister's nails:

She wanted me there in the background, it gave her security for me to be around but she wanted me not to come too close. I never thought, I never verbalized it that clearly. She wanted me to be there standing at the back of the room, sitting at the back of the room, painting her toenails – that's what she wanted me to do

but she didn't want me to ask her anything or even for there to be a space where she'd feel that she should say 'I realise I only have a few hours left'.

Initially, painting her sister's nails is a symbol of their connection; the nailpolish is something she carries forth after her death, a reminder of the kindness she was able to offer and of a moment of intimacy between them. Here, it is something quite different: a symbol of the distance between them and, as well, of her peripheral status. This assessment of their relationship, and particularly of the care she offered, is something she has 'never thought . . . never verbalized . . . that clearly'. It emerges in the context of the interview, and in relation to a discourse of 'the good death'.

A few of the people I spoke with explicitly invoked cultural images and fantasies about care for people who are dying, contrasting them with their own experiences:

Ms C: . . . just so different than what you might imagine it being, you know, like I think about what it would be like if I were going with S or you know, some of the other women in my life.

I: How, what's your . . .

Ms C: Well it was just, it was . . . I just, I guess I just wanted her to feel she could open up more to me. I mean we would spend three hours in the car together. And . . . wouldn't very often talk about/well, never talked about how she was feeling and her fears or whatever.

Or, as Ms N said, 'The best I can tell you is the time was hell, it was nothing like I imagined. It was not a romantic time together.'

Instances like this brought a central challenge of my research into focus: how would I position myself, in relation to dominant discourses about kinship, caring and dying? Gaining a greater understanding of the operation of cultural images and prescriptions in people's caring experience was, of course, an important outcome of my study. Yet in the course of interviews, as the good death discourse exposed research participants' failures, what should I say?

The woman I quote above who spoke wistfully about the distinction between her own experience and 'what you might imagine it being', did recount one incident in which the ill woman, in a private and particularly vulnerable moment, had said to her that she thought she was going to die.

Ms C: And you know, she had never said that I don't think to anybody before. But she, you know, she really knew this was really bad.

I: Probably said it in her head a million times.

Ms C: And probably told [her sister] too

I: Or maybe not.

Ms C: Maybe not.

This encounter prompted an unhappy entry in my research diary:

Why did I do this? What is this 'Or maybe not'? I seem to be trying to shore her up. Like I want to make it special for her, make her special, confirm that she's

unusual in being able to hear and respond to this kind of thing. It's like the whole interview is a string of failures of closeness and connection and so I take up this good death/good caregiver discourse, to tell her she was OK, she got it right, she was chosen. Plus I'm so grateful she's shoring up my precarious identity as researcher, I want to give her a valued identity back (or what I think is a valued identity). So I take up the discourses that created her failures in the first place, discourses that say we must have (the chosen ones have) death talk, disclosures, intimacy with the dying person. Don't do this again.

With the woman who described caring as 'not a romantic experience' (Ms N), I adopted a different relation to the dominant discourse, as I discuss in the later section entitled Implications for interview practice: avoiding, mitigating and repairing disruptions.

Failures of commitment My research participants' decisions to seek or expand their allocations of formal services was an important component of my research, something I wanted to ask each person about. In response to a question in this area, Ms B recounted her conversation with a staff member from her local Community Care Access Centre (the provincial government agency that assesses service eligibility and oversees its provision) about her mother's worsening condition:

We'd talked . . . about what she's going to need in the future. That, you know, my dad can't lift her anymore and we're not always there . . . like I can't go there every night, I can be there on weekends because my kids are home but . . .

A man spoke in similar ways about his wife:

I remember when she first had the bone problems, and again when we first had to get somebody, because I couldn't do it, and I couldn't lift her. (Mr M)

In both these interview excerpts, talk about services to meet the increasing physical needs of the ill person is inextricable from talk about the carer's own resources and capacities. The quotes capture, then, something my research set out to examine: how broad social and political realities unfold in the lives of informal carers. Yet in the immediate interview situation, reports about seeking services often sounded like confessions of failure. Research by Seale (1995) has revealed the cultural significance – indeed, the moral imperative – of accompanying terminally ill people to their deaths. In conditions of health system constraint, accompaniment of someone who is dying increasingly necessitates the adoption of nursing roles (Sinding, submitted). In interviews, then, when relatives and friends of dying people discussed their attempts to substitute health professional care for their own, their commitment to the ill person sometimes came into question. One man I interviewed emailed me afterwards about his decision to pursue nursing services from the CCAC. 'I know that [my wife] felt I was forsaking her,' Mr M wrote. From my researcher's perspective, this is gold: 'forsaking' is such a resonant word, linked as it is into marriage vows, situated in painful opposition to a discourse

of enduring love and commitment 'until death'. And, for exactly the same reasons, these words stand as a kind of danger to the man who spoke them.

