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# Occupation and Time-Use: The Narratives of One Individual with Tetraplegia

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# **Occupation and Time-Use: The Narratives of One Individual with Tetraplegia**

Presented in Partial Fulfillment of the  
Requirements for the Degree of  
Doctor of Occupational Therapy

Eastern Kentucky University  
College of Health Sciences  
Department of Occupational Science and Occupational Therapy

Amanda Balser  
2022

**EASTERN KENTUCKY UNIVERSITY  
COLLEGE OF HEALTH SCIENCES  
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY**

This project, written by Amanda Balsler under direction of Dr. Dana Howell, PhD, OTD, OTR/L, FAOTA Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY

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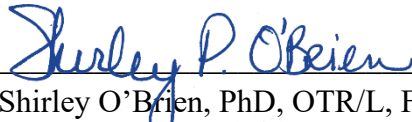
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THERAPY**

Certification


We hereby certify that this Capstone project, submitted by Amanda Balsler conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

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## Executive Summary

**Background:** Spinal cord injury survivors experience an abrupt onset of disability, and in a very short amount of time, must learn skills to participate in or complete ADL and health management routines. Collectively, basic ADL routines and health management practices have a high daily time burden for the person with tetraplegia.

**Purpose:** The purpose of this qualitative narrative inquiry was to explore the stories an individual with tetraplegia has about their ADL and health management time-use, occupational patterns and daily routines, as well as their feelings about quality of life and life satisfaction as it related to time-use.

**Theoretical Framework.** The theoretical foundation and framework that guided this research project included both a transactional perspective on occupation (Aldrich, 2008; Aldrich & Cutchin, 2013; Cutchin & Dickie, 2013; Dickie et al., 2006) and the capabilities approach (Bailliard, 2016; Hammell, 2015; Sen, 2005).

**Methods.** This capstone project design used the qualitative research methodology of narrative inquiry to understand one individual living with tetraplegia's time-use. In-depth conversational interviews were conducted, transcribed, and analyzed, and member-checked using McCormack's (2004) method of storying stories and followed a narrative inquiry framework.

**Results.** The interpretive stories were thematically represented in five sections: Caregivers, Relationships, and Learned Self-Efficacy Shaping Occupation and Time-Use, Framing the Morning Routine: Focus on Independence Shaping Occupation and Time-Use, Framing the Other ADLs: The Art of Doing Shaping Occupation and Time-Use, Meaning and Life-Purpose Shaping Occupation and Time-Use, and Disability Shaping Occupation and Time-Use. Each narrative demonstrated the complexity of occupation and how personal meaning was attached to both the high-burden, mundane aspects of self-care and health management routines as well as the more meaningful and personally important uses of time.

**Conclusions:** Research exploring the narratives of time-use that acknowledge the more complex and personal meanings of occupation can better inform occupational therapists working with individuals about the importance of the occupational experience following "loss of action" after traumatic spinal cord injury. Further research needs to be conducted to better understand the experience of occupation through the framework and lens of those with disabilities to create interventions that support well-being and quality of life.

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DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

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Occupation and Time-Use: The Narratives of One Individual with Tetraplegia

*Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.*

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Date of Submission: \_\_\_\_\_

*7/5/2022*

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## **Section 1: Nature of Project and Problem Identification**

The initial months following spinal cord injury (SCI) are critical for acquiring knowledge and skills to successfully navigate life in all areas and contexts. Spinal cord injury education includes helping survivors learn how their body functions following injury, key skills about self-care, and optimal activities of daily living (ADL) routines to reduce physical complications or adverse health consequences. Spinal cord injury education is necessary for developing successful health maintenance habits and routines and has been directly correlated with better quality of life and higher levels of community reintegration and occupational engagement (van Wyk et al., 2015). Adjustments in health systems policy have significantly reduced length of stay for inpatient rehabilitation, limiting the time available to learn a high volume of skills before discharge. Occupational therapists provide their clients with education and training in complex ADL and health management routines and SCI survivors return home with a vast array of education materials. However, individuals with SCI have very little time in inpatient rehabilitation to actually practice those skills to develop solid ADL and health management routines. Occupational therapy for individuals with tetraplegia at the outpatient level focuses on evidence-based intervention including bowel programs, structured self-management of skin health and maintenance, bladder protocols, and for self-directing or directing others in care routines. Due to time and reimbursement constraints, occupational therapists are left with little time to focus on how to balance an individual's occupational needs and wants to meet participation and engagement goals outside of ADLs and health management.

The ADL routines of people living with SCI extend well beyond participation in the basic ADLs of bathing, dressing, toileting/toilet hygiene, grooming/personal hygiene, feeding, and eating (American Occupational Therapy Association [AOTA], 2020). Health management

practices include activities people do to manage illness, prevent disease, promote health, and restore and maintain function after injury (AOTA, 2020). For people with SCI, health management routines also involve participation in practices aimed at preventing, responding to, and/or managing adverse health conditions or complications (van Wyk et al., 2015). This is due to changes in how their bodies function after injury. These additional health management practices include maintaining healthy bowel and bladder function, skin protection and pressure ulcer prevention/management, spasticity management, recognizing causes of autonomic dysreflexia, regulation of blood pressure, and managing respiratory and circulatory function (World Health Organization [WHO], 2013). Collectively, basic ADL routines and health management practices have a high daily time burden for the person with tetraplegia.

Herrmann et al. (2010) compared differences in functioning between individuals with paraplegia and tetraplegia and discovered those with tetraplegia had a significantly higher prevalence of problems in body functions such as bowel and bladder health, skin health, and circulatory and respiratory functions. The authors also found that individuals with tetraplegia had a greater percentage of problems with basic ADLs, moving around, changing body positions, completing meals, and managing their homes. As a result, people with tetraplegia oftentimes require partial assistance in ADL and health management activities, or the care must be performed completely by others. Hetz et al. (2008) reported that individuals with tetraplegia spent a greater amount of time engaging in bathing, dressing, and toileting, compared with individuals with paraplegia, and this resulted in less time to engage in other meaningful or productive activities. How individuals with tetraplegia spend their time, and how their time-use impacts quality of life, is an underexplored area in the literature.

## **The History of Time-Use Research**

Time-use research has been an important area of study among many disciplines. In a brief history of time-use research, Bauman et al. (2019) described time allocation studies as early as the 1920s that were conducted to develop production efficiency standards in the labor workforce. They also described how time-use studies by the information and entertainment industries were used to follow leisure activity patterns of consumers and document their time spent listening to the radio or watching television (Bauman et al., 2019). In more contemporary years, time-use studies have had increasing importance in the social sciences, health sciences, and public health. Researchers in these areas have been interested in how all activities and behaviors that occur across twenty-four-hour days have collective health benefits or health compromising consequences (Bauman et al., 2019). Time-use research in many fields of study have also looked at how time-use differs between general populations and those who have experienced permanent disability (Barclay et al., 2011).

## **Time-Use and Disability**

In labor economics work completed by Oi (1992) titled *Work for Americans with Disabilities*, it was argued that critical characteristics of disability are lost focusing only on limitations. In fact, Oi insisted that one of the most compelling characteristics of disability is that it “steals” time (1992, p. 167). Pagán (2013) expanded on this concept with examples of disabled individuals’ time stealers such as the need for additional rest throughout the day, increased time spent seeking and receiving medical care, and more time required to complete all daily activities including time used for transportation. Pagán (2013) was interested in the economic impacts related to time-use and suggested societal supports to decrease ADL burden and reallocate time in one’s day to contribute to work and labor forces. Researchers interested in the sociological

implications of time-use explored the disproportionate amount of time individuals with disabilities spend in passive leisure activities such as watching television, or in comparable isolated activities versus social and active leisure activities (Shandra, 2020). This author also explored the disparities that may contribute to these time-use choices including access to recreation and programs, environmental barriers, transportation, and social barriers. Time-use studies are also being conducted by researchers in other disciplines such as public health (Chau et al., 2019; Jonas et al., 2011) to explore trends in time-use and time allocation among disabled individuals. The founder of the *Journal of Occupational Science*, Ann Allart Wilcock, reflected on the “goodness of fit” (2014, p. 4) between occupational science and time-use studies being conducted by interdisciplinary researchers. Occupational therapists understand that time “provides an organizational structure or rhythm for performance patterns” (AOTA, 2020), and how time is used is influenced by temporal experiences. These qualities of time directly relate to how individuals adjust and organize life routines.

### **Time-Use and Occupational Therapy**

Looking back to early publications from the discipline of occupational science, theorists and researchers raised questions about time-use and its connection to occupational behavior. This included the grand question of “What is the relationship between human engagement in a daily round of activity (such as work, play, rest, and sleep) and the quality-of-life people experience including their healthfulness” (Yerxa, 1993, p.3)? Michelson (2005) stated “there is only a fixed amount of time to be distributed and traded off among necessary and desired activities” (as cited in Hunt & McKay, 2015). Occupational therapists and occupational scientists have been particularly interested in how a person occupies time as well as the relationship between life satisfaction and how time-use supports life values and goals (Hunt & McKay 2014; Yerxa,

1993). Hunt and McKay (2015) conducted a scoping review of time-use research by occupational scientists and occupational therapy researchers from 1990-2014. Sixty-one studies were completed during this time exploring time-use trends of individuals experiencing mental illness, sub-groups with specific clinical factors and various diagnoses (which included the four studies mentioned on time-use and SCI), and studies of well populations (Hunt & McKay, 2015). Occupational therapists understand how time-use and its ties to occupational engagement have both subjective and objective aspects that contribute to a person's level of occupational engagement (AOTA, 2020). This deserves further exploration considering the documented burden of time people with SCI experience to complete basic ADL and health management routines.

### **Occupational Science, Time-Use Research, and Spinal Cord Injury**

Despite the most recent literature acknowledging the influences time-use has on life satisfaction, meaning, and purpose, including the Occupational Therapy Practice Framework (AOTA, 2020), very few time-use studies by occupational therapy researchers have been completed in recent decades. In fact, only four studies have been completed studying time-use of SCI survivors (Pentland et al., 1998; Pentland et al., 1999; Yerxa & Baum, 1986; Yerxa & Baum Locker, 1990); this was confirmed in an examination of the literature by Barclay et al. (2011), with no findings in the literature after this 2011 review. No studies were located researching time-use of individuals with SCI resulting in *tetraplegia* by occupational therapy or occupational science researchers. This paucity in research is puzzling considering time-use data can inform occupational therapy practitioners by providing insight into clients' occupational roles and routines and whether they are engaged in occupations they find to be truly meaningful (Barclay, 2011).

One of the major limitations noted in these four articles was the reliance on quantitative methods and tools to gather data. This restricts the discovery of subjective experiences of time, or exploration of the intrinsic aspects of time-use including personal meaningfulness on engagement in occupations and perspectives about life satisfaction. The personal values of time-use and the social and environmental influences different cultures experience shape their available choices and life possibilities (Hammell & Beagan, 2017) and need to be explored to better understand issues related to health, well-being, and life satisfaction. There is a significant gap in research and no studies were found that incorporate qualitative methods while studying time-use of SCI survivors, which would add richness, detail, and personal meaning to the data collected.

### **Problem Statement**

Spinal cord injury survivors experience an abrupt onset of disability, dramatically changing how they are able to participate in activities and occupations. In a very short amount of time, people with SCI must learn skills to participate in or complete ADL and health management routines, as well as learn how their “new” body functions including recognizing the physiological signs of SCI-related health complications. Simultaneously, people with SCI experience the physical and psychological implications of navigating a world that is no longer built for them (van Wyk, 2015). Time-use, or how a person manages their activities, adapts routines, and organizes their days (AOTA, 2020), influences performance patterns necessary to achieve occupational goals and desired lifestyles. However, only four studies exist that examine time-use of SCI-survivors, none specifically exploring time-use patterns of individuals with tetraplegia, and none capture the full subjective experiences of those study participants (Pentland et al., 1998; Pentland et al., 1999; Yerxa & Baum, 1986; Yerxa & Baum Locker, 1990). It is

necessary to explore those experiences as well as the personal, social, and environmental contexts that influence time-use and performance patterns in order to guide interventions that support quality of life, equality of choice in selection of occupations, and engagement in meaningful occupations for this population.

### **Purpose of the Project**

The purpose of this qualitative narrative inquiry was to explore the stories an individual with tetraplegia had about their ADL and health management time-use, occupational patterns and daily routines, as well as their feelings about quality of life and life satisfaction. Time-use is defined as the fundamental way a person structures and organizes their daily lives (Edgelow & Krupa, 2011).

### **Theoretical Framework**

The theoretical foundation and framework that guided this research project included both a transactional perspective on occupation (Aldrich, 2008; Aldrich & Cutchin, 2013; Cutchin & Dickie, 2013; Dickie et al., 2006) and the capabilities approach (Bailliard, 2016; Hammell, 2015; Sen, 2005). The transactional perspective on occupation emerged in occupational science as a theoretical approach that attempts to better understand occupation (Bunting, 2016): a complex phenomenon that emphasizes the person-context relationship (Fisher & Marterella, 2019). The transactional perspective on occupation works from the key principle that an individual, their occupations, and the contexts in which occupations occur cannot be separated from one another (Bunting, 2016). Since these constructs are intertwined and influence each other, how a person performs, experiences, and engages in occupation is a constant coordination and re-coordination with the social and environmental factors present at any given time (Fritz & Cutchin, 2017).



Habits are formed in daily routines, and routines are adapted, modified, and adjusted following illness or an injury such as tetraplegia. Individuals with tetraplegia experience challenges in functional performance and face restrictions and limitations in social, built, and natural environments. An individual's past and present experiences, knowledge and skills, and existing habits shape a person's future actions and health behaviors (Fritz & Cutchin, 2017). Occupations performed and engaged in by people with tetraplegia re-coordinate often, and the continuity in which ADLs and health management routines are performed rely on many factors such as consistent care-giving and social supports (La Vela et al., 2016). These transactions that occur within the relationship of the individual, their occupations, and their environments directly influence the time-use of individuals with tetraplegia and form their self-care habits, rituals, and routines. People with tetraplegia may perceive a fixed or limited number of choices available to them in how they organize and structure their ADL and health management routines. Their choices in time-use outside of self-care routines may also be formed by opportunities or restraints present in the contexts where occupations occur (Dickie et al., 2006).

