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Qualitative interviewing with vulnerable populations: ethical considerations when conducting narrative interviews with young people with cancer

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Qualitative Interviewing with Vulnerable Populations: Ethical Considerations When Conducting Narrative Interviews with Young People with Cancer

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Abstract

Young people with cancer are increasingly recognised as a small but uniquely vulnerable patient cohort whose well-being is complicated by the dual crisis of the stressors associated with an unanticipated life-threatening diagnosis and treatment at a critical transitional stage in the life course. Drawing on my experience of undertaking a doctoral study examining how hospital care can promote the well-being of teenagers and young adults with cancer, involving multiple narrative interviews with young participants, this case study reflects on the ethics of conducting research with vulnerable populations on sensitive topics and considers the need to design and carry out qualitative research in a way that not only does 'no harm' but actively seeks to benefit participants. I describe how I actively sought to contribute positively to participant well-being in the study's design and methods while ensuring that the interview experience did not become confused with counselling. The use of participatory research methods including visual diagramming in qualitative narrative interviews is also examined as an ethical method of collecting rich information while offering support at a time of crisis.

Learning Outcomes

By the end of the case study, you should

- have a better understanding of the ethics and practice of designing and conducting narrative interviews with vulnerable participants on sensitive topics
 - be able to examine the dilemmas of achieving informed consent with vulnerable research populations
 - be able to consider the use of participatory and diagrammatic approaches in qualitative interviews
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Introduction

In 2009, I was awarded a Research and Development Fellowship by the Northern Ireland Public Health Agency, and seconded from my social work post with teenagers and young adults with cancer to complete a part-time qualitative doctoral study over 5 years, designed to identify the characteristics of optimal hospital care for this particular patient group. Reflecting on my experience of carrying out narrative interviews with this population, the case study presented considers the ethical responsibilities of researchers conducting qualitative research with vulnerable people, paying particular attention to methods design and implementation. The potential risks and benefits of narrative research with vulnerable populations and the application of participatory and diagrammatic interview approaches are discussed.

The Study

Young people with cancer are increasingly recognised as a uniquely vulnerable patient cohort whose well-being through treatment and into recovery is compromised by the experience of unanticipated life-threatening illness at a critical transitional stage in the life course. The healthcare of this patient population across the United Kingdom is currently fragmented with some young people cared for in paediatric settings or specialist units, while others (aged 14 years and above) are admitted directly to adult provision prompting the National Institute for Clinical Excellence Guidelines for Improving Outcomes in Children and Young People with Cancer in 2005 to identify the need for improved understanding of young people's psychosocial needs and the delivery of age-appropriate care. To address these knowledge gaps, my doctoral study examined the perspectives of teenagers and young adults (16–24 years) admitted directly to adult services, investigating how hospital care could promote their well-being throughout the treatment trajectory. To do so, I adopted a qualitative narrative research design based on interpretive phenomenology with a series of semi-structured interviews carried out with 14 young people with various forms of cancer, exploring identity, illness, relationship and healthcare narratives. Supplementary interviews were carried out with the young people's parents and 15 multidisciplinary professionals across medicine, nursing and allied health and social care professions.

Considering Study Design with Vulnerable Populations

Ethical Responsibilities When Carrying Out Research with Vulnerable People

An increasing body of qualitative research has overt social justice aspirations targeting vulnerable or marginalised populations as a means to ensure that their silenced voices are represented in social policy and service development debates (for more discussion of these developments in social research than can be included in the scope of this case study, see a number of chapters in the *SAGE Handbook of Qualitative Research* edited by Normal Denzin and Yvonna Lincoln, in particular Karen Charmaz's chapter on grounded theory and Susan Chase's chapter on narrative inquiry. Gayle Letherby's exposition of feminist research in theory and practice is also very pertinent as well as Suki Ali and colleagues' chapter on politics, identities and research in *Researching Society and Culture* edited by Clive Seale). While all research participants could to some extent be described as vulnerable given the inherent researcher/researched power imbalance, clearly, some are more vulnerable than others depending on, for example, age, ability/disability, gender, race and personal and social circumstances. Carrying out research targeting such groups presents ethical challenges, demanding particular attention to participant well-being as an essential aspect of the research process. While Research Ethics Committees focus primarily on reducing risk by means of informed consent, confidentiality and child and vulnerable adult protection, Paul Ramcharan and John Cutcliffe in their reflections on ethical approval processes suggest that we need to pay greater attention to the risk–benefit ratio, ensuring that the balance is always tipped in favour of participant benefit. In order to design and conduct ethical research with vulnerable groups, I would suggest that it is essential at outset to understand the challenges encountered by

the particular target population and what has been shown to support coping.

