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Making Qualitative Interviews in Music Therapy Research More Accessible for Participants Living With Dementia – Reflections on Development and Implementation of Interview Guidelines

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Abstract

Purpose. This paper reports findings from a project that sought to develop accessible guidelines for including people with dementia in qualitative interviews in a music therapy study, based on experience from people previously involved in qualitative music therapy research. *Method.* People with previous experience of qualitative music therapy research were invited to participate in semi-structured interviews about how the interview process could be made more accessible. Participants included four family-caregivers and three music therapy-researchers. Interview data were analysed using thematic analysis. Findings were used to develop guidelines for a subsequent study; reflections on the implementation of these guidelines are provided. *Results.* Five themes were identified: (a) motivators and barriers to participating in interviews; (b) pragmatic elements that impact interview participation; (c) relationship dynamics may impact the interview; (d) familiarity fosters comfort, enables preparation and support and (e) broader considerations for accessible research design. *Conclusions.* Themes identified align with reports from the extant literature. Reflections on implementation of the guidelines reveal the need for more clarity around the ethics of building rapport in qualitative research. Implications about future uses of the guidelines, including the use of music as a research tool are discussed.

Keywords

dementia, qualitative interviews, music therapy research, arts-based research, qualitative research, accessible data collection, inclusive research

There is growing interest in research relating to how music therapy can support people living with dementia. However, the perspectives of participants with dementia remain underrepresented in the music therapy literature, with studies often relying on observation or proxy report from caregivers possibly due to the assumption that people with dementia will not be able provide insights of their own (Dowlen et al., 2018). To effectively represent and collaborate with people who have lived experience, it is important to identify barriers and develop strategies to support participation in qualitative research. Both researchers and people with lived experience of dementia have previously identified ways to make qualitative interviews (including individual, dyad and focus groups) more accessible for participants who have dementia (Cridland et al., 2016; Novek & Wilkinson, 2019; Wilkinson, 2002). A recent review of qualitative research practices used with people living with dementia recommended considerations when planning,

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conducting and disseminating research (Novek & Wilkinson, 2019). These include the consideration of multiple factors, such as the role of caregivers as both gatekeepers and supporters, the relationship between participants and researchers and how this might impact participants, the research environment, appropriate language and communication strategies, and researcher knowledge and skills. Similarly, Cridland et al. (2016) reviewed both the literature and their own personal experiences of research to create a detailed set of guidelines for researchers to use in preparing for qualitative interviews specifically for people living with dementia, including examples of ways that questions and processes may be adapted to be more accessible.

While these review papers demonstrate a detailed body of literature that researchers can access to aid in preparing to interview people with dementia, the underrepresentation of perspectives of people with dementia is still noted (Novek & Wilkinson, 2019). This is particularly noted in the field of music therapy (Dowlen et al., 2018; Dowson et al., 2019; Novek & Wilkinson, 2019). Additionally, the potential for music itself to assist the interview process is under-explored, despite reports that music and music therapy can support people with dementia with communication and self-expression (Baird & Thompson, 2019; Brotons & Koger, 2000). Therefore, the present study aimed to seek feedback from participants and researchers on their experiences to improve accessibility of qualitative interviews in music therapy research.

Background to the Present Study

The impetus for the present study came from the first author's (ZT) preparation for her PhD research project, in which she was planning to interview participants of community-based choirs for people living with dementia that were newly formed as part of the Remini-Sing study (ACTRN12617001513303). Drawing on existing suggestions for inclusive research (Cridland et al., 2016; Novek & Wilkinson, 2019), ZT questioned what music therapy researchers were doing to support people with dementia to participate in qualitative interviews, and whether music had been or could be used as an additional support technique. Concurrently, ZT was facilitating a similar therapeutic choir that had formed as part of a pilot project for the Remini-Sing study, led by the second and fourth author (Tamplin et al., 2018). Upon learning of ZT's research activities, members of the choir (both family caregivers and those with dementia) who participated in the initial pilot study voluntarily provided (unsolicited) feedback to ZT regarding their experience of participating in research, and how she could improve the interview process in the next study. Given the amount of informal feedback, we felt it would be worthwhile to capture this in a more formal manner to aid in the development of interview guidelines for the Remini-Sing study. As music was not intentionally used during interviews in the pilot study, we decided to interview music therapy-researchers who had conducted qualitative interviews with participants who have dementia, to understand if and how they drew on music therapy techniques to assist in the interview process.

Research Aims

This study aimed to explore ways that music therapy researchers have previously included people with dementia in qualitative interviews, and how practices can be improved to be more inclusive and accessible. The following research questions guided our data collection:

1. How did participants of a music therapy pilot study describe the accessibility of participating in qualitative interviews
2. How do music therapy researchers describe the experience of supporting people with dementia to participate in qualitative interviews?

