



Episode 1: Dr Orie McDermott - The importance of music therapy for dementia patients

Orie McDermott (OM): I think music for me, is just a fundamental part of human being. Even like what I'm talking now is very much about using my voice, expressing myself, trying to communicate with someone and yes language does matter. The contents of language matters but it's often about the tone of your voice, speed, what you are trying to convey and for me music is very much about that direct link to emotion.

Kaitlyn Regehr (KR): That was Orie McDermott. Originally from Japan and now working in the UK as a Music Therapy Clinician. Orie is a Senior Research Fellow at the University of Nottingham's Institute of Mental Health, who has investigated how music effects people who are living with dementia.

Dementia describes a variety of cognitive disorders that trigger a loss of brain function. These conditions are usually progressive and eventually severe.

OM: I think as a clinician and as a family carer, music isn't just about reducing bad symptoms if you like. Music is very much about connecting with people, connecting with the external world. For me personally, I think reading quantitative research, so randomized control trial studies, really focusing on reduction of symptoms, personally made me feel quite angry. It made me feel quite agitated because I felt quite frustrated. Music isn't just that and for people with dementia, music is more than this. So that kind of frustration I guess was a motivation to go into dementia research and music.

[How Researchers Changed the World podcast introductory music]

KR: Welcome to How Researchers Changed the World, a podcast series supported by Taylor & Francis Group, which will demonstrate the real-world relevance, value and impact of academic research; and highlight the people and stories behind the research.

My name is Dr. Kaitlyn Regehr. I'm an academic researcher; an author and a scholar of digital and modern culture. I'm interested in how new technologies can broaden the reach and real-world impact of academic research.

In today's episode we're speaking with Orie McDermott and unpacking her 2013 paper: The importance of music for people with dementia: the perspectives of people with dementia, family Carers, staff and music therapists.

OM: My name is Orie McDermott. I'm currently a senior research fellow based in division of psychiatry and applied psychology at the University of Nottingham. At the moment I am working on several dementia projects as a post doctoral researcher, including managing a project called Distinct and Induct as well as leading a study on looking at the needs of people living with young onset dementia. The other side of my

research job is working as a post doctoral with a music therapy team based in doctoral program music therapy, all working at a university in Denmark. Finally, and importantly, I work as a clinician as a music therapist in CNWL Central North West London NHS Foundation Trust. I have been doing that since 2001.

KR: Orii has been a Music Therapist for nearly 20 years. Music therapy is an established psychological clinical intervention, which is delivered by a qualified and registered music therapist to help people whose lives have been affected by injury, illness or disability through supporting their psychological, emotional, cognitive, physical, communicative and social needs.

OM: I became a music therapist. Initially I wanted to become a special school teacher. That was something I was really interested in once, I don't know...primary school times. I was about 10-11 and there was a special need kids' class in my primary school and I just love it, going there. I decided I'm going to be a teacher in a special school and that was my ambition for quite a long time.

So, I did a music degree, an undergraduate degree at the University of Newcastle first. I had fun playing piano quite a bit. I did a one-year performance degree in Royal College of Music, just playing and making music. Then I did music therapy training but that was 20 years ago.

I think music for me is just a fundamental part of human being. This might be slightly more music therapy talk but even what I'm talking now is very much about using my voice, expressing myself, trying to communicate with someone. Yes, language does matter. The contents of language matters but it's often about the tone of your voice, speed, what you are trying to convey. For me music is very much about that direct link to emotion. That is something I really value. Music for me personally isn't really about performance or doing well but it's a very kind of raw, basic human need, I guess.

KM: So Orii is making the argument that the auditory system and the ability to enjoy music is a fundamental part of who we are. In fact, the auditory system of the human brain is the first of the sensory systems to fully function at only 16 weeks in-utero which means that we are musically receptive before almost anything else. That's why many people play music to their unborn children. As far as memory is concerned, perhaps it's a case of first in and last out as this is such a deeply rooted human ability.