The Challenges Faced by Young People with Cancer

Young people with cancer are clearly a vulnerable research group, and conducting qualitative research on their personal and social experiences of life-threatening illness runs the risk of causing distress. Studying this population at a personal crisis point, I was conscious of the many challenges they face and felt an ethical responsibility not only to answer my research question of how hospital care can promote young people's well-being, but to do so in ways that had the potential to enhance well-being through study participation – or at the very least not increase distress or undermine coping.

Research by authors such as Anne Grinyer and Roberta Woodgate indicates that young people with cancer face many illness-related challenges complicated by normative adolescent developmental processes. The abrupt loss of normal everyday life imposed by diagnosis, leading to formative years spent living with the unpredictability of treatment and an unknown future, and coping with overwhelming and confusing information and experiences beyond their life stage fundamentally unbalance life's stability for young cancer patients. Personal identity and self-esteem are jeopardised as young people fear losing their pre-cancer self to the new cancer patient and must manage an altered appearance and loss of social anonymity. For a period, they lose control of their own destiny, as they are catapulted out of their developing autonomy to a place where participation in everyday life is severely compromised, thrust back into the heart of family life and returning to a form of childhood, where they are in need of practical, physical and psychological assistance. The social and emotional isolation imposed by illness is also known to constrain important relationships with the young person's status between childhood and adulthood complicating communication.

Why Narrative Interviewing?

Illness literature identifies the capacity to make meaning of experience in a way that supports self-agency and the expression of identity as a fundamental prerequisite to successful coping and well-being. Although relationships are seen as the context in which the ill person co-evolves meaning, maintaining relationships in the context of illness is known to be problematic with conversation thought to become mutually guarded and 'body talk' dominates interaction. Illness has been described by therapist Peggy Penn as relationally traumatising when the natural impulse for listeners is to withdraw from conversation, and in sensing their apprehension, the ill person stops talking and isolation is intensified. In Arthur Frank's classic text *The Wounded Storyteller*, focus is placed on the creation of a space for 'voice' and storytelling, where the ill person can break illness-imposed silence and, by talking of their experiences, develop shared meaning, creating narratives of hope and connection. These prerequisites for coping are echoed in Roberta Woodgate's resiliency research specifically with adolescents with cancer, which identifies meaning-making and staying connected as key protective factors.

These ideas led me to decide on a qualitative research design using narrative semi-structured interviews with

young people and parents in order to not only potentially generate rich information about lived experiences but also contribute positively to participant well-being by providing a space for each person's story to be articulated, witnessed and listened to attentively in the context of the research interview.

The Risks and Benefits of Narrative Interviews

Qualitative researchers such as Maxine Birch and Tina Miller, and Liz Bondi suggest that interview participation has the potential to offer therapeutic benefit by providing an opportunity for storytelling in the context of a contained and interested relationship. Narrative researchers in particular propose that narration and the act of storytelling have a transformative power which might itself offer interview participants pathways towards psychological growth (see Susan Chase's chapter on narrative inquiry for further discussion). However, even researchers supportive of these assertions are aware that such interviews have the potential to be exploitative and can be experienced as intrusive causing further harm. By making distinct efforts to create rapport with participants in order to support them feel 'comfortable' in the interview setting, it is suggested that researchers, as Birch and Miller put it, 'invite intimacy', thereby running the risk of encouraging participants to say more than they may have originally intended, evoking distress and blurring boundaries between researcher and therapist/counsellor. While proposing that narrative interview participation can be therapeutic, Gabriele Rosenthal in her research with holocaust survivors and refugees contends that we cannot naïvely assume that all interviews will have a positive impact. She draws very useful distinction between interviewing people who have experienced adverse life events in their past but have recovered and gone on to establish some stability in life, and interviewing others who are currently in the midst of crisis and whose immediate future remains insecure. Whether positive or negative, however, we know that research interviews impact how participants view themselves and their lives. Playing with the metaphor of research 'fieldwork', feminist researcher Gayle Letherby suggests that we can't but leave footprints in our wake. Sharlene Swartz too notes that although unintended at outset, the young people from a South African township who participated in her ethnographic study reported that while they were talking with her about their lives, they were also thinking. She suggests that ethical practice demands researchers think of interviews as psychosocial interventions, opportunities for researchers to 'give back' to participants whose life and thoughts constitute the foundations of our research and essentially our career development. These debates drew my attention to the challenge of striving towards therapeutic benefit in the context of the research interview with vulnerable participants, galvanising my commitment to do what I could to design and enact interview protocols in ways that considered the young person's stage in treatment and imminent prognosis, actively seeking to utilise the interview process to affirm and support coping resources while maintaining a clear distinction between research and therapy.

