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ARTICLE

Ethical issues when interviewing older people about loneliness: reflections and recommendations for an effective methodological approach

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Abstract

Loneliness among older people is perceived as a global public health concern, although assumptions that old age is a particularly lonely time for everyone are not accurate. While there is accumulating quantitative and qualitative evidence on the experience and impact of loneliness amongst older adults, there is little exploration of methodological issues that arise in engaging with older adults particularly through research-oriented conversations. The sensitivity and stigma often attached to loneliness means that interviewing research participants presents ethical challenges for researchers navigating complex emotional responses. This paper presents reflections from three research projects that used research interviews to explore accounts of loneliness experienced by older people. The everyday methodological decisions of research teams are often hidden from view, but through a critical examination of reflexive accounts of fieldwork, this paper makes visible the internal and external negotiations of researchers responding to ethical complexity. The paper explores the key decisions that researchers make during interviews about loneliness: how to introduce the topic; how to phrase questions about loneliness; when to ask the questions; how to deal with the stigma of loneliness and respond to ageism; and how to manage the participant–researcher relationship post-interview. The paper concludes with recommendations for appropriately navigating ethical complexity in loneliness research, thus contributing to an effective qualitative methodological approach to researching loneliness in later life.

Keywords: loneliness; ethics; qualitative research; research interviews; ageism

Background

Loneliness is increasingly framed as an ‘epidemic’ (Batsleer and Duggan, 2020) with serious health consequences (Holt-Lunstad *et al.*, 2015) that has captured the attention of policy makers in the United Kingdom (UK) and overseas, and led to strategies seeking to ‘tackle’ the problem (*see e.g.* the UK Government’s loneliness strategy (HM Government 2018) and subsequent annual reports and the United Nation’s (2021) strategy for a ‘Decade of Healthy Ageing 2021–2030’, which includes a strand tackling isolation and loneliness). The global survey of loneliness by Barreto *et al.* (2020) suggests that experiences of loneliness vary by country and associated cultural factors, with reports of loneliness increasing amongst those living in individualistic (as opposed to collectivist) societies. Hansen and Slagsvold (2016) make similar claims about international variation, arguing that countries with generous welfare states promote better conditions of social integration and self-reliance, and thus are less likely to experience loneliness. Societal expectations of family ties and norms of independence likewise influence experiences of loneliness and these vary internationally by differing societal cultural norms (Tesch-Römer and Huxhold, 2019).

As a social phenomenon of public interest, or even a moral panic, loneliness is assumed to be more prevalent amongst older adults. However, assumptions that loneliness is a worsening phenomenon (Surkalim *et al.*, 2022) or that later life is a particularly lonely time are not necessarily accurate (Hagan, 2020). In fact, loneliness has been found to be stable over the lifecourse (Mund *et al.*, 2020) and recent national and international studies indicate that younger people are more likely to report experiences of loneliness compared to older adults (Office for National Statistics, 2018; Barreto *et al.*, 2020). There is evidence that people aged 18–30 in the UK have been most affected by the social distancing policies resulting from the COVID-19 pandemic (Bu *et al.*, 2020). Despite this, a £7.5 million UK loneliness fund announced in December 2020 mostly targets older people (*The Guardian*, 2020).

Researchers in the Finnish context have highlighted the importance of adopting a lifecourse perspective to studying loneliness, pointing to how traumatic or distressing life-events experienced in early and younger years impact on older people’s social ties and experiences of emotional loneliness in later life (Tiilikainen and Seppänen, 2017). Perceiving loneliness as a specific problem of ageing and old age is perhaps an example of an ageist association with vulnerability, and risks creating harm to both older people and also young people and other sub-groups who may not be prioritised despite their higher risk.

Regardless of the relative prevalence of loneliness among older people, the profoundly negative experience means researching loneliness in later life remains an important topic (Victor and Pikhartova, 2020), and one that will continue to be prioritised in both international research and policy. As gerontologists, we suggest it is important to recognise a ‘paradox’ that while it is vital to acknowledge and collect evidence of the experiences of older people who are isolated and/or lonely, conducting such research risks perpetuating stereotypes of older people as lonely (Stephens *et al.*, 2017). Also important to consider, there has been an argument for increased sensitivity when researching people in later life to avoid harm,

specifically where there may be disability, frailty or dementia (Szala-Meneok, 2013). However, if researchers internalise narratives of older people as 'frail and vulnerable', they also run the risk of overprotection and suppressing their stories for fear of doing harm (Russell, 1999; Stephens *et al.*, 2017). This, we argue, is ageism in the form of 'benevolent patronage' which risks 'othering' older people as needing paternalistic safeguarding (Friedan, 1993).

In this paper, we investigate the ethical challenges that emerge around these tensions when conducting interviews with older adults about loneliness. We draw on data from studies in England and Wales but argue that the ethical challenges are replicated internationally. In the UK, the Economic and Social Research Council (2020) lists two core principles that are especially relevant when conducting sensitive research: to 'maximise benefit for individuals and society and minimise risk and harm' and 'the rights and dignity of individuals and groups should be respected'. Loneliness research presents ethical challenges as it can be a sensitive, stigmatised and even distressing topic, which can elicit feelings of shame for participants. This can create challenges for both recruitment and developing a comfortable researcher–interviewee relationship (Jovicic and McPherson, 2019). Researchers must balance competing ethical principles, *e.g.* how to be sensitive to a participant's needs without depriving them of their right to participate in research.