SHE DIDN'T SUFFER –?

As I moved through my study I started to hear in respondents' accounts echoes of phrases commonly offered on the occasion of a death, by and to bereaved family members and friends: 'she didn't suffer', 'they did everything they could', 'it was for the best', 'what will be, will be', 'it was how she would have wanted it'. I labelled the phrases 'consoling refrains'.

In interviews, I felt stumped by consoling refrains, unsure about how to proceed. As Wilkinson and Kitzinger (2000) point out, formulaic expressions are used in talk in myriad ways. Particularly in relation to a death, idioms may wrap up what has been said and move the conversation on to less painful topics (Holt, 1993, cited in Wilkinson and Kitzinger, 2000). Idioms, as well, are 'particularly resistant to question or contradiction . . . in conversation, they are likely to attract agreement and endorsement' (Wilkinson and Kitzinger, 2000: 803). I could feel these conventions operating in interviews; I felt that pursuing painful topics was, at some level, disrespecting a boundary that research participants had set. As well, the more people I interviewed the more I came to think that consoling refrains played an important role in containing regrets – containing both sorrow and responsibility around a death, and functioning to narrow the distance between the 'good death' and the death research participants witnessed. I wondered about what would happen to the consoling refrain resource, as I pursued knowledge about sorrow and responsibility, and 'bad' deaths.

One woman I interviewed, speculating about what it might have been like had her mother lived longer and services provided by the Community Care Access Centre continued to prove unpredictable or inadequate, said:

Luckily for my mom, she . . . did die and she didn't have to . . . we were never in that place where we were waiting for someone that was promised, that we really felt we needed . . . I'm glad in a way my mom didn't have to suffer any more than she did, like that was . . . I think that we sort of got off easy in that sense, you know. (Ms B)

Another respondent noted that her partner was in pain before she died, 'but certainly not like my mother' (Ms L). After these interactions, I wrote in my journal (May 2001):

Do 'consoling refrains' become untenable – or at least get stretched – by these interviews? After one has spent half an hour describing suffering, surely it becomes less possible to say, 'she didn't suffer' –? Am I part of making 'bad deaths'?

I had coined the term 'consoling refrain' to describe what I thought research participants were doing with their talk. I eventually realised that the phrase spoke to my own worries: that my interviews could interrupt, and

perhaps rewrite, an important and comforting chorus in participants' stories about the death.

EVERYTHING POSSIBLE WAS DONE –?

A study participant recounted this conversation with his wife:

Mr F: And I said . . . '[the oncologist has] done his best for you, he's done everything he can.' . . . She was mad. She felt that he had let her down. I don't think he let her down. I think, again . . . She herself said many times throughout the three years, it's a crapshoot. And . . . what will be will be. But on the other hand I can see where she sort of felt . . . why her?

I: Is that your sense as well, I mean is that . . . [sighs] your feeling, that it was a crapshoot?

Mr F: Um . . . to an extent. I had, and maybe I still have/I don't like to think that I'm harbouring resentment but . . . You know, you always hold out hope that a miracle's going to come. [Cries]

In my question here, I had been trying to encourage Mr F to focus on his own experience, to shift us away from his perceptions of what his wife felt or thought. I had not in my own mind questioned his conviction that the physician had delivered the best possible care for his wife. After this passage, however, Mr F went on to describe interactions with the physician in which he had been given reason to believe his wife would qualify for a particular clinical trial, yet it was never offered to her.

In this interaction, my disruption of consoling refrains about the uncontrollable nature of life, death and illness ('it's a crapshoot . . . what will be will be') exposed the virtually unspeakable possibility that fate was not the only force operating, that the physician involved did in fact let his wife down. A significant consoling refrain about the (untimely) loss of someone's life – that 'everything possible was done' – was also unsettled in this moment. Many aspects of vulnerability can be seen to emerge here. Mr F encounters (again? for the hundredth time? for the first time, in talk?) the possibility that his wife need not have died when she did. He also encounters himself as a person he does not want to be – someone who 'harbours resentments'. As in Jane's interviews where a fraying of stoicism is also a fraying of respectability (see below), the repetition of consoling refrains may reflect the respectability conferred in a culture that values acceptance of loss and sets quite rigid limits around normal mourning (Foote and Frank, 1999).