From Deficits to Assets: Researching Well-being in the Context of Illness

With these ethical dilemmas in mind, I will briefly outline the theoretical framework used in this study

to understand the capacity for well-being in the face of life-threatening illness since it was on this basis that methods were designed. This study used the theoretical paradigm of salutogenesis and the Sense of Coherence construct, developed by medical sociologist Aaron Antonovsky to adopt a positive health approach to understanding how hospital care could support young people manage the experience of cancer.

Salutogenesis is now a well-established concept in public health policy which seeks to understand how some people stay well in the face of adversity. This 'asset' orientation is thought to complement and add value to the discourse of how to maximise well-being potential, by accentuating the capability of individuals to participate fully in the health development process. Antonovsky developed a stress-resource model called 'Sense of Coherence' or SOC, to help explain an individual's capacity for resilience. This model is composed of three distinct yet interwoven elements: *comprehensibility*, *manageability* and *meaningfulness*. Comprehensibility, the cognitive component of SOC, relates to the extent to which sense and order can be drawn from any situation and is associated with one's world being experienced as understandable, consistent and structured. Manageability, the behavioural component, refers to whether a person perceives they have the personal and social resources including important relationships at their disposal to meet life's demands. Meaningfulness, the motivational component of greatest significance to an individual's overall SOC, refers to the extent a person can make meaning of their experience emotionally and is fundamentally related to self-esteem and participation in everyday life. Applying SOC theory to young people with cancer, it is not hard to see how coping capacity and longer term resilience is threatened by uncertainty and unpredictability, constrained self-agency, the challenges to personal identity and relationships complicated by life stage and critical illness.

These salutogenic principles underpinned this study design and methodology and formed the basis of constructing interview protocols which moved from a pathogenic model examining 'the patient' and disease aetiology, to a well-being perspective which took a strengths-based approach to honour and understand everyday experience, paying attention to each young person's unique story and personal identity and affirming coping capacity, self-agency and relationships as essential resources for fostering well-being.

Methods in Action: Affirming Strengths in the Interview Process

This section reflects on how these principles were enacted in the actual interviews with young people with cancer, focusing on five core objectives: (1) giving back control, (2) affirming relationships, (3) supporting coherence, (4) promoting coping and (5) supporting positive identity construction.

Giving Back Control: Promoting Agency in the Interview Process

A key aspect of the experience of life-threatening illness is losing control of one's life and destiny for a period of time. Ill people talk of moving from a life in which they were actively engaged in the world, to that of a passive patient whose everyday life rotates around the demands of illness and whose survival rests in the hands of medical staff. In this study, interviews were therefore designed to proactively address this experience aiming to support self-agency and affirm young people's emerging adulthood. This objective was primarily

addressed via the recruitment and consent process, the involvement of young participants in information interpretation and the use of participatory methods.

Recruitment and Autonomous Consent

Much has been written about the need for informed consent as a fundamental prerequisite to ethical research. This is a core consideration of Ethical Approval Committees which can result in lengthy information sheets comprehensively addressing all issues of study participation. No coercion should be evident in the recruitment process. In reality, these objectives are not always so easy to achieve, with the study information sheet an important if single strategy to do so.

In this study, I was conscious that the target age of participants and the potential for power disparities in the recruitment process had the potential to increase the risk of unintended coercion. The role of authoritative gatekeepers is noted as a clear challenge to free choice. In order to recruit young people fitting this study's inclusion criteria, I had requested oncology consultants identify young people and seek their initial permission for me to make follow-up contact and talk through the lengthy information sheet. Although I explicitly requested each consultant clarify that research participation was not compulsory and would not affect their treatment or care, there remained a risk that young people might feel unduly influenced by the person responsible for medical treatment at a time of increased vulnerability. The influential role played by parents in young people's decision-making, both protective and supportive, is also highlighted in children's research literature and echoed in my own experience. My own personal profile as a White, middle-class and middle-aged woman, not dissimilar to the age of their parents, and professional background as a social worker, therapist and researcher also raised concerns about perceived pressure. In addition to these challenges, the potential for 'uninformed' consent was heightened by the fact that most young people are unlikely to have had prior research experience and will therefore inevitably have a limited knowledge of what taking part in an interview might entail.

