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The Experience of Songwriting in Music Therapy for Adults with Intellectual Disability

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This research was completed as part of the degree requirements for the Music Therapy Department at Molloy College.

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Running Head: THE EXPERIENCE OF SONGWRITING FOR ADULTS WITH ID

The Experience of Songwriting in Music Therapy for Adults with Intellectual Disability

A THESIS

Submitted in partial fulfillment of the requirements

For the degree of Master of Science

In Music Therapy

by

Jasper Lewis

Molloy College

Rockville Centre, NY

2019

THE EXPERIENCE OF SONGWRITING FOR ADULTS WITH ID

MOLLOY COLLEGE

The Experience of Songwriting in Music Therapy for Adults with Intellectual Disability by Jasper Lewis, MT-BC A Master's Thesis Submitted to the Faculty of Molloy College In Partial Fulfillment of the Requirements For the Degree of Master of Science April 2019 Thesis Committee:

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Abstract

This research study investigated the lived experience of adults with Intellectual Disability (ID) in a music therapy songwriting session. Three study participants, referred to here as Emma, Anne, and Abdoul, took part in individual songwriting music therapy sessions. The participants each completed an original song in collaboration with a board certified music therapist. The songs were recorded and the lyrics of the song were transcribed. After the songwriting experience was complete a 10-20 minute semi-structured interview was conducted to gather data about the participants' subjective experiences. This data was analyzed according to the interpretive phenomenological analysis (IPA) framework. Themes were identified intuitively and refined through multiple iterations and then compared across cases in order to answer the following research question: What is the lived experience of a music therapy songwriting session for an adult with intellectual disability? All three of the study participants reported that they found songwriting to be a positive experience. Additional themes were present in two interviews: Songwriting could be used to raise the individual's esteem in the eyes of their community, songwriting was a novel experience, and songwriting was related to feelings of altruism. Unique themes emerged in individual interviews which related to the participant's personal context.

The Experience of Songwriting in Music Therapy for Adults with Intellectual Disability

"People coming up and bothering me I wish they'd leave me alone with their problems. There's nothing to do today There's nothing to do today"

As Maryanne (whose name has been changed to protect her privacy) sang her original song that we had just finished composing in our music therapy session, a small crowd gathered in the workshop around us. Her peers listened to her sing and laughed as they recognized her honest assessment of the challenges of a boring day. They sang along with the chorus, and after the song someone asked her, "Did you really write that?"

Maryanne is an adult woman with moderate intellectual disability who spends her day at a day center performing menial work. She enjoys her work, but work is not always available. When there isn't any work assigned to her she passes the time with her friends. Maryanne has been described by some of her support staff as "depressed" or "troubled." On the day this song was composed she expressed feelings of frustration and anger. The lyrics of this song shared details of her daily frustrations in a way that her peers could immediately identify. When Maryanne finished singing the song she let out a loud, genuine laugh that echoed across the spacious workshop floor.

When I saw Maryanne the following week she greeted me with a smile. In the weeks and months that followed we collaborated together on other songs, and other sides of her personality were revealed. We wrote about her feelings of frustration and boredom, as well as the things she does to cope. It seemed as if songwriting was providing a unique way for Maryanne to explore her day-to-day life. Via songwriting her experiences were both validated and reflected back to her. She also developed a unique songwriting skill that gained respect from her peers.

For Maryanne, and many others with intellectual disability, there are barriers to communication which impact their overall quality of life (Baker, Oldnall, Birkett, McCluskey, & Morris, 2010). Issues with attention, memory, finding words, understanding complex concepts can contribute to poor communication (Law, Bunning, Byng, Farrelly, & Heyman, 2005). This deficit in communication skills may result in individuals becoming isolated or sequestered. The opportunity to write a song is one way in which the typical patterns of communication can be challenged. The songwriter is pushed to express themselves in a way that is novel and validates their unique perspective.

I began to work with adults with disabilities at adult day centers almost five years ago. Observing their profound responses to music is what led me to the field of music therapy. I feel strongly connected to these individuals and their hardships, and I see the toll that being relegated to the outskirts of society takes on them. Adults with disabilities are a marginalized group in society with limited access to self-advocacy tools and limited opportunities to build self-esteem (Wehmeyer, 2013). When I work with this population I sense that there is a depth of experience and awareness that is not always available on the surface. I have observed that writing songs can be a way for individuals with intellectual disabilities (ID) to express themselves more fully

I have personally used songwriting as a mode of expression since I was young. I have released several albums of original music and I have consistently been able to use music to articulate things about myself that I could not express without music. Writing an original song gives the writer an opportunity to express difficult concepts or emotions in a way which is approachable and relatable. I believe that this population has much to say that is not being heard. I think that songwriting can be a means for persons with ID to express their needs as well as to share their processes in a manner which invites collaboration and greater understanding.

Literature Review

The American Music Therapy Association (AMTA) defines music therapy 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" (2018, para.1). Music therapy is a person-centered practice which is used to accomplish a variety of goals depending on the individual needs of the clients. Music therapists use a broad variety of techniques and interventions in their work.

The use of music in a healing context is a concept that is almost as old as music itself. Music has been recommended as a cure for lovesickness, sadness, and anger (Horden, 2000). Music plays a role in religious ceremonies and shamanic rituals which aim to heal the body, mind, and spirit (Davis & Hadley, 2015). Many of these traditions continue today, but modern technology has changed the way the average person engages with music by making it much more accessible and portable than it was in the past (Krause, 2015).

Music in Everyday Life

DeNora (2000) wrote, "Music may influence how people compose their bodies, how they conduct themselves, how they experience the passage of time, how they feel - in terms of energy and emotion - about themselves, about others, and about situations" (p. 33). This conception of

music is that it is an ongoing process which is difficult to quantify or separate from context. Music transcends the boundary between the body and the mind and involves systematic responses at all levels of experience. Music is a process by which the human organism organizes and structures time (Denora, p. 47).

North and Hargreaves (1999) have a different perspective on the role of music. They see the transactional elements of music appreciation and culture, and observe that music is a primarily social construct. Music is used like a "badge" that an individual may use to signal their culture or tastes to others. It is not time itself which is being organized by music, but identity. Music serves to affirm the dimensions of the self and broadcast those dimensions to others.

