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PATIENT AND THERAPIST PERCEPTIONS OF RESPIRATORY FUNCTIONING DUE TO SPINAL CORD INJURY: IMPLICATIONS FOR MUSIC THERAPISTS

A'Marie Dotson
University of Kentucky, amarie.dotson1@gmail.com

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A'Marie Dotson, Student

Dr. Olivia Yinger, Major Professor

Dr. Lance Brunner, Director of Graduate Studies

PATIENT AND THERAPIST PERCEPTIONS OF RESPIRATORY FUNCTIONING DUE TO SPINAL CORD INJURY: IMPLICATIONS FOR MUSIC THERAPISTS

THESIS

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Music in the College of Fine Arts at the University of Kentucky

By

A’Marie Claire Dotson

Lexington, Kentucky

Co- Directors: Dr. Olivia Yinger, Associate Professor of Music Therapy

and Dr. Martina Vasil, Associate Professor of Music Education

Lexington, Kentucky

2022

ABSTRACT OF THESIS

PATIENT AND THERAPIST PERCEPTIONS OF RESPIRATORY FUNCTIONING DUE TO SPINAL CORD INJURY: IMPLICATIONS FOR MUSIC THERAPISTS

Decreased respiratory functioning is a common symptom of spinal cord injury (SCI) and can impact individuals' personal, professional, and social lives. In spite of this, researchers have not explored the use of music in the lives of individuals with SCIs or music's role in their healthcare professionals' treatment plans to improve respiratory functioning. The purpose of this qualitative study was to better understand how decreased respiratory functioning affects individuals with SCIs and healthcare professionals through a multiple case study design. Participants were two individuals with SCIs and three healthcare professionals (physical therapist, recreational therapist, and music therapist) who worked with individuals with SCIs. Findings showed that decreased respiratory functioning affected many aspects of life for participants living with SCIs and multiple factors of treatment goals for healthcare professionals. Anxiety, stress, sexual functioning, and trouble sleeping were among the factors affecting participants with SCIs, while decreased treatment times and lightheadedness/loss of consciousness were included in considerations for healthcare professionals. Most participants only used music for entertainment, but some noted the value of singing with preferred music and music for anxiety reduction. Individuals with SCIs may benefit from music therapy interventions to decrease anxiety and improve their quality of life.

KEYWORDS: Decreased Respiratory Functioning, Spinal Cord Injuries, Music Therapy, Physical Therapy, Recreational Therapy

_______A'Marie Claire Dotson_____

________________3/6/2022____

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By

A’Marie Claire Dotson

Dr. Olivia Yinger
Co-Director of Thesis

Dr. Martina Vasil
Co-Director of Thesis

Dr. Lance Brunner
Director of Graduate
Studies

Date: 03/06/2022

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CHAPTER ONE

INTRODUCTION

A spinal cord injury (SCI) is a challenging diagnosis that can affect multiple areas of an individual's physical, mental, emotional, and social health. SCIs are defined as "damage to any part of the spinal cord or nerves at the end of the spinal canal (or cauda equina)" (Mayo Clinic, 2021, para. 1). While each SCI presents itself differently, individuals with SCIs may experience decreased respiratory functioning, partial or full paralysis, inability to move appendages, decreased or nonexistent sensation, pain due to damage in the nerve fibers of the spinal cord, decreased motor control, bladder/bowel incontinence, sexual dysfunction, and other mental and emotional symptoms (Mayo Clinic, 2021). Injuries to the spinal cord can be acquired either traumatically, such as an accidental blow to the spinal column, or non-traumatically from prior medical conditions, such as spina bifida or spinal tumors/cysts. These injuries can also be classified as either complete or incomplete. An individual with a complete SCI has little to no residual sensation at or below the affected area, whereas someone with an incomplete injury may have some feeling or sensation remaining at or below the affected vertebrae (Mayo Clinic, 2021).

Each bone in the spine, or vertebra, is identified as being part of one of four different areas in the spine: cervical (C), thoracic (T), lumbar (L), or sacral (S). These vertebrae are then numbered based on their locations in the spine (e.g., the highest vertebra in the cervical area would be “C1”) (see Appendix A). Although any area of the spine could be affected by an SCI, the higher on the spine where the injury occurs, the greater the loss of sensation and movement will be. According to the National Spinal Cord Injury Statistical Center (NSCISC), over half of all spinal cord injuries are in the cervical area of the spine (C1–C8), another third are within the thoracic area (T1–T12), and the remaining injuries fall in either the lumbar (L1–L5) or sacral (S1–S5) segments of the spine (NSCISC, 2020). Spinal cord injuries can also be classified based on the areas of the body where functioning is affected by the injury. Paraplegia refers to a loss of function in part or all of the lower half of an individual’s body; many individuals with paraplegia still maintain most or full use of their upper appendages. Quadriplegia, or tetraplegia, affects the function and sensation in an individual’s arms, hands, torso, legs, and pelvic organs (Mayo Clinic, 2021). In 2020, 78% of SCIs occurred in men, and incomplete tetraplegia was the most common neurological category for an SCI to fall into (NSCISC, 2020). Since 2010, vehicular-related accidents are the leading cause of all spinal cord injuries at 39%, followed by falls (32%), acts of violence (14%), sports-related injuries (8%), medical issues (4%), and other various causes (3%) (NSCISC, 2020).

Almost every individual with an injury at T12 or higher experiences some form of decreased respiratory functioning due to the partial or complete paralysis of the diaphragm, which helps control the inspiratory and expiratory breathing movements of the lungs (WA Health, 2016). Whereas some individuals can breathe independently, others rely on a ventilator. Because of diaphragm paralysis, lung volume can be severely compromised in people with SCIs at T12 or higher, causing not only potential medical problems, but also impairments in personal, social, and professional aspects of an individual’s life. Individuals with SCIs at higher levels may lose functioning of all appendages, which may cause them to use a sip and puff wheelchair that uses an individual’s breath to control movement. Respiratory complications can occur for several reasons, including a weakened ability to cough; food particles becoming trapped in the lungs; paralysis of the diaphragm and other secondary muscles; infections from open wounds, such as bedsores, affecting already compromised immune and respiratory systems; and increased collections of fluids in the lungs for those who are bedridden (Tollefsen & Fondenes, 2012; University of Washington, 2007). Pneumonia is among the leading causes of death in individuals with quadriplegia (Brommer et al., 2016; NSCISC, 2020; Sezer et al., 2015; Tollefsen & Fondenes, 2012), underscoring just how serious respiratory complications can be for people with SCIs.

Many diverse types of rehabilitation techniques are being used to help people with SCIs combat symptoms, regain functioning, and improve quality of life (QoL). Numerous therapies can be started with individuals as soon as they are admitted to an inpatient hospital, even before they are medically stable, and most can and should be continued outside of the hospital setting. Healthcare professionals assess both short- and long-term functional goals using a measurement tool designed by the American Spinal Injury Association (ASIA). This tool, referred to as the *ASIA Impairment Scale*, is used by therapists to classify an individual’s SCI and determine functional goals based on the individual’s sensory and motor functioning (Nas et al., 2015). There are five grades on this scale ranging from Grade A to Grade E; Grade A states that the injury is complete and no functioning is left in the affected area, while a Grade E designation implies that the functioning is completely unaffected (American Spinal Cord Association, 2019). These grades help therapists and team members decide functional goals to realistically address during the inpatient stay to promote reintegration into society. Therapists and other team members must take into consideration an individual’s medical and social status and their personalized rehabilitation plan. Certified professionals in a variety of specialties come together to form an interdisciplinary team to best meet the individual’s unique needs.

Theoretical frameworks may also help improve the understanding of some of the challenges that individuals with SCIs may face as well as their families and healthcare professionals that work with them. For example, the biopsychosocial framework accounts for an individual’s biological, psychological, and social factors when explaining their health overall (Engel, 1980). The International Classification of Functioning (ICF) expounded on the biopsychosocial framework in 2001, adding environmental and personal factors as potential constituents for an individual’s overall wellness (Centers for Disease Control, 2021a). Social Determinants of Health (SDoH) include the effects of social factors that determine how individuals grow, live, work, and age. It includes five domains of social determinants that contribute to health (economic stability, education access and quality, healthcare access and quality, neighborhood and built environment, and social and community context), which can provide a clearer picture of how many different components must interweave for individuals with disabilities to seamlessly integrate and be successful in society. Because social environments are not always set up to accommodate those with disabilities, many individuals often start out at a disadvantage through no fault of their own. Hammel et al. (2015) further used the SDoH domains to develop a conceptual framework highlighting eight environmental barriers that can interfere with participation for individuals with disabilities. These frameworks help showcase the multidimensional and multi-faceted complexities of disability and the number of factors that must be considered for total inclusion and can provide avenues for effective interventions and advocacy for people with SCIs.

Music therapy effectively addresses need areas in rehabilitation settings. Researchers have found that music therapy was effective for reaching target goals such as gait regulation (Baram & Lenger, 2012; Benoit et al., 2014; de Bruin et al., 2010), speech clarity (Kotz & Gunter, 2015; Yamaguchi et al., 2012), balance and mobility (Bukowska et al., 2015; de Dreu et al., 2012), and cognition (Castro et al., 2015; Moreno, 2009; Särkämö et al., 2013). Scans of the brain while engaging with music showed that multiple areas of the brain are engaged, new neural connections are developed, and acquisition of new skills is obtained through the brain's plasticity (Habibi et al., 2018; Naeser & Helm-Estabrooks, 1985; Pascual-Leone, 2001; Raglio et al., 2016). This can also allow for potential reacquisition of skills using music; scans of the brain showed that music and language still garner information from the same high-level syntactic integration systems that are found in the subsection of the brain known as *Broca's area,* although language is primary processed in the brain's left hemisphere and music can be interpreted in areas of both the left and right hemispheres (Kunert et al., 2015). This can be beneficial for regaining language skills lost due to traumatic injuries, such as traumatic brain injuries, strokes, and spinal cord injuries.

While there is a plethora of literature validating the use of music therapy interventions for certain populations, the research for music therapy and spinal cord injuries is severely lacking. In 2010, Dr. Michael Thaut, one of the pioneers of *neurologic music therapy (NMT)*, which is a specialized approach of practicing music therapy, stated that NMT research with spinal cord injuries “lacks rigorous study so far” (Thaut & McIntosh, 2010, p. 8) and the music therapy research on SCIs over the past decade has been limited. The little research that exists suggests that music therapy interventions have promise in addressing goals for people with SCIs related to gait patterns, respiratory functioning, and vocal irregularities as well as an increased incentive to participate in therapeutic exercises (de l’Etoile, 2008; Tamplin, 2012, 2014). Although Tamplin’s (2012, 2014) research focused on the impact of music therapy interventions on respiratory functioning and speech clarity in individuals with SCIs, no research could be found on the effects of decreased respiratory functioning on an individual’s physical, mental, emotional, and social well-being. There also appears to be no research showing how decreased respiratory functioning affects the treatment interventions for the helping professionals who work with people with SCIs. Additionally, no studies could be found that show how both individuals with SCIs and helping professionals use music in their personal and professional lives, respectively. Because many music therapists address goals that encompass the whole person, often situated within a biopsychosocial framework, it is important to fill this gap in the research so that both individuals with

SCIs as well as their helping professionals can harness the power of music to help individuals with SCIS both regain respiratory functioning and have their emotional needs supported.

Operational Definitions

Complete spinal cord injuries are defined as the loss of all feeling and movement below the site of the SCI (Mayo Clinic, 2021).

Diaphragm is defined as a thin skeletal muscle at the base of the chest that contracts with inhalation, creating a “vacuum” effect that pulls air from the outside into the lungs (Mayo Clinic, 2021).

Dysarthria is defined as a speech disorder caused by muscle weakness that can make speaking difficult. Speech can be slurred, too soft, too slow, too fast, or sound choppy (Cleveland Clinic, 2020).

Dysphagia is defined as difficulty swallowing (Cleveland Clinic, 2020).

Fine motor skills are defined as small movements that use the small muscles in the fingers, toes, wrists, lips, and tongue. These are more precise than *gross motor skills* and require more exact movements (e.g., pinching, buttoning buttons, picking up coins) (Gonzalez et al., 2019).

Gross motor skills are defined as bigger movements that use the large muscles in the arms, legs, torso, and feet (e.g., throwing, sitting, standing) (Gonzalez et al., 2019).

International Classification of Functioning (ICF) is defined as “a framework for describing and organizing information on functioning and disability and provides a standard language and a conceptual basis for the definition and measurement of health and disability” (Centers for Disease Control, 2021b, para. 1). The ICF lists three main categories, or “core sets,” that all aspects of an individual’s life fall into: body functions/structures, activities, and participation. https://www.who.int/classifications/icf/icfbeginnersguide.pdf

Incomplete spinal cord injuries are defined as individuals with SCIs having partial sensation and feeling below the site of the SCI (Mayo Clinic, 2021).

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 (MT-BC) who has completed an approved music therapy program (AMTA, 2021a).

Music therapists (MT-BCs) are defined as credentialed healthcare professionals that assess physical, emotional, mental, social, and academic goals using music-based interventions. Music therapists must complete an approved bachelors, equivalency, or equivalency master's college music therapy curriculum (including an internship), then pass a national examination given by the Certification Board for Music Therapists (AMTA, 2021b).

Neurologic music therapy (NMT) is defined as "an evidence-based treatment model that uses standardized, research-based techniques to treat the brain using music and rhythm" (Neurologic Music Therapy Services of Arizona, 2021, para. 1). This is an additional certification and way of practice for music therapists who complete the NMT training.

Paraplegia is defined as a spinal cord injury to the lower section(s) of the spine where an individual's loss of function is in part or all of the lower half of their body; partial or complete use of upper appendages remains (Mayo Clinic, 2021).

Quadriplegia, also known as *tetraplegia*, is defined as a spinal cord injury to the upper section(s) of the spine that affects the function and sensation in an individual's arms, hands, torso, legs, and pelvic organs; limited or no use of upper appendages remains (Mayo Clinic, 2021).

Quality of life (QoL), also referred to as *health-related quality of life (HRQOL)* is defined as "a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning" (CDC, 2021a., para. 1).

Recreational therapy, also referred to as *therapeutic recreation,* is defined as "a systematic process that utilizes recreation and other activity-based interventions to address the assessed needs of individuals with illnesses and/or disabling conditions, as a means to psychological and physical health, recovery and well-being" (National Council for Therapeutic Recreation Certification, 2021, para. 1).

Recreational therapists (RTs or *CTRS)* are defined as nationally credentialed professionals who assess a wide variety of goals using recreation and other activity-based interventions. Recreational therapists complete a minimum of a bachelor's degree in recreational therapy or a related field, such as recreation and leisure studies with a concentration in therapeutic recreation, complete an internship of at least 560 hours, and pass a national certification exam (American Therapeutic Recreation Association, 2021).

Sip and puff wheelchairs are specialized wheelchairs that are controlled by an individual's inhalation and exhalation via mouthpiece to propel itself rather than by manual propulsion (Permobil Products, 2021).

Spinal cord injuries (SCIs) are defined as "damage to any part of the spinal cord or nerves at the end of the spinal canal (cauda equina) that often causes permanent changes in strength, sensation and other body functions below the site of the injury" (Mayo Clinic, 2021, para. 1).

Purpose

The purpose of this study was to a) examine how decreased respiratory functioning influences the lived experiences of individuals with SCIs as well as the professionals that help them, b) describe how people with spinal cord injuries use music in their daily lives, and c) explore ways healthcare professionals use music in their work with people who have spinal cord injuries. The research questions were:

1) How does decreased respiratory functioning influence the lives of individuals with spinal cord injuries?

2) How does decreased respiratory functioning in individuals with spinal cord injuries influence the treatment goals of helping professionals in different specialties?

3) How does decreased respiratory functioning in individuals with spinal cord injuries influence the interventions of helping professionals in different specialties?

4) How do individuals with SCIs use music in their daily lives?

5) How do professionals use music to improve therapeutic outcomes?

CHAPTER TWO

REVIEW OF LITERATURE

Research regarding music therapy and individuals with spinal cord injuries is limited. Therefore, this review begins with literature on four theoretical frameworks pertinent to individuals with SCIs: the biopsychosocial framework, the International Classification of Functioning (ICF), the Social Determinants of Health (SDoH), and a disability framework developed by Dr. Joy Hammel and colleagues in 2015. Studies that examined how a variety of barriers affect individuals with SCIs and how professionals in therapeutic helping fields (physical therapists, occupational therapists, speech-language pathologists, recreational therapists, and music therapists, respectively) target the unique needs of individuals with SCIs are also discussed.

Theoretical Frameworks

An extensive review of the literature revealed that four frameworks or classification systems were most relevant to respiratory functioning and individuals with SCIs: the biopsychosocial framework, the International Classification of Functioning (ICF), Social Determinants of Health (SDoH), and Hammel and colleagues' (2015) disability framework.

The biopsychosocial framework was developed in 1977 by George Engel, a doctor board-certified in both medicine and psychiatry, with influence from John Romano, a medical doctor, both from the University of Rochester. Proposed as "a blueprint for research, a framework for teaching, and a design for action in the real world of healthcare" (Engel, 1977, p. 129), the biopsychosocial framework includes biological, psychological, and social factors to help healthcare professionals determine the functional capability of their patients. Although other frameworks, such as the medical model, were prevalent in healthcare at the time Engel developed this framework and were often used to understand the biological components of an individual's disability, the biopsychosocial framework goes further to include psychological and social components. While not taking away importance from the biological factors, such as physical health, Engel (1977) stressed that psychological factors, such as mental health and coping skills, as well as social factors, like family dynamics, were key to understanding medical conditions. Looking at these factors allows healthcare professionals to determine functional capability and provide resources for the most accessible means of living more accurately. Engel further clarified how these ideas could be integrated into practice in 1980, giving a case study of the biopsychosocial model in use for a patient with a myocardial infarction; Engel also stated that the reason a medical patient was chosen rather than a psychiatric patient was to "emphasize the unity of medicine and to help define the place of psychiatrists in the education of physicians of the future" (1977, p. 535).

The biopsychosocial framework then became the foundation for the International Classification of Functioning (ICF), a framework for describing and organizing information on disability and functioning and a classification system for the foundation of measurement tools for various levels of functioning. The ICF was approved by the World Health Assembly in 2001 with a companion guide for youth and children in 2007. Unlike previous frameworks, the ICF accounts for environmental components of an individual's disability and how these components can impact individuals differently. Although personal factors are not currently classified as a factor in the ICF at this time and are not scored using the same codes as other factors, the framework does recognize their importance on the lives of individuals with disabilities.

Much like the biopsychosocial framework, the ICF shows that disability is both "multidimensional and interactive" (CDC, n.d., p. 2). The ICF uses the term *disability* as an umbrella term for impairments, activity limitations, and participation restrictions. The ICF includes *qualifiers,* which are codes used by healthcare professionals to "record the extent of functioning or disability in a domain/category, or the extent to which an environmental barrier is a facilitator or barrier" (CDC, 2021b., p. 4). Qualifiers range from 0–4 or 8–9. Zero means "no problem"; 4 means "complete problem"; and 8 and 9 mean "not specified" and "not applicable," respectively. The ICF also rates barriers, which can prohibit the normal functioning of an individual with a disability. Barriers are marked as .0 and act as a negative value on the overall score, while facilitators are marked as +0 and add a positive value to the overall score (CDC, 2021b, pg. 6). These ratings can be used to describe an individual's *performance* (what the individual does in their typical environment with or without assistance) and *capacity* (what an individual can so in a "standardized" environment). These constructs provide a way of measuring how the environment where assessment(s) have taken place can impact an individual's activities and participation while allowing a healthcare professional to gauge how environmental modifications may improve their overall functioning. The value of the ICF to healthcare professionals is that it provides a scientific basis for studying and sharing information about health across countries and other healthcare systems and a standard language and conceptual basis for both definitions and measurements of health and disability.