Ethics approval for this project was granted by The University of Melbourne, Ethics ID: 1852247.2. Findings from this study, in addition to the recommendations in the extant literature, were used to form flexible guidelines that were then piloted in the qualitative data collection process for the Remini-Sing study. Reflections on using these guidelines in the study will be discussed following the presentation of findings from the analysis of interview data.

Method

Participants

Three categories of participants were invited to join this study:

(a) music therapy researchers who had previously conducted qualitative interviews with people who have dementia,
(b) participants from the Remini-Sing pilot study who have a diagnosis of dementia
(c) participants from the Remini-Sing pilot study who are family caregivers (henceforth referred to as 'caregivers').

Procedure

Participants were recruited using purposive sampling methods; participants were either known to the authors, or suggested by another participant. Due to the pre-existing relationship between the authors and the participants of the pilot study, a research assistant who had no prior relationship with the pilot study participants contacted eligible participants via email. Once invitees expressed an interest in participating, ZT contacted them to answer any questions and schedule a time to complete the consent process and interview.

ZT conducted individual interviews with consenting participants at a time and place that was convenient to them; phone or online meetings were also offered. We used a semi-structured interview format, allowing for prompt questions about the participant's experiences, as well as broader topics should they come up during the course of the interview (Smith et al., 2009). A schedule of questions can be found in Supplemental online Appendix.

We analysed data using a six-step, inductive thematic analysis method (Braun & Clarke, 2006; Clarke & Keady, 2002) using MAXQDA software. We chose to use an inductive approach so that the analysis was data-driven, and to allow for areas not anticipated by the researchers to be explored (Braun & Clarke, 2006; Clarke & Keady, 2002). ZT completed transcription, initial coding and theme development. ZT, JT and FB met to review the emerging themes, and mind-maps were used to explore the relationships between themes and sub-themes. Themes were then named and defined, and reviewed by the FB, JT and IC.

Findings and Discussion

Four caregivers from the pilot study and three music therapy researchers consented to participate in this study. Despite efforts to recruit people with lived experiences of dementia, none whom were invited agreed to participate, generally due to not being able to recall the participating in interviews due to the length of time since the pilot study (2 years). Table 1 presents demographic information for each participant – participants were given the choice of using a pseudonym or a descriptive label – for privacy reasons, the researcher-participants have chosen to use a descriptive label.

The inductive analysis formed five key themes: (1) motivators and barriers to participating in interviews; (2) pragmatic elements that impact interview participation; (3) relationship dynamics may impact the interview; (4) familiarity fosters comfort, and enables preparation and support; and (5) broader considerations for accessible research design. Themes 1–4 were shared by both caregivers and researchers, and appeared to be interrelated, with the theme of 'familiarity' underpinning themes 1–3. (Figure 1). However, theme five related to the data from caregivers only, and reflected broader aspects of the research that caregivers felt were important. The following section will feature a summary of the themes with discussion of related literature integrated into each. This will be followed by a reflection on the creation and implementation of the guidelines, limitations of the study and suggestions for future research.

Theme 1: People with Dementia Were Motivated to Participate, But Faced Barriers

Both caregivers and researchers felt that in their experiences, people with dementia are generally able to participate in research, were willing to do so, and found enjoyment in being involved. Researcher 1 felt that participants generally enjoyed the chance to talk to someone and express their opinions, stating: ' …they loved the idea that someone was actually focusing on them, giving them kind of 100% attention, which they may not otherwise get in that [facility]…so they really loved the idea of sitting one on one with someone and talking

Table 1. Participant Demographics.

Participant	Experience in Qualitative Interviews
Researcher 1	Senior researcher and experienced music therapist Interviewed people with dementia 1:1 No pre-existing relationship with participants
Researcher 2	Experienced researcher and music therapist Conducted interviews with dyads Existing relationship with participants
Researcher 3	Early career researcher and newly graduated music therapist Conducted a mix of dyad and focus group interviews Had experience of knowing and not knowing participants prior to interviews
Edward (caregiver 1)	Edward's wife had been part of the pilot choir, and he supported her to participate in the interview (although he did not attend the choir). At the time of the pilot study, his wife had aphasia, although was able to answer some questions with short sentences or gesture
Louise (caregiver 2)	Louise participated in the pilot choir with her husband, and completed the interview with him in a 'dyad' model. At the time of the pilot study, her husband was having difficulty expressing himself verbally
Maureen (caregiver 3)	Maureen participated in the pilot choir with her husband, and completed the interview with him in a 'dyad' model. At the time of the pilot study, her husband was able to speak, although at times answered in his mother-tongue rather than in English
Albert (caregiver 4)	Albert participated in the pilot choir with his wife, and completed the interview with her in a 'dyad' model. At the time of the pilot study, his wife was in the early stages of primary progressive aphasia (semantic dementia), although was still able to communicate verbally relatively well