The links between music and memory have been studied formally since the 1970s, but only popularised within the past two decades. In 2011 the US charity Music and Memory produced a documentary about a man called Henry with dementia. The film showed the seemingly miraculous power music can have on people living with the condition and the video went viral. The concept of music therapy then entered the public consciousness.

Orii started before this. So, why did she decide to pursue Music Therapy?

OM: Being a music therapy clinician is one way of making a difference again but maybe dementia research and music, that's something that might make a bigger impact at a later stage so that's kind of in my head for a long time. Personally, I wanted to be a full-time clinician so that was my focus. As I said, back in 2009-10 I started thinking, yeah, research might be something to make a difference.

So basically, my PhD project was about music therapy outcome measure or the scale development and evaluation. As I said earlier that was very much driven by my frustration of there aren't good enough outcome measures in psychiatry or mental health that might capture the experiences of people with dementia when they are participating in music activities. So that was my PhD project.

KR: Although it's fair to say that today many people are aware of the role music and music therapy play, in working with people experiencing dementia and other cognitive impairments it wasn't always this way.

OM: Ironically 20 years ago, when I was doing a Masters, dementia wasn't really a big topic and in the last 5-10 years, obviously dementia has become quite a big topic in our lives.

KR: Currently, nearly 10 million people will develop dementia around the world every year, that's one every three seconds. This figure is set to triple by 2050, rising rapidly as we live longer. Plus, it's not just elderly people who can develop the disease.

Currently in the UK alone, 1 in 4 beds on the National Health Service are occupied by someone who has dementia. The expected costs are set to more than double in the next 25 years, from £26,000,000,000 to £55,000,000,000 in 2040. According to the World Health Organisation, dementia is a Public Health Priority.

So, how can Music and Music Therapy play a role in enhancing the quality of life of people living with dementia?

OM: The paper 'The Importance of Music for People with Dementia' we published in Aging and Mental Health back in 2014. It's a qualitative paper and basically, we did interviews and focus groups with people living with dementia, in care home settings and also people attending day services, family carers, care home staff and music therapists.

The full point of that was, again that time music was becoming quite popular. People were saying "music is good for people with dementia" but what we wanted to find out is, it's very well to say music is good for person with dementia but can we really find out how the person experiences music? If music is important or meaningful in any way for that person with dementia, how do we know?

KR: In the first part of the research Orii and her team focused on what they could see in the participants, what could they hear and what could they learn from these interactions. The second phase of her research attempted to develop a method by which this knowledge might be aggregated and applied.

OM: The second bit of that paper was trying to develop a music and social model that was like a summary model of what people said in focus groups and interviews. That was a way of us understanding and trying to put in a research context of perhaps this is how music might work for the person with dementia.

KR: It's important for us to contextualise this. As a practicing clinician, Orii needed to understand how qualitatively effective music therapy could be in connecting with people living with dementia. Her outcome was a scale which she could apply to her assessments.

OM: So, this qualitative paper was very much about the base of Music and Dementia Scale – MiDAS scale development. Without this qualitative paper we couldn't have done the scale development.

KR: In a moment, we will unpack and explain Music in Dementia Assessment Scales or MiDAS – and how it is now being used in Music Therapy around the world. Join us after the break.

This seems like a good point to pause our story and tell you about our supporting partner, internationally renowned publisher: Taylor & Francis. We've been working with Taylor & Francis to create a 12-week learning program to accompany this series. Aimed at academic researchers looking to supercharge their career, it's entitled: "How Your Research Can Change the World".

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We're speaking with Orie McDermott and unpacking her 2013 paper 'the importance of music for people with dementia: the perspectives of people with dementia.'

Before the break we were hearing from Orie McDermott about her work in music therapy for people with dementia. She wrote a paper in which she observed and interviewed hundreds of dementia sufferers who were participating in music therapy.

OM: So, this qualitative paper was very much about the base of music and dementia scale, MiDAS scale development. Without this qualitative paper, we couldn't have done the scale development.

KR: Music in Dementia Assessment Scales or MiDAS was developed in order to measure observable musical engagement of persons with moderate or advanced dementia, who may have limited verbal skills to directly communicate their musical experiences.

