The impact of music in the treatment of persons with dementia

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Abstract

The increase in life expectancy brings with it a side effect, the increase in cases of dementia. Non-pharmacological interventions are low-cost and low-risk options to avoid overloading the health system, while providing quality of life for people with dementia, their families and caregivers. Music has been increasingly used to alleviate the symptoms of dementia. Despite being a neurodegenerative disease, dementia does not immediately affect the parts of the brain where music is perceived. The present study aimed to investigate the impact of music in the treatment of dementia.

Method: semi-structured interviews, with open-ended questions, were conducted with 12 participants: four music therapists, two academics/ music therapists, one nurse, two healthcare workers, one musician, one occupational therapist, and one PwD's family member. The ten women and two men were from Brazil (n = 2), Denmark (n = 1) and Ireland (n = 9), and their ages ranged from 22 to 69 (M = 44.5, SD = 16.17). Thematic analsys of the interviews was conducted.

Conclusions: More than mitigate symptoms of dementia, music interventions are safe spaces for people with dementia freely express themselves, having personhood in the forefront all times.

Keywords: music interventions; safe space; self-expression.

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The impact of music in the treatment of persons with dementia

Dementia is a blanket term for a damage to the brain that can impair memory, the ability to think and communicate clearly, and perform simple daily chores (The Alzheimer Society of Ireland, 2022). The improvement in life expectancy has resulted in a greater number of older adults all over the world (Swall et al., 2020), and, consequently, more people with dementia since this population is the most affected - especially the group over 70 years old (Xue et al., 2022). Alzheimer's disease is the most prevalent type of dementia among older people (Ziv et al., 2007), and so far, there is no cure for it (Srivastava et al., 2021). It is a neurodegenerative disorder that gradually disables cognitive functions (Ziv et al., 2007; Swall et al., 2020) like thinking, comprehension and judgement - in a much larger scale than predicted for a regular human aging process (World Health Organization [WHO], 2020). The progressive impairment can lower the individual's threshold for stress (Gerdner & McBride, 2015), and debilitate social and emotional skills, which can lead some people to become agitated at times, aggressive, and prone to verbal or physically inappropriate behaviours (Ziv et al., 2007) and changes in mood (Kuot et al., 2021). The decrease of general cognitive capabilities over time (Ziv et al., 2007) also provokes disturbed thoughts and perception (Kuot et al., 2021), and behavioral disruption, like yelling, hyperactivity, and lack of inhibition (Ziv et al., 2007). More than half of the people with dementia (PwDs), especially in the middle and late phases of the condition, show dementia-related problem behaviours (DRPBs) such as wandering, (Phillips & Diwan, 2003), unstable sleep pattern (Heim et al., 2011), and agitation, which can be extremely frustrating and painful for the family, caregivers, and the patient themselves (Thomas et al., 1997; Ziv et al., 2007).

It is predicted that every two decades the amount of people with dementia will double getting as far as 65.7million in 2030, and 115 million in 2050 worldwide (Petrovsky et al., 2015). From 1990 to 2019, for example, there was a 147.95% increase in new cases (Xue, 2022). These alarming numbers make the disease a great concern for public health systems around the globe (Swall, et al., 2020; Sousa, et al., 2021) due to its substantial economic impact (Ahessy, 2017). Although there is evidence that pharmacological treatment can postpone and attenuate DRBPs (Soufineyestani et al., 2021; Swall et al., 2020), it is also possible to find literature on the limited efficacy of some medication (Chancellor et al., 2014) and the risks they can pose for PwDs, like cardiovascular deficiency (Sousa, et al., 2021), or even death (Dennis et al., 2017; Sousa, et al., 2021). Therefore, it makes sense that nonpharmacological interventions have been gaining ground (Kuot et al., 2021) as an alternative in dealing with dementia.

Expanding the options

Designed in a unique way that considers the relationship between patient, caregiver, environment, and healthcare system (Ziv et al., 2007), non-pharmacological interventions are lower in cost (Swall et al., 2020) and risk (Sousa, et al., 2021), more accessible (Sousa, et al., 2021) and considerably easier to put into practice (Sherratt et al., 2004) when compared to allopathy. Some of the alternative methods being applied are pet therapy (e.g. Baek et al., 2020), reminiscence therapy (e.g. Tominari et al., 2021), occupational therapy (e.g. Kim, 2020; Wenborn et al., 2021), aromatherapy (e.g. Jimbo et al., 2009), and music therapy/intervention (e.g. Kuot et al., 2021; Soufineyestani et al., 2021). Due to its peculiar pathways in the human brain, music has been increasingly studied in recent decades (Jacobsen et al., 2015; Peretz & Coltheart, 2003) and adopted as a tool on evidence-based interventions for PwDs (Ahessy, 2017), endorsed by medical professionals and caregivers as a valid form of mitigating symptoms of dementia and promoting quality of life (Dahms et al., 2021; Soufineyestani et al., 2021).

Music in the treatment of dementia

Powerful presence in our lives (Kelly & Ahessy, 2021), music is being used in dementia care in different capacities and forms, such as choirs (e.g. Ahessy, 2016), music in the background (e.g. Sherratt, et al., 2004, Ziv et al., 2007), sing along (e.g. Swall et al., 2020), live and recorded group music interventions (e.g. Clare & Camic, 2020), and music therapy (McDermott et al., 2014; Vaduva, & Warner, 2021), to cite some. Even though affected by a neurodegenerative condition, people with dementia are still capable of perceiving and being stimulated by music because the cognitive processing of music and language happen independently from each other in the brain (Angelucci et al., 2007; Gerdner & McBride, 2015). Jacobsen et al. (2015) found that the regions in the brain where normally musical memory is encoded are surprisingly preserved in Alzheimer's disease. That is why long-term musical memory tends to last longer in PwDs than regular short-term memory, autobiographical long-term memory, and language (Dahms, et al., 2021).

Interventions based on music have been known for producing benefits that permeate both physiological and psychosomatic fields (Soufineyestani et al., 2021). Literature has shown biological improvements, like blood pressure regulation (Raglio et al., 2014); and psychological boosts, with mood enhancements, (Blackburn & Bradshaw, 2014); to emotional uplifts, in the form of stronger self-esteem (Chancellor, Duncan, & Chatterjee, 2014), and cognitive progress, with better communication skills and environmental awareness (Soufineyestani et al., 2021). The positive effects can linger for hours or even days in people in severe stage of the disease (Dahms, et al., 2021; Sherratt, et al., 2004; Soufineyestani et al., 2021).

Unsurprisingly, activities involving music and dementia have been going on for decades, supported by studies, reviews, and interventions (Robb et al., 2010; Swall et al., 2020; Dahms, et al., 2021). Guidelines are being designed to offer methodology for interventions (e.g. Gerdner & McBride, 2015) and studies report (e.g. Robb et al., 2010), while research around the world has been collecting promising results in areas such as improvement in social interactions, moods, and quality life not only for PwDs but also the caregivers (Kuot et al., 2021); well-being and relaxation (Ziv et al., 2007); rediscovery of sense of self-identity, competence, belonging and independence (Hays & Minichiello, 2005).