Melville and Hincks (2016) highlight the need for researchers to reflect on their experiences of conducting sensitive interviews and publish accounts that add to our shared knowledge. We suggest that to navigate ethical issues in loneliness research, it is important to engage in a process of reflexive questioning: how do we prepare to initiate discussions about loneliness as a stigmatised topic; how do we sensitively co-construct narratives of loneliness with participants; and how do we minimise harm post-interview, in recognition that divulging such sensitive experiences can generate further distress and surface painful memories. With these questions in mind, this paper examines how a group of social researchers engaged in gerontological research negotiated ethical dilemmas while exploring loneliness with older people using a specific tool in qualitative research – the research interview.

Drawing on lessons learnt from three research projects conducted in England and Wales, we offer some reflections which can inform future research design. The paper first describes the research projects and methods used, and then examines, through collective reflection, how ethical issues were addressed within the projects. Five main reflections are explored, before concluding with some recommendations for developing an effective qualitative methodological approach to researching loneliness in later life that is ethically robust and partly addresses the loneliness paradox identified above.

The research projects

Three research projects concerned with loneliness among older people are drawn on to identify ethical challenges and useful learning during research interviews: Time to Shine (TTS), an evaluation of a six-year programme to reduce isolation and loneliness for older people living in Leeds (Wigfield *et al.*, 2021); the Older Men at the Margins (OMAM) study, an exploration of how older men from

seldom-heard or marginalised groups experience loneliness and overcome isolation (Willis *et al.*, 2022); and Productive Margins: Isolation and Loneliness Among Older People (ILOP), co-produced research with older people for identifying community-led solutions to loneliness and isolation (Barke, 2017; Manchester and Barke, 2020). Table 1 provides a summary of these projects.

Project 1: Time to Shine (TTS), Leeds, England

This research aimed to evaluate the impact of the Leeds-based TTS programme (2015–2022) on older people's (50+) experience of isolation and loneliness. TTS forms part of the Fulfilling Lives: Ageing Better Programme which is funded by the National Lottery Community Fund (Wigfield *et al.*, 2021). TTS engaged over 8,000 older people who regularly participated or volunteered. The data reported in this paper are from 11 interviews conducted in 2020 remotely due to COVID-19 social distancing requirements. These interviews were semi-structured and involved a series of questions, some relating specifically to the TTS Programme, and some relating to the broader experiences of isolation and loneliness, and how this changed during the COVID-19 pandemic. We did not ask direct questions about loneliness but explored a brief life history and asked some open questions adapted from the UCLA Loneliness Scale. The final sample was ten women and one man aged between 49¹ and 82.

Project 2: Older Men at the Margins (OMAM), England and Wales

The overarching aim of this cross-sectional, qualitative study (2016–2019) was to develop an in-depth understanding of (a) the formal and informal ways in which marginalised and seldom-heard groups of older men (65+ years) seek to maintain social engagement and social participation in later life and (b) how they experience and overcome social isolation (Willis and Vickery, 2020; Willis *et al.*, 2022). This included their experiences of participation in group interventions targeted at reducing loneliness among older men. The sampling strategy focused on recruiting men from five sub-groups: (a) men who were single or living in urban areas (N = 21); (b) men who were single or living alone in rural areas (N = 22); (c) men who identified as gay and were single or living alone (N = 21); (d) men who were carers for significant others (N = 25); and (e) men with hearing loss (N = 21). Interviews were used to generate discussion on men's experiences and the following topics were addressed: current social network membership; current and previous experiences of loneliness; everyday ways of coping with loneliness; and experiences of participating in groups aimed at addressing loneliness.

Project 3: Isolation and Loneliness Among Older People (ILOP), Bristol, England

This research was part of a large, co-produced Economic and Social Research Council-funded project (Productive Margins: Regulating *for* Engagement) that involved long-term collaborations between community organisations and higher education researchers (Howard *et al.*, 2020). Between April 2015 and September 2016, a researcher worked with a group of eight older people (peer-researchers)

Table 1. Research projects discussed in the reflective exercise

Research project	Project aim	Target population	Sampling	Sample	Types of interview	Question design
1. Time to Shine (TTS), England	To evaluate a five-year programme to reduce isolation and loneliness among older people living in Leeds	People aged 50+ who were lonely and/or socially isolated	Purpose and convenience samplings recruited through staff members at projects funded by the TTS programme	Ten interviewees (nine women and one man) aged between 49 and 82; all were from White British backgrounds and four lived alone	Semi-structured interviews on the telephone or video-call software as preferred. Interviews lasted between 30 minutes and two hours and were all audio-recorded and transcribed	Questions included a life history approach, and open questions adapted from the UCLA Loneliness Scale. Programme staff and TTS volunteers aged 50+ were asked for their feedback on the question design. No direct questions about loneliness
2. Older Men at the Margins (OMAM), England and Wales	To explore seldom-heard or marginalised groups of older men's experiences of loneliness and how they seek to overcome social isolation	Men 65+ years from seldom-heard groups including living alone, carers, and from rural and urban areas	Purpose and convenience samplings recruited through existing community groups and groups run by organisations	111 participating men between 65 and 95 years of age, the mean age being 76. The majority of the participants were from White British backgrounds, with six identifying with BAME (black, Asian and minority ethnic) groups. Twenty-one men (19%) identified as 'gay'; and the	Semi-structured interviews at participants' homes, or on the university campus if preferred	Questions included a social convoy exercise, and questions adapted from the UCLA Loneliness Scale

(Continued)

Table 1. (Continued.)

