

RESEARCH | PEER REVIEWED

The great reveal:

The experiences of an Australian Registered Music Therapist with a disability, an arts-based research project

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Received: 13 August 2019 Accepted: 21 January 2020 Published: 1 March 2020

Editor: Michael Viega Reviewers: Nicky Haire, Alpha M Woodward

Abstract

Disability is a human phenomenon experienced not by a small minority but a large percentage of our global population. Disability is encountered by people of all ethnicities, religions, genders (and non-conforming), sexualities, socio-economic backgrounds, and ages. Recent music therapy literature has advocated for a diverse workforce and others describe the value in music therapists adopting an intersectional lens, which considers the interconnectedness of social and political identities. However, there is limited dialogue featuring lived experiences of music therapists of underrepresented identities, such as disability. This research sought to canvass the experiences of Australian Registered Music Therapists who identify as having a disability and to explore how their disability may impact or inform their practice. One Australian Registered Music Therapist (RMT) who identified as disabled was interviewed. The student-researcher engaged with arts-based research through music composition to allow an embodied analysis and to present results in an accessible format. Several themes were revealed, including; hidden disability, disclosure of disability, alliance, positive transference, visibility, and identity. These findings demonstrate the importance of lived experiences in the music therapy community and calls to amplify diverse voices of those with disabilities and other intersecting identities within our profession. Acknowledging the work of disabled music therapists may further challenge ableist attitudes in our society and provide options to participants who might prefer to work with therapists who have relevant lived experience.

Keywords: *disability, disabled identity, lived experience, disclosure, music therapy, arts-based research*

Rationale

As a person with a lived experience of disability, I chose to explore this topic for my music therapy minor thesis. My music therapy studies were diverse in exploring tra-

ditional and contemporary models and approaches, yet ethical questions were raised when reading about the consensus model and what I understood as its focus on the normalisation of disabled people. I had concerns about music therapy literature which centralised diagnoses and used language such as *deficits*, which felt alienating. I also had conflicting thoughts around my emerging identity as a music therapist and the myth of the *healthy* therapist who is non-disabled, physically and mentally well, which seemed to be in opposition to my disabled body and fluctuating state of health. I have chosen to document this research in first-person language and therefore to situate myself deeply within the research as a disabled, cisgender, Greek-Australian woman. My use of first-person language symbolises for me a reclaiming of power that has been historically seized from people with disabilities. This grab at power is aligned with the concept of “claiming” disability as a significant part of one’s identity. This claim brings disabled voices to the forefront of the dialogue, celebrates our shared identity and calls for collective action against systemic oppression, akin to the Charlton (2000) notion, “Nothing about us, without us.”

Disability and language

Both identity-first language, “disabled person” and person-first language “person with a disability” has been utilised throughout this research. As the research participant’s preferred label risks identification, the participant has chosen person-first language to be adopted in describing their experience. Language within the disability community is an individual preference, with some choosing identity-first language such as “disabled” or “autistic person” and others prefer person-first language such as “person with a disability” (Dunn & Andrews, 2015). I have chosen to use the term “participant” to describe the people we work alongside, favouring this term over “client,” “patient,” or “consumer”.

Who are music therapists?

The way one views the world and makes meaning of everyday phenomena is through lived experiences which form our values, beliefs and attitudes (Wheeler & Baker, 2010). These lived experiences are often culturally prescribed, inherited from our families and communities, and construct the foundations of our identities (Cote & Levine, 2002). Warren and Rickson (2016), suggested that the professional identity of music therapists in New Zealand consist of an interaction between these multiple elements in an on-going nature throughout one’s career. Therefore, for a disabled person, the on-going and often-evolving relationship with one’s disability is an imperative part of how we create meaning in our daily lives (Lerner & Straus, 2006) and imaginably as a music therapist, how we create meaning in music therapy practice.

It is widely recognised that music therapists occupy a reasonable level of privilege in their ability to access higher education and become registered or certified in our profession (Hadley, 2013). In Australia, the Australian Music Therapy Association’s (AMTA) 2016 Workforce Census Report did not include any questions about disability or other intersectional identity markers amongst the professionals registered with the Association.

Hadley (2013) suggested music therapists apply a critical lens of reflexivity to their individual background, to become aware of how positions of power can communicate through practice. Examining the self in this way may support safer practice and avoid reinforcing the marginalisation of oppressed social groups. This is a principle of anti-oppressive practice, that is, a practice which addresses the breadth of oppression and works from a participatory approach towards social justice and change (Baines, 2013; Hadley, 2013). Hadley and Thomas (2018) continued to suggest that music therapists should consider firstly, how they relate to the person with whom they work and secondly, how they relate to the socio-cultural groups with whom the person identifies. This is compelling when considering a music therapist’s relationship with a person with whom they share an identity, such as disability. This concept is congruent with

being an “insider,” referring to someone with lived experience of the phenomenon or groups that they work alongside (Liudmila & Lejla, 2014). Liudmila and Lejla (2014), described advantages and disadvantages of being an “insider” as a researcher. They argued that whilst insiders may carry biases and assumptions about their shared social group, they possess intrinsic and embodied understanding of the shared phenomena.

Conceptualising disability

Disabled people have historically experienced and continue to experience discrimination, oppression, and are susceptible to higher instances of abuse (Hollomotz, 2012). Disability has been chronicled in Greek classical times through accounts of children born with physical and/or intellectual disabilities being subject to isolation, abandonment, segregation, institutionalisation, and infanticide (Laes, Goodey, & Rose, 2013). Further dominant historical narratives have framed disability as a repercussion of religious sin carried out by parents or the disabled individual, or as an intervention of the supernatural (Snyder & Mitchell, 2001). Other scholars portray disabled people in historical accounts of bravery, resistance and activism (Draycott, 2019; Shakespeare, 2018). All these historical portrayals of disabled people can be framed as problematic if considered through a feminist lens, as they are most commonly penned by privileged, non-disabled men (Draycott, 2019). A feminist lens favours accounts of lived experiences of actual disabled people in ancient times.

