THE PERCEPTION OF MUSIC THERAPY BY DIRECT CARE STAFF OF OLDER

ADULTS WITH INTELLECTUAL DISABILITIES: A PHENOMENOLOGICAL APPROACH

By

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Abstract

The purpose of this phenomenological study was to explore the experiences and perceptions of direct care staff of older adults with intellectual disabilities who participate in music therapy services. Participants (N=5) were direct care staff (DCS) over age 18, either currently working or formerly worked as DCS at Cottonwood Retirement, and observed a minimum of one music therapy session with their client(s). Participants shared their experiences in individual 60-minute semi-structured interviews. The interviews were recorded, transcribed, and analyzed using Interpretive Phenomenological Analysis (IPA). Six themes emerged: (a) DCS find music therapy effective in changing social, physical, emotional, and cognitive functioning, (b) DCS find personal enjoyment through connecting with consumers in music therapy experiences, (c) DCS are experienced and knowledgeable about consumers and encourage student music therapists (SMTs) to ask for help, (d) DCS apply and reinforce experiences practiced in music therapy to consumer activities outside of sessions, (e) DCS encourage SMTs to focus on physical, emotional, and social functioning, instead of cognitive functioning, of older adults with ID, and (f) DCS encourage SMTs to consider consumers' individual characteristics and preferences in order to increase therapist flexibility and intuition.

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Chapter 1

Introduction

A dark, ammonia filled room welcomes the investigative journalists and trailing cameras. Their lights pierce the dark, highlighting 60 children in fetal positions with grimaced faces, feces smeared everywhere. A lone female staff member stands in the middle of the room, breaking apart a fight between two moaning children—a sound echoed by the others. She looks into the camera, the crew aghast. Her face is painted with a half-smile. The only decoration hangs above her: "Merry Christmas" (Rivera, 1972).

Geraldo Rivera's *Willowbrook* (1972) investigative episode had a massive impact on my interest in the evolution of how we, as human beings, treat and care for people with intellectual disabilities. Currently, very little information exists regarding Willowbrook staff members besides court depositions. The investigative journalists did not interview the female staff member mentioned above. I found her image so striking; I wanted to know more about her and how she coped with being in charge of 60 residents in such hazardous and depressing conditions. What were her experiences working with these residents in this environment? How did the environment affect her experiences working with the residents?

Researcher Background and Interests

As a Direct Care Staff (DCS) member working with adults with intellectual disabilities (ID) in residential services since 2013, I experience situations full of joy, stress, and determination in order to help consumers maintain their independence in their daily lives. My duties include transportation, cooking, cleaning, daily hygiene, medication delegation, and behavior management—it is overwhelming at times.

Learning how to handle consumer behaviors, long hours, and late nights lead to many stressful situations unique to caring for individuals with ID.   For example, I was informed that a consumer needed to be monitored at night in case of her throwing up as she roamed the halls. When midnight arrived, I heard loud wet coughing over the monitor. I had to act quickly to prevent asphyxiation, clean her up, monitor her in the bathroom, and make the decision to call for help—the gut reaction told me she needed medical attention. After she was taken to the hospital at 2:30 a.m., I was left to work the rest of the weekend (i.e., 52 hours total, including overnights). I was shaken. I could not sleep for more than two hours at a time. I was overcome with worry.

However, these stressful moments are ameliorated by observing positive changes in my clients when they participate in psychosocial experiences such as music therapy. I observed several music therapy practicum sessions at a residential care facility. During the music therapy sessions, consumers became more alert, made choices when given prompts, spontaneously broke out into dancing, expressed themselves through instrumental play, and cooperated with their peers. While staff remarked they did not normally get along through the day. I and other DCS observed the differences in behavior when clients attended music therapy.

As a music therapy student, my third practicum was at Cottonwood Retirement, a place for consumers with ID over the age of 50 that helps them continue to thrive when they are unable to work at the main facility. This practica was my best experience as a student music therapist. Consumers communicated and opened up to me while using music, whether it was through instrumental play, movement to music, or their described favorite, group singing. The change in the air was electric and emotionally moving. One consumer, whose favorite song was "Roll Out the Barrel," cried with joy, grinning from ear to ear, while singing along. Positive behaviors,

such as sitting with the group and actually engaging in an activity, occurred as a result of participation in the music therapy group.

During my practicum, the DCS of Cottonwood Retirement discussed music therapy, and all the different interventions they observed throughout the years, with me. They commented on how music therapy affected the consumers, ranging from engaging in exercise to emotion regulation. In addition to commenting on the effects of music therapy on consumers, the DCS discussed the effect music therapy had on themselves. My background and experiences as a a student music therapist and a DCS for people with ID, along with conversations with other DCS regarding music therapy, sparked my research interest.

Intellectual Disability

Approximately 1% to 3% of the population in the United States has an intellectual disability, not including those who go undiagnosed (The Arc, 2011; National Institute of Health [NIH], 2015). Intellectual disability is defined by characteristics of significant limitations in adaptive behavior, such as conceptual skills (e.g., language, literacy, number concepts, and self-direction), social skills (e.g., interpersonal skills, self-esteem, gullibility), and functional skills (e.g., personal care, occupational skills, health care) (American Association of Intellectual and Developmental Disabilities [AAID], 2013; American Psychiatric Association [APA], 2013; NIH, 2015). Intellectual disability is diagnosed before the age of 18 (AAID, 2013; World Health Organization [WHO], 2015) and consists of a reduced ability to learn and apply new skills due to information being new or complex (APA, 2013; NIH, 2015). This reduced ability leads to problems with the development of independent coping skills during childhood and adolescence, and lasts throughout adulthood (WHO, 2015). Developmental delays and psychological

problems may also occur from social factors (e.g., family rejection) and environmental factors (e.g., being placed in an institution, inclusion policies) (WHO, 2015).

People with suspected ID complete comprehensive standardized assessments, such as the Abnormal Denver Developmental Screening Test or a standardized intelligence quotient (IQ) test (NIH, 2015). The Diagnostic Adaptive Behavior Scale (DABS), released in 2015, is conducted by professionals who work with the individual (e.g., school psychologists, social workers, occupational therapists) in order to receive an official diagnosis of ID (AAID, 2013 WHO, 2015). Clinicians use the DABS to diagnose and determine what services are needed to help with development and independence. These services may include: special education services, home and community-based waiver services, Social Security Administration benefits, and specific treatment within the criminal justice system (AAID, 2013).

Many factors can contribute to intellectual disabilities; however, doctors find specific causes in only 25% of all cases (NIH, 2015). The three most common types of intellectual disabilities are Down syndrome, Fetal Alcohol Spectrum Disorder (FASD) and Fragile X syndrome (The Arc, 2011). Causes of intellectual disabilities include, but are not limited to: genetic conditions, infections either present or occurring after birth, chromosomal abnormalities, environmental, metabolic (e.g., hyperbilirubinemia), nutritional, toxic (e.g., exposure to alcohol and drugs), trauma, and unexplained reasons doctors cannot diagnose (The Arc, 2011; NIH, 2015). Poverty and cultural deprivation can also contribute to the causes of intellectual disabilities due to the higher risks of malnutrition, inadequate health care, under-stimulation, and exposure to environmental health hazards (The Arc, 2011).

Deinstitutionalization

Before the introduction of Thorazine (chlorpromazine) and passage of the Community

Mental Health Act in 1963, people with ID were typically institutionalized and sheltered from

families and communities (National Institutes of Health [NIH], 2016; Torrey, 1997).

Deinstitutionalization and normalization for people with ID underwent several stages, with

decreasing populations in institutional settings from 1955 through the 1990s (Koyanagi &

Bazelon, 2007; Torrey, 1997). In 1955, 558,239 patients populated the nation's psychiatric

hospitals; this number decreased by 1994 to 71,619 patients (Torrey, 1997). The emphasis of this

change was to decrease the use of institutions and increase secured community integration (e.g.,

access to housing and jobs) (Koyanagi & Bazelon, 2007). In 1990, community settings and

group homes for people with ID started to develop, providing food, shelter, job opportunities,

and community integration (Koyanagi & Bazelon, 2007). Since the beginning of

deinstitutionalization, people with ID are now living much longer due to their involvement in

better health care and community settings, thus increasing the need for care due to longer

lifespans (Patja, Iivanainen, Vesala, Oksanen, & Ruoppila, 2000).

The approach to caring for and working with people with intellectual disabilities in the

United States has changed dramatically since deinstitutionalization began in the 1950s. The

current community integration approach looks very different than the pictures presented in the

investigative journalism report on Willowbrook. Although individuals with ID were empowered

to live as independently as possible, many still needed assistance with functional skills and

decision-making. It was then important to provide staff to care for these individuals and to help

them maintain the highest level of independence (Gray-Stanley, & Muramatsu, 2011).

Direct Care Staff

DCS are people who help those with ID maintain their health and well-being in many settings (Gray-Stanley & Muramatsu, 2011). Settings include, but are not limited to, nursing facilities, group residences, and home care (Gray-Stanley & Muramatsu, 2011). DCS duties may involve administering medication, assisting with hygiene, grooming, dressing, and oral health care (Gray-Stanley & Muramatsu, 2011). In addition to life needs, DCS work to manage challenging behaviors of people with ID (Gray-Stanley & Muramatsu, 2011). DCS also assist clients with professional and social development through vocational training and social integration in the community (Hatton et al., 1999).

Even though working as DCS may be fulfilling work, there are heavy stressors within the field. Stressors are defined as "physically or psychologically challenging events or circumstances" (Sarafino, 2006, p. 62). Researchers looking into the job of DCS discovered stressors that are more prevalent in the DCS field than other jobs, such as heavy workloads, client behavioral and health problems, and limited job autonomy (Gray-Stanley & Muramatsu, 2011). Strain - the physical and psychological response to a stressor (Sarafino, 2006) - may occur if these job stressors are not managed properly. Job strain may contribute to burnout of DCS and lesser quality of care for individuals with ID (Gray-Stanley & Muramatsu, 2011; Hatton et. al, 1999).

Several researchers identified variables associated with job strain of DCS working with people with ID, including wishful thinking (i.e., thinking that what you wish is real or likely to become real), lack of staff support, alienative commitment, role ambiguity, stress linked to low status job, and longer contracted hours (Hatton et al., 1999). In addition, the increase in workload continues to be a high cause of emotional stress (Kowalski et al., 2010), leading to a higher rate

of burnout (i.e., emotional and/or behavioral impairment resulting from high occupational stress levels) and turn over of DCS (Gray-Stanley & Muramatsu, 2011; Kozak, Kersten, Schillmoller, & Nienhaus, 2013; Mutkins, Brown, & Thorsteinsson, 2011; Sarafino, 2006). Researchers also found work-privacy conflict, emotional demands, role conflicts, job insecurity, and feedback all contributed to participants' feelings of burnout (Kozak et. al, 2013). Findings suggest that improving the psychosocial setting of the work environment may help increase job satisfaction and performance (Kozak et. al, 2013).

Music Therapy

According to the American Music Therapy Association (AMTA), music therapy is defined as "the clinical and evidence-based use of music interventions to accomplish individualized goals within a therapeutic relationship by a credentialed professional who has completed an approved music therapy program" (AMTA, 2015). In addition, Bruscia (1998) defined music therapy as "a systematic process of intervention wherein the therapist helps the client to promote health, using musical experiences and the relationships that develop through them as dynamic forces of change" (p. 20). To help elicit change within people with ID, a number of interventions are used in music therapy including, but not limited to: sensory stimulation processing interventions, instrument play, object manipulation, movement paired with music, and rhythmic stimulation (Farnan, 2007).

