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Establishing long term research relationships with older people: exploring care practices in longitudinal studies

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Abstract

Drawing on a recently completed longitudinal research project with 96 participants aged 55+ the paper provides insight into the challenges of carrying out ethical practices when engaged in longer term research relationships with older people. It builds on a body of work that purposely records in detail the ethical dilemmas researchers face; the options available to them and the rationale guiding their reaction. The Co-Motion research, led by the University of York, examined the impact of major later life transitions on mobility and well-being and was therefore focused on times of change that were, for some participants, accompanied by suffering. Over three years, the project used a range of methods to explore with each individual the dynamic nature of lived experience: change, continuity, endurance, transition and causality. The paper addresses the negotiation of informed consent over the life of long term research relationships; the `care work` involved; contested understandings of vulnerability; and the need for on-going ethical reflection. The paper concludes by calling for greater reflexivity and suggests a more participant-focused approach to ethics in the field demanding both greater self-awareness from researchers and allowing the participants to have greater voice in the research processes.

KEY WORDS: ethics, life transitions, qualitative longitudinal research, vulnerability.

Introduction

Increasing longevity in modern societies, although rightfully celebrated, presents well documented global and personal challenges (WHO, 2011). The international research community, by undertaking research that is both robust and ethical, has a major role in developing our understanding of ageing in the 21st century. In gerontology, Baars (1991) asserts that research contributes to the way societies and individuals make sense of their

own ageing while Minkler and Holstein (2003), Ziegler and Scharf (2014), building on this, assert the critical need to be aware of our role in the production of knowledge. Higher education, professional bodies and learned societies all contribute to determining both procedures for ethical work and critical reflexivity. Local and individual contexts need to be sensibly accounted for when designing and implementing ethics protocols; discussions of how we arrived at specific decisions in different settings and situations can foster valuable discussion in the research community and promote the adoption of an ethics of care.

This paper draws on the reflective journey taken by three of the six researchers, working under agreed university ethics protocols, who were involved as field-workers in a qualitative longitudinal research (QLR) project with older people that focused on transitions in later life, mobility and well-being. It explores the ethical challenges encountered when engaged in long term research relationships with older people, and how these were addressed.

The paper builds on the argument, laid out by Guillemin and Gillam (2004), that on-going reflexivity is crucial for the ethical practice of qualitative research. Acknowledging that reflexivity has been successfully used to scrutinize how knowledge is produced, Guillemin and Gillam propose extending the use of this research tool to the management of, sometimes subtle, ethical dilemmas surfacing during fieldwork, analysis and dissemination. They differentiate procedural ethics and ethics in practice. The former refers to the formal approval from an ethics committee, the latter encompasses a wide array of unforeseen issues that demand “ethics in the moment”, or situational ethics. In the context of long term research relationships there are greater opportunities to fine tune the ethics to the needs of the particular individual.

Researchers are now well-versed in the language of the ethics committee, with, it might be conjectured, the risk that applications to committee may be becoming routinized procedures devoid of intrinsic value. It is also evident that ethics committee approval does not guarantee that research will be carried out in an ethical manner. The ethics committee has no control over what researchers do in the field; neither can the committee predict the wide range of potentially complex and multi-faceted situations that may be encountered (Peter and Friedland, 2017). Finally the three `pillars` of ethical research: confidentiality + no harm + informed consent can be interpreted in variety of ways in the field and between researchers on the same project. This is not an argument for abandoning ethical approval procedures for they do provide a standard to follow and a reminder that ethics are an inherent feature of research (Guillemin and Gillam, 2004). They afford the researcher time to reflect on the challenges s/he may face and how s/he will act to minimise the risks of harm ensuring that the researcher enters the field with a mind-set tuned to ethical and sensitive practices.

Yet, while such preparation is useful, Guillemin and Gillam (2004) recognise it will not suffice to ensure all ethical moments are identified and acted upon, leading them to advocate the use of reflexivity in the field. Using a hypothetical scenario, in which a researcher exploring heart disease hears about potential familial sexual abuse, they demonstrate the value of being reflexive, acknowledging not only the broad legal and moral implications that such a disclosure entails but also the need to look for small clues as to whether the participant wishes to disclose more about their fears and state of mind or prefers to retreat to other subjects of discussion. These fine grain observations and change of enquiry can be a way of showing care towards the participant. Their point is convincing. However, the authors say little on how a reflexive state is arrived at in the first place or can be nurtured with respect to ethics to ensure that such `important ethical moments` are not missed (Guillemin and Gillam, 2004).

We believe that there is a need to create new spaces in academic journals for 'ethics talk' and teaching curricula and research teams should devote time to sharing stories about the innate messiness of doing research to inform future practice. By collectively construing 'ethics talk' as a valid academic subject we can influence individual behaviours and fine tune disciplinary practices and broaden debates about ethical processes and their relevance in different cultural and institutional contexts. We also believe that there are specific ethical concerns that arise when undertaking ageing research. Many readers of *Ageing & Society* will be familiar with the tendency of ethics committees to view older people as vulnerable and to interpret this vulnerability as being unagentic and therefore lacking capacity to give consent. This may be challenged as ageist although, as we reflect later, there are clearly complex and delicate issues to negotiate. There are vulnerabilities that are particular to late life that must be considered. The existential limitations that are inherent in human life come to the fore in later life and to ignore these is to live in the illusion that all problems can be "solved given the time, money and determination to do it" (De Grey, 2005, quoted in Baars and Phillipson, 2014: 25). As we live longer lives so we are made vulnerable, to a greater or lesser extent, by illness and disability while it becomes more likely that our network of loved ones that provide instrumental, emotional and companionship support will disintegrate (Seymour et al, 2018). Investigating old age is, therefore, a recording of pleasures and possibilities but also of suffering, limitation, and a coming to terms with the finitude of life. For the researcher this is not only a journey that we map with the participant but one that we inevitably explore in the context of our own lives.