Defining disability is a contended issue with disabled people, activists, and scholars divided in their opinions (Gross, 2018). Over the last 50 years, several “models” of disability have emerged which conceptualise its definition in contrasting ways, with the medical and social models being the most prominent (Haegele & Hodge, 2016). This historical oppression firmly anchored disability within the medical model, a model viewing disability as an abnormal and pathological phenomenon requiring medical interventions and the pursuit of cure (Haegele & Hodge, 2016). Medical and therapy interventions, advances, technologies, and cure for some disabled people have afforded greater quality of life and extended life span. Additionally, labelling disability brings access to health and welfare services (Linton, Mello, & O’Neill, 1995). However, critiques of the medical model argue that viewing disabled bodies as abnormal and the interventions that may follow, endeavour to normalise our bodies and minds (Shyman, 2016). This notion of normalisation gives power to non-disabled people within society and contributes to further oppression of disabled people (Haegele & Hodge, 2016). Furthermore, it is argued that medical objectification of disabled bodies reduces a person to an object and can be harmful to our mental health, contributing to structural oppression (Kafer, 2013).

Critical disability studies and studies in ableism have long detached from the medical model, and instead conceptualise disability as a social construct. The social model views disability as a consequence of societal oppression, implicating environmental, social, and attitudinal barriers as the disabling factors, rather than one’s body or mind (Fitzpatrick & River, 2018; Gross, 2018; Haegele & Hodge, 2016; Riddle, 2013). The social model helps to illuminate the way that the medical model positions people with disabilities as problems to be fixed. The social model therefore highlights the everyday ableism that many consider has been deeply internalised within contemporary society (Gross, 2018). This re-framing of disability views bodily diversity as something to be celebrated and “claimed” within one’s identity (Kafer, 2013). Critiques of the social model have stated that whilst the model addresses body diversity (Haegele & Hodge, 2016), its political and ideological focus fails to acknowledge that diagnoses can support agency through offering practical access solutions in our everyday lives; for example, employing a support worker or the use of assistive technology (Bell, 2017). Further commentary alleges that intersections of marginalization such as gender (and non-conforming), ethnicity, and socio-economic backgrounds are unaccounted for in the social model (Campbell, 2009).

Ableism is the discrimination towards disabled people in favour of non-disabled people (Shyman, 2016). Ableism can manifest on a smaller scale, such as people's assumptions, attitudes, or stereotypes and on a greater scale such as segregation and systemic oppression (Campbell, 2009). Disabled people internalise these ableist messages we receive throughout our lives that our bodies/minds are less than, that disability is a negative experience, and this results in internalized ableism (Campbell, 2009). Further theories in disability studies include Crip theory, which seeks to reframe the historically offensive word "cripple," making claim and celebrating one's "Crip" or disabled aspects of our identity (McCruer, 2006). Crip theory represents all disabled people, eliminating disability hierarchies. It is an inclusive term and through the lens of queer and feminist theory, aims to extend inclusion to diverse groups within the disability community such as disabled First Nations people, People of Colour and Lesbian, Gay, Bisexual, Transgender, Queer, Intersex and Allies + (LGBTQIA+, Kafer, 2013). To identify as "Crip" is to celebrate disability pride, which disrupts internalised ableism and societal narratives that our lives are unlivable, and our bodies/minds are undesirable. It celebrates difference and positions disability as part of the human condition (Clare, 2017). It is important to note that the social model, Crip theory, critical disability studies, and studies in ableism have been developed and led by self-identified disabled people.

Many in the disability community state the importance of individual medical diagnoses in claiming one's identity, particularly in connecting to sub-communities that relate to diagnoses (Clare, 2017). The wider disability community is made up of people who self-identify as having: physical or mobility disabilities, acquired brain injury, intellectual or learning disability, are blind or have partial vision, are Autistic, are Deaf/deaf or hard of hearing, are chronically ill, are living with chronic mental health, are amputees or have limb differences, are people with facial differences, and people living with degenerative conditions. So, whilst diagnoses are not the problem, according to the social model, they are still an important part of our identities. For example, the d/Deaf and neuro-diverse communities often align with the disability community. I feel it is important to describe these communities in order to illustrate the spectrum of disability and exemplify shared barriers. The uncapitalised "d" in deaf represents people who are hard-of-hearing and have been medically diagnosed with mild to moderate hearing loss, often using verbal language and hearing devices/technology to communicate (Senghas & Monaghan, 2002). Whereas the capitalised "D" in Deaf represent a community with a strong and proud culture, whom are often profoundly deaf and primarily communicate with sign-language (Radić-Šestić, Ostojić, & Đoković, 2015). Some in the Deaf community reject the term disability, whilst some align themselves with the disability community for solidarity on shared issues (Senghas & Monaghan, 2002). The neurodiversity movement typically consists of people diagnosed with autism in addition to people with other cognitive and neurological conditions. The Autistic and neurodiversity community strive to shift the focus towards acceptance of diversity and the advantages of their difference (Grandin & Panek, 2013).

In addition to these communities, people with chronic illnesses – an umbrella description for a myriad of illnesses – and chronic mental illnesses, may also identify as disabled (Bassler, 2014; McCruer, 2006). These disabilities are often described as invisible or hidden as they may not be seen in the public eye (Bassler, 2014; Yeh, Jewell, & Thomas, 2017), yet individuals often encounter the same societal barriers as people with more visible disabilities (Kafer, 2013).

The music of disability

With these models and theories in mind, how does a music therapist navigate this complex terrain of disability? Cameron (2014), controversially suggested that the music therapy profession's traditional alliance with the medical model is problematic and may reinforce oppression of disabled people. In the last decade of music therapy discourse, we have seen a detachment from the medical model and a move towards in-

clusive approaches. These approaches include resource oriented music therapy which focuses on nurturing people's strengths and inner resources (Rolvjord, 2010) and community music therapy which works from a participatory framework emphasising collaboration (Stige & Aarø, 2012). Both approaches reject pathologizing disability or illness and have been widely embraced by the music therapy community (Tsiris, 2013).