Music and health. There is a general perception that music contributes to good health. A 2016 large-scale survey of 25,000 Danish adults (with a 57% response rate) showed that respondents used music to regulate their mood, and perceived music making to be a health promoting activity (Bonde, 2016). Music can also have teleological function, and is employed on an individual basis as a tool for regulating affect and mood (Sloboda, 2005; Rickard, 2011). Batt-Rawden (2010) interviewed 22 individuals with long-term disease and illness about their experience using music to promote good health. Participants reported that music contributed to their sense of being whole. Music was a way for them to engage with the parts of themselves that were healthy. The participants each expressed their relationship to music differently, but an emerging theme was a sense of movement. Music was used to move forward, move through, or progress from illness to health.

Intellectual Disability

Intellectual disability has a long and sometimes painful history in the United States. (Wehmeyer, 2013). For most of the 20th century the standard practice for caring for those with intellectual disability was enforced institutionalization. Institutions varied in quality, cleanliness, and ability to provide adequate care. In 1972, Geraldo Rivera broadcast a shocking report on the conditions at one such facility, Willowbrook State School (Skinner & Rivera, 1972). This broadcast helped to raise awareness of the inhumane conditions at these facilities and contributed to an ongoing cultural shift towards greater inclusion and integration (Wehmeyer, 2013). The term "intellectual disability" itself is relatively new. In the 1990s, self-advocacy groups successfully lobbied to change the official designation from *mental retardation* to *intellectual disability* due to the increasing stigma of the word *retarded*. Rosa's Law (2010) replaced *mental retardation* with *intellectual disability* in all federal documentation.

Definition. The American Association on Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability as "a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills" (2018, para.1). A key factor is that the disability must originate before 18 year of age. This is differentiated from a developmental disability. "Developmental disability" is an umbrella term that encompasses intellectual disabilities, but includes other forms of disability as well (AAIDD, 2018).

Diagnostic criteria. The DSM-5 criteria for Intellectual Disabilities (ID) includes three domains: conceptual, social, and practical intelligence (American Psychiatric Association [APA], 2013b, para.1).

- The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
- The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
- The practical domain centers on self-management in areas such as personal care, job responsibilities, money management, recreation, and organizing school and work tasks.

The three domains were identified as a way to capture more nuanced information about the presentation and challenges of an individual person with ID. To be diagnosed with ID, individuals must display symptoms during the developmental period of their lives, or before the age of 18. Diagnosis is made according to the severity of their deficits. ID has many causes, and can co-occur with a variety of other conditions including autism spectrum disorder, depression, Down syndrome, or attention deficit disorder (APA, 2013b). A meta-analysis of population-based studies found that approximately 0.5% of the adult United States population is living with intellectual disability (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011).

Clinical needs. No comprehensive summary of clinical needs for the adult population with ID is available, due in part to the fact that ID is a broad diagnosis which does not have a uniform presentation. McLaughlin and Adler (2015) note communication, conceptual skill development, social skills, and activities of daily living as four areas of needs for children with ID. These delays have lasting consequences in adulthood, and contribute to the challenges adults with ID face in participating in society. The DSM-5 categorizes ID as mild, moderate, severe, or profound depending on the degree to which an individual's ability to function is impacted (APA, 2013b). The ongoing goal for individuals with ID in practice is increased independence and integration with society (The Arc, 2018). Profoundly disabled individuals need support to accomplish basic life activities but those with mild to moderate levels of disability often have a focus on job placement or independent living skills.

Treatment planning for adults with ID is person-centered, and the goal planning process for an adult with ID is not different than the goal planning process for a typically developing adult (Berghuis, Slaggert, & Jongsma, 2015). The difference lies in the goals themselves which may address activities of daily living, behavioral goals, or goals relating to job training or independent living. The process for determining whether a person is a candidate for music therapy is also not different for the two population groups.

Music Therapy and Adults with Intellectual Disability

Hooper (2008a, 2008b) conducted a comprehensive literature review in which 606 articles on music therapy, music aptitude, and individuals with intellectual disabilities (ID) from 1943-2006 were analyzed. The first part of this two-part article (2008a) details the descriptive and philosophical writing on this population group including case studies, outcome reports, and philosophical approaches. The Hooper (2008a) noted that case studies and philosophical writing "demonstrated the value of descriptive and philosophical writing not just as a medium for for identifying clinical outcome, but also for informing and advancing clinical practice and for demonstrating the efficacy of music therapy as an intervention for individuals with intellectual disability" (p. 74). The second part of the Hooper's (2008b) review examines experimental reporting, which formed a smaller part of the total body of works. The author reviewed 71 articles which reported individuals responses to active music therapy and 112 reports of receptive music therapy interventions. Hooper found that it was difficult to generalize the results of music therapy research in part because sample sizes in studies were typically small. There is a dearth of published research regarding music therapy and adults with ID, and the author questioned whether experimental research was the best method for understanding expressive interventions like improvisational music therapy.

Music therapy is frequently used as part of a comprehensive care plan for children with ID (Aigen, 1995). There are numerous published case studies on this work, especially involving the pioneering use of music in the relational context by Paul Nordoff and Clive Robbins (Nordoff & Robbins, 2004). However the research relating to the use of music therapy with adults with ID is limited. The published research involving adults with ID and music therapy tends to focus on behavioral applications of therapy as measured by outside observers such as caretakers or family members. Music therapy research has been published which pertains to the three domain areas defined by the APA (2013a) individually: conceptual intelligence, practical intelligence, and social intelligence.

Music therapy to address conceptual intelligence. Hoyle and McKinney (2015) employed a nine-week music therapy protocol designed to help adults with disabilities cope with bereavement and grief. As a result of this music therapy intervention, a decrease in negative behaviors was reported by caretakers in one of the three study participants. The other two participants did not show a significant change in their behavior after the experimental condition had concluded. The researchers emphasized the challenges that individuals with ID face in communicating their emotions or needs. Individuals with ID were typically excluded from funeral planning, were not informed about what was happening in a way they could understand, and their emotional reactions were typically suppressed by others.

Though not specific to individuals with ID, Hong (2001) observed the effects of songwriting on the cognitive faculties of older adults with dementia. Therapeutic songwriting was demonstrated to have a significant positive effect on language function, orientation, and memory which are all components of conceptual intelligence (Hong, 2001). The results of this study suggest that similar concepts could be applied to groups of adults with ID, but further research is required.