The aim here is to de-centre the focus from the research results to the research process so that academics may contemplate the decisions that were made and reflect on how they might

have acted in such situations. We therefore add to a growing and varied body of work that records the ethical dilemmas researchers face in the field, the options and resources available to them, and the rationale guiding their reaction. Some authors have addressed the needs of particular groups. For example, Dewing (2002, 2007) shows that, when working with people with cognitive impairment, informed consent must become an on-going “in the moment” process involving careful observation and care for participants. Others highlight the mismatch between the concerns of ethics committees and those of research participants (Zubair and Victor, 2015; Peters and Friedland, 2017; Buckle et al, 2010). Van Wijngaarden et al (2018) share their retrospective reflections on their conduct following interviews with older people with a wish to die, questioning whether they should, as researchers, have intervened in some way to disrupt some individuals’ plans to end life. The emotional burden of research is also reported, and how this might be managed by researchers (Bowtell et al, 2013; Corden et al, 2005; Duncombe and Jessop 2002) as well as some of the more challenging aspects of the relationship between the researcher and research participant (Holland 2009; Hubbard et al, 2001; Sherry, 2013). With regard to QLR, there is a general view that ethical concerns are no different from those encountered in any qualitative research process (Lloyd et al, 2017; Neale, 2018) but are nevertheless amplified due to the duration of the research process and intensity of the research encounters. Researchers who have engaged in QLR focus on some specific concerns: how to protect anonymity, and how far to share the more detailed individual narratives that are built up over time (Ellis, 2007; Taylor, 2015; Thompson, 2007); how researchers should seek to re-contact with participants as studies progress over time (Miller, 2015); and how researchers manage long term relationships with research participants (Warin, 2011). The literature signals how individual projects may generate various specific concerns and challenges, some predictable, others less so, highlighting the need for on-going reflection and sharing of concerns and potential

actions both within project teams and with the wider academic community.

Co-Motion – the study aims and methods

Co-Motion is a three year multi-disciplinary, cross-institutional project, designed as nine different work-packages that investigated the links between mobility and wellbeing amongst older people working with participants in three North of England locations. Led by the Centre for Housing Policy at the University of York, the research consortium included Computer Science, Health Sciences and the Stockholm Environment Institute at the University of York; the Institute for Transport Studies, University of Leeds; the School of Architecture, Planning and Landscape, Newcastle University; the Department of Psychology, Northumbria University; and the Bradford Institute for Health Research, Bradford Teaching Hospitals NHS Foundation Trust.

The reflections presented in this paper emerged from the Transitions Workpackage, a two-year longitudinal study that recruited 96 people aged 55 or older of whom 91 continued till the end of the project. This workpackage explored the inter-play between mobility and wellbeing of participants as they moved through one or more critical, but common life, transitions:

- Stopping work due to retirement, redundancy, illness or disability;
- Stopping driving (through health, financial reasons or simply choice);
- Losing a significant part of their sight or hearing;
- Starting to live alone due to bereavement, divorce, separation or a partner going into care;
- Taking on child care responsibilities;
- Becoming a carer for a relative, friend or neighbour or stopping care responsibilities;

- Starting or considering using a mobility scooter or mobility device such as a walker, a stick or wheelchair;
- Moving house.

In line with Grenier (2012) we rejected a simple notion that chronology has special relevance in determining our quality of life but focused rather on the experience of facing and managing transitions. All these transitions can, of course, be experienced at any time in life, but they tend to be more commonly and, perhaps, more acutely felt in later life. For example, coping with spousal bereavement, may be particularly challenging in later in life when support networks may be weakened due to loss of supportive friends or family, and when opportunities to build new relationships may be more limited. Hendricks' (2008:113) assertion that "human beings do not live life two variables at a time" is apt in considering later life. Older individuals may be trying to deal with one or several transitions that are overlaid onto changing health and physical or cognitive capacity; the changing capacity of their social resources of family, friends and support networks; the shifting terrain of streetscape and services as well as policy context that may govern the flow of financial and supportive resources, all of which impact upon well-being. The individual participant in our study was not constructed, however, as a victim of time and change with assumed vulnerability, as is so often the case in gerontological inquiry (Zubair and Victor, 2015), nor as a heroic person overcoming tragedy but as a person with agency who has some capacity to manage their well-being within shifting parameters. The inherent dynamism of these experiences is most appropriately captured by longitudinal methods that map both change and adjustment to change over time (Neale, 2018; Holland et al, 2009; Henwood and Holland 2012).

The Transitions Work-package involved multiple transactions over a two year period

between the participants and the researchers including a self-administered questionnaire at the beginning (spring 2014) and end of the research (autumn 2016), a first face-to-face semi-structured interview, four shorter telephone follow-up interviews to explore change at quarterly intervals, and a final face-to-face interview. In most cases a participant worked with only one researcher. Our approach was predominantly qualitative, however the focus on well-being led to us to explore and use two different quantitative measures. Below we outline the research process.