Research project	Project aim	Target population	Sampling	Sample	Types of interview	Question design
				remainder as heterosexual		
3. Isolation and Loneliness Among Older People (ILOP), England	To co-produce an exploration of older people's experiences of isolation and loneliness to identify local solutions and encourage community-led action	People aged 50+ experiencing isolation and loneliness	Purpose and convenience samplings through supported housing schemes, attending existing community groups, flu clinics and online	14 interviewees (seven men and seven women) aged between 52 and 88 (mean age = 72 years)	Semi-structured interviews conducted face to face with co-researchers in participants homes or preferred community spaces. Interviews lasted between 30 and 90 minutes, and were audio-recorded and transcribed	Questions and the interview schedule were created in co-design workshops with co-researchers

to co-produce an exploration of older people's experiences of isolation and loneliness across the local community to identify local solutions and encourage community-led action. The group ran engagement events to have conversations about loneliness with local people. Older people were asked to respond to postcards about loneliness and responses informed the development of the interview schedule. Interviews were completed with seven men and seven women (52–88 years of age). Topics addressed included: experiences of loneliness; managing loneliness and what prevents you feeling lonely; how you might help others; and community responses to loneliness.

Reflection as method

We interrogated our research with an approach commonly used in reflective practice in health care, Moral Case Deliberation, where professionals engage in collective reflection on case studies to explore ethical issues to improve practice (Rasoal, 2018). Similar to Moral Case Deliberation, Melville and Hincks (2016) suggest that sharing collective learning from research can improve methodological approaches. Reflexivity, the process of reflecting on practice with the aim of improving it, is an important everyday component of conducting qualitative research (Guba and Lincoln, in Mortari, 2015). However, the finer details of qualitative enquiry, such as in what order to ask questions through a structured interview schedule or how to respond a participant if they become distressed, are rarely made public.

Responding to this, we embarked on a process of collective reflection to identify the hidden ethical dilemmas we encountered during interviewing older people about isolation and loneliness. The three authors who had interviewed participants first completed a written reflective account of between 1,000 and 1,500 words describing methodological decision-making to overcome challenges encountered during planning, doing and closing research interviews for each research project, using data from field notes, interview transcripts and recollections from research meetings. These authors then read each other's reflections, noted similarities and differences, and held a series of four video calls to discuss our learning, which a further author who was the Research Lead on Project 3 joined. While not wanting to suggest a one-size-fits-all approach to ethical rigour in loneliness research, our findings illuminate commonality. Five main themes emerged and are described below: introducing an explicit focus on loneliness from the outset; threading loneliness into the interview questions: wording; threading loneliness into the interview questions: timing; normalising loneliness and challenging ageism; and continuing the conversations post-interview. First names presented below are pseudonyms for Projects 1 and 2. In the case of Project 3, peer-researchers requested the use of their real names in any publications.

Methodological reflections

Theme 1: Introducing an explicit focus on loneliness from the outset

A key ethical and methodological issue of concern for all three projects was the importance of language when introducing the topic of loneliness to potential

participants – how to introduce it sensitively and in a way that privileged the participant’s subjective experience and perceptions. Asking about loneliness can be challenging for service providers and researchers; they may feel uncomfortable asking about this stigmatised topic. For example, when researchers in Project 1 spoke to service providers to recruit participants, some expressed concern the older people they supported may be distressed by being interviewed. Probing difficult topics can jar with the ethical principle of ‘minimising harm’ (Economic and Social Research Council, 2020), but these concerns assume discussing loneliness is a wholly negative experience and do not weigh up the benefits of having difficult conversations for future benefit or being empowered through a research interview (Russell, 1999).

By contrast, the peer-researchers in Project 3 thought it was important to be direct and not avoid the topic of loneliness. They felt that avoiding the word ‘loneliness’ would contribute to perpetuating stigma and chose to use the word to normalise the experience. This perhaps partly comes from their own reasons for getting involved in the project. Peer-researchers spoke openly about loneliness from the start of their involvement; for many the topic was the main incentive for project involvement. Several peer-researchers reflected this when discussing their motivations for being involved:

The subject of loneliness is so important in this day and age. As someone who has experienced such moments, I was drawn to the topic. (Steve, Project 3)

I think the main thing is, for me, the topic. If the topic didn’t interest me, I wouldn’t be here. (Alex, Project 3)

The peer-researchers had agreed, in their conversations together during the project, that it was important not to stigmatise older people and their experiences of loneliness while also challenging ageist perceptions.

For Project 2, the research team elected to be explicit about the focus on experiences of loneliness when advertising the study and circulating recruitment notices. Some men contacted the team as potential participants but expressed reluctance to participate as their experiences of loneliness were not current and were attached to earlier life-events. This reinforces how experiences of loneliness are often situational and context-specific while also highlighting gendered perceptions of loneliness. For some older men involved in this project, it was easier to situate loneliness as a past problem now resolved rather than a current concern – discussing loneliness as a current concern may reflect a threat to perceived masculinity and associated attributes of autonomy and self-reliance (Ratcliffe *et al.*, 2021).

Theme 2: Threading loneliness into the interview questions: wording

Related to Theme 1, the second common consideration across projects was what questions to ask. Different interview strategies were developed across the projects through *either* exploring social aspects associated with loneliness or by directly focusing on loneliness as a personal experience. For Projects 1 and 2, questions were designed to avoid use of the word ‘loneliness’. Instead, questions were asked

about different dimensions of loneliness to explore participant's experiences. Researchers borrowed questions from established, validated scales for measuring loneliness – the UCLA (Hughes *et al.*, 2004) and De Jong Gierveld loneliness scales (De Jong Gierveld and Van Tilburg, 2010). These quantitative scales are used to measure self-perceptions of loneliness and ask questions such as 'How often do you feel left out?' or 'Do you have people you can rely on for practical support should you need it?'