The capabilities approach is considered a flexible and multi-purpose framework with two fundamental claims: (1) it is of moral importance that members of society have the freedom to achieve well-being, and (2) well-being should be understood through capabilities and functions (Robeyns & Byskov, 2021). Sen (2005, p. 153), who conceived the capability approach, described capability as "the opportunity to achieve valuable combinations of human functionings – what a person is able to do or be." The approach further developed Nussbaum's works on quality of life, human development, and social justice (Robeyns & Byskov, 2021) and has been adapted and used in occupational therapy and occupational science research (Bailliard, 2016; Hammell, 2015; Taff et al., 2014; Townsend, 2012). The capabilities approach has also been

promoted within the field of occupational therapy as an alternative lens to the occupational justice framework (Bailliard, 2016), that of which carries the dilemma of who decides what is just and unjust, and without regard to the concepts of opportunity or occupational choice (Hammell & Beagan, 2016). Learning more about how people with tetraplegia perceive the occupational choices available within their community will help develop interventions to support healthy behaviors and well-being.

### **Project Objectives and Research Question**

Through narrative inquiry into the stories of individuals with tetraplegia, researchers and occupational therapists can better understand how individuals with traumatic and chronic conditions select and engage in their occupations, what factors influence choice of occupation, and ultimately what becomes their time-use patterns. This study aimed to answer:

Grand question:

What is the experience of individuals with tetraplegia related to their time spent performing ADL and health management activities?

Sub questions:

Do individuals with tetraplegia experience time-use trade-offs and if so, what are they?

What factors influence the ability of individuals with tetraplegia to engage in wanted and necessary activities outside of ADL and health management routines?

### **Significance of the Study**

Occupational therapists recognize how important the relationship is between health and well-being and occupational engagement. This time-use study has particular significance because occupational therapy interventions aim to support clients in establishing habits and routines that

are efficient and promote desired health outcomes. By learning more about the subjective and objective experiences people with tetraplegia have with their ADL and health management routines, occupational therapists can better understand how these routines are constructed and how time spent in these routines might influence time-use patterns in other domains of occupation.

### **Summary**

Time-use research has been of significant importance across many disciplines including occupational therapy and occupational science, economics, sociology, public health, and psychology. Occupational therapy researchers have moved away from time-use research in recent years, yet it would be a valuable tool when exploring occupational engagement and participation through the lenses of the transactional perspectives of occupation and the capabilities approach. Exploring time-use through these frameworks should be of particular importance to the field of occupational therapy as we strive to better understand occupational performance, the experience of occupation, and the situational elements that intertwine and influence engagement in occupation beyond the widely used concepts of barriers and supports to participation.

## Section 2: Detailed Review of the Literature

### Introduction

This Capstone Project was proposed because limited research has been conducted exploring time-use requirements and patterns in the ADL and health management routines of individuals with traumatic SCI and tetraplegia. Currently, there is a lack of time-use research being conducted by occupational therapy researchers and occupational scientists, though time-use research has historically been important to the profession. Time-use studies are considered necessary among interdisciplinary researchers to gain insight about how individuals, groups, and population cohorts spend their time in different activities (Chau, 2019). The examination of patterns in time-use brings insight about individuals' behaviors and how health-promoting and health-compromising habits exist in daily routines (Bauman, 2019; Chau 2019). A better understanding of the ADL and health management practices of individuals living with SCI and tetraplegia can contribute to development of occupational therapy interventions.

The literature search was conducted to fully understand all current and existing findings from time-use studies by interdisciplinary and occupational therapy researchers. Time-use studies of general populations not compared with disability populations were omitted from this search as the literature is extensive and mostly conducted by labor and workforce researchers. Search terms did include time-use or time factors and disability, as well as separate searches specifically aimed to locate literature on time-use and spinal cord injury and time-use and tetraplegia. The literature revealed factors correlating quality of time-use with ratings of quality of life, life participation, and life-satisfaction. Therefore, additional searches were conducted using these key words along with spinal cord injury and tetraplegia. Searched databases included PubMed, CINAHL, Google Scholar, Cochrane Library, and six occupational therapy journals

accessed through AOTA. The aim of this capstone research study was to explore how individuals with traumatic SCI and tetraplegia perceive their time-use performing and engaging in ADL and health management routines. So, existing literature on SCI and ADLs and SCI and self-care or health self-care or self-management or health management was reviewed and synthesized. Finally, a literature search was completed to review all current and existing research using the transactional perspective on occupation framework and/or the capabilities approach as a theoretical framework.

### **Disability and Time-Use Research**

Several studies were located on time-use and disability and/or chronic illness and many of these studies aimed to prove or disprove Oi's argument that disability "steals" time (1993, p. 166). In a study on time allocations of people with disabilities, Pagan (2013) concluded that their findings were consistent with the hypothesis that disability steals time. Micro-data from the Spanish Time Use Survey were analyzed and compared time-use patterns of disabled and non-disabled individuals. This study focused on the areas of work, home management, what the authors' called tertiary activities (sleep, ADLs, and medical management), and leisure time. Pagan (2013) found that disabled individuals spent less time in paid work activities, and more time allocated to home management, ADLs, medical care, and passive leisure activities. The author also noted environmental and social barriers that restricted active leisure activity and suggested disabled individuals may possess a limited understanding of possibilities for healthier recreation and leisure activities (Pagan, 2013). In contrast, data from the American Time Use Survey were analyzed to study time-use of disabled individuals (Anand & Ben-Shalom, 2014), and the authors found no conclusive evidence that disability steals time except in the category of health-related activities. These activities include medical self-care and services, exercise or

therapy for medical reasons, and other health-maintenance routines (Anand & Ben-Shalom, 2014). The authors identified no significant differences in time-use between disabled and non-disabled people when performing everyday activities such as shopping and housework. Anand and Ben-Shalom (2014) suggested stolen time may not be the reason for less productive work and more time spent in passive leisure and argued impairment and capabilities may be the greater influencing factors on participation.

Additionally, results from a study exploring adults' time-use allocations for health-related self-care also concluded disproportionate time spent for non-working disabled individuals when compared with employed individuals (Jonas et al. 2011). Disabled individuals averaged 3.2 hours per week completing health-related self-care activities and were four times as likely as nondisabled individuals to report engaging in these activities (Jonas et al., 2011). Health-related self-care activities included need for additional rest, medication routines, exercise, or therapy due to medical conditions, and caring for wounds among other activities (Jonas et al., 2011). The authors recommended health care professionals acknowledge the time-use burden of engaging in health-related self-care and apply patient-centered approaches when prioritizing health management recommendations (Jonas et al., 2011).

A narrative review of time and chronic illness was completed by Jowsey (2016). This narrative review looked at ways people with chronic illness relate to time defined by temporal structures. One structure, clocked time, related to how much time people with chronic illness spend on health-related activities. Time allocations in this category ranged from two to seven hours daily, and the author concluded living with chronic illness had a high time-use demand including transportation to appointments and time spent waiting, for example, in waiting rooms for appointments (Jowsey, 2016). This time "waiting" may or may not be considered a "waste of

time” (Jowsey, 2016, p. 1095) depending on the social constructs a person experienced, or if the time was used socializing with others who are waiting.

While Jowsey looked at the temporal aspects and the experience of time-use with chronic illness, Nielsen et al. (2021) studied the self-reported quality of task performance in ADLs of people with chronic conditions. One of the key findings from this study was that individuals in four different subgroups of chronic illness all rated “using extra time/effort to complete” ADLs as a problem in subjective reporting of quality of performance (Nielsen et al., 2021). When looking at similarities across groups rating quality of performance in personal ADLs and IADLs, the primary indicator of decreased quality in performance was the “extra time/effort to complete” category above all other rating categories including “needing help” and “completely unable” (Nielsen, 2021). Like these studies conducted by interdisciplinary researchers, occupational therapy researchers and occupational scientists have conducted time-use research with various populations looking at how occupational performance and satisfaction with time-use relates to life satisfaction and quality of life.

### **Time-Use and Occupational Therapy**

Occupational therapists and occupational scientists have been particularly interested in how a person occupies time as well as the relationship between life satisfaction and how time-use supports life values and goals (Hunt & McKay 2014; Yerxa, 1993). Hunt and McKay (2014) conducted a scoping review of time-use research by occupational scientists and occupational therapy researchers from 1990-2014. Sixty-one studies were completed during this time that met inclusion criteria and the majority (48) of studies used time logs and captured data over a twenty-four-hour day (Hunt & McKay, 2015). Most of the studies were conducted in the field of mental health, but four studies were located that studied time-use of individuals with SCI. Studies that

aimed to capture the meaning of time were excluded from this scoping review, but the authors did acknowledge the need for both qualitative and quantitative data collection methods to capture the more complex and nuanced occupational experiences within the various contexts that occupations are performed (Hunt & McKay, 2015).

Studies in more recent years have focused on activity patterns and for understanding meaning and experience of occupation. In a study completed by Tatli and Akel (2019), temporal activity patterns of stroke survivors were compared with the patterns of healthy adults. The study group and control group each had 50 participants. Each group listed activities in order of most time consuming to least time consuming. The study group spent more time in rest, sleep, and watching TV, as well as therapeutic exercise, but less time in leisure/play and work activities. Also of interest, participants in the study group reported engaging in ADLs just to “go on with the routine of life” (Tatli & Akel, 2019, p. 293) but reported a lack of meaningful engagement in ADLs. The control group expressed more meaning with ADL routines when time use was balanced (Tatli & Akel, 2019).

### **Occupational Science, Time-Use Research, and Spinal Cord Injury**

A literature search revealed four articles about the time-use of individuals with spinal cord injury (SCI). No studies were located researching time-use of individuals with tetraplegia by occupational therapy or occupational science researchers. The studies completed by Yerxa and Baum (1986) and Yerxa and Baum Locker (1990) explored how people with SCI used their time, how they self-categorized and named the activities, and how they rated the quality of their time-use. In the studies completed by Pentland et al. (1998, 1999), convenience sampling recruited 312 participants but there is little detail about the recruitment process or response rate.



The studies explored disability severity, socioeconomic factors, time-use and life satisfaction, as well as information about time-use patterns.

More specifically, Yerxa and Baum (1986) were interested in how community-based individuals with SCI used their time, how satisfied they were with performance skills in home management and community/social domains, and whether or not there were connections between occupational engagement and life satisfaction. The Activity Configuration Log was completed and the mean hours per category were calculated based on a 24-hour, 7-day week diary. Categories included Self-maintenance, Work, Rest, Sleep, Play, and Other, and compared with a non-disabled control group. According to Yerxa and Baum (1986), in four categories (Rest, Sleep, Self-maintenance, and Play) differences between the groups were not statistically significant in terms of time-use. Differences in two categories were statistically significant: Work and Other. The authors reported that ten of the fifteen participants were unemployed which likely shifted time from the work category to the other category and did not appear to shift to play, self-maintenance, rest, or sleep. Yerxa and Baum (1986) reported future work should further explore activities that were categorized as other. Both groups appeared to be similar in terms of life satisfaction scores and there were positive correlations between occupational performance and life satisfaction. The data from this study was further analyzed by Yerxa and Baum Locker (1990) to explore quality of time use for adults with SCI. The authors recognized that individuals with SCI categorized activities differently than the nondisabled group, and different occupations existed for the SCI and nondisabled participants. Yerxa and Baum Locker (1990) stated that since the activities were classified across areas into differing categories, more research should be done to explore the meaning and purpose behind the activities that were recorded. The results also questioned the assumption that people with SCI spend more time on

self-care, but it is not evident that self-care tasks performed by others were calculated in this time-use study.

Pentland et al. (1998) also explored time use of individuals with SCI and were interested in participants' life satisfaction, overall perceived health, and adjustment to disability. The authors hypothesized that balance of time-use and satisfaction were highly correlated, which appeared to be true. They also found no linear relationship between severity of disability and time-use, however suggested further research needs to be done in terms of exploring severity of disability and time allocations as there is much variability within populations that cannot be accounted for in quantitative or statistical data collection methods (Pentland et al., 1998). Further analysis of this data by Pentland et al. (1999) explored the impact SCI has on men's time-use. Able-bodied participants averaged 2.7 hours per day in productive/paid work, and the SCI participants averaged 1.3 hours more per day in passive leisure activities. Unlike the Yerxa and Baum Locker (1990) study, Pentland et al. (1999) found that on average, men with SCI spent one more hour per day on self-care than nondisabled men which supported findings that disability does influence time allocations. They also found that passive leisure activities dominated the days of the SCI participants and further studies should be conducted that explore how inactive or isolated activity patterns influence a person's integration with society (Pentland et al., 1999). The authors also questioned whether severity of disability was less of a factor on social participation than other social and environmental factors.

There were several limitations in these studies. First, there was the reliance on only quantitative methods and tools to gather data. This restricts the discovery of subjective experiences of time which needs to be explored to better understand issues related to health, well-being, and life satisfaction. There is a significant gap in research and no studies were found

that incorporate qualitative methods while studying time-use of SCI survivors, which would add richness, detail, and personal meaning to the data collected. While not specifically considered time-use research, several studies were found exploring participation patterns, life satisfaction, and quality of life, and exploring self-care routines in people with SCI as well as for people specifically with tetraplegia.