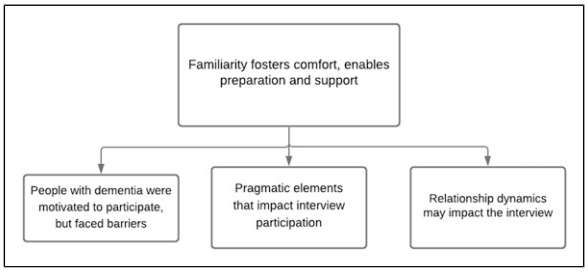


Figure 1. Depicting the relationship between Themes 1–4.

about their experiences'. Louise (C2 [C refers to 'caregiver']) recalled that being able to participate in the qualitative interview was important to her husband because giving his opinion was something he liked to do:

> "being able to think about things and respond, some of those questions were fine for him, so he could…still freely give his opinion…and always liked to give his opinion…So that in a way, that was really up his alley" (Louise, C2).

Researcher 2 described feeling surprised by the ability of some of the participants whom they anticipated might have difficulty contributing, stating '… she would just pipe up and say the most incredibly insightful things actually, like, you'd be like "phwoar, that was a…better get that down!"… comments that weren't prompted'. This researcher also described one participant who had aphasia and was surprised in their own ability to contribute during the interview: 'I remember her, at the end, saying "I'm so surprised at all these fabulous things I'm saying"'. These positive aspects of participating in research not only reflect past research that people with dementia can provide important insights into their experience ((Digby et al., 2016; Novek & Wilkinson, 2019), but also support the notion that participants may experience incidental benefits of participating in research (Hammersley & Traianou, 2016), such as sense of achievement and improved self-perception.

Both caregivers and researchers also described some of the barriers they observed during the interview processes. Researcher 1 observed some participants diverting the conversation away from the questions, and speculated that this may be a way that participants navigated not being able to recall or respond to a question: '… his cognitive challenges were such that he couldn't answer the questions anyway, and so I think diverting the conversation away was his way of steering the conversation away…rather than just say "I don't know" or "I don't understand"…'. Researcher 1 also observed some participants becoming distressed due to not being able to respond during the interview and questioned the ethics of including participants with dementia if it causes distress:

> "well, I'm making this person uncomfortable because they can't answer the questions, I'm not getting anything from this either, what's the…there's no point in putting a person through this if you know, they're not going to give me anything I can use." (Researcher 1)

These findings echo past research that acknowledges how cognitive challenges may affect a participant's ability to respond to qualitative interview questions (Clarke & Keady, 2002; Hubbard et al., 2003). However, it is also important to note that all three of the researchers in this study reported that they received no training specifically on how to interview someone with cognitive challenges other than drawing on their therapeutic skills and previous clinical experiences of working with people who have dementia. They also reported that they did not make specific preparations for the interviews beyond the interview location (i.e. having a quiet space). Hubbard et al. (2003) described a case where researchers lacked the skills to understand the communication styles of participants with dementia, which was exacerbated by the constraints of the interview setting (e.g. time pressure). Snyder (2006) has similarly explained that it is important to understand the context and adaptive ways that a person with dementia who has communication difficulty might express themselves, in order to understand their true meaning of their communication. Although music therapists are trained to support communication, the participants in the present study revealed that additional support strategies may be required to assist someone to participate in a research interview context. Therefore, researcher ability, training and knowledge of contextual factors that may be relevant to an individual's communication style should also be considered in conjunction with the ability of the participants in order to ensure accessibility in interviews.

Theme 2: Pragmatic Elements That Impact Interview Participation

Caregivers and researchers in this study each described several different pragmatic elements that they felt impacted the experience of the qualitative interview for participants with dementia. Four key sub-themes were identified that related to these elements: time, flexibility, environment and music.

Sub-theme 1: Time. Participants described different ways that time could be used to support people with dementia to participate in qualitative interviews. Researchers and caregivers alike felt that it was important to consider timing of interviews to optimise comfort and alertness for people with dementia.

> "Time of day can be an issue…[one] group…was an afternoon group, whereas the other group was a morning group, and it was pretty clear that those in the afternoon group were more agitated…they'd been there all day, and had lots of stimulation" (Researcher 1).

Louise (C2) noted the importance of being flexible in scheduling interviews, given that people's needs may change day-to-day:

> "…even on any given day, is going to be different, so that will always be a…challenge that needs to be met on the day, and that might require a bit of flexibility – if it's not a good day… reschedule" (Louise, C2).