While not intended for qualitative research, these open-ended questions were highly appealing as they invited participants to explore dimensions related to subjective feelings of loneliness, *e.g.* feeling left out or experiencing isolation, without asking about loneliness directly. These questions were most beneficial when participants did not want to discuss loneliness or gave very brief responses to loneliness questions. This strategy represents an attempt to work around the stigma associated with loneliness. On a deeper methodological level, it signals the loneliness paradox introduced at the beginning – the importance of discussing loneliness while also avoiding the reiteration of fixed assumptions on how loneliness is experienced, interpreted and constructed as a wider ageing discourse. It is important to acknowledge here that across both projects the focus on loneliness was made explicit to participants prior to interviews to avoid deception, as discussed above.

In the co-produced Project 3, peer-researchers spent much time developing an interview schedule and considering language. As part of the research training provided, peer-researchers discussed the purpose of interviews and developed a shortlist of questions, based on themes. They then read through and critiqued example interview schedules from other projects. The peer-researchers had experience interviewing in a range of contexts, in social work, journalism and counselling, and were able to interrogate the questions and schedule overall from these different perspectives. After several weeks, a consensus regarding the final interview schedule was reached. The peer-researchers were very clear that if conducting research into loneliness, it is important to name it. They felt that otherwise it would contribute to the stigmatisation of loneliness, something they were committed to challenging in their local community.

Using the scales and avoiding direct mention of loneliness may signify a more distant/principle-based approach that speaks more clearly and is more useful to the ongoing evidence in the field. In contrast, co-production signals a relational approach that aims to engage with participants emotionally in order to develop social actions at a community level, although findings from such research can enable stories about loneliness to emerge that can also be important evidence. We are not suggesting either of these approaches are better than the other, rather that researchers may choose different approaches based on intended outcomes and outputs. It is important to also take into account the possible ethical implications of these methodological decisions.

An additional technique used in Project 2 to safely initiate discussions about loneliness and to manage the impact of stigma was to frame questions in the third person: key questions here were 'How would you describe loneliness? How does it impact on other people?' Usually, this quickly led to the sharing of personal experiences or explorations of what it meant for the participant – some men in Project 2 leaped into these reflections without further invitation. Men taking part

in Project 2 also conveyed an array of metaphors to help describe the subjective experience of loneliness. Metaphors included ‘a bottomless pit’, evoking a sense of being trapped or restricted; ‘heavy cloud hanging over you’, pointing to the pervasiveness of loneliness; and ‘feeling discarded’, suggesting a deeper sense of social disconnection. Metaphors such as these provided scaffolding for men to capture their experiences of loneliness in words without necessarily referring directly to themselves or requiring disclosures of personal challenges associated with loneliness, at least not until they were more comfortable to speak more candidly about such experiences. Interviewers in Project 2 sought to sensitively reflect back these metaphors when summing up responses from participants – this technique often led to men speaking more openly about their own experiences. In the analysis of transcripts, these metaphors were also invaluable in making sense of the multi-faceted nature of loneliness, *e.g.* a simultaneous desire for increased social contact and a deeper sense of social dislocation and disconnection from the surrounding social environment.

Theme 3: Threading loneliness into the interview questions: timing

An equally important consideration is where to locate loneliness questions in the interview. Different approaches were developed across the projects. It was important to allow space for rapport building due to the highly emotive nature of the topic. For Project 1, the interview commenced by inviting the participant to share important events in their life, giving space for rapport to be built between participant and interviewer. This preparatory work enabled the researcher to make decisions during the interview on how to ask questions about loneliness, enabling ‘reflection in action’ (Schön, 1983). For example, one participant recalled their feelings of loneliness in their life history, signalling to the researcher that they were comfortable with direct questions.

Similarly, for Project 2 loneliness questions were inserted mid-point in the interview schedule. This allowed time for rapport building and to explore more tangible and less provocative questions about the participant’s current social network and general background (*e.g.* past careers, hobbies, family upbringing). However, this process was complicated by the varying sizes of participants’ social networks – for some men this part of the interview lasted 30 minutes while for others it lasted over an hour. For those with more extensive networks, there was a risk of interview fatigue interrupting the flow of the interview before questions about loneliness had been reached. This was partly mitigated by taking a short break and putting aside time for refreshments.

Peer-researchers in Project 3 deployed a creative strategy to decide on the flow of interviews. This began during initial engagement activities where participants were presented with three postcards and asked to complete them and post in a tin. The postcards asked: ‘loneliness is...’, ‘what would make life better for older people in our community?’ and ‘if you ever feel lonely what makes you feel better?’ The focus of the three questions differed so that people could choose to focus on a third-person perspective, share their own, individual experiences or consider community-level ideas for other people. The postcard ‘loneliness is...’ was included in order to explore the words and phrases people associated with loneliness. This exercise

revealed many of the older people were more comfortable talking about other people's loneliness or societal attitudes to loneliness before discussing personal experience. With this in mind, the interview schedule began by taking that third-person approach and asking about loneliness generally: 'We're interested in understanding if and how older people might feel lonely in this area, can you tell us what you think about this?' The schedule then asked about the interviewees' own experiences, 'Does loneliness affect your life?', and worked through a series of questions and ended by asking 'what is ageing well?', as several peer-researchers felt it was important to finish by asking about positive experiences to avoid the focus being solely on negative experiences.

