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Relationship Between Individuals with a Brain Injury and Their Paid Caregivers: A Grounded Theory

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RELATIONSHIP BETWEEN INDIVIDUALS WITH A BRAIN INJURY AND THEIR PAID CAREGIVERS: A GROUNDED THEORY

A DISSERTATION

submitted by

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RELATIONSHIP BETWEEN INDIVIDUALS WITH A BRAIN INJURY AND THEIR PAID CAREGIVERS: A GROUNDED THEORY

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Approvals
In the judgment of the following signatories, this Dissertation meets the academic standards that have been established for the Doctor of Philosophy degree.

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Abstract

Recent federal rulings have led to an increasing population of individuals with disabilities receiving support services from paid caregivers in their communities rather than in institutions. Paid caregivers are strangers who enter an individual's life and often spend prolonged periods of time in a one to one relationship with an individual. The dynamics between an individual and a paid caregiver are quite different than those between healthcare workers and patients in institutional settings or between an individual and a family caregiver.

Constructivist Grounded Theory methodology was used to explore the perceptions of individuals with brain injury and their paid caregivers within Connecticut's Acquired Brain Injury Medicaid Waiver program. Thirty-four interviews were conducted with eight participants over a six-month period. The interviews included two in-depth semi-structured interviews with each participant and, in between these interviews, short phone interviews using an adapted Ecological Momentary Assessment method.

Based on the study findings a model was developed which represents the factors and perceptions that influenced the day-to-day interactions between individuals with a brain injury and their paid caregivers. Individuals with brain injury and their paid caregivers had differing conceptualizations of brain injury and incongruent views of the paid caregiver's role. These differences, along with power imbalances at times led to conflict within the relationship however typically the respect and fondness between the dyad neutralized these issues. the medical model significantly influenced the beliefs of both the individuals with a brain injury and their paid caregivers. The core category that integrated all parts of the model was learning understood as an interactive process between the individual with brain injury, the paid caregiver, and the broader sociocultural community.

Dedication

To my father, James Blake, for the quiet example he set regarding the value of intellectual pursuits

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Chapter 1: Introduction

I began working with individuals with brain injury early in my career as an occupational therapist and over the years I have heard countless stories about how a brain injury instantaneously changed one's life, hopes, and dreams. I have heard stories of great loss and despair as well as stories of resilience and new beginnings. I initially believed that rehabilitation services were the primary factor impacting the outcome of these stories but I soon came to realize that time-limited rehabilitation services were only a brief episode in one's life after brain injury. Later, during my work at the Brain Injury Association of Connecticut, I met individuals who had lived with a brain injury for many years and it was at this time that I also became acquainted with Connecticut's Acquired Brain Injury Medicaid Waiver program (ABI Waiver). Connecticut's ABI Waiver provides up to 24 hours of support each day so that individuals who have moderate to severe brain injuries are able to live in the community rather than in an institution.

One of my duties at the Brain Injury Association was organizing and running a yearly two-day retreat. Each year approximately 40 individuals with brain injury attended the retreat. Some came alone, but many were accompanied by their paid caregivers. I noticed a variety of interactions between individuals with brain injury and their paid caregivers. Some caregivers appeared to be warm and nurturing while others were cool and distant. Some caregivers were very directive while others were consultative in their interactions with their charges. I observed genuine affection between some individuals and their paid caregivers but I also observed frustration and irritation between others.

These relationships between paid caregivers and the individuals they work with through the ABI Waiver program are unique because the caregivers spend a large amount of time in a one-to-one relationship in an individual's home and community. Unlike long-term medical settings, there are not other staff or patients to interact with, and unlike in family caregiving situations these individuals did not know each other prior to working together. It was clear to me that some of these relationships "worked" while others did not, but it was not clear why they worked. This question continued to perplex me as I began working closely with some ABI Waiver teams as a cognitive behavioral consultant, particularly because I also began to suspect that these relationships had an effect on the functional abilities of the individual with a brain injury. I turned to the literature but found that most research regarding caregiving relationships was either conducted in institutional settings or, if it was in the community, examined family caregiving. There was little literature relative to long-term, community-based caregiving provided by paid caregivers. This phenomenon, however, is becoming increasingly frequent.

In 1999, the United States Supreme Court ruled on Olmstead v. L.C., declaring that states may not segregate people with disabilities by forcing them to live in institutions because this violates Title II of the Americans with Disabilities Act (Hornbostel, 2005). This ruling was strengthened on June 18, 2001, when President George W. Bush signed Executive Order No. 13217, "Community-Based Alternatives for Individuals with Disabilities" that mandated federal agencies to take action to eliminate segregation of individuals with disabilities in institutions (Department of Health and Human Services, 2002). In order to comply with this mandate, states have begun to implement plans to promote community integration (Department of Health and Human Services, 2002).

Currently approximately 56.7 million people living in the community have a disability and of these, 12.3 million, or 4.4 percent, of adults need assistance with one or more activities of daily living (ADLs) such as dressing or bathing, or with instrumental activities of daily living (IADLs) such as cooking or cleaning (United States Census Bureau, 2012). Family and informal caregivers provide much of this assistance but approximately 35% of individuals with disabilities receive assistance from paid caregivers (National Alliance for Caregiving, 2009). These paid support staff provide assistance for the essential daily activities that make up an individual's life and therefore these paid caregivers have the ability to significantly contribute to one's quality of life.

The caretaking provided by paid support staff occurs within the context of a relationship (McCann & Baker, 2001). Studies have shown that in a healthcare environment the relationship between a patient and staff influences the care a patient receives (Linden & Redpath, 2011) and this has also been shown to be true in home health settings (Oudshoorn, Ward-Griffin, & McWilliam, 2007), but there is a lack of research regarding the factors that contribute to the relationship between individuals with disabilities and their paid caregivers in the community. The purpose of this study was to explore the relationships between individuals with brain injury and their paid caregivers. Specifically the study aimed to investigate how perceptions of brain injury and caregiving influenced the day-to-day interpersonal relationships between these dyads.

Context and Background

Home and Community-Based Waiver Programs

Home and community-based waivers are state-administered Medicaid programs that provide long term supports in home and community settings so that individuals with disabilities are able to remain in, or return to, the community (Centers for Medicare and Medicaid Services, n.d.). Services may include medical and non-medical supports such as case management, homemaker, home health aide, adult day health services, and respite care. Individuals served by these programs include individuals with developmental disabilities, persons over 65 with disabilities, individuals who have had a brain injury, and children with severe medical disabilities (Smith et al., 2000). Eligibility for these programs vary by state but in all states individuals are required to meet specific Medicaid financial eligibility requirements and health and functional criteria such as requiring assistance with ADLs and IADLs (Smith et al., 2000).

Home and community-based waiver programs have grown substantially in recent years. In 1988 only ten percent of Medicaid spending was for home and community-based services (Smith et al., 2000), whereas in 2012 these services comprised 49.5 percent of Medicaid spending (Eiken et al., 2014). It should be noted, however, that these programs are state-administered and consequently there is significant variability among state expenditures for these programs with states such as Oregon and Alaska allotting 77%, and 70%, respectively, of their budgets for home and community-based services, whereas New Jersey's expenditures for home and community based services was 28.9% and Mississippi's spending for these services was only 19% of their Medicaid budget. Connecticut was near the national average, allocating 44% of their Medicaid budget toward home and community based waiver programs (Kaiser Family Foundation, 2012).