Person-centred

One aspect in common in studies with positive outcomes is the attention to the PwDs' needs, rather than an approach that aims to suit everyone, as if people with a diagnosis of dementia were a homogeneous group with the same demands and necessities. These studies are aligned with Kitwood's person-centred approach that brought the PwDs from the margin to the centre of the treatment, where they can be seen, heard, and respected (McDermott et al., 2014), and no longer a "problem" (Kitwood, & Bredin, 1992). First proposed in beginning of the 1990s (Spector & Orrell, 2010), the person-centred approach symbolised a big shift from the archaic concept of mental handicap as once dementia was known (Willis, 1624 in Spector & Orrell, 2010). Kitwood advocated a care that took into account the "complex interaction between personality, biography, physical health, neurological impairment, and social psychology" (1993b, in McDermott et al., 2014, page 706). Preferred music, observation of behaviour of each individual separately and prior to a study, individualised and personalised sessions, respect to preferences and background appeared repeatedly in the data reviewed for the current study (for examples, Dahms et al., 2021; Heim et al., 2011; Sousa et al., 2021).

Present study

Although it seems that the field has been reaching positive milestones, it is paramount to bring to the fore some deficiencies that still need to be improved and adjusted. If, on the one hand, several countries are adhering to the National Dementia Plan and recommending music in a daily basis in the treatment of dementia (Alzheimer’s Disease International, 2020, in Dahms et al., 2021), thus demonstrating the relevance and strength of the intervention/ technique, on the other hand the existing literature requires more development (Heim et al., 2011; Sousa et al., 2021). Reviews and researchers have highlighted the necessity for more evidence-based studies, detailed interventions, randomised controlled trials, standardised data and measures, and even side effects better reported (as did Heim et al., 2011) in order to substantiate the intervention as a scientific reliable and feasible tool in dementia care (Heim et al., 2011; Sousa et al., 2021).

The present study sought to investigate, in the form of a qualitative research, how music can help PwDs, their families, caregivers and even the health system to navigate the difficult path of dementia in the safest and smoothest possible way. Interviews conducted with family members, music therapists, occupational therapist, nurses, musicians, academics, and healthcare workers explored their personal and professional perspectives about what is raised from the interaction between music and dementia. The qualitative format works with the collected data in a more exploratory way, enriching the statistical analysis of the quantitative research already so abundant in the literature on music and dementia (Gaskell, 2000; Sutton & Austin, 2015). The aim of the present study was to find answers to questions such as whether it is valid as a non-invasive, low-cost and low-risk procedure as stated in the literature; how it is applied, by whom and for whom; if there is any positive outcome from the intervention, how this translates into the daily life of a carer; whether in practice there is a difference between the results obtained in a music therapy session and non-structured music interventions; what needs to be done in order to be as effective as possible; if present, how the person-centred approach was applied; whether it is really possible to observe the benefits mentioned in the literature in PwDs; and, most of all, what participants think and see that music can bring to PwDs.

Music therapy/music intervention for PwDs is an evolving area, with the aim of establishing itself as a scientific procedure. Hearing directly from those who are working with music and dementia in different capacities, witnessing music being applied in a healthcare setting, and hoping that the relative benefits from the intervention, hopefully will add to the already encouraging and increasingly reliable discoveries and research on the topic.

Methods

Design

The study design was qualitative in nature, carried out from a phenomenological approach. A piece of research structured on a qualitative methodology enables a richer and deeper exploration of the data collected (Farrugia, 2019), even more so when one of the aims is to seek answers for ‘why?’ and ‘how?’ questions (Marshall, 1996) like the present one. The design can act in partnership with quantitative studies providing content for surveys (Sutton & Austin, 2015), or, conversely, deepening results obtained in quantitative studies (Gaskell, 2000), that way adding great material to standardised quantitative data within the scope of studies of themes such as aging and older adults (Luborsky & Rubinstein, 1995).

The present study collected data through interviews, more specifically, semi-structured ones, with open-ended questions. Although it is possible to find articles in the literature pointing to the format as suitable for a qualitative a type of investigation for features like malleability (Gaskell, 2000), versatility (Kallio et al., 2016), and reciprocity between the parts, i.e., reflexivity (DiCicco-Bloom & Crabtree, 2006), the premise does not have consensus among academics. For Potter and Hepburn (2005), for example, the method is used to excess in modern qualitative psychology and needs to be improved by fixing what they consider to be problems within it, such as lack of proper training from the researcher to perform an interview, different ways of transcribing that may lead to poorer analysis, and even a predetermined agenda discreetly permeating the interviewer's questions. Potter and Hepburn (2015) call for more studies on the subject and suggest naturalistic records as an alternative to it, whenever is possible.

While Thematic Analysis was the method through which data was analysed, the approach before and during the obtention of these data was phenomenological. That is because the technique would allow a deliberate attention to angles and details that, very often, are not noticed in daily life (Miller, Chan, & Farmer, 2018), creating an environment where interviewer and interviewee act together, in co-creation (Donalek, 2004). The researcher's appreciation for the topics here studied, both music as treatment and the treatment of dementia itself, converged with the phenomenological framework where the personal account for the theme can and should be incorporated (Donalek, 2004). However, this personal interest happened throughout the choice of topic and the interviews (in case of the latter, may have acted as a limitation in the end), but not during analysis of the data.

Participants

The participants were recruited online and in person using non-probability sampling and, for the most part, through purposive strategy was also applied but to a much lesser extent). The approach proved to be the most appropriate, as the focus of the study was to interview individuals directly or indirectly related to music intervention/music therapy in the treatment of dementia. In a non-probability sampling the selection is not random as the researcher looks for a very specific target in the population, which means that not all people have the same chance of being included/invited (Luborsky & Rubinstein, 1995). The sample for the present study was planned to cover a representative range of different perspectives and points of view on the subject. That is why the option for purposive strategy which widely used in qualitative studies (Farrugia, 2019; Marshall, 1996) and guided by a clearly defined objective (Farrugia, 2019; Luborsky & Rubinstein, 1995) in order to obtain insightful data on the topic being studied (Vasileiou et al., 2018).

To achieve the desired sample, the researcher sought participants in a from a variety of institutions. The Irish Association of Creative Arts Therapists (Iacat) was the starting point. The organisation's website makes available the names and specialisation of its members, some of them with contact number and email address as well (https://www.iacat.ie/find-a-therapist-form). The researcher emailed all the music therapists with experience in dementia, after additional online research on their body of work. The second front was the 14th International Dementia Conference- Fostering a Dementia Inclusive Ireland, promoted by Engaging Dementia in November 2022, in Dublin. There, the researcher met two future participants, one whom became the pilot interview and the other the lengthiest meeting of the study. From the pilot interview, the researcher learnt about a scale that measures the effect of music therapy in PwDs, developed by an international university. After reading about the institution's robust educational and research programmes in music therapy and dementia, invitations were sent to three academics/ music therapists. A choir dedicated to PwDs was another source of participants. The day centre responsible for the singing group responded positively to the researcher's request and liaised with the music director, who not only agreed to participate but also referred a relative of two members of the choir to the study. According to Marshall (1996), the referral was the snowball sample within the purposive technique since one subject suggested another good possible candidate to the study. The same happened later in the process when a participant recommended a music therapist whose expertise is in neurologic music therapy. There was an attempt to establish communication with this professional and also with 12 centres specialised in dementia care. Finally, based on the researcher's personal networking, four professionals were invited to join the study: a Brazilian occupational therapist, who took the same English course in 2019; a healthcare relationship manager from a previous workplace; and two healthcare workers related to a college classmate. Although the contacts came from a personal sphere, there were no ethical obstacles - as the first talked about work experience while living in Brazil before meeting the researcher, the second was no longer professionally linked to the researcher, and third did not have a relationship with the researcher prior to the study.

Thirty people were contacted overall, 25 by email, three by WhatsApp message, and two in person during the congress. Of these, fourteen answered and accepted the invitation.