This interaction can also be understood in the context of health system conditions that render informal carers responsible for securing care for ill people from health professionals. Subsequent to the comments above, Mr F went on to tell me that it was he who had initiated discussion about the clinical trial with the oncologist after reading about it in a newspaper. Once the oncologist had confirmed its significance and its relevance to his wife's case, he had gathered more information about the trial. As if to assure me that he did his part, Mr F noted: 'Several times through the course of the next couple of months I

brought up the subject.' My question surfaced the possibility that the oncologist had not, in fact, done everything possible; it may also have spoken to the respondent's doubts and regrets about his own actions. In the current policy context, my question became a challenge not only to the oncologist, but also to the respondent himself.

ELDERLY WOMEN RECEIVING HOME CARE – JANE'S STUDY

Failure to manage daily affairs Receipt of home care is, in itself, a form of exposure, an official signal that the recipient is not ageing 'successfully' – that she has failed in self-sufficiency and independence, failed in the performance of what are regarded as normal daily activities of managing a home and a body. Home care also represents a public intrusion into the private space of the home and, within that space, into areas usually deemed especially intimate or private (the bathroom, bedroom). Women's efforts to accommodate themselves to home care were often centrally concerned with minimizing or putting limits on this intrusion. My entrance as a researcher represented yet another intrusion. As well as being exposed in talk, then, the women I spoke with were exposed by virtue of my presence in their homes.

Especially in first interviews, participants commonly apologized for the 'untidiness' of their homes or their 'unkempt' appearances. 'Look at this place; I'm ashamed of it, it's not me you know,' said Mrs D. 'Don't look round too closely . . . it's a mess,' said Mrs F. Several of the women I spoke with commented on their appearance: 'I wish I could get my hair done properly. I've stopped having it permed, it's just too hard. I hate it like this. But you just have to let yourself go' (Mrs L).

Heilbrun (1998: 54) notes that for women growing older, letting themselves go suggests the end of femininity and, thus, of personhood. Interested in knowing more about what 'letting yourself go' with respect to clothing signified, I trailed the expression in the next interview with this woman:

I: You said something last time about having to let things . . . yourself . . . go. It sounded hard . . .?

Mrs L: Yes, it was at first.

I took Mrs L's rather clipped tone and the use of the past tense to mean that 'it' – both the difficulty of letting herself go, and our conversation about it – was 'over', not to be reopened. I pursued it no further.

Needing help with bathing ('personal care') is, perhaps, the most difficult intrusion, an exposure both of body and of the need for help with things usually taken-for-granted in daily adult life (Twigg, 2000). I approached the area almost never in first interviews, feeling tentative, prying. Participants answered briefly and tended not to offer elaboration:

I: Do you need her (home care worker's) help in the shower or . . .?

Mrs E: Just a bit . . . getting in and out really. It's embarrassing but I need it so that's all there is to it.

I took the clipped tone and her words as boundary making, a signal not to follow up.

Like their home care workers, I became an audience for what these women deemed insufficiencies and failures. Their embarrassment was occasioned by my presence, and by the exposure of the disparity between their daily lives and cultural images of femininity and successful ageing; they judged themselves harshly for not 'measuring up' (Bartky, 1990: 87). In many instances I felt an intentional moving me on to easier things, a deliberate shielding of their 'selves' from my observation.

Failures as social beings and worthy citizens Some of the women I spoke with described the ways their social ties had shrunk over time. Their isolation was heightened when they felt unable to invite people into their homes because of untidiness or unkemptness, or because they had nothing to offer by way of refreshment. One participant, who hired a support worker to stay with her in the evenings, said:

Mrs B: Since you last came, I'm paying not to be alone . . .

I: And is that . . . is it just her presence or are there practical things in the evening . . .

Mrs B: Her presence and some practical things, maybe a little laundry. We watch TV together, that's my evening activity . . .

These words were spoken slowly and on the edge of tears. Mrs B had been an avid reader and described a wide circle of friends and professional ties in her past. Elsewhere I have detailed the multiple forms of social isolation engendered by shifts in home care policy in recent years (Aronson and Neysmith, 2001). Yet my questions and presence in Mrs B's life highlight for her, not the punishing political surround, but her personal failure as a social being. Hey (1999: 107) notes that ending interview contact 'may well mean consigning elderly people back to a heightened awareness of social isolation'. It may also be the case that the interview interaction itself draws forward an especially textured awareness of social isolation – particularly interviews like the ones I did, which sometimes spanned both the immediate situation and respondents' earlier lives. The contrast between abundant social pleasures in this woman's past, and her current social circumstances, was apparent not only to me.