### **SCI, Participation, Life Satisfaction, and Quality of Life**

The literature focusing on participation and engagement in activities of individuals with SCI and tetraplegia also explored relationships these factors have on life satisfaction and quality of life. Studies exploring perceived participation, problems with participation, and the perception of health on participation, were studied in SCI populations (Lund et al., 2007; Piatt et al., 2016; Ripat & Woodgate, 2012). Lund et al. (2007) reported that men and women with SCI who reported problems with participation also reported lower life satisfaction. Individuals with the most severe problems in ADL performance also had the lowest scores in terms of life satisfaction. The authors cautioned against specific correlations as the relationship between participation and life satisfaction is complex but suggested the study does support interventions to address personal and environmental factors and not just the disability (Lund et al., 2007). Piatt et al. (2016) found that higher perceived rates of health directly correlated with higher levels of participation across the domains of participating in family roles, autonomy outdoors, social life, and work/education. There were no significant differences in scores between autonomy indoors and the high and low perceived health groups (Piatt et al., 2016). One limitation noted in this study was that participants were located by convenience sample and participated in community-based rehabilitation programs which may have impacted perceived health scores (Piatt et al., 2016). Finally, Ripat and Woodgate (2012) reported how multiple intervening conditions acted

as barriers or supports to participation such social and environmental factors as well financial and institutional resources. One participant discussed the importance of social and health care supports and how continuity and reliability of caregivers with personal care support and home management was imperative to participation goals (Ripat & Woodgate, 2012).

### **Spinal Cord Injury and Self-Care**

Studies were also located that focused on individuals with SCI as well as specifically tetraplegia and the area of self-care, which also explored patterns of ADL time burden. Self-care has different definitions among healthcare disciplines. In these interdisciplinary studies, self-care was generally defined as activities intended to promote health, manage disease, prevent illness or adverse health conditions, and restore health, and includes the broader term self-management (Conti et al., 2020; La Vela et al., 2016; van Diemen et al., 2021; van Wyk et al., 2015). It has been documented that the amount of time a person with SCI has in inpatient rehabilitation to learn necessary self-care skills after injury has greatly reduced in recent years due to changes in healthcare reimbursement policy and structures (van Wyk et al., 2015). However, a qualitative study completed by van Diemen et al. (2021) revealed learning self-care techniques and strategies through experiential learning was of greatest importance from the perspectives of individuals with SCI.

Research has also been conducted to better understand the necessary self-care behaviors of people with SCI. A systematic review and meta-synthesis of qualitative research on the subject was conducted by Conti et al. (2020) with the final review including twelve papers between the years of 2006 and 2020. Conti et al. (2020) reported self-care behaviors that included having a commitment to interpreting and identifying symptoms were behaviors that promoted well-being. SCI survivors also needed to follow highly organized routines including

planning for potential barriers to engage in self-care since everyday activities already take more time to complete (Conti et al., 2020). Other essential areas included negotiating, navigating, and directing caregivers in self-care activities, finding support from others, and knowledge of conditions including health literacy (Conti et al., 2020). Once again, ADL burden and increased time to complete ADLs has been documented in the most recent literature synthesized by Conti et al. (2020) and Jorgenson et al. (2021) who reported that people with SCI were least satisfied with ADL performance and routines. Another qualitative study completed by Lundstrom et al. (2014) explored experiences in everyday occupations of people with tetraplegia. The authors examined how coordinating and negotiating with caregivers led to prioritization of self-care over more meaningful occupations and how schedules of both the study participants and caregivers left little time for spontaneous activities (Lundstrom et al., 2014).

### **Research Framed with Capabilities Approach and Relevance to Occupational Therapy**

The capabilities approach is considered a flexible and multi-purpose framework with two fundamental claims: (1) it is of moral importance that members of society have the freedom to achieve well-being, and (2) well-being should be understood through capabilities and functions (Robeyns & Byskov, 2021). Sen (2005, p. 153), who conceived the capability approach, described capability as “the opportunity to achieve valuable combinations of human functionings – what a person is able to do or be.” The approach further developed Nussbaum’s works on quality of life, human development, and social justice (Robeyns & Byskov, 2021) and has been adapted and used in occupational therapy practice and occupational science research (Bailliard, 2016; Hammell, 2015; Taff et al., 2014; Townsend, 2012).

Health economics researchers Anand and Shalom (2014) conducted time-use studies exploring how working-age people with disabilities spend their time. In 2020, Anand et al.

applied a capability approach to health status assessment to study disability and quality of life. A representative sampling method was used by the authors to assure a cross section of respondents was captured in terms of age, gender, social class, and geographical location when collecting population survey data. An additional sampling was conducted of individuals registered to have a disability and specifically a mobility impairment. The total number of respondents included 633 individuals with a mobility impairment and 1,172 individuals without impairment (Anand et al., 2020). The authors found significant differences in quality of life between individuals with and without mobility impairments. People with mobility impairments reported lower subjective wellbeing and lower capability across functional domains (Anand et al., 2020). For this reason, the authors concluded (and cited other research in support) that interventions aimed at enabling participation in daily life are necessary to create capacity in capability of engagement in activities (Anand et al., 2020). This echoes statements from the World Federation of Occupational Therapists' Position Statement on Human Rights that "occupational rights are secured by addressing the capabilities, opportunities, and freedom of choice for individuals, communities and populations to participate in society" (2019, p.1). Occupational therapists and occupational scientists have explored the capabilities approach framework as an alternative lens to occupational justice when exploring disability and human rights (Bailliard, 2016; Mousavi et al., 2015).

Occupational scientists Pereira et al. (2020) described their experiences through a critical reflection of inclusive, client centered practices using the CORE Method: Capabilities, Opportunities, Resources, and Environments. The authors discuss the CORE element of capabilities to facilitate occupational potential. Pereira et al. (2020) explained how combining the elements of capabilities and opportunities provided accessible and novel opportunities during an

intervention to foster the development of capabilities to reduce occupational deprivation. Opportunities were explored that were relevant to clients' goals and beliefs to assure client-centered and culturally respectful interventions and delivery of occupational therapy services. The capabilities approach and the core tenet that everyone has the basic human right of capabilities and functionings (doings and beings) echoes the occupational therapy concepts of doing, being and becoming (Wilcock, 1998). Occupational injustices occur when capabilities and opportunities are restricted due to social and environmental constructs present in everyday life. These situational, and often complex, social and environmental contexts interact with the individual and influence occupational performance, experience, and engagement (Cutchin & Dickie, 2012). These transactions shape occupational choices and possibilities and in turn create habits, occupational patterns, and routines (Bailliard, 2016).

### **Research and Transactional Perspectives on Occupation**

The transactional perspective on occupation has been used to inform the work of occupational therapy and occupational science researchers. Shank and Cutchin (2010) used the transactional perspective to guide research exploring occupations of older women who were aging-in-place. Multiple case studies were conducted and used observations to explore patterns of occupations that occurred and used occupation to generate meaning in life, as well as instances where occupations were re-coordinated or negotiated in order to maintain meaning while aging-in-place (Shank & Cutchin, 2010). The authors discussed how it was difficult to discern how the participants defined meaning or how meaning in occupation may change over time. Opportunities for future research included exploring less successful occupational negotiations and transactions to discover how and why meaning changes over time (Shank & Cutchin, 2010).

Rosenberg and Johansson (2013) utilized narrative inquiry approaches to explore occupation and meaning of women living with chronic rheumatic conditions. The authors described how narrative meaning can be constructed through enactment of everyday activities and the occupation, the place, and the story intertwine to create an interpretation that evolves into a restorying narrative. Data revealed how women with rheumatoid arthritis strived for what the authors termed ordinariness while managing and negotiating activities related to roles such as mothering (Rosenberg & Johansson, 2013). Transactions were observed to occur in everyday occupations by how participation or engagement varied from situation to situation. (Rosenberg & Johansson, 2013). One important aspect of the transactional perspective when guiding research is how important it is to capture occupation and meaning in context (Bunting, 2016). The use of visual methods such as photovoice and photo-elicitation were suggested as methods to capture experiences and the complex contexts that transact with and influence occupation (Bunting, 2016). In-depth interviews accompanied by direct observation, narrative restorying, and ethnography have also been suggested to capture nuanced and complex occupational patterns and routines (Bunting, 2016). Individuals with conditions such as tetraplegia often find themselves negotiating and re-coordinating daily routines in response to personal factors including health conditions, environmental factors, and other social and contextual factors that shape and create performance patterns (AOTA, 2020). Using a transactional perspective on occupation and a capabilities approach framework to guide and inform this research study helped to better understand the experiences an individual with tetraplegia has with their time spent performing ADL and health management routines.



## Definitions of Terms and Concepts

### *Interdisciplinary Perspectives on the Definition of Self-Care*

In the literature self-care is not a clearly defined set of actions and the term has come to have different meanings as healthcare disciplines developed domain specific interventions. The World Health Organization (2009) has seven different self-care definitions depending on the context for which the term is being used. There are also multiple ideas and definitions across disciplines for health-related self-care, activities of daily living, self-management, health-management, health-maintenance, self-efficacy, and symptom management (Martinez et al., 2021). This is due to each profession's view on the topic and the domain from which practitioners are addressing health topics and interventions (Godfrey et al., 2011). The following terms and definitions from the Occupational Therapy Practice Framework: Domain and Process, 4<sup>th</sup> Edition (OTPF-4) (AOTA, 2020) were used throughout this capstone project to provide clarity and continuity during this study. The direct wording from OTPF-4 was used to prevent loss of meaning that may occur through paraphrasing.

**Activities of Daily Living (ADLs):** “Activities oriented toward taking care of one’s own body and completed on a routine basis” (p. 30). Includes bathing/showering, toileting/toilet hygiene, dressing, eating/swallowing, feeding, functional mobility (including wheeled mobility), personal hygiene and grooming, sexual activity.

**Instrumental Activities of Daily Living (IADLs):** “Activities to support daily life within the home and community” (p. 30). Includes care of others (including selection and supervision of caregivers), care of pets, child rearing, communication management, community mobility, financial management, home management, meal preparation, spiritual expression, safety/emergency maintenance, and shopping.

**Health Management:** “Activities related to developing, managing, and maintaining health and wellness routines, including self-management, with the goal of improving or maintaining health to support participation in other occupations” (p. 32). Includes social and emotional health promotion and maintenance, symptom and condition management, communication with the healthcare system, medication management, physical activity, nutrition management, personal care device management (including adaptive equipment).

### *Defining Time-Use, Spinal Cord Injury and Tetraplegia*

This study explored the time-use patterns of an individual with tetraplegia resulting from a traumatic SCI. Time-use is defined as the fundamental way a person structures and organizes their daily lives (Edgelow & Krupa, 2011). The term SCI is defined as damage to the spinal cord as a result of trauma, disease, or degeneration, resulting in neurologic impairment. Symptoms may include varying levels of sensory and motor loss depending on the extent of the injuries. The most serious SCIs, such as high-level cervical injuries causing tetraplegia, also affect breathing, heart rate regulations, blood pressure, and bladder and bowel functioning. Each year around the world, individuals acquiring a new SCI range between 250,000 and 500,000. According to the WHO (2013), SCI survivors have lower rates of school enrollment and economic participation, with high financial cost for both the individual and society.

Complete SCI results in absence of motor and sensory function below the level of the lesion, and an incomplete injury may have partial preservation of sensory and/or motor function below the level of the lesion (Gutman, 2017). People with traumatic tetraplegia have upper motor neuron lesions and likely experience spasticity, an increase in muscle tone below the lesion level that they are unable to control, which may interfere with self-care (Cardenas & Curt, 2014). Autonomic dysreflexia is an exaggerated sympathetic response that can occur from having a full

bladder, stimulation of pain receptors, or even an ingrown toenail for example (Gutman, 2017).

The result is severe hypertension, severe headache, profuse sweating, and flushed skin.

Autonomic dysreflexia is a serious condition and requires immediate emergency medical care.

Symptom and condition management of body systems and functions requires high health literacy

and an organized and systematic approach to mitigate adverse health events. Conditions like

autonomic dysreflexia experienced by individuals with tetraplegia may cause sudden

interruptions of activities that are causing symptoms, disrupt daily activities and routines, and

alter daily time-use (Conti et al., 2020).

### ***Social and Health Systems Data***

SCI survivors must cope with participation challenges in multiple functional domains including in-home activities, employment, education, social and community engagement, and

leisure activities (Conti et al., 2020). The nature of traumatic SCI in terms of disability is more

abrupt compared with other neurologic conditions that have a gradual and progressive onset.

Health care reimbursement structures often contribute to barriers to SCI education resulting in

SCI survivors needing to acquire most of their self-care skills during the acute rehabilitation

phases of recovery (van Wyk et al., 2015). Many barriers to SCI patient education contribute to

decreased occupational engagement. These include reduced access to quality resources,

decreased skill acquisition due to deficits in learning readiness, high knowledge volume in

contrast to available time, and a multitude of environmental and societal factors including health

care systems, resources, and family readiness, support, and adjustment (van Wyk et al., 2015).

As with many disabilities, people with tetraplegia require a level of personal health literacy that

exceeds the health literacy requirements of the general population (VanPuyumbrouck et al.,

2021). Learning the knowledge and skills to maintain health and well-being after SCI require a

significant amount of time, resources, and support to build successful and organized ADL and health management routines.

## **Conclusion**

This in-depth review of the literature demonstrates gaps in knowledge about how people with tetraplegia not only allocate their time, but knowledge about how they construct, reconstruct, and coordinate ADL and health management activities and routines.

Interdisciplinary time-use researchers have documented the complexities and nuances that influence time-use patterns and suggest narrative inquiry as one research method to gain a better understanding of temporal aspects of time and relationships with participation, life satisfaction, and quality of life. Occupational therapy researchers should be interested in how individuals with tetraplegia organize their daily routines and how ADL and health management skills and performance impacts their daily lives. This pilot narrative inquiry aimed to fill gaps in the current knowledge about time-use and individuals with tetraplegia and may be used to inform occupational therapists who work with clients from this population.