However, one did not respond to further correspondence and the other, after agreeing to participate in writing for reasons of time and convenience, received the questions by email but declined participation due to personal circumstances. The final sample of 12 participants is composed of four music therapists, two academics/ music therapists, one nurse, two healthcare workers (being one of them retired), one musician, one occupational therapist, and one PwD's family member. The ten women and two men were from Brazil (*n* = 2), Denmark (*n* = 1) and Ireland (*n* = 9), and their ages ranged from 22 to 69 (*M* = 44.5, *SD* = 16.17).

The literature is not unanimous when it comes to drawing an ideal number of participants for qualitative research. If on the one hand a sample size of 12 is cited by some authors as enough to richly explore themes, i.e. data saturation (e.g. Guest et al., 2006, and Schweitzer et al., 2015, as cited in Braun & Clarke, 2019; Luborsky & Rubinstein, 1995), on the other hand it is possible to find papers backing the idea that "saturation concept as a marker of research quality is not applicable to all qualitative methodologies" (Farrugia, 2019, p. 1) and that, as opposed to quantitative research, in a qualitative investigation more participants does not necessarily translates into more data (O'Reilly & Parker, 2012). The present study based its sample size on the feasibility of gathering participants, taking into account practical aspects like time and financial resources (Luborsky & Rubinstein, 1995) and if the group recruited was in enough sufficient to generate appropriate and rich content to answer the research question (Marshall, 1996; O'Reilly & Parker, 2012; Vasileiou et al., 2018).

Materials

Of the 12 participants, one joined the study via written text for the purpose of time and convenience, while 11 granted live-recorded, semi-structured interviews. The format can be described as being somewhere between a structured survey with fixed questions, and a participant observation or ethnography where the focus is on absorbing the environment and its symbols and signs rather than standard investigation (Gaskell, 2000).

Initially, three interview guides with open-ended questions were tailored for each category of possible participants (music therapists, a PwD's family member, and a healthcare worker and/or manager). The final sample, however, had some different professionals included (academics, occupational therapist, and musicians) and no healthcare manager, so the core of the guides was maintained, but adapted to each profile (see Appendix A). The flexibility to ask follow-up questions, and the possibility to adapt the script according to the interviewee profile are in accordance with the nature of qualitative research questions stated by Creswell (as cited in Doody & Bailey, 2016).

The research material was piloted, and its data included in the main analysis since no changes in procedures were necessary. The interviews sought to understand, through the questions, the impact of music in mitigating the symptoms of dementia in the light of the experiences, perceptions, and know-how of the participants. Prior research on the topic and on participants' body of work were conducted to align with the literature in semi-structured interviews (Kelly 2010; RWJF [Robert Wood Johnson Foundantion], 2008; Wengraf, 2001 cited in Kallio et al., 2016).

Procedures

All the interviews (except for the one in writing) were recorded and later transcribed for analysis. None were performed in person, in some cases for convenience, but in others by necessity, as one participant was overseas and two in Irish counties different from the researcher. Nine subjects were interviewed on a one-to-one basis, and two at the same time, as they were related and doing so was more convenient and less time consuming for both. Two participants were Brazilians like the researcher, so their interviews were carried out and transcribed in Portuguese and coded in English.

The participants recruited online first received an invitation message introducing the study (see Appendix B), and displaying NCI's Ethics Committee approval letter (see Appendix C). After demonstrating an interest in participating and having the date of the interview agreed, all the participants received a confirmation message where they could find attached the information sheet about the study (see Appendix D) and the consent form to be signed and sent back (see Appendix E). Whenever it was requested, the interview questions were sent beforehand. All participants received the debriefing sheet after the meetings (see Appendix F).

Interviews were held for 9 to 59 minutes, with an average interview time of 35 minutes (*M= 31.72*). The two longest conversations were with music therapists and the shortest ones with healthcare worker and family member of a PwD, where personal impressions and experience, although rich and informative, did not result in long interactions.

Eight interviews were conducted via Zoom, using the application BuildBetter for recording and transcription. One took place over the phone with the speakerphone turned on so that Zoom could capture the audio and consequently allow BuildBetter to record and transcribe the conversation. Microsoft Teams was the platform chosen by the two participants who were interviewed together. The messaging application has the facility to record and transcribe meetings, which was used by the researcher on this occasion. For backup purposes, some of the interviews were also recorded on a mobile phone application. All the recordings, with no exception, were made using the researcher's personal devices: computer Dell Inspiron 13, and Huawei P30 lite mobile phone, both password and fingerprint protected.

Ethical considerations

The current study adhered to the ethical guidelines from the National College of Ireland (NCI) and the Psychological Society of Ireland (PSI) and was fully approved by NCI Ethical Committee.

The participants were informed as to the purpose and nature of the study directly from the researcher by emails and/or messages, as well as through the documents sent before and after the interviews (information sheet, consent form, debriefing sheet, previously mentioned). The forms also contained the subjects' right to withdraw and the guarantee of complete anonymity after transcription.

To safeguard identities, any potentially identifiable information was omitted from the data upon transcription, and recordings were destroyed. Other documents containing identifiable information were password protected and stored on a personal computer to which only the researcher had access. The participants were identified as TCC (Trabalho de Conclusão de Curso) which means Final Year Project in Portuguese.

Data analysis

It is required to acknowledge that, as this is a qualitative study, the researcher's opinions and beliefs on the subject can affect the interpretation of the data. The researcher has great interest in investigating non-pharmacological interventions, mainly music, and mitigating the symptoms of dementia.

Data was analysed according to Braun & Clarke's thematic analysis framework (2006), adopting the inductive (data-driven) analytic way, from an essentialist theoretical position. The six steps were followed in the same order as recommended by the authors. First, the researcher transcribed the interviews, becoming familiar with their content. To ensure the written versions were accurate transcriptions of the recordings, the researcher re-examined them on multiple occasions. Codes were first generated during these transcriptions and then improved upon rereading each interview. To allow a full physical view of the dataset, the interviews were summarised and posted on the wall on A1 flipchart sheets (see Appendix G). Codes were then manually generated, resulting in forty-six of them. Nine different drafts were made organising codes into possible themes and subthemes, until the researcher was able to reach data saturation. The initial version of eight themes and eleven subthemes was refined to a final version comprised by two overarching themes and five subthemes (see Appendix H), selected and organised in a meaningful and coherent way in relation to the research question of the present study.

Results

Two overarching themes emerged from the analysis of the interviews (*n* = 12), which will be referred to as (1) Generating values and (2) It comes with the territory. While the first revolves around the outcomes from the relationship between music and PwDs, the second focuses on specific aspects of Music Therapy and its current status in Ireland. Both themes are composed of subthemes, which are indicated and discussed within each segment.

1. Generating Value

In addition to entertainment, music appeared in the study as a powerful instrument capable of generating valuable assets to PwD, like neuroplasticity, self-regulation, socialisation, brain exercise, and feelings of acceptance. According to a music therapist from the database, it all starts as a chemical reaction in the body, which can be particularly beneficial to regulate some symptoms of dementia:

> All those good hormones, like for example, oxytocin, 'good happy hormones' I call them, are released when we listen to music. We do get that boost. So that can help to improve mood, which for people with dementia is a big area of concern because moods can fluctuate so rapidly as well. So it's a bit of a natural non pharmaceutical mood stabiliser. (TCC4)

The "boost" was observed across the varied universe of interventions present in the study. A retired healthcare worker reported that Sunday musical performances in a nursing home changed the residents' mood for the rest of the day, "like somebody [had] put a switch in their heads, it was *unbelievable* (…) Some of them would get up to dance with the nurses, with us!" (TCC12). A choir presentation video, produced remotely during Covid to keep activities running, had a grounding effect on one of the members: "Now when I come home if my [relative] is having trouble, (…) we sit down and we watch the videos of this choir singing. And it will absolutely bring [them] back to some sort of normality" (TCC14).