Timing of interviews was also discussed in terms of the impact that it may have on a participant's ability to recall the programme under discussion. Researchers 1 and 3 described the challenge of some participants not being able to recall the music therapy groups during the interview, and commented that in future projects, they would endeavour to schedule interviews closer to the end of the programme:

> "I would give more thought to when the interviews were actually happening… doing something…as if it was actually a session…because it's there happening in the moment, and…often people [with dementia] are more able to reflect on that moment while they're experiencing it, rather than having to recall something that they did a couple of weeks ago" (Researcher 3).

Sub-theme 2: Flexibility. Participants highlighted the need for 'flexibility' on the part of the researcher during the interview, in regards to how they asked questions and supported responses. The researchers described different ways that they adapted the questions during the interview to maximise understanding and support the participants to respond. This included using simplified language, but also rephrasing some questions on the spot for easier comprehension: 'trying to keep questions quite simple and to the point…so that it's just a really kind of direct way of asking, or something that's really clear' (Researcher 3).

Researchers found that questions that were broad, or asked the participants to reflect on concepts that were somewhat abstract, were challenging for some participants, and that rephrasing such questions to focus on more specific or concrete elements was effective:

> "…when I could see that they were blank, they didn't know what I was asking them… I would use an example…let's just say the question was 'did you find it difficult or challenging to create the lyrics?' – and if they didn't really understand that, I would [use] an example like 'you know, when we had to find words that rhymed'…so I'd try to use an example" (Researcher 1).

Caregivers described how the interviewers in their project were able to adapt the questions to suit emerging needs during the interview. Louise (C2) commented on her experience with her husband, stating that she felt the researcher was 'very skilled at helping him…if he didn't quite…I think she was able to reframe those in a way that he could understand, so he didn't have too much trouble'.

Researchers and caregivers also commented on the importance of being flexible in terms of the length of the interviews and monitoring for any signs that participants may want to withdraw. Describing one participant, Researcher 2 explained that the interview 'may have been incredibly short…because she gets a bit distressed and I would have…backed off and left her, and… [her husband] just took over and did his bit'. However, Researcher 1 was also careful to note that while they monitored ongoing consent, they felt that participants were generally able to indicate their preferences. '…I found in my experience, if they didn't want to do it, they just said "no I don't want to"…they were quite confident to say that'.

Sub-theme 3: Environment. The third sub-theme focused on the impact that the interview environment could have for participants with dementia; both researchers and caregivers reported that they observed familiar environments to be most beneficial for qualitative interviews. Researcher 3 commented that they felt that conducting the interviews in the same place where the music therapy sessions were held may have helped some of their participants connect the questions they were being asked to their experiences, stating that '…it could have…connected it more to what we'd actually been doing in music therapy, being in the same environment and the same room'. However, they also acknowledged a potential limitation of this environment in regards to a change of routine:

> "It was the same group in the same room, but instead of doing a music therapy session, we were doing interviews and data collection, so it was a little bit tricky because I think even though it was a familiar environment…it kind of even went the opposite way where they were expecting something and they didn't get it, they got something else. So there was…a little bit of…reluctance to participate in that focus group" (Researcher 3).

Researcher 1 recalled that some participants found unfamiliar environments to be distracting, which may have impacted their ability to focus during the interview. They reflected: '…it was also an unfamiliar environment; this person doesn't go into the staff member's office, so I wondered whether just the fact that it was a new environment made it hard for this person to focus'.

Amongst the caregivers, there was consensus that being able to participate in an interview in one's own home was most beneficial in terms of comfort, which in turn impacted ability to participate:

> '[Wife] in particular is totally comfortable at home, but taking her out of the home puts her on the defensive…' (Albert, C4).

> 'It's comfortable for the person with the dementia, doing as much of the interview side of things in their own home is really important…I think that's a very comfortable space for them'. (Louise, C2)

Researcher 2 also felt that being in the comfortable home environment supported one participant to be able to articulate themselves more, despite their aphasia:

> "she was relaxed and in her own home, and I hadn't seen her like that before…I'm thinking she was a little more empowered in her own space…she'd made me a cup of tea and she'd given me the biscuits, and she was kind of looking after her guest in a sense, and she was much more able to…articulate herself" (Researcher 2).

Sub-theme 4: Music. The fourth sub-theme related to the use of music within the interview itself. All three researchers reported that they used music in at least some of the interviews conducted, however, they each reported that this was not something they had planned, but did spontaneously when the need arose. Researchers 1 and 3 used musical artefacts from the music therapy programmes that they had run to successfully prompt memories during the interviews. Researcher 1 described using music '… as a way of jogging their memory, and when I did it with the first participant who said "what songwriting? I haven't done any songwriting?", and then I actually sang the songs and brought them out…that was really helpful'. However, Researcher 3 also raised a potential challenge of using music, in the sense that it may trigger memories associated with a particular song, rather than the music therapy programme, suggesting that, 'for some people it might have triggered the memory of just that song'.