Social Determinants of Health (SDoH) is a place-based framework with five domains of social determinants: economic stability, education access and quality, healthcare access and quality, neighborhood and built environment, and social and community context (CDC, 2021a). It was created by Healthy People 2030, a commission established by the World Health Organization (WHO) in March of 2005. The five domains allow for more detailed descriptions of the health inequities that individuals in certain areas may face because of their location. For individuals to enhance their QoL, they need "safe and affordable housing, access to education, public safety, availability of healthy foods, local emergency/health services, and environments free of life-threatening toxins" (CDC, 2021a, para. 2). Poverty is highlighted as a factor on all levels (global, national, and local) that limits access to healthy food, safe environments, and quality education. These financial constraints may be of higher concern for individuals with disabilities due to a variety of factors, such as barriers to participating in the workforce, unforeseen circumstances causing issues in paying bills (e.g., medical bills, loss of income, previous financial fragility), difficulty planning ahead, difficulty managing financial products (e.g., credit/debit cards, student loans), and lack of financial knowledge (Goodman et al., 2017).

In 2015, Hammel et al. developed a conceptual framework to describe various environmental and social factors that influenced participation levels for individuals with disabilities. Hammel and colleagues organized various environmental factors into three levels (micro, mesa, and macro). Micro levels include personal or immediate interactions in an individual's environment, such as reliable personal transportation. Mesa levels encompass factors in an individual's neighborhood or community, such as ADA accessibility compliance for buildings in the city. Macro levels involve societal factors, such as an influence in societal, economic, and political issues. Social factors that negatively impact individuals with disabilities included financial troubles, systemic problems in healthcare, "disincentives" (i.e., going back to work if one made more money with Social Security), and job discrimination. Social factors that positively influence the lives of individuals with disabilities are familial/friend support; access to others with disabilities; and societal policies that increase resiliency, social opportunities, and social capital. Environmental and social factors often intersect, such as weather (e.g., rain and snow) as a natural environmental barrier intersecting with systems, services, and policy issues, like snow removal services and covered accessible bus stations.

Many individuals in Hammel et al.'s study also expressed their frustrations with their lack of knowledge of resources available to them, primarily via technology; many individuals felt that they were distanced from the online world, from discovering information on sexuality in the disabled community to making their voices heard on a societal level. With social media platforms continuing to gain traction in recent years, this can make the gap between able-bodied individuals and individuals with disabilities more pronounced. This can lead to feelings of distance from society, confusion about disabilities for those without a personal connection to someone who is disabled, and furthered isolation for individuals with disabilities. This could be characterized as both an environmental barrier as well as a social barrier; individuals could have limited or no access to a computer or may not know where to look for information, which may also be blocked by a fee to access. An individual’s social well-being may also be affected not being able to talk with others online and being supported by other individuals in similar situations.

These theoretical frameworks highlight the need for personalized care approaches for individuals with SCIs that encompass every aspect of their being, not just their medical diagnoses. Emotional, mental, and social needs play just as big of a role as their physical health and must be addressed with as much urgency as the healthcare profession addresses physical concerns. Factors such as safe housing, adequate transportation, and peer acceptance can seriously affect an individual's physical health as well as their overall quality of life.

Factors Impacting Quality of Life

Moving beyond theoretical frameworks, there has been some research on individuals with SCIs regarding the factors that may impact their overall quality of life. Respiratory functioning, quality healthcare accessibility and affordability, self-reported barriers, physical limitations, stress, environmental and social barriers, age, and respiratory functioning are only a few of the factors that can go into making a treatment process complex and can limit progress in recovery.

Respiratory Functioning

While an SCI has an ongoing effect on an individual in multiple domains, respiratory functioning remains one of the most consistent and problematic barriers for the individuals that live with them (Van Houtte et al. 2006). Respiratory complications, such as pneumonia, are also among the top reasons for rehospitalization in patients with SCIs (DeJong et al., 2013). Respiratory functions are regulated by respiratory rhythm generators in the medulla, located in the lower brainstem. These outputs are then translated as motor activities through premotor efferent networks in both the brainstem as well as the spinal cord (Ikeda et al., 2017).

The spinal column is made up of 33 vertebrae grouped into four regions: cervical (C), thoracic (T), lumbar (L), or sacral (S). These vertebrae are then numbered based on their locations in the spine (e.g., the highest vertebra in the cervical area would be “C1”) (see Appendix A). There are four muscle groups located along the spine: the diaphragm, accessory muscles, intercostals, and abdominals (WA Health, 2016). The diaphragm, located right under an individual’s rib cage, is the primary muscle involved during the process of inspiration. It allows for the expansion of both the length and diameter of the chest cavity, which in turn expands the lungs. This allows an individual to inhale, then promptly relaxes during exhalation. It is controlled in part by the phrenic nerve, which falls between C3 and C8, passing between the lungs and heart to reach the diaphragm.

Individuals with injuries to C3 and higher may require mechanical ventilation to breathe, as the loss of diaphragmatic control is partially or completely gone at that level of injury (WA Health, 2016).

The accessory muscles include the muscles in an individual's neck and shoulder girdle. This group can consist of the scalene muscles (located between C3–C8), the sternocleidomastoid (Cranial Nerve XI) and the pectorals (C5–T1). These muscles assist with expansion of the upper ribcage during the process of inspiration. The intercostals, located at T1 through T11, are two groups of smaller muscles located in between each of the ribs. While the external intercostals elevate the rib cage during inspiration, the internal intercostals assist with forced expiration, such as coughing and sneezing. Paralysis of these muscles can make these functions more difficult or impossible to do independently, forcing individuals with high injuries to rely on manual or mechanical cough assist, performed by either a caregiver or a specific "Respironics" machine, respectfully. Abdominal muscles, located at T6–T12, increase an individual's intra-abdominal pressure by their contractions. They are the primary muscles involved in forced expiratory operations, such as coughing and sneezing. They also assist in supporting an individual's abdominal contents and maintaining the optimal position of the diaphragm when the body is upright. This position makes breathing easier for SCI individuals when lying flat. The paralysis of any or all these muscles can lead to a weakened ability to cough and expel foreign particles that make their way into an individual's airway. This can then result in bacterial infections, such as pneumonia, which is the number one cause of mortality for individuals with SCIs (Brommer et al., 2016; NSCISC, 2020; Sezer et al., 2015; Tollefsen & Fondenes, 2012).

Decreased respiratory functioning can lead to many health problems in individuals with an SCI, including physical, psychological, and emotional complications. Sezer et al. (2015) and Raab et al. (2018) noted that respiratory complications are the most prominent cause of illness and mortality in both acute (i.e., soon after acquisition) and chronic (i.e., persisting for a long time) stages in individuals with SCIs. Results from a study by Postma et al. (2012) suggested that a decline in pulmonary function during the first year after inpatient rehabilitation can be attributed to lower inspiratory muscle strength as well as increased body mass and declined physical activity levels. Although Van Houtte et al. (2006) showed that individuals see respiratory therapy as a vital tool for functional recovery, a lack of motivation and limited or no access to trained professionals hindered an individual's progress both at the beginning of therapy and/or only a few months into beginning therapy.

Affordability and Accessibility in Healthcare

Healthcare cost and accessibility can influence the overall well-being of individuals with SCIs. Although access to quality healthcare options can ensure or improve an individual's quality of life (Kwan, 2013), it requires a multi-faceted approach that encompasses many aspects of care, both subjectively (e.g., perceived difficulty of obtaining healthcare) and logistically (e.g., distance from general practitioners) (Comber et al., 2011). Shinder (2019) discussed the discrepancies of accessibility and the barriers physicians faced in her study. In a group of 2,578 primary care physicians and specialists, results indicated that primary care offices were more accessible than specialists' offices. Less accessible or inaccessible spaces, lack of specialists' services, being unable to enter doctors' offices due to inaccessible facilities, and the lack of written guidelines on treating individuals with disabilities can negatively affect the well-being of these patients. Furthermore, 12 primary care physicians and specialists were interviewed regarding treating individuals with disabilities. More than half thought that costs were a barrier to healthcare accessibility and that hospital admission and readmission rates would decrease with improvements in healthcare accessibility.

Self-Reported Barriers

Self-reported barriers are also considered when planning treatment for individuals with SCIs. Some of these barriers were identified in a study by Silver et al. in 2012; a pilot study of 26 individuals with SCIs self-reported barriers within the first year of post-discharge from an inpatient rehabilitation hospital. These barriers included problems with mobility (i.e., transferring in and out of their wheelchairs), spasticity (abnormal muscle tightness), a lack of support when transitioning to a different living situation (e.g., acquiring caregivers for assistance with activities of daily living), inexperience with skills needed for maintaining a wheelchair, and accessible transportation. Factors such as the lack of environmental and home assistance as well as insurance barriers, lack of insurance coverage, and residing in a nursing home were also prominent topics of concern.

Stress

Enduring stressful situations for extended periods of time can cause many physical side effects for any individual, but those with a disability are often forced to endure stressful situations for the remainder of their lives due to their limitations. Yaribeygi et al. (2017) discussed many of the ways stress affects the human body; the compensatory responses triggered when an individual is presented with elevated levels of stress can affect the nervous system and change the physical structure of the brain. This in turn can affect the performance of many divergent functions in an individual's body, including short- and long-term memory loss, cognitive impairment, decreased appetite, decreased ability to absorb and retain nutrients, immune system inefficiency, narrowing of veins, gastrointestinal complications, and overall functioning for the endocrine system. This can also leave an individual at higher risk for certain diseases or complications from their high stress levels, such as declarative memory disorders, Crohn's disease, ulcers, irritable bowel syndrome, and kidney disease. Stress can also alter the sympathetic or parasympathetic nervous systems; if the sympathetic nervous system is activated it could cause increased heart rate and high blood pressure, while activation of the limbic system in the parasympathetic nervous system could cause low blood pressure and a decline, or even a complete stop, of an individual's heartbeat (Yaribeygi et al., 2017).

Specifically for individuals with SCIs, pain is a predominant factor for increased stress levels (Martz, 2005; Noller et al., 2017; O'Shea & Smedema, 2013). Increased levels of stress for extended periods of time were shown to cause inflammatory responses to the initial SCI and led to secondary damage (Bouchard & Hook, 2014; Noller et al., 2017). Additional side effects included obesity (Noller et al., 2017), changes in physical health (Bouchard & Hook, 2014), depressive symptoms and perceived stress levels (O'Shea & Smedema, 2013), as well as increased impact of previous pain or trauma (Martz, 2005). Potential intervention recommendations included focusing on the alleviation of pain to help with perceived stress levels as well as promoting healthy coping skills, which "generally support the biopsychosocial model" in terms of treatments (O'Shea & Smedema, 2013, p. 20).

Impairments in respiratory functioning may also create substantial barriers to autonomy in individuals with quadriplegia, especially those who use sip and puff wheelchairs (Sezer, 2015). The loss of independence has ongoing physical, psychological, and emotional effects on individuals who have experienced an SCI. Williams and Murray (2015) showed that the prevalence of depression after an SCI is substantially greater (22%) than that of the general population (13%). Le and Dorstyn (2016) also identified 18 different independent studies that investigated self-assessed anxiety levels in individuals with SCIs. While self-assessed anxiety rates ranged from 15% to 32% in individuals after an SCI, similarly high anxiety levels were reported both in a hospital setting (27%) and outside in the community (29%). They concluded that the early identification and treatment of anxiety are important in SCI rehabilitation, especially for individuals experiencing chronic symptoms.

Environmental and Social Barriers

Environmental and social barriers also play a role in the quality of life for individuals with SCIs (CDC, 2021a, 2021b). In a study by Silver et al. (2012), an environmental barrier was finding transportation to and from activities. Since an individual with an SCI often cannot drive independently, if at all, without accommodations made to their vehicle, they are often reliant on others for help. Vehicle accommodations quickly become expensive, as they may include a wheelchair ramp or automated lift, automatic doors, floor seatbelts, hand controls, and pedal extensions. The National Highway Traffic Safety Administration (NHTSA, 2021) stated that a potential cost of a new vehicle modified with adaptive equipment can range from \$20,000–\$80,000, though there is a wide range of adaptive equipment that can affect the overall cost of the vehicle. These vehicular accommodations also sometimes require a specialized training program to learn how to use them correctly.

The literature shows that environmental factors often overlap with social, preventing or hindering social activities or community involvement for individuals with disabilities (Hammel et al., 2015; Scelza et al., 2005; Tsai et al., 2017). For example, assistance barriers (e.g., a lack of transportation to/from services), lack of assistive devices (e.g., ramps and assistance from others), and lack of access to facilities with appropriate equipment play a significant role in the participation of those with disabilities in social activities (Scelza, 2005; Tsai et al., 2017). This can hinder access to quality services that could help people with SCIs improve their physical, mental, and emotional wellness.

Age

Rodaowski et al. (2014) listed age specifically to be moderately influential in how an SCI can affect some individuals' disability. In some cases, the older the individual is at the age they were injured, the more severely the disability can affect their everyday functioning (Cooke et al., 2010; Horne-Thompson & Grocke, 2008; Korhan et al., 2011).

Summary

There are a multitude of factors that can impact the quality of life for individuals with SCIs. While every individual with a disability will present with their own unique needs, knowing how these components can directly impact multiple areas of an individual's well-being is crucial for quality care as well as preventative measures to combat any pre-existing conditions an individual may already have.

Despite all the challenges that individuals with SCIs must overcome daily, they are now living longer and regaining more functional independence thanks to deeper knowledge bases, improved access to treatments and therapies, advances in technology, and better pharmacological management of symptoms (Ragnarsson, 2012). However, researchers are still learning about this unique injury and continually finding better and more efficient ways to manage it, including a multitude of therapies delivered by experienced helping professionals. In the next section, I review the literature on helping professionals who often work with individuals with SCIs: physical therapists, occupational therapists, and music therapists.

Physical Therapy

The American Physical Therapy Association (APTA) defines physical therapists (PTs) as “movement experts who optimize quality of life through prescribed exercise, hands-on care, and patient education” (2021, para. 1). These professionals develop plans based on an individual’s specific needs to improve QoL, decrease pain levels, assist with normalization of *gait*, or walking pattern, restore function, and prevent new or further disabilities. Additionally, PTs prevent the loss of movement by developing programs aimed at fitness and wellness to promote active, healthy lifestyles. PTs are also vital leaders in developing standards in PT practice as well as developing various healthcare policies to provide accessible, available, and optimal delivery of services in the healthcare community (APTA, 2021).

The United States National Library of Medicine (2020) noted that need-based therapy services for individuals who are hospitalized will often begin while they are still in the hospital but can begin before planned surgery as well. For individuals with SCIs, necessary therapy services typically begin in the Intensive Care Unit (ICU) and continue throughout the acute hospitalization stages; these sessions are usually the most intense in the inpatient rehabilitation setting. Interventions can be as physically demanding and challenging as the individual can handle and are specifically developed to the unique needs of the individual. The different types of muscle stretching that PTs can use can vary drastically depending on the targeted population they are working with. The primary goals for physical therapy (PT) to address with individuals with SCIs are

> modifying specific body impairments such as strength, cardiovascular fitness, joint mobility, muscle extensibility, bone loss, pain, and spasticity [to] improve the ability to perform activities without assistance from a caregiver, or to perform tasks using compensatory methods with or without equipment. (Toldra et al., 2014, p. 372)

These goals can fit into all categories of the ICF: body functions/structures, activities, and participation. While the focus of SCI care used to be purely for medical management, physical therapists now attempt to maximize an individual's QoL and maximum participation in the community. Dijkers (2003) noted that participation in individual, social, and communal activities can and should be considered as a key component of or a contributor to an individual's QoL, depending on how the QoL construct is conceptualized to best benefit the individual. Clearing as many potential barriers as possible to an individual's participation in everyday activities is also essential for their involvement; physical therapists can create a personalized treatment plan to improve their patients' overall mobility, help manage pain and other chronic conditions, and assist in preventing any future injury and chronic disease (APTA, 2021).

There have been several studies conducted on the effectiveness of physical therapy interventions for individuals with SCIs. Harvey et al. (2009) examined data from 31 different studies with individuals with SCIs—in 14 studies, researchers conducted interventions with individuals with acute, or newly acquired, injuries; 16 studies involved individuals with chronic injuries (defined as older than a year); and one study did not specify what stage of injury the participant had acquired. Topics of these studies included arm/leg strengthening training, gait training, hand therapy, hand splinting, stretching, and other therapies (e.g., hippotherapy). Results suggested that by reducing activity limitations, PT interventions may address the aim of rehabilitation, namely increasing participation and thereby improving overall QoL. Improved participation levels can also lead to increased independence, which may improve mood and lessen anxiety and depression levels (Harvey et al., 2009).

Occupational Therapy

The American Occupational Therapy Association (AOTA) states that occupational therapy (OT) practitioners possess the skills and education necessary to "facilitate collaborative goal setting and achievement by considering physical, psychosocial, occupational, and contextual factors that impact occupational performance" (2021, para. 2). Ultimately, their therapeutic goals may include identifying, exploring, and practicing activities important to the individual, modifying tasks temporarily or permanently on an individual's ability levels, identifying potential barriers in the home setting, and providing training, adaptations, and resources for individuals and their caregivers (2021, para. 3).

Like PTs, occupational therapists typically begin providing services in the ICU and continue throughout the acute hospitalization stages but still provide the most intense treatment in the inpatient rehabilitation setting. OT services may continue in an outpatient rehabilitation setting, such as an individual's home or at a designated outpatient facility, to improve skills learned in the hospital environment and to continue to increase an individual's independence in their daily life. Whereas PTs are typically more concerned with gross motor skills, OTs often work on fine motor skills, such as grasping, pinching, and maneuvering the hands (AOTA, 2021).

Specifically for individuals with SCIs, OTs have a variety of educational tools to help combat some of the barriers that individuals may face as they adjust to life in a wheelchair. One of the most common problems seen with these individuals are *pressure sores,* open or closed wounds caused from too much pressure being on one area of the body for too long without relief. This is particularly a problem for those on bedrest who are unable to move themselves, but even more so for individuals with SCIs due to the fact they are often unable to feel where the pressure is most painful. This can cause the wounds to be more severe than normal, which can take longer to heal and are more prone to infections. Ford et al. (2013) explained that the role of an occupational therapist in this instance is not only to consistently examine the skin and teach individuals and caregivers how to do it themselves, but to discuss causes for pressure sores, provide options for more appropriate seating (mattress, seat/wheelchair cushions), assist with easier transfers, and provide education about skin care management. This can prevent more complex medical treatments and longer hospitalizations, allowing an individual to return home more quickly and safely.

Rehospitalization is also a topic that OTs can help prevent during a patient's initial rehabilitation stay. DeJong et al. (2013) showed that patients who received less frequent or lower-intensity therapy interventions (PT, OT, and RT) were more likely to be readmitted during their first 12 months of injury. Factors such as the length of time between injury and beginning rehabilitation treatments, age, acquiring injuries during rehabilitative stays (e.g., urinary tract infections (UTI) or pressure sores), and the knowledge of SCIs with their physicians and interdisciplinary teams were among the leading causes for readmittance. Additionally, respiratory diseases, such as pneumonia, were among UTIs and pressure sores as the most common reasons for hospital readmittance.

OTs also work on a variety of goals with individuals with SCIs specifically tailored to their needs. Foy et al.'s 2011 study showed that patients with SCIs typically receive around 52 hours of OT during initial inpatient rehabilitation stays, with interventions focusing on activities of daily living (ADLs), strengthening and endurance, and range of motion. Seventy-seven percent of treatments happened in individual sessions with a primary focus of ADLs. Variations in time and focus of treatments was said to vary due to Functional Independence Measure (FIM) scores, neurologic injury grouping (level of SCI), and medical severity of injury.

Speech Therapy

The American Speech-Language-Hearing Association (ASHA) defines speech-language pathologists (SLPs) as "experts in communication that work with people of all ages, from babies to adults to treat many types of communication and swallowing problems" (2021, para. 1). Also referred to as *speech therapists,* ASHA states that SLPs can address problems with speech sounds, language, literacy, social communication, fluency, voice, and cognitive communication as well as troubleshooting issues with feeding and swallowing. Because there are so many aspects that go into communicating, SLPs value the application of anatomy and neuroanatomy knowledge to current practice and are considered experts in the anatomy of the oral-motor area (Martin et al., 2013). Like their PT and OT colleagues, an SLP's services are also administered early in the acute hospitalization process and are considered a crucial part of the recovery procedure.

