

Independent Project

**Music with Meaning: An artistic expression
of the self when living with a diagnosis of
dementia.**

Module: ADPA6000

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Part One: Documentary

The following links are of the same video via different streaming services or available to download. For the best viewing experience, headphones or speakers are recommended.

To download in 4K: [4K Fleur Sparrow-Gormley Independent Project VIDEO.mp4](#)

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To stream via YouTube: https://youtu.be/pac5_os6AX8

Part Two: Supporting Document

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Abstract

People with a diagnosis of dementia and their loved ones are currently being deprived of adequate support (Our Dementia Choir, 2019). Considering the evidence to suggest how common anxiety is for people with a diagnosis of dementia (Porter, et al., 2003) and their caregivers (Alzheimer's Society, 2019), it is imperative that we find ways to offer therapy. The difficulties in language and communication as the dementia progresses, mean we must be innovative and find therapy away from the conventional routes. Music has been shown to have a positive impact on those with a diagnosis of dementia and increase connection with loved ones (Chen, *et al.*, 2020) (Baird, *et al.*, 2020) (Osman, Tischler, & Schneider., 2014). It is important to consider one's life experiences and culture when making musical decisions (Rio, 2009). Singing has positive benefits on the brain and body (Woolveridge, 2023). Much of the literature surrounding people with a diagnosis of dementia is overly medicalised, and as a result our language and understanding is one dimensional. The arts have an opportunity to better represent people with a diagnosis of dementia and their loved ones, and this will have a positive effect on how society discusses dementia.

Research Questions

The overarching question for me is not *why* music has positive cognitive effects (as I am not a neurologist, but a musician!), but *how* best can we use music as therapeutic care for people living with a diagnosis of dementia *and* their loved ones. I set out wanting to find a formula for the best music, but there is no such thing, as we, as humans, are individuals.

So, my questions are as follows:

- How can music aid the wellbeing of people living with a diagnosis of dementia?
- How best can we connect to ourselves and others through music?
- Why must we consider a person's culture when making musical choices?
- How can art console us in grief?
- What narratives are currently being told of people living with dementia, and how can the arts change this?
- Why are community spaces necessary for people with a diagnosis of dementia and their loved ones?

Literature Review

When I began research, it was immediately clear that this is a widely explored topic with many books, studies, podcasts and videos. These had positive elements – books and studies were often full of useful information about the effects of music on the brain (Chen, *et al.*, 2020) (Nair, *et al.*, 2011), and the typical responses to music (Baird, Garrido, & Tamplin, 2020). Many videos showed the power of music in calming or animating people with a diagnosis of dementia. However, I often found that books were over medicalised, studies meant individuals become statistics, and in some videos, people were infantilised. I struggled to find a balanced view that talked of the physical and emotional benefits in a way that was centred to the individual. I also found that caregivers were often left entirely out of the frame. This is problematic because they too deal with anxiety around diagnosis and having to make important decisions around care (Alzheimer's Society, 2019).

The best all round resources I found were often podcasts by medical professionals who understood dementia, but unlike in medical writing, could voice the nuance. The issue with podcasts being they may not always be factually accurate, as they are not peer reviewed. Finding a balance of emotive and medical was almost impossible.

The book 'Connecting through music with people with dementia, a guide for caregivers', bridged the gap in many ways (Rio, 2009). The handbook is designed to support caregivers to share music (particularly singing) with the person with dementia, offering song suggestions and exercises. It talked of the benefits of singing on the brain and body, and in connecting with others, as well as the importance of recognising a person's life experience. It was also easy to read, without unnecessary medical jargon.

Another book, 'What dementia teaches us about love', felt artistic, poetic, and was written from both sides – the heartbreak, and the continued love of her father. The issue with this book being it speaks of one person with dementia, so cannot be the entire narrative. While I can't base an entire thesis on this one source, it was pivotal in my understanding of dementia and of how to present my research.

In the study, 'The effect of Baroque music on behavioural disturbances in patients with dementia' (Nair, *et al.* 2011), Baroque music was played for four hours a day through a CD player, at the same volume, to calm participants. This is lacking in thought as factors like life experience, hearing problems, and other sensory needs were not taken into consideration. This shows that the way we use, or present music and art, is *perhaps* more important than the content.