Connecticut has six Medicaid waiver programs including a home program for elders, a personal care assistance waiver, a mental health waiver known as the WISE program, a Department of Developmental Services waiver, the Katie Beckett waiver for children with severe disabilities, and the Acquired Brain Injury (ABI) waiver (My Place CT, 2014). The ABI waiver is administered by the Connecticut Department of Social Services. In order to be eligible for the program an individual must be an adult between the ages of 18 - 64 at the time of application, have an acquired brain injury, meet financial eligibility requirements, have the cognitive ability to participate in the development of their service plan or have a legal representative who can act on the their behalf, lack family or community supports to meet their needs, wish to live in the community, and meet the criteria for level-of-care which states that without waiver services an individual would require institutional care (Connecticut Department of Social Services, 2013). A variety of supports are provided through Connecticut's ABI waiver program including companion services, cognitive behavioral consultation, independent living skills training, and personal care assistance. Descriptions of each of these supports can be found in Table 1. Individuals may receive up to 24-hour support so that they can safely remain in the community (Connecticut Department of Social Services, 2013).

Table 1

Frequently utilized ABI Waiver Services

Service	General Description	General Qualifications
Companion	Provide supervision and socialization services.	Attend a 3-hour educational program about brain injury and pass a written quiz following the training.
Independent Living Skills Training (ILST)	A teaching service designed to enhance an individual's ability to live independently in the community.	Bachelors Degree and 1 year of experience working with people with brain injury or high school diploma and 2 years experience with brain injury.
Personal Care Assistant (PCA)	Provides assistance with eating, bathing, dressing, personal hygiene or other activities of daily living.	Attend a 3-hour educational program about brain injury and pass a written quiz following the training.
Cognitive/Behavioral Programs	Programming and interventions designed to improve cognitive function and promote community re-integration.	Neuropsychologists, Psychologists, OT, PT, or SLP with at least 3 years of experience with cognitive/behavioral programming for people with brain injury.

Brain Injury

Traumatic brain injury (TBI) occurs as the result of an external force that leads to an alteration in brain function, whereas an acquired brain injury (ABI) is any injury to the brain that occurs after birth and is not hereditary or degenerative. Therefore ABI is a larger category of brain injury which includes TBI as well as brain injuries that result from stroke, near drowning, hypoxic or anoxic injury, tumor, neurotoxins, electric shock or lightening strike (Brain Injury Association of America, 2012).

In 2010 (the latest available data) there were approximately 2.5 million emergency department visits, hospitalizations, or deaths due to TBI (Centers for Disease Control and Prevention, 2014) and an additional 795,000 non-traumatic acquired brain injuries (CDC Division for Heart Disease and Stroke Prevention, 2014). More than 6.1 million individuals have a lifelong disability due to a TBI or stroke (Brain Injury Association of America, 2014).

The physical, cognitive and behavioral consequences of a brain injury are dependent on the extent and location of the injury in the brain. Physical consequences may include headaches, sleep disorders, fatigue, double vision, dizziness, loss of hearing, or movement disorders (Ashman, Gordon, Cantor, & Hibbard, 2006). Cognitively, after a brain injury, an individual may have impaired attention and concentration, word finding difficulties, delayed processing, and decreased memory, as well as impairments in executive functioning such as the ability to plan, sequence, organize, think abstractly, and problem solve (Ponsford, Sloan, & Snow, 2012). Emotional and behavioral consequences of brain injury may include impulsivity or apathy, irritability, emotional dysregulation and socially inappropriate actions (Gentleman, 2001; Gouick & Gentleman, 2004). These impairments affect community reintegration resulting in individuals with brain injuries reporting fewer friendships and less involvement with meaningful activities than pre-injury (Mahar & Fraser, 2012b). Community re-integration will be further explored in Chapter 2.

Adult Learning Theory

In considering the learning that may take place between a care recipient and their paid caregiver the first characterization we may think of is that of the caregiver in the role of a teacher, teaching ADL, IADL, or social skills, however any formal teaching that may occur between a caregiver and care receiver is a relatively small contributor to the learning that takes place in this relationship.

Adult learning is an interactive process between the learner and the social context (Merriam, Caffarella, & Baumgartner, 2007). Most adult learning does not take place in formal learning environments such as a classroom, instead, it has been suggested that 80 percent of learning in work environments occurs through informal day-to-day interactions (Marsick & Watkins, 2001). Therefore it can be expected that both the care recipient and their paid caregiver are likely to learn within the context of their relationship. This learning is often tacit and taken for granted and it occurs in response to an internal or external stimulus which challenges knowledge or beliefs (Marsick & Watkins, 2001). When this learning results in guiding our future actions such as the decisions we make, revising our point of view, solving a problem, or changing our attitude or behavior, the learning can be considered transformative (Mezirow, 1991). Additionally within the framework of critical theory it has been suggested that an individual's identity is socially and politically constructed so that in order to understand transformative learning one must attend to the impact of dominant ideology on one's sense of self (Brookfield, 2012).

In order to appreciate how perceptions of behavior influence the day-to-day interactions between caregivers and care recipients we must first understand the sociocultural forces shaping each individual's worldview and the role that these implicit assumptions may play in the interactions between caregivers and care receivers. In Chapter 2 critical theory and disability theory will provide the foundation for thinking about these issues. Experiential learning will also be discussed as a framework for understanding the learning that occurs between caregivers and care recipients.

Statement of Purpose

The purpose of this qualitative grounded theory study was to explore the relationships between individuals with brain injury and their paid caregivers. Specifically the study aimed to investigate how perceptions of brain injury and caregiving influenced the day-to-day interpersonal relationships between these dyads. This study focused on understanding how paid caregivers and care recipients perceived the mood and actions of each other on a day-to-day basis, the learning that took place within these relationships, and the influence of cultural beliefs and attitudes on these perceptions. The study sought to give voice to both caregivers and the individuals with brain injury with whom they work. The specific questions addressed by the study were:

1. What are paid caregivers and care receivers' perceptions of brain injury?
2. What factors influenced these perceptions?
3. How are these factors and perceptions seen in the day-to-day interactions between individuals with brain injury and their paid caregivers?

Research Approach

Selection of Qualitative Approach

The aim of qualitative research is not to uncover a preexisting truth but, instead, to uncover how people make sense of their own experiences (Denzin & Lincoln, 2005). Ontologically I approach research as a relativist believing that concepts such as rationality, truth, reality, and right are influenced by society and culture and are distinct for each individual allowing for multiple individual realities (Guba & Lincoln, 1994). As one who understands research as a co-construction of meaning, my epistemology is constructivist and, as such, this study is rooted in the constructivist tradition viewing reality as individually constructed and influenced by experience, culture and society (Patton, 2002).

Qualitative methods give "voice" to the experience of individuals. This is particularly important for individuals, such as those with disabilities, in which past quantitative research served as a means of classification and categorization thereby leading to further prejudice, stereotyping and discrimination (Wappett & Arndt, 2013). In addition, because the aim of qualitative research is to understand the lived experience of participants, it is highly conducive to revealing subtle and intricate interactions within the context of everyday life (O'Day & Killeen, 2002). Therefore a qualitative approach is well suited to exploring the complexity of the relationships between paid caregivers and care receivers.

Design Overview

I obtained approval of Lesley University's Institutional Review Board to conduct this study of four pairs of individuals. Each pair was comprised of an adult with brain injury who received services through Connecticut's ABI Waiver and one of their paid caregivers. Each individual was interviewed privately, participated in a multi-week Ecological Momentary

Assessment (EMA) study and then was interviewed again. Each interviewee was identified with a pseudonym and all interviews were digitally recorded and transcribed verbatim. A grounded theory method was used to analyze the transcribed interviews.

Selection of Ecological Momentary Assessment (EMA)

Ecological Momentary Assessment (EMA) is not a single research method, rather it is a means of data collection in which assessment of a subject's current state is sampled repeatedly, in their natural environment, over a period of time (Shiffman, Stone, & Hufford, 2008). This repeated sampling provides a picture of experiences over time and across situations.