Similar perception was shared by the nurse who every morning turned on the radio for the wards: “I find once you have music in the background, it's something for them to concentrate on and it makes a huge difference to us”. Even for those in more advanced stages of dementia, music would still have an effect, as noted by the choir’s musical director: “they would be probably less, I suppose, actively involved, but even sometimes when you see somebody tapping their foot or tapping along or something, at some level it's happening for them” (TCC11).

Two studies carried out by participants have also collected promising results. In one them, six weeks of music therapy in a PwD aided the decrease of agitation, which made the team “assume that when psychological needs are met in music therapy, BPSD [behavioural psychological symptoms of dementia] decrease” (TCC8). In the second one, a pilot study conducted over two days in a hospital ward, “saw that there was a 90% increase in eye contact, 40% increase in laughter, and a 60% increase in vocalisation” (TCC1).

On some occasions during the research, the music sessions appeared to be as valuable for the facilitators as for the PwD, as the choir director and a music therapists reported. “Oh, it's very emotional. (...) When you see somebody respond… To the extent I benefit from it as well, I really do, because I come out of those sessions on a bit of a high” (TCC11). “Sometimes it can be difficult to quantify the effect and the value in something like music therapy because it's a very much felt experience” (TCC2).

Whether in highly structured methodologies or in simpler interventions, music was identified in the analysis as an effective medium being used by the participants for therapeutic reasons. As synthesised by the occupational therapist: “no matter how much brain damage a person has or dementia, music can activate some things that conversation cannot” (TCC6).

1.1 Music as a medium

Working with PwDs, who are mostly older adults (as supported by the aforementioned literature), was described as a delicate task as some of them in addition to regular symptoms, might also be dealing with “depression caused by the diagnosis” (TCC6), or “going through a difficult time or is experiencing stress or somebody who's having difficulty maybe even assimilating being in the nursing home” (TCC2). Music, then, seemed to be a more suitable medium than the spoken word for reaching this population in a caring but efficient way. “I really believe that music has many meanings and brings back many memories. (...) They [members of the occupational therapy group] could talk about the feelings related to those songs and even reframe the meaning of those experiences. (…) Therapies would start from music” (TCC6)

> You're already quite vulnerable in that instance, and it's not always inviting to someone who might be shy or nervous. So, music I would always say it's a non-invasive therapy. You don't have to talk. (…) You come in and you explore. (…) And if you're trying to process something, you can bang it out on a drum, or you can play it out on a keyboard. (TCC7)

Music could enhance communication (“When I knew about their life and preferences, I was able to have mutual contact with them through singing”, TCC8), and promote a gentle form of therapy when cultural context could impose a barrier for connection.

> If you think culturally here in Ireland opening up to or trusting a therapist might be difficult for an older person because back in the day, therapists were priests and clergy, and even then there was a certain amount of mistrust of how much you could disclose or open up. And then there was this other punitive element to kind of associate with the confession box. Music therapy breaks down that kind of mistrust of professionals. (TCC4)

Music was shown to be able to "access other memories of the person" (TCC10), "activate people who might be a bit withdrawn" (TCC2), and be used as a therapeutic resource to promote neuroplasticity in rehabilitation treatments - which would give PwDs more chances "to fight the disease or reduce the symptoms of depression, or the sadness of knowing the diagnosis and the disease progressing slowly" (TCC6). In some cases, music was the key to access PwDs.

> One of my regular clients, her sister said she found it so much easier to communicate with her sister through music. (…) a particular song that would mention the woman's name would initiate a conversation between her and her sister. (TCC3)

> There was this woman… you really weren't able to speak to her during the day. Normally she was quite agitated and ready to go and trying to leave the hospital. We carried out music therapy in her and she sat down, she was smiling, and nodding her head. And then she started telling us about stories when she was 22 years old, how she used to work in a bakery and that song used to play a lot on the radio when she was in the bakery. (TCC1)

But, above all, the analysis showed that the interventions with music are seen by most participants as a chance to offer some light and support when logic seems to be fading away, making life more challenging for PwDs.

> Sometimes people think is about happiness. It's not. (…) For dementia patients it can be about decluttering their minds. (…) Sometimes it's very obvious that they're struggling with being a part of our world. So, we have to try and be a part of their world and bring the two worlds together, in some way to make life better, easier for them. It's not about us. It's about them. (TCC3)

TCC3's account touches on the second subtheme identified by the analysis: the relevance of promoting a safe space for PwDs during the music interventions.

1.2 Safe Space

Analysis of the dataset revealed that in order to generate values, any type of music intervention carried out on PwDs should be flexible to adapt to their needs and circumstances, i. e. “meet each client where they’re at” (TCC4). “It’s about whatever they want the session to be. (…) You might go in with the plan, but the plan might go out the window because of how everybody is that day” (TCC3). It became clear in the analysis that when this premise is not met, it is difficult for PwDs to engage, enjoy, let alone benefit from any musical activity that is being presented.

> I was trying to get my [relative] involved in different things and to get [them] to go out during the day. (..) we started with a different choir, but the choir was very.. well, had nothing to do with dementia, and they were very serious about what they were doing. So, my [relative] wasn't fitting in because [they weren’t] doing exactly what [they were] supposed to or know what [they were] supposed to do. (TCC14)

The experience was completely different when the family found a choir focused on people living with dementia: “from day one absolutely fell in love with them (…). If my [relative] wants to sit there and not do anything, [they] just listen to the others (…) It's just easy going, relaxed, welcoming for everybody” (TCC14).

Being able to provide this space where PwDs feel comfortable and confident to be themselves and reassured they are seen and heard is the common ground the analysis found between all participants in the current study, regardless of it was a music therapy session, a choir practice, or a sing along music intervention. “My priority with people is the experience that gives them in the moment, the experience of being able to express themselves when maybe they otherwise find it difficult to” (TCC11).

> Hold that space for them and allow them to express anything they want. (…) sometimes the person might only have the words left or might only have the

> expression in their eyes left, be that sadness or be that happiness, because it's not always about a person being happy or sad, it's about being able to express the emotion they feel. (TCC3)

The influence of Kitwood’s person-centred approach (previously mentioned in this study) is clear in many interventions as the sessions were shaped first and foremost to respect PwDs’ personhood. “Sometimes I have my participants coming and someone might be in a really bad mood and might not want to participate in the group. That's okay. It's about respecting boundaries” (TCC7).

> Ultimately, I just try and make it a partnership. (…) I want the client to be as independent as possible, to have as much choice as possible. I don't feel like the expert. I'm just there to facilitate music experiences and try and follow the client's lead, whatever they offer. (TCC2)

And they surely had a lot to offer, as the examples below show. Analysis detected that the safe space held during music sessions reached some PwDs in meaningful levels.

> When I started out first, I remember one of my colleagues saying, ‘oh, don't worry about such a person’ and it was quite obvious that the person was very distressed and that was their kind of norm for part of the day. (…) I was singing Danny Boy (…) and I looked over after a while and I noticed this person had become very calm and was tapping along with their finger. And later on she was singing (…) Obviously something in her had awoken and she wanted to join in, express herself, become a part of what we were doing in the midst of all this chaos, because it's quite obvious that her mind was a little bit chaotic and she couldn't express that. (TCC3)

> [about a quiet, head bowed lady during the few times she attended a music therapy group carried out in a hospital waiting room] There was one week in particular where she just set out singing solo, on her own, and the group just were

> engaging with her but giving her the space to have her moment. (…) And you could see her almost come to life and you see it in people's eyes as well. (…) I could see in her that she really received something from that group. You could see her confidence blossom in those moments. (TCC7)

Two situations stood out in the study for having applied the same person-centred principles, but starting from different starting points. One was done instinctively, while the other was built upon a theoretical framework.

a) A Maternity Care Assistant (TCC13) during their healthcare worker training at the hospital worked a day with a PwD who had recently had a hip replacement. Over the day, the patient was becoming frustrated and annoyed because they were not allowed to stand up. With no experience in the area, and worried about the situation, TCC13 called a relative during lunch break, who advised playing some music to the patient.