When working with an individual with an SCI, the level of injury often dictates what services are considered most crucial with great variability of time spent on each treatment time. Brougham et al. (2011) recruited six rehabilitation centers with 600 patients with traumatic SCIs for an observational study of SLPs in acute rehabilitation treatment (SCIRehab). SLPs documented their time spent on each area of treatment and protocol during every encounter they had with a patient with an SCI. Results showed that SLPs were called in for consult in 40% of the SCIRehab patients. SLPs working with individuals with injuries at C1–C4 spent the most time working on swallowing therapy, while individuals with lower levels of tetraplegia and paraplegia spent the most time working on treatments more heavily focused on cognition and communication. The need for swallowing treatment administered by SLPs while in inpatient rehabilitation can be explained due to the amount of dysfunction that comes from the use of artificial airways and feeding approaches, which may not be helped by impaired cognition as well as secondary injuries.

Cognitive deficits, while not often considered the most pressing issue for an individual with an SCI, are also an important goal area that speech therapists can target in their sessions. Chiaravalloti et al. (2018) showed that individuals with SCIs have an increased risk for cognitive deficits, even more so than their age-matched peers as well as older individuals without SCIs. They estimated that a staggering 60% of individuals with SCIs demonstrate a cognitive impairment in some form due to many distinct factors. This can directly affect their recovery process and their overall QoL (or quality of life). Results suggested a closer correlation between the brains of individuals with SCIs and that of the healthy older adult group, which could be a sign of accelerated brain aging after their injury. This has proven to be the case as well with other neurological conditions, such as multiple sclerosis (MS) and Parkinson's disease (PD). While mobility and overall independence should still be a main priority when treating individuals with SCIs, the importance of SLPs targeting cognitive functioning should also take precedence when evaluating their rehabilitative goals.

Although research has suggested that SLPs are essential in the recovery of individuals with SCIs, staffing for SLPs in rehabilitation facilities is often lacking. McRae et al. (2021) showed that although the United Kingdom provides national recommendations for SLPs in critical care and rehabilitative settings, seven SCI units and four major trauma centers reported that no facility met the recommended number of SLPs. Post-acute and long-term care for individuals with SCIs are critical for an individual's overall prognosis, but facilities continuously communicated their limitations due to limited resources and overall capacity. This can place restrictions on the amount of therapy and the level of intensity patients can receive while hospitalized, which may impact their overall outcomes for both swallowing impairments and communication.

Respiration for individuals with higher injuries is often a priority, especially for those who have diaphragmatic paralysis. A device called an *abdominal binder* is often used to restore abdominal pressure in individuals with SCIs and is thought to help with increasing lung capacity. Wadsworth et al. (2012) showed that repeated use of an abdominal binder improved respiratory and vocal factors in 14 participants with injury levels ranging from C3–T1. Participants used their binders while seated in an upright position in their wheelchairs; measurements were taken at 3 weeks, 6 weeks, and 3 months. Results showed improvements in vocal loudness, forced expiratory strength, and sustained vowel time (holding vowel shape, such as “ooh,” for an extended period of time).

Recreational Therapy

Recreational therapy, also known as *therapeutic recreation*, is defined by the American Therapeutic Recreation Association (ATRA) as “a systematic process that utilizes recreation and other activity-based interventions to address the assessed needs of individuals with illnesses and/or disabling conditions, as a means to psychological and physical health, recovery and well-being" (2021, para. 1). Recreational therapists (RTs) use treatment services to restore and rehabilitate an individual’s level of functioning using everyday activities to help reduce or eliminate activity limitations or restrictions. These can look different depending on the likes and interests of individuals, but the intention behind all interventions is to help people regain as much normal functioning as possible that can be transferred to their daily lives. RTs can address a wide variety of goals, including improving QoL, promoting a greater sense of self-reliance, managing stress, re-integration into the community, and promoting healthy coping skills (ATRA, 2021; Thomas Jefferson University Hospital and Magee Rehabilitation, 2009.)

The ATRA highlights the fact that recreational therapy is not solely for fun. While many interventions that can be used are enjoyable, RTs are trained professionals that can be working on a wide variety of goals when choosing specific activities for their patients. These goals can include developing coping skills; improving QoL; increasing fine and gross motor skills; and reducing stress, anxiety, and depression (ATRA, 2021). Recreational therapy can have a positive effect on patients' overall health and well-being; elevated levels of stress over both short and long-term periods can be detrimental to multiple different organ systems in both healthy and immunocompromised individuals (Yaribeygi et al., 2017).

Recreational therapy has been shown to be effective with many different populations, including SCIs. RTs who work with this population must take the individual's level of injury into account when planning interventions; the level of injury often determines an individual's level of mobility. While an individual with paraplegia may have partial or complete use of their hands, an individual with a higher level of quadriplegia may not be able to use their arms or hands. For this reason, RTs sometimes co-treat with occupational therapists (OTs) because they specialize in occupational adaptations as well as safe movements that will help prevent future complications. Although important to note the distinct differences between OTs and RTs as both professionals go through unique programs to obtain their degrees, combining the expertise from both professionals can often allow for the most adaptive and beneficial outcome for their patients (ATRA, 2021).

As with music therapy literature, recreational therapy literature is relatively scarce with the SCI population. Cahow et al. (2012) sought to assess the associations of recreational therapy interventions in individuals with traumatic SCIs in terms of functional outcomes, participation, and overall quality of life. Their findings showed that recreational therapy interventions, coupled with exposure in the community as well as leisure activities, showed more positive outcomes both post-discharge and one-year post discharge. Patients also had a more likely chance of residing at home one-year post-discharge and were less likely to have a longer length of stay in inpatient rehabilitation.

There is also a high rate of perceived effectiveness for recreational therapy, which often holds more appeal for patients than traditional therapies. Lawrason et al. (2020) and Strydom et al. (2009) state that many patients prefer recreational therapy interventions rather than clinical exercises. Both studies stressed the importance of the insights that recreational therapists can bring to an interdisciplinary team. Patients may be more motivated to participate in therapy and are more likely to engage in activities outside of the inpatient hospital setting. This will necessitate a referral to a recreational therapist, who can work with patients to create an individualized plan to find activities the patient enjoys, provide adaptations as needed, and help locate other community resources for post-discharge (Lawrason et al., 2020; Strydom et al., 2009).

Music Therapy

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” (2021b, para. 1). Board-certified music therapists create individualized music-based interventions to target physical, emotional, cognitive, and social goals with individuals of all ages. Using and being actively involved in music therapeutically, an individual’s abilities strengthen and are often applied directly to other areas of their lives.

In 2008, de l'Etoile conducted a pilot study that examined the co-treatment of physical therapy with music therapy; working closely with a physical therapist, the researcher examined the entrainment level of patients with incomplete SCIs using *rhythmic auditory stimulation*, which allows patients to walk in time with a steady beat provided by a metronome or other musical instrument. Seventeen patients with either cervical or thoracic injuries walked four, ten-meter walks using different tempi, or speeds, and with or without the use of music. While no changes were statistically significant, patients with cervical injuries tended to increase their cadence, or rhythm, in their walking pace and participants with thoracic injuries showed improvements in both the length of their steps and their stride velocity at the normal tempo.

Tamplin (2012) used therapeutic singing to assess its effect on patients’ mood, QoL, respiratory outcomes, and vocal outcomes. Twenty-four individuals with chronic quadriplegia were assigned either to a control group (*n* = 11) or the experimental group (*n* = 13). The experimental group received group singing training three times a week for twelve weeks, while the control group received group music appreciation and relaxation for twelve weeks. Assessments of effectiveness were conducted pre-, mid-, immediately post-, and six months post treatment. The singing group showed a significant increase in the areas of projected speech intensity and maximum phonation length. Trends for improvements in the areas of muscle strength, respiratory functioning, and recruitment were clearly noted as well for individuals in the singing group; however, results were limited by a small sample size with large inter-subject variability. While singing training did not show a statistically significant benefit in respiratory strength and vocal function, individuals did report an overall boost in mood, which in turn affected their QoL. These results show that group music therapy can have a positive effect on physical outcomes as well as improving mood and QoL and increasing energy and social participation. These results can benefit individuals with quadriplegia as well as others who fall into an at-risk population category. Specific singing therapy techniques can also help improve vocal intensity, a common complaint of vocal change in individuals with SCIs.

Two years later, Tamplin (2014) looked at the impact of active therapeutic singing (TS) in comparison with a normal singing group. Twenty-four participants with quadriplegia were randomly assigned to either a singing intervention or an active music therapy control, both lasting twelve weeks. Recordings were taken of individuals' voices both singing and speaking were taken at baseline, 6 weeks, 12 weeks, and 6 months post-intervention. After 12 weeks, participants in the active TS group showed progress in the areas of *jitter* (a frequency instability), *shimmer* (an amplitude instability), and *noise-to-harmonic ratio* (additive noise in the voice), but results failed to reach statistical significance. Overall, both studies would be deemed inconclusive since none of the results achieved statistical significance; however, like the previous study by Tamplin, this study also noted that small sample size could have affected their overall outcomes.

Rationale for Present Study

There is a lack of research that conclusively identifies how specific music therapy interventions are used to target change in overall respiratory functioning in individuals with SCIs, and what effects those interventions have on the individuals themselves. Furthermore, no research could be found on how people with SCIs use music in their everyday lives, and it is unclear whether healthcare professionals other than music therapists incorporate music within their treatments to improve respiratory functioning for people with SCIs. A qualitative study of how decreased respiratory functioning affects people with SCIs and how they use music in their daily lives could provide useful information for music therapists seeking to design music-based interventions to help people with SCIs increase respiratory functioning. Additionally, interviewing individuals in the helping profession could provide ideas for working around the unique challenges of an SCI for both other helping professionals as well as individuals with SCIs and their caregivers.

The research objectives for this project were to a) better understand how decreased respiratory functioning impacts the lived experience of individuals with varying levels of spinal cord injuries as well as the professionals who work with them; b) describe how people with spinal cord injuries use music in their daily lives; and c) explore ways healthcare professionals use music in their work with people who have spinal cord injuries. The research questions were:

1) How does decreased respiratory functioning influence the lives of individuals with spinal cord injuries?

2) How does decreased respiratory functioning in individuals with spinal cord injuries influence the treatment goals of helping professionals in different specialties?

3) How does decreased respiratory functioning in individuals with spinal cord injuries influence the interventions of helping professionals in different specialties?

4) How do individuals with SCIs use music in their daily lives?

5) How do professionals use music to improve therapeutic outcomes?

CHAPTER THREE

METHODOLOGY

Purpose

The purpose of this study was to better understand how decreased respiratory functioning affects individuals with SCIs and their healthcare professionals. The aims were to develop a deeper understanding of how decreased respiratory functioning affects the daily lives of individuals with SCIs, how decreased respiratory functioning in these patients affects the therapeutic practices of healthcare providers, and how both individuals with SCIs and healthcare professionals use music in their daily lives and therapeutic practices.

Multiple Case Study

When planning my research design, I decided a qualitative framework would allow me to gain a deeper understanding of the challenges that individuals with SCIs and their healthcare professionals face due to decreased respiratory functioning. The research design used was a multiple case study, in which the researcher investigates and illustrates a central issue or phenomenon through the study of multiple cases (Creswell, 2013). For this study, the issue was how decreased respiratory functioning affects the lives of both the individuals living with the disability and the healthcare professionals working with them. Two bounded cases were included: individuals with an SCI and healthcare professionals. Each case had multiple participants—two individuals with SCI and three healthcare professionals. Because each individual with an SCI as well as the various healthcare professionals I interviewed had their own unique story, I did not want to limit my study to just one or two people. I chose a multiple case study to illustrate multiple perspectives, both from different healthcare specialties and level of SCI (Yin, 2009). A multiple case study approach allowed me to see multiple perspectives from individuals, both positive and negative aspects, and allowed me to see how music therapists can best serve the needs of both individuals with SCIs and the professionals that care for them. Multiple case studies increase validity because similar or alike findings in multiple cases are stronger than one standalone case (Creswell, 2013).

A multiple case study design is ideal for giving both readers and researchers the understanding to answer research questions by developing their own understandings of how the case functions within real-life scenarios (Yin, 2009). All case studies should have several well-developed, thorough research questions to view the phenomenon through multiple lenses. Descriptive research question (i.e., asking *what?*) and explanatory questions (i.e., asking *how?* or *why?*) allow for a detailed analysis of the phenomenon than closed-ended questions (i.e., can be answered by *yes* or *no*). An example of a descriptive question I used was: “What are some of the primary strategies you use when working with individuals with SCIs?” An example of an explanatory question I asked was: “How do you feel that decreased respiratory functioning affects your life (e.g., personal, social, work, activities of daily living)?

The findings from case studies cannot be generalized to fit the larger population, as with all qualitative research results (Creswell, 2013); however, findings are transferable to similar situations because readers can make connections to the study from their own firsthand experiences through the rich descriptions qualitative research provides (Thomas, 2011). For this study, this may also allow readers to make connections from participants' experiences to their own experiences or therapeutic practices.

Selection Strategies

All participants were contacted through a convenience sample (i.e., people I previously knew), response-driven sampling (i.e., referrals from a music therapist), and opportunistic sampling (through a Facebook posting by myself in a private spinal cord injury support group in which I was actively involved along with my friend with an SCI) (Creswell, 2013). I also used criterion sampling (Creswell, 2013) to ensure the participants did not have any other health conditions that could potentially affect their respiration, such as being on a ventilator or a secondary respiratory disease. Criterion sampling also allowed me to interview individuals who either had an SCI or had worked with individuals with SCIs for at least a year.

I used snowball, opportunistic, and convenience sampling to initially recruit participants, then implemented criterion sampling components to ensure participants met all necessary qualifications to participate (Creswell, 2013). I initially recruited three individuals with SCIs and three healthcare professionals (music therapist, physical therapist, and recreational therapist), who were among the first to respond to one of the modes of contact. Because of personal concerns that arose during the coding of an interview with one participant with an SCI, her information was omitted from the project after consulting with both thesis advisors and reviewing Dileo's (2000) ethical decision-making model. This left two individuals with SCIs and three healthcare professionals for the final project. The researcher submitted the research prospectus to the University of Kentucky Institutional Review Board (IRB). Approval was granted in May 2020, and the study began in the same month.

After obtaining IRB approval, I contacted my list of potential participants through telephone or Facebook Messenger. If they expressed interest in the study, I sent them a copy of the informed consent to review before agreeing to be a participant. Because I did not want to potentially exclude any participant with limited or no hand function, which is a common side effect of paralysis from SCI, the IRB approved a verbal rather than written consent; verbal consent was stated and recorded before the start of the interview and was documented in the interview transcripts. All interviews were conducted online via an audio-conferencing platform or over the phone due to the COVID–19 pandemic. Before participation, all participants read over a consent form based on their status as an individual with an SCI or a healthcare professional (Appendix B); since no signature was obtained due to the online method of obtaining data, continued participation in the study was an acknowledgement that they understand and consent to all aspects of the thesis project. Verbal consent was also obtained at the beginning of each interview recording. Participants could choose to skip any questions at any time and/or drop out of the study at any time without consequence or explanation.

Participants

The two participants with SCIs were medically stable, spoke fluent English, and had been injured for at least a year at the time of their interviews. The three healthcare professionals also spoke fluent English, had worked with individuals with SCIs for at least a year at the time of their interviews, and were in good standing in their respective fields. At the time of the interviews, one participant lived in Michigan, one in Indiana, one in Texas, one in Ohio, and one in Kentucky. Participants came from a wide variety of backgrounds, both professionally and personally; both individuals with SCIs were injured on different levels (C6 and T10–12) and all three healthcare professionals were certified in different specialties (recreational therapy, physical therapy, and music therapy).

Data Collection

According to Creswell (2013), data collection for case studies should include multiple forms to provide rich information. For this study, data included one semi-structured interview per participant (for a total of five interviews) and my researcher journal. What follows is a detailed description of these data collection methods and my rationale for using them.

Semi-Structured Interviews

Interviews help the researcher find common themes and draw conclusions from the data (Creswell, 2013). In this study, I conducted semi-structured interviews, which revolve around a clearly articulated interview script while allowing for follow-up questions based on the participant’s answers, much like an informal conversation. The semi-structured interview enables reciprocity between the interviewer and participant (Galletta, 2012). Each participant participated in one interview, which lasted an average of 40 minutes long (the range was 22–71 minutes).

All participants answered questions (see Appendix D) based on their subjective experiences that encompassed their unique outlooks as well as the use of music, if any, in their daily lives and treatment processes. Questions geared for individuals with SCIs centered on their own experiences with their disability, including aspects of their daily life, false perceptions about SCIs, and any past or current experience with therapies. Participants were also asked how decreased respiratory functioning affects them daily and answered questions about their use of music, if any, in their day-to-day activities. Questions geared for health professional were focused on the most challenging aspects about working with individuals with SCIs, the goals they most commonly work on with this population in their respective fields, and how they use music in their treatment goals, if applicable to their current scope of practice.

Researcher Journal

I kept a researcher journal throughout the thesis project at all stages to minimize the chance of researcher bias (Glesne, 2006). The researcher journal was a place where I could reflect on my own musings and develop a deeper understanding of the phenomenon. From reviewing literature, developing my research questions, conducting interviews, and analyzing data and codes that emerged from the data, I was able to reflect on my own thoughts and circle back to them as needed. Additionally, keeping a researcher journal increases trustworthiness and rigor in qualitative research (Glesne, 2006).

Confidentiality

Each participant was assigned a pseudonym to ensure confidentiality. All digital data were kept in my password-protected computer, which was backed up in a secure university-affiliated Dropbox account. Any physical data, such as handwritten notes from interviews and the researcher journal, were kept in a locked box in my home when not in use.

Procedure

After initial contact and participants expressed interest in the study, I sent over the informed consent, which all participants reviewed before scheduling an interview. All interviews took place virtually due to the COVID-19 pandemic; I was always alone at my private home to ensure sufficient privacy, while participants called in from their home or apartment when their interview was scheduled. I recorded each interview using two forms of technology (voice memo on iPad 5th generation and voice recorder on Dell Inspiron 3593) in case of technology failure. Interviews lasted 22–71 minutes, depending on the length of answers from participants. After data was collected, I transcribed and coded each interview within one to two weeks of the interview date.

Data Analysis

Creswell's (2013) data analysis spiral was used for analysis. Data management comes first, organizing files into the most accessible format. More detailed organization of the data comes next, followed by describing and classifying different themes of the data into open codes, then direct codes. Open codes are themes that arise from the data that may not be directly related to the research questions. Searching for open codes is an important part of the analysis, as it allows the data to "speak" and may reveal ideas that researchers did not anticipate. Direct codes are those directly tied to the research questions. These steps often circle back around as more information is gone through. I circled back to the literature I collected quite often as I analyzed the data (Creswell, 2013).

I read over all interview transcriptions a minimum of three times before coding, once with the audio recording, once without, and once again with the recording to help ensure accuracy of the written words. Next, I used ATLAS.ti Cloud (2020), a qualitative research-specific software program, to identify open and direct codes by analyzing the data and identifying themes and subthemes within the transcriptions. The codes that emerged were sometimes in-vivo, while other codes were drawn from specific terminology and concepts in the healthcare and SCI literature. An example of an in-vivo code were the effects that anxiety had in the lives of individuals with SCIs due to their disability; goals for individuals with SCIs based on FIM (or Functional Independence Measure) scores was an example of a code drawn from specific terminology used by healthcare professionals. I interpreted the data by written and verbal outlines that were all transcribed in my researcher journal, which allowed me to expound on the data further.

Trustworthiness

To increase validity, I sent parts of interviews back to the participants that agreed to look it over to ensure that I understood them correctly, also referred to as "member checking" (Creswell, 2013). Also, one of my thesis co-chairs read transcriptions and coded one of the five transcriptions independently. After we both coded the data, we discussed the codes that emerged as a mode of trustworthiness. I examined my own biases in my researcher journal (detailed more in the Role of the Researcher) and all interviews were transcribed within 24 hours. Creswell (2013) also discussed the non-linear process of moving back and forth between analysis stages increases validity in the qualitative research design. Revisiting the data from multiple angles provides a more in-depth and well-rounded look at the information presented.

Role of the Researcher

The following includes a transparent description of my role as a researcher. Glesne (2006) remarked that validity issues are important aspects to consider and reflect upon during the research process, both for analyzing data as well as monitoring one's own bias. I am a young researcher at the time of this publication at the age of 26 and have not previously conducted a project of this magnitude or depth before in my academic career. Throughout this project, I have had to constantly reexamine my potential biases from both professional and personal influences. I have been friends with someone who has had an SCI for the past 11 years; she has been my primary source of how individuals with SCIs live their daily lives due to the closeness of our relationship. Because she tends to view her disability with a relatively positive outlook, this may be a potential bias for me; not everyone views their disability in a positive light and their individual truths should be respected (Creswell, 2013).