Researcher 3 described using music as a means to make the interview environment more comfortable for participants, stating:

> "I think hearing something that may have been familiar, and was often quite joyful for them [participants] would have been a positive experience, especially with something that…intimidating like an interview" (Researcher 3).

Researcher 2 similarly described how they felt compelled to use music, even during quantitative assessments, in order to build rapport and create a sense of ease for participants:

> "I used music with [one dyad] big time…we took two hours over our first assessment – we had a great time, we didn't know each other, I remember using music then to engage [participant with dementia], but also because it just felt like the right thing to do" (Researcher 2).

While the caregivers in this project did not experience researchers using music in their interviews, they supported the idea that using music may enhance the interview experience for participants with dementia (and caregivers too). Maureen (C3) reported that she felt music would be a useful support for her husband's memory:

> "Oh that would definitely [help]… We did have the CD after a short time, and we would be playing it very often…but on a photo somehow he didn't connect that we were a singing group." (Maureen, C3)

Sub-themes 1–3 in this category each reflect findings from the existing literature that suggest various logistical and pragmatic advice to consider when preparing for qualitative interviews, particularly in relation to flexibility of time and interview style, and creating a comfortable space (Cridland et al., 2016; Mckillop & Wilkinson, 2004; Novek & Wilkinson, 2019). However, the fourth subtheme regarding the use of music to support the interview process is, to our knowledge, novel (Wood, 2020). Music is often cited as a way assist communication for people with dementia who also have language difficulties (Ayelet, 2018; Baird & Thompson, 2019; Brotons & Koger, 2000). This is due to both the capacity for music to stimulate neurological process involved in communication (Monroe et al., 2020), and to the capacity of music to express meaning and emotion, often more successfully than spoken word when the semantic meaning is challenging or not apparent to either the speaker or listener (Wood, 2020). For the latter reason, arts-based research approaches have been acknowledged to offer alternative accessible ways for people with cognitive challenges to express their perspectives and experiences (Haywood Rolling, 2013). The researcher-participants in the present study reported using music spontaneously, driven by their clinical instincts, in order to prompt memory and build rapport. The potential for music to be used in other ways, such as to aid participants in expressing themselves and in interpreting data, has yet to be investigated. Wood (2020) has proposed a method of musical transcription to understand dementia care environments, however, to our knowledge, no studies have attempted to use co-created music as data in understanding the experiences of people living with dementia. Given that music therapists in particular use music to support communication for people with cognitive challenges such as dementia (Ridder & Gummesen, 2015), the inclusion of music-based approaches to data collection and interpretation seems logical for music therapy researchers to consider in the future.

Theme 3: Relationship Dynamics May Impact the Interview

This theme explored the different ways that caregivers felt they supported their partners to participate in the qualitative interviews, and how relationship dynamics might impact the interview. The caregivers described feeling that they played an important role in supporting their partners to participate. Louise (C2) felt she was able to interpret non-verbal expressions from her husband:

> "There'd be something there, something about his eyes, or there'd be a little expression around his mouth where I'd think 'oh yes, that's a bit vintage [spouse]'. I can… tell what's going on there…" (Louise, C2).

This was echoed by observations from Researchers 2 and 3, who had experience conducting dyad interviews. Researcher 3 felt that 'family-caregivers know that person better than anybody else, so…some of the time they were able to…draw more out of the participant than I would have been able to if it was just the two of us'. However, both researchers and caregivers noted that while many caregivers were supportive, some caregivers may not have the skills to take on this role naturally. Researcher 2 described feeling challenged by some caregivers who perhaps did not understand why the researcher was attempting to interview their partner when they couldn't give a rounded response, stating 'she would give him space when I gave him a direct question and he would respond…but she would then correct him, so as soon as he'd finished…she'd say "oh no, it's not like that, it's [this]'.

Caregivers felt that in their situation, they and their partners were comfortable to share their experiences in front of each other, but emphasised that not everyone would feel the same. Louise (C2) stated: 'I wouldn't have been bothered by what [my husband] would say, I know there might be some people who find that a little bit challenging and might have wanted to be a bit more directive. But I wouldn't have been bothered by that'. Edward (C1) similarly observed: 'I think it's really one of those things that's probably different in each case… but you've got to go with the flow. Some people with dementia don't want their partner there'.