> When I asked [them] who [they] liked to listen to, [they] said Elvis. So I played a few Elvis songs on my phone and [their] mood just changed *so much*! [They were] tapping the feet and singing the lyrics. For the rest of the shift, [they were] in a much better mood (…), more chatty, asking questions and stuff like that. (…) Right after the music every time [they] would go to get up and I would say ‘would you sit down for me’ and [they'd be] like, ‘yeah, of course’ or ‘certainly’. (…) I was like ‘whoa’, this is like magic. (TCC13)

b) In this situation, as opposed to instincts and common sense of the power of music, validation technique was used to facilitate a nursing home resident to make their way back to their baseline after being distressed for most of the time prior to the one-to-one music therapy session. The citation below was extracted from a published case study carried out by TCC8, whose participation in this present study was in writing:

> (…) Mrs D has damages in her frontal lobes and is not able to be her own ‘conductor’. When she is in hyper-aroused state it adds to her anger if I mirror or match the anger. After the first two minutes of the session Mrs D does not join in the singing or verbalise anymore, and there is a clear decrease in her heart rate (…). The context and social cues make it clear to her what is going to happen and support her memory processing, and it is possible to regulate her arousal level by the songs. She calms down and later seems attentive and open for dialogue, and I sing familiar songs that I feel share her feelings of sadness or melancholy. In this way I use a validation technique acknowledging her emotions and responding to them. (TCC8)

Within the safe space philosophy, the analysis identified that choice was essential during an intervention. The genre, the song, or the type of music needed to come from PwDs (whenever possible), or be related and relatable to them, to their story, to their personal preference. It was about giving voice to PwDs and respecting what they said. “We'd go around and everyone would get to pick a song (…). Having your voice heard, being acknowledged in a group of your peers really boosts your confidence. It really helps with your self-esteem” (TCC7). In a hospital, the radio brought the sense of home to the wards in the mornings:

> If you're from [name of the county] this particular radio station is on in every household if you're over the age of 50. It's quite an integral part of everyone's life. So I always make sure it’s on. It kind of creates a calmer sense because they're listening to music they're familiar with. (…) People of that age group don't care about Beyonce or Coldplay. That's not any good. You have to really make sure it's relevant to them. (TCC1)

In fact, the use of familiar songs was a pattern among participants. Not only because it would be more immediately accessible for PwDs, but also because of the possibility of evoking memories and reminiscence. “Every Sunday they’d have someone come in [to the nursing home] (…) like one or two people to play music. (…) And when they played songs from years ago, it would bring them back!” (TCC12). “With the use of familiar music, we would encourage people to talk about memories associated with the music or why the music is important to them”. (TCC2)

> [in the choir] we’re trying to sort of theme performances, so it's not just a collection of songs, because part of the fun is when you have a theme and people have stories about how they remember (…). I think the fact that a song will trigger reminiscence, it'll trigger stories from their own lives. (…) There was one person told a story about the Theatre Royal [theme of their first performance]. Just to remember that story and tell us it, I thought it was brilliant! (TCC11)

The universal nature of music can open up a sort of gateway to a person. A really quick way to connect with someone is by asking them about the music that they like to listen to or songs that have meaning for them. Music therapy in that sense can facilitate reminiscence for older people while also remaining in the present, because music is very present, we're not disorienting the person. It's very much rooted in the present, but facilitates that piece of reminiscence. (TCC4)

Throughout the analysis it became clear that the careful and conscious development of a safe space was important to avoid negative effects on PwDs during music exposure. This has led to the conclusion that music interventions in the treatment of dementia may be of low-risk, as stated in the previously mentioned literature, but not completely free from causing an adverse effect.

1.3 Not risk free

The analysis spotted some possible negative effects from exposure to music. One is neurological. According to TCC10, who is music therapist and academic, after long contact with music, most of the structures of the frontal and prefrontal cortex of the brain start to be deactivated in favour of more internal structures related to the hypothalamus, midbrain, among others. This shift can lead to less conscious or even unconscious states of mind. “The same way music can provide several positive effects related to a person’s expression, it can lead to particular or altered states of consciousness that will be difficult for someone to handle without the support of a professional” (TCC10).

In the psychological hemisphere, a wrong choice of song can trigger emotional reactions in PwD:

> Sometimes someone would request a song, but it could be a sad song that maybe stirred a memory of a lost loved one. Or someone would say, ‘oh, when I was full of energy and I was running around’ and now they might not have that mobility. (TCC7)
>
> With patients with dementia it stirs a memory or evokes a memory and they might not even be able to tell you themselves what that memory is but you can see the change, could be something sad, somebody could cry. (TCC3)

Prior knowledge of the PwD’s life and background was shown to be an advantage to avoid some of the potential pitfalls. However, the study found that while a participant had the chance to structure sessions after preliminary assessments on “the musical preferences of the person and the family” (TCC10), others did not have the same opportunity - either because of the informal format of the nursing home or because families “don't necessarily think to tell you a piece of music that might upset or might impinge. If the client or the residents can tell you ‘oh, I hate such a song’, (…) but sometimes we don’t get that information” (TCC3).

These neurological and psychological risks involved in the use of music in dementia set off campaigns to make music therapy a state recognised profession.

> We have been asking for the regulation of the profession in several countries around the world so it is not anyone who acts as a music therapist. (…) you have to master the language, the tools to not offer any of those effects. (TCC10)
>
> The first thing anybody I know will say to me is, 'what about somebody who can't tell you that this is upsetting them?'. Well, this is where the involvement of family and the involvement of staff and the importance of multidisciplinary teams, because you're looking after the whole person. It's not just me doing a music therapy session (…). It's about me participating as part of a team. (TCC3)

The specificities of music therapy and the regulation of the profession, mainly in Ireland, emerged in the analysis as such a strong theme that it needed to be properly addressed, in its own theme within this study.

2. It comes with the territory

Of the 12 interviewees for this study, six were music therapists and all six, in one way or another, brought up the differences between music therapy and music interventions. Four of them mentioned in their arguments the benefits of other interventions, like sing along, band presentations, music in the background, but never losing sight of what they consider to be a big difference between procedures and results. However, the discussion about what is and what is not music therapy in many moments intersected with the validation campaign and future registration with CORU in Ireland.

2.1 Is everything music therapy?

"The difference that makes it therapy is that we are using music to achieve non-musical goals". (TCC4) This belief reflects, in some extent, the general feeling among the music therapists in the database of what may or may not be considered music therapy. Without undermining other types of music interventions ("really beneficial and so impactful for quality of life", TCC2), they were adamant in defining music therapy as a specific methodology with structure, theoretical framework, to be conducted by a professional trained to "work with people at a deeper level and work clinically with people and be part of a multidisciplinary team" (TCC2).