Music therapy to address practical intelligence. Research regarding practical intelligence has investigated the link between musical play and cognitive functioning and the use of music to improve cognitive functioning. Luck et al. (2006) used Music Interface Digital Instrument (MIDI) encoding and computational analysis to identify the components of musical improvisation most closely correlated with degree of intellectual disability. The researchers identified temporal elements such as note duration, duration of silences, and variation in note durations as the musical elements which most accurately predicted the individuals degree of severity of diagnoses of ID. For instance, individuals with more severe disabilities were found to have longer durations of silences in their playing.

Music therapy to address social functioning. Social deficits are common for persons with ID. Music therapy has been shown to be an effective modality for improving social skills in children with this diagnosis. A study of 45 children aged 6-17 years old found that a five-session

music therapy program with an emphasis on teaching social skills resulted in significant improvement in social functioning before, after, and during school (Gooding, 2000). Pasiali (2004) used prescriptive songs to teach children with disabilities social skills. The songs were composed by the therapist based on the individual children's needs and lyrics were set to familiar melodies. The author found that learning and practicing these songs resulted in significant improvements in school and peer relationships.

Oldfield and Adams (1990) studied the effectiveness of music at promoting engagement in 12 adults with profound disabilities. This study determined that music was effective at drawing attention and evoking appropriate social behavior. Hooper (2001) recorded the frequency and quality of interactions between four adult roommates with ID under three conditions: a baseline (unstructured free time), five structured ball games, and five collaborative music sessions structured around songs sung by the therapist. The research showed that music and structured ball playing were both effective means of encouraging positive interactions with greater frequency. Hooper speculated on the underlying mechanisms of this change was the nonverbal nature of interactions through music or play.

A long-term case study of an adult male with ID explored the influence of music therapy interventions on behavior, both inside and outside of the therapy environment, over a period of four years (Wager, 2000). Progress was not linear, but the music therapy sessions served to reinforce positive social interactions in the music therapy environment such as spontaneous verbalizations and smiling. These changes extended outside of the therapy environment, as the study participant used music as an expressive outlet in his group home and activities by singing, playing, or listening to music with others. Soshensky (2011) analyzed data collected from lyrics, interviews, written materials, and clinical observations to identify five areas in which clients with long-term disabilities including ID experienced positive change: self-efficacy, engagement, self-expression, affiliation, and enjoyment. This article approached the issue of social functioning obliquely, in the context of self-advocacy. However it is important to note that music seemed to give these individuals a voice and a platform that they were lacking. The impact of providing an opportunity for disenfranchised persons to "have a voice" can be one important effect of music therapy.

Music therapy to change behavior. Therapy and therapy research may address the underlying issues affecting clients or it may focus on achieving desired behavioral outcomes. A pair of research studies observed the link between music and relaxation from two different perspectives. Ford (1999) measured the instances of self injurious behaviors in a profoundly disabled 23-year-old woman 10 minutes before and after exposure to pre-recorded music and interactive music using a keyboard. The participant exhibited a significant decrease in teeth grinding after music listening, but the results of the study were otherwise inconclusive. The data was not sufficient to point to interactive music or music listening as being a deterrent to self-harming behavior. Behavior tended to be unchanged before and after interventions, and it was noted that a larger sample size is required to obtain meaningful results.

Groenweg, Stan, Celser, Macbeth, and Vrbancic (1988) also studied the use of music as a background stimulus. In their study, 12 adults with ID listened to relaxing music as they performed their tasks at work. The music in this study was chosen by the researchers and consisted of three Western classical music compilations and a compilation of music from movie soundtracks. The study marked a significant increase in productivity as well as a decrease in counterproductive behaviors.

Songwriting in Music Therapy

Songwriting is a compositional activity in music-making identified by Bruscia (2014) as one of the four main methods of music therapy. Compositional music therapy experiences may consist of the composition of original music with or without lyrics, the rewriting or transformation of existing music, the composition of music using notational systems, or the creation of musical collages. Songwriting is a form of composing in which the client creates original melody and/or lyrics with some level of support from the therapist. The final product is usually notated or recorded in some fashion so it can be re-experienced or altered.

A survey of 477 music therapists practicing in 29 countries found that songwriting is frequently used with the developmental disability population (Baker, Wigram, Stott, & McFerran, 2009a, 2009b), but the authors note that this work is underrepresented in the literature. The survey reported a diverse collection of goals such as developing self confidence, gaining insight, choice and decision making, and telling the client's story. The researchers found a lack of literature on songwriting with the developmental disability and ASD populations.

Songwriting with populations other than ID. Songwriting in music therapy has been examined with a variety of other clinical populations. A study of 89 psychiatric inpatients found that songwriting in a psychoeducational context was as effective as traditional talk therapy at teaching basic coping skills (Silverman, 2011a). Silverman also noted that there was a significantly higher therapeutic working alliance in the music therapy condition than the traditional talk therapy condition.

Jones (2005) determined that a single songwriting session may be effective at producing change with adults in a substance abuse program. Study participants were given visual analog mood scales before and after the songwriting intervention. The data indicated that participants reported greater joy, happiness, and enjoyment, and significantly reduced guilt, blame, and regret after the songwriting experience. Songwriting using the Guiding Original Lyrics and Music (GOLM) protocol lead to measurable changes in perceived mood by adult cancer patients (O'Brien, 2012). GOLM is a five stage songwriting process which begins with brainstorming and ends with a recording and presentation of the finished work. Silverman (2011a, 2011b) found that music therapy is an effective way to foster greater alliances between patients and healthcare workers as well as helping patients express and change their mood.

Other factors that influence songwriting. Songwriting itself is commonly considered as a vehicle for the expression of emotions (Stewart, 2016). Emotional expression is best understood in the cultural environment that produced the song. A series of surveys addressed the cultural issues inherent in songwriting (Baker, 2013a, 2013b). The results illustrated the diverse approaches that different cultures have to songwriting and the role of the songs. The therapist's knowledge of and responsiveness to cultural factors and group dynamics has a profound impact on the therapeutic songwriting experience.