Pratt (2002) has previously reflected on the role that caregivers can play in an interview, and suggested that they may be able to help with framing questions in an accessible way, and also provide additional information. However, Pratt also acknowledges that this may not be the case where participants do not have a good relationship with caregivers, which may result in participants with dementia being spoken for. It has also been noted in the literature more broadly that while dyad interviews can help provide multiple perspectives, the format can also present challenges in allowing individual voices to be heard, and in discussing topics that may be more personal (Kendall et al., 2010). This reflects both the positive and negative aspects of dyad interview formats that the participants in this study reflected on. However, for the caregivers in this study, the dyad format appeared to be preferable in relation to supporting their partner. Therefore, researchers should take into consideration the relationship between caregiver and person with dementia in their planning, and consider how caregivers could work more collaboratively in interviews. Having knowledge of the participants' relationship dynamics and good rapport can assist the researcher to prepare to manage these dynamics in the context of the interview to ensure that all perspectives in the dyad are being heard.

Theme 4: Familiarity Fosters Comfort, Enables Preparation and Support

This theme focused on the importance that both the caregivers and researchers placed on familiarity between interviewers and participants for both creating a comfortable and supportive atmosphere for participants with dementia (and caregivers), and for enabling researchers to prepare support strategies. Edward (C1) described the first interview as being distressing for his wife due to having a stranger come to their house and ask questions. He stated that she was 'really not quite too good for the next couple of days'. In comparison, the final qualitative interview, he felt they had built a strong sense of rapport with the researcher over the 20-week programme:

> "Well I suppose I sort of got to know [researcher] a bit better…so it was sort of like…almost by that stage we were old mates, whereas when we first met [researcher], it was much more business-like…" (Edward, C1).

Edward felt so strongly about the importance of familiarity that he suggested future research implement a time for building rapport prior to the initial assessments:

> "If [initial assessments] could have been done the week or two after when she's met everybody…I know that you've got to get the base data, but if the base data could be one or two weeks into the project" (Edward, C1).

Researcher 2 described how they felt their relationship with participants benefited the interview itself, comparing it to when they first met the participants for baseline assessments:

> "I don't think it would have worked for someone without that connection…I just feel like with all the people I know, having that rapport is…important if you want to sit down and have a chat with somebody. Even when I met everybody for the first time and had our very first assessments… they're supposed to take half an hour – they took me nearly two hours…with each dyad… I think we needed to build some rapport before I could even ask them, you know, basic things." (Researcher 2)

Both the researchers and caregivers also felt that having some level of familiarity with participants prior to the interview is beneficial in helping researchers prepare to support the specific/individual needs of each participant with dementia. Albert (C4) felt strongly that he would not want a stranger interviewing his wife, as they would be unprepared:

> "It would always, I think, be more beneficial to know the person who's doing the interview, rather than just someone out off the street…it would be more difficult for her certainly, because strangers who do not know her and her difficulties might be probing too much and wanting a rounded response"(Albert, C4).

Researcher 3 similarly reflected on interviews where they had no prior connection to the participants, and how this may have detrimentally impacted the interview: 'If I came along…for one other group at least, so I knew [the participant]

a little bit better, and then might have been able to tailor the interview a little bit more to her'.

Familiarity and rapport have been recognised as an important way to create a sense of trust, safety and comfort during interviews (Kirkevold & Bergland, 2007; Novek & Wilkinson, 2019; Nygård, 2006). Several authors advocate for time to build familiarity for both comfort and pragmatic reasons, such as to tailor interviews to suit the needs of participants (Kirkevold & Bergland, 2007; Pratt, 2002; Wilkinson, 2002). Familiarity was not only highlighted in this theme, but was also present in themes 1–3, where participants highlight that familiarity between researchers and participants can improve a researcher's preparation and interviewing skill (Themes 1 and 2), and can help researchers understand relationship dynamics in order to support participants and balance voices during interviews (Theme 3).

However, others highlight that established relationships between researcher and participant can present risks regarding to both participant safety and interpretation of data (Nygård, 2006; Quinney et al., 2016). These challenges will be discussed in more detail in the section below, as we reflect on the implementation of a rapport building period.

However, others highlight that established relationships between researcher and participant can present risks regarding to both participant safety and interpretation of data (Nygård, 2006; Quinney et al., 2016). These will be discussed in more detail in the section below, as we reflect on the implementation of a rapport building period.

Theme 5: Broader Considerations for Accessible Research Design

Although not related directly to the initial research question, participants spoke more broadly about how researchers could consider how to engage with participants' perspectives throughout the research process.

Sub-theme 1: Contributing to research is important. Caregivers frequently expressed a desire to contribute to research. Louise (C2) felt that research is 'a really important thing to be doing, on lots of levels'. Albert (C4) similarly stated that contributing to research was motivating: 'we came…because we wanted to be in a choir…this was an added bonus…that we were part of that research project'. Edward (C1) described a similar motivation, however, he urged for more meaningful collaboration with participants: 'I think it's really just got to be meaningful…it's got to be more than tokenism'.