As a healthcare professional with experience in the rehabilitative setting, I may also have a bias toward viewing aspects of a disability as something to be corrected rather than an aspect of someone's daily life. As a neurologic music therapist, I am often brought into situations to help regain lost function(s) or shape new behaviors; it can still sometimes be challenging to view certain aspects of a disability as a normal part of someone's daily routine rather than something I can help "fix." This has been something I have had to examine internally both before and during my thesis project. Every individual has their own unique way of completing tasks, whether it is the way one might think is typical or using compensatory measures. This is one aspect where neurodiversity makes everyone different, regardless of ability level. I say this having made mistakes myself as an able-bodied individual, although having the best intentions behind my actions; I have made countless mistakes in my friendship with the individual with a SCI on how she would prefer to have certain tasks completed. When we first became friends, I would see her struggling to open a soda can and would take it out of her hands and open it myself; although I was trying to be helpful, she gently reminded me that "it was okay to watch her struggle" and that she would gladly ask me for help if she needed it. This can be said for many people with disabilities; many people are still trying to figure out how to accomplish certain tasks and need to discover how to do it themselves to achieve independence. Sometimes embracing that "discomfort" that comes from not helping someone do a task will bring them more satisfaction and confidence than helping them in the short-term. Some people may embrace their ways of doing things while others may not want to bring it up in conversation, but if something works for individuals with disabilities that is not hurting them in any way, we all need to accept that there is more than one way to do anything and be okay with letting individuals with disabilities struggle in the short-term to gain long-term independence.

CHAPTER FOUR

RESULTS AND DISCUSSION

In this section, I first discuss participants' backgrounds, including their demographic information. Next, themes are described as they relate to each research question; this section also includes one theme that arose through open coding that was not directly related to the research questions. Lastly, I discuss how these themes relate to previous research.

Participants' Backgrounds

Participants were two individuals with SCIs (one traumatic and one non-traumatic acquisition) and three healthcare professionals that had experience working with individuals with SCIs. Kaitlin (female, 20s) had a non-traumatic SCI acquisition from a chondroblastic osteosarcoma (COS) from T10–12 and Peter (male, 60s) had a traumatic SCI acquisition at C6. At the time of their interviews, Kaitlin had been injured for 6 years and Peter had been injured for 30 years. The three healthcare professionals interviewed had worked with individuals with SCIs for over four years at the time of the interviews. Zach (male, 30s), the recreational therapist, and Amy (female, 40s), the music therapist, worked in inpatient hospitals, while Paul (male, 40s), the physical therapist, worked for a private outpatient clinic.

All participants were white, and all resided in different states (one from Michigan, one from Indiana, one from Texas, one from Kentucky, and one from Ohio). One participant had sung recreationally, but other than the music therapist, none were trained musicians or played an instrument in their free time. What follows is a detailed description of each participant's background (see Table 1).

Table 1.1

Description of Participants

Pseudonym	Age range (in years)	Gender	Level of injury	Clinical specialty
Kaitlin	20s	Female	T10-T12	N/A
Peter	60s	Male	C6	N/A
Zach	30s	Male	N/A	Recreational Therapist
Paul	40s	Male	N/A	Physical Therapist
Amy	40s	Female	N/A	Music Therapist

Kaitlin, 20s, Injured for 6 Years

Kaitlin described herself as a "walking, healthy, 25-year-old girl" before receiving her diagnosis of a malignant chondroblastic osteosarcoma, a rare cancerous tumor that most often appears in individuals in their 20s, from T10–12 in 2014. At the time of the study, Kaitlin worked part-time as the host of a podcast highlighting the challenges of disability. In her free time, she enjoyed painting, spending time with friends and family, and taking care of her two dogs.

Peter, 60s, Injured for 30 Years

Peter grew up as an able-bodied individual before sustaining a traumatic SCI from a swimming pool injury. He worked in the business industry both before and after his injury before retiring two years prior to our interview. At the time of the interview, he spent most of his time at home with his wife and dog while keeping up with current business affairs. He worried about what would happen if he were to be diagnosed with COVID-19, which was a large driving force behind his staying at home almost exclusively at the time of the interview, which was unusual for his schedule typically filled with helping his neighbors and visiting with family and friends.

Zach, 30s, 4 ½ Years of Clinical Experience with SCIs

At the time of this study, Zach was a certified recreational therapist who primarily worked with individuals with SCIs in a large rehabilitation hospital. He pursued both his undergraduate and master's degrees in recreational therapy and was pursuing his doctorate in recreational therapy at the time of the interview while working for one of the Veterans Affairs hospitals.

Paul, 40s, 11 Years of Clinical Experience with SCIs

Paul was a physical therapist who worked for an outpatient physical therapy clinic at the time of this study. He completed his bachelors in recreational therapy and worked in the field for a few years before earning his doctorate in physical therapy.

Amy, 40s, 16 ½ Years of Clinical Experience with SCIs

Amy was a music therapist who worked for a large rehabilitation hospital the time of this study. She completed her undergraduate and master's degrees in music therapy and held an additional fellowship in neurologic music therapy (NMT-F), which she practiced daily in her work environment.

Direct Coding

Table 1.2

Themes and Subthemes

Theme	**Subthemes**
Anxiety	Difficulty breathing Financial worries Cognitive functioning Resource inaccessibility Patient and caretaker anxiety Shifts in patients’ attitudes
Endurance	Shifts in treatment goals/interventions Shorter treatment times Effects on FIM score totals
Lightheadedness/Lack of Consciousness	Additional staff to monitor consciousness More frequent breaks

For direct coding, three themes arose related to each of the research questions: (1) anxiety, (2) endurance, and (3) lightheadedness/lack of consciousness. Sub themes included causes for anxiety (i.e., difficulty breathing, financial worries, cognitive functioning, and resource inaccessibility) and effects of decreased endurance and lightheadedness (i.e., shifts in treatment goals/interventions, shorter treatment times, more frequent breaks, additional staff to monitor consciousness), effects on FIM score totals, patient/caretaker anxiety, lack of accessible information regarding patients’ disabilities, and shifts in patients’ attitudes. Below I discuss each research question in light of the themes and subthemes discovered.

1) How does decreased respiratory functioning influence the lives of individuals with spinal cord injuries?

Both participants with SCIs shared that the main way decreased respiratory functioning influenced their lives was that it created anxiety. A heightened sense of anxiety over respiration impacted many areas of their day-to-day activities, including sleep. Peter shared that his anxiety from not being able to breathe often affected his ability to fall asleep; after the TV and all the lights were turned off, he would lay in bed and just keep thinking “Why am I not breathing better?” or “Oh, if you could breathe deeper, you could relax right now.” He said that falling asleep because of his respiration was a common cause for anxiety and would often keep him awake. Kaitlin commented that respiratory functioning “has so much to do with anxiety, pain management, and depression control in people with spinal cord injuries” and stated multiple times that decreased respiratory functioning is not something that is often the topic of detailed research. This was an additional source of anxiety for her since she felt she had to advocate for herself and her needs more than her able-bodied counterparts. She pointed out the number of times she had to be her own advocate when it came to her care, which could be exhausting.

Kaitlin also discussed how her respiration affected her sexual life; while saying her fiancé is a “bigger guy,” she stated that she sometimes has to “push [him] off when he’s on top of me because of the pressure” he placed on her lungs. She went on to say:

> It's not a vaginal female pain; it's my lungs and my paralysis ... it takes my breath away because those muscles are so weak when I'm with my fiancé in that intimate way. I feel like my ability to stay in certain positions are limited due to

> my respiratory functions. I can't have him laying flat on top of me always and I'll need to have him get off because just the pressure [on me] is hard.

Endurance was an important issue of concern for Kaitlin. She stated that she felt most comfortable breathing in her wheelchair, but “my chair is not the place where I want to breathe my best.” Her respiration was compromised when she was lifted out of her chair in any way, whether through transfers, being carried with her arms around her fiancé's neck and his arm under her knees, piggyback rides, or “anything with my butt hanging heavy behind me.” Kaitlin also discussed her endurance on outings; whether having to turn around for something else at the grocery store, working out, or being outdoors with friends, she had to take breaks “just to catch my breath,” which was “tiring” and “exhausting.” While explaining that she “can’t go as far as an able-bodied person” when riding with her hand cycle because of her respiration and stamina, explaining to others why she needed to take more frequent breaks helped her tremendously.

For both Peter and Kaitlin, their anxiety from decreased respiratory functioning increased even more due to COVID-19. Both thought that their day-to-day activities were more impacted because of the knowledge they most likely would not survive contracting the virus. Peter specifically stated that he “considered himself an ‘at-risk’ part of the population who would end up on a ventilator” if he “even caught a whiff” of the virus. Kaitlin expressed, “every time I [go out], I’m putting myself at risk.” Anxiety over the possibility of contracting COVID-19 sent both participants into extreme isolation. Both Kaitlin and Peter seemed to have active social lives pre-COVID, and at the times of their respective interviews, both were staying strictly homebound unless absolutely necessary. Peter discussed not being able to help his wife with grocery shopping and not being able to gather with friends and family in public places regularly like he used to do, stating that "I just feel like I really shouldn't do it until the coast is clear or at least more clear." Kaitlin stated that COVID "has made a big difference" in her day-to-day life; she was not burning as many calories due to limited outings, her in-person SCI support group meetings were canceled, and her doctors' appointments moved strictly to telehealth.

COVID also limited Kaitlin's access to healthcare, which caused even more anxiety. She shared that she had not been able to see her doctors in-person, and residents she saw via telehealth seemed to be in a rush, making those visits shorter than usual. Kaitlin specifically mentioned waiting two hours for a doctor to see her, despite arriving 45 minutes early for the appointment, and then was asked if she had any feeling in her legs. She expressed that it was "infuriating" waiting that long to be seen and then to have the doctor "not even take the time to read [her chart]" once he finally came in was an additional cause for stress and anxiety.

Both Kaitlin and Peter discussed solutions they have found to help with decreased respiratory functioning and the anxiety it causes. Intentionally focusing on their breathing was a focal point for increasing respiration and decreasing anxiety in both participants; Kaitlin stated that focusing on her breathing when she had an anxiety attack helped her calm down and focus on the task(s) at hand, while Peter mentioned that he would "conscientiously stop and make myself take deep breaths in and out 10 times" to help calm his thoughts over not breathing well when he was trying to fall asleep. Kaitlin also mentioned "flexing my body and really bearing down to push myself up" to try and combat decreased respiratory functioning from a change in posture (i.e., lying down to sitting, transferring). Peter talked specifically about "sitting up straighter just so I can get air into my lungs" once or twice a day and "actually telling myself to breathe" when it became difficult to do so.

2) How does decreased respiratory functioning in individuals with spinal cord injuries influence the treatment goals of helping professionals in different specialties?

All three healthcare professionals agreed that decreased respiratory functioning affected patients in multiple aspects (i.e., endurance, lightheadedness/loss of consciousness, FIM score totals, patient/caretaker anxiety, lack of accessible information regarding patients' disabilities, and shifts in patients' attitudes) that in turn influenced both their treatment goals and interventions. Insurance policies related to patients' conditions also affected treatment goals and interventions.

Amy mentioned that because decreased respiratory functioning can cause reduced endurance levels, patients may not be able to participate in aggressive therapies if they are not breathing properly. She stated that "respiratory functioning is going to affect not only your speech, but the entire body." Any compromise in respiratory functioning, like Amy described, can produce a multitude of problems that can generate further physical and emotional harm both in and out of the hospital. Zach described treatment goals having to be modified because of an individual's endurance as well. In one scenario, a patient experienced decreased upper extremity mobility and strength goals because of his respiration. Because of decreased respiratory functioning affecting his overall endurance, he was unable to participate for long periods of time and often used a sling to support his elbow when participating in therapy. This limited the amount of active time participating in his therapies and most likely extended his recovery time, according to Zach.

In terms of lightheadedness/loss of consciousness, Paul explained that if patients lost consciousness due to their breathing ability, this could potentially cause a shorter time span for participation and less time actively participating in interventions. He noted that this tends to be more of an issue for individuals with quadriplegia; because the diaphragm is more likely to be paralyzed, patients with quadriplegia rely on accessory muscles, which assist with the expansion of the upper ribcage during the process of inspiration. This does not provide enough oxygen to the body, causing lightheadedness or fainting. Paul stated that this is further exacerbated by the circulation change when a patient goes from sitting in their chair to standing; they will often not have the ability to circulate and reoxygenate their blood, leading to the shorter time span. However, he said that many individuals with paraplegia he sees “can stand indefinitely without any impact on their breathing.”

Zach explain how FIM scores impacted how healthcare professionals can address treatment goals. In his experience, respiration was not an area always addressed in the speech FIM scale along with many other areas of need. This can directly affect the treatment goals that healthcare professionals can even make when beginning treatment; they cannot bill for services targeting goals that insurance will not cover. The lack of addressing respiratory concerns may also affect treatment progress, such as decreased time patients are able to actively engage in therapy due to endurance or loss of breath/consciousness. To Zach, it seemed that the priority often fell to just discharging someone to "get another body in" the hospital doors for increased funding without taking independence into account; "they weren't really focusing on getting [individuals with SCIs] back to baseline or close to it."

Anxiety for both individuals with SCIs and their caregivers were also discussed as affecting treatment goals. Zach shared that the diagnosis of an SCI can not only be anxiety-provoking for the individual experiencing it, but also for their family and caregivers. The realization that life will never be the same was sometimes overwhelming; Zach specifically mentioned individuals with SCIs and their caretakers not having enough mental capacity or time in a day to "deal with the trauma" of a newly acquired injury. He talked about this dynamic specifically in the inpatient rehabilitation setting when dealing with new self-care techniques; it can often be daunting for both the patient and the family as they learn different ways to take care of themselves that are not a part of typical self-care routines. Bowel programs, catheter changes, assisted coughing, airway suctioning, checking for pressure sores (or "hot spots") that can lead to skin breakdown, wheelchair transfers, and injections were only some of the items on the list that Zach remarked that individuals get "bombarded" with during their short training period in the hospital. This overload of information can be "really, really, really tough to rationalize" for both the individuals and their caregivers and can impact what he is able to do with patients during their time at the hospital. Seeing medical procedures performed on a loved one can also be a shocking experience; Zach noted that “you just see the fear of God” in the eyes of a family member or caregiver while seeing their loved one trached (a term used when someone has had a tracheostomy tube placed) since there is typically blood involved. Fear from someone not trained in the medical field performing various medical procedures can certainly be applied to other aspects of disability care; someone’s entire state of well-being may rest in the hands of someone who feels completely unprepared to handle the responsibility. Amy also described how decreased respiratory functioning in the rehab setting is “overwhelming and can bring a lot of anxiety” for both patients and their families; individuals may not be able to verbalize their wants and needs clearly and family members may feel helpless not being able to understand them. She expressed that this could continue outside the hospital as well; patients may have to have a caregiver doing a lot of speaking for them or advocating on their behalf due to their intelligibility, which “takes away from their independence and who they are.” This can lead to a decrease in speaking, which may cause changes in treatment goals as well as vocal complications later from lack of use.

The lack of accessible information regarding patients’ disabilities can also affect treatment goals. Time to learn new information is a luxury not often available during inpatient stays for caregivers or healthcare professionals. Hospital staff often do not have the time or resources to train caregivers, though Zach mentioned that caregivers are typically too overwhelmed to take in that much information even if the proper resources were available. While Zach mentioned that some families may have additional resources and more family members to help with care, he clearly articulated that this is not the typical representation for most individuals with disabilities. The lack of resources after leaving an inpatient hospital can also add to the anxiety individuals and their caregivers feel when they realize their care often lies in the hands of loved ones or paid help. The cost of paid help can be a source of anxiety since it is not always covered by insurance plans. Most caregivers must “figure [aspects of care] out on the fly,” according to Zach, since “there's just not enough time in a day and enough capacity in these caregivers’ brains to deal with the trauma of that new injury” as well as coping with the reality that caring for their loved one in this way could be a lifelong commitment.

Lastly, shifts in patients’ attitudes from their injuries were topics talked about at length in healthcare professionals’ interviews. Zach talked about this shift in attitude in patients from his perspective, saying that a few of the patients he had seen were “standoffish” regarding their attitude towards therapy. He claimed this most likely was due to the “complexity and recency of their injuries,” though this could be just the top layer of the mountain of challenges they are beginning to face in the inpatient setting. He went on to say, “One of the people I worked with once was like, ‘Dude, I'm just trying to get my damn pants on. I don't really care what you’re offering.’” This could also impact engagement in activities outside the hospital; Zach specifically discussed how life-changing adaptive sports could be for individuals with disabilities. Not only did adaptive sports allow for a different way to engage in a pastime one may have enjoyed prior to their injury, but also provided a built-in support system of people that “just get it” in terms of going through the ins and outs of disability.

3) How does decreased respiratory functioning in individuals with spinal cord injuries influence the interventions of helping professionals in different specialties?

Similar to how the pandemic exacerbated existing complications for individuals with SCIs, these shifts were also felt by the healthcare professionals treating them. Because individuals with SCIs have compromised immune systems and a weakened ability to cough, patients with SCIs were at a greater risk for both contracting and dying from the virus. Healthcare professionals adjusted interventions due to increased health and hygiene precautions, but these measures sometimes led to the reduction or pausing therapy sessions entirely because of the increased risk to their patients. Zach mentioned that the friends he had with SCIs take both the health and hygiene precautions “a lot more seriously” than most people due to their compromised immune systems. While saying that he “can’t speak to their feeling of uneasiness” regarding their hesitancy towards the virus, he has “definitely noticed that there is a greater level of care taken with those with spinal cord injuries and the current state of things.” Similarly, Paul discussed the effects of COVID-19 on the frequency of therapy for individuals with SCIs, specifically those with higher-level injuries, saying that certain patients had not returned to therapy because of the risk the virus posed to their health. At the time of the interview, he stated that two individuals with paraplegia and two patients with quadriplegia had not returned to therapy because of the COVID-19 pandemic. Although Paul assumed that their increased vulnerability and anxiety over contracting the virus was the reason for not returning to therapy, he mentioned that "the quads actually called out the lung function" as a reason for postponing their sessions. While both individuals with paraplegia and quadriplegia have compromised immune systems, he thought it was interesting that only the individuals with quadriplegia specifically mentioned lung function as a reason for their absence, saying that patients with quadriplegia stated, "This thing may kill me if I get it. I can't take any chances." Amy noted that one of the groups specifically designed for individuals with SCIs that combined the expertise of both speech and music therapy had been "taken away" from patients; because of the increased risk of spreading COVID through water droplets expelled while singing and practicing breathing strategies, this group had been cancelled until further notice. Although the group provided an extra hour of desired therapy for patients, participants did not have the option of receiving anything to replace the lost time. Amy was also not currently allowing patients to use wind instruments (i.e., harmonicas, recorders, and kazoos) because of the increased amount and propulsion of salivary droplets spread in the air, which also limited the interventions that could be done to combat respiratory weakness and its effects on the body.

Decreased respiratory functioning may also affect the therapy session as a whole based on the individual's needs. Paul mentioned a particular patient with quadriplegia who had fluid in their lungs and the therapists could hear it when he spoke. The patient had said they were thinking it was time to go to the hospital because they were unable to cough it up by themselves and it was becoming difficult to breathe. Although not part of the patient's typical therapy sessions, Paul and his team performed assisted coughing and percussion techniques, or specific clapping movements on the patient's chest and back, over a therapy ball to relieve the patient of "infectious sputum" that had filled their lungs. Paul stated:

> By the time we got done, they were coughing up clear; you could start to hear them breathe normally again, the rattle was gone, they could talk again, and you could just see normal color start to come back. We've treated this person many times a lot of different ways, but we never got a thank you like that. They just said that it was the biggest change in how they felt in a session ever.

Last, since individuals with SCIs were so greatly affected by decreased respiratory functioning, the interventions helping professionals could use in their sessions were sometimes limited by their patients' abilities. Zach described one specific patient scenario where decreased respiratory functioning "changed the whole treatment plan for him." While the patient relied heavily on a sip and puff wheelchair for mobility, he was often limited to small amounts of time moving around because of the patient's weakened lung capacity. This prevented him from attending group outings Zach would organize for wheelchair mobility and community accessibility as well.

4) How do individuals with SCIs use music in their everyday lives?