An early precursor to EMA was the Experience Sampling Method which was developed in the 1970's as a means to study "flow" -- a psychological state of mind characterized by complete immersion in an activity -- in order to explore the phenomenon as it was occurring (Csikszentmihalyi & Csikszentmihalyi, 1988). The experience sampling method asked participants to carry pagers and, when the pagers indicated, the participants completed a self-report form known as an Experience Sampling Form.

The availability of technology has recast this original method so that now EMA includes sampling techniques ranging from paper and pencil diary studies to the use of handheld computers, and ambulatory physiological monitoring (Shiffman et al., 2008). This study utilized telephone contacts at random intervals when the dyad was together, to gain information regarding each individual's perceptions of their own emotions and emotional antecedents, and the other's emotions and perceived antecedents at the same point in time. A full description of this process can be found in Chapter 3.

The advantage of using EMA is the ability to sample repeatedly over time in natural environments. In addition, one key advantage of using EMA in this study was that it did not necessitate significant reliance on autobiographical memory. Research has illustrated that autobiographical memories are fraught with distortion based on an individual's context and mental state at the time of recall (Shiffman et al., 2008). In addition, short-term memory impairment is one of the most common results of brain injury (Podell, Gifford, Bougakov, & Goldberg, 2010).

Selection of Constructivist Grounded Theory Method

Constructivist grounded theory is a descendent of the original method conceived by Glaser and Strauss (1967) and further popularized by Strauss and Corbin (1990). Mills, Bonner and Francis (2006) have characterized the variations of grounded theory as a methodological spiral reflecting the researcher's epistemological foundation so that the form of grounded theory that a researcher uses is dependent on the researcher's views regarding the relationship between the researcher and participant and the explication of what can be known in a field. Within constructivist grounded theory, research is viewed as a construction rather than a discovery (Charmaz, 2014). It is understood that the researcher is neither a neutral observer nor scientific authority. Rather, researchers bring their past experiences, cultural contexts, and personal beliefs to the research process which exists within a particular time and place in history and, further, these experiences and temporal contexts influence the research process and findings. Charmaz (2014) describes constructivist grounded theory as offering an "*interpretive* portrayal of the studied world, not an exact picture of it" (p. 17). I have chosen to use constructivist grounded theory because it offers a systematic, yet flexible process to analyze data and ultimately construct theory (Charmaz, 2014).

The Researcher

Because my life experiences, perspectives, interests, and values direct and influence the research process (Charmaz, 2014), it is essential to share my background and assumptions with which I approached this research project. I have an undergraduate degree in occupational therapy and a master's degree in neuroscience and I have worked with individuals with brain injury for a large part of my career. I have worked in an in-patient rehabilitation setting, an outpatient setting, within a brain injury advocacy organization, and in a community-based ABI Waiver program. As an occupational therapist I have been trained to take a holistic view of an individual in order to support health and participation in life through engagement in occupation (American Occupational Therapy Association, 2008). As our national organization, the American Occupational Therapy Association (AOTA) explains

> Occupational therapy practitioners ask, "What matters to you?" not "What's the matter with you?" (American Occupational Therapy Association, 2014).

As a professional who was trained in, and has primarily worked in, a medical model I spent many years believing that disability was an individual condition that required rehabilitation and that health and wellness equaled independence. These attitudes have slowly shifted over the years so that I now view disability as an environmental and social construct whereby one's physical and social environment can cause, define, or exaggerate a disability (Smart, 2009). My understanding of brain injury, therefore, is that brain injury is a biological condition where day-to-day functioning is largely influenced by one's physical, social, and emotional environment.

Significance of study

There is currently little research that explores the perceptions of paid caregivers in the community and there is even less research that also includes the perceptions of the care receiver. This study provides voice to both paid caregivers and their care receivers. In addition this study introduces the use of a modified Ecological Momentary Assessment approach as a technique that can enhance qualitative research with individuals with memory impairments. Finally, it is anticipated that a more sophisticated understanding of the perceptions that affect the relationships between paid caregivers and care recipients will be able to be used to inform training for paid caregivers. Although the care recipients in this study had brain injury, findings from this study may have useful applications for paid caregivers who work with individuals with other disabilities besides brain injury as well as for paid caregivers who work with older adults.

Summary

This dissertation explored the relationships between individuals with brain injury and their paid caregivers. Specifically the study aimed to investigate how perceptions of brain injury and caregiving influenced the day-to-day interpersonal relationships between these dyads. The purpose of this research was to understand how paid caregivers and care recipients perceived the mood and actions of each other on a day-to-day basis, the learning that took place within these relationships, and the influence of cultural beliefs and attitudes on these perceptions.

Key Terms

Acquired Brain Injury (ABI): A "combination of focal and diffuse central nervous system dysfunctions, immediate or delayed, at the brainstem level or above. These dysfunctions may be acquired through physical trauma, oxygen deprivation, infection or a discrete incident that is toxic, surgical or vascular in nature. The term "ABI" does not include disorders that are congenital, developmental, degenerative, associated with aging or that meet the definition of mental retardation as defined in section 1-1g of the Connecticut General Statutes" (Connecticut Department of Social Services, 2013).

Acquired Brain Injury (ABI) Waiver: A state-administered Medicaid program that provides long term support in home and community settings so that individuals with a moderate to severe brain injury are able to remain in, or return to, the community (Centers for Medicare and Medicaid Services, n.d.). Individuals must meet financial and level-of-care criteria to be eligible for this program. Services may include medical and non-medical supports.

Care receiver: an individual who receives services from a paid caregiver. In this study these care receivers are individuals with brain injury. Within this dissertation when the content is specifically related to brain injury the care receiver will be referred to as "an individual with a brain injury" elsewhere the descriptor "care receiver" will be used.

Community re-integration for persons with brain injury: residing in a home-like environment with acceptance and participation in a social network and involvement in regular meaningful activities (van de Ven, Post, de Witte, & van den Heuvel, 2005).

Paid caregiver: a non-family member who is employed to provide care to another individual.

Chapter 2 Literature Review

This chapter examines the available literature and theoretical perspectives that are relevant to understanding the relationships between individuals with brain injuries and their paid caregivers. The chapter begins with an overview of brain injury, brain injury treatment models, and an exploration of beliefs about brain injury. I then delve into the literature regarding caregiving and care receiving. The chapter concludes with an examination of relevant theoretical perspectives regarding interpersonal relationships and adult learning.

Overview of Brain Injury

A brain injury can have a lasting impact on one's life. Even so called "mild" brain injuries can have long term effects on cognitive and emotional functioning (Konrad et al., 2011). Common impairments following brain injury include visual perceptual deficits such as visual field loss or impaired depth perception (Anderson & Lehman, 2014); cognitive impairments such as poor prospective memory, impaired decision making and poor judgment (Demery, Larson, Dixit, Bauer, & Perlstein, 2010; Fleming et al., 2008); changes in behavior such as emotional dysregulation and egocentricity (Fowler & McCabe, 2011); as well as physical symptoms such as impaired balance (Peterson & Greenwald, 2015) and chronic fatigue (Mollayeva et al., 2014). The specific consequences of a brain injury are dependent upon the extent of damage and where the injury occurs in the brain (Bigler, 2013). Those with more severe brain injuries are more likely to receive rehabilitation services (Boake & Diller, 2005). Five years after rehabilitation for traumatic brain injury, approximately one-third of individuals require supervision overnight and part of their waking hours (Corrigan et al., 2014).