In the self-administered questionnaire used at the very beginning and end of the research, alongside standard demographic questions, we used Ann Bowling's 35 well-being questions (Gabriel and Bowling, 2004) based on extensive qualitative research with older people speaking freely about issues that they valued. These required a tick box on a Likert scale with responses ranging from `agree strongly` to `disagree strongly`.

In the first in-depth face-to-face interviews we explored participants' patterns of "getting out and about", regular and less regular trips and destinations, preferred means of travel, the purpose, nature, value, importance, and practical challenges of outings and journeys. Participants were also invited to reflect on journeys that they would like to make. We also talked about their recent transition and how this impacted on mobility.

At each of the four briefer telephone follow-up interviews we asked about changes to mobility routines and practices. For brevity and to enable comparison with other data sets, at the end of the interview we asked the four well-being questions used by the UK Office for National Statistics.¹

- Overall how satisfied are you with your life nowadays?

- Overall to what extent do you feel the things you do in your life are worthwhile?
- Overall how happy did you feel yesterday?
- Overall how anxious did you feel yesterday?

These four questions require respondents to reply by giving a numerical answer on a scale between 0 -10.

In the final face-to-face interview we asked how their patterns of mobility had changed over the course of the project, how participants had adjusted to the transition that had brought them into the project, and other transitions that had since occurred. These multiple research interactions generated rich textured data about real lives with joyful and painful memories revisited, strategies to cope with sometimes traumatic transitions and loss, reflections on social and learned family practices, and shared subjective experiences that were affecting to both participant and researcher.

Processes and responsibilities in multi-strand projects

The University of York and its research partners followed the Social Policy Association ethical guidelines on evaluations and research.ⁱⁱ These bind researchers to work to ethical practices that have been declared and approved by university committees. For Co-Motion, approval was granted by the University of York's Social Policy and Social Work Departmental Ethics Committee. Specifically there is a commitment to avoid harm to an individual participating in evaluations or research and that anyone participating must clearly give their free and informed consent. In practice, this means that researchers must be satisfied that an individual understands what s/he is being asked to do and that s/he does not feel pressured to participate. Buckle et al (2011) suggest that qualitative research, with its open-ended nature, has, by definition, unpredicted outcomes, and thus needs to use the information and

consent stage to communicate the characteristics of the interview and allow the participant to build a sense of what might be expected. In the field would-be participants are asked to pay attention to the statements on the information sheet and in giving written consent, understand that they may leave the research at any point without having to give a reason. These are common practices, with consent forms, information sheets, and interview questionnaires being validated by the ethics committee prior to fieldwork.

The dominant conceptualization of ethics as a procedure that occurs before the start of the project can create discomfort for any research team members that join after all protocols have been determined and agreed as is increasingly the case with of large cross-faculty and multi-institution teams set up for the duration of a funded programme of research - such as Co-Motion - and dissolved on completion. In a large team, determining where the locus of ethical responsibility lies is not as evident as in a narrowly-bounded project such as an individually directed doctoral study. Team members may have divergent views on when ethical judgements are to be made and by whom, and multi-institutional projects may not always allow dedicated time for the open and detailed discussion of ethical concerns.

Researcher 1 (R1) reflects that as a research assistant employed some months after Co-Motion had begun and ethical approval secured, she felt the following options were available if she encountered any ethical dilemmas: firstly to assume that it had been identified during the discussions that took place prior to her arrival and that the protocol presented to her could safely be followed. Secondly to assume and accept that a submission to the ethics committee is only the first step in the process of ethical researching and that ethical responsibilities now lay with her, meaning she should apply discretionary judgment and modify the interview guide as necessary, or thirdly that any modification should be made after discussion with the

Principal Investigator (PI).

R1 recalls becoming aware of the potential inadequacy of some questions for a small subgroup of participants when she first met Hannah, ⁱⁱⁱ recently widowed, confronting not only bereavement but a marked decrease in her mobility. Hannah had relied upon her husband for night time and motorway driving. His loss coupled with poor public transport links resulted in difficulties in maintaining her usual activities. In the first face-to-face interview, Hannah made several comments about how she missed her husband and her hands became agitated. In those circumstances, asking some questions felt inappropriate, especially the question that explored how the transition had affected enjoyment of life. R1 decided against raising the question and wondered whether she ought to remove it for other bereaved participants but would this create a gap in the data that then caused problems at analysis stage? As a new member of the team, she was not sure how best to raise this concern. R1 reflects that the close relationship she developed with a senior researcher (R3) facilitated discussion of concerns first informally before presenting what emerged as a shared concern to the Principal Investigator and larger team. Other team members had worked together frequently before and were willing and confident to have open discussion. However, not all teams may enjoy such open collaboration. We conclude that it would be highly beneficial for the PI to be charged with the responsibility of ensuring that there are mechanisms to encourage frank and regular reflection on ongoing ethical concerns. This applies to any research project – but the need to do this in QLR is amplified, and also made more complex when working in multi-disciplinary and multi-institutional teams.