### Section 3: Methods

#### Project Design

This capstone project design used the qualitative research methodology of narrative inquiry. Qualitative researchers embrace the importance of reporting the complexity of a situation and use these methods when the issue, problem, or phenomena cannot be easily quantified or measured (Creswell & Poth, 2018). Qualitative research empowers individuals to tell their stories through a collaborative process with the researcher. This capstone project was an in-depth exploration of one SCI survivor's time-use, layered with further inquiry and exploration into the time-use phenomena, using the transactional perspectives on occupation framework. This perspective has two key components: first, it acknowledges the person-context relationship, and second, occupation is a repeated response to situational elements (Fisher & Marterella, 2019). It is anticipated that additional participants will be recruited for this study following the capstone.

Since the response to and between occupation and these situational elements influence one another, the result is an understanding that the person cannot be separated from existing contexts in which occupation is framed, nor can a person be separated from their past, present, and future experiences (Fisher & Marterella, 2019). Narrative inquiry as described by Clandinin and Connelly (2000) is a way of understanding experience. Both the transactional perspective on occupational (Cutchin & Dickie, 2013) and Clandinin and Connelly's (2000) work in narrative inquiry were influenced by philosopher and thinker in education, John Dewey. Dewey's philosophical writings on action provided the basis for occupational science researchers to understand and investigate occupation as a relational action (Cutchin et al., 2008). Rosenberg and Johansson (2013) discussed the strength of the transactional perspective as able to behold the

complexity of occupation. However, there are methodological challenges when using this perspective within occupational therapy research, as conducting the research requires a simplification of the transactional perspective (Bunting, 2016). They suggest that the *situation* can be used as a unit of analysis to gain knowledge and understanding about how and when transactions happen (Rosenberg & Johansson, 2013). The *situation* described by Clandinin and Connelly (2000) supports the use of narrative inquiry as a sound methodology for studying occupational transactions. Narrative research considers the temporality and person-context interactions that Dewey described in his work and influenced this type of inquiry into human experiences (Clandinin & Connelly, 2000). Narrative inquiry can capture the meaning and experience linked to occupations adding richness to data which would otherwise be lost through only the use of time allocation diaries. Framing this study with the transactional perspective of occupation and the capabilities approach helped to gain understanding of patterns in quality of time-use and how performance-experience-engagement connections shaped and formed the daily habits and routines of one individual living with tetraplegia.

## **Methods**

### ***Inclusion and Exclusion Criteria***

Inclusion criteria was an individual who has lived with a SCI, specifically tetraplegia, for at least two years, who resided in the community either renting or owning their own dwelling which are not considered group, CO-OP, or long-term care or assisted living residence, had the ability to provide informed consent, and was at least eighteen years of age. The participant was required to speak English. They must also have been cognitively capable of understanding the study aims and capable of participating in the study. Exclusion criteria was any participant who was under the age of eighteen, who resided in a community group home or institutional setting,

and who was unable to understand and provide informed consent. Individuals were also excluded if medical complications prevented them from participating in typical routines, such as full-time bed rest due to pressure injury, or if there was planned engagement in activities that were different than normal routines.

### ***Recruitment Procedures***

The primary researcher was an occupational therapist working in the practice area of adult neurological rehabilitation and who supported clients with tetraplegia from a wide geographic region of a Western State. Connelly and Clandinin (1990) explained narrative inquiry as a collaborative experience that requires a close relationship above acquaintanceship to allow for the possibility of stories of empowerment. For this reason, prospective participants who were known to the researcher were invited first since rapport and trust were historically established with the researcher. Participants were invited via email as well as asked in person. In the event all invited participants declined to participate in this study, the researcher planned to implement snowball sampling to recruit participants outside the region of participants known to the researcher. Flyers were also be provided to rehabilitation facilities and outpatient therapy practices known to work with clients with tetraplegia. The process was repeated until two to five participants were successfully recruited. For this capstone project, only one of the recruited participant's interviews were used due to time constraints.

### ***Setting***

The setting for this narrative inquiry was the home of the participant, which is where many of their occupations occurred. This was the preferred location for this participant to engage in the conversational interviews and to be observed by the researcher when they participated in

aspects of their daily routine. Other environments frequented by the participant were explored during the interviews, but not directly accessible due to Pandemic restrictions at the time of the study. These environments included the workplace of the participant who was temporarily performing all job duties remotely from home. Field texts, notes, recordings, and other methods of data collection that occurred in these environments was approved by the participant for further analysis and research composition. This was necessary since the depth of inquiry using transactional perspectives captured the “messiness of human life, by allowing for the multi-faceted aspects, variables, or phenomena to be included in our understanding of human actions” (Rosenberg & Johansson, 2013, p. 151). For this reason, the participant was invited to set boundaries and request omissions of certain aspects of the inquiry and these requests were honored by the researcher.

### *Data Sources*

The narrative inquiry consisted of multiple interviews with the participant:

1. The interview process began with completion of a time-use log modified from the Day Reconstruction Method (DRM) Instrument (Kahneman et al., 2004). The DRM was designed to capture feelings and experiences within situations and daily activities (Diener & Tay, 2014). It was developed as an alternative to the Experience Sampling Method (ESM) where the DRM has been described as being less burdensome for participants.

The interview was conducted in a single session and the participant was asked to divide their day into activities such as bathing, getting ready for work, eating, etc. The participant reported on and estimated the time each activity was started and ended, and described any feelings that may have been experienced during the activity. The interview explored the 24 hours experienced in both a previous weekday and previous weekend day



in order to capture real and true experiences and feelings, reducing the chance of memory and recall bias (Diener & Tay, 2014). The DRM was filled out by the researcher on behalf of the participant during the interview and the interview was audio recorded to later fill in details that may have been missed during written note taking. Table 1 is an example of the diary template used to collect preliminary time-use data for this inquiry.

Table 1. Modified Day Reconstruction Method Instrument Documentation

What time did you go to bed?		What time did you go to sleep?	
What time did you get out of bed?		What time did you wake up?	
<b>Morning</b> (from waking up until just before lunch)			
Episode Name	Began	Ended	Activity details/Feelings
1M			
2M			
3M			
4M			
5M			
6M			
7M			
8M			
9M			
<b>Afternoon</b> (from lunch until just before dinner)			
1A			
2A			
3A			

4A

5A

6A

7A

8A

9A

**Evening**

(from dinnertime until just before you went to sleep)

1E

2E

3E

4E

5E

6E

7E

8E

9E

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Adapted from The Day Reconstruction Method (DRM): Instrument Documentation (Kahnemen et al., 2004).

2. During and following the data collection using the DRM, the researcher engaged in conversational interviews that allowed the participant to control the direction of the conversations surrounding time-use, ADL and health management experiences, and discussions about the round of their daily life. Momentary focused observation during ADL and health management routines also occurred to collect field texts about person-context interactions and coordination of occupations. These included activities that

involved caregivers and helped to gain insight about patterns and development of the participant's behaviors, habits, and routines.

3. Follow up interviews were conducted to fill in gaps in the narratives and questions asked followed the path of the participant's told stories. Questions included:
  - a. "Tell me more about how your ADL routine used to be compared with now?"
  - b. "Tell me more about how you worked with your caregiver during that particular activity?"
  - c. "Would you tell me more about how you felt during that experience?"
  - d. "Have you experienced any time tradeoffs based on how long this took to complete?"
  - e. "Tell me a story about a time that your day did not work out as planned."

Additional data sources were photos and artifacts and included images of schedules and calendars.

### ***Trustworthiness***

Triangulation methods were employed throughout this research study. A reflexive journal was kept for journaling the researcher's thoughts feelings, ethical concerns, and personal biases that may impact this research study. During transcription of the stories, the researcher listened to the audio recordings and reflected on how they were positioned during the conversations, as well as exploration of the various frameworks that formed the lenses the stories could be viewed through and interpreted (McCormack, 2004). Member checking occurred by reviewing transcripts with participants and throughout the storying process of moving field texts to research texts, and when turning the participant's stories into narratives. This was necessary to confirm that the true essence of participant's stories had been captured during the storying process. An audit trail was employed by using the participant's own exact words during creation of the

original story lines, and in the study report, to show validity in the data analysis. Peer debriefing also occurred to assure the primary researcher's narrative texts were meaningful to others outside the primary investigator's own experiences.

### ***Data Collection and Analysis***

The purpose of the study was explained to the participant through reading of the verbal recruitment script, and informed consent was provided and reviewed with each participant prior to beginning the data collection process. No data collection occurred until informed consent was signed and received. Consent was signed by the participant's typical method of signing formal documents as physical limitations prevented traditional forms of acquiring signatures from some participants. This included use of their signature stamp, or a proxy designated by the participant to sign for them.

Data collection was congruent with narrative inquiry methodology (Creswell & Poth, 2018). The first interview last nearly 120 minutes and included focused momentary observations. All interviews were audio recorded and transcribed for later analysis. This process required the researcher to be an active listener while listening to the tapes several times. First, the researcher checked for accuracy in the transcriptions. Next, the researcher relistened to the recordings and journaled assumptions that may influence how the stories could be interpreted or perceived. Field texts, researcher observations, and artifacts, were also categorized and labeled by type.

Once the audio recordings were transcribed, data analysis followed McCormack's (2000, 2004) method of narrative analysis which the McCormack termed storying stories. Storying stories uses both types of narrative inquiry framework described by Polkinghorne (1995): 'analysis of narrative' and 'narrative analysis.' Using the method of 'analysis of narrative,' stories are framed as data and analyzed looking for common themes across stories. With

‘narrative analysis,’ the researcher compiles gathered descriptions of events and actions and this data is used to generate stories through the emplotment process (McCormack, 2004).

McCormack (2004) explained the use of both approaches allows the researcher to gather personal experience stories while also composing new stories about those experiences. With this method, the researcher can explore the participants’ understanding of their own personal experiences in everyday life while also reflecting on the broader social/cultural influences that help people make sense of their lives (McCormack, 2004).

Following active listening of the transcribed recordings, the researcher then located all the stories found within the texts. As described by William Labov and Elliot Mishler cited by McCormack (2004) and Kim (2015), stories can be distinguished from one another by recognizable boundaries. The beginning is labeled the ‘*Orientation*’ and describes who, what, where, and when. The ‘*Coda*,’ or ending, brings each story to a close. Between these two descriptors, each story has an ‘*Abstract*’ which summarizes the story’s point, the ‘*Evaluation*’ which is the explanation for why the story is being told (and becomes the title of each story), and finally the linked events and actions in the story that answers the question “*And then, what happened?*” (McCormack, 2004). Twenty-one distinct stories were initially located and compiled using this framework. The stories were then arranged by story title (the ‘*Evaluation*’) and reorganized using temporal and chronological ordering processes. The following example illustrates each of the story parts as described above. These stories were all compiled using direct quotes and the exact words from the transcribed interviews to develop an audit trail.

### **Story 6**

#### ***Evaluation***

Because...life, you know.

### ***Orientation***

I teach them how to do stuff just in case.

### ***Abstract***

And I know that's why it makes it all so hard because I staff it that way, because someone doesn't show up or gets sick or takes vacation...and so 'cause if I only staff two people then the odds of them calling off and not getting covered is hard. The odds are greater you know...

### ***What happened?***

So... like if I need something like, they like, if I don't feel like doing art that day, I'll go eat somewhere, or do something like, like I structure my day this way...Like this is what I like to do on the regular. But sometimes I like to, you know...I'll switch things up. So, I teach them how to...they still learn how to put me to bed, they learn how to get me up and stuff just in case. Yeah, that's my...I got smart about it that way. That's why I got a crew of four or five. I always make sure that I have at least four to five good caregivers.

### ***Coda***

So that's why I try to keep at least four people on my staff.

Once all the stories were located and chronologically and temporally ordered, the stories were then viewed through multiple lenses. The first lens was locating the narrative processes identified as narrations (or stories), descriptions, argumentations, theorizing (Rosenthal, 1993) and augmentation (McCormack, 2004). These processes provide one manner in which a storyteller applies meaning in their life and can help to confirm the meaning of the story as it was intended by the storyteller. For example, the storyteller may be trying to work something out (theorizing), demonstrate conflicting thoughts or ideas within a story (argumentation), present specific structures that scaffold a story (descriptions), tell or retell an actual or fictitious story of past events that are linked together (narrations), or build on a story that was previously told (augmentation) (McCormack, 2000; Rosenthal, 1993). The following segments are representations of this participant's stories being reread through the lens of narrative processes:

### ***Theorizing***

**Amanda:** And so, making that relationship or developing those relationships in a positive way allows you to get your health maintenance and self-care stuff accomplished?

**Ray:** Yes.

**Amanda:** How would you compare health maintenance and ADLs in those situations?

**Ray:** Well because I also tell people we're given this opportunity to be independent. Independent *is* living. And it's how would you want to take care of yourself if you're walking? Just look at it that way. What would you do for yourself? How would you take care of yourself? And then the limitations that you have, and then that's when you tell your workers...you know, a lot of them are like yeah...I'm your...I'm your hands, what can I do to help, you know, I'm your hands on this...

### ***Argumentation***

...it's not a facility. What pisses me off is times people say that, and I'm like it's not a facility...that's a facility. You know, this is not...you allow it to be that because that's what you want. I don't allow it to be that because that's not what I want, you know. I want to live as close as I can to being independent as I can.

### ***Augmentation***

**Amanda:** Tell me about that?

**Ray:** Because they're doing it the way I want it to be done. This is the way I would do it. And so, I feel like I am living through them and like, not living through them but I feel like I'm like, like Ghost, you know. Like I'm in her body doing something...I want to do that...and it allows me to be independent, and they are, you know, taking the information and using it...

The second lens that the stories were viewed through was the lens of language as what is said, how it is said, as well as what was unsaid can impact the interpretation of the words in a story (McCormack, 2000). Words were located that reflected concepts of inquiry through the research question (e.g., time, appointments, health, routine, caregivers), words that assume common understanding (e.g., you know), words that were used to talk about their environment, relationships, self-image (e.g., being independent, developing that relationship in a positive way, that working environment), words that reflect a participant's relationship to self and society (e.g.,

but I've built it, you allow it to be that, how would you take care of yourself?), and words that are used to make space or time for reflection (Umm, Ahh, or a sigh). The following excerpt from the interview transcript show examples of words that can be viewed through the language lens as described above.