Lubet (2011) proposed that western music can be disabling, and Lerner and Straus (2006) suggested that this is due to the alignment of western music theory with the medical model, encouraging listeners to determine abnormal and normal musical structures and harmony. Lerner and Straus (2006) further hypothesised that non-normative bodies and minds experience music differently due to the diversity of cognitive, psychological, sensory, and physiological differences in our embodiment of music labelled "disablist hearing." Churchill (2015), a hard-of-hearing musician, described the connection between power and listening and how the ability to hear is viewed through a medical model lens as laden with privilege.

Music therapists with disabilities

At the time of commencing this research, there was no known available literature exploring the professional experience of disabled music therapists. Since then, a PhD dissertation has been published, *Developing post-ableist music therapy: An autoethnography exploring the counterpoint of a therapist experiencing illness/disability* (Shaw, 2019). In this significant body of work, Shaw (2019) shared her autoethnographic exploration of acquiring illness/disability and its impacts on her music therapy practice using arts-based research methods in the form of expressive writing, poetry, photographs, images, and music improvisations. During this process, Shaw (2019) developed a post-ableist music therapy framework, which draws on multiple disability definitions and models and is defined as:

a creative process that seeks to work with a person and community to provide an environment and experience that is less disabling through addressing barriers, exploring connections, and providing new/less restrictive spaces through primarily musical or music related experiences. It welcomes different ways of being and resists a one-size fits all approach. Instead, the client and contexts guide the therapist. (p. 218)

Shaw (2019), illustrated this model through vignettes from her music therapy practice.

In addition to this, in the medical memoir, *Trauma, Disability and the "Wounded Healer"*, Abbott (2018) self-identified with the concept of the "wounded healer," a term created by Carl Jung. Abbott proposed that disabled therapists or therapists with history of trauma, have unique qualities and vulnerabilities which can enhance their practice.

Research Question and design

The research question is stated: What are the experiences of Registered Music Therapists who identify as having a disability, and how do their experiences impact and/or inform their practice?

I arrived at this main question after considering my own relationship with disability and passion for disability rights and advocacy. As I have experienced and continue to experience therapy and health interventions throughout my life, would these experiences inform or hinder my music therapy practice? Would I over-identify with people with whom I worked? Where would I now be situated in the disabled community as someone part of the healing/allied health professions? As humans often do, I looked for someone like me – a music therapist experiencing disability – and found a lack of literature or visibility. Whilst disability is a uniquely individual experience, we share many realities that come with difference and I felt I needed these questions answered. I felt they could be best answered by adopting an interpretivist research approach, engaging with an arts-based research design which was as a result of a number of considerations described below. Firstly, the concept of embodying knowledge through art-making to understand and uncover meaning was parallel to the bodily nature of

disability. Secondly, as I had extensive missed learning opportunities throughout my education, being Hard of Hearing (and currently wearing a Cochlear Bone Anchored Hearing Aid) and having a chronic condition. Prior to the acquisition of my Cochlear, I often heavily relied on sensory aspects of language such as body language and non-verbal cues to fully understand language which I felt was congruent with the use of music-making, a sensory experience. Finally, my own music-making is imperative to my self-care practice, which shapes how I experience disability, so once more, arts-based research felt like an organic and instinctive approach.

Arts-based research methodology

I engaged in an arts-based research design with music composition as a primary method for both the analysis process and presenting results. Arts-based research allows opportunities for the researcher to experience an interplay of intrinsic and intellectual knowing of the phenomena using art-making as a vehicle to create meaning (Barone & Eisner, 2012). Utilising art-making in research can capture qualities and essences that are unable to be verbalised or best captured through artistic medium (Viega, 2016a). This embodied dialogue with the phenomena can create opportunities in the researcher for self-growth and insight (Viega, 2016b). Applying arts-based research in disability contexts seem compatible, as it had potential to challenge conventional ideas of normalcy and construct new ideas and narratives around what it means to experience disability (Mykitiuk, Chaplick, & Rice, 2015). I approached the methodology through a hermeneutic phenomenological lens which allowed me to highlight rich, descriptive experiences of the participant and consider the relational process of phenomenology, whilst also freely considering my own experiences without having to separate them or bracket off (Finlay, 2002). An ethics application and plain language statement was submitted to the University of Melbourne and was approved by the Australian Music Therapy Associations (AMTA) Music Therapy Ethics Board.

Recruitment

Purposive sampling was utilised to capture lived experiences and portray authentic voices within the data. The criteria included RMT's registered with the AMTA who self-identified as having a disability. The recruitment process consisted of an advertisement in the AMTA email e-bulletin which ran for two weeks, in addition to the professor of music therapy emailing colleagues across Australia. One participant was recruited through a known source and after email discussions of the project content they agreed to participate, arranging an interview. The participant was emailed the plain language statement and consent form prior to the interview for review.

Data generation

A semi-structured interview was conducted over a one-hour duration with the participant at their place of work. The consent form was signed and dated, and verbal consent was also given within the recorded interview. The interview was recorded on two devices, an iPad and iPhone and transcribed using the software Transcribe. The interview questions consisted of work history and motivations to study music therapy, perceived barriers to employment, influence of disability on theoretical orientation and populations and disclosure of disability to employers and clients. The semi-structured interview format allowed for flexibility of any conversation points which arose, aligning with the flexible boundaries of arts-based research (Viega, 2016a).

I initially planned to offer the option of holding focus groups with several participants sharing experiences together, however, due to lack of participants, the only option was to have an individual interview, which the participant was comfortable with. It is acknowledged that the student-researcher and participant have a professional relationship which brought some level of power dynamic. I have great respect for the



Figure 1

Five themes of disclosure, tension/release, alliance, positive transference, visibility/identity surrounding central theme of hidden disability

participant and noticed I was gentle in my interview approach, and this relational aspect also brought a deep sense of responsibility to convey their experiences accurately.