Brain Injury and the Medical Model

Brain injury is a significant event that requires prompt medical attention, therefore when one sustains a brain injury they automatically enter the medical system. Within the medical system disability is considered a problem that must be fixed so that the individual can adjust and manage in society (Ralston & Ho, 2010). This medical model ideology permeates the brain injury literature. Research relative to outcomes after moderate and severe brain injury in adults frequently measure functional ability (see Bender, Bauch, & Grill, 2013; Chan, Zagorski, Parsons, & Colantonio, 2013; Curran, Dorstyn, Polychronis, & Denson, 2014; Klein et al., 2013) and cognition (see Dikmen et al., 2009; Millis et al., 2001; Salmond & Sahakian, 2005) as the most important measures of successful outcomes. These constructs fit within the classic medical model view of rehabilitation where an individual's physical independence and improved cognitive capacities are the primary determinates of success. The latest edition of the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) has added diagnostic criteria for TBI (American Psychiatric Association DSM-5 Task Force, 2013). This has been heralded as a major advance because it will allow for the "provision of recovery-promoting education to individuals with such injuries" (Wortzel & Arciniegas, 2014, p. 621). The addition of TBI to the DSM -5 further cements brain injury as an individual pathology within the medical model and promotes addressing the symptoms of the brain injury without recognizing the "relational, contextually based whole person" (Van Dyke & Hovis, 2014, p. 87).

Brain Injury and Community Integration

Between 26% to 45% of individuals with brain injury are characterized as being poorly re-integrated into the community (Doig, Fleming, & Tooth, 2001). In the 1990's, as interest in community integration for individuals with brain injury expanded, Corrigan (1994) defined community integration as "the assumption or resumption of culturally and developmentally appropriate social roles following disability" (p. 109). Currently, within the brain injury literature, community integration is most often viewed as encompassing independent living, social and leisure activity, and work or other productive activity (Sander, Clark, & Pappadis, 2010). A review of the literature by Mahar and Fraser (2012a) identified the following as barriers to successful community integration: difficulty with formulating goals and plans; difficulty adjusting behavior; memory deficits; impairments in self-regulation; impaired self-awareness; difficulty sustaining concentration; aggression; impulsivity and irritability; disinhibited behavior; depression and anxiety; and apathy and fatigue (Mahar & Fraser, 2012a). The measures that are the most frequently used to assess community integration include the Community Integration Questionnaire (CIQ), the Craig Handicap Assessment and Reporting Technique (CHART) and the Participation Index of the Mayo-Portland Adaptability Inventory-4 (MPAI-4) (Sander et al., 2010). However these objective measures focus solely on predetermined concepts of community integration such as independence with grocery shopping and housework and return to work, which may not be considered a priority by all individuals (Sander et al., 2010). In addition, these measures may not be culturally sensitive. For instance Sander et al (2010) points out that in the CIQ, persons are labeled as less socially integrated if they socialize mostly with family members but this does not take into account that in some cultures the extended family is prized as a primary social network by all individuals whether they have a brain injury or not. Finally, these measures reflect the common positivist assumption that it is possible to objectively measure one's "re-integration" into the community after a brain injury.

Another way of defining and measuring community integration is qualitatively. A qualitative study of individuals with brain injury by McColl et al (1998) reported nine factors as important to community integration -- being able to fit in, acceptance, oriented to the community, close relationships, diffuse relationships, productivity, leisure, independence, and living in a place where one has control over their activities. Similarly, a more recent qualitative study of individuals with disabilities resulted in a definition of community integration as being able to function in an ordinary way without receiving special attention, interacting with others without being ignored, taking part in and contributing to society, striving to realize potential, and being the director of one's life (van de Ven et al., 2005). Both of these definitions allude to the larger social context in which community integration occurs. Community integration is not just dependent on individual factors, it occurs in a social environment. Environmental influences on community integration have been recognized by the World Health Organization in their framework for measuring health and disability, the International Classification of Functioning (ICF) (2001), in which determinants such as family functioning, social support, governmental policies, and societal attitudes are viewed as environmental components that interact with personal factors such as gender, age, past and current experience, social background, and overall behavior pattern to influence function.

With this in mind we need to look beyond specific neurocognitive impairments as the primary limiting factor for community integration for people with brain injury and at the broader home and community environment. Does the environment promote health, well-being and social inclusion (Gibson et al., 2012)? We must recognize the reciprocal relationships between people and place which includes all relationships and activities that make up a space (Cummins, Curtis, Diez-Roux, & Macintyre, 2007). Gibson et al (2012) suggests that "social dignity", or the ways in which respect and worth are recognized within social conditions and interactions, are key to enabling participation in social life.

Beliefs and Assumptions about Brain Injury

Beliefs and assumptions about disability are shaped by the socially dominant culture (Riddell & Watson, 2014). Prior to the 20th century, disability was typically attributed to sin, karma, or divine punishment, but as medicine and science progressed, disability began to be viewed as a medical issue in which the abnormalities of the body or mind can be prevented or cured (Shakespeare, 2013).

In the 1980's interest in the connection between people's thoughts and their physical health became popular as research demonstrated a connection between stress and cardiovascular disease (McKinney et al., 1987; Wheatley, 1984). Subsequently, researchers began exploring the link between personality and health and suggested that one's innate personal characteristics may impact recovery from disease (Holroyd & Coyne, 1987). For instance in a recent study by Shanmagusegaram et al. (2014) it was concluded that individuals who had a depression-prone Type D ("distressed") personality were less likely to benefit from cardiac rehabilitation. Other researchers have linked a coping style called catastrophizing to chronic endometriotic pain (Martin, Johnson, Wechter, Leserman, & Zolnoun, 2011) and poorer functional recovery from total knee arthroplasty for individuals who were deemed "melancholic". Although there are other studies that caution that this linkage between personality type and recovery is overly simplistic (Herron, Turner, Ersek, & Weiner, 1992; Linder, 2000; Segerstrom & O'Connor, 2012), and it is clear that other factors such as social inequities affect health (Phelan, Lucas, Ridgeway, & Taylor, 2014), the idea that our innate characteristics control the course of recovery from illness and disease is a prevalent cultural belief (Capitanio, 2008).

These cultural beliefs and assumptions about disease recovery are also applied to brain injury. For example, in a questionnaire about brain injury that was completed by 318 individuals at a shopping mall, 53% believed that how quickly someone recovers from a brain injury mainly depends on how hard they work at recovering, and 72% were of the opinion that complete recovery from a severe brain injury is possible if the person wants badly enough to recover (Hux, Schram, & Goeken, 2006).

Yuhasz (2013) asked 155 medical workers within the correctional system to complete the same questionnaire used by Hux, Schram and Goeken (2006). Educational levels of the participants ranged from high school graduate to doctoral degree with a mean of 17.4 years of experience in a health-care related field. The majority of the sample (61.9%) indicated that they knew someone with a history of TBI. In this study 23% believed how quickly a person recovers from a brain injury depends mostly on how hard they work at recovering and almost 60% of the medical workers believed that complete recovery from a severe head injury was possible if the individual really wanted to recover. Similar findings were reported for school psychologists (Hooper, 2006), nursing students (Ernst, Trice, Gilbert, & Potts, 2009), and students preparing to be special education teachers (Hux, Bush, Evans, & Simanek, 2013). It is not clear whether individuals with brain injury hold these same misconceptions.

A number of qualitative studies have explored the experience of living with a brain injury. For instance Jumisko, Lexell, and Soderberg (2005) interviewed twelve individuals who had been living with a moderate or severe brain injury between four and thirteen years.

Each individual was interviewed twice and each interview was between 60 to 75 minutes. The interview data was analyzed using a three-phased phenomenological hermeneutic method. The researchers identified two primary themes -- "losing one's way" and "struggling to attain a new normalcy" (Jumisko et al., 2005). Within each of these primary themes were subthemes. Within the theme of "losing one's way" was the experience summarized as "waking up to the unknown" in which participants described waking up in the hospital feeling as if they lost everything and were ashamed because they had become helpless and dependent on others. The subtheme of "missing relationships" characterized the loss of friends and changes in their relationships with family members, and the subtheme of "experiencing the body as an enemy" included the physical issues associated with brain injury such as pain, fatigue, and impaired sensory functioning (Jumisko et al., 2005). The second theme, "struggling to attain a new normalcy" was comprised of four subthemes. "Searching for an explanation" was a subtheme in which participants vacillated between feeling fortunate to be alive, and bitterness because they felt their lives had been ruined, and the brain injury survivors attempt to find a justification for their injury. Participant's struggle to understand their behavior and functional difficulties were categorized in the subtheme of "recovering the self". The final two subthemes were "wishing to be met with respect" and "finding a new way of living". These subthemes summarized the participants experiences of struggling to be understood by others, developing compensation techniques for physical and cognitive changes and striving to accept their new lives (Jumisko et al., 2005).