Training, as matter of fact, came up as one of the key components that differentiate a session with music from therapy through music. "There's a lot written about playlists and all that kind of thing. And while I think that's beneficial to a point, you're not really assessing if you're not actually actively engaging with the person" (TCC3). According to the professionals present in the database, the therapist goes beyond the music in order to create a meaningful experience to PwD. TCC7 describes how many relevant elements might be under the radar when facilitating a group session (in TCC7's case, in a hospital setting):

> You would have families, partners or children that would come along and visit their parents in the day hospital and they'd sit with them and they might take part in the group music therapy. (…) obviously, you're researching, putting sessions together, trying to create interventions that will help facilitate various opportunities for these people. (…) It's not just about playing a few music instruments, there's so much more going on beyond that. We are playing music, but the therapist is trained to be observing so many different things, whether that's cognition, whether that's your behaviour, whether it's communication, motor fine growth, motor skills. (TCC7)

The misunderstanding of what can be called music therapy even happens among music professionals. "I do come across people who tell me that they're music therapists or that they're doing music therapy and they don't have the qualifications" (TCC7).

> "I've seen music teachers with all the best intentions (…) saying that, because they're working with a class in a special education school, they're doing music therapy, when maybe their goals are more educational than therapeutic" (TCC4).

One of the strategies found to cement music therapy as an evidence-based intervention, and that way mitigate misunderstanding around it, was the development of a scale. The aim was to translate subjective data, like reactions, into a systematic, scientifically valid measure:

> Most of the time people who want to explain (…) music therapy end up using subjective reports, or perspectives that we are not sure if the person's improvement was because of music therapy or for some other reason. So it was necessary to create tools that could generalise what we evaluate or what we intend as a goal, but also mainly tools that are the same as in other areas. (…) Nowadays for us to be able to create guidelines in the profession, (…) regulate the profession, one of the first things to ask is whether there is quantitative evidence. (TCC10)

In an event previously reported in this study, a healthcare worker (TCC13) witnessed a patient decompress enormously after 10 minutes listening to Elvis Presley. As the participant TCC13 said themselves, in the end, it was not possible to affirm that music was the only responsible for that improvement since on that same day nurses cheered the patient up pretending to be a relative on the phone. The scale might have helped clarifythat.

Analysis showed a possible inconsistency in the database around the concept of music therapy. TCC1 addressed the pilot study carried out in a hospital as being music therapy throughout the interview. Although it was quantified in a systematic way using the above-mentioned scale, and had a therapeutic goal, the study did not seem to meet other criteria established by the music therapists in their interviews to the present study, such as deeper involvement and relationship with PwD or a trained background in music therapy.

“There's constant advocacy work involved and trying to get across that differentiation between what music therapy is and what it's not. It's not listening to an iPod, it's not somebody playing in the foyer of a hospital" (TCC7). Clarify those grey areas is one of the aims music therapists seek with the state formal recognition of the profession.

2.2 Registration path in Ireland

A surprising finding of the present study was the struggle currently faced by music therapists in Ireland to have the profession validated and registered with CORU (Ireland's multi-profession health regulator). "We need (…) people out there being fully recognised on the same level as an OT or physio, because that's what we are, that's our qualification" (TCC3). For one participant, the absence of regulation "is restrictive in itself and it holds the profession back" (TCC7), while for another, it would help define clear guidelines for the profession.

> And what is expected of a therapist, especially when dealing with vulnerable people. So, we can make sure that the people who are going in and delivering therapeutic services to different facilities they're suited to be qualified, are engaged in professional development all the time, and are fully competent. All those things that state regulation offer it's really important that we have because, in my own opinion, it means safer practise, and accountability as well. (TCC4)

The state recognition, as argued by one participant, would enable the creation of a specific rubric for music therapists within the healthcare system:

> In this country, even though there are several qualified music therapists, most of us are probably working as something else as well. There's very few full-time music therapy posts to be had because it is not ratified or accepted in the same way as it is in France and in the UK. (TCC3)

Among the four music therapists interviewed for this study, one participant sounded hopeful that in the future the statutory recognition will eventually happen.

(…) we're a very new profession and a lot of the permanent posts that exist in Ireland only in the last ten years they've come into place. But there's still a lot of work to be done. A profession like occupational therapy, in the 1970s, was in the same position that maybe music therapy was in ten years ago. And it has taken it thirty or forty years to become a registered profession, become to kind of fully be integrated into multidisciplinary team. So it makes sense. And there's a lot of occupational therapists, there's much fewer music therapists, so these things do take time. (TCC2)

Discussion

This study used a qualitative approach to explore the use of music in the treatment of dementia. After a thematic analysis was conducted on the transcripts of the interviews, two overarching themes were constructed: 'Generating Values', composed by the subthemes ‘Music as a medium’, ‘Safe place’, ‘Not risk-free; and 'It comes with the territory', divided into the subthemes 'Is everything music therapy?’ and ‘Registration path in Ireland’.

The first theme, ‘Generating Values’, received this name in an attempt to capture the essence of what participants most demonstrated in theirs interviews: the wide and rich range of benefits that music can offer PwDs. From the good hormones produced in the brain during a music audition to regulation of BPSD (behavioural psychological symptoms of dementia), the reports echoed the literature. Sarkamo (2017) is categorical in stating that music is one of the most vigorous sensory, motor, cognitive and emotional experiences processed by the human brain, which can still be lived by PwDs as the parts of the brain responsible for music-induced emotions and memories are not as severely damaged even in later stages of the condition. The comfortable, grounding and familiar effect background music sometimes can create, e.g., a radio on in a hospital ward, agrees with Sung et al. (2010) whose findings show that this kind of sound ambience blocks out the surrounding noises, allowing PwDs to turn their attention to a more positive emotional state, thus feeling more relaxed, both physically and mentally.

The use of familiar and preferred songs, especially with the assistance of families providing information, adheres with strands of research. In a literature review Pithie (2016) mentions how the effectiveness of an intervention is linked to the songs chosen for (or by) the PwD. Sung et al. (2010) conducted study where residents with dementia of a nursing home had levels of anxiety reduced by preferred music listening technique. Thomas et al. (1997) conducted an experiment on the efficacy of music to aid cooperation during bath time, and concluded that “when assessing music preferences, it is critical to specifically identify the precise music that has traditionally satisfied the individual” (page 257). Jacobsen et al. (2015) cites a study by Demorest et al. (2009) where it was observed how culturally familiar songs are easier assimilated than the culturally unfamiliar ones.

The subtheme ‘Music as a medium’ is also consistent with other studies. Garabedian (2020) is a case study about a music therapist responding to an urgent call to help a PwD in high distress, so much so that no one in the nursing home could provide the basic assistance. After three hours of music therapy, it was possible to bring the PwD to baseline, managing state of mind and mood through music. According to Garabedian (2020), the ability music had to connect with the individual made an impression even on the doctor present to the scene.

Another strong argument detected in the dataset during the analysis was how important it is to be able to provide a safe space, based on person-centred principles, for PwD during interventions. According to Pithie (2016), an intervention must consider the PwD’s preferences in the first place, while Sung et al. (2010) emphasise the relevance of being culturally and socially sensitive when carrying out an intervention.

The possibility of music causing negative side-effects was seen in Heim et al. (2011) where intervention with Baroque music increased behavioural problems. To the best of the researcher’s knowledge, research in this area is limited and requires future studies.

The theme ‘It comes with the territory’ condensed the concerns and considerations that music therapists from the database showed in relation to what can be called music therapy, and why. Literature is mixed in that area. While in some articles the term is only mentioned with no further explanation of what it is or what it takes to perform it (e.g. Swall et al., 2020; Thomas et al., 1997; Ziv et al., 2007), in others, some of them written by music therapists, the distinction is given (e.g. Soufineyestani et al., 2021) alongside details about the specifics of the profession. (e.g. McDermott et al., 2013; Petrovsky et al., 2015). When it comes to which intervention is ideal, the literature is also mixed. Studies carried out by Kuot et al. (2021) showed that non-therapist-led intervention is as efficient as music therapy (this term cited only twice, with no definition to it). Sarkamo (2017) and Sung et al. (2010) on the other hand, show the possibility of more integration; having, for example, music therapists training and supervising nurses, healthcare workers applying music interventions.