Over the three years of the study, many participants' entitlements to public care were reduced, often with brutal clarity about the excess of their demands in relation to the public purse. As I explored feelings around service reductions, one woman said, 'I was humiliated' (Miss M). My presence and questions, then, also entailed participants' reporting and reliving their failures as worthy citizens.

A worried research diary entry after the second interview with Miss M:

Our conversation prompts out loud stocktaking about her situation and how she's faring. I know she has a choice about what to confide or tell me, but I fear that my presence and demands exact a response that she may regret. My

questions lift her 'failures' into words. Am reminded of ironies in Finch's piece on interviewing. That I do the interviews well (connect responsively, let them know I remember earlier stories and details) engages and extracts very 'efficiently'. And there's a responsibility then for me. I can't translate that into 'taking care of' (except by a card after the interview etc.) but must translate it into using their insights/revelations well . . .

MAKING DO –?

The cultural call to age actively requires self-sufficiency and, failing that, containment of complaint, vulnerability or suffering (Katz, 2000; Tulle-Winton, 1999). Acceptance of declining health, reduced circumstances and inadequate supports was a central theme in the interviews I conducted, echoing findings of other research: 'raging against its realities (loss of function in old age) was seen as a route to pain and unhappiness, and the dominant approach was one of acceptance and of taking each day as it came' (Twig, 2000: 48).

In early interviews, most of the women I spoke with expressed stoicism about their situations: 'You have to make do, just accept it' (Miss S). In second and third interviews, though, participants more frequently described occasions when their need, frustration and vulnerability seeped out and was voiced to case managers who determined their eligibility for service: 'I asked her why I couldn't shower as often as she could . . .' (angrily); 'I said what about the laundry etc. . . . I can't do it myself . . .' (distress, pleading) (Mrs H). And at times, again in later interviews, they reflected out loud to me: 'I thought well, how am I supposed to manage now?' (Mrs A). 'I was so upset. And I'm afraid, think I'll have to go to some sort of sheltered place' (Miss M).

In examining changes in the nature of participants' talk over time, I came to realise that the longitudinal nature of my study combined with broader policy changes to present a particular kind of ethical dilemma. In the interviews I became audience for participants' chronicling of their ups and downs over time. Ruptures and breakdowns in stoicism became apparent, then, as they 'accounted' to me over the course of successive interviews. As assistance shrank and infirmities mounted, I witnessed the unsettling of participants' commitments and abilities to 'make do'.

Most participants spoke, at least at times, of their efforts to take charge of their situations, to establish some control over their circumstances at home. One woman, Mrs N, shored up her sense of self and continued activities that she enjoyed and that defined her, with a complex arrangement of publicly and privately paid helpers. 'My family call me the supervisor!' she reported proudly. When I asked at the end of our second interview if it was alright for me to call back in a few months she said yes, but added 'you do realise, though, that I'm living on the edge'. She then described exactly how precariously she knew her life at home was balanced. Another woman, Mrs J, spent much of our interview recounting her often thwarted efforts to 'teach' her home care workers to do things as she liked, to find a better cleaner, to get her wheelchair

fixed. 'I feel sorry for those timid old souls who haven't a hope,' she said. And yet later, she confided: 'But, you know, you're not really in control with home care. They run your life' (Mrs J). Again, the control women claimed over their circumstances tended to shift and diminish in later encounters. As erosions of control became more apparent to me, I worried that they also took on a clarity for study respondents that they might not have, had the women not participated in my research.

For some women, a facet of their acceptance was the belief that the government was doing what it could for them. They referred to strains in the system, and noted that case managers' budget shortfalls required everyone to manage with less. Mrs R, a participant who often asserted this contacted me before our third interview to let me know that her case manager had visited and had allotted her more homemaking hours: 'It's important for your study to hear this. The government's more liberal now, they know what they're doing.' Later, her hours were reduced to their former levels and she returned to stoically making do:

I liked it when I could get out for a bit of a walk with her, it made a big difference. But, now, if I want that I'll have to give up something else . . . and I can't really. I've never been a taker, you know, but I miss it. (Mrs R)

Another participant had to reconcile a similar disruption. At our first meeting, she explained that her case manager had assured her 'that they'll do whatever's needed to keep me here'. After a round of province-wide cuts and new rationing regulations, she observed: 'there's nothing for me to count on. I'm on my own with this, I know that now' (Mrs K).