Negotiating informed consent: a continuous process

Formal processes – only the starting point

In any qualitative research it might be stated that gaining consent is not a single transaction: consent may be given for an interview or for a voice to be recorded in a workshop but would need to be re-negotiated if it were used in a public facing exhibition. Other participants may wish to place limits on what is made more widely available as research data. Consent in any project is therefore best viewed as continually negotiated and supplementary to the more conventional consenting process of form signing at the beginning of a project, but in QLR, such as the Transitions Workpackage, there is an imperative to revisit informed consent at each wave or for additional participation beyond the core study.

The information sheet provided at the entry to the Transitions Workpackage, sets out the freedom of the participant to withdraw from the project at any time without the need to give any reason, and implicit in this is the prohibition on the researcher to ask for reasons. The information sheet also talks about the ongoing nature of the work that may imply that in agreeing to take part, the participant has considered that they will be making a long-term commitment (Neale and Hanna, 2012) though consent over a lengthy period cannot be assumed from an initial agreement.

At the end of the first interview the participant was reminded that they would be called every three months for a short “follow-up” telephone interview lasting 10-15 minutes. At each follow-up the participant was telephoned and after greeting was reminded about the research, asked if they still agreed to participate and, if so, asked for consent to record the interview.

These multiple practices follow Ellis (2007) who posits that obtaining consent from participants should be conceived as an ongoing task throughout the research and writing process rather than a one-off procedure at the start of the project. She insists that the

ownership of the data remains with the participant and that, therefore, it should be made clear to him/her that they can disengage from the research process at any time. This includes offering options for the data they have contributed during the course of an interview to be later omitted from the analysis. Yet, as Rooney (2015) highlights researchers often end up making decisions themselves rather than in collaboration with people they research, using the vague principle of “doing no harm” for guidance. In her paper about researching intimate relationships she presents two instances of such solo decision-making: one involving not reporting some data to protect the participant’s relationship with her intimate other; another when parts of a recorded interview were omitted from the dataset despite no formal request to do so but because the interviewee in the course of the off-the-tape discussion briefly stated “leave that stuff out, would you?”. The latter exemplifies the subtlety of ethical situations researchers may face, but also how essential the interviewer’s ability to recognize when the participant expresses discomfort indirectly and the fact that conducting research ethically encompasses more than being bound by a limited number of rigid rules intended primarily to protect the university from legal challenge.

Reading signals and silences

The importance of looking for non-verbal and/or non-formal requests to interrupt involvement in a study was confirmed when carrying out the fieldwork for the Transitions Workpackage. Repeated engagement with participants, described by Neale (2012) as “walking with” participants, can impact on the nature of the relationship between the researcher and the researched. The researcher, as time elapses, is potentially less of an outsider/ stranger but part of circle of familiar acquaintances. This may help us to better understand complex processes as participants are more likely to confide in us. This is the value of QLR enabling insight into a life over time that would not be gained through a single interview, helping the

researchers meet their aims and hopefully, through more insightful policy recommendations, be a positive force for change. This blurring of the boundaries between researcher and participant also carries risk as participants might find it more difficult to voice their unwillingness to continue with the project as the researcher is less and less an unknown face. Therefore stating “you can drop out anytime”, while important, may not be enough. It is important to offer opportunities to decline further engagement without having to speak/ write the words, “I do not want to be involved anymore”. We found that one option is that after a number of failed attempts at reaching someone, e-mailing or writing and stating that if the participant does not reply, the team will assume that s/he wants to opt out. These are complex issues to balance with the need to get data and the real possibility that people might be away, or might not mind the researcher trying to contact them several times and even expect her/ him to do so rather than being expected themselves to make contact after a missed attempt. The following three examples from field work illustrate the complexity of these decisions.

Elsie had mental health issues. She was difficult to contact and did not return calls but then replied to a letter and signalled interest in continuing. A date and time were fixed to phone but Elsie did not pick up though several calls were then made. An email was sent but there was no answer, and it was felt it would be wrong to make any further attempts despite the fact she had given consent about further involvement. This interaction prompted discussion about whether the number of calls should be limited in case the participant judged our persistence as coercion. It was agreed that there should be three attempts only. However this too raises issues as the following examples illustrate.

Verity was originally enthusiastic about the study and very open in the first face-to-face interview (July, 2014) about very challenging circumstances: the loss of her home,

redundancy, and caring for a sick husband. During the first two telephone catch-ups (October 2014, and January 2015 respectively) she appeared less enthusiastic and less engaged, providing shorter answers. In the third telephone call (April 2015) the line went dead after R1 introduced herself. This was counted as the first attempt. At the second attempt Verity's husband said she was in the shower and suggested R1 rang back later. When R1 enquired whether a call in half an hour would be suitable, a slightly embarrassed voice answered, `No, call another day`. He did not say that his wife wished to withdraw. Should this be counted as an attempt to contact as there was no certainty the message was delivered, however it was counted as such. A paper version of the telephone interview questions was sent by post, with the option to opt out by not returning the questionnaire in the free post envelope. The questionnaire was returned completed in early October 2015, six months after the third telephone interview was due, and as the final face-to-face interviews were being scheduled. It felt appropriate to offer Verity the option to participate in the final face-to-face interview, which she gladly accepted. She did not state her reasons for temporarily exiting the project, and when asked in the final interview about her experience of interacting with the team and the appropriateness of the mode and frequency of contact, no issue was raised.