The findings of the present research add to the literature data about the importance of a non-pharmacological treatment as types of music interventions. The final analysis shows that beyond mitigating symptoms, music interventions are about the person, about providing them a safe space to be, to express, to exist. Honoring their personhood. The contribution to the literature is the human component behind the interventions that, during this research, came to forefront of the findings.

Study limitations and future research

The present study has some limitations. Though the sample size was a strength (12 participants, from three different nationalities) it also worked as a limitation, with the researcher requiring more time for data analysis. The variety of participants was beneficial, with music therapists from different moments of their career, healthcare workers with no experience in music, an occupational therapist, and academics, but there could have been improvement with the addition of more family members and healthcare workers. The Researcher's inexperience also posed as a limitation as some interviews could have been more substantial and explorative. According to Onwuegbuzie and Leech (2005, in O'Reilly & Parker, 2012), the researcher needs to pay attention not only to sample size, but also the length of interviews.

Literature about music in the treatment of dementia would benefit with more research regarding the possible side effects of music and how it can be mitigated. The field could also improve with more studies and testimonials from music therapists and healthcare workers conducting interventions in hospitals and nursing homes.

To conclude, the study highlights how music can provide benefits to PwDs, their families and caregivers. But most of all, the findings show how, more than mitigate BPSD, music interventions - when based on person-centred approach - can create a safe space where PwDs can find comfort, support and acceptance. It is all about them.

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Appendices

Appendix A

Interview questions

Music Therapist

1- When did you start working with music therapy with PwD?
2- What is the structure of your approach/session?
3- Did you base your methodology in previous literature?
4- What kind of results you first got at the beginning? Did it change after a while?
5- Could you tell us if there is any psychological, physiological, emotional and social effect music can bring to a PwD?
6- What brought you to this kind of therapy?
7- Could you describe to us your personal experience during a music therapy session?
8- What would you say that music brings to a PwD? To what would you attribute its effectiveness?
9- Do you think there is enough literature and studies to support music therapy as a formal treatment for PwD?

Family member

1- How long has your relative been participating in sessions of music therapy?
2- What made you all decide for this intervention?
3- What did you know about music therapy before the intervention started?
4- Would it be ok to share with us the stage of dementia your relative is right now?
5- Did you notice any difference in your relative since he/she has started the sessions?
6- What would you say that music brings to your relative?
7- What is the structure of the intervention? One-to-one? In group? Did the therapist investigate with you all your relative preferred songs at any time of the intervention?
8- What is necessary to deliver a good and useful music therapy session in your opinion?

- Some questions were changed or added depending on the interviewee, e.g, questions related to a pilot study, a choir or occupational therapy methodology.

Appendix B

Invitation/introduction email 1

Dear Mr/Mrs/Ms *full name*.

My name is Melissa Luz Barbosa, and I am a final year psychology undergraduate student at National College of Ireland (NCI). I am currently working on a study about the impact of music in the treatment of persons with dementia.

As part of my research project, I am conducting a series of **short** interviews with persons who may be in a position to contribute to building a body of materials to best investigate the application of such alternative treatment for dementia.

I would like to invite you, should you be willing to contribute your time, to take part in this series of interviews. I understand you might be very busy, but your knowledge and experience would be of enormous value to my study. The interview lasts around 20, 25 minutes, and it can be in person, online via Teams meeting or even in written form, whatever is more convenient for you.

All subject detail, personal information etc. will be entirely anonymised once the interviews are transcribed. The results of this study will be presented in my dissertation, which will be submitted to National College of Ireland as part of my final degree in psychology. Please find attached NCI Ethics Committee approval letter.

Thank you for your attention.
Looking forward to hearing from you.
Yours sincerely,

Melissa Luz Barbosa
083 351 9489

Confirmation email

Dear Mr/Mrs/Ms *full name*.
As agreed in previous messages, I would like to confirm our interview scheduled for:
Date:
Time:
Place:
Please find attached the information sheet with relevant content about the interview and the research.
You also find the consent form attached, that needs to be signed before the interview.
Please do not hesitate in contact me if you have any query.
I thank you in advance for contributing your time and knowledge to my research.
Regards,
Melissa Luz Barbosa
083 351 9489

Appendix C

National College of Ireland (NCI)
Mayor Street
IFSC
Dublin 1

DATE

Re: Ethical Approval for Study

To Whom It May Concern:

This letter is to confirm that Melissa Luz Barbosa has received approval from the Ethics Filter Committee at NCI to carry out her study: The impact of music in the treatment of persons with dementia.

The study is being carried out under the supervision of Dr Caoimhe Hannigan. If you have any further questions, please contact me at the email address below.

Best regards,

Michelle Kelly.

Dr Michelle Kelly (on behalf of the Psychology Ethics Filter Committee)
Assistant Professor of Psychology
National College of Ireland
Tel: + 353 1 6599256
Email: michelle.kelly@ncirl.ie

Appendix D

Information Sheet

The impact of music in the treatment of persons with dementia

You are being invited to take part in a research study. Before deciding whether to take part, please take the time to read this document, which explains why the research is being done and what it would involve for you. If you have any questions about the information provided, please do not hesitate to contact me using the details at the end of this sheet.

What is this study about?

I am a final year student in the BA in Psychology programme at National College of Ireland. As part of our degree, we must carry out an independent research project. My study is about the impact music can have when treating people with dementia. Studies have shown that music therapy/ music sessions can bring biological, behavioural, psychological, emotional, and cognitive enhancement to people with dementia. The treatment does not cure dementia itself or its symptoms but is able to positively affect for hours or even days the ones in severe stage of the disease.

The study is supervised by Dr Caoimhe Hannigan.

What will taking part in the study involve?

If you decide to take part in this research, you will be asked to give an interview, that will be audio-recorded and then transcribed. The conversation will be mostly around aspects related to the use of music in the treatment of persons with dementia.

Who can take part?

People directly or indirectly related to the use of music therapy in the treatment of people with dementia.

Do I have to take part?

Participation in this research is voluntary; you do not have to take part, and a decision not to take part will have no consequences for you. If you do decide to take part, you can withdraw from participation at any time during the interview.

You can withdraw your data from the study after the interview has been completed, up to the point that its content has been transcribed (which will happen in two weeks' time after its competition). After that withdrawal will not be possible as all identifiable information will be removed.

What are the possible risks and benefits of taking part?

There are no direct benefits to you for taking part in this research. However, the information gathered will contribute to research that helps us to understand how a low cost and low risk intervention like music therapy/ music sessions can be beneficial to people suffering from dementia.

Will taking part be confidential and what will happen to my data?

All data will be treated in the strictest confidence. The interviews will take place one-to-one in a location that is convenient to the participant and provides sufficient privacy. All interviews will be recorded using a Dictaphone, and these interviews will then be transcribed for analysis. Audio recordings will be destroyed once the data has been transcribed. Any information in the interview transcript that could identify the participant or any other individual (e.g. names, locations) will be anonymised.

Each participant will be assigned a unique ID code, and their data will be stored under this ID code, separate from their name or other identifying information.

Only the researcher and academic supervisor will have access to the data collected. However, in the unlikely event that the researcher or academic supervisor believes that there is a significant risk of harm or danger to the participant or another individual, or a law has been broken, they would then be required to share this information with the relevant authorities. In this very unlikely event, the researcher would discuss this with you first, but they may be required to breach confidentiality with or without your permission.