In another qualitative study of individuals living with brain injury, Petrella, McColl, Krupa and Johnston (2005) utilized grounded theory to explain the perspectives of individuals with brain injury relative to the intrinsic and extrinsic factors that influenced their participation in productive activities. Productive activities were defined as "engagement in activities that provide social or economic contribution and are primary organizers of an individual's day" (Petrella et al., 2005, p. 645). Examples included paid employment, unpaid work such as volunteering, homemaking/parenting, and education. Six participants were recruited to participate in the study. These participants had lived in the community following their brain injury for at least ten years. Participants were interviewed two to three times for, on average, 58 minutes per interview. The extrinsic factors that influenced the participants' process of returning to productive activities were: being given the opportunity to try, support from others, and feedback from others. The intrinsic factors influencing their participation in productive activities were their willingness to experiment and test their perceived abilities, ability to put aside their beliefs about themselves based on their lives prior to brain injury, and reconciling abilities and disabilities as a result of the brain injury (Petrella et al., 2005). The researchers suggested that becoming aware of one's deficits was a crucial component in returning to productive activities and that this awareness can be facilitated through supported engagement in meaningful productive roles (Petrella et al., 2005).

In each of these qualitative studies the participants discussed the impact that other's beliefs had on them. For instance, Jumisko et. al. (2005) indicated that participants found it "insulting and exhausting to be checked constantly and inspected by various authorities in order to get a drivers license, an allowance for home equipment, or home help. They were afraid of the power of authorities over their lives. The participants searched intensively for help and rehabilitation where the personnel listened to them, respected their goals, and showed an understanding of their situation. Sometimes it took a long time to find this kind of help" (p. 46). A participant in Petrella et. al's (2005) study described the experience of being hindered by others based on a pre-judgment of capabilities. "We've both been through that period where all we heard was you are not doing this, you can't do that anymore, you can't do this anymore, things are never going to be this way or that way. And, lo and behold, a lot of things they said we couldn't do, now we're doing everyday. Okay, there are some things that we couldn't do that we realized with time, but you don't know until you try" (p. 649). One's life experiences after brain injury appear to be influenced not only by changes within the brain, but also by being categorized by others as brain injured.

Brain Injury and Caregiving

Most caregiving literature regarding brain injury focuses on the effect on family caregivers who are caring for an individual with brain injury. A perusal of these article titles would lead one to believe that living with an individual with brain injury is almost always a burden. For instance, "Caregiver burden at 1 year following severe traumatic brain injury" (Marsh, Kersel, Havill, & Sleigh, 1998), "Factors associated with strain in carers of people with traumatic brain injury" (Boycott, Yeoman, & Vesey, 2013), Psychological distress and family satisfaction following traumatic brain injury" (Perlesz, Kinsella, & Crowe, 2000) and "Primary caregiver distress following severe head injury" (Novack, Bergquist, Bennett, & Gouvier, 1991). However the investigators in these articles found only 20-45% of the caregivers reported significant amounts of stress. While these numbers certainly indicate that family caregivers require support, the article titles perpetuate the idea that individuals with brain injury are always difficult and disruptive to the family system. There is a general discourse in the brain injury literature that has deemed brain injury as a problem located within an individual whom caregivers need to cope with. Through a Foucauldian lens, individuals with brain injury can be understood as both a subject *of* (medical) study and subject *to* medical power (Grue, 2011). The literature highlights brain injury as a burden for family caregivers but this appears to be from the perspective of researchers' aim to substantiate the need for support for family caregivers of individuals with brain injury.

There are few studies that have explored the experience of paid caregivers with individuals with brain injuries in community settings. Chapparo and Shepherd (2010) conducted a qualitative study to examine the decision making of eleven residential care staff in Australia who worked with people with traumatic brain injury in a transitional living center. Transitional living centers combine short-term housing with rehabilitation programming allowing individuals with brain injury to be gradually re-integrated into community and family life (Minnes, Harrick, Carlson, & Johnston, 1998). Residential care staff are expected to provide emotional and environmental support for residents in order to increase their independence and social functioning. In this study residential care staff were observed interacting with clients over a 4-month period. Some of these interactions were video taped and used as prompts for reflection during later interviews with the staff. The researchers identified two perspectives that influenced decision-making about the nature and timing of work with clients -- hospital rules and house rules. Hospital rules were organizational factors such as job description and service guidelines, and house rules were personal perspectives about what should be done and how it should be done. Staff alternated between these two perspectives depending on the task at hand. Chapparo and Shepherd (2010) noted that house rules were used most frequently to guide staff decision making however these decisions were typically congruent with organizational expectations.

The relationship between the caregiver and care receiver from the perspective of the individual with brain injury has been largely ignored in the literature. Wells, Dywan and

Dumas (2005) included individuals with brain injury in their study of life satisfaction in family caregivers. Study participants were 72 dyads consisting of an adult with brain injury and their family caregiver, however life satisfaction was reported only for the caregivers, not the care receivers. The only data reported for the individuals with brain injury was the correlation between their self-reports of impairment on the Brock Adaptive Functioning Questionnaire (BAFQ) to the caregiver's assessment of these same areas of impairment.

Although not specifically about the caregiver and care receiver relationship, Nichols and Kosciulek (2014) qualitatively explored how seven adults with brain injury describe their social interaction experiences. All participants in this study were attending an outpatient rehabilitation program and lived either alone or with family. Participants' perceptions of themselves were affected by their social interactions, particularly interactions with family members. Participants were critical of their ability to meet social norms and rules and this self-criticism limited meaningful social interactions with others outside of their family and other individuals with brain injury. None of these participants required assistance from paid caregivers, but it was noted that several participants expressed sympathy for others at the outpatient center who required full time care and they empathized with "having to deal with somebody telling them what to do for the rest of their lives" (Nichols & Kosciulek, 2014, p. 27).

Matsuda et al, (2005) conducted focus groups with individuals with spinal cord injury and their personal assistants. Similar to individuals with brain injury, individuals with spinal cord injury may receive long-term assistive services in the community. The care receivers expressed that they preferred personal assistants who were reliable, trustworthy, respectful, loyal, committed and compassionate. They particularly valued personal assistants who had the ability to listen and had a caring attitude. Many of the participants considered the personal assistants to be their friends. The caregivers in Matsuda et al's (2005) study reported dissatisfaction with their wages but stated that they derived a sense of meaning and satisfaction from their work. Some of the caregivers indicated that they had a friendship with the care receiver, and others stated that they consciously chose to maintain a professional boundary between themselves and the care receiver.

Interpersonal Relationships and Caregiving

There are a number of theories that are helpful in understanding and explaining the interactions that occur between caregivers and care receivers. Bylund, Peterson and Cameron (2012) proposed a useful classification schema for examining these theories that divides the theories into three categories -- individually centered theories, interaction-centered theories and relationship-centered theories. I have adopted this same classification schema as a way to organize these theories.