Overall, I found that information was easy to find, but was often difficult to understand, or lacked in thought and nuance. This shows the need for further exploration in the subject area, to make resources more accessible, reflecting the important findings from each study, while making space for empathy and self-expression.

Methodology

Autoethnography can be described as placing the researcher in their field of study, so that they may better understand the social, political issues surrounding their subject area. (Gannon, 2017) This method helped me to find more nuance in the conversation of music as therapeutic care for people with dementia.

To achieve an autoethnographic approach, I joined a community space, Forget Me Not Chorus, for three sessions. I attended as a participant, sitting with the chorus, socialising and singing, and made notes retrospectively after practise. I chose to do this so I could physically understand the benefits of singing in community, and so that taking notes wouldn't steer my attention away from being present or make anyone feel as if they were being observed. This experience taught me a lot about the benefits of singing, as well as the necessity of community.

As well as this, I held an interview with Kate Woolveridge (the co-founder of Forget Me Not Chorus), and had recorded conversations with Gill, Tanya, and Carri, who each had experience of caring for a parent with a dementia diagnosis. I used the term 'discussion' as opposed to interview, to deter restrained formality. To prepare for these discussions, I considered the ideas and questions we may explore prior to the meeting. Then during the conversation, I focussed on listening and responding to what was being offered. These conversations taught me of each persons lived experience, as well as of the issues around support, societal stigma, and misuse of language. Discussions were qualitatively analysed, drawing from themes and then investigating patterns further.

The flaws of this approach are that it is easy to follow your emotions, wanting to see systems change and society treat people with more respect. It also places the researcher at the centre, which is beneficial to understand the topic, but runs the risk of becoming overly personal. This means that research can be less balanced, and it gives the viewer less opportunity for their own self-reflection.

Ethics

Due to my research involving people sharing deeply personal experiences, it was important to consider ethics. I wanted to add to the conversation (which includes the challenges), without causing further harm to the participants. I spoke to a mental health practitioner prior to approaching participants, to ensure I was equipped to support others when exploring sensitive topics. Before beginning each discussion, we went for a walk to find the boundaries and consider what was likely to be discussed. I would tell them how I would use the information, and received informed consent from everyone involved.

Limitations

My biggest challenge was in setting up discussions, as I feared saying the wrong thing. This fear manifested in questions to participants being very unclear in the early stages, though by the end my confidence had developed. This meant I missed some opportunities to develop ideas with participants.

An issue with the balance of my thesis is the lack of diverse voices. All discussions were held with women, most of a similar age and ethnicity. This is for multiple reasons – I have fewer non-female friends, so my open call for discussions was answered by all women.

It could also be argued that men of the generation likely to have experience of dementia are of a generation that were taught not to share their feelings (CALM, 2024) (Mental Health UK, No Date), and the topic requires a level of vulnerability. *“The socialization of men and the resulting masculine ideologies may be a significant factor in men's decisions to seek help”* (Galdas, Cheater, & Marshall., 2005)

I also did not *knowingly* involve anyone with a dementia diagnosis, as I wasn't sure of how to approach finding someone open to talk about their experience. This means that it is not as inclusive as I'd hoped but does highlight the need for this in the future.

Reflections of the Documentary

I produced a documentary because I wanted to make something accessible and easy to digest for a person in the early stages of their dementia diagnosis, and for their loved ones, to learn about the charities, resources and communities available to them, and how music can be of benefit. I consider it an audio-visual collage of the useful information from each resource, adding nuance and empathy, while still being educational.

The challenges were as follows:

i. Budget

Firstly, I didn't have a big budget, so the audio and visuals weren't to my liking in places. For example, I borrowed a tripod that wasn't tall enough to achieve the desired angle. I did much of the recording myself, with the occasional assistance from one other person to scroll the script or move the camera. This meant parts of the video aren't completely central.

ii. Technical skill

My technical skill is somewhat limited in terms of video editing, so this was a slow process, making many mistakes and learning as I went. While these do not detract from the content, they *may* distract the viewer.

iii. Time

Time was possibly the biggest constraint, as I wanted to film it outside to reflect this idea that music is nature and nature is musical (Meymandi, 2009). However, with it being winter, and Wales being Wales, finding a clear day was difficult, meaning much of the filming happened later than I'd hoped. I also held an interview late in the process, which I learnt a lot from, but also meant the script wasn't complete for some time. The delay was due to apprehensions about holding interviews.

iv. Apprehension in holding discussions

My apprehensions were that I wanted to avoid further harm, as this is a sensitive topic. To prevent this, I thought a lot about language, and the types of questions I should avoid. It also meant developing my listening skills – knowing when to ask something in a different way, and when to change topic. This is also why I chose to meet participants outdoors, as there is evidence to show that walking talking therapies can be conducive to healthy discussions (Callingham, 2021).