As this is a qualitative study, direct quotes from interviews may be included in the presentation of the results, but these quotes will be anonymised and will not contain any information that could identify the participant or any other individual. The audio recorded will be stored and managed in line with GDPR guidelines. Any concerns or queries in relation to data protection for this research project, please contact the NCI data protection officer, Niamh Scannell (Niamh.Scannell@ncirl.ie)

What will happen to the results of the study?

The results of this study will be presented in my final dissertation, which will be submitted to National College of Ireland. The results of the project may be presented at conferences and/or submitted to an academic journal for publication.

Who should you contact for further information?

Researcher: Melissa Luz Barbosa
x20123582@student.ncirl.ie

Supervisor: Dr. Caoimhe Hannigan
caoimhe.hannigan@ncirl.ie

Appendix E

Consent form

Student responsible for the study: Melissa Luz Barbosa

Project: The impact of music in the treatment of persons with dementia.

Participant's name:

In agreeing to participate in this research I understand the following:

- The method proposed for this research project has been approved in principle by the Departmental Ethics Committee, which means that the Committee does not have concerns about the procedure itself as detailed by the student. It is, however, the above-named student's responsibility to adhere to ethical guidelines in their dealings with participants and the collection and handling of data.

- If I have any concerns about participation, I understand that I may refuse to participate or withdraw at any stage by exiting my browser or requesting the end of the interview.

- I understand that once my participation has ended, and my interview is transcribed (in two weeks' time from the day it happened) I cannot withdraw my data as it will be fully anonymised.

- I have been informed as to the general nature of the study and agree voluntarily to participate.

- All data from the study will be treated confidentially. The data from all participants will be compiled, analysed, and submitted in a report to the Psychology Department in the School of Business of National College of Ireland (NCI).

- I understand that my data will be retained and managed in accordance with the NCI data retention policy, and that my anonymised data may be archived on an online data repository. No participants data will be identifiable at any point.

- At the conclusion of my participation, any questions or concerns I have will be fully addressed.

☐ Please tick this box if you have read and agree with all of the above information.

☐ Please tick this box to indicate that you are providing informed consent to participate in this study.

Appendix F

Debriefing sheet

Dear *participant*,

Thanks for taking part in this study. As informed before, the interview you granted was audio-recorded, for posterior transcription. Any information that could potentially identify you or anyone you mentioned in the interview will be removed. If you wish to withdraw your data, you can do so before your data has been transcribed (in two weeks' time from today) by contacting me via email (x20123582@student.ncirl.ie). After that withdrawal will not be possible as all identifiable information will be removed.

The results of this study will be presented in my dissertation, which will be submitted to National College of Ireland as part of my final degree in psychology.

Other interviews will be conducted around the topic 'The impact of music in the treatment of persons with dementia'.

If you have any questions at all or if you wish to know the results for this study, you can do so by contacting me in the email above.

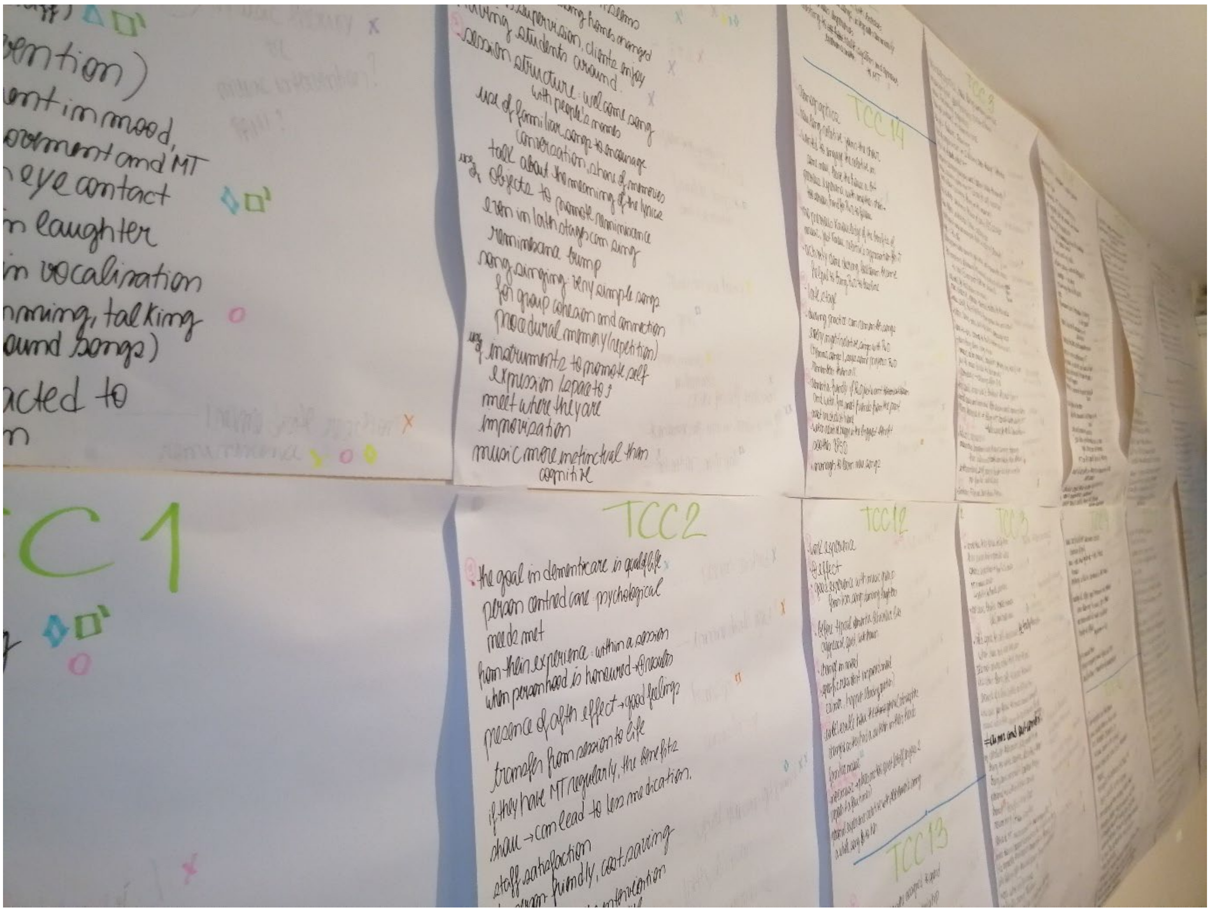
Once again, thank you for volunteering in this study.

Regards,

Melissa Luz Barbosa

x20123582@student.ncirl.ie

Appendix G



ention)
ent in mood,
ronment and MT
n eye contact
n laughter
n vocalisation
mming, talking
ound songs)
acted to

…ing homes changed
supervision, clients enjoy
having students around.
session structure: welcome song
with people's names
use of familiar songs to encourage
conversation, share of memories
talk about the meaning of the lyrics
use of objects to promote reminiscence
even in late stages can sing
reminiscence bump
song singing: very simple songs
for group cohesion and connection
procedural memory (repetition)
use of instruments to promote self-
expression (space to
meet where they are
improvisation
music more instinctual than
cognitive

TCC2

- the goal in dementia care is qual of life
person centred care: psychological
needs met
from their experience: within a session
when personhood is honoured → results
presence of after effect → good feelings
transfer from session to life
if they have MT regularly, the benefits
show → can lead to less medication.
staff satisfaction
person friendly, cost saving
intervention

Appendix H

Thematic map