In my original proposal, I had hoped to close the focus groups with a short group musical improvisation to capture any final essences of the conversation and add an alternative means of expression. I had also intended to analyse the audio nature of each participants voice and consider central pitch ranges, intonation, quality, and rhythmic elements to be interpreted through short musical compositions around the themes. However, as there was one participant, I felt both the improvisation and capturing vocal qualities was perhaps too intimate and exposing. I asked the participant if they would be comfortable if I instead created compositions devised from the themes. This ability to change course fitted within the generous and malleable boundaries of arts-based research (Viega & Forinash, 2016).

I absorbed myself with the data by listening to the interview several times whilst reading the manual transcript and taking physical notes. I highlighted words and concepts that reoccurred or I found interesting. I made notes and found that I needed to question my own interpretations to ensure I was not creating themes that were congruent with my own values and experiences. I found it useful to journal and write simple poetry to process my own experiences that felt close to the participant's. Over a period of four weeks, I identified six themes using this process.

I created five "tiny songs," short musical compositions representing each theme or grouped theme. As described, I was very conscious of my internal feelings and dialogue when I listened to the audio and explored these themes. I tried to capture these feelings in the musical elements – tempo, rhythm, melody, dynamics, qualities, and contours – of each of the tiny songs, whilst also corresponding to each theme. It felt authentic at the time, to use voice and hand clapping only, as an instinctive means to represent the bodily nature of disability. However, in retrospect, assistive devices, aids, and technology are often a big part of the disability experience, including my own bionic implant. The creation of the songs formed part of the analysis process. Through the embodiment and play in the creation of tiny songs, I felt I was able to deepen my understanding of each theme and in my mind, gave life to each theme through the tiny songs. Each tiny song shared a central melody line and key which threaded the themes in a sequential manner, however the musical elements within each tiny song change to suit the theme and feelings. The tiny songs are presented in the results below.

Results and discussion

The central theme of how the participant experiences hidden disability is surrounded by overlapping themes of disclosure, tension/release, alliance, positive transference, and visibility/identity. I view these themes as sequential in striving to depict the participant's experiences as a story of what it means to be human. The themes have been described in sequence below. I have provided a short description of my musical choices of each tiny song; however, I encourage the listener and reader to forge their own meaning and interpretation.

Please note a soundcloud link is attached in each box which will take you to a playlist. I encourage you to listen to each track sequentially alongside each theme.

Central theme: Hidden disability

Hidden disability

Hidden disability,
is something that I know.
I am viewed as able-bodied,
I am not alone.
I don't know if I should tell you,
this extra mental load.
Hidden disability, Hidden disability.

Audio: <https://soundcloud.com/user-226968250/hidden-disability>

The concept of *Hidden* disability was a compelling central theme, where the participant described a “dual experience” of living with disability, yet often viewed by society as able-bodied. This concept of experiencing hidden disability has been termed “passing” and can be seen as a level of privilege over those with visible disabilities (Clare, 2017). It was also discussed that society often assumes that one is able-bodied if they do not have visible disability. A subsequent notion within this theme was not feeling “disabled enough” in some settings and on the opposite spectrum, feeling “too disabled” in other contexts. In their workplaces, people with hidden disabilities have reported to utilise this concept of passing, concealing their disability to their advantage yet many feel the burden of keeping a secret and may not receive necessary accommodations (Lyons, Volpone, Wessel, & Alonso, 2017). The term “hidden disability” was used at the time by the participant and this term is sometimes used interchangeably with “invisible disability” in disability studies literature and disability community. However, the words hidden and invisible are quite different, with hidden perhaps capturing the notion of disability needing to be hidden due to shame and stigma, whereas invisible may be more neutral.

In creation of the tiny song, I explicitly placed the word disability within the song several times to illustrate to the listener that it is not a phenomenon which is undesirable or to be avoided.

Theme 1: Disclosure

The great reveal

It's the great reveal,
It's my time to steal the light.
To tell you, to tell you.
I never know, how this will go.
It's the great reveal, the great reveal.

Audio: <https://soundcloud.com/user-226968250/the-great-reveal>

The participant described disclosing or not disclosing their disability to employers, colleagues, children, families, students and other people in life more generally, with

mixed results. In a music therapy practice context, the participant chose not to disclose to children or families with whom they work, as it was not deemed relevant and little to no environmental adaptations were needed. The participant viewed disclosure to children and families as not helpful to the relationship and the populations with whom they worked but implied they were open-minded on the subject. The participant described how the nature of a hidden disability means they have the choice to disclose to others. This choice brings power and control over how “the story” of disability is verbalised and this was described as “the great reveal,” emphasising the suspense that comes prior to disclosure and the uncertainty of other responses after disclosure. Despite the power and control over how disability is disclosed, it was revealed that there is no control over or containment of how someone will respond, and this response can result in a change to the relationship, described in the consequent theme. These findings of disclosure are congruent with parallel discourse around disclosing disability generally and self-disclosure in talking therapies. In relation to disclosing to employers, one study highlighted the stigma of disability as a reason participants delayed or refrained from disclosing, particularly if their disability was not easily visible (Lyons et al., 2017). It was found that people with disabilities often weigh up the potential benefits versus the potential risks before making a decision to disclose, and those with visible symptoms/behaviours or most needing adaptations were most likely to disclose (Reed et al., 2017). Other people experienced negative consequences of disclosure which often impacted future decisions to disclose (Reed et al., 2017), with some consequences including lowered expectations, isolation in the workplace and in some cases, termination (von Schrader, Malzer, & Bruyère, 2013). One study highlighted the importance of employers establishing a culture of transparency and inclusion which encouraged disclosure amongst all workers to reduce negative effects (von Schrader et al., 2013).