**Ray:** That's where it gets...like I get burned out some...like I'm not...I tell people all the time...cause people are like aww...how do you do it...how do you...? And I'm like I bitch and complain just like everybody else [laughs]! Like I'm not always motivated to get outta bed right away, I'm not always motivated to start the day or feel great. I do it, though...you know...just...I want a better life. I want to enjoy my life. So that's what I do.

The lenses of contexts and moments were also identified and analyzed throughout the interview and storying process during the creation of interpretive stories. The researcher, an occupational therapist, recognized some stories were told within the interview conversations with the assumption that both researcher and participant shared common language in terminology such as, bowel program, dysreflexia, "cath changes," and paratransit, which demonstrated a context of situation during the interactions (McCormack, 2000). Moments are found by searching for key words or phrases that are turning points in the stories, self-reflections, moments of happiness or sadness, and unexpected or surprising moments (McCormack, 2000). The following example was labeled as a moment in the interview transcript and represents this lens through which to view Ray's stories:

**Ray:** Knock on wood...this will be the first year in a long time that I wasn't hospitalized.

**Amanda:** First time, like this whole year?

**Ray:** The first time in probably the years since my twenties that I wasn't hospitalized.

**Amanda:** At least once a year?

**Ray:** Yeah.



**Amanda:** What is different?

**Ray:** I'm paying attention to my needs more. Addressing concerns as they arise quicker...trying to stay healthier and paying attention to my health a lot better.

Viewing the stories through these various lenses added layers of depth and applied meaning to the stories that would otherwise be lost. Meaning is constantly constructed and reconstructed as people gain experiences, revisit the past, and look toward the future (Clandinin & Connelly, 2000; McCormack, 2000). Stories are told and also interpreted by those for whom the stories are being told, and the process of storying these stories required multiple lenses as an acknowledgement that these complex narratives cannot be fully understood through a single lens or perspective of the researcher (McCormack, 2000).

### **Ethical Considerations**

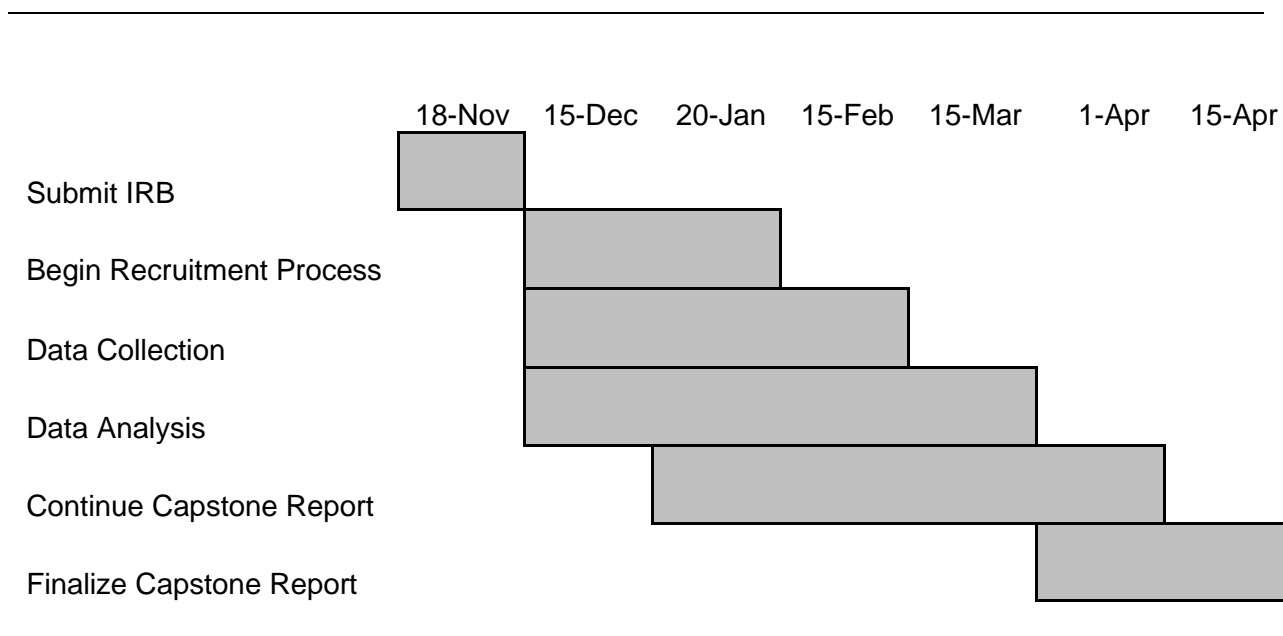
This study was approved by the Eastern Kentucky University Institutional Review Board (IRB). Given the nature of narrative inquiry, there were potential risks to the participant's confidentiality. All identifiable data was removed from the study documents and the participant's identity was described in the most general terms possible. A pseudonym was used for the participant and all data and identifiable information was locked up. A potential risk was lack of privacy or that the participant may feel vulnerable due to the study topic. Potential benefits from this study were that the participants would be providing information that may help other people living with tetraplegia. The risks and benefits were explored during informed consent so the participant could weigh whether or not it was worth participating in this study. Relational ethics needed to be negotiated as the researcher knew the participant prior to beginning the narrative inquiry (Clandinin & Connelly 2000). Lastly, it is the researcher's responsibility to cause participants no harm, so field texts needed to be presented thoughtfully as the participant was the

first and most important audience. The researcher needed to address concerns with ownership and reconciled what should and should not be made public at the research writing stage (Clandinin & Connelly, 2000). The researcher began a reflexivity journal at the start of the research proposal development which will continue through the final composition of the research text. This journal reflects the researcher's thoughts and feelings as well as document ethical concerns that arise at all stages of the project.

### Timeline of Project

Table 2 illustrates the estimated timeline of the capstone study.

Table 2. Project Timeline



## **Results**

Narrative research is a first-person retelling of an individual's personal and social experiences about a particular phenomenon (Ollerenshaw & Creswell, 2002). The results of this study were written in first person to acknowledge the relationship the researcher had with the participant as the one to which the stories were being told. For this Capstone Project, I examined the experiences of time-use of Ray, one individual living with tetraplegia. At the time of this study, Ray had been living with C-4 tetraplegia for 22 years. He lived alone and resided in a Western State where he managed and directed his own care for the past several years, a term he called "self-direct" as opposed to an agency hiring, managing, and directing caregiver support, transportation, and resources for him. Ray had a master's degree and engaged in productive work in a health-related field seeing clients five days per week as well as engaging in creative artwork. Additional demographic information has been omitted as an attempt to maintain anonymity.

The following weekday routine is used as a starting point for examining Ray's past and present life experiences and time-use that shaped his performance patterns and his perspectives on participation and engagement to better understand the transactional processes that influence occupation, environmental adaptation due to disability, and independence.

### **A Typical Weekday**

During the work week, Ray began his day at either 6:00 a.m. or 7:00 a.m. depending on the agenda for his morning ADL routine. A 6:00 a.m. wakeup signified a bowel program day. The nurse arrived at his apartment getting the mechanical lift ready to help Ray into the rolling shower/commode chair. Ray thought to himself, "OK... I'm going to work today so...what am I

gonna do at work? Alright...” Ray’s bowel program routine took about an hour and concluded with a personnel exchange from the nurse to his regular morning caregiver he called his Personal Assistant, or “PA” for short. Ray transitioned directly to the shower for bathing “around twenty minutes to a half hour probably,” and then, assisted by his PA and the mechanical lift, it was back to bed where she checked Ray’s skin for signs of pressure injuries. While Ray was still in bed, his PA completed his stretching and range of motion (ROM) program, and then assisted Ray with getting dressed for the day. “That process can be anywhere from twenty to forty minutes,” said Ray, “because not every day I feel that great. I try to stretch when I am getting dressed.” Ray explained that depending on how things are going, he is usually up in his power chair headed to the kitchen and his home office between 8:00 and 8:30.

Once Ray was up in his power chair he engaged in a brief meditation, worked with his caregiver to cook breakfast, eat, and drink some tea. Ray asked his PA to turn on his computer so he could get ready for the workday. He worked with clients virtually due to Pandemic restrictions. “For the most part, things don’t get rolling until 10:00. So, while she’s making breakfast and kind of straightening up, I’ll be like checking my emails or making appointments.” Laughing, Ray stated, “so it is kind of like cramming a lot.” In addition to this ADL routine, Ray described engaging in health management activities that included recurring medical appointments for blood draws due to his history of blood clots, Botox® injections to manage the spasticity in his bladder, catheter changes, and regular appointments with primary care and physical medicine physicians. Ray described how all these appointments require careful coordination to assure he has a caregiver present for transportation, as well as the need to schedule appointments after the ADL routine and to adjust work hours to accommodate his

health management appointments. Ray explained, “I got to try to fit everything in when there is someone here.”

Ray worked with his clients until 2:00 p.m. Another PA arrived and stayed for about 30 minutes to quickly help Ray eat some lunch, hydrate, empty his catheter leg bag, and if there was time, a few stretches before he went back to work until 5:30. “Zoom meetings make for a long boring day. I will be putting hours in at the clinic on Tuesdays and Thursdays when things open back up.” Ray described how coordinating ADL and health management routines during work hours in the community required him to take paratransit back to his apartment to meet a caregiver for his lunchtime routine, and then return to the office to conclude his workday. “During the day things are hard...because some of my caregivers work other jobs so...that's why I gotta do it that way. In the evening after work, I can usually schedule a caregiver to pick me up.”

After work, Ray relaxes, checks in with friends on social media, and “just takes a break from the world” before his next PA arrived at 6:00 p.m. Ray explained,

“I try to eat earlier because when I eat later, I just get lazy and don't want to do nothing. I try to keep my evenings open so I can do art and stuff. And then...yeah...I do work...I do artwork in the evening, and they come in around six, so...because now that I'm working late, things got pushed back. So... because it was like 4:00 before...but now that I'm working, it's a couple hours later. So, my PA comes around 6:00 p.m., artwork...until 9:00...at least 8:30 or 9:00...because I like to get a couple hours in.”

Mondays, Wednesdays, and Fridays, Ray said he has this additional PA come in to help with painting: mixing the colors, clean his paint brushes, and set up his easel. Tuesdays and Thursdays, when Ray is home by himself, he has an earlier caregiver set up his art room so he can do pen and ink drawings which do not require support from a PA if it is set up properly.

“I set up my paper and pen so when I'm here by myself I can just drive in there and draw when I want. And the days they're not here I'll do pen drawings and stuff. I'll work on my art, doing pens or pencils, or I'll find things that I need to work... like it's all... it's based around art. Mondays, Wednesdays, and Fridays I have someone designated just for art, and to like... socialize.”

Around 9:00 p.m., Ray's evening PA arrives to help him get ready for bed, which concludes around 10:00 p.m. Ray reflected, “I structure my day this way, it just doesn't always play out that way... because...life. You know?”

### **Narratives on Occupation and Time-Use**

The following interpretive stories illustrate the complexities and challenges of navigating everyday life while living with tetraplegia. Our conversations explored actual time spent performing ADL and health management routines. Ray's stories captured the essence of his experiences of time-use within the whole of his daily life. Ray's stories were set in a three-dimensional framework space of narrative inquiry (Clandinin & Connelly, 2000). The temporal dimension spans the twenty-two years Ray has been living with tetraplegia. The spatial dimension includes Ray's time living with his mother after his injury while finishing high school and his transition to living alone, and moving several hundred miles away to an urban community with healthcare resources. Finally, the sociopersonal dimension included my conversations with Ray, as well as the stories Ray had about his interactions with caregivers, family, friends, peers, work colleagues, and other members of the disability community.

Ray detailed how his time-use and performance patterns within his daily routines have changed over the years and how his views on independence have evolved while living with tetraplegia. Ray also shared descriptions of personal, social, and environmental factors that

influenced the shaping of his ADL and health management habits and routines, and how these patterns are more greatly connected to his current life roles and his sense of life purpose. Lastly, Ray described the many ways his daily plans are currently disrupted due to factors or circumstances beyond his control that influence his occupational choice. He detailed the realities of living with disability and tetraplegia and the impact this has on time-use that non-disabled individuals take for granted. This included concepts such as spontaneity in time-use and freedom of occupational selection. The following stories are shared chronologically within each of the thematic representations. Table 3 lists the themes and interpretive stories.

Table 3. Narratives on Occupation and Time-Use

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<b>Themes</b>	<b>Interpretive Stories</b>
Caregivers, Relationships, and Learned Self-Efficacy Shaping Occupation and Time-use	<i>Family as Caregivers</i> <i>Life Managed by Others</i> <i>The Beginning of Life Managed by Self</i>
Framing the Morning Routine: Focus on Independence Shaping Occupation and Time-Use	<i>Mindset Influencing Occupational Experience</i> <i>Caregivers Influencing Occupational Experience</i>
Framing the Other ADLs: The Art of Doing Shaping Occupation and Time-Use	<i>How I Would Do It if I Could Walk and Use My Hands</i>
Meaning and Life-Purpose Shaping Occupation and Time-Use	<i>Looking Ahead</i>
Disability Shaping Occupation and Time-use	<i>Schedules and Waiting...and Waiting</i> <i>Health-Management Doesn't Always Stick to the Schedule</i> <i>Caregiver Continuity and Caregiver Relationships</i> <i>Barriers to Maintaining Social Connections</i>

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### *Caregivers, Relationships, and Learned Self-Efficacy Shaping Occupation and Time-Use*

#### **Family as Caregivers**

Ray was attending high school when he sustained his spinal cord injury. He lived in a remote area with limited health resources but described his family as supportive.

“My injury happened in August, and I got out of the hospital in December. That winter and spring I had a lot of issues that kept me from returning to school. Then, that summer I had to take summer school and that’s when I started learning to schedule and my family started getting adapted to our schedule.”