Edmund had also started the study with much enthusiasm, talking candidly at first face-to-face interview about a recent bereavement. Part of Edmund's strategy to deal with this loss was, as he described, to "connect" more with other people. Taking part in the project, along with other new social and voluntary activities were part of this "connecting" intention. He also took part in another Co-Motion work package, documenting through a photo-diary barriers to everyday mobility in public spaces, taking great care with the pictures he took. When contacted to arrange the second telephone interview he explained that "it was not a great time", but arranged a time to be interviewed. He did not, however, answer the phone when

called. R3 left a voice mail message to say she had called as arranged, and asked him to email or call her to rearrange the interview. He did not get in contact. R3 decided not to persist and try to re-arrange, as previously Edmund had been very clear and well organised about arranging interviews. His statement that this “was not a great time” and subsequent silence were read as a clear signal to be left alone certainly in the short term. R3 was also mindful that the anniversary of his bereavement was approaching. However, it was not clear that he wished to completely withdraw from the study. When the time came to arrange what would be the third telephone interview R3 wrote to Edmund (rather than calling), explaining that although the second interview had been missed he could continue to participate, but she would wait to hear from him. By not “pestering” Edmund with calls which might have been intrusive, but signalling in the letter that the door was open to continue his participation if he wished, R3 felt that she was acting on what Edmund had shared with her regarding his loss and also his intention to connect. Edmund then contacted R3 to say he wanted to continue his involvement and remained with the study until the end.

Deepening trust and knowledge informed practices

Familiarity can also result in the participant trusting the researcher with very personal details. Indeed the interviewer uses their skills and experience to build rapport to help the interviewee talk freely. There is a clear tension between the conscious need to use personal skills in the pursuit of data and the need to be mindful that interviewees may be led to greater disclosure than they might wish to make (Duncombe and Jessop, 2002; Holland, 2009). The researcher has a duty to regularly remind the participant that they are meeting within the framework of a research project. This may feel odd and counter-productive as encounters (both formal and informal in certain research projects) multiply, but it is necessary to ascertain whether certain facts, anecdotes and feelings are indeed revealed for the researcher to ‘exploit’ as data or

whether they merely form part of a conversation as with a friend. The importance of such clarification is revealed by Ellis' (2007:11) account of the Fishneck community's negative reaction to her sharing with her readers some of the facts the islanders had confided in her, "as they thought (they) "were friends, just talking"". This applies particularly to ethnographic research when many meetings, with marked degrees of informality, may take place. For the Transitions Workpackage, telephone interviews were often preceded by "small talk", where after greeting, introductions and confirming consent the next obvious (and courteous) question was `how are you?`. This often led to the participant commenting on their life and their emotional reactions to recent events. Should this be data?

It is not unusual in qualitative interviewing for people to say quite a lot, and sometimes speak more freely once the recorder is switched off. While this is not recorded or transcribed, in longitudinal research where there is continuity of a relationship the researcher still has this "knowledge" as context for the next encounter. Edmund's case above illustrates that R3's knowledge and reflection on a particularly anniversary – the details of which were not audio-recorded, but recorded in her notes - informed her approach to working with him. Such knowledge should be noted, not to go into the wider public domain, but as an ongoing "ethical" on-going process to ensure that questions are asked sensitively at next interview, particularly if the interview is undertaken by a different researcher.

Doing no harm

As expected from a participant group of older people the majority were single with a small group of never marrieds but most in the divorced or widowed groups. For some whose partner had passed away there was a discussion of that person almost as if that partnership and person had to be acknowledged. Benjamin in the final interview confessed to R2:

“I’ve always found difficulty in talking about Selena’s (wife) illness...I’m not one who easily resorts to tears but there are times, and there were times when I used to just sit in the chair and just weep”.

However in the first interview it was Benjamin who very early in the conversation talked unprompted and at length about his wife’s dementia from the small changes he had noticed prior to her diagnosis, her entry into care, and eventual death as someone who no longer recognised his face. Clearly Benjamin had suffered but had decided to share his wife’s story with a stranger though the insight into his continued grief he kept for our last encounter. Are these encounters harmful to the participant or is it, as Buckle et al (2011) assert reflecting on their experiences of interviews with bereaved parents that these encounters are a bearing witness to pain that is already there rather than inducing pain and as such are potentially valued by those given an opportunity to talk.

Yet, as an extract from a research diary for the Transitions Workpackage illustrates the fear of doing harm creates anxiety in the researcher.

Extracts from R2’s *Personal Research Notes*

Face-to-face interview with Clara tomorrow. She joined the project six weeks after she became a widow. Very worried about blundering and causing her pain or rather greater *pain than she must be feeling. She has not cancelled the interview however so...*

Usually look forward to meeting a new participant- listening to the stories and seeing the person fill out. Dreading tomorrow. Think I will get her a bunch of flowers, good florist in the square. June 2014

Interview completed with Clara. She liked the flowers. She talked about her husband and his death. As I thought she struggled with the question, “What makes you feel down?” She said, “*It goes without saying*”. *Yes it does*. Ought I to have asked her that? It felt crass and blundering. June 2014.

As noted above, we had decided to use the four ONS well-being questions in the telephone follow-ups. How these might be asked of participants such as Clara, recently widowed? R2 offers further reflection:

Need to call Clara for first phone call. Hope she is having a good day, feeling uneasy about asking those four well-being questions. How can I ask a widow of five months how happy she felt yesterday? September 2014.