Music therapy research tends to focus on the client; it is rare to focus on the family caregivers, and rarer still to focus on direct care staff. However, caregivers may attend music therapy sessions, and music therapy may affect caregivers as they observe and/or participate in the sessions with their loved one. Previous music therapy research included interviews to examine family and staff perceptions of music therapy in palliative care (O'Callaghan &

McDermott, 2007) and bereavement (O'Callaghan et al., 2013). Within intellectual disability research, there is no literature pertaining to direct care staff and their perceptions and experiences with music therapy.

The purpose of this study is to explore the experiences and perceptions of direct care staff when their clients with intellectual disabilities participate in music therapy. What are the experiences of DCS with music therapy? What are their perceptions of music therapy? What are the perceived benefits, if any, they observe in having their clients with ID participate in music therapy?   How does music therapy impact them both personally and professionally? Due to the nature of these questions and the dearth of research in this area, the researcher chose a phenomenological design to explore the lived experiences of direct care staff and their experiences with music therapy.

Chapter 2

Review of Literature

The history of Direct Care Staff (DCS) and individuals with Intellectual Disabilities (ID) spans from the 1800s to the present. Attitudes towards individuals with ID and their DCS continue to evolve through the beginnings of institutional care and deinstitutionalization in the 1960s. The following section outlines the evolution of said history, highlighting important advancements of care for people with intellectual disabilities and concluding with the purpose statement and research questions for this research study.

History of Direct Care Staff for Individuals with Intellectual Disabilities

During postrevolutionary times (i.e., 1800s) in the United States, those with ID were stigmatized with labels such as feeble-minded, idiot, and simpleton (Trent, 1994). As people with ID aged, they were sheltered in family or neighbors' homes, placed in almshouses (i.e., charitable housing), became homeless, or were thrown into jail (Trent, 1994). In the mid-1800's, in order to help care for the "dependent," states started to open private schools and institutions to house those who had no homes (Trent, 1994). Hervey B. Wilbur, a former teacher who became a physician, read articles about schools for the deaf and blind opening throughout Europe, and wanted to open a private practice to help those in need (Brown, 1886; Trent, 1994). His school became publically funded by 1850, gained accolades, and subsequently he was hired by the New York Commission on Idiocy in 1851 to become director of an experimental school near Albany, New York (Trent, 1994). Wilbur visited Europe twice, reporting his findings to the Governor of New York and the State Board of Charities (Brown, 1886). He helped shape programs that allowed those with ID to develop new skills (e.g., singing, dumb-bell exercises, reciting geography, and basic arithmetic) (Trent, 1994). These accomplishments helped to shape Wilbur

and Howe's definition of the capability of those with ID, writing "…idiocy may be defined to be that condition of a human being in which, from some morbid cause in the bodily organization, the faculties and sentiments in the bodily organization remain dormant or underdeveloped, so that the person is incapable of self-guidance, and of approaching that degree of knowledge usual with others of his age" (Trent, 1994, p. 18).

People with more extreme cases of ID required increased attention from teachers in these schools, making it hard for the instructors to attend to the needs of the others (Trent, 1994). This discussion resulted in expansion into asylums, with a push for medication instead of education starting to take place (Trent, 1994). To keep institutions running, superintendents ran into an all too familiar problem, employee costs and employee retention (Trent, 1994). In order to cut costs, institutions started to use patients as labor, requiring fewer staff to watch over patients, and eliminating employee turnover (Trent, 1994). DCS did not care for long hours, unpleasant conditions of caring for those who were "uncurable," and were showed little to no appreciation for their work (Trent, 1994). DCS often committed themselves solely to their job, merging with patients, and locking away their personal identities within the walls of the asylum (Trent, 1994).

The population of asylums increased by 1915 by the thousands (Trent, 1994). Organizations formed for staff, often having a "matron" (i.e., female supervisor) and "supervisor" (i.e., male supervisor) in charge of attendants who moved up the ranks to higher positions (Trent, 1994). Supervisors did not provide training. Therefore DCS learned from their peers, resulting in good training and bad training (Trent, 1994). Corporal punishment started to emerge; Illinois Asylum attendants were given permission to "spank, box the ears of, and paddle inmates who were disobedient" (Trent, 1994, p. 126). Hoping to gain a humane atmosphere in

the institutions, superintendents started to focus on the needs of the attendants (i.e., direct care staff).

 Deinstitutionalization. The roles and responsibilities of DCS for people with ID underwent drastic changes as a result of deinstitutionalization in the 1950s. Deinstitutionalization began in 1955 with the introduction of chlorpromazine (i.e., Thorazine, one of the first anti-psychotic drugs), which contributed to a decrease in the institutionalized patient population (Torrey, 1997). In 1963, the Community Mental Health Act provided government funding for community mental health centers under the Kennedy administration (Mental Retardation Facilities and Community Mental Health Centers Construction Act, 1963). The acceleration of the deinstitutionalization process took off in 1965 with the adoption of Medicaid (Mental Retardation Facilities and Community Mental Health Centers Construction Act, 1963). This contributed to group homes, mental health centers, and opportunities for independent living. Due to the push for mainstreaming (i.e., integrating students with special needs in regular classroom settings) and community integration in the late 1990s, the number of people with ID in institutions started to decline (Koyanagi & Bazelon, 2007).

 Willowbrook was one institution among many that existed during this time. Although deinstitutionalization began in 1955, Willowbrook, along with many other institutions, continued to function for several decades. In 1972, Geraldo Rivera and a camera crew did an exposé on the conditions of Willowbrook, highlighting the treatment of patients with ID and the direct care staff who were expected to provide care. This news report gave the public access to what was happening behind the doors of these institutions.

 The staff were outnumbered (e.g., one staff per 60-80 clients) and ill trained, resulting in poor quality of care and patient deaths (Grossman, 1987; Rivera, 1972). For example, in

Willowbrook, an 18-year-old staff worker prepared a shower for an individual that was scalding hot, to the point where the patient passed away (Rivera, 1972; Rothman & Rothman, 1984). A patient who was taken to a registered nurse had his leg in a cast, broken and rotting in several places (Rothman & Rothman, 1984). This is only a small glimpse into the unpreparedness of DCS and the horrible conditions patients faced in an institution.

Although changes such as deinstitutionalization led to a better quality of life for people with ID, progress was still on-going and extremely slow (Koyanagi & Bazelon, 2007). DCS were still needed to ensure people with ID could function in group homes and community settings.

Intellectual Disabilities.

Need areas for people with ID. DCS' job responsibilities and client interactions are affected by the needs of the specific people they work with, in this case the needs of people with ID. Communication is imperative to help express wants and needs, develop basic self-care skills, independence, and self-determination (MacDonald, O'Donnel, & Davies, 1999). Despite personal skills, people with ID face many issues, including: (a) basic health care, (b) nutrition, (c) housing, (d) education, (e) civil rights, and (f) economic and social stability (Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001). Individuals with ID are at risk by having specific syndromes that can lead to associative developmental disabilities (e.g., autism, cerebral palsy, epilepsy, head injury, and sensory impairments) (Evenhuis et al., 2001). Medication side-effects and long term use of medications may also result in associative developmental disabilities (e.g., movement disorders resulting from prolonged use of neuroleptic medications) (Evenhuis et al., 2001).

Need areas for older adults with ID. Improvements in health care have increased the lifespan of individuals with ID (Patja et al., 2000). As individuals age, there is a decrease in

mobility and physical activity (Hilgenkamp, Reis, Wijck, & Evenhuis, 2012). Maintaining good mobility and physical activity helps to increase personal health and wellbeing, as well as decrease the levels of support and future health care costs (Hilgenkamp et al., 2012). Older adults with ID can also develop dementia (Sinai, Bohnen, & Strydom, 2012); however, with all the cognitive issues people with ID endure, it is difficult to diagnose older adults with dementia (Sinai, Bohnen, & Strydom, 2012). Overall, there is a need for daytime activities and housing with more available assistance given the limited mobility and frailness of older adults with ID (Sinai, Bohnen, & Strydom, 2012).

Direct Care Staff of People with ID.

In studies that assess the livelihood of DCS, specifically those who work with people with ID, consistent themes and variables emerge. The variables that appear to affect DCS daily work include: stress, burnout, and support of DCS. The following studies outline these themes from the research focused on DCS of people with ID.

Stress and Burnout. In a study by Hatton et al., (1999), researchers identified variables that contributed to stressors and fluctuating morale of direct care staff that greatly affected the quality of care for people with intellectual disabilities. In a large-scale survey collected from 450 DCS for people with ID, staff was asked questions pertaining to "general distress, job strain, and work satisfaction" (Hatton et al., 1999, p. 256). Using path analyses, it was determined that using the coping strategy of wishful thinking, stress linked to work/home conflict, and role ambiguity accounted for 28% of variance in general distress scores. Fifty percent of the variance in job strain scores spanned six variables including wishful thinking, stress linked to a lack of staff support, alienative commitment (i.e., employee commitment by not given choices), role ambiguity, stressors linked to a low status job, and working longer contracted hours. In overall

work satisfaction scores, 66% of the variance accounted for stress linked to a low status job, support from supervisors, influence over work decisions, alienative commitment, support from colleagues, and older staff age.

Kowalski et al., (2010) looked into the specifics of burnout (i.e., emotional exhaustion, depersonalization, and decreased personal performance) when studying people working in human services in Western countries. According to Kowalski et al. (2010), the first phase of burnout (i.e., emotional exhaustion) is challenging to prevent and could be causing increased turnover and leading to a lesser quality of care. The aim of Kowalski's study was to look into possible associations between emotional exhaustion, social capital, workload, and latitude in decision-making. The majority of participants were German professionals working as DCS of persons with intellectual and physical disabilities. Using a survey, burnout was measured with the German version of the Maslach Burnout Inventory-General Survey (MBI-GS) followed by a multivariate logistic regression analysis. Three variables were identified by logistic regression: workload, latitude in decision-making, and male gender. These results demonstrated that specific factors in the work organization are associated with emotional exhaustion.

Gray-Stanley and Muramatsu (2011) also studied work stress among DCS who serve people with ID. They conducted a survey (N=323) from five community-based organizations that provide people with ID residential, vocational, and personal care services. The survey asked participants about their perceptions of work stress and social support, locus of control, and burnout relative to their daily routine at work. A multiple regression analysis was used to test the main and interaction effects of work stress and resources for burnout. The researchers found work stress - specifically work overload - limited participation decision-making, along with client disability care, had a signification positive association with burnout. The relationship

between work, social support, and burnout as well as the association between locus of control and burnout significantly depended on the levels of work overload. The latter also depended on participation in decision-making. The researchers stated in their discussion "as far as we know, this is the first U.S. study with DCWs in the ID field which demonstrated that the association between coping resources (work social support and locus of control) and burnout depends on the kinds and levels of stress" (Gray-Stanley & Muramatsu, 2011, p. 1072).