Following summer school, Ray returned that fall to begin his junior year of high school, beginning his school day at 10:00 a.m. instead of the regular 8:20 a.m. start time. Ray reflected on his younger years living with SCI and stated that while he was in the hospital, his rehabilitation team inquired about what his routine would need to be once he returned home.

**Ray:** I have always gotten up at six or seven in the morning.

**Amanda:** You’ve always been an early riser, huh?

**Ray:** No...my mom worked, and she took care of my bowel care needs, so...six o’clock has always been my bowel care routine. So, you know, I came home...they were teaching us in the hospital, and they were like, ‘So how’s it gonna be when you get home?’ My mom was like, ‘I’ll have to do it because we don’t have nurses up there.’ So, my mom did my bowel care.

**Amanda:** And so that part of your routine was really kind of guided by your mom’s routine as well then?

**Ray:** Yes.



**Amanda:** So, the early morning part of your self-care routine has been pretty similar over the years...and you started that routine...

**Ray:** Right out of rehab.

**Amanda:** And that habit formed and it just kind of stuck this whole time?

**Ray:** Well, like, it had to. Like, my mom was working, and I had to go to school, and then I moved here. So, that's what I knew because I was doing it for two and a half years or so.

Ray's morning ADL routine, including the timing of his bowel program, was shaped early by factors that existed within the context of his environment. These included caregiver availability and limited access to health care personnel resources in his geographic location. Decisions about establishing ADL routine practices also had to accommodate family work and school schedules that contributed to the establishment of time-use patterns within Ray's daily routine.

### **Life Managed by Others**

After learning how Ray structured and ordered his present-time daily routine, and what he hoped his days would be if everything went as planned, Ray explained that he has not always been this organized. He also stated in the past he was not disciplined in following a solid ADL and health management routine.

“When I moved here in my early twenties, I wasn't managing...I had a case manager, I had a life coach. I had all that stuff. So, I didn't worry about taking care of anything. I just [messed] around while everybody else took care of everything.”

During this time in Ray's life, his caregivers' time and schedule were managed by an external agency. Instead of the three to four hours each morning he currently spends with his PAs, Ray said during this phase of his life he was allotted sixty minutes (ninety minutes on bowel care days) with a caregiver to assist him with his morning routine. This provided enough time for an

every-other-day bowel program, showering, and getting dressed. Ray explained, “I didn’t have time to exercise...and since I wanted to shower every day, I didn’t eat breakfast either.” Food and nutrition were challenges because of this caregiver schedule. While caregivers were available for lunch and dinner assistance, Ray said he only had an hour of time designated for meal preparation, eating, and other home management tasks. “They were only here an hour so it’s not like you get good meals...so I ate a lot of processed box food. Quick microwave food...now I cook. I’m able to cook more than I used to.”

Ray remembered being a passive participant in his health routines and had conversations about his health management and community mobility with his case manager.

“She used to try and get on me [laughing] but I was young. I didn’t care...I just wanted to have fun. And I didn’t really know how to access the community, so I only went places when it was nice out and I could go in my wheelchair. For the most part, I didn’t know how to get around and do stuff in the community.”

Ray recalled spending a lot of time in the hospital during this period. Early on, it was mostly hospitalizations for bronchitis and pneumonia, then he began having bladder and catheter issues, as well as wounds that required IV antibiotics. Ray reflected how he did not worry about his health back then and attributed current health-related problems to a lack of structured ADL and health management routines during the early years. Ray stated, “Back in my twenties, I just let the agency run everything, run over me, tell me how to think, and how it’s gonna be, you know?”

### **The Beginning of Life Managed by Self**

“I met someone when I was twenty-eight. She moved in with me.” Ray remembered this experience as a pivotal moment in the development of self-efficacy that marked the beginning of

becoming a more active participant in his life and in self-directing his care needs. He remembered how his thinking changed because someone in his life had expectations of him. Ray started thinking about the consequences of making poor health management decisions and how it affected his ability to be present and enjoy his relationship.

“The whole thing with dating someone... I don’t know...not being able to spend time or hang out with someone because you’re worried about things. When you’re on antibiotics and things like that...so I started paying attention more.”

Ray’s relationship ended but what he learned about his capabilities and potential for greater independence continued to progress.

Ray also contributed his personal growth and desire for independence as influenced by his enrollment in college classes as well as meeting other people with tetraplegia through an employment opportunity.

**Ray:** I started going to school when I was twenty-eight.

**Amanda:** You did? So, was that the big shift?

**Ray:** Yeah. Going to school...and working. I met other people with spinal cord injury that were working, and I became a peer advocate. So...so that was kind of a big deal...being around people that were living independently, too. They started teaching me how to be independent and how to take care of myself.

**Amanda:** So, you had some peers with similar injuries that were living a life that was different than what you had kind of set up for yourself?

**Ray:** Yeah. And I was learning. Just observing.

**Amanda:** So just kind of watching and assessing your own situation was part of it?

**Ray:** Mmhhh. Just that and having a few relationships where they wanted more for me, too... for me to be more independent.”

Ray described these relationships as the beginning of a shift in his thinking about what independence could look like while also living with tetraplegia and a disability. Ray said he had

more free time in his day before he attended college and engaged in productive employment. However, prior to participating in these life roles, he did not have a reason to worry about his health nor did he have the drive to engage in better ADL and health management practices. In this storied moment, Ray explained how his thoughts about spinal cord injury shaped his choices of occupation and time-use when he was younger.

“Back then I never thought I would be this old, either. I believed...you know...I always looked at the statistics and I’d seen a lot of people pass from back home. There’s a lot of quads and paras back home that are gone. So, I was like well, you know, I’m going to enjoy my life now, because I wasn’t expecting to be this old. The stats are like ten to twenty years for quads so I was like, wow...I might as well go out having fun, you know?”

Ray reflected on how this mindset had consequences for his future health. He described how his understanding of tetraplegia at the time influenced his choices in occupation and time-use. Ray continued, “I didn’t think about prevention, or risk factors, or any of that health-related stuff that can cause life to be hard for me now.”

### ***Framing the Morning Routine: Focus on Independence Shaping Occupation and Time-Use***

#### **Mindset Influencing Occupational Experience**

The burden of morning ADLs, depending on others, pain, discomfort, and the actual amount of time required, were all factors that affected Ray’s experience of engagement in his ADL and health management routines. Ray explained this part of his day required some serious work with a counselor to develop positive thinking strategies and a shift in occupational focus to stay motivated. “Now, I try to think about what I have to look forward to.” Ray reported that keeping a positive attitude is hard work. He said one important component for improving the

occupational experience of morning ADLs was explaining to caregivers his need for limited vocal interaction during the first parts of the routine: getting out of bed and the sixty minutes required to complete his bowel care program. Ray needed his caregivers to understand that he experiences a lot of pain when he first gets up in the morning and that this part of the day is uncomfortable and hard on his body.

**Ray:** I needed to let people know that getting up and out of bed is not the most comfortable part of my day and bowel care is not comfortable. There is a lot of dysreflexia with that So it's just trying to...I used to analyze the whole getting up process which made it complicated.

**Amanda:** Like you were anticipating it as a bad experience?

**Ray:** Like...it used to be like oh, I gotta get in the Hoyer, I gotta get in the shower chair, I gotta get back...just planning it...it was hard to want to wake up. You know, it's like...[sigh].”

**Amanda:** Because the routine was so hard?

**Ray:** Just because the routine was so *long*. I was like...here we go again. That's why I have been trying to meet with counselors. I've been trying to look at it differently, to be more positive. 'Like...Oh. I'm going to work today so...what am I gonna do at work? Alright.' You know...being more positive and optimistic about it now and it's helping.

Ray continued to explain how his point of view shifted beyond this part of his daily routine reminding me that this was something he cannot change...the process of getting up. He cannot change the fact that he needed someone to help him get out of bed and get into his commode chair, have a nurse help him with his bowel care routine, then have his PA take over and help him take a shower, stretch his muscles for him, and to get him dressed. Ray elaborated,

“So why dwell on it? Because it's not gonna change. I am not going to get better. So, let's start looking toward what makes my day happy...what do I look forward to doing

once I am up and can be independent...because before that is all about depending...depending on someone else.”

### **Caregivers Influencing Occupational Experience**

Ray said his self-work in looking beyond his morning ADLs to the parts of his day that make him happy changed his occupational experience during these activities, but the experience was also influenced by his caregivers. He needed his practice of optimism to be reflected in the attitudes of his caregivers for it to work. Ray described having caregivers in the past that brought negativity with them when they helped him during morning ADLs, or wanted to share their own life stresses, or spent that time venting about personal problems while he was in the shower or while getting dressed. Ray stated, “I have caregivers now that are not so negative. If they come in with a positive attitude it works...even if they aren’t really “morning people.”

Trying to maintain his positive outlook surrounding the morning routine also required consistency and continuity of his PA staff. In the following storied moment, Ray explained how the challenges of keeping caregivers also influences his attitude and mindset during his morning ADL routine.

“You know, getting a new caregiver is always the hardest because that’s...I get the most depressed because we have this whole routine and I have to teach it all over again. I have to take someone through that whole process of learning this routine. Just like...I miss the days when I was able to roll off the bed and crawl in the shower and get ready for the day and then be done in what...a half hour? I just need to tell them and show them how to do it, and hope they take initiative and start doing it...without me having to nag.”

## *Framing the Other ADLs: The Art of Doing Shaping Occupation and Time-Use*

### **How I Would Do It if I Could Walk and Use My Hands**

During our conversations, many of Ray's stories outlined the different ways he worked with his personal assistants: morning ADLs, support during creation of artwork, social activities, transportation, and support in health management procedures. While we talked about life roles and performance patterns in his daily routines, cooking and cleaning were clearly identified as activities Ray enjoyed engaging in. When Ray made statements such as, "now that I can cook..." I wanted to know more about his occupational experiences and time-use with these activities that fell outside the other areas of life participation we had explored. Ray stressed the importance of demonstrating his independence in these activities to his caregivers even though he was physically unable to use his hands.

"Being able to live here on my own...I have this opportunity to be independent.

Independence *is* living. How would you take care of yourself if you were walking? Just look at it that way. Caregivers begin to understand and then they realize the role they are playing. They become my hands."

Ray went on to further explain his viewpoint. He described the importance of being an active participant in all aspects of what he would be expected to do for himself if he were able to walk and use his hands.

**Amanda:** I have a question and I hope this makes sense. Going back to what you said about working with your caregivers...and they begin to view their role as being your hands for you... Does that allow you to feel like you are doing the task?

**Ray:** Mmhmm.

**Amanda:** Can you tell me more about that?

**Ray:** Because they're doing it the way I want it to be done. This is the way I would do it. And so, I feel like I am living through them doing the activity and it allows me to be independent.

**Amanda:** And so, things like cooking...

**Ray:** Yes. I love cooking. I like teaching people and a lot of people don't know how to cook these days...[laughing]

**Amanda:** So, you actually feel like you are actively engaging in the act of cooking?

**Ray:** Yes. I'm sitting next to them and telling them...I'm not just sitting there watching TV and letting them do things that...I'm actually engaging, so I feel like I'm doing it myself. So, I don't say someone cooked it for me, I say I cooked dinner for myself.

Ray described the same mindset and attitude about cleaning and rearranging the furniture in his apartment. He has maintained these habits and rituals that formed while he was young and still living with his mom. "I always rearranged my room. My mom was like, 'you were always rearranging!'" Ray explained the sense of accomplishment he feels when he and his PA clean together or cook a meal. "I feel like, aah...no more clutter. Or when I cook, I feel like I made something bomb! But then they are also learning how to cook and eat better, too."

### *Meaning and Life-Purpose Shaping Occupation and Time-Use*

#### **Looking Ahead**

The Day Reconstruction Method (DRM) tool was used as a starting point for our conversations to gather information about Ray's occupation and time-use. This information provided details about his past and present-day ADL and health-management time-use patterns and led to questions about how Ray's ADL habits and routines changed over time. Ray said that before he attended school and began working, he had more passive leisure time in his day but spent almost two hours less time engaging in his health management and ADL routines, which



negatively impacted his health and well-being. Ray explained how meeting people in the community living with SCI and tetraplegia led to an opportunity to work as a peer advocate where he developed an interest in helping others with disabilities. Ray's experience working as a peer advocate led him to finish his undergraduate degree and pursue a graduate degree in a health-related field where he now works indirectly with clients. Ray attributed his decision to better manage his self-care and health management to his desire to work helping others and create his artwork. Ray explained how finding life-purpose factored in decisions he made about engaging in a more disciplined and time-extensive morning ADL and health-management routine.

“I feel like my quality of life is better now because I live for so much more. I go to work, and I do this job where I love serving people and helping people. And I also love doing my artwork and I can't do it if I am sick. So, that's why I get up and I manage my health and manage my care even though that means I have a smaller window of time to do other stuff.”

Ray acknowledged he would have more time in his day to explore other leisure activities if he spent less time engaging in his health management and self-care routines. “But I don't know if I would have the drive. I love being busy at work and love doing the job I do...it keeps me wanting to stay healthy and work on things,” Ray explained.

Ray shared how important it was that he continue focusing his energy on future goals and fulfillment of life-purpose and quality of life. Ray reflected on his past accomplishments and looked toward the future. He shared with me that his decision to pursue his master's degree in order to work with clients provides him with a sense that he can make real change in society. “I feel like it's a start to somewhere, but I don't know...I don't feel like I'm gonna do this forever.” Ray stated he has worked on a way to keep his clinical practice and to also carve out some time

in his day to do more writing. “I kind of want to be a motivational speaker...and I want to work with kids. Community change starts with young kids and children, you know, and teens. That’s my passion.” Ray was also looking forward to a time post-pandemic where he can return to the stage and start performing his comedy skits again. “I’ve been doing a few comedy sketches in front of my PAs. I want to be around people again...I miss being around people.”