R3 reflects that one of her participants (Oscar), a gentleman in his eighties, had also recently been widowed. In all the interviews he engaged fully with the questions about mobility, however every thread of discussion led back to the loss of his wife, his unrelenting grief, and subsequent loneliness. He often wept during the interviews. He had no children or other close family. R3 decided not to ask the four ONS well-being questions in the telephone follow-ups, as she felt that they were insensitive given the experiences and feelings that Oscar shared. Following discussion of shared concerns within the team about the use of these and some other questions that were felt to be inappropriate with some participants, it was decided that each researcher should use their own judgement as to which questions should be avoided. This “fits” with ethical practice of doing no harm, and as a researcher having to make in the field judgements that must err on the side of caution in order to protect the interviewee.

It can be rightly argued that the developers of these ONS questions did not intend their insertion into a long term research relationship. There is a difference between using these in a postal questionnaire as part of “blunt instrument” survey, where there is no expectation of any prior knowledge of individual circumstances, and adopting them once you have knowledge of an individual’s particular circumstances that could be bereavement, but might also be some other irrevocable change – loss of sight for example. Buckle et al (2011) suggest an alternative ethical reading in that “the procedure of mailing questionnaires to bereaved participants leaves the researcher less able to observe and address the impact of data collection” (p. 117). Any questions, even on seemingly everyday matters, can arouse distressing memories or pain but in QLR studies, given the researcher is layering up knowledge of individuals, there is a greater imperative to continually reflect on “doing no harm”, both in the “moment” but also as part of the on-going research process. These challenges are present in the course of all qualitative research even where the inter-action is limited to one encounter but are magnified in QLR where there are multiple inter-actions.

Care work among research team members

It is also clear that vulnerability is not confined to the participant as Sherry (2013) discusses in her concept of a ‘vulnerable ‘researcher. Various authors (Bowtell et al, 2013; Corden et al, 2005; Duncombe and Jessop 2002) reflect on how the emotional loading might be managed as well as some of the more challenging aspects of the relationship between the researcher and research participant (Holland 2009; Hubbard et al, 2001; Sherry, 2013). Dickson-Swift et al (2009) highlighted that qualitative social scientists researching sensitive issues have not commonly been categorized amongst professionals undertaking emotional labour (Hubbard et al, 2001). This omission, they suggest, is due to a lack of research

examining emotions in research but Dickson-Swift et al's (2009) findings provide a strong case for inclusion. Consequently, they advocated devising strategies both at the University and at the individual level to reduce the distress that researchers undertaking emotional labour may experience. Corden et al (2005) discuss how group psychotherapy was built into the research process to support a research team investigating sensitive issues. Yet, to this day, as highlighted by Sherry's (2013) account of the self-care strategies she employed when researching the lives of youths involved in a community programme, protecting oneself against emotional harm remains the responsibility of the individual rather than the collective responsibility of academic institutions. Sherry (2013) underlined how research ethics committees focus on avoiding harm to participants but do not formally acknowledge the need to apply the same precautions to researchers. The risk of physical harm has been better recognized and `buddy systems` and `calling in` can provide reassurance that the researcher is physically unharmed. Contrary to Dickson-Swift et al's (2009) hope, informal debriefing with trusted colleagues or family members and keeping research notes remain the ways that researchers manage the emotional toll. R2 reflects that keeping a research diary for the Transitions Workpackage was motivated by the need, as a researcher physically located away from the main research team, to have `a conversation with herself`.

We might reflect on the particular nature of enquiry into older people for those researchers who could also be considered older people. R2 became 60 in the course of the research and R3 55 making us both outsiders and insiders in the research (Corbin-Dwyer and Buckle, 2009). For the older gerontologist is there a greater shared understanding; a realisation that some narratives might mirror ones' own fears about later life or conversely offer potential models that we might hope to replicate? Or does it, as Warin (2011, p 811) warns, mean that in the process of building rapport with our participants, we might identify with some of them

as their actions or attitudes are reminiscent of our own and we might fail to identify what differentiates us, “creating blind spots” in the research. For R1 as a younger researcher there was the surprise of encountering unrecognised fear in herself.

So, when Hannah stated in the first telephone call “I think I miss my husband more”, R1’s first instinct was that she should move quickly on to the next question, as she assumed that Hannah did not want to talk about her loss. A pause in the conversation due to R1’s hesitation was indeed filled by the respondent who then spoke at length of her bereavement. On reflection, not giving Hannah the space to talk might have deprived her of the potential comfort of a listening ear and, as we discussed in our team meetings, opportunities to talk or talk repeatedly about the loss of a loved one might be welcomed. R1’s instinct to move the interview along may also have arisen from her own unexpected pain.

R1: I did not foresee any of the emotions I felt, particularly towards bereavement, despite having embarked before interviewing on a reflexive contemplation of my beliefs towards old age, mainly to prevent any form of ageism. I knew I held positive views of older people, in part shaped by the close relationship I have had with my grandparents. I also knew that I did not idealize this part of the life course, having intimate knowledge of some of the challenges it can present (dementia). Yet, I could not have anticipated the sadness I was to feel after listening to the story of a widow missing her husband.