Theme 4: Normalising loneliness and challenging ageism

Normalising experiences of loneliness within the interview was a shared technique used in Projects 1 and 3. For Project 1, this involved some element of self-disclosure from interviewers and was particularly helpful when there was limited space for rapport building. During telephone interviews, older people were asked about their experiences of being lonely during the COVID-19 pandemic, and the disconnection of being on the telephone often made it difficult to build rapport. The researcher found participants were more comfortable discussing loneliness if the question was preceded by some carefully considered and non-leading disclosure; for example:

I know I haven't seen anyone for weeks, and that is starting to make me feel lonely. It doesn't seem to affect some people, some people don't mind being on their own, but I do. What has your experience been?

We are not condoning forced disclosure here but did find that the context of COVID-19, where everyone was experiencing isolation to some degree, immediately allowed for some common experiences which facilitated rapport-building conversations. In practice, this technique elicited a range of responses, including participants who disclosed feelings of intense loneliness and those who expressed it had not troubled them. Self-disclosure can facilitate rapport building; this was a useful approach to normalise feelings of loneliness in the context of a telephone call about a sensitive topic. However, it is important to state we are by no means suggesting that this should be contrived or 'faked' to facilitate disclosure, which would clearly present ethical issues in itself.

Engaging peer-researchers in loneliness studies can have a similar effect – in Project 3, peer-researchers often drew on their own experiences during interviews in a conversational way: 'I find because I live alone as well if there's a focus and that gets cancelled and that's a bit scary isn't it?' (Alex). Peer-researchers shared reflections on ageing with interview participants, often assuming shared experiences, such as changes to appearance or health as they aged. Others directly commented on age: 'You don't come across as a 79-year-old' (Carol). During the interviews peer-researchers reflected on experiences of loneliness across their, and interviewees' lives, asking if social lives had changed and whether they had been lonely at other times in their lives. This both normalised the experience of loneliness

and generated interesting insights on the experience of loneliness across the lifecourse.

Peer-researchers and other researchers involved in studies around loneliness often give a lot of themselves to this process, for instance through engaging in self-disclosure. It is important that project teams put in place buddying procedures or other mechanisms to ensure peer-researchers have the support that they might require. In Project 3, for instance, peer-researchers were encouraged to meet with the researcher to 'debrief' after interviews and signposting to other support services was a key part of the researcher role, where required. Additionally, the group of peer-researchers met regularly to talk through their experiences of interviews and share practice. Researchers were 'buddied' with other members of the research team to discuss any personal issues that might come up during the research process.

Theme 5: Continuing the conversations post-interview

All three projects considered how to end interviews sensitively and the support required by participants post-interview. While closing interviews sensitively and considering post-interview care and signposting is standard in qualitative research interviewing, holding a conversation about loneliness and then leaving a person alone can be a particular ethical challenge for researchers. In all three projects, standard practice included a combination of follow-up contact with participants over telephone post-interview and the provision of information detailing local support services. In two of the projects, contact between researchers and participants continued post-interview in beneficial ways, highlighting the ongoing therapeutic impact of interview participation and the positioning of the interview encounter as an intervention as well as source of data generation.

A feature of Project 3 was that older people from the local community were interviewing other older people in the same community. During interviews, connections were made between peer-researchers and participants and some remained in contact, and even made friends afterwards. This seems to have had some positive outcomes for reducing loneliness on an individual level; several years on some friendships are continuing. Some of the interviewees have started working with the peer-researchers and have formed a local action group and continue to meet and consider how to improve the lives of older people locally.

Maintaining connections was facilitated in Projects 2 and 3 through knowledge exchange events. As part of the research design in the former, older men participating in interviews were invited to four half-day workshops held in the final six months of the study. The workshops were designed to present initial findings for feedback and to bring older men and service providers together to discuss potential innovations and gaps in service design. Fifty per cent of workshop attendees were male study participants and, while not expected, some spoke candidly about their experiences of loneliness to other attendees and often stayed on after the workshops to speak to other men involved. In one workshop (focus on gay men's social connections) some attendees exchanged contact details and agreed to stay in touch outside the project – new and unanticipated connections were formed, blurring the boundary between the workshops as platforms for knowledge exchange *versus* an informal method of intervention.

In Project 3, knowledge exchange activities included the peer-researchers developing a series of monologues which they performed at festivals and other public events. After the performance, peer-researchers facilitated discussions with audiences about their experiences of loneliness. This opened up intergenerational conversations about loneliness across the lifecourse.

Our reflections suggest that it is important that gerontologists are clear with interviewees whether the interview will be a one-off encounter or if some further connection might be possible after the interview. In two of our projects, we found ways to enable older participants to continue to meet with others and to talk about loneliness following the interview, which older people appreciated. The example above for Project 2, where some men attending workshops exchanged contact details, highlights the benefits of bringing participants together for shared conversations, despite the stigma attached to the topic. As Project 3 ended, the peer-researchers developed a series of community interventions to which interviewees were invited. Many attended and through this became involved in these initiatives and other community groups and activities.

Discussion and recommendations for future loneliness research

Our collective reflection highlights that there are multiple ways to engage in research interviews around loneliness, differing in methods, aims and approaches. However, we have identified some common challenges and ethical practices/responses around the idea of the ‘paradox’ of researching the loneliness experienced by older people. To address this paradox we make four recommendations – these recommendations are in addition to the more practical fieldwork strategies outlined above.