Making Meaning of the Songwriting Experience

Lyric analysis is one of the most common tools used to understand songs generated in a therapeutic context (O'Callaghan & Grocke, 2009). Baker (2017) used deductive analysis to study 36 songs composed by 12 adults with acquired neurological injuries. The researcher identified self-concept as being closely associated with the songwriting process, in that

participants tended to use their songwriting to reestablish their personal identities and sense of self. However this type of analysis of lyrics leaves room for subjectivity on the part of the researcher as well. A meta-analysis of published client written song lyrics found that there was low inter-reporter reliability in the analysis of the lyrics (McFerran, 2011). This suggests that lyric analysis cannot be accurately completed without contextual knowledge of the clients and their circumstances. Despite this caveat, lyric analysis remains a useful method for identifying emerging themes and topics in therapeutic songwriting (Thompson, 2009).

Analyzing the music. Songs have a musical dimension as well, and a comprehensive analysis framework should consider the musical components of the song. A modified grounded theory put the focus on the role of music in a study of the therapeutic songwriting process (Baker, 2015). This study noted that the actual music is typically overlooked in favor of lyric analysis in contemporary research, and found that music is used for a variety of purposes, most relating to self-expression. This study supports the inclusion of musical analysis as an additional way of gaining perspective on the totality of the songwriting experience.

Mixed methods analysis. Viega and Baker (2017) approached the question of song analysis by using different approaches to separately analyze songs written by a 20-year-old woman with an acquired neurodisability. The songs were analyzed using a deductive approach and an arts-based research approach. The deductive approach identified thematic elements of the songs, while the arts-based research approach found more complex and heuristic experiential data, which allowed the reader to engage with the research on an emotional level. The report recommended that multiple approaches be utilized as a way to provide more comprehensive and compelling results. The experience of the client. Current research has been focused on the interpretation of meaning as derived from the product of the therapy session, the song. It seems that the intention and experience of the songwriter requires consideration to interpreting meaning as well. Studies by Baker (2018c) and O'Brien, (2016) included the direct reported experience of the songwriter as part of the data. Baker (2018c) used interpretive phenomenological analysis (IPA) to understand the experience of four adults with dementia in a ten-week songwriting workshop. Interviews were also conducted with members of the support staff to obtain additional perspective on their experiences. Overall, the group members found the experience enjoyable and fun. There were benefits noted in the personal area, overcoming challenges related to songwriting, and in the interpresonal, working together as a group to create something new.

Research Agenda

The available research on the topic of music therapy with adults with intellectual disabilities (ID) is limited. There is support for the use of music therapy with this population, but the research tends to focus on behavioral outcomes and omits the lived experience of the research participants. Quantitative studies support the use of songwriting as a music therapy method, and qualitative examinations have examined the underlying mechanisms of change present in therapeutic songwriting with other clinical populations. This research study was conducted to investigate the lived experience of songwriting for individuals with ID.

Research involving the self reported experience of adults with ID is sparse and further examples of the lived experience of these individuals will help music therapists develop interventions and goals for therapy. This study addressed the following questions:

- 1. What is the subjective experience of writing a song for individuals with intellectual disabilities?
- 2. How do these individuals make sense of their songwriting experience? What is their process for meaning-making?

Method

This study was conducted to investigate the lived experience of songwriting in music therapy with three to four adults with ID. Three participants took part in one music therapy songwriting session of approximately 45 minutes. The session was followed by a brief 10-20 minute interview with each participant. The lyrics of the finished song were transcribed. Because the purpose of this study was to learn about how the clients experience the music therapy songwriting experience, the interpretive phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009) was chosen as the methodology for analyzing the data collected. The interview was analyzed for themes and then compared to the results of analysis of the other interviews to determine commonalities and differences.

Participants

Three adults (age 18+) who were able to participate in and verbally process a songwriting experience were recruited from an adult day center to participate in a single music therapy songwriting session of approximately 45 minutes. The participants were chosen according to convenience of scheduling, by their availability on the day of the session. The session was conducted by the primary researcher, a board-certified music therapist (MT-BC). Study participants have a confirmed diagnosed of intellectual disability (ID), and are capable of

communicating verbally. The diagnosis of ID was confirmed by the staff psychologist by consulting the individual's PCP (Personal Care Plan).

Seven potential participants were identified among the attendees at the day center. In order to be considered as a possible study participant individuals had to have a legal designation of self advocate, meaning that they were able to sign their own consent forms. To prevent the possibility of mistakenly working with an individual who is not a self advocate, client records were consulted in collaboration with the social services staff at the center to ensure that each participant was a legally designated self advocate.

Of the seven potential participants one was absent from the program for the duration of the research period and was excluded from the study. The remaining six individuals were approached by the principal researcher and three of the six agreed to participate. Informed consent was obtained from the participants (Appendix A). The research project was verbally explained to the participant and a written copy of the consent form was provided. Participants had a week to consider whether or not they would like to be part of the study before the research began. To shield the identities of the study participants pseudonyms have been used in place of their real names.

Emma. Emma is a 67-year-old female with moderate intellectual disability. Emma has previously attended group and individual music therapy sessions which focused on songwriting.

Anne. Anne is a 62-year-old female who has attended music therapy for several years in small groups but has not previously had one-on-one sessions.

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Abdoul. Abdoul is a 33-year-old male with moderate intellectual disability. For several weeks before the research project I had been engaged in individual sessions with Abdoul helping him develop his identity as a rapper.

In any qualitative research it is important to consider the role of the researcher and their possible biases or impact on the data generated by the research study (Wheeler & Kenny, 2005). I have been working with the adults at this day center for nearly five years. Our preexisting relationship informed the process that took place in this research project, and the research cannot be taken out of this context. There are advantages and disadvantages which present themselves in this circumstance. One of the first priorities in a qualitative interview is the establishment of rapport (DiCicco-Bloom & Crabtree, 2006). Because I have already developed a rapport with the individuals at this location we have already laid the groundwork for communication and understanding. However since I occupy a position on the staff at the day program and may be seen as a figure of authority, it is also possible that individuals feel pressured to answer questions in a way they think will make me happy. I did my best to counter this tendency by using open ended language, being mindful of the participant's affect and energy level, and offering opportunities to take breaks if necessary.