Mutkins, Brown, and Thorsteinsson (2011) stated prior literature pertaining to increased potential of DCS burnout focused on examining predictors; however, there was little consensus. The researchers examined direct and indirect relationships between work stressors, staff emotional response to behavior from clients/consumers, social and organizational support resources, and staff burnout. A short survey was given (*N*=80), examining client/consumer behavior, DCS psychological stress, anxiety, depression, social support, organizational support and burnout. In this study, burnout levels were slightly lower or similar than normed values for human services staff. Using cross-sectional regression analyses, results indicated depression symptoms and organizational support were associated to "worse emotional exhaustion and depersonalization" (Mutkins, Brown, & Thorsteinsson, 2011, p. 500). These studies indicate organizational support, staff relations, locus of control, and the care of individuals with ID contribute to stress and burnout.

Support. A consistent theme throughout these studies is that organizational support and positive social support helps increase job satisfaction and has the potential to increase the quality of care provided by DCS. In Hatton et al. (1999), work satisfaction and job strain, not general distress, are associated with turnover and job searching behaviors of DCS. These determining factors affect staff quality and the quality of care that people with ID receive. Organizational

systems were found to help by clarifying relationships between staff, users, organizations, and staff outcomes. In addition, Kowalski et al. (2010) found strategies that can be used to reduce emotional exhaustion should strive for improvement in work organizations and reducing work overload, which although initially cost-intensive, would level with reduction in DCS burnout risk and increased retention.

In a systematic review examining staff that work with individuals with ID and burnout, Thompson and Rose (2011) yielded 21 articles and placed them in two different categories. Early studies focused on deinstitutionalization versus more recent studies that focused on work-stress theories. Researchers found an "organizational climate that has a better 'person-environment fit' (i.e., relation between staff and working environment,) promotes greater job satisfaction and reduced burnout" (Thompson & Rose, 2011, p. 177).

Although burnout more than likely begins at the individual level, factors derived from work organizations play a prominent role in helping DCS cope with stress and problems at work (Kowalski et al., 2010). Gray-Stanley and Muramatsu (2011) found that locus of control effects depended on different workload levels, with less burnout associated with DCS perceptions of lighter workloads. Policies and/or interventions, including strategies to develop work-based social support networks and interventions to help workers develop personal stress management resources, have the potential to contribute to improved job moral and better care of clients/consumers.

Gray-Stanley and Muramatsu (2011) found work social support only made a difference in stress levels that were high rather than prior studies that claimed it was effective for both high and low stress levels. Devereux, Hastings, Noone, Firth, et al. (2009) did not find any interaction effects between social support and work demands. Gray-Stanley and Muramatsu suggest

different measures are used to measure and conceptualize "work social support as staff perceptions of the presence, type, and satisfaction of supports available, using different measurement instruments" (Gray-Stanley & Muramatsu, 2011, p. 1072). Individuals that possessed an internal locus of control were more likely to assume responsibility and use problem-solving and other positive coping strategies to help manage stress (Koeske & Kirk, 1995). Dyer and Quine (1998) also found that work social support did not lessen the effects of non-participation in decision-making for any stress level.

Characteristics of organizations are more influential on staff stress and well-being rather than the characteristics of staff or service users/consumers, suggesting organizations can help reduce staff stress and improve morale (Mutkins, Brown, & Thorsteinsson, 2011). Mutkins, Brown, and Thorsteinsson (2011) suggest symptoms of depression and lower organizational support were frequently concurrent with symptoms of burnout, indicating DCS's personal and organizational supports may have helped increase their sense of personal accomplishment. However, it may be far reaching to expect organizations to change due to the amount of specialty training for extreme behavior outbursts and how to develop on the job coping skills (Gray-Stanley & Muramatsu, 2011).

Music Therapy and People with ID

People with ID have been involved with music therapy as far back as the beginnings of professional music therapy in the 1950s (Hooper, Wigram, Carson, & Lindsay, 2008). In Great Britain in 1959, Juliette Alvin described how 24 children, ranging in age from six to 16 years old with a range of intellectual disabilities, responded to six short concerts, including contact with her as the performer and her cello (Hooper et al., 2008). Immediate changes in their curiosity and level of engagement became apparent; children became entranced with the music by moving

their hands and feet, tapping to the beat with their fingers, singing softly, and whistling to the music (Hooper et al., 2008). Alvin also noted how self-control and confidence increased as they approached the cello to play a note (Hooper et al., 2008).

Juliette Alvin was not the first music therapist to experience this phenomenon, nor the last. An extensive dive into music therapy literature pertaining to people with ID results in a variety of active and receptive music therapy techniques. Different music therapy applications developed overtime, creating a wealth of strategies that touch on emotional regulation, physiological communication, and cognitive development—all domains that affect DCS everyday work with the people they serve.

Hooper et al. (2008) outlined common goal areas associated with people with ID and music therapy: social (e.g., communication, relating to others, cooperation, peer acceptance), cognitive (e.g., motivation, concentration, perceptual ability, learning, music development), physical (e.g., movement, body awareness, spatial awareness, limb extension), and emotional and psychological (e.g., expressing emotion, alleviating agitation, pleasure, accomplishment, self-esteem). Music therapy reportedly had benefit for people with ID in all of these areas; thus, music therapists use a variety of strategies, depending on the needs of the clients (Hopper et al., 2008).

Many different intervention strategies are found throughout music therapy research with people with ID. Music therapists may use rhythmic stimuli paired with movement, along with vibrations and tactile textures, to promote sensory stimulation, encourage exercise and movement, and improve processing and integration (Farnan, 2007). Music therapists address physical needs by incorporating interventions that focus on fine and gross motor skills, including grasping objects and instruments and completing range of motion exercises (Farnan, 2007).

Rhythm may also stimulate pro-social behaviors, such as cooperation, with the music therapist, peers, and staff (Farnan, 2007). In addition, instrument play and object manipulation assists with both initiating and receptive communication, such as when consumers choose instruments, share instruments, and play instruments with the music therapist and others in a group setting (Farnan, 2007; MacDonald, O'Donnel, & Davis, 1999). Furthermore, participants can communicate their wants and emotional needs, and improve their coping skills (Pavlicevic, O'Neil, Powell, Jones, & Sampathianaki, 2014). Engaging in music therapy helps those with ID feel successful within the session and feel included within their peer group (Pavlicevic et al., 2014).

Music Therapy and Direct Care Staff

Music therapy research focused on direct care staff is limited. O'Callaghan and McDermott (2007) conducted a grounded theory study in an oncology center by giving a survey with short open- and closed-ended questions to visitors, patients, and staff. DCS described, in general, music therapy as helping them work together with the patients. Five themes emerged by using a constant comparative analysis method of grounded theory (O'Callaghan & McDermott, 2007). More specific findings include: (a) DCS described MT helping to create an increase in helpful emotions, self-awareness, improving work life both individually and as a team, and the ward environment; (b) DCS described MT having a positive effect on patients, helping them negotiate their illness and connect with people; (c) DCS reported MT helped visitors sometimes; and (d) DCS expressed good wishes for continuing to expand their MT program to address "wholistic patient care" (O'Callaghan & McDermott, 2007). Findings indicate that music therapy may promote a positive work environment, possibly influencing job satisfaction and quality of care provided by DCS.

In a study of caregivers who worked in bereavement, O'Callaghan and colleagues (2013) gave semi-structured interviews to eight individuals about their thoughts on music and its effects on their emotion, grief, experiences in music therapy, and recommendations for music in hospitals and for other caregivers. Participant interviews were condensed into 442 codes, 11 categories, and six themes. Themes identified in the constructivist qualitative study were as follows: music enhanced lives of those mourned was supportive, music-elicited memories can be purposive, music improved mood and helped to not intensify sadness, feeling positive when musical efforts extend the legacy of the deceased, what was shared and created in pre-loss music therapy could help both before and after death, and recommending music for other caregivers to support their bereavement (O'Callaghan et al., 2013). These findings suggest music therapy helped DCS and caregivers with their bereavement and helped them express their emotions.

Music Therapy and Direct Care Staff of People with ID

A few studies have shed light on interactions between DCS of people with ID and music therapy. North (2014) details her experiences working in music therapy on communication through music. As a speech and language pathologist in addition to a music therapist, she focused on communication and building relationships with her clients through music (North, 2014). In response to North's findings of the value of communication through music, Watson (2014) notes that North's findings inspired her to look into not only working with clients, but also supporting staff through music therapy. In Watson's experience, she states DCS work with clients during music therapy and in the sensory interaction group, valuing it as a place where individuals with ID develop "strong, trusting relationships and communicate through music" (p. 805). In this setting, DCS reported that music allowed individuals to bring out their personalities, express their ideas, play independently, and influence their group (Watson, 2014). After DCS

observed clients interacting in music therapy, they were able to transfer those skills in understanding and communicating with clients, strengthening the staff/client relationship (Watson, 2014). Watson assists DCS 'outside the room' when working towards the ultimate goal to help clients gain independence. Powerful music moments were used to help initiate experimental learning and training for DCS (Watson, 2014). Watson also adds that DCS need a place to reflect and process the difficult emotions that arise when working with people with ID. For example, it can be hard for DCS to process emotions that arise from treating people who are similar in age to themselves and treating them as adults versus children (Watson, 2014). By reframing the way DCS approaches interacting with people with ID, they can develop new ideas and strengthen the relationship with their clients (Watson, 2014).

In a study by Pavlicevic et al. (2014), music therapy for individuals with ID was discussed with parents and professionals after music therapists voiced concerns about the value of improvisational, music-centered music therapy. Researchers formed two focus groups: (a) Group one consisted of a "teacher, a senior manager…and provision leader in a small specialist school, a dance movement therapist, an advisory teacher in autism, and an in home personal assistant," and (b) Group two consisted of "a speech and language therapist, an occupational therapist, a learning support assistant at a special needs department for 16-19 year olds, and a speech language therapist" (Pavlicevic et al., 2014, p. 10). Within these focus groups, researchers started to compare and contrast the participants' familiarity with music therapy. Researchers used a three-phase interview structure with predetermined questions and prompts based on their experiences of the needs of people with intellectual disabilities. After answering these questions, participants were presented four audio/filmed excerpts of music therapy in action and then asked how these sessions related to their own understanding of the needs of

people with intellectual disabilities. Themes that developed throughout interviews consisted of communication needs and skills, emotional needs and coping skills, social needs, the need for self-values/self-image, and the need for supported independence/independent living and the transition to adult facilities (Pavlicevic et al., 2014). Regular sessions provided emotional and social support during times of stress, commenting on the feeling of "musical equality" where they accepted one another and increased positive self-worth (Pavlicevic et al., 2014, p. 15). An unexpected finding in this study came from the parent and family groups who shared that having regular music therapy sessions built a sense of community not only for the direct clients, but for them as well (Pavlicevic et al., 2014).

These two studies indicate that DCS observe and acknowledge benefits of music therapy for their clients with ID. No study to date explores the relationship between DCS of older adults with ID and music therapy in terms of benefit, expectations, job satisfaction, quality of care, and coping with stress and burnout. In order to better understand the lived experiences of direct care staff experiencing this phenomenon, a qualitative approach was chosen for this research study.

The purpose of this study was to explore the experiences and perceptions of direct care staff of older adults with intellectual disabilities who participate in music therapy services. The following questions were answered: What are the direct care staff experiencing as they observe their clients in music therapy? What are their beliefs about potential benefits or detriments of music therapy for their clients? How do they perceive music therapy services as affecting their work as direct care staff? How does music therapy affect them personally and professionally?