Individually centered theories seek to explain how an individual's innate cognitive activities shape their interactions with others. For instance Goals-Plans-Action Theory (Dillard, 1990) was developed to explain how one can influence others in the context of a relationship. According to Goals-Plans-Actions Theory (GPA) individuals can enter into a relationship with primary goals and secondary goals. Primary goals are one's intention of changing another's behavior. This primary goal is modified by secondary goals that the communicator may have such as the wish to not offend the receiver (Dillard, 1990).   The "Plan" in GPA refers to the internal cognitive process of choosing a plan from memory that is deemed the most likely to accomplish the goal. The third step in the GPA process is "Action" in which the communicator enacts the plan and adjusts the plan as needed to accomplish the intended goal (Dillard, 1990). Brundage et. al. (2006) did not name GPA, per se, in their analysis of clinicians' verbal behaviors in a community reintegration program for individuals with TBI, but their findings echo GPA theory. The researchers found that the most frequent communication behavior between clinicians and individuals with brain injury was "clinician initiated discourse" and the second most frequent was "explanation". These codes accounted for almost 70% of the clinicians' verbal interactions with the individuals with brain injury. The identified purpose for most communication was to address a treatment goal such as improving organizational skills, memory, problem solving, or awareness of disability. Interestingly, these two codes were also the only two of the five identified communication codes that did not require a response from the client. These communications were used to introduce an activity and keep it going, provide clarification, and summarize performance of the group. The researchers suggested that these communications encouraged problem solving and may be positively reinforcing since "by providing feedback regarding the client's work, the clinicians are showing that they value the work the clients are doing" (Brundage et al., 2006, p. 86). Therefore, as in GPA theory, it appears clinicians were communicating with a clear goal in mind in order to influence the behavior of the individual with brain injury. The authors note that they did not analyze the verbal behaviors of the individuals with brain injury and were therefore unable to characterize their interactions.

The second group of interpersonal theories is relationship-centered theories. One example is Social Penetration Theory which postulates that relationships develop over time through a process of self disclosure (Altman & Taylor, 1973). An onion metaphor is often used to explain Social Penetration Theory -- the surface layer is the layer seen by others and includes characteristics like height, weight, etc. Underneath the surface layer is the peripheral layer containing general information shared in social situations, and beneath this layer are the intermediate layers of information that are only infrequently shared. Lastly, is the central layer of private information that is shared with only select individuals (Bylund et al., 2012). Social penetration is measured through both the number of different topics discussed as well the depth of the layers discussed.

Gantert et al's, (2008) qualitative themes regarding older adults' perceptions of the relationship building process with in-home service providers highlights the gradual process that occurs in caregiving relationships. These themes were *connecting to larger life context; seeking mutual knowing; balancing knowledge, status and authority; creating shared patterning; and building and maintaining bonds.* Seniors who perceived that they had developed positive relationships with their in-home service providers highlighted consciously making an effort to know one another and facilitating reciprocity within the relationship.

The last group of interpersonal theories is interaction-centered theories. These theories focus on the transactional aspects of communication between the communicator and receiver thereby recognizing that when two people interact they are affected by and affect each other at the same time (Bylund et al., 2012). An example of an interaction-centered theory is Communication Accommodation Theory (CAT). The focus in CAT is on the ways in which individuals modify their communication in response to nonverbal and verbal interactions (Giles, 2008). CAT recognizes that intergroup and interpersonal factors affect communication including the effect of power differentials. When two individuals communicate they do so on the basis of their perceived social identities. For instance, when a person's social group is negatively stereotyped, communication is modified in a way that reflects that stereotype (Giles, 2008). Although there is no literature that specifically uses

CAT to explore relationships between individuals with brain injury and their caregivers, Lagace et al. (2012) conducted a relevant study that examined the impact of ageist beliefs on the relationship between caregivers and institutionalized elders using CAT. Ageist beliefs about the elderly include beliefs that elders are incapable and childlike, weak and unhappy, depressed and self-centered (Lagace et al., 2012). Lagace et al. interviewed 33 seniors who resided in four long-term care facilities in Quebec. All participants required assistance in daily activities secondary to chronic disease but were cognitively intact. The seniors reported that communication with caregivers was frequently patronizing, authoritative, constraining or dismissive. However the seniors often tried to rationalize these communications to the researchers and described that they preferred to accommodate rather than confront caregivers. The researchers suggest this was because the older adults recognized the power imbalance between themselves and their caregivers and adapted their communication. Therefore the seniors implicitly chose to avoid confrontation rather than behave in a way which could sever the social tie with the caregiver (Lagace et al., 2012).

Individually centered theories, interaction-centered theories, and relationship-centered theories assist in understanding the ways that caregivers and care receivers communicate but they do not delve deeply into how these communications are learned and perpetuated. Therefore in the next section of this literature review I will discuss how adult learning theory may be useful in understanding the ways in which experiences and culture shape interactions.

Adult Learning Theory

Traditionally studies of disability have been grounded in literary analysis, sociology, anthropology, and Marxist political economy (Grue, 2011). However in light of the analysis of the literature outlined above I would like to turn to adult learning theory as a source for thinking about the influences on the relationships between individuals with brain injury and their paid caregivers. As linguistic scholars Lakoff and Johnson (1980) state, "our conceptual system . . . plays a role in defining our everyday realities . . . but our conceptual model is not something we normally are aware of. In most of the little things we do everyday, we simply think and act more or less automatically along certain lines." (p. 3).

As we interact with others we are guided by our attitudes and beliefs, which in turn are shaped by dominant culture and past experiences. Attitudes and beliefs, however, are not stagnant -- they can be modified, or even changed, as one moves through their life. Within this study both the caregiver and care receiver are considered learners. In the context of their relationship both individuals are influenced by social, cultural, and historical contexts. "Disability plays a critical role in how we formulate relationships between ourselves and others -- all of them connected to Western concepts of difference, variation, and the meaning of human variation" (Snyder & Mitchell, 2006, p. 34). If we examine this learning process through the lens of adult learning theory we can utilize components of experiential learning theory and critical theory to understand one's development of attitudes and beliefs about brain injury and how these may contribute to the relationship between an individual with brain injury and their paid caregiver. In this section I will briefly discuss experiential learning, transformational learning, and critical theory.

Experiential learning

Experiential learning was first theorized by Dewey (1916) who proposed that learning occurred through doing. Since that time adult learning theorists have explored different facets of experiential learning. For example, Kolb (1976) examined the processes associated with making sense of, and learning from, concrete experiences, and Mezirow (1991) explained how thought, feelings, and actions can shift as a result of experience.

Kolb (1984) viewed learning as a process of creating knowledge as the result of a transaction between social knowledge and personal knowledge. Kolb (1976) envisioned learning as a cycle in which concrete experience is followed by reflective observation, then abstract conceptualization and active experimentation. A learner can begin at any point in the cycle but the steps remain sequential. Concrete experience is a particular action or event but for learning to occur, the next step, reflection observation, requires a learner to reflect back on this experience. Abstract conceptualization takes place when a learner attempts to draw conclusions and conceptualize new ideas or modify an existing concept. In active experimentation a learner applies an idea or concept to see what happens. In this way a learner can build and generalize knowledge, continually revising and reshaping learning based on what happens in a particular situation (Fenwick, 2010).

Transformative Learning

Like Kolb, Mezirow viewed reflection as critical to learning and believed, under the right circumstances, it can result in transformation of one's worldview. Mezirow was also influenced by Freire's idea of "conscientization'"-- the development of consciousness which has the power to transform reality (Kitchenham, 2008). Mezirow (1991) stated that reflective learning occurs when assumptions or beliefs are found to be inauthentic or invalid, therefore learning is a process of meaning making. Generally when one learns something their established expectations guide their interpretation of the experience, but in transformative learning, experiences are reinterpreted, leading to new meanings and perspectives. This new interpretation can then be used to make decisions, make associations, change a point of view, solve a problem or change behavior (Mezirow, 1991). Learning is influenced by:

- the frame of reference in which the learning takes place;
- the conditions of communication and discourse;
- the line of action in which learning occurs;
- the self-image of the learner and
- the situation in which the learning occurs (Mezirow, 1991).