Kaitlin's and Peter's use of music in their lives were remarkably different. Kaitlin highlighted the importance of music throughout her life; from singing for pleasure to participating in her high school and church choirs pre-injury, singing was something that Kaitlin immersed herself in regularly. She recalled "feeling really sad" after her injury when she woke up from her tumor removal surgery “not having the lung capacity [she] used to have” and was afraid she would never be able to sing again. Kaitlin would sometimes sing as a means of testing her respiratory strength and to increase her overall endurance to try and regain some of her prior abilities. While notably mentioning that she felt that “she still just didn’t have the lung capacity anymore” to sing the way she used to, she has recently gotten back into it in the past few years, such as singing on her church’s worship team. Kaitlin “knew how beneficial music was for her” and how “life-changing singing has been for me to focus on my breathing.” Although she perceived some of her skills to be weakened, such as her vocal range, vocal tone, and her ability to “release and fill with air,” she still endorsed how important it was for her to “show up and put in the effort [to sing,] even if it wasn’t perfect.”

Peter disclosed that while he only used music for entertainment purposes, he never worked out with it, although he knew other people that did so. He also noted that music played a larger role in his life than he initially thought, saying that a song would often run through his head, whether it was a theme song to a show he was watching or even a song he had not heard in years that he would remember suddenly.

5) How do professionals use music to improve therapeutic outcomes?

Only Amy, the music therapist, used music daily to work to target a variety of goals: breath support, vocalization, verbalization, overall strength and endurance, use of bilateral upper and lower extremities, balance, speech clarity, speech volume, and ambulation. As a neurologic music therapy fellow (NMT-F), Amy implemented many evidence-based techniques to address areas of need. Interventions could look like playing wind instruments, such as a recorder, harmonica, melodica, or kazoo, singing along to patient-preferred music, and practicing various respiratory support exercises. These could all be used to address a wide variety of vocal-related needs, including endurance, vocal clarity, tone, and volume. Amy also discussed a voice group she conducted pre-COVID with a speech therapist to specifically address respiratory needs; while the group had been discontinued due to the pandemic, she stated that patients benefitted from the expertise of both professionals and appreciated the extra hour of therapy specifically focusing on their respiration and vocal needs. Although noting that music therapy interventions may look different if a patient is on a ventilator or diaphragmatic pacer (a machine that stimulates your diaphragm muscles and nerves), patients were typically able to take part in Amy's sessions without many adjustments to make them accessible.

Amy noted that music therapy may also be brought in for more reasons than just the goal charted; "the doctor knows that music therapy would help a patient both socially and psychologically and motivate them to work, so sometimes I'm just there to work on that kind of coping and adjustment." The use of evidence-based practice has allowed Amy to "have the freedom to do what [she] thinks is most beneficial" when treating patients. Because of her work, she stated that doctors will often request certain techniques by name because they understand how the interventions will fit into a patient's individualized treatment plan. She also stated how important it was to work with clinicians from different specialties, specifically mentioning how she has re-built guitars for patients with prior guitar experience with the assistance of occupational therapists, who are experts in the movement of the hands and the fine motor coordination needed to play.

Neither Paul the physical therapist nor Zach the recreational therapist used music purposefully to improve therapeutic outcomes with patients although they occasionally listened to music during their sessions with patients. Both Zach and Paul admitted that music was largely used as background sound and sometimes to set a mood. Zach said he may use it as an anxiety reducer for his patients if appropriate, but he referred any patients who showed an interest in music to the music therapist on staff for any goals that could be addressed through music. Because the Pandora station the clinic used was not something the therapists and staff wanted to “fiddle with all day,” Paul said the staff tried to keep it family-friendly and please as many people as they could with the music choices. Although Paul verbalized that he did have patients that would specifically ask for the music to be turned up so they could work out to it, music “fell on a very low level on the list of priorities, unfortunately.”

Open Coding

In open coding, three themes emerged that were not related to any of the research questions, but which nevertheless bore reporting: the importance of respiratory therapy, a desire for more resources on how to wean off OxyContin, and extending common courtesies to individuals with disabilities.

The importance of respiratory therapy was a topic that both Peter and Paul discussed in their respective interviews. This idea is especially significant as it was mentioned both by an individual with an SCI as well as a professional. Peter mentioned that he needed intensive respiratory therapy to wean off the ventilator when he was first injured 30 years prior to our interview. Since he was ventilated for 7 weeks post-injury, he needed respiratory therapy for approximately 3 weeks to fully get off the ventilator and “get to the point where I could use my lungs again.” He divulged later in the interview that although he knew his lungs were still compromised by “approximately a third,” he needed the assistance of a respiratory therapist to have the functioning he has today. Paul stated that respiratory therapy was considered if the individual was in inpatient rehabilitation and then it was not something that was even thought about after discharge. Paul continued to say that this trend seemed to continue over to the physical medicine rehabilitation doctors; respiratory therapy did not seem to be a resource considered in an outpatient setting to his knowledge. He later expressed that most of his patients considered respiratory therapy a “step back” from independence because of its stigma as something only done in the hospital setting. Paul noted that this could be a systemic problem or just an issue in the area where he was practicing but would have no idea where to send someone for outpatient respiratory therapy if asked by a patient.

Kaitlin talked about her desire for more resources on how to wean off OxyContin, one of the most addictive opioids prescribed for pain. While she was previously on 80 milligrams (mg) of OxyContin a day and could only feel “right below her breasts," she weaned herself down to 20 mg and can now feel to her navel along with decreased "mental cloudiness." She also spoke of a friend whose body "reregulated in a sense" after weaning themself off OxyContin and found that their persistent abdominal cramping after their accident 24 years prior was a side effect of the medication. In both cases, weaning off this medication was done on their own, according to Kaitlin, and there was not enough accessible information to help with the process.

Peter spoke at length about extending "common courtesies" to individuals with disabilities. He shared:

> [I] wouldn't expect the average person, even an average friend or neighbor, to know all the challenges and complexities of an SCI. [What] I would like people to know, for just the general public, is it takes so little to make a difference in the life of a person with a spinal cord injury.

Using the example of opening a glass door for someone, he asks, "How hard is it for someone, since they're coming that way anyway, to go first and open the door versus standing there and watching me open it?" He also spoke of being in challenging situations and having to "engage an innocent bystander ... and that's not an easy thing." He said that although a small percentage of people he encounters are "jerks" or "dumbasses" and would be that way to everyone, most people are genuinely more than happy to lend a helping hand. His overarching message throughout our interview was:

> It just takes so little to be kind. I don't expect complete empathy ... I definitely don't want sympathy ... I'm really not looking for a great form of empathy either.

> I’m really just looking for just a couple little things to put us on an even playing field when I’m trying to accomplish a task. That’s all.

Summary of Research Findings

In conclusion, decreased respiratory functioning played an important role in the overall well-being of individuals with SCIs and the treatment objectives of the healthcare professionals who worked with them. Themes included anxiety for both individuals with SCIs and their caregivers, concerns from the COVID-19 pandemic, and physical setbacks from decreased respiratory functioning (stamina, endurance, and lightheadedness/loss of consciousness). Subthemes included causes for anxiety, shifts in treatment goals/objectives, effects of decreased stamina and endurance, potential complications from the COVID-19 virus, and preventative measures from the COVID-19 pandemic.

Most participants felt that decreased respiratory functioning was something that had to be considered, whether in their daily lives or in their respective therapeutic practices. All participants also spoke to the overall effects of decreased respiratory functioning, including heightened anxiety, decreased endurance, lightheadedness/loss of consciousness, reduced stamina, decreased circulation, limited intelligibility of speech, decreased vocal quality (range, loudness, and endurance), increased dependence on caregiver(s) for advocation of needs, decreased sexual functioning, loss of ability to cough while in certain positions, increased isolation, rejection/hesitancy to participate in therapies, and overall outlook on prognosis.

Both participants with SCIs shared that the main way decreased respiratory functioning influenced their lives was that it created anxiety. Whether not being able to take deep breaths and feeling like they were not breathing as well as they could be, worrying about contracting the COVID-19 virus and its potential side effects due to their weakened immune system and impaired coughing, or its effects on their voice (i.e., reduced volume, reduced endurance, increased breathiness), decreased respiratory functioning was a cause for anxiety in both of their lives. While both participants discussed strategies to try and combat any shortness of breath and the anxiety it caused, decreased respiration was still a prevent presence in their lives.

Complications from decreased respiratory functioning was also shared by all three healthcare professionals. Aside from Amy, the music therapist, who often specifically targeted patients' respiration, both Paul, the physical therapist, and Zach, the recreational therapist, stated that decreased respiratory functioning was something that affected their treatment goals and interventions. Anxiety, loss of consciousness, lightheadedness, hesitation/rejection of therapies, overall endurance, socialization, self-advocation of needs, and participation in therapies were all topics of discussion among the three professionals. Anxiety was discussed at length; an injury of this severity comes with many changes, for both the individual and their family/caregivers. These changes can often be overwhelming as individuals are flooded with information. Changes of this magnitude could also impact what individuals were able to do during their stay at an inpatient hospital and the interventions professionals could use to help them.

The COVID-19 pandemic had also affected how individuals with SCIs and their healthcare professionals conduct their day-to-day lives. Increased isolation, fear of being put back on a ventilator, and limited/no interaction with friends and family outside their immediate households were concerns shared by both individuals with SCIs. These changes had impacted therapists as well; smaller patient intake, loss of patients, postponing services and group therapy, and increased health and hygiene precautions had modified the way that typical therapeutic interventions had to be conducted, which required more energy and flexibility for healthcare professionals. Many participants also brought up the increasing need for respiratory therapists, both before and during the pandemic, stating that while many individuals within this population see respiratory therapy as something only needed in an inpatient rehabilitation setting, it can be beneficial post-inpatient stay as well. However, no one was aware of where these services could even be found outside of the inpatient setting at the time of their respective interviews.

The use of music strictly as entertainment was consistent among one participant with an SCI, Peter, as well as both Zach and Paul. Peter claimed he may have it playing in the background while he was working, much like Paul having a radio station on for his patients while they worked out and Zach using music as an anxiety reducer or to set the mood for a session. However, Kaitlin and Amy both used music daily, whether for themselves or for their patients, to address respiration. Kaitlin spoke of her singing, whether by herself or in a church choir before the COVID-19 pandemic, to address her respiration as well as her vocal clarity and tone. Amy directly used music to address respiration concerns with her patients through interventions such as therapeutic singing, respiratory exercises, using wind instruments (melodicas, harmonicas, recorders, and kazoos), and voice groups collaborating with a speech therapist. Through interventions such as these, Amy was able to target a wide variety of goals, including endurance, vocal clarity, tone, and volume.

Discussion and Implications

In this section, I summarize findings from my own research and synthesize how the themes relate to previous research conducted. Implications for both individuals with SCIs and music therapy practice, ties into theoretical frameworks, limitations of this study, and suggestions for future research are also discussed.

Results from this study provided new information not previously seen in the literature about how, specifically, decreased respiratory functioning impacts the lives of individuals with SCIs and their healthcare professionals. Decreased respiratory functioning limited the amount of physical exertion an individual with an SCI could perform at one time; self-care tasks, such as showering, or therapeutic tasks, such as standing/walking a certain amount of time, were specific examples of efforts thwarted by their decreased lung function. This aligns with the findings of research completed by Silver et al. (2012), where individuals with SCI self-reported general barriers they faced in their lives: problems with mobility, spasticity, a lack of support when transitioning to a different living situation, inexperience with skills needed for maintaining a wheelchair, accessible transportation, lack of environmental and home assistance, insurance barriers, lack of insurance coverage, and residing in a nursing home were all barriers experienced by participants in Silver's study.

All participants in the present study mentioned strategies they used to try and combat the side effects of decreased respiratory functioning; both participants with SCIs reported various mindfulness exercises (e.g., consciously breathing more deeply, meditation, taking a certain number of deep breaths before bedtime). Healthcare professionals revealed specific techniques to prolong participation (e.g., pumping patients' calves to promote blood flow, bringing in additional staff to monitor consciousness and breathing ease, and using targeted respiratory exercises). There is a need for more literature on how decreased respiratory functioning impacts the lives of individuals with SCIs and their healthcare professionals.

As healthcare professionals continue to implement patient-centered care, which encompasses the unique needs of the patient for individualized treatment plans, they need to prioritize the thoughts and feelings of patients living with conditions when conducting research to achieve the most useful outcomes. This study revealed that anxiety was the biggest issue individuals with SCIs experienced due to their decreased respiratory functioning. This aligns with findings from a study by Peterson et al. (2020), where adults with SCIs often experienced higher incidences of anxiety and depressive disorders when compared to other adults without SCIs. Armed with this information, MTs may be able to better address mental health, whether directly or indirectly, through other interventions.

Results from this study revealed that the family and caregivers of individuals with SCIs must be taken into consideration. Resources can be overwhelming, such as when patients and their caretakers receive staggering amounts of information during an inpatient hospital stay. Resources can also be inaccessible; almost all participants in the study commented that materials could be hard to access outside of the hospital. This inaccessibility of resources can leave an individual with a disability and their caregivers to feel that they are going through this journey alone and have nowhere to turn when they need help. Ferguson et al. (2021) showed that patients as well as their caregivers have difficulty remembering information in the initial acute care phase of injury, which can lead to discrepancies about proper care long-term. Patients shared concerns about the validity of support groups, which were said to sometimes give conflicting or inaccurate information. This sometimes led to uncertainty about the reliability of information shared, although highlighting the benefit for emotional and social support. Because of the plethora of information online from both valid and invalid sources, results suggest a need for new methods of information sharing for patients and caregivers.

Some participants in this project also noted that they felt there was not enough research being done with this population, although no SCI will ever be the same in two individuals; Abma (2005) showed a similar finding between group members when asked about their perceptions of research. Although additional articles and studies have taken place since Abma's study was published, it is important to note that these feelings are still prevalent almost 16 years later for members of the disabled community, including

Kaitlin. These changes in thought processes are important to embrace during the ever-changing development process; as Abma (2005) stressed, the experiences of those living with the conditions being researched should not play a passive role in any stage of research.

Additionally, some of the therapists in this study stated that support groups and other community resources supplied a means for resources and support for both individuals and their families as well as mentoring for what may be expected in the years ahead regarding their injury. However, as highlighted by Hammel et al.,'s (2015) study, there may be barriers to attending these groups (built, natural, assistive technology, transportation, information and technology access, social support and attitudes, systems and policies, and economics). Additionally, a study by Forchheimer and Tate (2004) suggested minimizing the push for Independent Living Services (ILS), showing that there was no statistically significant difference between individuals who participated in ILS groups and individuals who did not. Unemployment records for individuals enrolled in the program were also significantly lower both pre-injury and a year after community re-integration. Factors such as obtaining government benefits, legal needs, and vocational services were higher in the ILS group, but program participants were less likely to report unmet needs for services such as housing and insurance benefits. However, individuals who did not feel they needed ILS services benefitted more from support groups than those who said. Although sample size was reported to be small (*n* = 81), conflicting evidence suggests that findings from my study may be inconclusive and not fully supported by previous research.

Furthermore, this study revealed barriers such as reduced social interactions (social support and attitudes), lack of access to resources (information and technology access), inaccessible facilities (built/natural), and unaffordable and inaccessible healthcare (systems and policies/economics) for both individuals with disabilities and their healthcare professionals. Although some barriers were shared among individuals in this study, it is important to note that every person's experience is unique and deserves to be treated as such. The importance of discussing a client or patient's distinctive experiences and barriers is important for developing a good rapport and creating an individualized intervention plan that target what matters the most to them with their input at the forefront. Addressing these barriers has the potential to impact many aspects of an individual's life, including physical, emotional, and mental health. This is reflected in previous literature; factors such as increased mortality from bacterial infections (e.g., pneumonia) (Brommer et al., 2016; NSCISC, 2020; Sezer et al., 2015; Tollefsen & Fondenes, 2012), decreased access to resources (Comber et al., 2011; Kwan, 2013; Shinder, 2019; Silver et al. 2012), and increased stress levels (Martz, 2005; Noller et al., 2017; O'Shea & Smedema, 2013; Yaribeygi et al., 2017) have repeatedly been shown to be barriers to better qualities of life for individuals with SCIs. Perhaps if society would address concerns from both participants in this study as well as Hammel and colleagues (2015) along with embracing aspects that encompass the biopsychosocial model of care, some of the barriers that individuals with disabilities face to participate in everyday activities would be lessened or alleviated.

The results of this study indicate that decreased respiratory functioning is not specifically listed in the ICF, even though it is a physical barrier that impacts all three aspects of the International Classification of Functioning (ICF): impairment (speech, mobility, verbal intelligibility, consciousness, self-care, self-advocation of needs, and sexual functioning), participation restrictions (participation in therapies, quality of life, and energy), and activity limitations (singing and quality of life) (World Health Organization, 2002). Contextual factors, which consist of environmental factors (living situations, access to quality healthcare, and facility accessibility) and personal factors (support system(s) and attitudes) were also of interest. Stress and anxiety may also be affected by increased respiratory functioning, although it can't be classified under one of these categories. Looking at these factors individually, connections can be made to show how one aspect of someone's being can affect multiple areas of their life. For example, literature has shown that understanding verbal intelligibility can be a taxing effort on the brain and can affect working memory (Francis & Nusbaum, 2009). Because of this, individuals who have difficulty speaking intelligibly may feel uncomfortable with their voice; this can affect social interactions and cause frustration for both the speaker and the listener (Coppens-Hofman et al., 2016) and may be a cause for anxiety when having to speak to others (Kisala et al., 2015).

This study showed that the use of music by both healthcare professionals and people with SCIs varied greatly. The music therapist used music extensively with patients with SCIs, but the recreational therapist and the physical therapist only used music for background noise and setting a mood for their sessions. Since only two therapists from two different fields were interviewed for this study, this may not accurately reflect what others are doing in the field; Craig (2008) and Paul and Ramsey (2001) showed that music is being used increasingly in the fields of rehabilitation medicine and occupational therapy. For both participants with SCIs, the role of music was vastly different; one individual with an SCI did not use music in his daily life outside of entertainment, while the other used music extensively—she sang daily to try and improve her vocal quality and respiration. There is currently no research on how people with SCIs use music beyond the few studies in music therapy, which does not focus on the use of music outside of the therapeutic setting.

Individuals with SCIs and other therapists might consider using more music, however, since music therapy has been shown to achieve a variety of non-musical goals, including decreasing stress (De Witte et al., 2020; Fancourt et al., 2016; Linnemann et al., 2016; Taets et al., 2019) improving mobility (Alashram et al., 2019; de l'Etoile, 2008; Elsner et al., 2019), regaining gross and fine motor skills (Raglio et al., 2017; Schneider et al., 2010; Street et al., 2019), improving mood (Fancourt et al., 2016; Hars et al., 2013; Seinfeld et al., 2013), speech and vocal improvements (Brooks et al., 2021; Elefant et al., 2012; Lim et al., 2013) and increasing respiratory functioning (Tamplin, 2012, 2014). While every individual with an SCI will have unique needs and objectives, these can all be important areas affected by their injury where music could be provided by healthcare professionals (e.g., a personalized music playlist) or incorporated into specific interventions via a music therapist. These goal areas may also have the potential to impact other disciplines of health and wellness that may vary based on the goal or objective targeted. Amy’s interventions reflect the current research-based practices for neurologic music therapists, though her interventions may differ from other music therapists because of Amy’s additional certification in NMT.

Although the healthcare professionals interviewed for this study were seemingly aware of the impact respiration has on a patient’s overall success, they could be limited treatment-wise by what insurance is willing to pay for. Numerous healthcare practices use the Functional Independence Measure (FIM) scale and its correlating scores to determine a patient’s level of functioning and what insurance is willing to pay for during a patient’s stay. As Zach mentioned, FIM scores may not address all areas of a patient’s needs before and after discharging from the hospital, even though they are although intended to make sure a patient receives a standard level of care. Zach did not remember respiratory functioning being a goal that was assessed using FIM scores and noted that respiration was not often a focus for healthcare professionals. Patients were often discharged to get another patient in the facility without improving respiration. These findings corroborate Doctor et al.’s (2003) study, which showed that subjectivity in determining patients’ FIM scores may cause healthcare professionals to be overconfident in their own abilities to judge the accuracy of their ratings, which may cause scores to vary from professional to professional. Doctor also suggested that subjective scores may lead to conflicting documentation of patients’ statuses, both between professionals and other healthcare systems, which could impact an individual’s quality of care, their actual progress in therapy, and comprehensive ability levels (Doctor et al., 2003).