Chapter 3

Method

Participants

Participants in this study were direct care staff (DCS) of older adults with intellectual disabilities at Cottonwood Retirement, part of a non-profit organization that helps individuals with ID throughout the day with jobs, therapies, and residential care in group homes. Participants were adult female direct care staff (N=5, M=41.8 years, SD=14.55) recruited by phone and e-mail through Cottonwood, Inc. (Appendix A). Participants worked an average of 6.9 years (M=6.9, SD=4.95) with older adults with intellectual disabilities. Participants did not receive any compensation for being interviewed. Participants were included in the study if they were over age 18, either currently working or formerly worked as a DCS at Cottonwood Retirement, and observed a minimum of one music therapy session with their client(s).

Research Setting

The Cottonwood, Inc. mission statement is "we help people with disabilities shape their own future" (Cottonwood, 2011) and is a 501(c)(3) not-for-profit organization established in 1972 (Cottonwood, 2011). Through the Developmental Disability Reform Act of 1963, Cottonwood, Inc. became the Community Developmental Disabilities Organization (CDDO) for Douglas and Jefferson counties in Kansas (Cottonwood, 2011). Cottonwood includes both a main site for consumers ages 18-55 and a retirement center for consumers ages 55 and over.

Cottonwood Retirement provides activities and therapy for those individuals with intellectual disabilities who are in their retirement years. Facility goals include exercise and social interaction with peers and staff. DCS help consumers throughout daytime hours, observing and assisting in activities, therapies, and volunteer events. DCS also participate in activities and

therapies, including the music therapy practicum provided by the local university. DCS working at Cottonwood Retirement all share the same specific experience, which is unique—they work exclusively with older adults with ID during the day and also observe, and sometimes participate, in music therapy services offered on site.

Study Approach and Design

Due to the nature of the research question, a qualitative approach was chosen as the best method of obtaining information regarding DCS perceptions of music therapy. In order to understand a person's lived experience, one probes for and assesses subjective answers, with relationships in quality rather than in quantity. Qualitative research can be used within a phenomenological experience that cannot be reduced to variables and numbers (Bruscia, 1998). Themes in qualitative research can help develop a research philosophy, meaning "the use of abstract ideas and beliefs that inform our research" (Creswell, 2012, p. 16).

Phenomenology may be considered both a philosophical perspective and a qualitative research design.   Phenomenology is a transcendental viewpoint that naturally occurs in a specific phenomenon, with the idea that in order to gain insight, researchers must study the viewpoints of people in the midst of the experience (Sokolowski, 2000). A phenomenological study is the gathering of themes from individuals who share a specific experience (Creswell, 2012) in order to provide insight as to how people "live" in the phenomenon (Ivey, 2013; Sokolowoski, 2000). An advantage of using a phenomenological study is to dig into the experience and gain insight of individuals within an event that rarely occurs or happens through scattered populations (Ivey, 2013). Cottonwood retirement is a small facility, holding activities and events for 20-25 consumers ages 55-88 during the day, supported by three to five active DCS. In this particular setting, the DCS may have unique insights into their lived experiences

regarding the effects of music therapy on themselves, their consumers, and their own job experiences.

In order to collect data for this phenomenological study, the researcher conducted interviews using questions based on a review of the literature and personal insider experiences working as both a DCS and student music therapist. Individual interviews are helpful in (a) gathering rich data from participants; (b) probing for more information; (c) discovering questions pertaining to the phenomenon that were not taken into consideration before; and (d) collecting data when participant responses cannot be observed, or when participants need to recall or provide history of their experiences and the site itself (Creswell, 2014).

Informed Consent and Recruitment

The University of Kansas Human Subjects Committee-Lawrence approved this study with agreement from Cottonwood, Inc. The researcher worked with human resource personnel of Cottonwood Inc. and the coordinator of Cottonwood Retirement to follow rules and regulations for interviewing direct care staff. The researcher recruited DCS participants by flier, e-mail, phone, and in person (Appendix A). After DCS participants agreed to participate, the researcher scheduled a 60-minute interview on the Cottonwood, Inc. site or over the phone. After meeting at the interview site or receiving a phone call, the researcher went over the Informed Consent document and asked if the participant had any additional questions. Each participant signed the Informed Consent form before the researcher conducted respective individual interviews.

Procedure

After participants signed the informed consent document, the researcher conducted individual 60-minute semi-structured interviews using a series of open-ended and follow-up questions (Appendix B). Interviews were audio recorded using a Sony ICD-UX200 recording

device, then transcribed and loaded into Atlas.ti, a qualitative data analysis software program. Pseudonyms (e.g., fake names) were used to maintain confidentiality of participants. The researcher stored recordings and transcriptions on a thumb drive in a locked cabinet in a locked office. Once uploaded to Atlas.ti, the researcher analyzed the information using Interpretive Phenomenological Analysis (IPA) (Smith, Flowers, & Larkin, 2009). After themes evolved, the researcher contacted participants for a 20-minute member check follow-up interview to review and clarify the findings from the viewpoint of the participants.

Data Analysis

Using the guidelines from Smith, Flowers, and Larkin (2009) for Interpretive Phenomenological Analysis (IPA), the researcher followed a step-by-step process for analysis of participant interviews. IPA acknowledges the researcher as part of the process of describing and interpreting information provided by participants (Van Manen, 1990), and not separate from it. The researcher completed these steps (Smith et al, 2009):

1. Reading and re-reading: The researcher began the process of coding by reading and rereading to ensure understanding of the data. This enabled the researcher to mine for rich themes and possible contradictions, if any existed.

2. Initial noting: The researcher notated key points and themes to start to shape the final themes. Steps involved in this process consist of descriptive comments (i.e., describing context of what the participant has said and the subject of what was asked), linguistic comments (i.e., exploring the use of language), and conceptual comments (i.e., understanding at a more interrogative and conceptual level.)

3. Developing emergent themes: The researcher put the codes – data retrieved from transcripts as noted in step 2 - into a table and highlighted codes with similar thematic meaning.

4. Searching for connections across emergent themes: By taking the emergent themes, the researcher started to piece the themes together in order to find connections. Specific patterns can be found by using abstraction (i.e., identifying patterns between emergent themes and creating a cluster to obtain a 'super-ordinate' theme), subsumation (i.e., helps to bring a series of related themes together), polarization (i.e., finding oppositional relationships between emergent themes by focusing on the differences instead of the similarities), contextualization (i.e., identifying contextual or narrative elements in the analysis), numeration (i.e., finding frequency in themes), and function (i.e., specific function of themes.)

5. Moving to the next case: The researcher combed through each interview again to test emerging themes and connections found.

6. Looking for patterns across cases: Using a master table for codes, the researcher was able to find connections among all interviews to help develop and form major themes.

Chapter 4

Results

The researcher explored the experiences and perceptions of direct care staff (DCS) of older adults with intellectual disabilities who participated in music therapy services. Six common themes emerged from participant interviews: (a) DCS find music therapy effective in changing social, physical, emotional, and cognitive functioning; (b) DCS find personal enjoyment through connecting with consumers in music therapy experiences; (c) DCS are experienced and knowledgeable about consumers and encourage student music therapists (SMTs) to ask for help; (d) DCS apply and reinforce experiences practiced in music therapy to consumer activities outside of sessions; (e) DCS encourage SMTs to focus on physical, emotional, and social functioning, not cognitive functioning, of older adults with ID, and (f) DCS encourage SMTs to consider consumers' individual characteristics and preferences in order to increase therapist flexibility and intuition. Even though all DCS shared experiences related to the following six themes, not all quotes are included in each section.

Major Themes

DCS find MT effective in changing social, physical, emotional, and cognitive functioning. All participants in the study shared their observations of the effectiveness of music therapy for older adult consumers at Cottonwood Retirement. All DCS reported changes in consumers' social, physical, and emotional functioning during music therapy, with some DCS also mentioning an increase in cognitive functioning after consumers participated in music therapy. Many DCS noted that consumers come to Cottonwood Retirement with low energy on Mondays due to the weekend. However, when music therapy sessions are on Mondays, consumers exhibit unique behaviors such as an increase in energy, a motivation to engage in

movement, and a willingness to change their snack schedule in order to participate in music

therapy. DCS also commented on consumers consistently choosing to attend music therapy and

that music therapy is beneficial for consumer enrichment and engagement.

　　Social. DCS described an increase in social functioning in consumers participating in

music therapy. Consumers interacted with people outside of the community (e.g., SMTs,

supervisors, observers) and DCS spent time with the consumers outside of their duties. Several

DCS mentioned that music therapy was one thing during the week in which all consumers

wanted to participate, making it easier on DCS.

> I love it because like I said it gets a large majority of the consumers that we serve
> everyday involved in one activity. I mean, they all love it, they all enjoy it. They get a
> kick out of it. It's a positive experience in their day. The last few sessions have been on
> Mondays which has been great because they come in from the weekend and are generally
> tired and they generally don't want to get involved in a whole lot. But when they know
> it's music therapy day, they are super excited…they really enjoy that, and so I guess
> that's the best is you know having them have someone to interact with, having new music
> to listen to, instruments to use. It gets them moving, I mean, there are so many benefits to
> it that you know, keep coming! ~Valerie

> Outside of that we do a lot of art but it's totally selective if they want to participate or not.
> We have an art class they can attend at the art center, but then again it's totally up to them
> if they go are not. So it's kind of hit and miss who will go every time, so some people go
> once and some never go. So having something that comes here that enriches their lives
> but also gets them moving, gets them interacting with the community is a big deal.
> ~Valerie

> Well, I think [music therapy] is really important. I hope it continues and I hope that they
> continue to have that at work also…I will say that even though I don't get to join in and
> have fun like I used to. They do have SMTs that come to work services. And so a couple
> of our guys, two to three from our group building three, can go over and join in.
> [Consumers] always enjoy it and it gives them a break from work. So I hope it continues
> and I think it's really beneficial. ~Zoe

> And to have one activity the majority of the consumers wanted to participate in was kind
> of a big deal. We generally see that in group outings, but outside of group outings most
> all don't want to participate at the same time in one activity. It's usually just individual
> desires and activities. I mean you may have as many as four to five that want to
> participate in another class and activity, to have such a large group [of] 10, 12, 15 all
> participating at the same time is huge. ~Valerie

[Music therapy is] very, very beneficial…we play music at lunch every day and they have the ability to listen to music privately but, outside of that there's only so much we can do and there's only so much knowledge that we hold. So having somebody that can bring other instruments—you know as a nonprofit we don't have the budget to purchase and we don't have the money to experiences those. Not only that, we don't have the [money] to experience new people—they love meeting new people…learning what that person has to offer compared to the last one. And that's kind of the nicest anyway. They remember at times if old students come in with the group, they remember them. But they always enjoy meeting the new ones. You know it's always a good experience for them to have. ~Valerie

In response to an interview question about prior experiences with people with ID and music therapy, one participant mentioned increased communication and connection with a nonverbal person with intellectual disabilities – who was also a family member – through music experiences.

I would say [music therapy] was also good for socialization. It gave us a way to interact and socialize that was non verbal [and] not physically demanding. [It was] something that we could to do together as a family. We could go and listen to music at a local vicinity, a park, a concert, we could go do those things, playing favorite types of music. All those different things were important because you could speak to him but he couldn't speak back. And not being sure what other things might be enjoyable or not for him, you know? Had—not ability—but the opportunity to have a middle ground found and provided for you and so that was really important, so they have a way to communicate and interact that was not the norm. ~Valerie

Physical. DCS reported consumers were more animated and more likely to participate in movement exercises while engaging in music therapy versus being prompted to do their daily exercises outside of music therapy sessions.