### ***Disability Shaping Occupation and Time-use***

Ray’s narratives on occupation and time-use illustrate his personal journey of living with tetraplegia that included the process of learning independence, developing self-efficacy skills to fulfil life roles and routines, building capacity to direct his own care, and realizing capabilities to engage in productive work and create his artwork. In the closing of Ray’s first story that illustrated his typical day, Ray stated, “I structure my day this way, it just doesn’t always play out that way... because...life. You know?” The following stories reveal Ray’s reality of living with tetraplegia and disability, and the many transactions he faced every day that altered, disrupted, or restricted his occupational decisions and his ability to participate in his desired routines.

### **Schedules and Waiting...and Waiting**

Ray explained that everything he wants to do in his day has to be scheduled and pre-planned, which influenced Ray’s occupational choice, occupational selection, and time-use. The following interaction I had with Ray informed me about his experience of engagement in creating art, how inspiration happens, and what it means to be an artist with physical limitations who depends on others to engage in meaningful activities.

**Ray:** I’m always waiting. Even though I schedule a lot of things, it sucks that I have to wait until that time comes up...wait for someone to help...or wait and someone

doesn't show up. I have to wait until the scheduled time and then, by the time that happens, sometimes I don't feel like doing it anymore.

**Amanda:** Really?

**Ray:** Like art. Like...I get in this mode, and I want to paint...like I got an idea that I want to do but it's not the scheduled time for my PA to come in. And then say, I timed art for a Saturday, and she comes in and she's ready to help me with art...and then I'm just like...[sigh].

**Amanda:** Like the window has passed?

**Ray:** Yeah, It's like I'm tired today...

**Amanda:** So, you're planning the activities you enjoy the most, but sometimes this...because you can't just spontaneously go and do it...it doesn't always match up with how you are feeling when the time comes around?

**Ray:** Yes. Art is a lot about feeling. To me it's what is inside. The visions. I visualize and I see something...I wanna do it right then so I don't lose that idea, or that feeling, or that drive. And so, a lot of the time I have to push myself to do it and once I get started, I feel good.

Ray wanted me to understand this phenomenon occurred in all aspects of his life and his daily routine. Running errands, going to the post office or mailing letters, getting work documents completed and returned to the office, all of these everyday tasks require another person to assist Ray. He explained missing a last-minute meeting, or other obligations, was a familiar consequence when prioritizing necessary activities like opening important mail or attending to time-sensitive paper documents which must take priority when he has caregivers available to assist him with these tasks.

Ray developed strategies over the years that attempted to limit disruptions in his daily routine and reduce the amount of waiting he must do between desired occupations. Ray said he tried to keep at least four or five people on staff at all times. He had designated personal assistants for certain aspects of his daily routine: a morning routine PA, a "put to bed" PA, a PA designated just for artwork assistance and socializing, a weekend PA etc.

“I teach them all how to do stuff just in case. I build my staff that way because someone doesn’t show up, or gets sick, or takes vacation...if I only staff two people the odds are greater, you know? Everyone still learns how to put me to bed and how to get me up just in case. Yeah...I got smart about it that way.”

Ray also reported he learned to maintain relationships with past caregivers, and while they no longer work with him on a regular basis, he valued these sustained friendships.

“Once you’ve built that you can call. Like, I have a few people in the community that if I ever need something I can call. So, those friends are out there for just in case something goes awry, or I get stuck in a hard place. They will help me.”

### **Health-Management Doesn’t Always Stick to the Schedule**

Certain aspects of Ray’s health management routine were predictable, recurrent events that occurred daily, weekly, or monthly. Daily stretching and range of motion to prevent contractures averaged forty minutes per day. Blood draws and catheter changes were two times per month, and Botox® injections to manage his bladder health and reduce spasticity usually occurred every four months. Health-maintenance appointments with primary care and physiatry occurred quarterly. It took a few moments for Ray to calculate clocked hours spent completing these routine appointments. “The blood draws take about 45 minutes, and I usually schedule doctor appointments for about an hour. Bladder injection appointments end up being an all-day thing because I have to go under so, someone drops me off and picks me up from the hospital.” Ray stated he was allotted twelve hours per month for transportation to and from medical appointments, and he typically used between six and eight hours per month. Even though these were the scheduled, predictable health routines Ray engaged in to maintain health while living with spinal cord injury, he reported that he must coordinate scheduling of these appointments

between work obligations, caregiver schedules, and transportation availability. “I have to fit all of this in before I start work. I only have so many hours...so much time.”

“Knock on wood...I hope this will be the first year that I won’t need to be hospitalized.”

In this storied moment, Ray described that even though he had been diligent about his health management routine compared with his younger years, he still had to deal with significant disruptions in life due to health concerns. Ray was frustrated that last year pressure injuries on his elbows went unnoticed and took a turn for the worse. “I think my elbows were rubbing on my armrests while I was riding in the van.” Ray ended up in the hospital and required IV antibiotics. “I had a PICC line for a month. So, I was in the hospital for a week, and I had another three weeks of the antibiotics. I never broke down like that...it scared me.”

Ray discussed situations where health management disrupted his work schedule and routine. He shared how he had to be vocal with his employers about what is happening with his body and his loss of privacy was palpable as he described how he felt he had to share information about his health complications with employers.

**Amanda:** So, would you say that compared with your colleagues, you have less privacy with your employer when it comes to your health?

**Ray:** Yeah. I gotta be more vocal about things that a lot of other people don’t realize happens.

**Amanda:** Because those things might disrupt your work and you don’t want it to cause an issue?

**Ray:** Like Monday my catheter was kinked for some reason. I don’t know...it got kinked up a little bit and I was in the middle of a meeting. And they were like, ‘Are you ok?’ And I was like trying to be ok, but I was just sitting there dripping sweat, trying to finish up that meeting and I was finally like, ‘I gotta go...something’s not right.’ So, they asked me to check in and asked a hundred questions about why that happened.

**Amanda:** So, they wanted to know more about why that happened?

**Ray:** Yeah...and I hate that I always have to be so open about my life when they...like everybody else...you know...just...

**Amanda:** Takes it for granted?

**Ray:** Yeah. I wish they would just understand that there's an issue and we believe them...instead of, 'So, what's the issue and why is it so complicated?'

Ray also explained that these communications with his employer helped them better understand Ray's needs and the unpredictable nature of living with SCI and disability that may disrupt work routines or require accommodations. He reported that these "communications" and meetings were necessary for Ray's employer to better understand how he managed his work schedule within the overall context of his daily routine that included his time-use for ADL and health management. "I get prone to sickness...or situational things come up that go along with my disabilities that may interrupt my day. So, she's starting to understand my daily routine is not always smooth."

### **Caregiver Continuity and Caregiver Relationships**

"Right now, I have a pretty stable group working with me. The reliability is probably why I am so healthy right now." Ray said his current staff of PAs consisted of caregivers with differing backgrounds and included a nursing student, someone who has been a lifelong caregiver with more extensive experience, and staff members who have been more reliable and "show up and really enjoy helping people and really enjoy their job." Ray described it as a unique type of employment and caregiver relationships can often become difficult to navigate. He explained that when people show up and come into his house every day, it becomes a situation where it no longer feels like an employer-employee relationship. Ray further explained,

“I had to create an environment where I’m not asking them to be at my beck and call but I’m asking them to be here in a way that we get along, and communicate and they enjoy showing up.”

Conflicts with caregiver caused disruptions in daily routines or a shift in occupational choices and selection which impacted Ray’s participation in desired activities. Ray described how his occupational experience and time-use was directly affected by the successful orchestration of the very delicate caregiver relationship. Some of the most difficult situations to navigate surrounded the balance of work relationship and social relationship with caregivers.

**Ray:** You have to remember, someone like gets me up every morning and sees the whole world. They get me up, shower me, dress me...they see the worst of me and the best of me. Just navigating that is hard because it’s not private. So sometimes these types of relationships become difficult when I need someone to hurry up or move faster.

**Amanda:** Are those difficulty conversations to navigate?

**Ray:** Well, yeah. Because they think I am being a jerk and I am not trying to be a jerk. Like, I am only allotted so much time and I cannot pay them to stay here longer.

**Amanda:** Yeah.

**Ray:** So, I need them to hustle, hustle sometimes. Or they come in and I need to explain that I know it doesn’t feel like a workplace, but I need you to understand that it is. But then at times I get relaxed with things because I like to have conversation, so I try...a lot of the time they are my only social network.

**Amanda:** That’s a really hard thing to balance.

**Ray:** I want to socialize, you know...but sometimes they take advantage.

Navigating these relationships became an integral part of Ray being able to carry out his desired daily routines. He stressed that he had to learn to adjust how he interacted with individuals to keep the relationships that he relied so much on working in order to spend time doing all the things he values once he is in his power chair and can be independent.

“You know, I learned we all grow up differently, we all handle things differently, and we all come with our own culture and background. Sometimes I question if I am really being true to myself because I have to find ways to adapt to people’s personalities and things. The reason I do that is so I know I can have these caregivers. I need to act a certain way, so they stick around. It’s not like people are knocking down your door looking for jobs like this. I’ve burned bridges in the past, so I know what I need to do.”

### **Barriers to Maintaining Social Connections**

The following conversation was a starting point of a discussion about the challenges Ray faced with social participation within the community. Environmental( factors and logistics surrounding transportation, timing of caregiver availability, and weather, all became factors that influenced Ray’s decisions about how to spend his available leisure time outside of work and ADL/health management routines.

**Ray:** I am trying to get back into comedy again because I need to get out and socialize. And I don’t like working from home. I told them...

**Amanda:** Yeah?

**Ray:** ...and that’s why I was sad when the clinic shut down. It was like...[sigh]

**Amanda:** Back at that again?

**Ray:** Yeah.

**Amanda:** Because I remember you telling me that you were a little worried when school was done...it was kind of a bittersweet ending.

**Ray:** Mmhmm

**Amanda:** You were ready to be done with the school part of it, but you were going to miss other things about going to school. Tell me more about that.

**Ray:** I’m just a...every time I take that introvert-extrovert test I align right in the middle. I like to spend time alone, but I also like to be around people and socialize, too. So, I need to be around people.



**Amanda:** Living where we live...does that factor in from season to season?

**Ray:** Yeah. It makes it harder from season to season because I don't like depending on people that much either. I don't like depending on people to socialize and do things.

Ray provided insight into the other challenges surrounding social participation, telling me that it was not just about the transportation. "You get a ride back and forth, but you still have to sit with your coat on...and can't really access the stuff I need to get...you know...until someone shows up." Ray stated during the warmer months, he accessed the trails, met people in the park, and drove his power chair to meet friends out for dinner. During the times of the year when transportation and weather factor in decisions about time-use, Ray explained that most socializing occurred at his apartment and he had friends that would stop by and check in adding, "it's just more enjoyable to go out and meet up somewhere else." In this final storied moment, Ray shared that impact social restriction and isolation had on well-being. All three contextual factors: caregiver access, transportation, and weather challenged Ray and his friend Derek, who also used a power wheelchair, while they tried to meet during the past few months.

"Derek and I have been hitting and missing each other because we both depend on people when the weather is like this. He's been kind of in a funk and then I get in a funk and we're just trying to figure out how we can get together and see each other."

## Discussion

The aim of this narrative inquiry was to examine the experiences of Ray, one individual with tetraplegia, related to his time-use spent performing ADL and health management routines. This study also explored Ray's perspectives on time-use tradeoffs and aimed to better understand what factors supported or restricted Ray's engagement in wanted or necessary activities beyond ADL and health management routines. Ray's stories spanned his twenty-two-year history living with tetraplegia and disability and illustrated the complexity of occupation from a transactional perspective. The stories also revealed the complexity of time-use beyond the temporal structure of clocked time, as time intersected with disability for an individual living with tetraplegia. These narratives demonstrated that a person's past, present, and future cannot be separated from how occupations are learned, performed, engaged in, and experienced. Ray's stories about occupation and time-use also brought insight to how situational contexts including social and environmental influences impacted occupational experience and performance patterns altering or disrupting engagement in desired life roles and routines. These contextual factors often complicated Ray's ability to successfully achieve his planned daily activities and his stories provided a window for examining how changes in circumstances such as health management needs, caregiver access, transportation, and weather influenced occupational selection, occupational choice, and time-use patterns. Examination of Ray's stories in each the of the thematic representations revealed the challenges and tensions present as life intertwined with disability and occupation.

### **Caregivers, Relationships, and Learned Self-Efficacy Shaping Occupation and Time-Use**

Ray's stories captured his experiences from the onset of his SCI and spanned twenty-two years ending with our conversational interviews about occupation, time-use and living with

tetraplegia. The first theme highlighted the beginning of Ray's transformation from what he described as a "passive to active participant" in his life, as he began to apply meaning to the idea of independence. Within the meaning-making process, Ray began to link independence to action in occupational engagement as he transitioned from having family as caregivers while he was still in high school, to life managed by others when he began living alone in the community, to life managed by self when he took charge of his caregiving needs and caregiver schedules. Fritz and Cutchin (2017) described how a transactional perspective on occupation explains that occupational behavior is a "dynamic process that unfolds through time as current behavior builds upon previous behavior and shapes future actions" (p. 450). Ray's social interactions with caregivers and others with whom he had relationships created opportunity to develop positive changes in habits in his ADL and health management routines. Ray described these relationships as the beginning of a shift in his thinking about what independence could look like while also living with tetraplegia and a disability. The transactional view of Ray's evolution toward independence and participation showed the functional coordination involved between himself and those who provided his caregiving needs. Ray's own habit formation was directly related to the habits and actions of those with whom he shared these interactions and within the context these occupational experiences existed (Cutchin et al., 2008; Cutchin & Dickie, 2013). This means the attitudes, behaviors, skills, and caregiving structure all influenced Ray's occupational experience and engagement. Positive role models helped Ray build positive health behaviors. As Ray's self-efficacy skills grew, he also learned he could take personal action and regained control of his life choices by directing others involved in his care and needs (VanPuymbrouck et al., 2021).