As the project progressed, it was clear that as a team we had particular concerns about some of the participants who had experienced recent bereavement. Our first thoughts were to investigate the possibility of some sort of awareness training for team members. We were fortunate in having the opportunity to discuss our concerns with another academic colleague

with considerable experience of working with the bereaved who provided us with valuable insights, and also reassurance. This led to our understanding that bereaved participants had more agency than we may think; are often able to regulate their engagement and that giving them space to talk might be beneficial to them (Parkes, 1995; Buckle et al, 2011). This also led to reflection that in working with older people, particularly those suffering the loss of a life partner, we confronted deep fears of our own later life. It is telling that our first thought was to gain support from bereavement experts to avoid harm to our participants rather than realizing that our own concerns were partly shaped by the impact the research had on us at a personal level.

We also struggled as individuals and as a team with the narratives of those participants with deteriorating health for whom there would be no positive transformation; those who were becoming progressively blind or living with degenerative (and incurable) conditions where the research focus was to draw those people back to their struggles. Dorothy could no longer drive following a stroke. Long made retirement plans were no longer possible. At first interview she was optimistic about her recovery - although she knew it would be slow. She was hopeful that she would eventually be able to take another driving test and return to her old self. Over the course of the project her recovery did not progress well, and other difficult life events occurred. R3 reflects:

At the final face-to-face interview, Dorothy appeared transformed from the person I first met. Her previous optimism had gone, and she was understandably angry and frustrated with the course her life had taken. Despite the regular telephone interviews, and my knowing that all had not gone as hoped, I was greatly saddened to see such a change in her when we met. Afterwards, I was profoundly distressed. I felt taking part

in the project had served as a regular reminder to Dorothy of thwarted hopes, abilities lost probably for ever. With the regular contacts and on-going revisiting of changes, had we asked too much of people generally, but of some in particular?

Other narratives also prompted internal struggle for the researchers, particularly from those whose lives were characterised by profound loneliness. Walter was a widower living alone whose daily routine never varied: he walked out every day to collect a few groceries and walked home. He had two friends, one of whom he rarely saw, and most days he spoke to no one except for shopping or banking transactions. In response to questions about happiness and worthwhileness of his life he scored himself less than five.

R3 speaks for all of us when she reflects:

Thinking back across the interviews, those I conducted and the transcriptions of interviews conducted by the other researchers, the narratives on unrelenting loneliness and isolation are those I find most distressing. Will I find myself in a similar situation?

How is such a situation to be avoided?

Does holding up a mirror to lonely people do harm? Is it potentially a trigger for despair? The renewed research and policy attention to loneliness suggests a need to explore the ethics of care in the researcher and participant relationship and the considerable potential for deepening distress.

It might be difficult to foresee the emotional challenges a research project will generate for a researcher or how his/her emotional responses to the research may impact on the study itself. In that regard, being cognizant of one's positionality might be easier. This is partly

because time is devoted during our undergraduate and postgraduate training to identify how our beliefs and values may shape our epistemological stance. Conversely, there is limited space in the curriculum and in research team to discuss emotions. Despite previous calls to engage in such conversations, we still fail to acknowledge them as worthwhile, valid and important moments in the research project. In spite of feminist scholarship that asserts “emotion [is] a[s] relevant feature of the ethical landscape” (Holstein, 2010, p. 631) there is still a dominant concept that the researcher is ‘value-free’ and objective that militates against recognising the personal and relational nature of the research process. The researcher is aware that s/he risks calling down judgements of being unprofessional (particularly as a woman) when displaying emotions and therefore these emotional responses remain unspoken.

Conclusions

This paper adds to a body of work that records some of the ethical dilemmas researchers face in the field; the options and resources available to them and the rationale guiding their reaction. Our reflections on our own “ethical” challenges and responses are intended to help us all develop what Neale (2012) describes as “ethical literacy”, and our ability to think and act ethically “in the moment”.

The particular “ethical” challenges of the Transitions Workpackage – the need for researcher autonomy when faced with decisions “in the moment”, how to negotiate on-going consent, how best to record our “knowledge” of participants and respond to their individual needs in order to do “no harm”, and crucially how to recognise and deal with the emotional burden of a prolonged and intense research process where we “walked with” participants who were adjusting to profound life changes – lead us to a number of conclusions.

Recognising research as a caring process

There is a need for continued ethical and methodological reflections as a project progresses, both within the research team, and also with participants that demonstrate a more nuanced on-going approach that is “up close” incorporating an ethic of care (Barnes, 2012), where we acknowledge relationships within the research team and with participants to be caring relationships that require an attentiveness to needs over time, and take responsibility to ensure needs are met.

On-going reflection and review

There is an imperative to make space for open and honest “ethical talk” as part of the research process, and thought given to the level of experience of individual team members. Such “ethical talk” must be underpinned by a realisation that each researcher has some level of autonomy in the field and should be allowed the freedom to make a judgement about “appropriateness” or not of particular questions at a given moment. Methodological tools need to be revisited and debated about their fit with the field work encounters. What might seem like reasonable questions at the beginning of a project might become “crass and blundering” as the project continues, or “crass and blundering” within the context of the narratives of certain participants.