Materials

The session took place in a closed room to minimize distractions, furnished with a desk and two chairs. There was scrap paper and a pen for writing lyrics. The session and subsequent interview were recorded on a Zoom H2n Handy Recorder. The room was also furnished with a full size acoustic guitar in standard tuning, a half size acoustic guitar in an open tuning, a tambourine, a tubano, a set of maracas, and an electric keyboard.

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Procedure

The procedure for this songwriting experience was designed to offer the client agency in terms of determining the lyrical and musical content of the song while allowing the therapist to offer support as needed (Bruscia, 2014). The songwriting session was semi-structured so that the therapist and client could collaborate to create the lyrics of the song first, before determining the musical content and finally recording (Davies, 2005). I remained reflexively engaged throughout the process and responded to moment-to-moment changes in affect and mood. Two of the three sessions proceeded by the following steps. The third session deviated from the established protocol and will be described below:

- I began the session by introducing the songwriting activity and asking open-ended questions to generate a theme. I used my relationship with the client to investigate their interests in the present moment and identify a possible theme for songwriting.
- 2. The client was invited to share associations and lyric ideas on the topic as the therapist took notes with the notebook and pen. I collaborated with the client to write lyrics for the song based on associations and ideas supplied by the clients.
- 3. The client was given the opportunity to experiment with the instruments in the room and choose one to play.
- 4. The client was given choices as to the musical structure and content of the song. The client was given choices as to the musical elements of the song: fast or slow, happy or sad, and examples of various idiomatic chord progressions representing different genres. These choices were given by me as options or emerged organically as I met the client's affect and energy level musically.

 The song was performed and the client was given the opportunity to suggest changes.

The session with Abdoul deviated from the above protocol. Abdoul preferred to work in the hip-hop idiom using pre-recorded beats that he found online. Since Abdoul and I have previously written music in this style, I chose to follow Abdoul's lead. Abdoul recorded his song by improvising directly into the agency's computer using Garageband software.

After the songwriting session has ended, I conducted an interview of approximately 20 minutes with the clients about their experience in the songwriting session. The qualitative interview is a powerful tool for understanding the subjective experience (DiCicco-Bloom & Crabtree, 2006). The interviews in this study were semi-structured, as I entered the interview with a predetermined set of questions designed to elicit responses about the interviewee's experience in songwriting (see Appendix B). The semi-structured format of the interviews allowed me to follow the lead of the study participant and shape the interview to accommodate their unique perspectives.

The interview consisted of simple open-ended questions about the meaning and experience of songwriting. Lloyd, Gatherer, and Kalsy (2006) have identified some of the special challenges that may present themselves when conducting qualitative interviews with individuals who have expressive language difficulties. The authors recommend using simple grammatical structures, mirroring language whenever possible, and asking questions multiple ways to ensure understanding. They also point to deeper issues which may present themselves, as these individuals are especially vulnerable to being disempowered, however this does not imply that the interview is not the correct method for investigation: "It is argued that the process

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of empowerment can and should begin simply by providing individuals with a voice and the right to express their own perspectives" (p. 1390). I remained reflexively engaged with the interviewees and made dynamic adjustments to the questions in order to encourage accurate understanding (Flynn, 1986; Hollomotz, 2011; Lloyd, Gatherer, & Kalsy, 2006).

Data Analysis

The phenomenological nature of this inquiry suggested data analysis which seeks to understand how the client makes sense of the experience of songwriting (Hiller, 2016). This data analysis process and conceptual approach was inspired by a similar study done using lyric analysis and interviews (Baker, 2018c). The interpretive phenomenological analysis (IPA) method "is concerned with an individual's personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself" (Smith & Osborn, 2008, p. 53). IPA has been used as an analytical paradigm for understanding the subjective experience for adults with learning disabilities in group analytic therapy (MacDonald, Sinason, & Hollins, 2003). It has also been used to explore the facets of the relationship with music of three individuals with Williams Syndrome (Erasmus & Van Der Merwe, 2017) and participants in an improvisational music therapy program for cancer patients (Pothoulaki, Macdonald, & Flowers, 2012).

The transcribed lyrics and interviews were encoded and grouped into themes which emerged naturally from the data by an intuitive process informed by the literature as opposed to being encoded according to a pre-existing framework or strictly by occurrence of words or phrases. After thematic areas had been established and linked through multiple iterations they were compared to the literature to provide additional context. I took note of the client's affect, level of engagement, and energy level during the songwriting session.

Songwriting Sessions

Emma. Emma's songwriting session proceeded according to the research protocol. After a brief check-in, Emma responded to open-ended questions and chose to write a song about her love for country music. I accompanied on guitar as Emma improvised lyrics about listening to country music on the radio and watching country music concerts on television. The song was rehearsed with several iterations that resulted in a loosely adhered to form that allowed Emma to improvise the material in the verses and then return to a simple repetitive statement: "I enjoy that very much, it's something that I enjoy" (see Appendix C).

The songwriting portion of this session lasted approximately 45 minutes and culminated in a recording of the song. The interview with Emma occurred directly after the session. Throughout the songwriting and interview Emma presented with an engaged and positive affect.

Anne. Anne's session also proceeded according to the research protocol. Anne chose write her song about an upcoming transition in the program, as it will soon be moving to a new building. This had been a much discussed topic within the program, and Anne had engaged with the subject in groups that I have facilitated. Anne had seen other music therapy clients write songs about this upcoming move and responded to the suggestion of this topic with enthusiasm.

Anne's session was the shortest of the three. The song itself was written in about 30 minutes and was composed by setting Anne's associations with the upcoming to a simple melody. The melody was spontaneously sung by Anne. I repeated this melody and set it to a simple chord progression chosen to reflect Anne's affect and energy level. The simple and

repetitive lyrics of the allowed Anne to explore her anticipated experience of the impending move (see Appendix D).

Abdoul. There were difficulties in scheduling the session with Abdoul, as he was absent from the program for two weeks prior to the session. The session took place on Abdoul's birthday, a fact that I was unaware of until after the song had been completed. During the songwriting and interview portion of the session Abdoul presented as being tired, yawning, and sitting forward with his eyes half closed. After the songwriting portion of the session a break of several hours was taken before the interview portion could be completed so that Abdoul could have lunch and rest. During the verbal interview Abdoul paused several times to take out his phone and play a beat, improvising over it.