[Music therapy] is more fun and they don't realize like if you're trying to lead an exercise group and say "OK everyone you know raise your arm up!" It's kind of like "yeah right I'm not going to do that." But everybody gets enthused and the music elevates their mood, it makes it fun, so if you're beating your drum up here high and down low and over here that's more fun than "OK raise your arms up" who wants to do that!? And they don't even realize that they are moving. ~Zoe

Emotional. DCS indicated music therapy would often evoke an emotional response in consumers such as mood regulation, engagement, and alertness.

I feel like music therapy is very, very important in retirement and one on one in retirement because music can bring joy and can bring peace. And motivation I think you can get a lot from music therapy. I would say music therapy should be continuing in this kind of environment because it brings joy to people. ~Quinn

[After a] couple of years' period of time, [a consumer] started participating in music therapy and ended up really loving it and enjoying it. And her moods weren't affected negatively--instead, positively. And so it was emotional [and] it became again an activity that was an opportunity for bonding, for lifting her mood and her spirit, giving her joy, and helping her to move through that grief…of having loss that experience with her family. That's how I viewed it. I'm not a clinician…So that's an example of the ability [that] music has [on] a healing level. ~Nancy

I see the music therapy, I see [emotional changes] in their faces. When they have music therapy here they get excited and they are ready to sit down and listen.   I can tell the emotional and physicality [shows], I think does help them. ~Quinn

Cognition. Some DCS commented on an improvement in cognitive awareness during and after music therapy sessions.

I think most striking thing to me about music therapy here is how much some of our consumers just light up when they hear a familiar song…And particularly working with aging consumers it's really amazing to see you know somebody who's 88 years old and doesn't interact with a whole lot with her environment on a regular basis just come to life when they recognize a song from their youth. I mean we have so many consumers who don't really want to participate in a lot of activities we have here but they will NOT miss music therapy. It is something they look forward to all week long. ~Wendy

One DCS shared an experience she had with a consumer before and after a music therapy session. She noticed an increase in this consumer's memory recall immediately after the session concluded.

So, there was one day where he just wasn't really following or processing what we were telling him, or he wasn't absorbing it really well. He would ask us the same question numerous times in a very short amount of time…The book he was looking for was from a month and a half earlier and we hadn't had this book for quite sometime. He kept asking where it was and he was pretty convinced someone had taken it and hidden it…After music therapy, he walked up to me and says, "Thank you for going to the library next time and getting the book for me." It was just like a really uncanny experience for me just to see that mental unfold, you know? He was kind of disoriented and not associated with reality during the day and something just turned on and his synapses just made those connections in music therapy. ~Wendy

DCS found personal enjoyment through connecting with consumers in music

therapy experiences. Each of the five DCS interviewed shared their overall enjoyment of music

therapy sessions at Cottonwood Retirement including enriching experiences while engaging with

consumers and how music therapy provides a break in the day. Some DCS mentioned

purposefully scheduling their breaks around music therapy so they would not miss the

opportunity to attend. Participants shared that music therapy created a positive break in the day

where DCS could take the opportunity to engage with the consumers on both social and

emotional levels.

Engagement. Several DCS shared how they felt music therapy was an enriching

experience in which they could engage with consumers and experience meaningful moments

with music on a personal level.

> I felt they were enriching because I enjoyed them and had fun. I had my own personal enjoyment that came out of being a part of the sessions [and] watching others respond to them was enriching. ~Nancy

> Personally I love [music therapy sessions]! I always try to schedule my break so I'm not on break during music therapy because I really enjoy [it]. I have a really strong connection to music myself. I can sit around in a music therapy session--that is so lucky for me as a provider. But also just getting to see some of the emotional responses that my consumers have and be side by side with them and be an active part of that with them. It's something that you can engage with consumers in--that's unlike anything else I would say. ~Wendy

> I might of had a really trying stressful day up to that point and I looked forward to music therapy and I was usually one of the ones that wanted to be in on all the fun, you know! I'm not taking my break now! Or doing paperwork! I wanna do music therapy! I really enjoyed joining in and doing it along with [them]. A lot of times I didn't even get handed an instrument because there wasn't enough to go around or whatever--and I didn't care because I would just do the movement, you know? I enjoyed going along with it. ~Zoe

Breaks. DCS mentioned music therapy makes the staff workload easier and allows for

breaks to complete work on days when they are short staffed. All consumers typically engage

and participate in music therapy, thus freeing DCS that during other activities may be occupied

with helping individuals who did not want to participate. Music therapy sessions offered a

window of time that allowed DCS to take care of extra tasks they needed to finish completing

(e.g., paper work, time cards). The opportunity to complete work during music therapy instead of

engaging themselves was reportedly taken on days only when they were short staffed.

> Well…it is something that most of our consumers choose to participate in…so really it's kind of a relaxing time for staff also. Staff have the opportunity [to get] stuff you have to get done at the time and it's just easier to get it done when they are focused on something. And you can participate too and get to, you know, enjoy the session right along with them! We normally have our snack at 2PM and we change it to 1:30PM on music therapy days because everyone is SO excited about it. ~Wendy

> It was easy because everyone was so engaged at the same time for one thing. So it allowed the staff with all the needs that I was talking about before [to] try to have two people at least one to two people sit with the group. At least one depending on what was going on and then the other staff could get caught up on paperwork. ~Zoe

> Maybe you have like an hour to sit with [the consumers]. You have other things you're supposed to do. So when although you're enjoying, you have tasks to do and you have time to finish the job or your task. Although that point does affect it a little bit, [but] not much. But most of the time you are not alone you have other staff. ~Quinn

> I didn't have to bring the fun which was real nice! It was my…it was a little bit of a break for me also. ~Nancy

> I'm thinking [music therapy] makes it easier because normally [the consumers] are kind of are slow to get together and they enjoy the music. Also staff will sit with them, but I think it makes it easier. [The consumers] sit down and listen to music and play the instruments, and exercise--so I think it makes it easier on DCS. ~Quinn

> Well, it definitely helped having something the majority of the consumers wanted to participate in and engaged in. It allowed us opportunities to play catch up more or less. We normally take turns rotating and sitting in with the music therapy…all sorts of different needs that may arise. We had [DCS] that could catch up on cleaning, paper work, maybe assisting somebody that wasn't participating that needed assistance. It just kind of gave us a breather which we don't get every day—so it was definitely helpful. ~Valerie

> Everyone looked forward to it. And it was a big help to us. And we didn't have to try to fill that void of a whole afternoon--like what are we going to do to keep everybody entertained. ~Zoe

> We mostly try to have everything done we can so that staff could be participating alongside. But also I mean, this might be weird--it's a good time for staff if there's

something you need to do but it's a little bit difficult to get done when all the consumers are, well, aren't actively engaged in something…. But for the most part all the staff is on the same page of [getting] everything done beforehand to engage in music therapy. And in the session we're still we're giving personal care that needs to happen or checking to make sure if the consumer seems like they're [okay]. So you're still in that role of work provider, it's just more of a relaxed atmosphere. ~Wendy

Overall, DCS shared their appreciation of music therapy sessions for themselves and consumers at Cottonwood Retirement. Two participants summed up their enjoyment and appreciation for music therapy by stating, "I think MT is needed all the time (Quinn)," and, "I don't know much about the therapy part, I just know it was a good time (Zoe)."

DCS are experienced and knowledgeable about consumers and encourage student music therapists (SMTs) to ask for help. DCS shared their observations of student music therapists and provided suggestions for SMTs working with people with intellectual disabilities and their direct care staff. All participants suggested SMTs should not be afraid to ask for help. Many DCS work with their consumers 40 or more hours a week, and are aware of consumers' likes and dislikes as well as knowing what kind of day a consumer is having before the music therapy session starts. However, many of them did not want to "step on toes" (i.e., offend students or supervisors) and acknowledged that they were not trained in music therapy themselves.

> I would say not being afraid to ask for help if you need it…I don't always feel like I'm comfortable interjecting, but if you need help flag one of us down. It's not a problem at all…We may know more about that specific person than they're telling you…Our home is your home when you're here. ~Valerie

> I think I was able to give [help]. It's kind of tricky because [SMTs] have [supervisors] to tell them what to do so you don't want to step on any toes or anything. But, every once in awhile when they would have their meeting next door I might be over there for something and I would say "Well, you know, most of our guys can't read…do you think maybe pictures would be better?" you know. Over the course of 10 years there were a few times that I did have suggestions on things that they could do better that maybe they haven't thought of with our population. That always made me feel good. And I encouraged them and [I made] them feel positive. ~Zoe

[SMTs should] consider the fact that we know these people more than you do. But we don't know how to be music therapists and we're not trying to. I can't speak for everyone, but if they get the feeling that things aren't going right or something, don't be afraid to ask questions. I felt like I didn't want to step on toes or I didn't want to tell them how to do it…So go ahead and come in and meet everyone and be really relaxed, including the staff, figure out what kind of music they like to listen to--but then ask, and find out "is there anyone here that's hard of hearing?" "Is there anyone here that has, how many can read…"--and just kind of the general [questions] to begin with. And then as things get going then ask about individuals and just ask us if we have any ideas about something that maybe could go better with people. But we don't want to feel like we're just telling them how to be music therapists because we don't know. ~Zoe

One DCS also shared her experience with language barriers with international students.

Even though some struggled with English, she felt for them and enjoyed helping them.

Some of the girls could hardly speak English and they struggled, you really felt for them, but I also liked being of help to them…So, I over the course of 10 years there were a few times that I did have suggestions on things that they could do better, that maybe they haven't thought of with our population. So, that always made me feel good. And [I] encouraged them and make them feel positive. ~Zoe

DCS apply and reinforce experiences practiced in music therapy to consumer activities outside of sessions. DCS shared they use music demonstrated in music therapy throughout the day outside of the sessions. DCS shared multiple music experiences utilized to regulate mood, increase physical movement, and stimulate memory recall. They use music listening in groups and for individual consumers to help regulate mood. DCS also use scarves paired with music to increase engagement in physical activity versus only using verbal prompts. DCS also used donated instruments to help facilitate physical movement imitation and stimulation. Some DCS also shared they use music to help with memory recall by playing games paired with music (e.g., "Name that Tune").

They love working with the scarves and that's something we do here on a regular basis also…they love playing instruments and we have our own stock of instruments that are not quite the same but they have the same things like egg shakers and stuff like that. They enjoy using those outside of music therapy sessions. So we do that from time to time as well. Dancing—we dance all the time.   But we listen to music everyday at lunch and sometimes outside of that—depending on you know who's doing what. And they always

have the ability to listen to music privately with headphones and the stereo. Music is a big part of some of their activities depending on the individual and the day. ~Valerie

When I was in retirement, we did a lot of driving back and forth in the van. I used music to help people get in a good mood for the ride. [I] put on some music that they liked, you know? Kind of [like what's] the majority we listen to --[do we do] country, do we do oldies? I would sing a lot and sing along and some stuff. Some of my fondest memories are sitting up in the front seat in the van with D and him singing Blondie songs, you know? He was just SITTING and one time R sat in the back seat and sang a whole Crystal Gale song--So, it, you really get to learn…it just makes everybody in a good mood. And less quarrels…people might be sitting there thinking how uncomfortable they are squished in the van and [thinking] "I really wish this guy next to me would get his elbow out of my rib" and "the seat belt is too tight"--it's the whole experience of cramming everybody on the van and hollering back and forth--and it just seemed like it went a lot better if you had music and make it fun and give them something else to focus on other than bickering and squabbling with each other. Which can sometimes really escalate into a big deal. And then it gets physical in there with close proximity. So, I enjoyed doing that. ~Zoe

Another point one participant made in regard to using music outside of music therapy was the absence of sessions during university summer and winter breaks. These were difficult times for the consumers because of dealing with termination, ending something they really enjoyed, and having to wait for the next session to begin. DCS also noted it was hard on them as staff because they were the ones expected to fill the void that was left while music therapy sessions stopped over summer and winter breaks.