Connections to Theoretical Frameworks

Data derived from the results directly tied back to all four theoretical frameworks: the biopsychosocial framework, the International Classification of Functioning (ICF), Social Determinants of Health (SDoH), and Hammel et al.'s (2015) disability framework. Various aspects from multiple interviews fell into categories that could be classified under multiple frameworks.

These various support systems highlight multiple areas in all four frameworks; while a support system may outwardly address physical and potentially mental needs for individuals with SCIs, emotional and social needs can also be met throughout this process. Taking Zach's example from adaptive sports, an individual with disabilities may discover a new sport or a new way to play a previously enjoyed physical activity with similarly-abled teammates. Not only could their physical health be improved by participating, but they have the potential to gain valuable insights about many aspects of disability as well as mental, emotional, and social supports from teammates and their families. These can specifically be tied back to both the biopsychosocial framework and ICF. However, participation in these types of activities is exponentially more difficult without a support system of their own, such as a parent or significant other, that is willing to invest their time and resources into helping with the logistics of getting their loved one involved; this could include transportation, availability of activities in their area, accessibility of facilities, finances, and encouragement. All these factors must be considered and addressed before deeming something truly "accessible" for an individual with a disability; where a person lives and the resources available to them can deeply affect their QoL.

Accessibility to resources can directly fit into both Hammel et al.'s (2015) framework and the SDoH; without the proper resources or access to them, both in proximity and physically, individuals with disabilities are at a disadvantage over individuals who are able-bodied and/or in a more resource-rich community. Kaitlin briefly discussed this in her interview regarding her hand cycle; while receiving it free of charge from a non-profit foundation, the cycle's accessibility was limited by her environment. While the cycle itself was fully accessible to her by use of its hand propulsion, she had no place to park it in her apartment complex where she could get in and out of it on her own. Additionally, the streets outside her complex were unfit to ride, causing her to have to travel by car to more accessible bike paths. Although acknowledging that she can drive independently thanks to modifications on her car, this is not a reality for everyone with an SCI. Zach and Amy also discussed the importance of adaptive sports and support groups for individuals with disabilities, but groups like these may not be readily available to many individuals. Theoretical frameworks played an important role in understanding the many facets of disability and had multiple ties to each other in numerous cases. Looking at Kaitlin's example of her "accessible" hand cycle, while the cycle was given to her to directly improve her physical health and potentially impact her mental and emotional health, the limits her environment placed on her directly affected her means of using it. While the cycle itself was fully accessible to her and would allow her to bypass the use of her legs to exercise, her ability to use it also relied on her environment's accessibility to get in and out of it independently as well as the act of riding it. Although Kaitlin stated that she was able to transport herself in a car to get to more accessible bike paths, acquiring accessible transportation can be a costly and difficult process. As accessible vehicles can range from $20,000-$80,000 with varying accessories depending on the individual's needs (National Highway Traffic Safety Administration, 2021), this could make transportation difficult, even for those with uncompromised upper appendages. The same argument could be made for Zach and Amy stating the importance of adaptive sports and support groups for individuals with disabilities; while these types of programs can benefit individuals at any stage in recovery, they may not be readily available to everyone that needs them. Factors such as distance, availability, accessibility, and transportation are barriers that can prevent individuals from receiving services such as these. These were also considerations that were brought up specifically in Hammel et al.'s (2015) framework; just like her participants, individuals in this study mentioned potential barriers to participation, including accessible doors, transportation, and attitudes of participants. Individuals in rural areas were also at a significant disadvantage; the Rural Health Information Hub (RHIhub) highlights a wide variety of areas that are specifically aimed at helping bridge the gap between individuals in rural areas and needed resources. At the time of publication, top hits included resources for COVID-19 relief, childcare deserts, housing market barriers, and medical-legal partnerships in rural areas (RHIhub, 2021).

Strengths and Limitations

Strengths of this study primarily revolved the overall diversity of participants. Both individuals with SCIs had injuries at different levels (Peter at C6 and Kaitlin at T10–12) and had acquired their injuries in different ways (Peter with a traumatic accident and Kaitlin with a non-traumatic cancerous tumor). Peter was also a male in his 60s residing in Kentucky, while Kaitlin was a female in her 20s living in Michigan. Likewise, the diversity among healthcare professionals was similar with 3 different specialties, both male and female participants, differing places of work among inpatient and outpatient facilities, and 3 different states represented (Texas, Ohio, and Indiana).

One limitation of this study was that experiences of all participants were from individuals who were white. Experiences may differ from counterparts of color, which means that future research may be needed with a more diverse racial sample. Another limitation was the fact that although participants engaged in member checks at various stages of the writing process, they were not given a copy of the entire transcript prior to data analysis. Furthermore, both the lack of experience of the primary researcher as well as a potential preoccupation of one of the participants due to interviewing during a hurricane may have also affected the shortest interview time (22 minutes). Additionally, the lack of expertise from both an occupational therapist and/or a speech-language pathologist may have also changed the overall results for this study. Despite attempts to connect with professionals in each specialty from both personal and outside connections, no therapists from either professional volunteered to be a part of this study. Lastly, the omission of one individual with an SCI (pseudonym “Sidney”) may have also affected the themes and sub-themes for both individuals with SCIs as well as the project as a whole.

Suggestions for Future Research

Because participants reported decreased respiratory functioning playing a key role in both everyday life and therapeutic outcomes for individuals with SCIs and their healthcare providers, further research is needed to investigate how decreased respiratory functioning plays a role for individuals with SCIs’ QoL and their healthcare professionals' goals and interventions. Researchers could investigate the effects of decreased respiratory functioning on anxiety, stress, participation in therapies, QoL, personal factors, and intervention shifts due to patients’ respiratory functioning. These findings may be beneficial for individuals with other disabilities where respiration is affected, such as chronic obstructive pulmonary disease, asthma, cystic fibrosis, sleep apnea, and lung cancer. Future researchers might investigate potential solutions to decreased respiratory functioning, both in and out of the inpatient rehabilitation setting, for individuals with SCIs and their healthcare professionals. Additionally, further exploration of how the effects of stress on the body play a role in disability care for both individuals with SCIs and their caregivers may be of interest. Furthermore, more research may be beneficial to see if results vary for individuals with higher-level injuries; because individuals with injuries at C1 and C2 require the use of a ventilator, respiratory functioning may be of even more importance since they have no control over their inspiration or expiration.

Many individuals in this study also commented on how important respiratory therapy was for this population; however, no one knew of any ways to access respiratory therapy outside of inpatient rehabilitation hospitals at the times of their interviews. Especially with the prevalence the COVID-19 pandemic took during the time this study took place, future researchers should consider ways to make resources for respiratory care more easily accessible to those searching for them. Future researchers may also investigate why respiratory therapy was viewed as an “inpatient therapy” rather than a therapy used to maintain and improve an individual’s current respiratory health for multiple participants.

Research on the effects of the COVID-19 pandemic on individuals with disabilities, including SCIs, would be helpful for the disabled community. Additional research may provide additional insights on how individuals with disabilities must navigate the world differently than their able-bodied counterparts. Since the COVID-19 pandemic, many in-person groups for those with disabilities had been postponed or cancelled altogether for the safety of their members; additional research may be conducted looking into the effect of isolation had on the overall well-being of individuals who relied on these groups for assistance. Furthermore, future researchers may delve into how to make these groups more accessible to those who may not be able to be physically present at all meetings, such as using audio conference platforms.

Based on the data obtained from this project stating that some healthcare professionals feel limited by FIM scores, initial research into the accuracy of these scores from the healthcare professionals’ perspectives may be beneficial for both the professionals and the patients they serve. Further research may also investigate how healthcare professionals feel about using these scores to document patients' progress since scores do not allow for flexibility in documentation of goals/objectives.

Participants' uses of music also varied greatly in their daily lives, but no questions were asked for this study regarding the emotion behind their uses of music. Future researchers may consider Sloboda and O'Neill's (2001) perspectives on how emotions may play a role in the use of music in individuals' daily lives and how cultural and personal differences may affect these emotions.

Suggestions For Music Therapists

I initially wanted to pursue this topic to describe barriers and design interventions to target decreased respiratory functioning in individuals with SCIs; however, the results given from my participants showed that there may be more pressing topics in the SCI community that music therapists could address. Anxiety was a topic brought up among all five participants in some form; whether overwhelming amounts of information during inpatient stays, financial worries from additional medical bills and equipment, self-advocation of needs, breathing deeply enough to avoid lightheadedness, or dealing with the challenges that come with a disability in general, all participants noted that stress levels for individuals with SCIs and their caregivers were very high. There also may be additional environmental barriers preventing integration into society that are not being addressed properly, if at all. The need for additional resources was also made clear, especially for outpatient respiratory therapy; neither

Peter, Paul, or myself knew of where to find services, though Peter was more confident that he could find what he needed through his healthcare team.

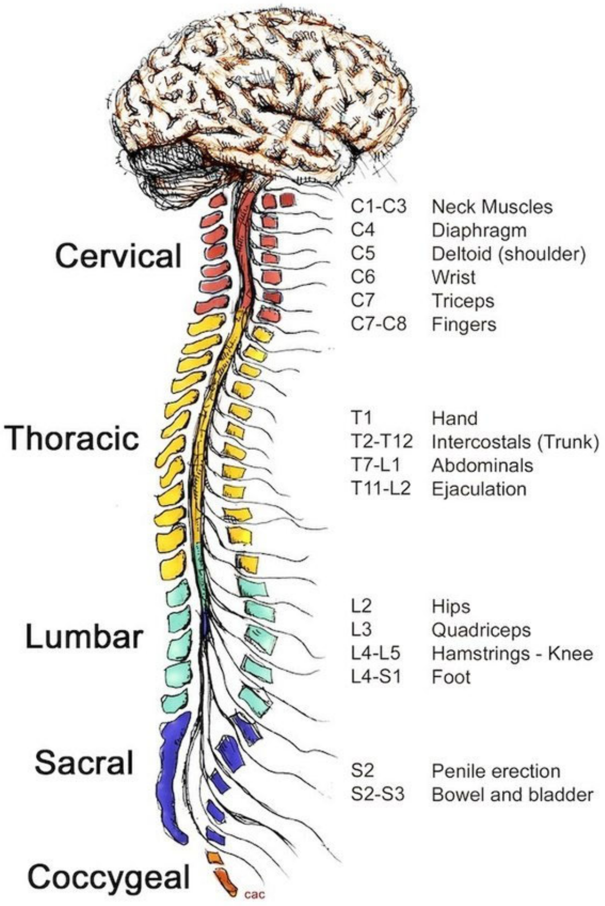
From the information gathered in this study, addressing stress and anxiety may lead to increased respiration, improved emotional state, and decreased heart rate. Previous research has shown MT targeting stress and anxiety to improve depressive symptoms (de la Rubia Orti et al., 2018; Gutiérrez & Camarena, 2015) improve emotional regulation (Landis-Shack et al., 2017; Hakvoort et al., 2013) reduce pain (Mondanaro et al., 2017) and reduce distress signals (Rossetti et al., 2017). Due to the findings of this research, specifically highlighting the prevalence of mental health, specifically anxiety, may be of the most benefit for individuals with SCIs; however, the unique needs of everyone must be considered before designing any treatment plans.

Conclusion

This study showed that decreased respiratory functioning plays a large role in the treatment and overall health of individuals with SCIs. It can interfere with multiple components of treatment and recovery processes, including anxiety, speech, mobility, independence, outlook, and overall health of the individual. Theoretical frameworks related to the themes of this study suggest a multi-faceted approach to disability may allow helping professionals to better understand the challenges that individuals with disabilities face to participate in society’s happenings and allow for a more individualized treatment plan. Individuals with SCIs would benefit from additional resources on the importance of respiratory health, where to find supplemental materials, and access to support groups in their area, when available, and online. Healthcare professionals who work with individuals with SCIs or are interested in working with them would benefit from additional knowledge of resources in the area and online, more experience on overcoming the effects of decreased respiratory functioning, and more resources about the importance of language preferences in the therapeutic setting.

Appendix A: Diagram of the Spine

This diagram shows the different vertebrae in their respective place in the spinal column (cervical, thoracic, lumbar, and sacral) as well as the functioning that will be affected from the level of injury and below. While an individual may have some functioning or control over some of their muscles below to point of injury, movement will be limited, if present at all.



Appendix B: Consent Form for Individuals with SCIs

Consent to Participate in a Research Study

Form for Individuals With SCI- No Signature

KEY INFORMATION FOR “DECREASED RESPIRATORY FUNCTIONING IN INDIVIDUALS WITH SPINAL CORD INJURIES”

We are asking you to choose whether to volunteer for a research study about the overall impact of decreased respiratory functioning in individuals with spinal cord injuries. We are asking you because you are an individual with a spinal cord injury at T12 or higher and at least a year post-injury. This page is to give you key information to help you decide whether to participate. We have included detailed information after this page. Ask the research team questions. If you have questions later, the contact information for the research investigator in charge of the study is below.

WHAT IS THE STUDY ABOUT AND HOW LONG WILL IT LAST?

The purpose of this study is to identify the primary issues that individuals with spinal cord injuries and their helping professionals face as a result of decreased respiratory functioning as well as the impact music can have on decreased respiratory support. By participating in this study, we hope to learn how individuals with different levels of SCIs are impacted by decreased respiratory functioning and how any decrease in respiratory functioning plays a role in a therapeutic setting. Your participation in this research will last about 30-60 minutes, depending on the length of your answers. You may skip any question at any time for any reason without explanation.

Interviews will be conducted either in person or via phone/Skype. Audio recordings will be taken for the sole purpose of transcribing your responses. They will not be shared with others and will be stored in a password-protected file folder. You may be asked questions about your prior experience in various therapies as treatment for your SCI, impact of decreased respiratory functioning on personal and social life, and other personal experiences.

We will keep confidential all research records that identify you to the extent allowed by law. However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court or to tell authorities if you report information about a child being abused or if you pose a danger to yourself or someone else. Also, we may be required to show information which identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as the University of Kentucky.

WHAT ARE KEY REASONS YOU MIGHT CHOOSE TO VOLUNTEER FOR THIS STUDY?

By participating in this study, you will be adding to the knowledge base for both individuals with spinal cord injuries as well as the professionals that work with them daily. For a complete description of benefits and/or rewards, refer to the Detailed Consent.

WHAT ARE KEY REASONS YOU MIGHT CHOOSE NOT TO VOLUNTEER FOR THIS STUDY?

It is possible that talking about your spinal cord injury may make you uncomfortable. If this happens, you may end the interview at any time, or you may decline to answer any questions you do not want to answer. In addition to risks described in this consent, you may experience a previously unknown risk or side effect. For a complete description of risks, refer to the Detailed Consent.

DO YOU HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any services, benefits, or rights you would normally have if you choose not to volunteer. You may choose to drop out or withdraw from this study at any point.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS OR CONCERNS?

If you have questions, suggestions, or concerns regarding this study, or you want to withdraw from the study, please contact A'Marie Dotson of the University of Kentucky, Department of Music Therapy, at acru228@uky.edu or (859) 802-4355. You may also contact the thesis advisor for this study, Dr. Olivia Yinger, director of the University of Kentucky music therapy program. Her contact information is: olivia.yinger@uky.edu or 859-218-0997.

If you have any concerns or questions about your rights as a volunteer in this research, contact staff in the University of Kentucky (UK) Office of Research Integrity (ORI) between the business hours of 8am and 5pm EST, Monday-Friday at 859-257-9428 or toll free at 1-866-400-9428.

DETAILED CONSENT:

ARE THERE REASONS WHY YOU WOULD NOT QUALIFY FOR THIS STUDY?

You will not quality to participate if you are under the age of 18, have a spinal cord injury not at T12 or higher, had a spinal cord injury within the past 6 months, do not speak or understand English, not medically stable, actively ventilated, or unable to give consent to participate in this study.

WHERE WILL THE STUDY TAKE PLACE AND WHAT IS THE TOTAL AMOUNT OF TIME INVOLVED?

Your interview may either be conducted in person or over the phone or video software, depending on your preference and your distance from the Lexington area. You will be asked to answer a series of questions during one 30-60-minute interview. The total amount of time you will be asked to volunteer for this study is 60-90 minutes.

WHAT WILL YOU BE ASKED TO DO?

The researcher will ask you a series of questions about any changes in respiratory functioning that occurred as a result of your spinal cord injury. You will also be asked about any effect that decreased respiratory functioning has on your personal, social, and physical well-being, and to describe your experiences in physical therapy, occupational therapy, speech therapy, and music therapy. You may skip any question at any time for any reason without explanation.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

It is possible that talking about your spinal cord injury may make you uncomfortable. If this happens, you may end the interview at any time, or you may decline to answer any questions you do not want to answer. In addition to risks described in this consent, you may experience a previously unknown risk or side effect.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?

We do not know if you will get any benefit from taking part in this study. However, if you take part in this study, information learned may help you and others by providing information for music therapists about the experiences of people with spinal cord injuries and professionals who work with individuals who have had spinal cord injuries.

IF YOU DON’T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?

There are no costs associated with taking part in this study.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?

When we write about or share the results from the study, we will write about the combined information. You have the option to share your name and other identifying information taken for the purpose of the masters’ thesis or you may choose to keep the information private.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. All audio recordings and interview copies will be kept on a password-protected drive on the primary researcher’s personal computer. If you wish to remain anonymous for the thesis, your name will only be known by the primary researcher and the thesis advisor, and you may select a pseudonym to be used in place of your real name in the thesis document. For those that allow us to share your identity, your name will be published along with your answers to the interview questions. All information taken will be for the purpose of completing the primary researcher’s thesis, but results may be considered for future publication in a music therapy journal.

We will keep confidential all research records that identify you to the extent allowed by law. However, there are some circumstances in which we may have to show your information to other people For example, the law may require us to show your information to a court or to tell authorities if you report information about a child being abused or if you pose a danger to yourself or someone else. Also, we may be required to show information which identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as the University of Kentucky.

For individuals who choose to interview via Skype: Please be aware, while we make every effort to safeguard your data once received from the online audio-conferencing company, given the nature of online conferencing software, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey/data gathering company’s servers, or while en route to either them or us. It is also possible the raw data collected for research purposes may be used for marketing or reporting purposes by the survey/data gathering company after the research is concluded, depending on the company's Terms of Service and Privacy policies.

CAN YOU CHOOSE TO WITHDRAW FROM THE STUDY EARLY?

You can choose to leave the study at any time. You will not be treated differently if you decide to stop taking part in the study.

If you choose to leave the study early, data collected until that point will remain in the study database and may not be removed.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?

You will receive a total of 15 dollars for your participation in this project. Individuals that withdraw from the study at any time before completion will receive a total of $7.50.

WILL YOU BE GIVEN INDIVIDUAL RESULTS FROM THE RESEARCH TESTS/SURVEYS?

Generally, interviews done for research purposes are not meant to provide results that apply to you alone.

WHAT ELSE DO YOU NEED TO KNOW?

The investigator is a graduate student and is being guided in this research by Olivia Swedberg Yinger, PhD, MT-BC. There may be other people on the research team assisting at different times during the study. There will be approximately 8 people in total participating in this study.

WILL YOUR INFORMATION BE USED FOR FUTURE RESEARCH?

Your information collected for this study will NOT be used or shared for future research studies, even if we remove the identifiable information, such as your name.

By continuing with the interview, you are consenting to participate in this study.

This consent includes the following:

- **Key Information Page**
- **Detailed Consent**

Appendix C: Consent Form for Professionals

Consent to Participate in a Research Study

Form for Professionals- No Signature

KEY INFORMATION FOR "DECREASED RESPIRATORY FUNCTIONING IN INDIVIDUALS WITH SPINAL CORD INJURIES"

We are asking you to choose whether to volunteer for a research study about the overall impact of decreased respiratory functioning in individuals with spinal cord injuries. We are asking you because you are a professional who has worked or is currently working with individuals with spinal cord injuries at T12 or higher. This page is to give you key information to help you decide whether to participate. We have included detailed information after this page. Ask the research team questions. If you have questions later, the contact information for the research investigator in charge of the study is below.

WHAT IS THE STUDY ABOUT AND HOW LONG WILL IT LAST?