The songwriting session deviated from the research protocol in that Abdoul preferred to work with a prerecorded beat that he found online and compose lyrics in the hip hop idiom. The beat was prepared on the computer using GarageBand, and Abdoul improvised lyrics three times over the beat. The first improvisation was spontaneous and on the topic of money. At my prompting the second improvisation began with written lyrics, statements that Abdoul made on the topic of helping others. Reading the written lyrics seemed to impede Abdoul's ability to improvise comfortably with the beat so Abdoul improvised over the beat a third time. This version of the song was similar in theme to the first one, which seemed to imply that it was a more authentic expression of Abdoul's artistic intent than the second improvisation which was heavily influenced by my presence. The final version of the song was comprised of the third improvisation with several short sections of the first improvisation spliced in (see Appendix E). **Data Analysis**

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Three verbal interviews were conducted with study participants on the topic of the experience of songwriting. Two of the interviews (Emma and Anne) were conducted directly after the songwriting was completed while the third (Abdoul) was conducted after a break for lunch. The content of the interviews was analyzed according to the procedures developed by Smith, Flowers, and Larkin (2009). After the interviews were conducted they were transcribed verbatim. The verbatim transcriptions were then analyzed line by line to determine the possible significance of the statements being made. The line by line analysis was condensed into themes. These themes were identified intuitively by the researcher and then further developed as similarities between themes were identified within individual interviews (Appendix F). These themes were then compared and contrasted between interviews.

Results

One theme was identified as being present in the discussions with all three participants: All three participants reported that they associated the songwriting experience with positive emotions and enjoyed it. In addition to this theme there was a trend among the three participants to experience difficulty expressing insight. Emma and Abdoul spoke about their difficulty directly. Abdoul referred to talking about his creative process as "hard work" and paused frequently to "find the words." When I asked Emma to explore what she meant by the word good she replied, "I don't know how else to say it." Anne demonstrated a lack of insight by returning to several repetitive phrases, "It's good," and "I like it."

There were several themes which emerged in two of the interviews:

1. Two participants saw songwriting as contributing to an improvement in their esteem within their communities.

- Two participants connected songwriting with feelings of altruism and helping others.
- 3. Two participants reflected on the novelty of the songwriting experience.

There were additional themes which occurred only in one interview which reflected concerns or impressions that were specific to the individual's personal context.

Theme 1: Songwriting Was a Positive Experience.

All three of the participants reported that songwriting was a positive experience. Both Emma and Anne used the word "good" repeatedly to describe their experience. Emma stated, "If it didn't feel good I wouldn't be sitting here." Anne repeated the phrase, "The song is good, and the song is nice," numerous times. Neither were able to expand on their definition of the word "good," but this word was used repeatedly and seemed to me to be an authentic expression based on their overall affect and body language. It is always possible for participants to simply be agreeable (Lloyd, Gatherer & Kalsy, 2006), but this did not seem to be the case in either interview.

Abdoul had a more complex presentation. During the songwriting portion of the experience Abdoul was engaged and enthusiastic. As we approached the end of the songwriting session Abdoul began to show signs of feeling tired, yawning and leaning forward in his chair. When the songwriting session concluded we took a break so that he could eat lunch. The interview commenced about two hours later. During the interview he repeatedly stated that the songwriting experience was positive, saying that rapping "makes me feel good," and, "It makes me express myself," even though he presented as being tired. When I asked him if he was tired or if he wanted to stop he indicated that he wanted to continue but felt "sleepy."

Theme 2: Esteem in the Community

Emma and Anne both saw the finished song as having utility to improve their esteem in their community. Emma fantasized about bringing the song to a radio station and getting it played on the air: "Now I don't know if you took it to the radio station and they would hear it, for themselves, and hear what I.. how I sing or something, and record it, I don't know." As the interview progressed this shifted to a desire to present the song to staff: "Maybe we should let the staff hear it."

Anne stated repeatedly that she wanted to perform her song for others so that they could hear it: "They will hear this song, and they will like it." She seemed eager to share the result of her work with the members of her community.

Theme 3: Altruism

The lyrics of Abdoul's song described his relationship with money, and considering the lyrics of his song lead him to think of using money to help others in an altruistic sense, "It's about if I had opportunity and I had a lot of money I would help a lot of people that need help." Anne also saw a chance to help others by giving them her song. Anne's song addressed an upcoming move to a new building, a major change which affects all of her peers in the day center. Anne saw the possibility that others could use her song to help them with the transition as well: "If they like this, they could use it. I think that's a good idea."

Theme 4: Novelty

Both Anne and Emma reflected on the novelty of the songwriting experience. Emma couched her aspirations of having her song played on the radio with the phrase, "Maybe, this is

all new to me." Anne responded to the question of whether she had written a song before by answering, "No, but it's good, the song is good."

Individual Themes

Songwriting also was a way for participants to address individual concerns that were a part of their unique context.

Emma. Emma made comments in her interview which indicated that songwriting was a way for her to affirm her own identity: "I don't know about anyone else, but I know myself," and, "Since I love country music the way I do; you know it, I know it." She also expressed pride in her ability to create, "I sure have a talent for this."

Abdoul. Abdoul was the most discursive of the three participants and our interview touched on a number of unique themes. Abdoul explored morality and the concept of *dunya* - an Arabic word that describes material pursuits which are not spiritually fulfilling, or as Abdoul defined it, "Ok, that's, let's say, a lot of people chasing money, womens, cars, that's what it means in Arabic. In Arabic we say dunya." He contemplated whether music making was right or wrong: "You singing good music, and good music without curses, without shooting, I think it's good for that."

Abdoul also connected songwriting to a sense of mastery and progression, "The more I practice the better I get." Abdoul stated that his goal in music was to move forward and "if I don't keep practicing I won't get better."

Late in the interview, after telling me that he emigrated from Senegal when he was young, Abdoul found an African instrumental on his phone and began to improvise lyrics which reflected a low sense of self esteem. He repeated the phrase, "You wasting a lot of time talking to me, I'm not worth it." It was unclear from our discussion if Abdoul was simply expressing his tiredness during the interview or something deeper. When I asked him what he meant by that, Abdoul changed the subject and declined to go in depth into his meaning.