As far as daily activities, when the end of the semester came…there was a big hole left where music therapy had been. So we would have to figure out a way to fill that hole so that the end of the semester didn't feel like a big bummer, you know? ~Nancy

You want continuity. [It] is so important and so you didn't want to lose that sense of continuity. So if you had a high spot in the week, you didn't want to lose that. That would then affect the way [we] planned activities and things but for the most part, we didn't have to do a lot of preparing consumers to be able to be up for music therapy. We really had to work hard to get consumers up for going to art at the arts center because you have to leave your comfort zone, you know? You have to transport one more time, I mean, it just wasn't the same level of impact on DCS for example or consumers because SMTs came to us and brought the joy and then when they left us, then they were always just, there was an empty spot and that was our responsibility to fill that. ~Nancy

DCS encourage SMTs to focus on physical, emotional, and social functioning, not cognitive functioning, of older adults with ID. DCS had different opinions on what domains were most important while working with their consumers. Common domains shared were physical, emotional, and social functioning.

Physical, emotional, and social domains. The physical domain was highlighted by DCS due to the need for exercise for the aging population with whom they work. DCS also commented that the emotional and social domains go hand in hand. They are important in regards to mood regulation, processing emotions (e.g., grief), and being able to interact with peers and DCS.

> Physical--watching people using the music to encourage movement. And dance and physical expression and then and moving a little bit further to feeling comfortable to movement and dance expression and feeling confident about it. And using the physical movement to shift a person's energy level and shift their level of engagement. ~Nancy

> I think that emotional skills are very important. And also physical skills--the emotional I think more when they have [to] interact with [one another] and when they are not in a good mood or when they are having challenges. ~Quinn

Avoiding cognitive specific goals. A few DCS mentioned some SMTs used applications focusing on the cognitive domain. This was met with disagreement regarding the appropriateness of attempting to teach new skills to older adults with intellectual disabilities, specifically those experiencing dementia.

> I would say because of where they are at, we I mean, we're retirement enrichment department so they are either at the retirement age or going through dementia. I would say the most important thing would be going through the physical and maybe working on some memory as far as playing a song and asking them "Who sings that song?" or talking about their favorite kinds of music. We sometimes talk about "Who's your favorite music as a kid?" and so we'll try to find some of that music to play when they were kids to help them remember things they may have done in the past. I would think those things are more important than working on new skills as far as color recognition compared to the instrument paired [with] it—things like that are not necessarily skills that they can acquire at this point if they don't already have them. ~Valerie

Like I would say with the retirement group--not cognitive--they already learned probably all they're going to learn. And, while they are some of them having dementia and losing cognitive ability…they aren't really going to bring back. And I think theirs' would be physical or just even though they can't do a lot physically, but just trying to get them to try to move. Or maybe the ones that don't want to be involved in anything, trying to bring them in and get them engaged. With maybe a younger group I would say things like social like things revolving around behavior issues. Like, moods and taking turns, and you know, being polite to each other or cooperating together in a group. ~Zoe

There was an exercise done where they wanted them to close their eyes and listen to the music and you know "OK everybody wiggle your toes," "OK everybody you know flex this muscle," and again just the cognitive ability to track that wasn't really present with most of the consumers. There were a couple that understood some of the movements that they wanted them to do. But most of them weren't on that same page…half of them fell asleep and the other half wondered off! Things like that you know that aren't working, and those are the things that I would hope that they would see and adjust for the next time. [It] didn't always happen that way. But that was tough. [I was] feeling kind of out of place where I wanted to make suggestions--but at the same time I feel like it's a learning experience too observe those things and make adjustments. ~Valerie

DCS encourage SMTs to consider consumers' individual characteristics and preferences in order to increase therapist flexibility and intuition. When asked what DCS observed during music therapy sessions, DCS shared considerations that SMTs could use to help build their craft and make the most while working with the consumers. The most common suggestions were getting to know consumers on an individual level and developing intuition through close observation of clients and practicing flexibility within the sessions.

Individual characteristics and preferences. DCS encouraged SMTs to be open to discovering more about the consumers' individual characteristics, preferences, and personalities. DCS suggest SMTs ask the staff and consumers about ages, needs, strengths, abilities, interests, behaviors, responses, personalities, accommodations, religious beliefs, coping strategies, and music preferences. DCS also encouraged SMTs to use age appropriate interventions and ask about preferences outside of music to help avoid triggering emotions or escalating behaviors of consumers.

I think that [SMTs] should consider who [consumers] are personally and [their] individual personalities. And take their time in getting to know the individual and particularly if they have anything that is triggering to them, to ask those questions upfront. And then learn a little bit about the person. What is the best most effective way to help them move through a triggering event. ~Nancy

I think [SMTs] should just ask more questions about what people's' abilities are. I think they should just [ask] initially "so can most of these folks read?" Or "is it better to use you know visual cues?" They should also not just assume that people hear when they're in the older group setting. They don't consider the fact that some people just can't hear and you have to speak up or it could be they're just not hearing what you are wanting them to do. ~Zoe

It depends on the person. Modern day music as well as past—we have another consumer who is advancing in her dementia and so her ability to recognize even modern day TV and movies is struggling. But if you put on an old black and white [movie]—she recognizes it, and if you play the music from you know when she was a child which is--she's one of our older consumers and so you know it's quite a bit farther back than others are familiar with. If you play that she recognizes that to where the modern day things even the things from 60s, 70s, and/or 80s she may not recognize everyday. ~Valerie

At the end of the day, what I think is the most important thing is to support their own interests. So, even though health is my thing, and I'm happy to impose it on anyone, at the end of the day I think the most important thing is supporting the individual's personal self expression, self desire, self interest, and helping them to just really realize their own, abilities and interests. So just supporting them in who they are as individuals. ~Nancy

Bringing positive energy with you is also very important. If you're stressed or having a bad day or unfocused or very short with them when you are communicating verbally—they pick up on all those things and it's harder for them to open up to you and meet you on a positive level. ~Valerie

Intuition and flexibility. DCS also suggested that student music therapists must be observant and flexible when working with this population. Consumers vary daily, according to DCS, and student music therapists must be observant and ready to adapt their session plan accordingly. Flexibility does not solely depend on consumers' daily moods, but also depends on the complexity of an application (i.e., too complicated or too simple). Student music therapists must consider accommodations (e.g., hearing impairments, physical limitations) as well while

conducting sessions. DCS also shared they felt the same as some SMTs when they first started

working with people with ID. While working with this population – which may be one that

students never experienced before – students seem to become more observant and develop

insight and intuition to meet the needs of the consumers.

> Being observant is definitely key. Even if you've managed to create ways to meet the consumers at their level of cognitive ability and physical ability—recognizing that everyday is different and so something that everybody may have been really excited about last week may not work this week because they may just be having a bad day. You know the weather might be bad or they're not feeling it or they are having to change it. Having the flexibility to let that original plan go and not be afraid to fly by the seat of your pants. They're not going to recognize if you mess up, they don't know what your plan was, they don't care, they just want to have fun and interact with you. ~Valerie

> And so, having to feel and [having] intuition for [consumers], how to best meet the needs of that person. ~Nancy

> [Something] that I realized after working here for awhile is that, I hate to say it but, there's this stigma--social stigma--of regarding people with ID… In general, unless you know of or have a family member or close friend that has ID or unless you insert yourself into a situation where you are going to be working with them, you probably have misconceptions of people with disabilities. So the thing that I would refer to SMTs [that] it applies to everybody. You can tell when a SMT first comes in and they've never worked with consumers before that they're nervous and you know understandably so. It's definitely a transition for them. You can tell when they've only ever worked with children…maybe they don't know much about people with ID in general or have never worked with them personally. Yeah, it's a little tough on them at first but they get used to it. ~Wendy

DCS mentioned it takes intuition to key in on what is going on with consumers to prevent

consumers from escalating or disengaging. A big piece of intuition is being flexible during the

session. According to DCS, some SMTs noticed their plan was either too simple or too complex

for the consumers and practiced flexibility, adapting the session plan to better meet consumers'

needs. Other SMTs were unable to break away from their plan, leaving some consumers

confused or disengaged (e.g., spacing out, getting up to wander away).

> Learning that people aren't getting this because they're not cognitively able to do what you're asking them to do or it's way over their head or some of them would have like

games that were too complicated or more [appropriate] for kids. Like spin the wheel--too many options. They don't understand the cognitive level that would be like a medium level. Like, they shouldn't go too high and they shouldn't go too low you have to kind of hit in the middle so that you know you're not eliminating and you're only working with maybe a couple people in the group that are high functioning enough to get what you're wanting to do and all these people are left out. So if you kind of aim for the middle then you're including more people. ~Zoe

Too many steps [and] too many options…and it's not just with older people, some people's' memories they cannot remember, they don't retain memory. And I [heard] people saying "Well, what did you do last Saturday" and they want to make a song out of it. Some people just don't know what they do last Saturday--sometimes I don't know what I did last Saturday…they should just say "What do you like to do? What do you like to go out to eat?" Those were the best ones, but you know, things like "what do you like" rather than "what did you do" because sometimes they are just not going to remember. ~Zoe

Instruments generally work out well. They love to play the instruments and so there were some experiences where there would only be instruments for one song in the middle of the hour…And so not having [instruments] is tough to keep them engaged. They're engaged up until they get the instrument because they know it's coming and you took it away and they're like, "aww, we're done now because you took the instrument away." ~Valerie

One DCS who experienced observing multiple SMTs shared an interesting observation among SMTs and how they affected consumers. This DCS acknowledged that although students may have different personalities, different skill sets, and different ways of interacting with consumers, all SMTs could find a way to engage consumers in a meaningful way.

Each therapist brought something different and had a different skill set and had a different way of connecting, had a different way of really engaging people. ~Nancy

DCS interviewed for this study provided rich data that blossomed into well-rounded themes. DCS found music therapy effective with their consumers and encourage SMTs to ask for DCS input. Given the six themes that emerged from these interviews, clinical implications can be made for students, educators, clinicians, and other DCS. These findings also open other avenues for future research and elicit further discussion.

Chapter 5

Discussion

Throughout this study, direct care staff (DCS) shared unique insights, experiences, perspectives, and suggestions for student music therapists (SMTs) about their work with older adults with intellectual disabilities. The six themes highlighted the major ideas from participant interviews and provided students, supervisors, educators, clinicians, and administrators with perspectives of DCS and their views on music therapy that may better inform practice. Exploring DCS experiences with older adults with ID and their perspectives on music therapy facilitated by students allowed for a better understanding of the perspectives of DCS, the value of DCS services for this population and other populations, how music therapy may be perceived by DCS in this setting, and supported the use of board certified music therapy clinicians for this population in order to provide increased continuity, clinical wisdom, and clinical experience.