Challenge ageist stereotypes

Critical theorists suggest that reflection can help to uncover hidden power dynamics (Mortari, 2015). Our experience leads us to conclude that we need to consider power and agency within the research interview. It is potentially ageist and paternalistic to assume that talking about loneliness is difficult for older people; equally, recent national and international studies highlight the consistency of reports of loneliness across age groups and that loneliness is not a specific problem tied to old age (Office for National Statistics, 2018; Barreto *et al.*, 2020; Mund *et al.*, 2020; Surkalim *et al.*, 2022). As Russell (1999) argues, it may be that taking part in a research interview and discussing their experience is empowering for older people. Power and agency are built through a research interview and it is important to see participants as active subjects rather than disempowered victims. Across the projects, we found that although loneliness can be a distressing topic, older people were happy to participate and were not especially ‘vulnerable’. The interview encounter is a co-constructed event between the participant and the interviewer (Charmaz, 2006) and, as such, the participant can exercise power regarding if, how and when sensitive topics are discussed.

Discussing loneliness with older people, despite sometimes being difficult, led to information to help evaluate and plan programmes to alleviate it (Project 1),

highlight the previously unheard voices of marginalised men (Project 2) and suggest, and develop, local area solutions (Project 3). Our reflections align with Russell (1999: 415), who argued that not interviewing older people about their experiences of loneliness for fear of doing harm risked ‘excluding from the public domain those very voices that otherwise remain muted’.

While giving space for voice, it is also important to be sensitive. Procedural and institutional ethics processes offer helpful guidelines and aid reflection and good practice, and they support us in the planning of interviews and aid reflections on the doing and ending. However, ethics are not simply a set of rules to follow (Brydon-Miller and Coghlan, 2019), ethical dilemmas arise throughout the research process and relate to complex contextual or interpersonal issues that need to be attended to in the moment. Ethical concerns are relational, embodied and practically applied in interviews around loneliness and therefore cannot be ‘held’ in a university ethics form (Brydon-Miller and Coghlan, 2019).

Adopt a relational ethical position

We suggest that research exploring loneliness in older age adopts a relational ethical position; this can challenge normative ethical codes based on individual understandings of agency and experience of loneliness and instead adopt an intersubjective and relational view both of ethical practice and of loneliness as a phenomena. Relational ethics suggest that researchers think ‘What should I do now?’ rather than ‘This is what you should do now’ (Bergum and Dossetor, 2005). Guillemin and Gillam (2004) explain that there is more to ethics than choosing the right thing to do and discuss the importance of ‘ethically important moments’ across the research process. In these moments, the approach taken, or a decision made, is important and warrants reflection but is not always a huge dilemma or challenge. These moments can be normalised as part of the research interview.

Adopting a relational ethical framing foregrounds engagement, embodiment, mutual respect and environment as key values in research practices around loneliness in older age. Relational ethics can support researchers to manage the paradox of loneliness research, enabling researchers to collect rich stories that reflect the everyday lives of older people in order to develop social and political actions that may be of benefit. Relational ethical practice involves engagement with older people as interdependent social actors and focuses on building mutual respect where we are appreciative of each other’s differences and positions. This approach may minimise harm and maximise benefit to the participant. This approach also aligns with the lifecourse perspective proposed by Finnish researchers which suggests that a dual focus on individual and social factors that shape people’s experiences of loneliness over time and cumulate in later-life experiences are important, while also recognising older people’s agency (Tiilikainen and Seppanen, 2017).

Normalise loneliness but acknowledge differences

It is often assumed later life is a particularly lonely time, although this has been challenged in international literature and research (Barreto *et al.*, 2020; Hagan, 2020; Mund *et al.*, 2020; Surkalim *et al.*, 2022). Further, loneliness is often

stigmatised, leading to people hiding it through shame, thus delaying seeking help and creating a downward spiral. In order to normalise and destigmatise experiences of loneliness, it may be important to explore loneliness, and its construction, across the lifecourse (Tiilikainen and Seppanen, 2017), rather than just focusing on older people, and to recognise commonality in experience that transcends chronological age. The insights garnered from younger generations about loneliness may also help inform how older people cope with loneliness or at least highlight commonality in responding to and coping with feelings of loneliness. For example, a recent Belgian study points to the ways in which adolescents situate loneliness as a temporary state connected with certain life events, such as losses and conflict (Verity *et al.*, 2021). The intergenerational conversations evident in Project 3 illustrated the usefulness of an intergenerational approach. Gerontologists may focus on loneliness among older people but might also work alongside colleagues in youth studies to ensure loneliness is not siloed as an experience only occurring in later life. The resulting semantic paradigm shift is small, but it has a great impact by removing the ageist association of later life with inevitable loneliness. More critically, these approaches could foster collective dialogue on how useful the language of loneliness is in the context of enhancing social connections and developing stronger social ties.

One way to destigmatise research into ageing and loneliness may be to find ways to work with older people themselves and involve them in research design, activity and dissemination. This could involve recruiting older people to be project advisors, or to work on specific areas of a project, or researchers could take a co-produced approach and work with older people as peer-researchers. It is essential to acknowledge that involving people in research and co-producing research effectively entails careful planning, additional resources, more time, and needs to be budgeted for and written into grant applications.