In each of these instances, I considered asking more about how these events affected the woman's sense of her future at home. Aware that the security of home care services had been undermined in a very material way, though, I was reluctant to pursue – and perhaps heighten – personal or emotional responses to the retraction of care. I was concerned that further questions might emphasize the ways home care had failed to match the women's expectations. The confidence each had felt and expressed in the services had clearly mattered; I worried that my presence and probing might encourage them to further name and experience uncertainty about home care, and thus about their capacities to manage at home.

MUSTN'T COMPLAIN –?

At our fifth interview, Mrs A, a woman long-committed to stoicism who had gradually condensed her daily life to accommodate her diminishing strength and the limits to her daughter's ability to help her, explained that her already curtailed home care was to be cut back further:

Mrs A: I was so upset when she (case manager) told me. I just couldn't see how I could go on here . . .

I: It sounds very hard...

Mrs A: Yes, well, I'm not one to complain. You know that. I never have been, I've always told you that. And I wouldn't now but it just seems so unfair . . .

Another particularly stoic woman, Mrs V, bolstered her own acceptance of her diminishment and reduced assistance with harsh evaluations of older people who 'expect everything' and 'think the world owes them'. In one of our later interviews, she spoke sadly of the mounting struggle of everyday life and of 'giving up' and moving to a nursing home. She noted that those around her, including her doctor, kept reminding her how good she was for her age: 'So you can't complain. I shouldn't really complain, should I . . . (pause) . . . should I?' Her question surfaced an important dilemma of my role as an interviewer in this study. Most of the women I spoke with valued stoicism in themselves and others, and disparaged 'complainers'. This woman in particular had fashioned an identity out of non-complaint. While on the one hand her venturing into less 'accommodating' territory was part of what I wanted from the interview, I also worried about its implications for her sense of self. My questions not only exposed a failure in stoicism (she spoke of herself as someone distressed by her losses) but also disrupted the respectability of her non-complaining posture. What was I to say in response to her unsettled and insistent questioning?

As I began my second round of interviews, I was conscious of wanting to delve further behind the common utterance 'I mustn't complain'. I wanted to find out more about what the respectable resolve not to complain obscured. Following is an excerpt from one interview:

Mrs J: I don't complain (about my situation, the discomfort), I don't tell people how I'm feeling, they don't want to hear. Be cheerful . . . you know . . .'

I: So if I said to you that for me to understand what it's like for you day to day . . . the things that concern you . . . if I said I'm inviting you to complain . . . what would you say?

Mrs J: Where to start (laugh). I don't know that's an exercise I haven't . . .

I: Maybe it's a road you don't want to go up . . .?

[. . . she then described depression, loneliness, not telling, pretending . . . fear . . .]

Mrs J: You're the first one I've ever mentioned it . . . I don't usually bring it up . . . think about it too much . . . because what's the point?

I: And I hope you don't mind me asking you directly, it's just . . .

Mrs J: Well . . . It's OK, you've got to learn. Next question! (Laughs)

My saying, 'maybe it's a road you don't want to go up' is a form of process consenting (Munhall, 1989, cited in Hutchinson and Wilson, 1994), an assessment in the moment of the respondent's willingness to go further into difficult territory – and, perhaps more accurately, an offer of a way out if she wishes not to. Particularly in later interviews, with greater rapport established, some participants expressed strong feelings about their situations: humiliation, fear, shame, depression and anger. While this was 'good data' I was sometimes troubled that I had elicited difficult and seldom acknowledged

or shared feelings and stories and then left just rawness behind. No one ever asked me not to come back, arguably an indicator that the interview encounters were not that painful or damaging. However, like Finch (1984) and Hey (1999), I knew that some participants were very isolated and that our meetings represented welcome social contact. I also imagined that, despite the proclamations on the ethics forms that participants could withdraw at any time and despite my careful checking that they wanted to proceed, asking to discontinue might have seemed impolite or unhelpful; asking to discontinue, then, would require yet another kind of challenge to a valued, and precarious, identity.

Implications for interview practice: avoiding, mitigating and repairing disruptions

In the analysis above we explore how vulnerability may be produced in qualitative research interviews by the confluence of interview factors with broader public discourses and social policies framing research participants' stories. In this section, drawing upon the work of researchers who attend to qualitative research ethics, we offer a summary of what we do (and wish we had done, and have considered doing) to handle our power of disruption wittingly and responsibly.