From the information provided in the interviews, DCS have an appreciation for music therapy and how it affects both consumers and themselves. DCS shared personal accounts of their experiences with consumers before, during, and after music therapy sessions. There were effective changes in consumers' social, physical, emotional, and cognitive functioning as a result of music therapy sessions. These changes were consistent with domains targeted by music therapists throughout the literature (Davis, Gfeller, & Thaut, 2008; Hooper et al., 2008).

DCS also found personal enjoyment during music therapy because it gave them a chance to engage with consumers on a level that was personal and not authoritative. This finding is consistent with Watson (2014), in which the relationship between DCS and consumers improved through music therapy. The results from this study indicate there is a connection between DCS

and consumer relationships developing through the opportunity to engage with consumers through music therapy sessions.

DCS encouraged future SMTs to not be afraid to ask for help. Some DCS are hesitant to assist, not wanting to "step on toes" or interrupt what the music therapist has already planned. All participants in this study have worked full time over two years with the same consumers and have significant experience and knowledge when it comes to consumers' behaviors, preferences, and individual characteristics. Previous literature in regards to this theme was not found by the researcher, perhaps due to the specific research setting or nature of the sessions provided by student music therapists.

DCS shared multiple ways they use music in their everyday interactions with consumers outside of the music therapy sessions. DCS commonly used music listening at lunchtime, during car rides, or with headphones to help regulate mood and memory recall. Some DCS play memory recall games with music the consumers have experienced in music therapy sessions (e.g., "Name that Tune!"). Using donated instruments and movement aids (e.g., scarves) with music, DCS facilitate physical movement with consumers. One DCS shared that consumers' will remember music and what physical movement matches to the music based on past sessions, making it easier to complete their physical exercise for the day.

Given DCS's perspective on music therapy being effective, DCS encouraged SMTs to focus on physical, emotional, and social functioning when working with older people with ID, rather than improving cognitive skills. Due to some consumers' starting to experience dementia, improving cognitive skills may not be the most functional or beneficial goal area for students to target. In a study by Sinai, Bohnen, & Strydom, (2012), dementia is difficult to diagnose in older people with ID due to cognitive challenges and difficulty with assessment. The increased quality

of care of people with ID has increased lifespan; therefore, more consumers are facing dementia as they age (Sinai, Bohenen, & Strydom, 2012). DCS interviewed for this study verified this as their reality working with their consumers on a daily basis.

The DCS interviewed also stressed the importance of considering individual characteristics and preferences and the connection of this to therapist flexibility and intuition. They suggested getting to know the consumers on an individual basis versus focusing on the group as a whole. Having questions ready for consumers and DCS such as their likes and dislikes in addition to their history can help mold the session based on many preferences and avoid triggering consumers. Knowing a consumer's preferences and history can help increase engagement and create a more therapeutic experience. Getting to know consumers also improved SMTs observation skills and ability to adapt effectively in the moment. Intuition, or clinical wisdom, can improve through observation of client behaviors and better understanding of how music therapy is affecting the consumer. If SMTs identify frustration, confusion, or other signs of the application being too complicated or too simple, the SMT can adapt, bringing the consumer back into the therapy, making it effective for the consumer rather than losing consumer engagement. DCS shared multiple stories of having to be flexible with this population in every aspect of the job, not just music therapy. DCS understood that these were student music therapists gaining experience and learning to be flexible versus working with a board certified music therapist.

Clinical Implications

Students, educators, clinicians, and direct care staff may benefit from this study in multiple ways. From this study, students may better understand music therapy experiences from the perspectives of direct care staff. These perspectives may be helpful in SMT planning,

facilitation, and reflection on sessions. Although DCS interviewed wanted to be helpful, they also mentioned they were afraid to "step on toes" when it came to offering unsolicited advice. DCS mentioned SMTs in this setting have supervision throughout their practicum and they did not want to overstep any boundaries. DCS also mentioned they did not know much about music therapy and what therapists need to provide (e.g., goals, objectives), but they do know the consumers' preferences, behaviors, and histories that can be beneficial for SMTs to incorporate into their plans. Lastly, it is important that students understand that DCS are a knowledgeable and an invaluable resource. Having an open mind and a humble attitude to be able to reach out and gain insight from DCS is another step in the right direction for the well being of current and future consumers.

Music therapy educators may also benefit from this study. Given the specifics of the setting, the DCS have only experienced music therapy facilitated by SMTs. This provides educators with information about multiple SMTs across several years (e.g., different approaches of multiple SMTs.) Educators may use these perspectives of DCS to help train their own students working with people with ID as well as students working with direct care staff of other populations. Educators may also encourage SMTs to ask questions and interact with DCS in a professional manner. When approaching staff with a sense of humbleness, both SMTs and DCS can work together for the benefit of the consumers. This will help the students grow and mature in their professional practice while enriching the lives of consumers.

Although the DCS interviewed for this study experienced music therapy conducted by SMTs, board-certified clinicians may also benefit from this research. Given the amount of time spent with their consumers, DCS have insights and experiences that they may share with clinicians working with older consumers with ID. Participants in this study shared their personal

lived experiences with music therapy and what they viewed as effective and ineffective for consumers. Clinicians may use the perspectives shared in this study and compare and contrast them with their own experiences and research with the population in order to improve their clinical practice. In addition, this study highlights that therapists should be encouraged to ask DCS about consumers. Although this may already be a part of the initial assessment process for clinicians, DCS may be overlooked as valuable sources of information for consumers from session to session.

Clinicians can benefit greatly and improve clinical effectiveness by working together with DCS. For example, clinicians can work with DCS by providing ideas on how to incorporate music outside of music therapy sessions in order to reach consumer goals at a quicker pace. Coon, McCarthy, O'Toole, Rio, and Bontrager (2015) found through focus groups of caregivers, families, and direct care staff who care for others with dementia that staff were able to sing to help with challenging personal care tasks (e.g., steps to hygiene routines). By incorporating music throughout the time spent with consumers outside of music therapy, staff can also build and maintain relationships with their consumers in addition to working towards targeted goals and objectives (Watson, 2014). However, this current study also indicated the impact on consumers and DCS due to inconsistent sessions because of the student semester schedule (i.e., holiday breaks, summer break). This inconsistency placed stress on the DCS to fill the absence and denied consumers access to a valuable, effective, and consumer-preferred therapy. A board-certified music therapist could provide a high quality level of service without the long breaks and semester-by-semester termination that occurs due to university schedules.

Direct care staff may also benefit from this study. DCS have the opportunity to work with a wide range of ages of consumers. This study provides insight into what it is like working with

older people with ID. This study also demonstrated how DCS in this setting use music and music experiences practiced in music therapy with consumers in activities outside of sessions. DCS can further support and enhance consumer progress in music therapy by utilizing "prescribed" music applications supervised by board certified music therapists. Practicing these music applications outside of music therapy sessions may allow DCS to identify what is most effective and suggest alternatives that may improve the effectiveness of treatment. Overall, DCS are a knowledgeable and invaluable resource for music therapists when working with consumers with ID. Other DCS reading this study may relate to the perspectives shared by participants and realize they are a vital part in the quality of life for the populations they serve.

Recommendations from this Study

Using the study information provided, the following can be put into practice for students, educators, clinicians, and DCS:

- Students
  - Interview DCS within the initial assessment process to learn more about consumers
  - Ask questions and talk with DCS before and after sessions to gather important information
  - Develop goals and objectives for this population using DCS insight in addition to other resources
  - Observe consumers' responses during sessions and adapt the session plan to fit needs and preferences
- Educators
  - Encourage SMTs to incorporate DCS in initial assessment to increase knowledge of consumers

- Encourage SMTs to interact and communicate with DCS to help increase professionalism

- Interview DCS about SMTs to better understand students' needs and strengths to improve music therapy education and training

- Clinicians

    - Interview DCS during assessment and gather feedback from them before and after sessions throughout the treatment process

    - Talk with DCS about their perspectives regarding effective and ineffective practices for consumers

    - Collaborate with DCS by "prescribing" applications they can use throughout the week with consumers

- DCS

    - Collaborate with the site MT-BC to use "prescribed" applications outside of sessions

    - Compare and contrast DCS experiences with older adults with ID to your population and/or setting

- Researchers

    - Explore DCS experiences at different facilities and with different populations

    - Explore different theoretical approaches and philosophies used by music therapists and their impact on DCS perspectives.

Limitations, Delimitations, and Assumptions

Limitations are potential weaknesses of a study that are out of the researcher's control (e.g., time, funding) (Depoy & Gitlin, 2011). Given this small and unique setting, the study included a limited number (N=5) of participants. Future research studies could include a larger

number of participants or participants from multiple care settings. All participants were female, only allowing for a female perspective rather than male perspective. Future research could further investigate the male perspective or differences or similarities between genders. In addition, music therapy sessions observed by DCS were conducted by student music therapists for practicum rather than sessions conducted by board certified music therapists. Future research with DCS who observe professional music therapists rather than students may indicate differences in outcomes.

Delimitations are identified parameters the researcher controls in order to limit the scope of the study (e.g., population, research question) (Depoy & Gitlin, 2011). The setting chosen for the study was specific to older adult consumers with intellectual disabilities. DCS in settings that include young, middle, and older adults with ID may have different experiences in caring for consumers. Future research could investigate DCS across multiple settings and ages of consumers to identify common themes associated with music therapy. In addition, the researcher only conducted one in-depth interview rather than a series of interviews, allowing for a brief "window" into the participants' lived experience. Future research could include more interviews across time to investigate changes in DCS perspectives based on experience.

Assumptions are characteristics the researcher assumes are present, but out of his/her control and without them the study is irrelevant (Depoy & Gitlin, 2011). Given the data from the DCS interviewed, it is assumed DCS either watched and/or experienced music therapy with the consumers. However, DCS may have been distracted or not paying attention during music therapy sessions.

Future Recommendations

Given the unique setting and specific population for this study, this research can be furthered by exploring different facilities and populations in regard to staff perspectives. This study could be expanded to gather the perspectives of DCS at residential facilities and DCS of younger people with ID who experience music therapy, as well as DCS who work with other populations (i.e., hospital, hospice). In addition, differences in types of theoretical approaches used by music therapists could be explored, or different philosophical orientation and background of the researcher may affect themes that emerge from the data.

The current study included DCS who experienced music therapy sessions facilitated by students. Perspectives of DCS experiencing music therapy facilitated by clinicians may be explored for differences and similarities among themes. The music therapy provided in this setting was also limited to practicum students from the same university. Studying perspectives that occur because of students and settings from multiple universities in rural, suburban, inner city, and international settings may reveal new and interesting results.

References

American Association of Intellectual and Developmental Disabilities (AAIDD). (2013).

    Definition of Intellectual Disability. Retrieved from

    http://aaidd.org/intellectual-disability/definition#.VOeLZubF_T9

American Association of Intellectual and Developmental Disabilities (AAIDD). (2013).

    Diagnostic Adaptive Behavior Scale. Retrieved from

    http://aaidd.org/intellectual-disability/diagnostic-adaptive-behavior-scale#.VOeO3ebF_T

    8

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders*

    (5th ed.) Arlington, VA: American Psychiatric Association.

American Music Therapy Association (AMTA). (2015). What is music therapy? Retrieved from

    http://www.musictherapy.org/about/musictherapy/

The Arc. (2011). Introduction to intellectual disability. Retrieved from

    http://www.thearc.org/page.aspx?pid=2448

Brown, G. (1886). In memoriam—Hervey B. Wilbur, M.D. *Proceedings of the association of*

    medical officers of American institutions for idiotic and feeble-minded persons.