On-going reflection offers an opportunity to broaden the focus from the needs of the research to individual needs of those participating in the research, whether to adjust our interview content or format. This would allow the integration of concerns emerging through research participant encounters rather than to respond solely to the concerns of ethics committee members, as it is too often/ too quickly assumed that they match (Zubair and Victor, 2015;

Peter and Friedland, 2017). Such practices appear to exist in some parts of academia; for instance Truman (2003) reflects on her experience of conducting research with/for people at risk of mental illness and shows the benefits of trusting the researcher-users judgement when faced with some ethical dilemma, even if they may feel at odd with ethics committee wisdom. Truman (2003) also demonstrates the value of adaptability in the field; in her case, initial thoughts of carrying out focus groups were abandoned when participants voiced their discomfort with group settings due to their personal circumstance but expressed a desire to share their experience on a one-to-one basis. By exposing her practices to her peers through publication in a journal, she opens herself to potential criticism, condemnation and productive dialogue. Such recording of the reasoning behind changes made to research tools and practice through research notes that record ethical dilemmas and how they were addressed, if made available publicly can not only ensure transparency and accountability but can also support the researcher on his/her ever-ongoing journey to becoming a reflexive and moral researcher. We might also suggest that such deliberations might usefully inform both the training and procedures of ethics committees.

Participant-focused ethics in QLR

We also offer early thoughts on a decision to ask participants in the final face-to-face interview about their experience of the research, inviting criticism and comment on the frequency of contact, issues raised and our conduct. It may be argued that where the researcher has “walked with” a participant over time, it is more difficult for the participant to criticise nevertheless the responses have been reassuring and would inform future projects. Edmund, one of the bereaved participants, when asked if the questions were too personal or intrusive, said that he clearly understood that he didn’t have to answer questions he didn’t want to, and could stop the interview at any time, and although he didn’t not answer or

withdraw, he seemed to find it liberating to know that he could. Others shared the same view on their ability to adapt their level of engagement to preserve their well-being, suggesting that participants were well able to determine their own sense of vulnerability at different points in the research. Moreover, while some saw their involvement in the study as a civic duty to help further knowledge and produce better outcomes for others, it was reassuring that some people found taking part worthwhile at an individual level, as it had made them think differently about their own mobilities and life plans, or provided them with an opportunity not previously afforded to just talk and reflect. We know a little about older research participants' motivations to enter the research field (see for example Littlechild et al, 2015), and have researchers' accounts of working with older people as co-researchers (Tanner, 2012; Littlechild et al, 2015; Buffel, 2018) but less about older people's experience of the research encounter itself. Further investigation of this topic, maybe within the framework of a doctoral dissertation, could add to our reflections on what conducting ethical research means, especially from the standpoint of the researched.

Particularly pertinent to QLR, where the on-going relationship and greater knowledge gained of individual participants over time provides the opportunity to almost "fine-tune" the ethics to a particular individual's needs is a more participant-focused process that invites research participants to say how they want the process to be conducted and reviewed as their understanding deepens (Peter and Friedland, 2017). This de-centring from a focus on fixed procedures and on ethics committees as the sole locus of ethical guidance is overdue if only because committees cannot foresee the full extent of the dilemmas that might be encountered in the field. Elwood (2000) exploring lesbian households' residential pathways and Houghton (2015) on young survivors of domestic abuse both illustrate how practices that were not acknowledged by ethics boards as potentially harmful were a cause of concern for

their participants (namely potential disclosure of home location and researchers greeting participants in public spaces). Or, as Zubair and Victor (2015) poignantly illustrate in their study of Pakistani Muslims growing older in the UK, committees may unknowingly produce frameworks that result in the “othering and disempowering of” (p. 979) some of the so-called vulnerable and ethnic minority participants. The inclusion of perspectives from the field, we argue, could help overcoming shortcomings, be it by allowing the researcher in the field to be guided by his/ her “moral imaginations” (Hay, 1998) and acknowledging his/ her ability to act autonomously, or by allowing for flexibility and possible alterations to the rules if requested by the participants.

There might be some value in introducing “views from the field” at an early stage in a research project, either during the development or pilot phases, with ethical committees being informed by, and responding to suggestions made by potential or early participants on ethical issues; this would go some way towards challenging existing power imbalances between researchers and research participants, and recognise participants as knowing agents. The usual approach whereby researchers and committee members make decisions about how participants are to be engaged and protected, place the participant in a position of subordination and fail to recognise that they may want “to be more than informers to research produced by others” (Beebeejaun et al, 2015, p.559). Beebeejaun et al (2015) suggest having a broader ethical board membership as a solution to participants' lack of control over the research process. While we support this approach in principle, its implementation may raise challenges and have its limits, with the main question being that of representativeness: could one or two community members represent the whole range of communities that ethics boards encounter? Similar concerns have been raised when older people have worked co-researchers (see Littlechild et al, 2015; Tanner, 2012). Thus our preference is for a more

tailored approach, with individuals from a group targeted by a project being asked to comment and shape ethical practices as a project progresses.

Finally we suggest that for projects, particularly longitudinal projects, working on life transitions, there needs to be careful thought about what these mean and how they can be probed in ways that manage not only our need to `care` for the participant but also to be aware, in an unembarrassed way, that we researchers are also people whose emotional needs must be recognised and supported. A final recommendation is that we maintain a high level of self-awareness tempered by a non-judgmental acceptance of our own humanity and emotional self.

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<https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/methodologies/personalwellbeingfrequentlyaskedquestions>

ii See: http://www.social-policy.org.uk/downloads/SPA_code_ethics_jan09.pdf

iii In the field Workpackage 5 participants had numerical identifiers. In subsequent publications they are given pseudonyms to provide further anonymity