In order to address these concerns and strive to promote the young person's autonomous choice, I became increasingly careful of the language used in recruitment conversations with young people and their parents. Interestingly, all parents were very encouraging of their child's involvement, often seeing it as an opportunity for them to talk of their experience since they were often reluctant to say much to them. I was conscious also that in the course of a time-constrained PhD, it is easy to become organised by sample size and neglect the ethical intricacies of the recruitment process. Like narrative researchers Lucia De Haene and colleagues, I have increasingly come to understand study refusal as a critical expression of self-agency and affirmed this in recruitment conversations. While of course giving the young person and their parent study information in a positive and encouraging manner, I offered examples of questions and always ended the conversation by stating that although of course I would like you to participate in the study, and perhaps your Mum or Dad also, the decision is very much up to you – and I would encourage you to have a think and make a decision that is good for you.

This additional phrase sought to promote the young person's autonomous choice. I also emphasised that

they could withdraw from the study at any time or not answer a question if they wished. In reality, only two young people with whom I had this introductory conversation refused participation. Interestingly, both were among the youngest in the study aged 16 years and had just finished treatment, hoping to return to school and college as soon as possible. While one stated that he just wanted to get back to everyday life, the other reported a desire to forget about the experience. In contrast, however, many of those who did choose to take part simultaneously expressed their desire not to talk about their experience with parents and friends as a means of not worrying others and getting through the experience, while reporting a positive effect of speaking about their experience in the contained environment of the research interview. This diversity starkly highlights the need for researchers to recognise and actively promote potential participants to make autonomous decisions between 'talking' and 'not talking' as different coping strategies at any given moment in time. I also took the opportunity in these early recruitment conversations to specifically outline the time-limited and ring-fenced nature of research involvement and the possibility of referral for ongoing therapeutic support if desired.

Participatory Methods

Participatory research (PR) combines a philosophical and political orientation towards human rights, empowerment and community action, which has come to be associated with particular research methodology and methods (see the chapter by Stephen Kemmis and Robin McTaggart on participatory action research for exploration of the roots of PR models and further discussion of their use in different contexts. Various chapters in Susan Greene and Diane Hogan's edited book on researching children's experience, and Sue Heath and colleagues exploration of the issues associated with researching young people's lives also provide useful debate on the philosophy of PR as it relates to research with children and young people and various ways PR models have been put into practice). Like SOC, PR is based on the ideological commitment that every person has the capacity to reflect on reality and become an active agent in their own life, with researchers contending that an ethical research process should itself be experienced as transformative, addressing power differentials by emphasising reciprocal learning and democratising the research process from research 'on' participants to research 'with'. Although power differentials operate between adult researchers and adult participants, it is argued that these are exacerbated in the adult-child/young person research relationship requiring additional effort to address. One way proposed to reduce these power differentials is the use of participatory and creative methods as discussed by children's researcher Angela Veale and others such as Sue Heath and colleagues specialising in research with young people. While methods vary, they share the aim of involving young people proactively in the data generation process, ensuring that ownership and control of the material generated is, to some extent, in the hands of the participants. These principles were primarily enacted in this study by the creation of a young survivors' Research Reference Group which assisted at each stage in the research process, the involvement of young participants in information interpretation and the use of visual diagramming in interviews. For the purposes of this 'methods in action' case study, the following paragraphs concentrate on interview design and practice.

Information Interpretation: Affirming Young People as Experts in Their Own Lives

Fieldwork in this study involved three interviews with each young participant over a period of 9–12 months. A number of benefits of conducting research over a longer period have been highlighted by researchers such as Greene and Hogan including the potential of capturing the dynamic and changing nature of life experience and placing less reliance on selective memory. Although multiple interviews are not without risk of increasing vulnerability or distress by eliciting unintended disclosures as discussed above, they are, however, also recognised as helping interviewees feel more relaxed in the interview process and, from an ethical standpoint, offer the opportunity to check back with participants to ensure the researcher's attempts to understand that the information generated are correct. This strategy was adopted in this study to keep faith with the ethical goal of promoting participant involvement in the research process and affirming young people as experts in their own lives. Young people were also offered a transcript of their interviews, although interestingly none were requested, suggesting that this may not be such a useful strategy with this age group. Final interviews also sought views on my developing recommendations for optimal hospital care, the core research task, thereby opening myself and the research to participant scrutiny and critique and attempting to enact collaborative research practice.