Disclosure with participants or people with whom we work, often termed self-disclosure in psychotherapies, is a contentious issue (Hill, Knox, & Pinto-Coelho, 2018) with self-disclosure considered a boundary-crossing (Medcalf & Skewes McFerran, 2016), which can be both contributing to and impairing of the therapeutic alliance (Hill et al., 2018). A recent study exploring self-disclosure of life experiences amongst talking therapists were perceived as helpful to clients, strengthening the therapeutic alliance and normalising the therapy experience (Hill et al., 2018). I theorise that in music therapy, the theoretical orientation and population with whom the therapist works alongside may predict the implications of disclosure on the therapy relationship.

For this tiny song, I intentionally did not use the word disability to represent the anticipation of the disclosure or “great reveal.” I adopted a swung rhythmic feel to emphasise the dramatic nature of disclosure

Theme 2: Tension/Release

Tension/Release

Tension and release,
Tension and release.
Tension and release,
Tension and release.

Audio: <https://soundcloud.com/user-226968250/tension-release>

Tension was a subsequent theme after disclosure. A tension or feeling of otherness was depicted as arising within a relationship after disclosure of disability and described as a “shift” in the relationship. This tension was sometimes met with a release and relief for the participant after disclosure. This theme is compatible with much disability discourse. In one study, all 72 participants responded that they were treated differently after disclosure in their workplace and felt a sense of “otherness” which was experienced as loss of power, expressions of pity, a carefulness in conversation, and gener-

al avoidance (Reed et al., 2017). In feminist narratives, this concept of otherness has been described in relation to intersectionality, where disability has been labelled as the extreme “other,” as non-disabled people fear becoming disabled, knowing the high incidences of acquired disability over the lifespan (Hirschmann, 2013). When considering systems of oppression and power, this concept of tension has also been illustrated as the contrast of social inequities between groups of those who are marginalised and those who experience social advantage (Hadley & Thomas, 2018). Sajnani (2013), suggested that adoption of an intersectional lens by creative arts therapists can assist them to identify the interactions and internal experiences causative to feelings of otherness and tension by the therapist and people with whom we work with aim to cause disruption.

This tiny song uses tight and block harmonies and the predictability of a suspenseful chord resolving to the tonic.

Theme 3 & 4: Alliance/Positive transference

Positive transference

I really believe you can do it.
 I don't have no pity for you.
 I know you have that extra grit.
 'Cuz that's how I always knew it,
 Positive transference, positive transference
 Positive transference, positive transference, positive.

Audio: <https://soundcloud.com/user-226968250/positive-transference>

A coupled theme of alliance and positive transference was revealed, which described the participant's approach to their work with children with disability through the lens of understanding and identifying with how society may view disability as limiting a child's capabilities and the unspoken understanding of tension and otherness. The participant's strong belief in each child's capabilities allowed them to work not from a place of pity but a rooted empathy. This approach and action can represent positive transferences within the relationship. The interplay between therapist and participant with inclusion of transference and countertransference's have been described as a crucial feature to a positive therapeutic relationship with these relational dimensions having the potential to cultivate positive outcomes for the person (Markin, McCarthy, & Barber, 2013).

This tiny song attempts to represent an earnest dialogue from the participant to an imagined child with a disability.

Theme 5: Visibility/Identity

Where do we go from here?
 I try hard to be brave and be visible,
 Easy to say but not to do.
 How do I show authenticity?
 When it is and it isn't my identity?
 Where do we go from here?
 Where do I go from here?
 Where do we go from here?
 Where do we go from here?

Audio: <https://soundcloud.com/user-226968250/where-do-we-go-from-here>

Themes of identity and visibility are partnered as they exemplify a paradox that many people with disabilities experience. The participant described a pressure from the self to be brave and inhabit visibility as a music therapist with a disability. This

was defined as being authentic, however, the participant also described disability as “it is, and it isn’t” part of their identity. They suggested that once disability is disclosed to others, it is often seen as a significant part of one’s identity, however “it is, and it isn’t.” Within this theme of identity and visibility also comes advocacy, as the participant has an embodied understanding of some of the barriers people with disabilities face in the world, this deepens the pressure to be visible and advocate for others with disability. Additionally, the participant discussed the room for improvement in current disability discourse and how some discourse is hierarchical and speaks for certain members of the disability community, rather than include them.

Identities categorise how we make meaning of ourselves in the world and how we are understood by others; this means our identities are perceived through visibility (Sevinc, 2010). This bears a strong argument as to why visibility is important to counter ableism with the term “out and proud,” commonly utilised in LGBTQIA+ communities adopted by the disability community, visibility declares that we are here, living in the community and our rights must be upheld. However, alternative discourse suggests visibility is not a binary of invisible versus visible and does not contribute to progress or change attitudinal barriers (Thomsen, 2015). This tiny song explores this identity paradox lyrically and also questions and leaves space and openness for what may come next.

There were two fringe themes worth mentioning. The participant discussed having boundaries in place in order to support well-being, explaining that knowing the self and being consistently reflexive ensures these boundaries are maintained and these boundaries not only ensure effective practice but support a desired level of wellness.

Another fringe theme was a short commentary of critical disability and music therapy discourse. The notion of “fixing” disability, particularly arising from the consensus model, can be desirable within music therapy yet this approach may not be parallel with disability discourse. They described a professional move away from this notion towards a collaborative approach.

Implications

The most important implications from these results relate to the concept of visibility and representation. It is imperative we promote the fact that music therapy is a diverse profession. We can achieve this in part by centring the diverse voices among us that do exist and include these voices in all aspects of dialogue about us and between us. If we are visible in our communities and professions it can help to challenge ableist notions that seem to imply that therapists are always “perfect” or “healthy” (Campbell, 2009). These results align well with disability studies literature which highlight the importance of disability representation across all health professions, in order to support practices which are anti-oppressive.