Plan, do and end carefully

In practical terms, we suggest that researchers should consider carefully how to adopt a person-centred, relational approach and consider how to address the paradox across the planning, doing and ending of the research process:

- (1) *Planning.* Plan and pilot interview schedules carefully, interrogate with others, ask opinions of older people (as co-researchers/advisors). Do not be afraid to ask the difficult questions but do consider when and how to ask them. Asking direct questions about loneliness is one way to normalise experiences of loneliness; if researchers do not use the words this could contribute to stigma. Ensure information sheets and invitations to interview are clear about the study purpose – if it is about loneliness say so.
- (2) *Doing.* Carefully consider the speed and tempo of the interview, plan a structure in advance but be adaptable. Consider ways to open up conversational space so that participants' feelings and experiences can be sensitively explored in a conversation rather than be avoided. Also consider the ethics of self-disclosure; sharing personal experiences of loneliness was a tool effectively used by researchers in projects discussed in this paper. This, along with inviting participants to discuss other people's experiences, was

found to create connection and dialogue about loneliness where conversation was difficult.

- (3) *Ending.* Think carefully about follow-up support for interviewees, particularly if you are not recruiting through a community group. Consider if and how connections can be maintained beyond the interview encounter and be transparent and realistic about these. Recognise that sensitive interviews regarding loneliness can have a particular emotional impact on interviewees and ensure that appropriate self-care strategies are in place and followed, and that adequate space for reflection is available to explore assumptions.

Limitations and concluding remarks

There was commonality in our reflections, but this subject would benefit from further reflection from other researchers in the field both during and following research. Our reflections were limited by our own experience within the research projects. In Project 1, the sample was not very diverse, the majority of the participants were white, female professionals, and were not representative of TTS beneficiaries. Further, Projects 1 and 2 recruited participants through gatekeepers of community services and thus did not engage with older people who were socially marginalised and completely disconnected from local services and community resources, and were therefore (potentially) at higher risk of loneliness and social isolation. Project 3 again was a small sample size and engaged primarily with white peer-researchers and interviewees. In two of the above projects, some participants were not 'older' (*i.e.* under 65 years). However, given the pervasive stigma attached to loneliness and associated feelings of shame, we argue that the reflections and recommendations shared here would equally apply when involving younger participants and are transferable to studies of different age groups.

We suggest that researching older people's experiences of loneliness, in particular carrying out respectful, destigmatising research interviews, requires researchers to develop reflective practice. This includes being critically mindful of what we have named 'the loneliness paradox' and the researcher's role in generating research accounts that contribute to and sustain a wider public and policy narrative on loneliness and associated assumptions. We suggest researchers should attend to the many ways that older people themselves discuss and frame 'loneliness', paying particular attention to the words used by older people. It is essential to recognise the challenging and negative impacts of loneliness while also recognising the positive experiences of being alone that many older people convey. Here we suggest there might be important differences between how older people understand and experience 'solitude' as opposed to loneliness and further research might focus in on these differences. For instance, Davies (1996: 3) discussed the theoretical differences between loneliness and solitude, pointing to the deficit model of loneliness as a negative state while highlighting solitude (or 'aleness') as 'desirable, healthy and integrative', pointing out that confusion between the two concepts is a common occurrence in studies of loneliness.

We suggest that researchers should adopt a person-centred, relational approach and consider how to address the paradox of loneliness research across the research process. For qualitative researchers, reflective practice involves having plans to mitigate potential issues and challenges but also the confidence and ability to be flexible, to recognise moments as ‘ethically important’ and emotionally respond in order to address the challenge. As Ellis (2007: 4) suggests, relational ethics ‘requires researchers to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences’.

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Note

1 The 49-year-old was interviewed as she was accepted by the project despite her age as she was experiencing isolation and loneliness, is disabled and has health problems, and identified with feeling ‘older’. Many of the things she used to like doing, she could not, and she saw that as related to her age and her health.

References

- Barke J** (2017) Community based research and approaches to loneliness prevention. *Working with Older People* **21**, 115–123.
- Barreto M, Victor C, Hammond C and Qualter P** (2020) Loneliness around the world: age, gender, and cultural differences in loneliness. *Personality and Individual Differences in Loneliness* **169**, 110066.
- Batsleer B and Duggan J** (2020) *Young and Lonely: The Social Condition of Loneliness*. Bristol, UK: Policy Press.
- Bergum V and Dossetor JB** (2005) *Relational Ethics: The Full Meaning of Respect*. Hagerstown, MD: University Publishing Group.
- Brydon-Miller M and Coghlan D** (2019) First-, second- and third-person values-based ethics in educational action research: personal resonance, mutual regard and social responsibility. *Educational Action Research* **27**, 303–317.
- Bu F, Steptoe A and Fancourt D** (2020) Who is lonely in lockdown? Cross-cohort analyses of predictors of loneliness before and during the COVID-19 pandemic. *Public Health* **186**, 31–34.
- Charmaz K** (2006) *Constructing Grounded Theory – A Practical Guide Through Qualitative Analysis*. London: Sage.
- Davies MG** (1996) Solitude and loneliness: an integrative model. *Journal of Psychology and Theology* **24**, 3–12.