Discussion

The primary conclusion of this study is that all participants experienced songwriting as an enjoyable experience. This aligns with the primary conclusion of a similar study conducted with adults with dementia (Baker, 2018c). No participants were able to put into words what it was about the experience they found enjoyable, or make insightful comments about what enjoyment of the songwriting process meant for them. Participants tended to see songwriting as a results-oriented process and considered the utility of the finished song.

Participants also connected songwriting to their community, either as a way to improve their own standing or as a way to help others altruistically. This supports the conception of music as a way of broadcasting elements of personal identity to others (North & Hargreaves, 1999). The study participants saw the product of their songwriting experience as benefiting them in their social spheres.

Participants had unique associations with songwriting. Abdoul in particular connected rapping to multiple parts of his identity, his religion, morality, community, and sense of self. This is aligned with Denora's (2000) presentation of the role of music as a unifying construct in the identity which weaves together disparate parts of person's lived experience.

Limitations and Suggestions for Future Research

This study was limited in scope to only three participants. Working with a larger cross section of the population would allow for richer interview data and may lead to the identification

of additional themes as subgroups. Future studies should focus on capturing the impressions of a larger group of writers.

Limited ability to express insight proved to be a common challenge across the three interviews and made it difficult to draw conclusions from the research data. As a result, as researcher, I felt pressed to take a more active role by reflecting words and phrases used by the participants and in some cases changing the subject of the conversation to approach the topic of songwriting from different angles. This approach resulted in opportunities to uncover additional material but it also in some cases was applied too aggressively and resulted in the suggestion of ideas like "flow" which were not a part of the participant's vocabulary before the interview started. These introduced concepts were left out of the final data analysis.

In my opinion this study supports the use of songwriting in the music therapy context. Songwriting was generally perceived as an enjoyable activity, which encourages engagement with the therapy process. Songwriting is also a way for individuals to increase their perceived standing in their communities.

Conclusion

This study found that three adults with intellectual disabilities experience songwriting as a positive and enjoyable activity. All three study participants had difficulty expressing insightful observations about their songwriting processes. Participants tended to see the product of their songwriting effort as a tool for improving their esteem in the eyes of their communities. Study participants also used songwriting to express unique facets of their identities.

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Appendix A

Consent form



Music Therapy Department 1000 Hempstead Ave, **Rockville Centre, NY 11570** 516.323.3320

Title of Study: The Experience of Songwriting in Music Therapy for an Adult with Intellectual Disability

This study is being conducted by:

Jasper Lewis, MT-BC (Primary Researcher): 201-638-5487 jlewis@lions.molloy.edu

Heather Wagner, PhD, MT-BC (Faculty Advisor): 860-550-4884 hwagner@molloy.edu

Key Information about this study:

This consent form is designed to inform you about the study you are being asked to participate in. Here you will find a brief summary about the study; however you can find more detailed information later on in the form.

The purpose of our study is to gain an understanding of the subjective experience of songwriting for adults with intellectual disability. Adults with intellectual disability who are able to both participate in and talk about their experience in songwriting are invited to participate in this study by writing an original song in collaboration with the primary researcher and then answering questions in a semi-structured interview.

This study will take no more than 65 minutes to complete for each participant. This includes the typical 45-minute music therapy session and no more than 20 minutes for an interview.

Study participants will receive a recording of their original song as well as a print out of the lyrics for the song. No other compensation is provided in exchange for participation in this study.

The interview data and recordings will be stored on the primary researchers personal computer and will not be shared with anyone who is not directly involved in this study. All study participants will have their names and identifying details changed in the written report to protect their confidentiality. Identifying details such as the location of the study will also be masked in the final report. There is a risk that information from this study may be used to identify study participants.

Why am I being asked to take part in this study?

Available research on music therapy and adults with intellectual disability lacks the unique perspectives of the adults themselves. By participating in this research study you are helping to create a better understanding of the experience of songwriting, and contributing to the evolution of songwriting as a therapeutic tool.

What will I be asked to do?

The research portion of this study will have two parts:

- 1. Participants will collaborate with the primary researcher to write an original song. A performance of the song will be recorded and the lyrics of the song will be printed and given to the study participant.
- 2. The researcher will engage the participant in a brief (10-20 minute) interview about the experience of songwriting.

Where is the study going to take place, and how long will it take?

The songwriting and interview portions of this study will take place at the AHRC Weingold facility. Both combined activities will take no more than 65 minutes.

What are the risks and discomforts?

It is not possible to identify all potential risks in research; however, reasonable safeguards have been taken to minimize known risks. If new findings develop during the course of the research which may change your willingness to participate, we will tell you about these findings.

Every effort will be made to maintain the confidentiality of study participants. However the risk remains that participants may be identified by material provided in the course of this study.

Study data will be password protected and securely stored at all times. However there is a risk that the research data may be compromised or stolen during the course of the study, which may result in the identification of study participants.

The act of songwriting may bring to the surface emotional material which causes discomfort. Participants may become uncomfortable or distressed during the songwriting or interview portion of the study. Participants may choose to withdraw from the study at any point.

What are the expected benefits of this research?

Individual Benefits: The participant will compose an original song and be provided with a recorded copy of that song as well as printed song lyrics.

Do I have to take part in this study?

Your participation in this research is your choice. If you decide to participate in the study, you may change your mind and stop participating at any time without penalty or loss of benefits to which you are already entitled.

What are the alternatives to being in this study?

Participation in this study is not required in order to benefit from music therapy services or participate in any music activities at the day center. Instead of being in this research, you may choose not to participate.

Who will have access to my information?

Access to the data (sound recordings and printed materials) in this study will only be granted to the primary researcher and faculty advisor.

To ensure that this research activity is being conducted properly, Molloy College's Institutional Review Board (IRB), whose members are responsible for the protection of human subjects' rights for all Molloy-approved research protocols, have the right to review study records, but confidentiality will be maintained as allowed by law.

Can my participation in the study end early?

Yes. You may choose to withdraw from this research project at any time without penalty.

Will I receive any compensation for participating in the study?

You will receive a recording of the original song as well as a printed copy of the lyrics of the song.

What happens if I am injured because of the study?