Sub-theme 2: Sustainability of programmes post research. Sustainability of the programme beyond the conclusion of the research project was highlighted by caregivers. Edward (C1) emphasised the importance of building sustainability into study designs, particularly when other opportunities are lacking:

> "…sustainability…it's an issue, it's no use…coming up with all these great findings and…just lip-service paid to implementation…some of us would argue that maybe some of that research money would be better off put into psychosocial programs around the suburbs" (Edward, C1).

Others also talked about how important it was to them that the programme that they had been involved in had been extended beyond the research:

> "… the researchers…have become part of our lives, rather than just an academic doing a study…you are very much part of our lives…it's something we very strongly support…as an ongoing thing." (Albert, C4).

Although this theme does not relate directly to the research question of making the interview process more accessible, it highlights important considerations that researchers should make when designing studies, in order to make research more inclusive and beneficial to participants. This supports current trends in research that call for participants to be included at all levels of research design to ensure research is meeting the needs of the people it intends to help (Australian Government, 2018). Recognising that people with lived experience are willing to be involved in research is also an important finding of this theme, as it challenges assumptions that participants find research to be burdensome (Wilkinson, 2002). Although the lack of participants with dementia is a limitation of the present study in this sense, we feel that it is noteworthy that the people we invited felt empowered to decline. This also adds support to existing reports that some circumstances, people with dementia can make informed choices about participation (Wilkinson, 2002).

Development and Implementation of Inclusive Interview Guidelines

Several findings from this study echo what existing literature suggests about how researchers can create safe and accessible procedures that support people with dementia to participate in qualitative interviews, particularly in relation to preparation of pragmatic elements (Cridland et al., 2016; Novek & Wilkinson, 2019; Wilkinson, 2002). Following data analysis, we created a list of important considerations that emerged from the data, and created guidelines for data collection in the subsequent Remini-Sing study. We compared this to suggestions in the existing literature, and added any important considerations that did not arise from our data (such as monitoring for ongoing consent during the interview process (Wilkinson, 2002). Table 2 depicts the guidelines developed in relation to which theme they were linked to. The following discussion contains reflections on the implementation of these interview guidelines in the

Table 2. Guidelines prepared for Remini-Sing interviews.

Remini-Sing Study Interview Guidelines	
Theme	Proposed Actions
Familiarity	'Getting to know you' period with choirs to be scheduled (researcher attends multiple sessions prior to interviews to build rapport with participants and get to know their individual needs and preferences) Offer of 'multiple interviews' option – participants can select to do multiple interviews over time (including interviews in different formats if they wish, such as a focus group interview, followed by an individual interview) Gathering information about participant preferences (including communication styles, support/access needs) through discussion with participants and/or music therapists facilitating the choirs (prior to interviews)
Pragmatic elements	Adapting initial interview questions to include alternative ways of asking/prompts, etc. (example in supplemental Online Appendix 2 Preparing visual tools (e.g. printed questions) for participants to use if required Offering participants choice re time and location of the interview Preparing list of songs/repertoire that participants have used within sessions to prompt memory, build rapport and/or to make the interview more enjoyable (and ensuring these were easily accessible during the interview should they be needed)
Role of caregiver/Relationship dynamics	Offering options for mode of interview (e.g. focus group, individual or dyad) Clarifying purpose/requirements of the interview (e.g. that any answer is acceptable/open to hearing any responses) Preparing information to provide to caregivers as to how they could be supportive during the interview (if required) Monitoring ongoing consent during interviews (not discussed by participants of this study, but recommended by previous literature (Wilkinson, 2002)

Remini-Sing study, and the implications to the broader literature.

Reflections on Implementation of Guidelines in the Remini-Sing Study

In the Remini-Sing study, ZT sought to interview participants of two choirs that had been newly formed as part of a 20-week RCT, and had continued on beyond the end of that project. Once the RCT component was complete, we began with implementing a 'getting to know you' period, which we hoped this would provide time for ZT to build rapport with participants, and to learn about their individual preferences and support needs. However, due to unforeseen circumstances, this was not able to be implemented across both choirs involved in the study; ZT attended Choir A for 8 weeks prior to data collection, but was only able to attend one session with Choir B. Although not ideal, the situation presented a number of learnings about implementing a rapport building period for the purpose of conducting qualitative interviews.

ZT observed a difference in level of participant comfort during the interviews between the participants from Choir A who, by the time of the interview, knew her well, and those in Choir B whom she had only met briefly. Additionally, participants in Choir A associated ZT with the choir, which seemed to aid in their recall of the programme, compared to some participants from Choir B, who appeared to have more difficulty recalling details of the programme.