- De Jong Gierveld J and Van Tilburg T** (2010) The De Jong Gierveld short scales for emotional and social loneliness: tested on data from 7 countries in the UN generations and gender surveys. *European Journal of Ageing* 7, 121–130.
- Economic and Social Research Council** (2020) *Research Ethics: Our Core Principles*. Available at <https://escr.ukri.org/funding/guidance-for-applicants/research-ethics/our-core-principles/>.
- Ellis C** (2007) Telling secrets, revealing lives: relational ethics in research with intimate others. *Qualitative Inquiry* 13, 3–29.
- Friedan B** (1993) *The Fountain of Age*. London: Penguin Classics.
- Guillemin M and Gillam L** (2004) Ethics, reflexivity and ‘ethically important moments’ in research. *Qualitative Inquiry* 10, 261–280.
- Hagan R** (2020) Loneliness, older people and a proposed social work response. *Journal of Social Work* 21, 1084–1104.
- Hansen T and Slagsvold B** (2016) Late-life loneliness in 11 European countries: results from the Generations and Gender Survey. *Social Indicators Research* 129, 445–464.
- HM Government** (2018) *A Connected Society: A Strategy for Tackling Loneliness – Laying the Foundations for Change*. London: Department for Digital, Culture, Media and Sport.
- Holt-Lunstad J, Smith TB, Baker M, Harris T and Stephenson D** (2015) Loneliness and social isolation as risk factors for mortality: a meta-analytic review. *Perspectives on Psychological Science* 10, 227–237.
- Howard M, McDermont M and Innes M** (2020) Introduction: From the regulation of engagement to regulating for engagement. In McDermont M, Cole T, Newman J and Piccini A (eds), *Imagining Regulation Differently: Co-creating for Engagement*. Bristol, UK: Bristol University Press, pp. 1–22.
- Hughes ME, Waite LJ, Hawkey LC and Cacioppo JT** (2004) A short scale for measuring loneliness in large surveys: results from two population-based studies. *Research on Aging* 26, 655–672.
- Jovicic A and McPherson S** (2019) To support and not to cure: general practitioner management of loneliness. *Health and Social Care in the Community* 28, 376–384.
- Manchester H and Barke J** (2020) Regulating for ‘care-ful’ knowledge production: researching older people, isolation and loneliness. In McDermont M, Cole T, Newman J and Piccini A (eds), *Imagining Regulation Differently*. Bristol, UK: Bristol University Press, pp. 67–84.
- Melville A and Hincks D** (2016) Conducting sensitive interviews: a review of reflections. *Law and Method* 1, 1–26.
- Mortari L** (2015) Reflexivity in research practice: an overview in different perspectives. *International Journal of Qualitative Research Methods* 14, 1–9.
- Mund M, Freuding MM, Möbius K, Horn N and Neyer FJ** (2020) The stability and change of loneliness across the life span: a meta-analysis of longitudinal studies. *Personality and Social Psychology Review* 24, 24–52.
- Office for National Statistics** (2018) *Loneliness – What Characteristics and Circumstances Are Associated with Feeling Lonely?* Available at <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/lonelinesswhatcharacteristicsandcircumstancesareassociatedwithfeelinglonely/2018-04-10>.
- Rasoal D** (2018) Concept clarification of moral case deliberation. *Open Journal of Nursing* 8, 390–403.
- Ratcliffe J, Wigfield A and Alden S** (2021) ‘A lonely old man’: empirical investigations of older men and loneliness, and the ramifications for policy and practice. *Ageing & Society* 41, 794–814.
- Russell C** (1999) Interviewing vulnerable old people: ethical and methodological implications of imagining our subjects. *Journal of Aging Studies* 13, 403–417.
- Schön DA** (1983) *The Reflective Practitioner*. London: Temple Smith.
- Stephens C, Burholt V and Keating N** (2017) Collecting qualitative data with older people. In Flick U (ed.), *The Sage Handbook of Qualitative Data Collection*. London: Sage, pp. 632–651.
- Surkalim D, Luo M, Eres R, Gebel K, van Buskirk J, Bauman A and Ding D** (2022) The prevalence of loneliness across 113 countries: systematic review and meta-analysis. *British Medical Journal* 276, e067068.
- Szala-Meneok K** (2013) Ethical research with older adults. In Mertens DM and Ginsberg PE (eds), *The Handbook of Social Research Ethics*. London: Sage, pp. 507–517.
- Tesch-Römer C and Huxhold O** (2019) Social isolation and loneliness in old age. In Knight BL (ed.), *The Oxford Encyclopedia of Psychology and Aging*. Oxford: Oxford University Press, pp. 1146–1167.

- The Guardian* (2020) Government announces 75m fund to fight loneliness in England. *The Guardian*, December 29. Available at <https://www.theguardian.com/society/2020/dec/29/government-announces-75m-fund-to-fight-loneliness-in-england>.
- Tiilikainen E and Seppanen M** (2017) Lost and unfulfilled relationships behind emotional loneliness in old age. *Ageing & Society* 37, 1068–1088.
- United Nations** (2021) *Decade of Healthy Ageing (2021–2030): Advocacy Brief: Social Isolation and Loneliness Among Older People*. New York, NY: United Nations.
- Verity L, Schellekens T, Adam T, Sillis F, Majorano M, Wigelsworth M, Qualter P, Peters B, Stajniak S and Maes M** (2021) Tell me about loneliness: interviews with young people about what loneliness is and how to cope with it. *International Journal of Environmental Research and Public Health* 18, 11904.
- Victor CR and Pikhartova J** (2020) Lonely places or lonely people? Investigating the relationship between loneliness and place of residence. *BMC Public Health* 20, 778.
- Wigfield A, Leyland A and Martin C** (2021) *Tackling Social Isolation and Loneliness in Later Life Through the Time to Shine (TTS) Programme, Report 1*. Leeds, UK: Time to Shine.
- Willis P and Vickery A** (2020) *Older Men at the Margins Study: Findings Summary*. NIHR School for Social Care Research. Available at <https://www.sscr.nihr.ac.uk/projects/p110/>.
- Willis P, Vickery A and Jessiman T** (2022) Loneliness, social dislocation and invisibility experienced by older men who are single or living alone: accounting for differences across sexual identity and social context. *Ageing & Society* 42, 409–431.

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