Transformative learning can be a difficult emotional process because it forces an individual to become aware of their assumptions and beliefs and to transform habitual frames of reference to allow for new beliefs and opinions (Mezirow, 2009). A frame of reference involves cognitive and emotional aspects as well as mental drive which shapes perceptions, thoughts, and feelings by predisposing intentions, expectations, and purposes and thereby guiding one's views of the world (Mezirow, 2009). These meaning schemes operate outside of conscious awareness and determine perceptions of what one sees and how it is seen. When an event calls one's frame of reference into question it can lead to what Mezirow (1991) termed a "disorienting dilemma". This is the first step of a ten-step process of transformation. The sequence of steps is as follows:

1. A disorienting dilemma.
2. Self-examination with feelings of fear, anger, guilt or shame.
3. A critical assessment of assumptions.
4. Recognition that one's discontent and the process of transformation are shared.
5. Exploration of options for new roles, relationships and actions.
6. Planning a course of action.

7. Acquiring knowledge and skills for implementing one's plans.
8. Provisional trying of new roles.
9. Building competence and self-confidence in new roles and relationships.
10. A reintegration into one's life on the basis of conditions dictated by one's new perspective (Mezirow, 2009, p. 86).

Therefore a complete transformative cycle involves rejecting all or part of existing taken-for-granted assumptions and the construction of new learning perspectives. Although the cycle is presented as a step-wise process, it may actually occur in a circular or spiraling manner and may not include all phases (Taylor & Snyder, 2012).

Individuals who sustain life changing medical conditions such as a brain injury are often faced with disorienting dilemmas. Kessler, Dubouloz, Urbanowksi and Egan (2009) used a grounded theory approach to explore transformative learning in twelve individuals who had sustained a stroke. The average length of time since the onset of the stroke was 6.5 years with a range of 3 - 11 years. The researchers found that four main factors contributed to moving participants toward transformation -- triggers, support, knowledge, and choices to action (Kessler et al., 2009). The two triggers identified were the experience of limitations following the stroke and feelings of vulnerability. These triggers led participants to examine their definition of self, their approach to life, and their priorities in life. The second factor that moved participants toward transformation was the support they received from others including family, friends, peers, and health professionals which allowed for a sense of shared experience, continuity, and feeling valued. Third was knowledge. The participants in the study obtained knowledge through reading and speaking to others. This helped them understand what happened, how to prevent another stroke, and to learn about the possibilities for recovery and living. In particular, this served to prompt reflection on the stroke survivor's own experience relative to others. The fourth factor that moved participants toward transformation was what the researchers referred to as, choices to action. These were the actions participants took to regain more choice in their lives. These actions included seeking knowledge and choosing to participate in recovery-related activities. This combination of factors appeared to facilitate a transformative learning process for the individuals in the study. These same factors may or may not be those that propel transformative learning in individuals with brain injuries, but this study, as well as similar studies with other populations such as those with rheumatoid arthritis (Dubouloz, Vallerand, Laporte, Ashe, & Hall, 2008) and chronic illnesses (Dubouloz et al., 2010), illustrate the role that transformative learning may play after undergoing a life changing event or diagnosis.

Mezirow (1991) also suggests that initial meaning perspectives are constructed though a process of socialization regarding the common understandings, beliefs, values, perceptions, and rules from the groups to which one belongs. Mezirow (1991) states transformative learning "involves an enhanced level of awareness of the contexts of one's beliefs and feelings . . ." and a "more critical understanding of how one's social relationships and culture have shaped one's beliefs and feelings" (p. 161). However transformative learning has been criticized for not taking into account how one's current context, gender, and class influence learning (Brookfield, 2012).

Critical theory

While Kolb's (1976) experiential learning theory and Mezirow's (1991) transformative learning theory can be characterized as constructivist theories focused on the individual -- an individual "constructs", through reflection, a personal understanding of a situation that allows for learning and personal growth -- critical theory moves beyond a focus solely on individual concrete experience, to include the wider social environment as a contributor to learning. Critical theorists are particularly interested in the idea of hegemony, or the process in which dominant ideologies become accepted as truths (Merriam & Bierema, 2014). Fenwick (2010) states "to understand human learning we must, from a critical cultural perspective, analyze the ideologies and other structures of dominance that express or govern the social relationships, and competing forms of communication and cultural practices within that system" (p. 30).

Critical disability theory was derived from critical theory and considers the political, theoretical, and practical issues related to disability. Earlier in this literature review I described how brain injury has become cemented within the medical model and how this impacts beliefs about brain injury such as the idea that community reintegration is largely dependent on recovery of individual capacities, and independence is the primary measure of success. Critical disability theory recognizes that it is these types of representations of disability that dis-locate people with disabilities (Goodley, 2013). In response to the medicalized hegemony of disability, critical disability theory perceives disability as a function of the confluence of social, cultural, economic and political factors. Snyder and Mitchell (2006) suggest that our views of disability have also been historically influenced. For instance, the adoption of Charles Darwin's evolutionary theory as a means to justify eugenics of individuals with disabilities in the United States has had long lasting effects on our cultural views of disability. By 1914 it was illegal in every state for "feebleminded" and "insane" people to marry and by the 1930's thirty-two states had passed laws permitting sterilization of the "unfit" (Snyder & Mitchell, 2006). It wasn't until the 1970's that the last of these laws were overturned (Murdock, 2013). This idea of disability as a problem that must be eliminated continues to permeate society (Snyder & Mitchell, 2006). Additionally our views of disability have been historically shaped by charitable institutions which characterized disability as a tragedy and those with disabilities as dependent and in need of public assistance; segregation of those with disabilities into institutions and specialized classrooms; and mainstream media's portrayal of people with disability as "other" (Snyder & Mitchell, 2006).

Critical theory suggests that these cultural conceptions of disability not only serve to shape our views of disability, they are also a means through which society chooses to oppress individuals with disabilities (Goodley, 2013). In her discussion of Georgina Kleege's essays about blindness Mintz (2002) asserts that the rhetoric about disability is not about disability at all. Instead the social discourse serves to guarantee the privileged status of the non-disabled individual. " . . . a need that, in its turn, emerges from fears about the fragility and unpredictability of embodied identity" (p. 162). The starting point, states Fenwick (2010), is "challenging those naturalized definitions and categories through which we learn experientially to separate and polarize ourselves from others, or to assure our success and comfort at the expense of others" (p. 33).

Chapter Summary and Implications for this study

This literature review serves to situate this grounded theory study of how perceptions of brain injury and caregiving influenced the day-to-day interpersonal relationships between individuals with brain injury and their paid caregivers. It identifies a myriad of factors including brain injury as situated within the medical model, beliefs about brain injury, the caregiving relationship, interpersonal communication approaches, and the learning that may influence the relationship between a caregiver and care receiver. A confluence of these factors contributed to the findings of this study.