Visual Diagramming

This study used visual timelines and ecomaps as methods to support conversation with young participants, many of whom prior to interview expressed their under-confidence about talking. Both ecomaps and timelines are simple pen-and-paper exercises which, as outlined by Jonathan Parker and Greta Bradley, are utilised in social work as assessment, planning and intervention tools carried out in this case with flipchart and markers. These techniques were primarily used in this study to support active engagement in the interview enabling participation by those lacking in confidence, and encouraging discussion of abstract issues such as support or relationships. Co-constructing these pictorial exercises has, however, been recognised in social work and therapeutic modalities as having significant by-products for participants and the worker–client relationship. This was echoed in my experience of conducting this research. By supporting young people who were able to sit on the floor with me shoulder-to-shoulder and take the pen in their own hands, power differentials were minimised and they were affirmed as experts in their own lives taking control of what they depicted and talked about. Working closely with those who were physically unable to do their own writing, going back and forth checking whether what I was depicting fitted for them necessitated careful and attentive negotiation, supporting agency and fostering a collaborative respectful partnership in the interview context. The great potential for visual impact when using such tools should also not be underestimated. A number of young people interviewed noted the emotional significance of the maps, and how it had supported them to see themselves, their experience and relationships in a different way, heightening their awareness of the many challenges they had faced and coped with successfully. As one 17-year-old young man put it,

I didn't realise how interesting my life would seem on paper. I have never actually spoken about my life properly ... to think that somebody else actually had an interest in what I had to say, made me feel like maybe it is nice to tell it to somebody else.

Ecomaps: Affirming Relationships

While not unproblematic, research has shown that peer, family and professional relationships have a critical positive impact on the young person's well-being in the context of cancer. Ecomaps in this study were not only used as tools to support discussion as discussed above but also to affirm supportive relationships. Based on general systems theory, this tool pictures the family or individual in their life space and was implemented in this study to explore relationships which were important to them. Young people were invited to first put themselves in a circle in the middle of the page, and then add circles at different distances representing people outside the hospital who played a part in their illness experience. Lines were drawn from the young person to each significant person and between people to show connections and lines of communication. The strength of relationship was indicated by variations between a solid double-line for those who were very close to a weaker dashed line for those who played a more peripheral role. Once the significance of these relationships was explored by means of questions such as 'In what ways was your Mum helpful to you? If you could describe the role she played, how would you name it?', the young person was invited to add important professional relationships in a different coloured pen. On completing the ecomap (Figure 1), one young man commented that 'although I am conscious of everybody that is close to me ... you don't really realise it until you write it down on paper, I didn't really think about it'.

Figure 1. Sample ecomap.

Timelines: Supporting Coherence

Timelines were utilised to support discussion of each young person's illness narrative. A straight line was drawn length-ways on the page, and the young person invited to begin wherever they felt illness started, marking events that stood out for them as significant. Timelines have a particular resonance in the context of serious illness when life is thought to be experienced as a fragmented and chaotic story without end. This can be especially true when illness impacts out of sequence with normative life stage expectations, fracturing life's coherence for both the young person and their family. Using timelines in this context therefore had the potential to support the young person find and tell a coherent illness narrative, allowing movement backwards and forwards as they remembered illness- and non-illness-related events in a recursive and looping, as opposed to linear, manner. On reviewing his timeline (Figure 2), one young man commented, it is weird looking back over everything and seeing how everything has panned out because I completely forget about it, like everything they do in the hospital is just thrown out the window as soon as it is done. But whenever

you talk about it you realise just how much has happened.

Figure 2. Sample timeline.

While the activity clearly had the potential to elicit difficult memories, interestingly, it also offered the opportunity to remember happy times and supportive events that had assisted the young person through their experience, reflecting on the present and looking forward towards an anticipated, if uncertain, future.

Promoting Coping: The Power of Language

Although having different core objectives, both narrative therapists (see, for example, the work of Jill Freedman and Gene Combs) and narrative researchers have long recognised the power of language and questions to not only elicit information but also generate experience. Many qualitative researchers now think of interviews as co-constructed conversations in which data are 'generated' in dialogue between interviewee and interviewer, as opposed to collected by a process of 'extraction'. In this frame of reference, researcher and participant become mutually engaged in a process of joint meaning-making (for further exploration of these concepts, see Bridget Byrne's chapter on qualitative interviewing and Andrea Fontana and James Frey's account of how concepts of interviewing have developed from a stance of neutrality to political involvement). These ideas highlight the need to pay close attention to how we conduct an interview, the

questions we ask or choose not to ask and the language we use.