The purpose of this study is to identify the primary issues that individuals with spinal cord injuries and their helping professionals face as a result of decreased respiratory support and how music can play a part in the therapeutic process. By your participation in this study, we hope to learn how decreased respiratory functioning affects the therapeutic goals, interventions, and perspectives of professionals that work with individuals with spinal cord injuries. Your participation in this research will last about 30-60 minutes, depending on the length of your answers.

Interviews will be conducted either in person or via phone/Skype. Audio recordings will be taken for the sole purpose of transcribing your responses. They will not be shared with others and will be stored in a password-protected file folder. You may be asked questions about your thoughts on intervention effectiveness, your perspectives on how decreased respiratory support affects your desired goals in a therapeutic setting, and how music is used in your sessions, if at all.

WHAT ARE KEY REASONS YOU MIGHT CHOOSE TO VOLUNTEER FOR THIS STUDY?

By participating in this study, you will be adding to the knowledge base for both individuals with spinal cord injuries as well as the professionals that work with them daily. For a complete description of benefits and/or rewards, refer to the Detailed Consent.

WHAT ARE KEY REASONS YOU MIGHT CHOOSE NOT TO VOLUNTEER FOR THIS STUDY?

You may choose not to volunteer for this study if you do not want to answer questions about your work with people who have spinal cord injuries. In addition to any risks described in this consent, you may experience a previously unknown risk or side effect. For a complete description of risks, refer to the Detailed Consent.

DO YOU HAVE TO TAKE PART IN THE STUDY?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any services, benefits, or rights you would normally have if you choose not to volunteer. You may choose to drop out or withdraw from this study at any point.

WHAT IF YOU HAVE QUESTIONS, SUGGESTIONS OR CONCERNS?

If you have questions, suggestions, or concerns regarding this study, or you want to withdraw from the study, please contact A'Marie Dotson of the University of Kentucky, Department of Music Therapy, at acru228@uky.edu or (859) 802-4355. You may also contact the thesis advisor for this study, Dr. Olivia Yinger, director of the University of Kentucky music therapy program. Her contact information is: olivia.yinger@uky.edu or 859-218-0997.

If you have any concerns or questions about your rights as a volunteer in this research, contact staff in the University of Kentucky (UK) Office of Research Integrity (ORI) between the business hours of 8am and 5pm EST, Monday-Friday at 859-257-9428 or toll free at 1-866-400-9428.

DETAILED CONSENT:

ARE THERE REASONS WHY YOU WOULD NOT QUALIFY FOR THIS STUDY?

You will not qualify to participate if you have never worked with people who have spinal cord injuries at T12 or higher, are not in good standing in your chosen profession, or do not speak or understand English clearly.

WHERE WILL THE STUDY TAKE PLACE AND WHAT IS THE TOTAL AMOUNT OF TIME INVOLVED?

Your interview may either be conducted in person or over the phone or video software, depending on your preference and your distance from the Lexington area. You will be asked to answer a series of questions during one 30-60-minute interview. The total amount of time you will be asked to volunteer for this study is 60-90 minutes.

WHAT WILL YOU BE ASKED TO DO?

The researcher will ask you to describe any unique challenges that people with spinal cord injuries often face, goals you address, what interventions you commonly use, and how music is involved in your sessions, if at all. You may skip any question at any time for any reason without explanation.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

You may choose not to volunteer for this study if you do not want to answer questions about your work with people who have spinal cord injuries. In addition to any risks described in this consent, you may experience a previously unknown risk or side effect.

WILL YOU BENEFIT FROM TAKING PART IN THIS STUDY?

We do not know if you will get any benefit from taking part in this study. However, if you take part in this study, information learned may help you and others by providing information for music therapists about the experiences of people with spinal cord injuries and professionals who work with individuals who have had spinal cord injuries.

IF YOU DON’T WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

If you do not want to be in the study, there are no other choices except not to take part in the study.

WHAT WILL IT COST YOU TO PARTICIPATE?

There are no costs associated with taking part in this study.

WHO WILL SEE THE INFORMATION THAT YOU GIVE?

When we write about or share the results from the study, we will write about the combined information. You have the option to share your name and other identifying information taken for the purpose of the masters’ thesis or you may choose to keep the information private.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. All audio recordings and interview copies will be kept on a password-protected drive on the primary researcher’s personal computer. If you wish to remain anonymous for the thesis, your name will only be known by the primary researcher and the thesis advisor. For those that allow us to share your identity, your name will be published in the primary researcher’s thesis document along with your answers to the interview questions.

We will keep confidential all research records that identify you to the extent allowed by law. However, there are some circumstances in which we may have to show your information to other people For example, the law may require us to show your information to a court or to tell authorities if you report information about a child being abused or if you pose a danger to yourself or someone else. Also, we may be required to show information which identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as the University of Kentucky.

For those who choose to interview via Skype: Please be aware, while we make every effort to safeguard your data once received from the online audio-conferencing company, given the nature of online conferencing software, as with anything involving the Internet, we can never guarantee the confidentiality of the data while still on the survey/data gathering company’s servers, or while en route to either them or us. It is also possible the raw data collected for research purposes may be used for marketing or reporting purposes by the survey/data gathering company after the research is concluded, depending on the company’s Terms of Service and Privacy policies.

CAN YOU CHOOSE TO WITHDRAW FROM THE STUDY EARLY?

You can choose to leave the study at any time. You will not be treated differently if you decide to stop taking part in the study.

If you choose to leave the study early, data collected until that point will remain in the study database and may not be removed.

WILL YOU RECEIVE ANY REWARDS FOR TAKING PART IN THIS STUDY?

You will receive a total of 15 dollars for taking part in this study. Individuals that withdraw from the study at any time before completion will receive a total of $7.50.

WILL YOU BE GIVEN INDIVIDUAL RESULTS FROM THE RESEARCH TESTS/SURVEYS?

Generally, interviews done for research purposes are not meant to provide results that apply to you alone.

WHAT ELSE DO YOU NEED TO KNOW?

The investigator is a graduate student and is being guided in this research by Olivia Swedberg Yinger, PhD, MT-BC. There may be other people on the research team assisting at different times during the study. There will be approximately 8 people in total participating in this study.

WILL YOUR INFORMATION BE USED FOR FUTURE RESEARCH?

Your information collected for this study will NOT be used or shared for future research studies, even if we remove the identifiable information such as your name.

By continuing with the interview, you are consenting to participate in this study.

This consent includes the following:

- **Key Information Page**
- **Detailed Consent**

Appendix D: Interview Questions

Individuals with SCI

Level and Type of Injury:

Years injured:

1. What does a typical day look like for you?
2. How often do you experience decreased respiratory functioning?
3. How often does decreased respiratory functioning affect your life?
4. In what ways do you feel that decreased respiratory support affects your life? (For example, personal, social, work, activities of daily living)
5. Could you describe your perception of therapies you are receiving currently or have received in the past as treatment for your SCI?
6. Have you ever done therapy/interventions to try and increase your respiratory functioning? If so, what?

7. How do you use music in your everyday life?

8. What do you wish people understood about your experience with an SCI?

9. Do you see a need for more resources tailored specifically to help individuals with SCIs improve respiratory functioning? If so, what types of resources do you think would helpful?

10. Do you have any final comments?

Healthcare Professionals

Name:

Title:

Years practicing:

1. How long have you worked with individuals with SCIs?

2. What are some of the primary goals you work on with people who have SCIs?

3. You mentioned that one of the primary goals you address with people who have SCI is _____ [mention the first goal the interviewee stated in response to question 2]. If you were addressing this goal with someone who has an SCI who also had decreased respiratory functioning, would your treatment look different? If so, how?

4. Could you give me some examples of treatments you may use when working with people with SCI?

5. How do you feel decreased respiratory support affects people with SCI, both in and out of the rehabilitation setting?

6. Do you feel that respiratory support is something most professionals consider when working with these individuals? If so, how?

7. Do you see a need for more resources tailored specifically to help individuals with SCIs improve respiratory functioning? If so, what types of resources do you think would helpful?

8. Are there any opposing viewpoints on how treatments should be implemented in your field regarding individuals with spinal cord injuries and decreased respiratory functioning? If so, how?
9. Do you ever use music in your treatment of people with SCI? If so, how?

10. Do you have any final comments?

References

Abma, T. A. (2005). Patient participation in health research: Research with and for people with spinal cord injuries. *Qualitative Health Research, 15*(10), 1310–1328. https://doi.org/10.1177/1049732305282382

Alashram, A. R., Annino, G., & Mercuri, N. B. (2019). Rhythmic auditory stimulation in gait rehabilitation for traumatic brain and spinal cord injury. *Journal of Clinical Neuroscience, 69,* 287–288. https://doi.org/10.1016/j.jocn.2019.08.080

American Music Therapy Association. (2021a). Educational requirements for music therapists. https://www.musictherapy.org/about/requirements/

American Music Therapy Association. (2021b). How to find a music therapist. https://www.musictherapy.org/about/find/

American Occupational Therapy Association. (2021). Occupational therapy and the care of individuals with spinal cord injury fact sheet. https://www.aota.org/-/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/RDP/Facts/SCI-fact-sheet.pdf

American Physical Therapy Association. (2021). Role of a physical therapist. https://www.apta.org/PTCareers/RoleofaPT/

American Therapeutic Recreation Association. (2021). Become a recreational therapist. Retrieved from https://www.atra-online.com/page/BecomeAnRT

American Speech-Language Hearing Association. (2021). Who are speech-language pathologists, and what do they do? https://www.asha.org/public/Who-Are-Speech-Language-Pathologists/

American Spinal Cord Association. (2019). International Standards for Neurological Classification of Spinal Cord Injuries. https://asia-spinalinjury.org/wp-content/uploads/2019/04/ASIA-ISCOS-IntlWorksheet_2019.pdf

American Therapeutic Recreation Association. (2021). Become a recreational therapist. https://www.atra-online.com/page/BecomeAnRT

ATLAS.ti Cloud. (2020). *ATLAS.ti Cloud* [Computer software]. https://atlasti.com/cloud/

Baram, Y., & Lenger, R. (2012). Gait improvement in patients with cerebral palsy by visual and auditory feedback. *Neuromodulation, 15*(1), 48–52. https://doi.org/10.1111/j.1525-1403.2011.00412.x

Benoit, C. E., Dalla Bella, S., Farrugia, N., Obrig, H., Mainka, S., & Kotz, S. A. (2014). Musically cued gait-training improves both perceptual and motor timing in Parkinson's disease. *Frontiers in Human Neuroscience, 8,* 494–495. https://doi.org/10.3389/fnhum.2014.00494

Bouchard, S., & Hook, M. (2014). Psychological stress as a modulator of functional recovery following spinal cord injury. *Frontiers in Neurology, 9*(5)*,* 1– 9. https://doi.org/10.3389/fneur.2014.00044

Brommer, B., Engel, O., Kopp, M., Watzlawick, R., Müller, S., Prüss, H., Chen, Y., DeVivo, M., Finkenstaedt, F., Dirnagl, U., Liebscher, T., Meisel, A., & Schwab, J. (2016). Spinal cord injury-induced immune deficiency syndrome enhances infection susceptibility dependent on lesion level, *Brain, 139(*3), 692–707. https://doi.org/10.1093/brain/awv375 !

Brooks, C., Porter, D., Furnas, D., & Wingate, J. (2021). The effects of therapeutic group singing on voice, cough and quality of life in Parkinson's disease. *Clinical Archives of Communication Disorders, 6*(2), 79–88. http://doi.org/10.21849/cacd.2021.00395

Brougham, R., Spivak-David, D., Adornato, V., Gordan, W., Dale, B., Georgeadis, A., & Gassaway, J. (2011). Speech-language pathology treatment time during inpatient spinal cord injury rehabilitation: The SCIRehab project. *Journal of Spinal Cord Rehabilitation, 34*(2), 186–195. https://doi.org/10.1179/107902611X12971826988174

Bukowska, A., Krężałek, P., Mirek, E., Bujas, P., & Marchewka, A. (2015). Neurologic music therapy training for mobility and stability rehabilitation with Parkinson's disease–A pilot study. *Frontiers in Human Neuroscience, 9*(710)*,* 1–12. https://doi.org/10.3389/fnhum.2015.00710

Cahow, C., Gassaway, J., Rider, C., Joyce, J., Bogenshutz, A., Edens,K., Kreider, S., & Whiteneck, G. (2012). Relationship of therapeutic recreation inpatient rehabilitation interventions and patient characteristics to outcomes following spinal cord injury: The SCIRehab project. *Journal of Spinal Cord Medicine, 35*(6), 547–564. https://doi.org/10.1179/2045772312Y.0000000066

Castro, M., Tillmann, B., Luauté, J., Corneyllie, A., Dailler, F., André-Obadia, N., & Perrin, F. (2015). Boosting cognition with music in patients with disorders of consciousness. *Neurorehabilitation and Neural Repair, 29*(8)*,* 734–742. https://doi.org/10.1177/1545968314565464

Centers for Disease Control (2021a). About social determinants of health. https://www.cdc.gov/socialdeterminants/about.html

Centers for Disease Control (2021b). The ICF: An overview. https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf

Chiaravalloti, N., Weber, E., Wylie, G., Dyson-Hudson, T., & Wecht, J. (2018). Patterns of cognitive deficits in persons with spinal cord injury as compared with both age-matched and older individuals without spinal cord injury. *Journal of Spinal Cord Medicine, 43*(1), 88–97. https://doi.org/10.1080/10790268.2018.1543103

Cleveland Clinic (2020). Dysarthria and speech: Symptoms, causes, and treatments. https://my.clevelandclinic.org/health/diseases/17653-dysarthria

Comber, A., Brunsdon, C., & Radburn, R. (2011). A spatial analysis of variations in health access: linking geography, socio-economic status and access perceptions. *International Journal of Health Geographics, 10*(44), 1–11. https://doi.org/10.1186/1476-072X-10-44

Cooke, M., Moyle, W., Shum, D., Harrison, S., & Murfield, J. (2010). A randomized controlled trial exploring the effect of music on agitated behaviours and anxiety in older people with dementia. *Aging and Mental Health, 14*(8), 905–916. https://doi.org/10.1080/13607861003713190 $

Coppens-Hofman M., Terband, H., Snik, A., & Maassen B., (2016). Speech characteristics and intelligibility in adults with mild and moderate intellectual disabilities. *Folia Phoniatr Logop, 68,* 175–182. https://doi.org/10.1159/000450548

Craig, D. (2008). An overview of evidence-based support for the therapeutic use of music in occupational therapy. *Occupational Therapy Health Care, 22*(1), 73-95. https://doi.org/10.1080/J003v22n01_06

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Sage Publications, Inc.

de Bruin N., Doan, J. B., Turnbull, G., Suchowersky, O., Bonfield, S., Hu, B., & Brown, L. A. (2010). Walking with music is a safe and viable tool for gait training in Parkinson's disease: The effect of a 13-week feasibility study on single and dual task walking. *Parkinson's Disorders, 2010,* 483530. https://doi.org/10.4061/2010/483530

de Dreu, M., van der Wilk, A., Poppe, E., Kwakkel, G., & van Wegen, E. (2012). Rehabilitation, exercise therapy and music in patients with Parkinson's disease: A meta-analysis of the effects of music-based movement therapy on walking ability, balance and quality of life. *Parkinsonism & Related Disorders, 18,* S114–S119. https://doi.org/10.1016/S1353-8020(11)70036-0

DeJong, G., Tian, W., Hsieh, C., Junn, C., Karam, C., Ballard, P., Smout, R., Horn, S., Zanca, J., Heinemann, A., Hammond, F., & Backus, D. (2013). Rehospitalization in the first year of traumatic spinal cord injury after discharge from medical rehabilitation. *Archives of Physical Medicine and Rehabilitation, 94*(4), 87–97. https://doi.org/10.1016/j.apmr.2012.10.037

de la Rubia Ortí, J., García-Pardo, M., Iranzo, C., Madrigal, J., Castillo, S., Rochina, M., & Gascó, V. (2018). Does music therapy improve anxiety and depression in Alzheimer's patients? *Journal of Alternative Complimentary Medicine, 24*(1), 33–36. https://doi.org/10.1089/acm.2016.0346

de l'Etoile, S. (2008). The effect of rhythmic auditory stimulation on the gait parameters of patients with incomplete spinal cord injury: an exploratory pilot study. *International Journal of Rehabilitation Research*, *31*(2), 155–157. https://doi.org/10.1097/MRR. 0b013e3282fc0f44

De Witte, M., Van Hooren, S., Lindelauf, E., Moonen, X., & Stams, G. (2020). Music therapy interventions for stress reduction in adults with mild intellectual disabilities: Perspectives from clinical practice. *Frontiers in Psychology, 11*, 527–549. https://doi.org/10.3389/fpsyg.2020.572549

Dijkers, M. (2003). Individualization in quality-of-life measurement: Instruments and approaches. *Archives of Physical Medicine and Rehabilitation, 84*(2), S3–S14. https://doi.org/10.1053/apmr.2003.50241

Dileo, C. (2000). *Ethical decision making in music therapy.* Jeffrey Books.

Doctor, J., Wolfson, A., McKnight, P., & Burns, S. (2003). The effect of inaccurate FIM instrument ratings on prospective payments: A study of clinician expertise and FIM rating difficulty as contributing to inaccuracy. *Archives of Physical Medicine, 84*, 46–50. https://doi.org/10.1053/apmr.2003.50063

Elefant, C., Baker, F., Lotan, M., Lagesen, S., & Skeie, G. (2012). The effect of group music therapy on mood, speech, and singing in individuals with Parkinson's disease--A feasibility study. *Journal of Music Therapy, 49*(3), 278–302. https://doi.org/10.1093/jmt/49.3.278

Elsner, B., Schöler, A., Kon, T., & Mehrholz, J. (2019). Walking with rhythmic auditory stimulation in chronic patients after stroke: A pilot randomized controlled trial. *Physiotherapy Research International, 25*(1), 1–7. https://doi.org/10.1002/pri.1800

Engel, G. (1977). The need for a new medical model: A challenge for biomedicine. *Science, 196*, 129–36. https://doi.org/10.1126/science.847460

Engel, G. (1980). The clinical application of the biopsychosocial model. *American Journal of Psychiatry, 137*(5), 535–544. https://doi.org/10.1176/ajp.137.5.535

Fancourt, D., Williamon, A., Carvalho, L., Steptoe, A., Dow, R., & Lewis, I. (2016). Singing modulates mood, stress, cortisol, cytokine and neuropeptide activity in cancer patients and carers. *ECancer, 10*, 1–13. https://doi.org/10.3332/ecancer.2016.631

Ferguson, K., Mitro, J., Bhanji, A., Yang, S., Gerber, L., Cai, C., Garfinkel, S., & Weinstein, A. (2021). Qualitative Investigation of Health Information Resources for Caregivers and Individuals Living with Spinal Cord Injury. *Topics In Spinal Cord Rehabilitation, 27(4),* 79– 98. https://doi.org/10.46292/sci20-00032

Forchheimer, M., & Tate, D. (2004). Enhancing community re-integration following spinal cord injury. *Neurorehabilitation, 19,* 103–113. https://doi.org/10.1310/sci16-00055

Ford, S., Keay, A., & Skipper, D. (2013). *Occupational therapy interventions for adults with a spinal cord injury* [brochure]. https://aci.health.nsw.gov.au/__data/assets/pdf_file/0004/155191/occupational-therapy-interventions.pdf

Foy, T., Perritt, G., Thimmaiah, D., Heisler, L., Offutt, J., Cantoni, K., Hseih, C., Gassaway, J., Ozelie, R., & Backus, D. (2011). The SCIRehab project: Treatment time spent in SCI rehabilitation. Occupational therapy treatment time during inpatient spinal cord injury rehabilitation. *Journal of Spinal Cord Medicine, 34*(2), 162–175. https://doi.org/10.1179/107902611X12971826988093

Francis, A. L. & Nusbaum, H. C. (2009). Effects of intelligibility on working memory demand for speech perception. *Attention, Perception, & Psychophysics, 71,* 1360–1374. https://doi.org/10.3758/APP.71.6.1360

Galletta, A. (2012). *Mastering the semi-structured interview and beyond: From research design to analysis and publication.* New York University Press.

Glesne, C. (2006). *Becoming qualitative researchers: An introduction.* (3rd ed.). Pearson Education, Inc.