At the most general level, we strive to employ interview strategies that enable participants to control the degree of exposure or disruption they will tolerate, and to maintain valued narratives about themselves. In keeping with Munhall's (1989) notion of process consenting we preface questions tentatively and offer ready exits in an effort to open choices for participants in each moment of interview. For instance, when fear or anxiety about 'giving up' came to the surface for Jane's participants and the spectre of need outstripping resources loomed large, Jane phrased questions about the future very tentatively: 'I'll call again in a few months, probably _____. Is there anything particular on the horizon for you between now and then . . . or on your mind . . .?' Sometimes, that prompted quite concrete and relatively mundane statements like 'I have an appointment for my new glasses' (Mrs N). At other times or with other women, it evoked something much larger: 'I just hope I'm still here' (Mrs C). In terms of interview practice, the aim is to explore participants' relationships to an increasingly precarious future while ensuring that mundane responses to the question remain possible. When participants speak about experiences directly relevant to the research question in ways that carry some threat to identity, Jane adopts a 'trailing' approach, offering their own words back to them provisionally, speculatively, as when she said to Mrs L, 'You said something last time about having to let things . . . yourself . . . go. It sounded hard . . .?' Here Jane is essentially asking Mrs L to take up her words again, while allowing ample room for her not to.

In some instances, we handle our power of disruption through retreat:

encountering words or gestures that seem to set boundaries around topics, experiences or feelings, we abandon lines of investigation. Our practice of retreat counters the ethical guidance offered by Rubin and Rubin (1995), who suggest that because certain research participants (they offer the example of AIDS patients) 'know that what they are doing will be painful for them, but still want to do it, an interviewer could ethically press them for information' (p. 98). Part of the point of this article is to suggest that interview participants do not entirely know what they are doing – and neither do interviewers. Neither of us can fully anticipate how a question we ask, or a story they begin, will link with a discursive or policy context to expose a 'failure' or unsettle a strategy of accommodation. It behoves us as researchers, though, to work towards mapping this particular ethical terrain prior to engaging in interviews, as we discuss below.

This is not to say, of course, that we never tried to move past a perceived boundary, or that we entirely failed to pursue participants' accounts of distress. The distinction we draw in our research practice is between interactions which seem to contain 'don't go there' messages, and those which are accounts of suffering without 'don't go there' content – a distinction that may not be apparent in written reports, but which we strive to become more attuned to in the interview itself. As well, the choice to retreat from a line of questioning is not without its own analytic reward. One of Chris's interests, for instance, is in understanding high reported levels of satisfaction with palliative care services. The 'don't go there' messages she interpreted in some respondents' words, their comments that indicated an incident had been pushed away or deliberately forgotten, led to an analysis of how reports of satisfaction are shaped in part by the unbearability of memories of the ill person's suffering (Sinding, in press). It is also well worth noting that what we interpret as boundary-setting gestures, or evasions or diversions, can be appreciated as resistance to the researcher's power to define the terms of the interaction (Hey, 1999).

Insofar as research interviews can be understood to 'expose failures' and 'unsettle accommodations', they can be seen to threaten study participants' identities. After interviews with participants, then, we often make a point of affirming valued identities. A participant in Jane's study, Mrs R, spoke with warmth about her grown grandchildren. With difficulty, she still cooked for them – cooking being, as she said, her 'last claim to fame'. When Jane arrived for their fourth interview Mrs R was preparing a meal for her granddaughter's birthday. In a thank-you note after the interview, Jane wrote:

You speak with such resilience and clarity about what it's like to navigate growing older and the challenges of uncertain health (especially your uncertain eyesight) and add much to my research – thank you. I hope the roast chicken was a success? It looked wonderful and was such a lovely gift to be giving!

Mrs N, who had been a physiotherapist in her working life, told Jane at their

second meeting about seeing a man in her local mall whose cane was the wrong height, and fixing it for him. In a card, Jane wrote:

I found myself relishing your story about helping the man with the too long/too short cane whom you approached while shopping – thanks for that. Once a physio, always a physio perhaps!?