This work also highlights the value of lived experience and how it can positively inform a therapeutic relationship through collaboration and authenticity. Yet it must be questioned, if we do not feel comfortable or safe disclosing lived experience of disability, how do we encourage visibility and inclusion in our profession? Furthermore, if we as disabled music therapists do not disclose hidden disabilities, are we complicit in silencing and reinforcing the oppression of disabled participants we work alongside? Despite a broad reach, only one research participant made contact and was subsequently interviewed. This poses further questions: Disabled music therapists, where are you? How do we create safe environments in order to have the opportunity to disclosure? Perhaps focusing on and normalising access needs of disabled music therapists is one way of creating safer spaces? Whilst there was a limitation of one participant, this is hopefully a rich description of their unique experience which also highlights the individuality of disability. Personally, I found this research offered me opportunities for self-growth and insight into my own experiences, as well how to approach my transition into the workforce as a disabled music therapist. I feel encouraged and excited to

connect with other music therapists who identify with the disability community and explore further ideas and opinions.

Concluding reflections

Whilst my main objective of the tiny songs was analysis and as a format for results, a secondary objective became apparent. Viega (2016a) spoke to the art-making process and results as not essential to be aesthetically pleasing. However, I felt a yearning to create beautiful songs which included the words disability in the lyrics, representing disability in a joyful, honest, and positive form. I have reflected on whether this project was self-indulgent and sometimes questioned its worth. I occasionally felt exasperated when I read occasional music therapy and other literature that was deeply ableist.

This research process raised for me the potential of experiencing vicarious trauma versus vicarious resilience. Vicarious trauma is defined as a therapist experiencing trauma after repeated exposure to traumatic material, whereas vicarious resilience is defined as professional and personal growth from witnessing growth in participants of therapy (Hernandez-Wolfe, Killian, Engstrom, & Gangsei, n.d.). Is there risk of vicarious trauma for disabled therapists when repeatedly exposed to stories of ableism and trauma or through working in the systems which can create oppressive conditions for the disability community? Alternately, can disabled therapists experience vicarious resilience, which benefits both participant and therapist resulting from working with-in community?

The Australian Music Therapy Association's (AMTA) Code of Ethics (2014), which all Australian music therapists must adhere to, states several ethical responsibilities which may impact disabled music therapists. These responsibilities include; avoiding any "harm to their clients" and refraining from practice when "personal or emotional difficulties, illness, alcohol, drugs or any other cause significantly impairs their effectiveness" (AMTA Inc, 2014). These standards of practice are necessary for the professionalism of the music therapy community and protection of music therapy participants. However, it is difficult to define both "harm" and "effectiveness" in these statements. The research participant touched on having strong self-care practices in order to retain boundaries and their personal level of wellness in order to practice. However, if I am experiencing a flare of my chronic condition and share with music therapy participants that I need to sit down in a music therapy session, is this impairing my effectiveness, or am I simply being human? If I do not hear what a music therapy participant has said vocally, again, is this impairing my effectiveness, or am I simply human?

Future research is needed to explore and elevate diverse perspectives from music therapists and the people with whom we work through a participatory approach. It is important to consider that there are many ways of understanding and experiencing disability across different cultural contexts. In an Australian context, the voices of First Nations people are not often heard or privileged in disability literature and spaces, despite high incidences of disability in these communities. These are voices we must center.

At times, when engaging with the data, I felt a sensitivity and closeness to the work, and it was a feeling I have known well – vulnerability. In disability discourse, the word *vulnerable people* is employed regularly in relation to the concept of dependency. Whilst it is evident that we, disabled people, experience greater incidences of violence and abuse, which could be perceived as a vulnerability related to our social group, the concept of independence for disabled people and their families and networks is often viewed as the ultimate destination upon which to arrive. This word, vulnerable, is often used in music therapy discourse and by not-for-profit organisations as a protection measure and stems from compassion and care. However, it is important to acknowledge that this word can be met with animosity in the disability community and is discouraged. Mingus (2010), described the "myth of independence" as being a miscalculated attempt at inclusion, suggesting that society consists of layers of interwoven

human dependency, which should not be viewed as undesirable or vulnerable. For me, this feeling of vulnerability is rife with conflict as I work on unlearning internalised ableism and on accepting and celebrating my disabled body.

Préfontaine (2006) suggested that experiential learning, which involves the body and mind is crucial in becoming an efficient and conscious music therapist and this involves exploring one's own vulnerabilities. Yet, if you are labelled as part of a "vulnerable" group, is vulnerability something you can switch on and off, or it is a state of being? This vulnerability through the creation and exploration of this small body of work felt exposing to the research participant and also to me. Where does this place me now, where do I go from here and where do we go, collectively, from here?

This research project sought to uncover experiences of a Registered Music Therapist who identifies as having a disability and to understand how their disability impacts and informs their practice. Findings highlighted the value of how lived experiences can enhance our profession and encourage inclusion and visibility, bringing attention to the great need for diversity in our profession.

Acknowledgement

I wish to acknowledge the Boonwurung and Wurundjeri people of Eastern Kulin Nation on whose land I live and work. I pay my respects to their elders, past, present, and emerging and acknowledge that sovereignty over this land has never been ceded.

About the author

Zoë Kalenderidis is a music therapist and musician living in Naarm/Melbourne, Australia. Zoë graduated in 2018 with a Master of Music Therapy at the University of Melbourne, prior to this obtaining a Bachelor of Contemporary Music, majoring in voice at Southern Cross University, Lismore. She enjoys working alongside both disabled adults and young people who have experienced trauma, in community music therapy settings. She has a passion for disability rights and making music accessible for all. Zoë strives to work from a collaborative approach which leans toward social change.