### **Framing the Morning Routine: Focus on Independence Shaping Occupation and Time-Use**

Ray's narratives on occupation and time-use that fell within the theme of "Framing the Morning Routine" included stories about strategies Ray used before and during performance of morning ADLs to cope with the negative occupational experience of this routine. These strategies included positive thinking techniques he learned through the help of a counselor and a shift in focus toward the more meaningful and enjoyable aspects of his day. Ray found this to be a necessary strategy to tolerate the physical discomfort experienced during his bowel care program and the feeling of dependency he experienced while working with caregivers during morning ADLs. Shifting focus toward the parts of his day when he was in his power chair and independent helped Ray cope with the negative thoughts that emerged when thinking about the time-burden required to complete these activities. Ray looked forward to working with his clients and engaging in artwork and it was these occupations that gave Ray the drive to create continuity in his morning ADL performance patterns and to develop positive health behavior habits. Ray's perspective supports statements made by Pentland et al. (1998) and Yerxa and Baum Locker (1990) that personal meaning and experiences of time-use are important factors and provide more understanding about quality of time-use than just the clocked time spent performing occupations. The meaning Ray attributed to morning ADLs echoes what Fisher and Marterella (2019) described as occurring between the elements of occupation in their Transactional Model of Occupation. Occupational performance (doing), occupational experience, and participation (engagement) are all connected and Ray's method of looking beyond morning ADLs to what he looked forward to in his day helped him find value in the "doing" of the morning routine despite the physical discomfort he continued to experience. It is important to note that Ray's occupational experience during performance of morning ADLs did not improve in terms of the

physical discomfort Ray felt during his bowel care program, nor did his occupational experience change in terms of the personal meaning Ray attached to having dependence on others. The ability to engage in meaningful occupations *after* the morning routine gave Ray a reason to tolerate the discomfort he experienced with ADLs and to maintain his health so he could continue to engage in personally meaningful occupations that provided quality of life and fulfilled his sense of life-purpose.

### **Framing the Other ADLs: The Art of Doing Shaping Occupation and Time-Use**

Another example of this connection between doing, experience, and value in occupation was demonstrated in Ray's engagement in cooking and home management. His determination to be an active participant in his life led Ray to be present and participate in these activities with his caregivers who he viewed as instruments for his "doing" during cooking and cleaning ADLs. His enjoyment and satisfaction with home management differed from participants in the Yerxa and Baum Locker (1990) study who reported low levels of satisfaction with home management and described home management skills as "not applicable" possibly indicating that they delegated these tasks to others. While Yerxa et al. (1989) discussed that the practice of occupational therapy relies on the premise that engagement in occupation influences health, early research conducted by Hammell (2004) challenged the traditional assumptions about the concept of doing when quality of life after high spinal cord injury was explored. Hammell's findings suggested that physical participation is not necessary to experience enjoyment or a sense of accomplishment in a particular occupation and that a "virtual" (p. 21) link can exist between health and well-being and an occupation regardless of an individual's physical ability (2004). Occupational therapists assisting clients with physical impairments should inquire about their clients' occupational experiences to explore why certain occupations may be delegated to others

based on perceived capabilities, so opportunities to support meaningful engagement and occupational choice can be further explored.

### **Meaning and Life-Purpose Shaping Occupation and Time-Use**

Ray's narratives on occupation and time-use demonstrated how his experiences and understanding of quality of life and life-purpose were intertwined and his perspectives on independence, meaningful occupation, and time-use required a gradual evolution of thought and action as he discovered his capabilities to live independently, manage and direct his own care, and personally structure his daily routines. Ray's decision to set goals and pursue dreams led to his understanding in the importance of doing his morning ADLs and health management and was linked to his desire to contribute to society through his work and so he could create his artwork. Ray described how solid self-care and health management routines had less meaning during his younger years living with spinal cord injury when he also engaged in more passive forms of time-use that included occupations that were not considered health-promoting behaviors. Ray's narratives on occupation and time-use as they related to quality of life and sense of life-purpose support the findings of Hammell's research (2004) on quality of life and high spinal cord injury. Ray shared his stories about how he learned to take control of his life and direct his care and routines, how learning from peers and partners showed him what was possible in terms of independence, and how discovering more meaningful use of his time lead to life satisfaction, better quality of time-use, and a gain in sense of life-purpose. Hammell's work (2004) also described how autonomy, discovery of the importance of doing, and relationships (including the importance of contributing to others), contributed to high levels of perceived quality of life for individuals who had experienced a loss of the "actions of life" (p. 22) after sustaining traumatic tetraplegia.

## **Disability Shaping Occupation and Time-use**

The examination of Ray's experiences over time provided insight about how Ray learned to become an independent and active participant in life to accomplish goals leading to a higher sense of life purpose and better quality of life. Despite Ray's high level of self-efficacy and ability to self-direct his own care routines, maintain productive work, and engage in creative artwork, situational elements that existed within the context of Ray's occupations also disrupted, altered, or modified how and when he was able to engage in his desired occupations and daily routines. In consideration of a capabilities approach perspective on occupation (Bailliard, 2016; Hammell & Beagan, 2017; Hammell, 2021) circumstances such as transportation, caregiver consistency and access, weather, health management needs, and societal attitudes including attitudes of hired caregivers were all transactional forces or circumstances that shaped Ray's available choices or ability to engage in intended occupations each day. Ray described how highly organized, planned, and scheduled routines reduced disruptions as much as possible. Factors such as a caregiver not showing up, transportation problems, or an unanticipated need to address a health-related concern were constant factors impacting successful participation. Careful consideration of whether to act on a social invitation in the community was also part of Ray's reality as he had to time these activities in coordination with caregiver availability. Ray's challenges with social engagement often restricted and tested his autonomy and independence once he navigated beyond his front door and into the community. This correlated with research completed by Lund et al. (2007) where problems with community and social participation coincided with lower levels of life satisfaction due to restrictions in occupational choice.

## **Limitations**

Similar to other studies that use single-subject narrative inquiry as a methodology, there were some limitations to this study. First, one participant was chosen for this study as an in-depth inquiry into the full experience of occupation and time-use as it pertained to living day-to-day with tetraplegia. There should be caution with generalizing the results to the SCI population as a whole. Second, as reconstructions of personal accounts, narratives are not always the exact reproductions of the participant's experiences. The narratives were composed by the participant and the researcher since the researcher shaped the direction of the story through the questions that were being asked. Finally, this study is an account of the stories of the participant's experiences at one point in time. New experiences of the individual following this interview would shape recall and inform new stories. Despite these limitations, narrative inquiry is a sound methodology to examine the lived experiences of individuals with tetraplegia and other disabilities as it provides a richness in detail that would be lost using other methodologies. This is an important consideration when examining the complexity of occupation which includes all the elements of participation, performance, and experience (Fisher & Marterella, 2019).

## **Implications for Future Research**

Since the studies of Pentland et al. (1998; 1999) and of Yerxa and Baum (1986) and Yerxa and Baum Locker (1999), no studies have been completed within the fields of occupational science and occupational therapy that studied the qualitative aspects of time-use of individuals with tetraplegia until now. While these hallmark studies aimed to better understand the impact of SCI on time-use, quality of time-use, and connections between time-use and life satisfaction, the quantitative nature of these studies left little understanding about the meaning



attributed to occupations, how important the connection of experience is to occupational performance and occupational engagement, or how time-use is influenced.

This study of the narratives on occupation and time-use of one individual with tetraplegia captured the complexities of occupation while also uncovering the various temporal structures of time-use attached to these occupations. This type of research methodology offers a more contextualized understanding of occupation as viewed through the framework of a transactional perspective (Bunting, 2016). Future research should include replications of this study with larger samples to continue exploring time-use, the connection between person and context, and how performance, experience, and participation are ultimately connected within the complexities of occupation (Fisher & Marterella, 2019). Gathering in-depth individual experiences and comparing those experience across populations with similar characteristic and conditions can help to inform occupational therapy practice and occupational therapy education. This can occur through the understanding of the rich, contextualized, time-use phenomena as experienced by individuals with tetraplegia or other conditions.

### **Implications for Occupational Therapy Practice**

Occupational therapists provide SCI education for their clients in the areas of ADL and health management routines. During inpatient rehabilitation, these interventions occur in a very short amount of time in proportion to the high volume of skill necessary to return home and successfully navigate life with SCI and tetraplegia. Due to reimbursement and time constraints, occupational therapists often focus on the procedural aspects of skill acquisition in performance of basic ADL and health management routines, yet this emphasis decontextualizes the activity being learned and ignores the other occupational elements of lived experience and engagement (Fisher & Marterella, 2019). Solid health management and ADL routines have been directly

linked to better health outcomes of individuals living with SCI (van Wyk et al., 2015). In Ray's case, finding the value and meaning of engaging in ADL and health management routines directly related to his discovery of meaningful occupation in the form of productive work and creative expression through his artwork. This supports Hammell's (2004) argument that the focus of occupational therapy should not be solely about acquisition of skills such as getting out of bed or performance of basic ADLs, but also an exploration in finding client's reasons for wanting to do so. Ray's development of positive health behaviors occurred when he linked their value with the ability to engage in occupations that provided him quality of life and life satisfaction. This did not exist directly following Ray's injuries but unfolded over time as he gathered necessary experiences. This concept was further supported by Fritz and Cutchin (2017) when they described how people need time and opportunities to refine their approaches to occupation and support engagement. Ongoing occupational therapy support beyond inpatient rehabilitation may or may not be available based on access, available resources, or geographic location. Occupational therapists can assist their clients to be better prepared for occupation-context interactions that impact participation and time-use so they can address problematic situations that would alter performance patterns or engagement.

## **Conclusion**

This study has made important contributions to the understanding of occupation and time-use as experienced by an individual with tetraplegia. For Ray, looking toward the more enjoyable parts of his day provided a reason and meaning to engage in basic ADL and health management routines even though the routines required a high burden of time. Future studies can gather the narratives of experiences of others living with disabilities to better inform occupational therapy practitioners by exploring each client's personal meaning of the link

between occupation and well-being to restore engagement in meaningful occupations and promote positive health behaviors and skills in performance of self-care and health management routines.

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**Appendix A: Institutional Review Board Approval for Capstone Project**

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**Consent to Participate in a Research Study  
Individuals with Tetraplegia: Narratives on Occupation and  
Time-Use**

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**Institutional Review Board  
Protocol Number**

4403

**Approval Valid**

11/22/21-8/6/22

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## Appendix B: Schedule

### Ray's Morning ADL Routine Schedule for Weekdays and Weekends

#### Modified Day Reconstruction Method Instrument Documentation

What time do you go to bed? 9:00 pm weekdays and 10:00 pm weekends  
 What time did you go to sleep? 9:15-9:30 on weekdays and between 11:00 and 12:00 on weekends

What time did you get out of bed? 6:00 am weekday bowel care days and 7:00 weekend bowel care day; 7:00 am weekday non-bowel care days and 8:00-8:30 weekend non-bowel care days

What time did you wake up? 6:00 (weekday) or 7:00 am (weekend) on bowel care days, 7:00 am on non-bowel care days both weekday and weekend. Lie in bed and think and relax on weekend, but always typically wake up at 7 no matter what.

#### Morning

(from waking up until just before lunch)

Episode Name	Began	Ended	Activity Details
Up and out of bed: Bowel Program: every other day for example M-W-F-Sun- T-Th-Sat over two- week period.	Weekday: 6:00 am Weekend: 7:00 am	7:00 am 8:00 am	Nurse arrives at 6:00 am to assist M with Hoyer transfer to rolling shower/ commode chair and procedures to complete bowel elimination program
Shower (and up and out of bed on non-bowel care days)  ***Occurs every day	Weekdays: 7:00 am Weekends: sometime between 8:00 am and 8:30 am	7:20-7:30 am Between 8:30 and 9:00 am depending on time up. Takes longer shower on weekends, at least 30 minutes	Nurse departs at end of bowel program and personal assistant (PA) arrives to begin shower routine (While M in shower/water warming up, PA initiates some home management tasks
Getting dressed Time frame also includes: Stretching/Range of Motion (total assist from PA) Skin management:	Weekdays: appx 7:30  Weekends: between 8:30 and 9:00	Weekdays: between 8:00 and 8:15  Weekends: 45-60 minutes ending between 9:30 and 10:00	Getting dressed requires transfer back to bed. During dressing PA performs PROM and skin checks

checks/assessment for pressure areas or wounds			
Come out to living room. Smudge.	Weekdays: between 8:00 and 8:15 Weekends: between 9:30 and 10:00	Five to ten minutes total	Burn sage/sweetgrass; meditate; get mind ready for the day
Make and eat breakfast and turn on computer, check emails, look at schedule for the day, make appointments	Weekdays: appx 8:15	Usually takes around 45 minutes to 1 hour. Warms up quick breakfast on days with medical appointments or scheduled work at 9:00 and will cook hot breakfast on days where work doesn't begin until 10:00	Directing PA to do some home management, cooking, etc. Eating breakfast (assisted by PA for feeding).
<b>Total ADL time (morning routine) with occasional activities co-occurring: Three to four hours.</b>			



### Appendix C: Calendar

#### Artifact 1: Calendar/Schedule of Daily Routine

	Sun	Mon	Tues	Wed	Thur	Fri	Sat
8/9	smudge exercise	smudge errands	smudge errands work @ 9	smudge errands	smudge errands work @ 9	smudge errands work @ 9	smudge Exercise
10	Errands/clean	Work	Staffing	Work			Errands/clean
11	ART		Supervision				ART
12							
1	Podcast! Exercise						
2		Eat/Exercise 30 min. BREAK	Eat/Exercise 30 min. BREAK	Eat/Exercise 30 min. BREAK	Eat/Exercise 30 min. BREAK	Eat/Exercise 30 min. BREAK	Exercise
3		Work	work	Work	Work	PAPER WORK	Pen Art
4	Pen Art						
5	Exercise Party!	Exercise ART @ 7	Exercise ART! @ 6	Exercise ART @ 7	Exercise ART! @ 6	Exercise ART!	Exercise Party!