Being more familiar with the members of Choir A also assisted ZT in tailoring the interview to meet the specific needs of participants, and, surprisingly, assisted in interpretation of data. For example, during rehearsals, some participants repeated stories about experience in their past related to music, which they also described during the interviews. Because ZT was familiar with the stories, she was able to distinguish these from participants' perspectives of the present-day choirs, which enabled her to ask clarifying questions during the interview, and also aided when interpreting the data during analysis. Additionally, having knowledge of these stories also helped ZT to support the participants with dementia in instances where the stories related to negative experiences from their past.

The findings from this study and ZT's reflection support the notion that building rapport with participants who have dementia has positive implications for participant comfort and interview quality (Kirkevold & Bergland, 2007; Novek & Wilkinson, 2019; Nygård, 2006). While past research has suggested that familiarity can help researchers prompt participants by drawing on their knowledge of the participant's experiences (Kirkevold & Bergland, 2007), to our knowledge, the potential for familiarity between participants and researchers to assist in interpretation has not been explored. The possible disadvantages of researcher-participant relationships, such as influencing or misinterpreting participant responses, have long been acknowledged (Fleming, 2018; Quinney et al., 2016). Although these are important considerations, the

emphasis on comfort and safety of participants, as well as the potential to aid in interpretation, suggests that the benefits of familiarity in this context may outweigh the risk of bias.

Practicality of Implementing Familiarity

While some research designs allow for dual roles of therapist-researcher, this will not be practical in every project. Incorporating time to build familiarity/rapport has implications for research funding, and further investigation is required to understand what 'minimum' amount of time is required for adequate familiarity to be established. Bolger et al. (2018) reported that contextual factors of a music therapy project influenced how much time and structure was needed for researchers to 'hang out' with participants before they were willing to 'buy in' to a collaborative project. Although this study related to action research and collaborative practice, similar conclusions could be drawn for building rapport for the purpose of creating an accessible interview environment. The length of time participants have been involved in the group under investigation, individual personality styles and skill/experience of the researcher may all impact the length of time required (Bolger et al., 2018). Future research should take into account such contextual factors, and make allowances in budget and planning for a flexible approach.

Although the findings of this study strongly favour developing familiarity between participant and researcher, the ethics of building rapport with participants solely to get a 'good' interview from participants should be considered (Quinney et al., 2016). Ethnographic research has a rich history of exploring boundaries in relationships between participants and researchers that offers insight into how benefits and risks of participant-researcher relationships can be managed (Iphofen, 2015). Ethnographic researchers advocate for clarity in communication about the role of the researcher and purpose of their presence (Sanjari et al., 2014) and how to facilitate closure when researchers eventually depart (Phelan & Kinsella, 2013; Stokes, 2019). Reflexivity is also recommended as a means to navigate the potential benefits and risks of familiarity; this can help researchers to anticipate potential 'ethically important moments' (Guillemin & Gillam, 2004), and be aware when boundaries between the researcher and participants become blurred (Quinney et al., 2016).

Limitations and Future Research

This study is limited in that it represents the experiences and perspectives of a small group of people, and therefore the findings cannot be generalised to other contexts. Despite our best attempts to recruit participants with dementia, their perspectives are lacking in this study, which further adds to disempowerment and underrepresentation of their experiences in the literature. We attempted to rectify this by amending our inclusion criteria to include people with dementia who had participated in other qualitative studies (other than our pilot study), however, the people we approached also declined to participate due to logistical challenges. Future research should seek feedback from people with dementia about their experience of qualitative interviews – this could be achieved by seeking feedback during the research process, so that participants can reflect on the experience as it is occurring. Despite these limitations, our findings do reflect what both researchers and people with lived experience have discussed in the literature previously (Cridland et al., 2016; Novek & Wilkinson, 2019). This adds support to the growing calls to recognise the importance of approaching qualitative research in ways that are specific to participant needs.

The guidelines included in this study may be useful for researchers intending on conducting qualitative interviews with participants who have dementia in the future, particularly those researching music-based programmes. Although these guidelines are relatively brief and specific to the Remini-Sing study context, they may be used by other researchers as a guide to preparing their own interviews. More in-depth recommendations for interviewing people with dementia have previously been published by Cridland et al. (2016).

The finding that music may be used as a support during interviewing is a novel finding in this study; future researchers can consider preparing musical tools, including artefacts from the programme under investigation, to support the interview process. These findings also support the potential for music-based research methods to be used in conducting research with people with dementia in the future; further research is needed.

This study highlighted the importance of approaches that are individualised and adaptable, and adds to the discourse calling for more specific training and preparation when conducting research with people living with dementia. Themes 1 and 5 of this study support the idea that people living with dementia are not only able to participate in qualitative interviews, but also willing and keen to share their perspectives and contribute to the knowledge base about dementia. Including people with lived experience of dementia in all stages of research design and implementation can ensure that adequate planning, preparation and execution are achieved.

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Supplemental Material

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