OM: So, the intention was that... I guess the personal driving force for that paper, apart from us wanting to make sure we were using a clinical data for the scale of development. Apart from that, my personal driving force for that paper was that most of my participants, especially people with dementia, care home staff and family members, they were from my NHS trust, so I knew I chose the study participants quite well. For me, I felt that I just had to use this opportunity to have a voice, to tell the world...not necessarily to tell the world but just, I had this opportunity to say, this is what happens in a clinical reality. Again, making that inclusive clinician day-to-day happenings and what is meaningful in terms of music for our care home residents.

KR: Orie had a very personal connection with the subjects of her clinical trials, including family members of her own.

OM: I had this opportunity say it in a more explicit manner, through research and through this paper. So that has become quite a personal journey to say, this is what happens in the reality and not just seen as anecdotal evidence or something nice happened today. There's actually a solid continuous responsive from people with dementia, how the music might mean something

I wanted to publish in that journal not because my PhD supervisor happened to be the editor, but the first issue of that journal had Tom Kitwood's article in it which is very much part of me and really important.

KR: It's impossible to talk about dementia care without mentioning Thomas Kitwood. Thomas Kitwood, born in Lincolnshire in 1937 was a pioneer in the field of dementia care. Kitwood wanted to understand, as much as possible, what care is like for a person living with dementia.

His major innovation was Dementia Care Mapping, a method for observational evaluation of the quality of care that is provided in formal settings, such as care homes.

Orie didn't wish to continue the work of Thomas Kitwood or to continue in the same narrative, but simply to remain true to a person-centered approach to Dementia Care that came out of Kitwood's work. Her MiDAS scale was born out of this person-centered approach.

OM: So, MiDAS, Music in Dementia Assessment Scales was my PhD project. We developed that scale items directly from focus groups and interviews being conducted with people with dementia, care home staff, families and music therapists.

We wanted to have scale items which were scientifically rigorous but clinically related. So we came up with five key scales which were interest, response, initiation, involvement and enjoyment.

KR: We asked Orie what the impact of her paper has been and how the MiDAS scale is being adopted and used in Dementia Care.

OM: As far as we know MiDAS is being used by clinicians and researchers over 12-13 countries. It came as a bit of a surprise to me. As I keep repeating myself, this was very much about personal frustration driven project, but it just seems to be something that other clinicians can relate to. So yeah, that's cool.

KR: So why was Orie's paper and subsequent measuring tool so popular, or cool – as she would say?

OM: I think that qualitative data we had again going back to our paper, the reason I think potentially part of the popularity is that it's quite ordinal. Lots of clinicians and lots of non-academics said "Oh yeah we've got people like that in our care home." So, it seems to be fairly kind of common with presentation over how people respond to music, so people seem to be able to relate.

KR: Given the startling statistics concerning the increase prevalence of dementia globally, the work of researchers and clinicians like Orie will be of increasing importance in the years to come.

People who dedicate their life and work to the compassionate and creative care of people experiencing dementia aren't only changing the world but they're changing it for the better. From conception to the end of our lives, music plays a fundamental part of how we connect to one another and to ourselves. As Stevie Wonder said: "Music, at its essence, is what gives us memories. And the longer a song has existed in our lives, the more memories we have of it".

To find out more about this podcast and today's topic, visit howresearchers.com. We'd love to hear your feedback so please follow us on Twitter, Facebook or LinkedIn at @howresearchers and use the hashtag #howresearchers.

On the next episode of How Researchers Changed the World we welcome Ron Wasserstein, Executive Director of the American Statistical Association, as our guest researcher, and with him we'll be exploring the misuse of p-values (or probability values) in research over the past few decades.

This podcast was written and produced by Monchü, recorded at Under the Apple Tree Studios. Our producers were Ryan Howe and Tabitha Whiting. Editing, mixing and mastering by Miles Myerscough-Harris at WBBC.

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I'm Dr. Kaitlyn Regehr. Join us next time for How Researchers Changed the World.

Thanks for listening.