    Philadelphia, PA: J. B. Lippincott Company.

Bruscia, K. E. (1998). *Defining music therapy* (2nd ed.) Gilsum, NH: Barcelona Publishers.

Coon, D. W., McCarthy, M. C., O'Toole, L., Rio, R., & Bontrager, V. (2015). Music

    performance and music therapy: An interdisciplinary collaboration in dementia care.

    Gerontologist, 55(2), 328-329.

Cottonwood. (2011). About us. Retrieved from http://www.cwood.org/cwood/about/

Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.) Thousand Oaks, CA: SAGE Publications, Inc.

Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods.* Thousand Oaks, CA.: Sage Publications, Inc.

Davis, W. B., Gfeller, K. E., & Thaut, M. H. (2008). *An introduction to music therapy and practice* (3rd ed.) Silver Spring, MA: The American Music Therapy Association, Inc.

Devereux, J., Hastings, R., Noone, S., Firth, A., & Totsika, V. (2009). Social support and coping as mediators or moderators of the impact of work stressors on burnout in intellectual disability support staff. *Research in Developmental Disabilities, 30*, 367-377.

Depoy, E., & Gitlin, L. N. (2011). *Introduction to research: Understanding and applying multiple strategies*. St. Louis, MO: Elsevier.

Dyer, S., & Quine, L. (1998). Predictors of job satisfaction and burnout among the direct care staff of a community learning disability service. *Journal of Applied Research in Intellectual Disabilities, 11*(4), 320-332.

Evenhuis, H., Henderson, C. M., Beange, H., Lennox, N., & Chicoine, B. (2001). Healthy aging – adults with intellectual disabilities: Physical health issues. *Journal of Applied Research in Intellectual Disabilities, 14*(3), 175-194.

Farnan, L. A. (2007). Music therapy and developmental disabilities: A glance back and a look forward. *Music Therapy Perspectives, 25*(2), 80.

Gray-Stanley, J. A., & Muramatsu, N. (2011). Work stress, burnout, and social personal resources among direct care workers. *Research in Developmental Disabilities, 32*(3), 1065-1074.

Grossman, J. B. (1987). Review: Beyond the Willowbrook wars: The courts and institutional

    reform. *American Bar Foundation Research Journal, 12*(1), 249-259.

Hatton, C., Emerson, E., Rivers, M., Mason, H., Mason, L., Swarbrick, R., Kiernan, C., Reeves,

    D., & Alborz, A. (1999). Factors associated with staff stress and work satisfaction in

    services for people with intellectual disability. *Journal of Intellectual Disability Research,*

    43(4), 253-267.

Hilgenkamp, T. I. M., Reis, D., van Wijck, R., Evenhuis, H. M. (2012). Physical activity levels

    in older adults with intellectual disabilities are extremely low. *Research in*

    Developmental Disabilities, 33(2), 477-483.

Hooper, J., Wigram, T., Carson, D., & Lindsay, B. (2008). A review of the music and intellectual

    disability literature (1943-2006) part one—descriptive and philosophical writing. *Music*

    Therapy Perspectives, 26(2), 66-79.

Ivey, J. (2013). Interpretive phenomenology. *Pediatric Nursing, 39*(1), 27.

Koyanagi, C., & Bazelon, D. L. (2007). *Learning from history: Deinstitutionalization of people*

    with mental illness as precursor to long-term care reform. Retrieved from

    http://www2.nami.org/Template.cfm?Section=About_the_Issue&Template=/ContentMan

    agement/ContentDisplay.cfm&ContentID=137545.

Koeske, G. F., & Kirk, S. A. (1995). The effect of characteristics of human service workers on

    subsequent morale and turnover. *Administration in Social Work, 19*(1), 15-30.

Kowalski, C., Driller, E., Ernstmann, N., Alich, S., Karbach, U., Ommen, O., Schulz-Nieswandt,

    F., & Pfaff, H. (2010). Associations between emotional exhaustion, social capital,

    workload, and latitude in decision-making among professionals working with people with

disabilities *Research in Developmental Disabilities: A Multidisciplinary Journal, 31*(2), 470-479.

Kozak, A. Kersten, M., Schillmöller, Z., & Nienhaus, A. (2013). Psychosocial work-related predictors and consequences of personal burnout among staff working with people with intellectual disabilities. *Research in Developmental Disabilities, 34*, 102-115.

MacDonald, R. A., O'Donnell, P. J., & Davies, J. (1999). An empirical investigation into the effects of structured music workshops for individuals with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 12*(3), 225-240.

Mental Retardation Facilities and Community Mental Health Centers Construction Act, 70 Stat. 717 USC 292-2921 (1963).

Mutkins, E., Brown, R., & Thorsteinsson, E. B. (2011). Stress, depression, workplace and social supports and burnout in intellectual disability support staff. *Journal of Intellectual Disability Research, 55*, 500-510.

National Institutes of Health (NIH). (2015). Intellectual disability: MedlinePlus Medical Encyclopedia. Retrieved from http://www.nlm.nih.gov/medlineplus/ency/article/001523.htm

National Institutes of Health (NIH). (2016). Chlorpromazine. Retrieved from https://www.nlm.nih.gov/medlineplus/druginfo/meds/a682040.html

North, F. (2014). Music, communication, relationship: A dual practitioner perspective from music therapy/speech and language therapy. *Psychology of Music, 42*(6), 776-790.

O'Callaghan, C., & McDermott, F. (2007). Discourse analysis reframes oncologic music therapy research findings. *The Arts in Psychotherapy, 34*(5), 398-408.

O'Callaghan, C., McDermott, F., Hudson, P., & Zalcberg, J. R. (2013). Sound continuing bonds with the deceased: The relevance of music, including preloss music therapy, for eight bereaved caregivers. *Death Studies, 37*, 101-125.

Patja, K., Iivanainen, M., Vesala, H., Oksanen, H., & Ruoppila, I. (2000). Life expectancy of people with intellectual disabilities: A 35-year follow-up study. *Journal of Intellectual Disability, 44*(5), 591-599.

Pavlicevic, M., O'Neil, N., Powell, H., Jones, O, & Sampathianaki, E. (2014). Making music, making friends: Long-term music therapy with young adults with severe learning disabilities. *Journal of Intellectual Disabilities, 18*(1), 5-19.

Rivera, G. (1972). *Willowbrook.* New York, NY: Random House, Inc.

Rothman, D. J., & Rothman, S. M. (1984). *The Willowbrook wars.* New York, NY: Harper & Row, Publishers.

Sarafino, E. P. (2006). *Health psychology: Biopsychosocial interactions.* 5th ed. New York, NY: John Wiley.

Sinai, A., Bohnen, I., & Strydom, A. (2012). Older adults with intellectual disability. *Current Opinion in Psychiatry, 25*(5), 359-364.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research.* Los Angeles, CA: Sage Publications, Inc.

Sokolowski, R. (2000). *Introduction to phenomenology.* Cambridge, United Kingdom: The Press Syndicate of the University of Cambridge.

Thompson, L., & Rose, J. (2011). Does organizational climate impact upon burnout in staff who work with people with intellectual disabilities? A systematic review of the literature. *Journal of Intellectual Disabilities, 15*(3), 177-193.

Torrey, E. F. (1997). *Out of the shadows: Confronting America's mental illness crisis.* New York, NY: John Wiley & Sons.

Trent, J. W. (1994). *Inventing the feeble mind: A history of mental retardation in the United States.* Oakland, CA: University of California Press.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy.* Albany, NY: SUNY Press.

Watson, T. (2014). Relationship and communication in music therapy: A response to North (2014). *Psychology of Music, 42*(6), 800-808.

World Health Organization (WHO). (2015). Definition: Intellectual disability. Retrieved from http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability

Appendix A

Dear Cottonwood Direct Care Staff:

My name is Kori Wells and I am a music therapy graduate student at the University of Kansas. I am currently conducting a study called *The Perception of Music Therapy by Direct Care Staff of Older Adults with Intellectual Disabilities: A Phenomenological Approach.* As a direct care staff member, I would like to invite you to participate in the study. You may participate if you are over the age of 18, are currently working for or retired from Cottonwood, Inc. for two months or more, and have observed clients participating in at least one music therapy session.

If you choose to participate, you would be asked to talk with me during an initial 60-minute interview and a shorter 20-minute follow-up interview a few weeks later. During the interview, I will ask you about your experiences as a direct care staff and your thoughts about the effects of music therapy on clients, yourself, and your work experience. The interviews will be scheduled on a day and time convenient for you, and held within either the building next to Cottonwood Retirement or the conference room at Cottonwood Inc. All of your responses will remain confidential; your name will never be connected to the information.

Please let me know if you are interested in participating in this study. If you are interested in participating or have questions, please contact me via email K514W017@ku.edu or phone (785-410-8426. Thank you for considering this request to share your perspective as a direct care staff member.

Sincerely,
Kori Wells, RBT
Registered Behavior Technician
KU Graduate Equivalency Music Therapy Student
Email: K514W017@ku.edu
Phone: (785) 410-8426

Appendix B

Introduction and Confidentiality
Thank you for taking time to meet with me for this 60-minute interview about your experiences as a direct care staff at Cottonwood. Everything you share with me will be confidential; your name will never be associated with the information. There are no right or wrong answers, you may skip any questions in which you feel uncomfortable answering, and you may stop the interview at any time for any reason.

Demographics
What is your name?
Where are you from?
What is your age, gender, education?
How long have you worked as a direct care staff member?
How long have/did you work at Cottonwood, Inc.?
What position(s) did/do you have at Cottonwood, Inc.?

DCS Specific Questions
What brought you to working with people with intellectual disabilities?
What were your feelings about people with intellectual disabilities before starting your DCS position?
What are/were your responsibilities working as DCS?
What are/were your most challenging tasks working as DCS?
In your experience as DCS, what are the most important areas (e.g., social, cognitive, physiological, physical, emotional) regarding people with intellectual disabilities?
What are some of your fondest memories/experiences working as DCS?
What are some of your most challenging memories/experiences working as DCS?
How have your feelings developed about working with people with intellectual disabilities throughout your time as DCS?

Music Therapy Specific Questions
What did you know about music therapy before working as a DCS?
What did you think music therapy was before seeing it in Cottonwood Retirement?
What were your views about music therapy before experiencing it at Cottonwood Retirement?
What were some things (e.g., domains, skills) covered by music therapists?
How did the objectives of the music therapist affect individuals with ID?
How has your knowledge changed about music therapy?

DCS Perspectives of Music Therapy Regarding People with Intellectual Disabilities and Self
How did music therapy sessions affect your daily tasks as DCS?
How did these sessions affect the consumers in your experience as DCS?
How did these sessions affect you personally as DCS?
How did these sessions affect you professionally?

What are some applications conducted by the music therapist that could be used outside of music therapy? If none, what are some applications and objectives that could be used and targeted by the music therapist?

What are things music therapists must consider when working with people with intellectual disabilities?

What are things music therapists must consider in regards to your job as DCS?

Probing Questions
Tell me more…
You mentioned (topic/experience), I would like to know more.
I would like to explore this idea with you…

Follow-Up Questions
What is your understanding of the results of this study?
Are the results accurate in regards to your experiences? How so?
If not, please share what I have missed or misinterpreted so I may best reflect your experience?
Is there anything you would like to add?