In the flow of each interview, I sought to use questions to affirm young people's coping capacity. While not recoiling from the potential for distress by exploring some of the experiences which young participants identified as particularly demanding, I was careful to include strength-orientated questions such as 'I'm wondering when you look back on these experiences, are you surprised that you have managed these difficulties ... and what do you think has helped you cope?' Reaching for positive gains, without minimising or avoiding distress, not only allowed me to understand how young people made meaning of their experience but also provided a new lens for participants to reflect on their experience. One such question used was as follows:

I'm going to ask you what may seem a strange question given that you have told me about some of the very difficult challenges you have experienced since becoming ill – but some people have told us that even though life since they became ill has been difficult, that there have been changes that they see as positive – I'm wondering if this fits for you, or not, and whether you identify anything positives or any gains from this experience?

I found that using the tentative concept of 'wondering' offered the participant the opportunity to accept or reject this construction. Interestingly, all participants identified positive corollaries of their illness experience.

While eliciting strengths, I needed, however, to take care not to rush over or ignore distress since Frank warns that it is in the telling of the ill person's 'chaos narrative' when illness is at its 'deepest' that listeners tend to withdraw. When young people spoke of distressing events, I attempted to follow their language to expand the conversation and in due course return to coping questions, performing what Gabriele Rosenthal calls a balancing act between supporting narrative about challenging events and simultaneously holding back from unexpectedly delving too deep. This was especially critical when talking with young people whose prognosis was still uncertain and who were in the midst of suffering the debilitating impact of disease and treatment.

Supporting Identity outside Illness

While this may seem a basic point, it is very easy to become caught up in the 'problem story'. I have found it particularly important in this study to enquire at outset about the young person themselves, their hobbies, interests, school, friends and family. This 'problem-free' conversation was not only useful as a means to establish rapport but also and more importantly a core ethical ingredient of affirming the young person's identity outside illness, an issue highlighted as difficult for young people with cancer who fear losing their 'real self' to the 'cancer self'. The information elicited in these early discussions also provided fertile ground for more stabilising conversations to return to, when closing the interview, an issue identified as vitally important when inviting people to recount challenging life events.

Final Reflections

I would like to conclude with some reflections on what Karen Ramsay calls the 'emotional labour' involved in qualitative research as one can't but be impacted in some way at a human and emotional level when, as researchers, we ask and people take the time to tell us about very difficult aspects of their life story. During the course of the interviews described in this case study, I experienced sadness, anger, frustration, uncertainty and joy. I felt privileged to be welcomed and trusted with personal accounts of extreme difficulty, and the emotions evoked in me during these interview conversations provided rich ground not only to try and understand young people's experiences but also to review each interview process in an effort to ensure that the next would build on my experience of carrying out such interviews and use that learning to create a more beneficial and potentially therapeutic encounter for the participant. This ongoing process of self-reflexivity and relational reflexivity (for further discussion of these concepts and their outworkings in practice, see Gayle Letherby's exploration of 'the self', autobiography and standpoint epistemology in feminist research practice and the links between 'process and product'. Useful additional reading material includes classic texts by feminist researchers Liz Stanley and Sue Wise, Sherryl Kleinman's chapter on emotions, fieldwork and professional lives and Lisa Adkins' critical review of paradigms of reflexivity and the politics of qualitative interviewing in social research), not only in relation to the emotional impact of interviewing but also the impact of our own autobiography on the final product, is I believe essential to the ethical enactment of research with vulnerable people, and fieldwork must be paced accordingly. To neglect the actual process of conducting interviews risks poor outcomes for vulnerable participants and unethical research practice.

Exercises and Discussion Questions

In this case study, I suggest that qualitative researchers have additional ethical responsibilities when carrying out narrative interviews with particularly vulnerable populations. Do you agree?

What do you think of the idea that interviews should be conceived of as psychosocial interventions which offer benefit to interviewees? Are there any risks associated with this idea? How might you seek to address these risks in your research?

What are the strengths and limitations of using visual diagramming in an interview context? Are there any other participatory methods you might suggest could be used when exploring lived experience?

What do you think of the idea that research interviews are co-constructed researcher–participant experiences? How does this fit with the research objectives of validity and reliability?

I argue that considering the 'self of the researcher' is essential for ethical qualitative research practice. Do you agree? Can you think of any criticisms of this viewpoint, and might this stance raise any dilemmas for the wider perception of qualitative research?

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