Gonzalez, S., Alvarez, V., & Nelson, E. (2019). Do gross and fine motor skills differentially contribute to language outcomes? A systematic review. *Frontiers in Psychology, 10,* 1–16. https://doi.org/10.3389/fpsyg.2019.02670

Goodman, N., O'Day, B., & Morris, M. (2017). Financial capabilities of adults with disabilities. National Institute for Disabilities and FINRA Investor Education Foundation. https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/01/ndi-finra-report-2017.pdf

Gutiérrez, E., & Camarena, V. (2015). Music therapy in generalized anxiety disorder. *The Arts in Psychotherapy, 44,* 19–24. https://doi.org/10.1016/j.aip.2015.02.003

Habibi, A., Damasio, A., Ilari, B., Veiga, R., Joshi, A., Leahy, R., Haldar, J., Varadarajan, D., Bhushan, C., & Damasio, H. (2018). Childhood music training induces change in micro and macroscopic brain structure: Results from a longitudinal study, *Cerebral Cortex*, *28*(12)*,* 4336–4347. https://doi.org/10.1093/cercor/bhx286

Hakvoort, L., Bogaerts, S., Thaut, M., & Spreen, M. (2013). Influence of music therapy on coping skills and anger management in forensic psychiatric patients: An exploratory study. *International Journal of Offender Therapy and Comparative Criminology, 59*(8), 810–836. https://doi.org/10.1177/0306624X13516787

Hammel, J., Magasi, S., Heinemann, A., Gray, D., Stark, S., Kisala, P., Carlozzi, N., Tulsky, D., Garcia, S., & Hahn, E. (2015). Environmental barriers and supports to everyday participation: A qualitative insider perspective from people with disabilities. *Archives of Physical Medicine and Rehabilitation, 96*(4), 578–588. https://doi.org/10.1016/j.apmr.2014.12.008

Hars, M., Herrmann, F. R., Gold, G., Rizzoli, R., & Trombetti, A. (2013). Effect of music-based multitask training on cognition and mood in older adults. *Age and Ageing, 43*(2), 196–200. https://doi.org/10.1093/ageing/aft163

Harvey, L., Lin, C., Glinsky, J., & De Wolf, A. (2009). The effectiveness of physical interventions for people with spinal cord injuries: A systematic review. *Spinal Cord, 47*(3), 184–195. https://doi.org/10.1038/sc.2008.100

Horne-Thompson, A., & Grocke, D. (2008). The effect of music therapy on anxiety in patients who are terminally ill. *Journal of Palliative Medicine, 11*(4), 582–590. http://doi.org/10.1089/jpm.2007.0193

Ikeda, K,. Kawakami, K., Onimaru, H., Okada, Y., Yokota, S., Koshiya, N., Oku, Y., Iizuka, M., & Koizumi, H. (2017). The respiratory control mechanisms in the brainstem and spinal cord: Integrative views of the neuroanatomy and neurophysiology.

Journal of Physiological Science, 67(1), 45–62. https://doi.org/10.1007/s12576-016-0475-y

Kisala, P. A., Tulsky, D. S., Kalpakjian, C. Z., Heinemann, A. W., Pohlig, R. T., Carle, A., & Choi, S. W. (2015). Measuring anxiety after spinal cord injury: Development and psychometric characteristics of the SCI-QOL Anxiety item bank and linkage with GAD-7. *The Journal of Spinal Cord Medicine, 38*(3), 315–325. https://doi.org/10.1179/2045772315Y.0000000029

Korhan, E., Khorshid, L., & Uyar, M. (2011). The effect of music therapy on physiological signs of anxiety in patients receiving mechanical ventilatory support*. Journal of Clinical Nursing, 20*(7–8), 1026–1034. https://doi.org/10.1111/j.1365-2702.2010.03434.x

Kotz, S. A., & Gunter, T. C. (2015). Can rhythmic auditory cuing remediate language-related deficits in Parkinson's disease? *Annals of the New York Academy of Sciences, 1337*(1), 62–68. https://doi.org/10.1111/nyas.12657

Kunert, R., Willems, R., Casasanto, D., Patel, A., & Hagoort, P. (2015) Music and language syntax interact in Broca’s area: An fMRI study. *PLOS One, 10*(11)*,* 1–16. https://doi.org/10.1371/journal.pone.0141069

Kwan, M. (2013). Beyond space (as we knew it): Toward temporally integrated geographies of segregation, health, and accessibility. *Annals of the Association of American Geographers, 103*(5), 1078–1086. https://doi.org/10.1080/00045608.2013.792177

Landis-Shack, N., Heinz, A. J., & Bonn-Miller, M. O. (2017). Music Therapy for Posttraumatic Stress in Adults: A Theoretical Review. *Psychomusicology, 27*(4), 334–342. https://doi.org/10.1037/pmu0000192

Lawrason, S., Todd, K., Shaw, R., & Ginis, K. (2020). Physical activity among individuals with spinal cord injury who ambulate: A systematic scoping review. *Spinal Cord, 58*(7), 735–745. https://doi.org/10.1038/s41393-020-0460-4

Le, J., & Dorstyn, D. (2016). Anxiety prevalence following spinal cord injury: A meta-analysis. *Spinal Cord, 54*(8), 570–578. https://doi.org/10.1038/sc.2016.15

Lim, K. B., Kim, Y. K., Lee, H. J., Yoo, J., Hwang, J. Y., Kim, J. A., & Kim, S. K. (2013). The therapeutic effect of neurologic music therapy and speech language therapy in post-stroke aphasic patients. *Annals of Rehabilitation Medicine, 37*(4), 556–562. https://doi.org/10.5535/arm.2013.37.4.556

Landis-Shack, N., Heinz, A. J., & Bonn-Miller, M. O. (2017). Music therapy for posttraumatic stress in adults: A theoretical review. *Psychomusicology: Music, Mind, and Brain, 27*(4), 334–342. https://doi.org/10.1037/pmu0000192

Linnemann, A., Strahler, J., & Nater, U. (2016). The stress-reducing effect of music listening varies depending on the social context. *Psychoneuroendocrinology, 72*, 97–105. https://doi.org/10.1016/j.psyneuen.2016.06.003

Martin, K., Bessell, N., & Scholten, I. (2013). The perceived importance of anatomy and neuroanatomy in the practice of speech—language pathology. *Anatomical Sciences Education, 7*, 28–37. https://doi.org/10.1002/ase.1377

Martz, E. (2005). Associations and predictors of posttraumatic stress levels according to person-related, disability-related, and trauma-related variables among individuals with spinal cord injuries. *Rehabilitation Psychology, 50*(2), 149–157. https://doi.org/10.1037/0090-5550.50.2.149

Mayo Clinic. (2021). Spinal cord injury. https://www.mayoclinic.org/diseases-conditions/spinal-cord-injury/symptoms-causes/syc-20377890

McRae, J., Hayton, J. & Smith, C. (2021). Speech and language therapy service provision in spinal injury units compared to major trauma centres in England: Are services matched? *International Journal of Language and Communicative Disorders*. https://doi.org/10.1111/1460-6984.12671

Mondanaro, J., Homel, P., Lonner, B., Shepp, J., Lichtensztejn, M., & Loewy, J. (2017). Music therapy increases comfort and reduces pain in patients recovering from spine surgery. *American Journal of Orthopedics, 46*(1), E13–E22.

Moreno, S. (2009). Can music influence language and cognition? *Contemporary Music Review, 28*(3), 329–345. https://doi.org/10.1080/07494460903404410

Nas, K., Yazmalar, L., Şah, V., Aydın, A., & Öneş, K. (2015). Rehabilitation of spinal cord injuries. *World Journal of Orthopedics, 6*(1), 8–16. https://doi.org/10.5312/wjo.v6.i1.8

Naeser, M., & Helm-Estabrooks, N. (1985). CT scan lesion localization and response to melodic intonation therapy with nonfluent aphasia cases. *Cortex, 21*, 203–223. https://doi.org/10.1016/s0010-9452(85)80027-7

National Council for Therapeutic Recreation Certification (2021). Become a CTRS. https://www.nctrc.org/new-applicants/become-a-ctrs/

National Highway Traffic Safety Administration. (2021). Adapting Your Vehicle. https://www.nhtsa.gov/road-safety/adapted-vehicles

National Spinal Cord Injury Statistical Center. (2020). Spinal cord injury facts and figures at a glance. https://www.nscisc.uab.edu/Public/Facts%20and%20Figures%202020.pdf

Neurologic Music Therapy Services of Arizona (2021). What Is Neurologic Music Therapy? https://www.nmtsa.org/what-is-nmt Noller, C., Groah, S., & Nash, M. (2017). Inflammatory stress effects on health and function after spinal cord injury. *Top Spinal Cord Injury Rehabilitation. 23*(3), 207-217. https://doi.org/10.1310/sci2303-207

O'Shea, A. & Smedema, S. (2013). Understanding depressive symptoms among individuals with spinal cord injuries: A biopsychosocial perspective. *Rehabilitation Counseling Bulletin, 58*(1), 20–28. https://doi.org/10.1177/0034355213512210

Pascual-Leone, A. (2001). The brain that plays music and is changed by it. *Annals of the New York Academy of Sciences, 930*(1), 315–329. https://doi.org/10.1111/j.1749-6632.2001.tb05741.x

Paul, S., & Ramsey, D. (2000). Music therapy in physical medicine and rehabilitation. *Australian Occupational Therapy Journal, 47*(3), 111–118. https://doi.org/10.1046/j.1440-1630.2000.00215.x

Permobil Products (2021). Sip and Puff System. https://www.permobil.com/en-us/products/accessories/drive-controls/permobil-sip-puff-system

Peterson, M., Kamdar, N., Chiodo, A., & Tate, D. (2020). Psychological morbidity and chronic disease among adults with traumatic spinal cord injuries: A longitudinal cohort study of privately insured beneficiaries. Mayo Clinic Proceedings, 95(5), 920–928. https://doi.org/10.1016/j.mayocp.2019.11.029.

Postma, K., Haisma, J., de Groot, S., Hopman, M., Bergen, M., Stam, H., & Bussmann, J. (2012). Changes in pulmonary function during the early years after inpatient rehabilitation in persons with spinal cord injury: A prospective cohort study. *Archives of Physical Medicine and Rehabilitation, 94*(8), 1540–1546. https://doi.org/10.1016/j.apmr.2013.02.006.

Push Diaries Podcast (2020). Retrieved from https://www.pushdiariespodcast.com/

Raab, A., Krebs, J., Perret, C., Pfister, M., Hopman, M., & Mueller, G. (2018). Evaluation of a clinical implementation of a respiratory muscle training group during spinal cord injury rehabilitation. *Spinal Cord Series and Cases, 4*(1), 40–48. https://doi.org/10.1038/s41394-018-0069-4

Raglio, A., Zaliani, A., Baiardi, P., Bossi, D., Sguazzin, C., Capodaglio, E., Imbriani, C., Gontero, G., & Imbriani, M. (2017). Active music therapy approach for stroke patients in the post-acute rehabilitation. *Neurological Sciences, 38,* 893–897. https://doi.org/10.1007/s10072-017-2827-7

Raglio, A., Galandra, C., Sibilla, L., Esposito, F., Gaeta, F., Di Salle, F., Moro, L., Carne, I., Bastianello, S., Baldi, M., & Imbriani, M. (2016). Effects of active music therapy on the normal brain: fMRI based evidence. *Brain Imaging and Behavior, 10*, 182–186. https://doi.org/10.1007/s11682-015-9380-x

Ragnarsson, K. (2012). Medical rehabilitation of people with spinal cord injury during 40 years of academic psychiatric practice. *American Journal of Physical Medicine and Rehabilitation, 91*(3), 231-242. doi: https://doi.org/10.1097/PHM.0b013e3182489f5e

Rodakowski, J., Skidmore, E., Anderson, S., Begley, A., Jensen, M., Buhule, O., & Boniger, M. (2014). Additive effect of age on disability for individuals with spinal cord injuries. *Archives of Physical Medicine and Rehabilitation, 95*(6), 1076–1082. https://doi.org/10.1016/j.apmr.2014.01.022

Rossetti, A., Chadha, M., Torres, B., Lee, J., Hylton, D., Loewy, J., & Harrison, L. (2017). The impact of music therapy on anxiety in cancer patients undergoing simulation for radiation therapy. *International Journal of Radiation Oncology, Biology, Physics, 99*(1)*,* 103–110. https://doi.org/10.1016/j.ijrobp.2017.05.003.

Rural Health Information Hub. (2021). https://www.ruralhealthinfo.org/

Särkämö, T., Tervaniemi, M., & Huotilainen, M. (2013). Music perception and cognition: Development, neural basis, and rehabilitative use of music. *Wiley Interdisciplinary Reviews: Cognitive Science, 4*(4), 441–451. https://doi.org/10.1002/wcs.1237

Schneider, S., Müünte, T., Rodriguez-Fornells, A., Sailer, M., & Altenmüüller, E. (2010). Music-supported training is more efficient than functional motor training for recovery of fine motor skills in stroke patients. *Music Perception: An Interdisciplinary Journal, 27*(4), 271–280. https://doi.org/10.1525/mp.2010.27.4.271

Scelza, W., Kalpakjian, C., Zemper, E., & Tate, D. (2005). Perceived barriers to exercise in people with spinal cord injury. *American Journal of Physical Medicine & Rehabilitation, 84*(8), 576–583. https://doi.org/10.1097/01.phm.0000171172.96290.67

Seinfeld, S., Figueroa, H., Ortiz-Gil, J., & Sanchez-Vives, M. V. (2013). Effects of music learning and piano practice on cognitive function, mood and quality of life in older adults. *Frontiers in Psychology, 4*, 1–13. https://doi.org/10.3389/fpsyg.2013.00810

Sezer, N., Akkus, S., & Ugurlu, F. (2015). Chronic complications of spinal cord injury. *World Journal of Orthopedics, 6*(1)*,* 24–33. https://doi.org/10.5312/wjo.v6.i1.24

Shinder, L. H. (2019). *People with disabilities and the inaccessibility of healthcare: A two-part quantitative descriptive research design, a phase one, retrospective study on accessibility of providers in California and phase two, a pilot study of perspectives of physicians and physician extenders in Oklahoma* (Order No. 27670959) [Doctoral dissertation, Northcentral University]. ProQuest Dissertations and Theses Global.

Silver, J., Ljungberg, I., Libin, A., & Groah, S. (2012). Barriers for individuals with spinal cord injury returning to the community: A preliminary classification. *Disability and Health Journal, 5*(3), 190–196. https://doi.org/10.1016/j.dhjo.2012.03.005

Sloboda, J. A., & O'Neill, S. A. (2001). Emotions in everyday listening to music. In P. N. Juslin & J. A. Sloboda (Eds.), *Music and emotion: Theory and research* (pp. 415–429). Oxford University Press.

Street, A., Fachner, J., & Magee, W. (2019). Upper limb rehabilitation in chronic stroke using neurologic music therapy: Two contrasting case studies to inform on treatment delivery and patient suitability. *Nordic Journal of Music Therapy, 28*(5)*,* 382–404. https://doi.org/10.1080/08098131.2019.1606848

Strydom, G., Wilders, C., Moss, S., & Bruwer, E. (2009). A conceptual framework of biokinetic procedures and referral system: An integrated protocol for the various health paradigms. *African Journal for Physical Health Education, Recreation and Dance, 15*(4), 641–649. https://doi.org/10.4314/AJPHERD.V15I4.49550

Taets, G., Jomar, R., Abreu, A., & Capella, M. (2019). Effect of music therapy on stress in chemically dependent people: A quasi-experimental study. *Revista Latino-americana De Enfermagem, 27*, 1–7. https://doi.org/10.1590/1518-8345.2456.3115

Tamplin, J. (2012). Effect of singing on respiratory function, voice, and mood after quadriplegia: A randomized controlled trial. *Archives of Physical Medicine and Rehabilitation*, *94*(3), 426–434. https://doi.org/10.1016/j.apmr.2012.10.006

Tamplin, J. (2014). The effect of singing training on voice quality for people with quadriplegia. *Journal of Voice*, *1*, 19–26. https://doi.org/10.1016/j.jvoice.2013.08.017

Thaut, M., & McIntosh, G. (2010, March 24th). How music helps to heal the injured brain: Therapeutic use crescendos thanks to advances in brain science. *Cerebrum*, p. 1–12. https://www.dana.org/article/how-music-helps-to-heal-the-injured-brain/

Thomas, G. (2011). *How to do your case study: A guide for students and researchers.* Sage Publications.

Thomas Jefferson University Hospital and Magee Rehabilitation (2009). Recreational Therapy-Spinal Cord Injury Manual. *Spinal Cord Injury Manual (English).* Manual

15. https://jdc.jefferson.edu/spinalcordmanual_eng/15

Toldra, N., Sliwinski, M., & Dijkers, M. (2014). Physical therapy after spinal cord injury: A systematic review of treatments focused on participation. *Journal of Spinal Cord Medicine, 37*(4)*,* 371–379. https://doi.org/10.1179/2045772314Y.0000000194

Tollefsen, E., & Fondenes, O. (2012). Respiratory complications associated with spinal cord injury. *The Journal of the Norwegian Medical Association,* 132, 1111–1114. https://doi.org/10.4045/tidsskr.10.0922

Tsai, I., Graves, D., Chan, W., Darkoh, C., Lee, M., & Pompeii, L. (2017). Environmental barriers and social participation in individuals with spinal cord injury. *Rehabilitation Psychology, 62*(1), 36–44. https://doi.org/10.1037/rep0000117

United States National Library of Medicine. (2020). Physical medicine and rehabilitation. https://medlineplus.gov/ency/article/007448.htm !

University of Washington (2007). Understanding and Managing Respiratory Complications after SCI [Fact sheet]. University of Alabama at Birmingham. https://sci.washington.edu/exercise/respiratory%20factsheet.pdf

Van Houtte, S., Vanlandewijck, Y., & Gosselink, R. (2006). Respiratory muscle training in persons with spinal cord injury: A systematic review. *Respiratory Medicine, 100(11),* 1886–1895. https://doi.org/10.1016/j.rmed.2006.02.029

WA Health. (2016). Respiratory function following spinal cord injury: A resource for health service providers. http://spinalwa.org/wp-content/uploads/2013/11/Respiration.pdf?fbclid=IwAR1DjG0wzdjsLufRj9K-sm7_YUqi0hh4okBUzfiMaRxcNJWvpN2hSi47yRs

Wadsworth, B., Haines, T., Cornwell, P., Rodwell, L., & Paratz, J. (2012). Abdominal binder improves lung volumes and voice in people with tetraplegic spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 93*(12), 2189–2197. https://doi.org/10.1016/j.apmr.2012.06.010

Williams, R. & Murray, A. (2015). Prevalence of depression after spinal cord injury: A meta-analysis. *Archives of Physical Medicine and Rehabilitation, 96*(1), 133-140. https://doi.org/10.1016/j.apmr.2014.08.016.

World Health Organization. (2002). Towards a common language for functioning, disability and health: The ICF. https://www.who.int/classifications/icf/icfbeginnersguide.pdf

Yaribeygi, H., Panahi, Y., Sahraei, H., Johnston, T. P., & Sahebkar, A. (2017). The impact of stress on body function: A review. *EXCLI Journal, 16,* 1057–1072. https://doi.org/10.17179/excli2017-480

Yamaguchi, S., Akanuma, K., Hatayama, Y., Otera, M., & Meguro, K. (2012). Singing therapy can be effective for a patient with severe nonfluent aphasia. *International Journal of Rehabilitation Research, 35*(1), 78–81. https://doi.org/10.1097/MRR.0b013e32835032f8

Yin, R. K. (2009). *Case study research: Design and methods* (4th ed.). Sage.

VITA

A’Marie Dotson, MT-BC

EDUCATION

May 2022 University of Kentucky

Expected Completion of Music Therapy Master's Program

December 2017 University of Louisville

Bachelor of Music in Music Therapy

PROFESSIONAL EXPERIENCE

August 2018— Present EDGE Music Therapy

Music Therapist

November 2020— Present Self-Employed

Private Ukulele Instructor

August 2018 — April 2019 University of Kentucky

Graduate Teaching Assistant

SCHOLASTIC HONORS

- Dr. Louis D. Dubilier Music Education Award | 2021
- Research grants from the Friends of the College of Fine Arts | 2019 and 2020
- Northern Kentucky/Greater Cincinnati UK Alumni Club Fellowship | 2019