Each location was a familiar environment to me and to the participants, which calmed the nervous system.

Overall, the process was successful, and I learnt a range of new skills. The video took the viewer on a journey of discovery with me, and while imperfect, did show the need for further entertaining and educational resources for this subject area.

Recommendation for Future Study

In the future I hope to see further studies focusing on (or at least involving) caregivers. The qualitative study, ‘Singing for the Brain’ (Osman, Tischler, & Schneider., 2014), interviewed participants of the choir, and showed a great example of the benefits of a singing community for people with a diagnosis of dementia and their loved ones. There should be future investigations following a similar model, but should include a wider pool of participants, to cover a range of ages, socioeconomic, and cultural backgrounds.

Conclusion

The following is written in support of my final ‘Reflections’ section of the documentary.

There is a wealth of resources on the benefits of music for people with a diagnosis of dementia, including many convincing studies (Chen, *et al.*, 2020) (Osman, Tischer, & Schneider., 2016) and books (Rio, 2009) (Baird, Garrido, & Tamplin., 2020) by medical professionals. There is however a demand for material that is less medical. The documentary was created in response to this – to bring more nuance into the conversation of music as therapeutic care for people with dementia. I produced it with the view that one could learn about how best to support themselves and/or their loved ones through the medium of music. Making it informative, without being dry and dull, and more accessible than the written word.

People with a diagnosis of dementia and their loved ones are likely to experience anxiety, due to; the change in communication, memory, the need to make difficult decisions around care, and fear of losing the person (to name a few) (Spector, 2015) (Alzheimer’s Society, 2019) (Porter, *et al.*, 2003). Therefore, there is a need to find accessible therapeutic solutions. Arts therapies have been shown to aid in expressing emotions (Potter, 2013). Music is a recognised source of therapy, and can be implemented in daily life (Rio, 2009). In particular, singing is shown to have physical and emotional benefits that are conducive to reducing symptoms of anxiety (Woolveridge, 2023), and would be a viable alternative to talking therapies. The value of music is partially due our natural musicality as human beings (Meymandi, 2009) (Levitin, 2008).

Initially, I sought to find a formula for music that is beneficial to people with a diagnosis of dementia – in particular, opera or classical music. Instead, I learnt that it is more beneficial to consider a person's musical identity. Music should be tailored to the individual by holding discussions and reading body language to adapt the music where necessary (Preston, *et al.*, 2020). There is evidence to suggest that music that links to a person's culture is more likely to have a positive, therapeutic effect (Prifysgol Bangor, 2019) (Chen, *et al.*, 2020)

Early on in conversations I noticed peoples use of language, often hearing ‘patients’ in non-medical contexts. The language we use can be reflective of our perception, and therefore treatment of a person or community (Evans, 2020).

Theatre has the potential to resist this, and force us to reconsider our prejudices (Munn, 2024).

Caregivers have often been excluded from the conversation, and deserve better support (Alzheimer's Society, 2019). Many caregivers have found benefit from participating in musical communities, so this would be an interesting area for further research. (Osman, Tischler, & Schneider., 2014) (Woolveridge, 2023).

In conclusion, music is a part of our natural world, and instinctual to us as humans (Meymandi, 2009). The therapeutic use of music should therefore be considered as an alternative or supplementary to talking therapies for people with a diagnosis of dementia and their loved ones. Music is likely to enhance a person's wellbeing and can be implemented in daily life (Rio, 2009). There has not been enough focus on funding for the therapeutic use of music for people with a diagnosis of dementia (Our Dementia Choir, 2019), however, there are a number of charities offering music, community, and support.

Reading List

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