It may be that identity-affirming words and gestures are especially salient in longitudinal studies. As noted earlier, Jane's study design meant that she witnessed change – most often decline – in elderly women's material circumstances and physical health, and in their capacities to 'make do'. In later interviews, then, research participants had less freedom to create representations of themselves they might have wished to create; the shared knowledge of decline served to bound their narratives. Interviews may well have become, then, more of a threat to identity over time (rather than less, as is generally assumed). Hey notes that in her research 'conversations about the past were seen by some elderly people as a rare opportunity to reclaim "the self"' (p. 102). Offered accounts of past and valued selves in her own study, Jane made a point of reflecting those selves back to research participants – confirming, especially in later interviews, that she saw a fuller self than the one women currently had to present.

Affirming valued selves is not without its own complexities, however. The valued identities most available for affirmation in any particular study are in many cases embedded in the very discourses and policy contexts implicated in participants' marginalization or suffering. In the case of the man who expressed such anguish over 'forsaking' his ill wife when he pursued nursing services for her, Chris might have responded to him with some reflection about how moved she was by the steadfast way he stood by his wife, how consistently he acted as both care provider and advocate even when nurses were providing much of the hands-on labour. The statement would be, essentially, 'I saw you caring well'. Yet such commentary – while affirming a valued identity, and potentially experienced as supportive – reinforces the imperative (generated in part by the retreat of state-funded services and in a moral discourse about 'the good caregiver' and 'the good death') that family members take up nursing care for ill relatives and friends. There may be a distinction to be drawn, then, between affirming participants' valued identities and countering marginalized or socially devalued identities. As the latter are hooked more directly into the cultural discourses at play in the interviews, their affirmation is more problematic. Thus, in the examples from Jane's work above, her strategy is to say, essentially, 'I see the ways you are still you,' rather than to say, 'I see you ageing well.'

Feminist participatory research approaches (see, for example, Lather, 1991; Maguire, 1987) describe interviews as a reciprocal dialogue, a kind of mutual consciousness raising. This framework offers us another means to repair disruptions that emerge in our interviews: when 'failures' are exposed,

we might offer critique of the institutional contexts and discourses that give rise to those failures. A feminist analysis of the institution of marriage is, clearly, unwarranted by the situation Chris describes above. Reflecting back to this participant some of his own words about the organization of home care services might, however, have eased some of the disruption that the image of 'forsaking' carried. Chris might have noted, for instance, that the system of home care did not make the transition to professional care easy; if nurses had been more consistently present, and more caring, their hands moving in where his had been may not have meant 'forsaking' at all. Along these lines, with the woman who described caring as 'not a romantic experience', Chris adopted a different relationship to the dominant discourse of dying and caring than she had in previous interactions. Ms N's words were evidence of failure, perhaps both on the part of the respondent and the dying woman. Caring was not 'romantic'; it was not intimate, it was not otherworldly. It was difficult, tense, crazy-making; it failed to transcend daily life. In one section of talk, she spoke of the ill woman as demanding, the children resentful, a brother giving the nurses a hard time. Instead of trying to highlight the few moments of closeness Ms N did share with her sister, Chris said, 'It's so much more complicated and messier than it gets set out to be.' While she wasn't particularly conscious of it in the moment, Chris was pointing to the ways people's experiences of caring for someone who is dying quite often diverge from popular images. As Foote and Frank (1999) suggest, drawing attention to a dominant discourse may be a way of easing some of the vulnerability that is produced when personal situations of loss are set against cultural prescriptions.

In working to shift the balance of power between researchers and 'the researched', feminist scholars have also transformed the status of the stories research participants tell. Framing participants' stories as socially important (and, in some cases, hidden) knowledge carries multiple virtues in relation to the configurations of vulnerability we describe in this article. Hey (1999: 107) expresses concern that loneliness may propel elderly people 'to disclose information in order to retain the company of the researcher. Subsequently, they may regret engaging in too much personal talk.' On occasions when Jane's study participants described particularly painful aspects of their lives they would often go on to express doubt about the relevance of their words. In these situations Jane made a point of positioning their words as important context for her work, citing her need to know about people's wider life stories in order to understand the present. This was true from Jane's perspective, of course, but for the research participants it also lent a purpose to their revelations, serving to lift their talk out of the realm of ill-considered disclosures. Similarly, when participants 'complained' – exposing their failures of stoicism – Jane framed their talk as both helpful and relevant. In a card to the participant (Mrs J) whom Jane invited to complain and then worried she had left raw or unsettled when the woman did, Jane wrote:

Thank you again for continuing to tell me about your health, home care and how you're feeling. What you sometimes refer to as 'moaning and groaning' that you think I won't want to hear gives me insight into the detailed, everyday challenges of living at home and relying on others' assistance. That's exactly what my project aims to record and understand better so your thoughtful reflections are enormously helpful and I appreciate your generosity in sharing them.