References

- Abbott, D. (2018). Trauma, disability and the "Wounded Healer". *Music and medicine, an interdisciplinary journal*, 10(3).
- Australian Music Therapy Association Inc. (2014). *Code of Ethics*.
<https://www.austmta.org.au/system/files/Code%20of%20Ethics%202014.pdf>.
- Baines, S. (2013). Music therapy as an anti-oppressive practice. *The Arts in Psychotherapy*, 40(1), 1-5, <https://doi.org/10.1016/j.aip.2012.09.003>.
- Bakan, M. (2014). Ethnomusicological perspectives on autism, neurodiversity, and music therapy. *Voices: A World Forum For Music Therapy*, 14(3), <https://doi.org/10.15845/voices.v14i3.799>.
- Barone, T., & Eisner, E. W. (2012). *Arts based research*. Oaks Cal: Sage Publications Inc.
- Bell, A. P. (2017). (dis)Ability and music education: Paralympian Patrick Anderson and the experience of disability in music. *Action, Criticism & Theory for Music Education*, 16(3), 108-128, <https://doi.org/10.22176/act16.3.108>.
- Boggan, C. E., Grzanka, P. R., & Bain, C. L. (2018). Perspectives on queer music therapy: A qualitative analysis of music therapists' reactions to radically inclusive practice. *Journal of Music Therapy*, 54(4), 375-404, <https://doi.org/10.1093/jmt/thx016>.
- Bruscia, K. E. (2014). *Defining music therapy*. Dallas: Barcelona Publishers.
- Cameron, C. (2014). Does disability studies have anything to say to music therapy? And would music therapy listen if it did? *Voices: A World Forum For Music Therapy*, 14(3), <https://doi.org/10.15845/voices.v14i3.794>.

- Campbell, F. K. (2009). *Contours of ableism*. [electronic resource]; *The production of disability and abledness*. <https://doi.org/10.1057/9780230245181>.
- Charlton, J. I. (2000). *Nothing about us without us: Disability oppression and empowerment*. University of California Press. <https://ebookcentral.proquest.com>.
- Churchill, W. N. (2015). Deaf and hard-of-hearing musicians: Crafting a narrative strategy. *Research Studies in Music Education*, 37(1), 21-36, <https://doi.org/10.1177/1321103x15589777>.
- Clare, E. (2017). *Brilliant imperfection: Grappling with cure*. Duke University Press. <https://doi.org/10.1215/9780822373520>.
- Côté, J. E., & Levine, C. (2002). *Identity formation, agency, and culture: a social psychological synthesis*. L. Erlbaum Associates. <https://doi.org/10.4324/9781410612199>.
- Draycott, J. (2019). On a limb. *History Today*, 69(3), 72-83.
- Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264, <https://doi.org/10.1037/a0038636>.
- Finlay, L. (2002). Negotiating the swamp: The opportunity and challenge of reflexivity in research practice. *Qualitative Research*, 2(2), 209-230, <https://doi.org/10.1177/146879410200200205>.
- Fitzpatrick, S. J., & River, J. (2018). Beyond the medical model: Future directions for suicide intervention services. *International Journal of Health Services*, 1(189), <https://doi.org/10.1177/0020731417716086>.
- Grandin, T., & Panek, R. (2013). *The autistic brain: Thinking across the spectrum*. New York: Houghton Mifflin Harcourt.
- Gross, R. (2018). The Social model of disability and music therapy: Practical suggestions for the emerging clinical practitioner. *Voices: A World Forum For Music Therapy*, 18(1), <https://doi.org/10.15845/voices.v18i1.958>.
- Hadley, S. (2013). Dominant narratives: Complicity and the need for vigilance in the creative arts therapies. *The Arts in Psychotherapy*, 40(4), 373-381, <https://doi.org/10.1016/j.aip.2013.05.007>.
- Hadley, S., & Thomas, N. (2018). Critical humanism in music therapy: Imagining the possibilities. *Music Therapy Perspectives*, 36(2), 168-174, <https://doi.org/10.1093/mtp/miy015>.
- Haegele, J. A., & Hodge, S. (2016). Disability discourse: Overview and critiques of the medical and social models. *Quest*, 68(2), 193-206, <https://doi.org/10.1080/00336297.2016.1143849>.
- Hernandez-Wolfe, P., Killian, K., Engstrom, D., & Gangsei, D. (n.d.). Vicarious resilience, vicarious trauma, and awareness of equity in trauma work. *Journal of Humanistic Psychology*, 55(2), 153-172. <https://doi.org/https://doi.org/10.1177%252F0022167814534322>
- Hill, C. E., Knox, S., & Pinto-Coelho, K. G. (2018). Therapist self-disclosure and immediacy: A qualitative meta-analysis. *Psychotherapy*, 55(4), 445-460, <https://doi.org/10.1037/pst0000182>.
- Hirschmann, N. J. (2013). Disability, feminism, and intersectionability. *Radical Philosophy Review*, 16(2), 649-662, <https://doi.org/10.5840/radphilrev201316247>.
- Hollomotz, A. (2012). Disability, oppression and violence: Towards a sociological explanation. *Sociology*, 47(3), 477-493, <https://doi.org/10.1177/0038038512448561>.
- Kafer, A. (2013). *Feminist, queer, crip*. Indiana: Indiana University Press.
- Laes, C., Goodey, C. F., & Rose, M. L. (2013). *Disabilities in Roman antiquity*. [electronic resource]: *Disparate bodies, a capite ad calcem*. Retrieved from <https://ebookcentral.proquest.com/lib/unimelb/detail.action?docID=1214122>.
- Lerner, N. W., & Straus, J. N. (2006). *Sounding off*. [electronic resource]: *theorizing disability in music*. Indiana: Indiana University Press.