If you are injured during the course of this study, you should seek immediate medical treatment from your primary provider or at an emergency care facility. Also, contact Jasper Lewis at phone number 201-638-5487 or JLewis@lions.molloy.edu. Payment for any medical treatment must be provided by you and your third party payer (such as health insurance or Medicaid). This does not mean that you are releasing or waiving any legal right you might have against the researcher or Molloy College as a results of you participation in this research.

What if I have questions?

Before you decide whether you'd like to participate in this study, please ask any questions that come to mind now. Later, if you have questions about the study, you can contact Jasper Lewis at 201-638-5487 or jasperlewis@gmail.com, or Heather Wagner at 860-550-4884 or hwagner@molloy.edu.

What are my rights as a research participant?

You have rights as a research participant. All research with human participants is reviewed by a committee called the *Institutional Review Board (IRB)* which works to protect your rights and welfare.

If you have questions about your rights, an unresolved question, a concern or complaint about this research you may contact the IRB contact the Molloy IRB office at <u>irb@molloy.edu</u> or call 516 323 3000.

Documentation of Informed Consent*:

You are freely making a decision whether to be in this research study. Signing this form means that

- 1. you have read and understood this consent form
- 2. you have had your questions answered, and
- 3. after sufficient time to make your choice, you have decided to be in the study.

You will be given a copy of this consent form to keep.

Your signature

Your printed name

You consent to having audio from the songwriting and interview portions of the research project recorded.

Your signature

Your printed name

Date

Date

Date

Date

Signature of researcher explaining study	Date
Printed name of researcher explaining study	Date

Appendix B

Interview Questions

I'm going to ask you some questions about the song we wrote. Is that ok?

What is the name of the song?

What is the song about?

What was writing a song like?

Have you written a song before?

Is there anything you'd like to change about the song?

How does the song make you feel?

Is there anything else you would like to say?

Appendix C

Country Music

-Emma & Jasper

I like country music

I like it very much

I watch on TV a lot

And I see all the stars

I see them get awards

For their best performance

I enjoy that very much

It's something I enjoy

Listen to it a lot

I learn all the songs

Just by listening to the music

I sing along

That's how I know the songs really good

And I really enjoy that

A lot

I really enjoy it a lot

Dolly parton and Conway Twitty

And Loretta Lynn, I like those three

Those are my favorite ones

That I listen to

I really enjoy that very much

It's something that I enjoy

I enjoy that very much

Seeing it on TV

Appendix D

Goodbye workshop and hello the new place

-Anne & Jasper

Goodbye workshop, goodbye workshop, goodbye workshop now

We gonna miss you, we gonna miss you, we gonna miss you now

We're gonna have a party, we're gonna have a party, we're gonna have a party now

Hello the new place, hello the new place, hello the new place now

Appendix E

Money

-Abdoul & Jasper

Yeah.. ok, uh-huh..

Talk about me, talk about me, money

talk about me, talk about me, money

Don't talk about it

Because I ain't talking

I ain't talking

If it's not about money you ain't got nothing for me

If it's not about money you ain't got nothing for me

It's always coming and go

It's always coming and go

But when you see me in the hood

Or if you see me in the hood

You know what i'm about

You know what I'm about

I'm about money though

I'm about money though

These girls looking up on me

They looking up on me

Those girls don't got nothing for me

You ain't got nothing for me

Take a seat please,

Oh please, take a seat

These boys hating on me

These boys hating on me

Everybody see me down

Everybody see me down

They see me who I am

If you see me who I am

That's why I'm in the studio every day

Trying to put the money

He's always mad at me

He's always mad at me

For something that I'm doing good

For something that I'm doing good

It ain't that easy homie

It ain't that easy homie

For you to come and take away from me

For you to come and take away from me

Homie you might think you easy

You might think you easy

But it's hard homie

As a rapper it's hard for you to sing out here Homie it's hard for you As a rapper to rap Because it ain't that easy If I got it homie Imma give those who got it Imma give those who got it If you see me in the hood (unintelligible) If you see me in the hood I got the money Times coming and go Time coming and go You just call on your boys You just call on your boys But friends don't last forever Friends don't last forever You might see me here

Appendix F

Major Themes

Abdoul interview

Concept	Theme	Quote
Positive Experience	Positive experience	"Makes me feel good."
		"It makes me express myself and I feel good about it."
	Intuition	"It say, 'Come watch me, come watch me.'"
Insight	Difficulty expressing insight	"I just got to think what I'm going to say."
Morality	Dunya	"Dunya. You wasting time, you wasting a lot of time. Dunya coming and go."
		Ok, that's, let's say, a lot of people chasing money, women's, cars, that's what it means in Arabic. In Arabic we say Dunya.
	Morality	"you singing good music, and good music without curses, without shooting, I think it's good for that."
Self Image	Low self-esteem	"You wasting a lot of time talking to me, I'm not worth it."
Mastery	Mastery	"The more I practice the better I get."
	Aspirations	"My goal is to keep moving forward."

	"It's about if I had opportunity and I had a lot of money I would help a lot of people that need help."
	neeu neip.

Concept	Theme	Quote
Positive Experience	Positive experience	"The song is good, and song is nice."
	Sense of achievement	"I like that, I played it."
Community esteem	The experience of others	"Fun is when people hear this song. They'll like that song."
Altruism	Helping others cope	"If they like this, they could use it. I think that's a good idea."
Novel Experience	Novel Experience	"J: Have you ever written a song before?" Anne: "No, no, but it's good. The song is good."

Anne Interview

Concept	Theme	Quote
Positive Experience	Positive experience	"It felt good." "If I didn't enjoy it I wouldn't be sitting here."
Pride	Sense of pride	"The other day I had taken a piece of scrap paper and I wrote it down on a piece of scrap paper, by myself. Just to see how it would, um, come out." "I sure have a talent for this."
Identity affirmation	Identity affirmation	"Since I love country music the way I do. You know it, I know it." "I don't know about other people, but I know about myself."
Community esteem	The experience of others	"Now I don't know if you took it to the radio station and they would hear it, for themselves, and hear what I how I sing or something, and record it, I don't know." "Maybe we should let the staff hear it."
Novel experience	Novel experience	"This is all entirely new."
Insight	Difficulty with insight	"it came from I don't know how to The words just came to me, and we wrote it down." "I don't know how else to put it."

Emma Interview