In a similar vein, after Ms N had exposed her 'failures' as a caregiver, Chris wrote:

The piece you wrote paints such a splendid picture of S. I love the image of her in her cowboy boots, with the gown around her – that swaggering, and that vulnerability, all in one. I especially appreciate your willingness to speak the story underneath the story – to describe, as you so eloquently do, the ways things actually unfolded, with all the human tensions and disappointments intact.

With these kinds of words, we confirm that the 'failures' participants expose lend insight into important social processes, insight that would not be available unless they had spoken in the ways they did. We do this not only because it is true and polite, but also because it provides a context that may buffer the 'felt' failure that can emerge in research interviews.

We must also, however, try to ensure that our responses to what we perceive as potentially unsettling interactions do not obscure or pathologize participants' suffering. Foote and Frank (1999) note that therapists (and, we suggest, interviewers) are implicated in policing boundaries between 'normal' and 'abnormal'. In gesturing to repair the disruption that the term 'forsaking' carried, for instance, Chris might well have found herself shoring up the boundary between normal and abnormal grieving, between what is pathologized as 'complicated grief' and the 'irresolutions, unfinished business . . . regrets' – including, in some cases, the regret of having been unable to care, in all the ways one might have wished, for a loved one – that are normal complications of dying and bereavement (Foote and Frank, 1999: 170). Rather than working to repair the 'failures' the word forsaking carried, Chris might have said something like 'there are always regrets, aren't there?' and perhaps – in an invitation to comment on the social rules that insist grief be hidden – 'we don't seem to talk much about the regrets, do we?'

As is clear from this discussion, many possible avenues exist for avoiding or mitigating the particular conditions of vulnerability we highlight in this article. If we were to offer one key encouragement to other researchers, it would be to consider how the discursive and policy context of research participants' stories may play out in interactions with them. Researchers might ask, 'in this context, what are the norms or standards of conduct? What kinds of experiences are valued? How might my interviews expose disparities between an individual's experience and valued or dominant images? What personal strategies of accommodation might these discourses or these social policies engender? How might my interviews unsettle the accommodations individuals have made?' And, critically, 'what will I do, when accommodations are unsettled and failures exposed?'

Conclusion

Among the many things research respondents do during interviews like ours (as we all do, in various settings) is create liveable stories – stories about loss that can be ‘lived with’. In creating liveable stories the people who took part in our studies reached for powerful discursive resources. The stoicism expressed by participants in Jane’s research, and the consoling refrains threaded through Chris’s respondents’ accounts, can both be understood as ways research participants created liveable stories. Accommodations are, in this sense, important social and psychological resources for individuals facing loss. At a collective level, however, accommodations of this nature may leave situations of suffering or diminishment unheard and unchallenged.

As feminist researchers we have an interest in unsettling collective social and political accommodations – in unsettling, that is, the unseen structural and discursive conditions that inhibit movement towards things being different. We want to disrupt the collective ‘making do’ with fewer and less responsive services; we want to challenge the notion that health professionals ‘doing their best’ in a context of health system constraint constitutes adequate care. Our work is also directed towards exposing failures – exposing the disparities between people’s experiences and the cultural prescriptions and images related to those experiences. We want to make visible the ways that ‘real life’ is not always active ageing or a good death.

It is not our intention, of course, to disrupt or challenge or expose individuals. Yet as Denzin (2001) reminds us, ‘words and language have a material presence in the world . . . words have effects on people. Words matter.’ In this article, we explore how the words we speak in research interviews intersect with dominant discourses and political realities to create conditions of vulnerability for research participants. Theoretical discussions about concepts like ‘the good death’ and ‘active ageing’ may sometimes seem remote from the experiences of interview participants. But such analyses can assist us to see what research participants are up against as they tell their stories – how difficult it can be to tell a story of caring for someone dying or a story of receiving home care that does not have elements of failure threaded through it; how important accommodations can be in these situations; how easily accommodations might be unsettled.

In attempting to draw from the analysis presented in this article to offer guidance to others in the field, we want to make quite clear that we are not making the claim that our approaches are the correct or ‘most ethical’ ones. We agree with Kaplan Daniels (1983: 213) that ‘probably the best encouragement to ethical behaviour is the open discussion, as much as one can manage, of one’s day-to-day experiences in the field with one’s colleagues.’ Our hope is that we can manage open and careful attention to our powers of disruption, particularly those occasioned by the policy and discursive frame of research participants’ stories.

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