- Linton, S., Mello, S., & O'Neill, J. (1995). Disability studies: Expanding the Parameters of diversity. *The Radical Teacher*, 4(47), <https://radicalteacher.library.pitt.edu/ojs/radicalteacher>.
- Liudmila, K., & Lejla, V. (2014). *Insider research method: The significance of identities in the field*. SAGE Publications.
- Lubet, A. (2011). *Music, disability, and society*. Philadelphia: Temple University Press.
- Lyons, B. J., Volpone, S. D., Wessel, J. L., & Alonso, N. M. (2017). Disclosing a disability: Do strategy type and onset controllability make a difference? *Journal of Applied Psychology*, 102(9), 1375-1383, <https://doi.org/10.1037/apl0000230>.
- Markin, R. D., McCarthy, K. S., & Barber, J. P. (2013). Transference, countertransference, emotional expression, and session quality over the course of supportive expressive therapy: The raters' perspective. *Psychotherapy Research*, 23(2), 152-168, <https://doi.org/10.1080/10503307.2012.747013>.
- McCruer, R. (2006). *Crip Theory: Cultural Signs of Queerness and Disability*. New York University Press.
- Medcalf, L., & Skewes McFerran, K. (2016). A critical interpretive synthesis of music therapy case studies: Examining therapeutic boundary themes in the context of contemporary practice. *British Journal of Music Therapy*, 30(1), 22-35, <https://doi.org/10.1177/1359457516639556>.
- Mingus, M. (2010). *Interdependency (excerpts from several talks)*. Retrieved from <https://leavingevidence.wordpress.com/2010/01/22/interdependency-exerpts-from-several-talks>.
- Mykitiuk, R., Chaplick, A., & Rice, C. (2015). Methodology: Beyond normative ethics: Ethics of arts-based disability research. *Ethics, Medicine And Public Health*, 1, 373-382, <https://doi.org/10.1016/j.jemep.2015.07.005>.
- Préfontaine, J. (2006). On becoming a music therapist. *Voices: A World Forum For Music Therapy*, 6(2), <https://doi.org/10.15845/voices.v6i2.255>.
- Radić-Šestić, M., Ostojić, S., & Đoković, S. (2015). Attitude of deaf culture toward cochlear implantation. *Specijalna Edukacija I Rehabilitacija*, 14(1), 101-124, <https://doi.org/10.5937/specedreh1-7156>.
- Reed, K. S., Meade, M., Jarnecke, M., Rumrill, P., Krause, J. S., Koch, L. C., & Rumrill, P. D. (2017). Disclosing disability in the employment setting: Perspectives from workers with multiple sclerosis. *Journal of Vocational Rehabilitation*, 47(2), 175-184, <https://doi.org/10.3233/jvr-170893>.
- Riddle, C. A. (2013). Defining disability: metaphysical not political. *Medicine, Health Care and Philosophy*, 16(3), 377-384, <https://doi.org/10.1007/s11019-012-9405-9>.
- Rolvsvjord, R. (2010). *Resource-oriented Music Therapy in Mental Health Care*. Dallas: Barcelona Publishers.
- Sajnani, N. (2013). The body politic: The relevance of an intersectional framework for therapeutic performance research in drama therapy. *The Arts in Psychotherapy*, 40(4), 382-385, <https://doi.org/10.1016/j.aip.2013.05.001>.
- Senghas, R., & Monaghan, L. (2002). Signs of their times: Deaf communities and the culture of language. *Annual Review Of Anthropology*, 69, <https://doi.org/10.1146/annurev.anthro.31.020402.101302>.
- Sevinc, N. (2010). *In/visibility of identities and identity politics: The case of invisible disabilities*.
- Shakespeare, T. (2018). *Disability: the basics*. Routledge.
- Shaw, C. M. (2019). *Developing post-ableist music therapy: An autoethnography exploring the counterpoint of a therapist experiencing illness/disability* (Doctoral dissertation). New Zealand School of Music, Te Kōki / Victoria University of Wellington, New Zealand. Retrieved from <http://hdl.handle.net/10063/8247>.

- Shyman, E. (2016). The reinforcement of ableism: Normality, the medical model of disability, and humanism in applied behavior analysis and ASD. *Intellectual and Developmental Disabilities, 54*(5), 366-376, <https://doi.org/10.1352/1934-9556-54.5.366>.
- Snyder, S., & Mitchell, D. (2001). Re-engaging the body: Disability studies and the resistance to embodiment. *Public Culture, 3*(367), <https://doi.org/10.1215/08992363-13-3-367>.
- Stige, B., & Aarø, L. E. (2012). *Invitation to community music therapy*. New York & London: Routledge.
- Thomsen, C. (2015). The Post-raciality and post-spatiality of calls for LGBTQ and Disability visibility. *Hypatia: A Journal of Feminist Philosophy, 30*(1), 149-166.
- Tsiris, G. (2013). Voices from the 'ghetto': Music therapy perspectives on disability and music (A response to Joseph Straus's book Extraordinary Measures: Disability in Music). *International Journal of Community Music, 6*(3), 333-343, https://doi.org/10.1386/ijcm.6.3.333_1.
- Viega, M. (2016a). Aesthetic sense and sensibility: Arts-based research and music therapy. *Music Therapy Perspectives, 34*(1), 1-3, <https://doi.org/10.1093/mtp/miw010>.
- Viega, M. (2016b). Science as art: Axiology as a central component in methodology and evaluation of arts-based research (ABR). *Music Therapy Perspectives, 1*(4).
- Viega, M., & Forinash, M. (2016). Arts-Based Research. In K. Murphy & B. Wheeler (Eds.), *Music therapy research* (3rd ed., pp. 980-1006). Dallas: Barcelona Publishers.
- von Schrader, S., Malzer, V., & Bruyère, S. (2013). Perspectives on disability disclosure: the importance of employer practices and workplace climate. *Employee Responsibilities and Rights Journal, 26*(4), 237-255, <https://doi.org/10.1007/s10672-013-9227-9>.
- Warren, P., & Rickson, D. (2016). What factors shape a music therapist?: An investigation of music therapists' professional identity over time in New Zealand. *Journal of Music Therapy, 14*, 55-81.
- Wheeler, B. L., & Baker, F. A. (2010). Influences of music therapists' worldviews on work in different countries. *The Arts in Psychotherapy, 37*(3), 215-227, <https://doi.org/10.1016/j.aip.2010.04.006>.
- Yeh, M. A., Jewell, R. D., & Thomas, V. L. (2017). The stigma of mental illness: Using segmentation for social change. *Journal of Public Policy & Marketing, 36*(1), 97-116, <https://doi.org/10.1509/jppm.13.125>.