Chapter 3: Research Methodology

Introduction

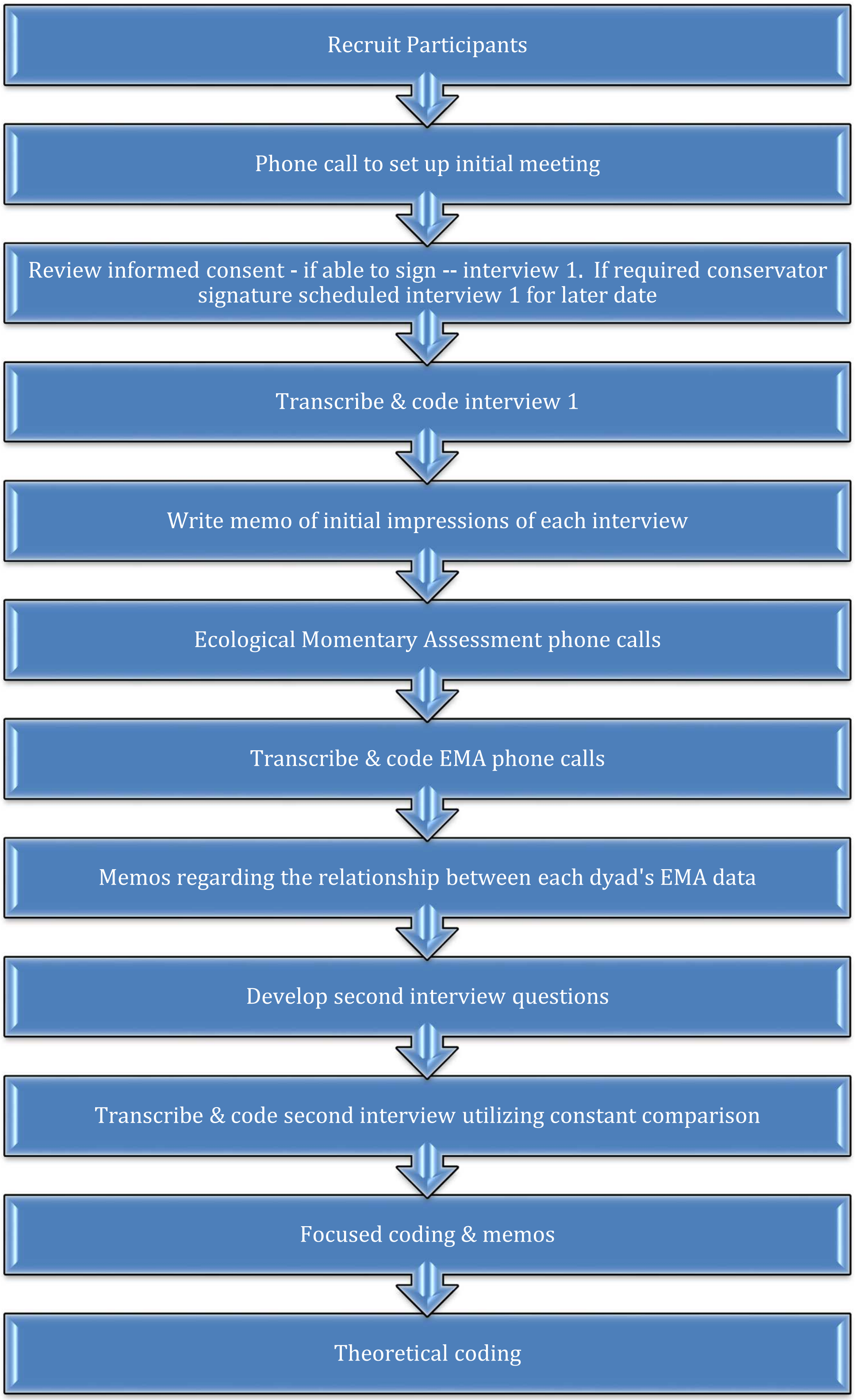
The purpose of this chapter is to explain the research methods and rationale for their use in exploring the relationship between individuals with brain injury and their paid caregivers. This chapter provides an overview of the study's methodology, which utilized constructivist grounded theory to guide the research process and outcome, and modified ecological momentary assessment to enhance data collection by obtaining data at multiple points over time. Through the development of a substantive theory of how perceptions of behavior influenced the day-to-day interpersonal relationships between individuals with brain injury and their paid caregivers, this study fills an existing gap in the literature. The questions addressed by this study were:

1. What are paid caregivers and care receivers' perceptions of brain injury?
2. What factors influenced these perceptions?
3. How are these factors and perceptions seen in the day-to-day interactions between individuals with brain injury and their paid caregivers?

Overview of the Research Design

This is a qualitative study that used constructivist grounded theory methods to guide data collection and analysis. I employed interviews and a modified ecological momentary assessment process to explore these relationships. The participants were dyads composed of an individual with a brain injury and one of their paid caregivers. Each individual participated in an independent semi-structured interview at the beginning and at the conclusion of the study. Between the two interviews, individuals were contacted by phone two to six times and asked to respond to a brief series of questions about their emotions and behavior at that point in time, and their perceptions of their partner's emotions and behavior at that same point in time. They were also given the opportunity to share any additional information that they would like to tell me about the day. These multiple contacts over time, combined with the two interviews, provided a mosaic picture of these relationships between and across pairs. Grounded theory methods were employed for data analysis, hence analysis took place concurrently with data collection. Interviews were transcribed verbatim and analyzed utilizing the grounded theory procedures described later in this chapter.

Figure 1: Research Design



Rationale for Research Design

Like all qualitative research, this study " . . . is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible" (Denzin & Lincoln, 2005, p. 3). When I decided to use ecological momentary assessment (EMA) as one of my data collection methods, I initially considered conducting a mixed methods study since EMA can readily capture quantitative data. However after reflecting on the intent of my research I decided to conduct a purely qualitative study because I was more interested in individuals' day-to-day perceptions and the meanings behind those perceptions than in analyzing the number of times particular behaviors or emotions occurred. Creswell (2007) notes that increasingly, qualitative research seeks to situate a study " . . . within the political, social, and cultural context of the researchers, the participants, and the readers of the study" (p. 37). Although my research participants represented two "groups" of people -- those with brain injury and paid caregivers -- I sought to not only understand their stories as experiences within that group but to explicitly theorize to larger sociopolitical formations because no group can be understood without an understanding of outside relations within which they exist (Fine & Weis, 2005).

Interviews are a commonly used data collection method in qualitative research. I chose to use interviews for the reasons that many qualitative researchers use them -- they allow us to enter another person's perspective (Patton, 2002). Additionally Charmaz (2014) suggests interviews serve as ". . . emergent interactions in which social bonds may develop" (p. 91). One of the disadvantages of interviews is that they rely on autobiographical memories which are fraught with distortion based on an individual's context and mental state at the time of recall (Shiffman et al., 2008). Further, short-term memory impairment is one of the most common results of brain injury (Podell, Gifford, Bougakov, & Goldberg, 2010) therefore, in order to supplement my interview data and capture perceptions of behavior as it unfolded I decided to use EMA. The goal of using EMA in this study was not to increase the accuracy of the data, since as a constructivist it was the individual's perceptions I was most interested in, but to allow for a deeper understanding of the influences on perceptions over time. Although EMA is often used as a quantitative method I adapted it for this study. The customary uses of EMA and my adaptations to this technique will be described later in this chapter.

Within the tradition of qualitative research there are a number of design options. I chose grounded theory because it does not rely on what has already been discovered but, instead, provides a rigorous method for examining qualitative data so that theory can emerge. My intent in choosing a grounded theory approach was to establish a framework for understanding the influences on the relationships between individuals with brain injury and their paid caregivers.

Mills, Bonner and Francis (2006) have proposed that there are three primary variations of grounded theory and that these can be thought of as existing on a methodological spiral. The three variations begin with the original Glaser and Strauss (1967) methodology. The second is that put forward by Strauss and Corbin (2015; 1990) and the third, constructivist grounded theory, advanced by Charmaz (1990, 2014). This concept of a spiral nicely represents how the variations have built upon earlier grounded theory ideas and concepts but erroneously gives the impression of an evolution of a single grounded theory approach. In fact there are currently three primary grounded theory approaches - Classic Grounded Theory, Straussian Grounded Theory, and Constructivist Grounded Theory.

Followers of Glaser such as Simmons (2010) and Gynnild (2011) advocate that each type of grounded theory must be viewed and utilized only as a discrete method. I agree that the three approaches have distinct characteristics, but they also share some underlying structural components and aspects which are complimentary rather than in opposition. Therefore although I chose to use constructivist grounded theory, I did consult all three grounded theory approaches throughout the study. Overall, my underlying epistemology most closely matches Charmaz's (2014) constructivist approach in that it recognizes the interaction between the researcher and participants. It is assumed "that neither data nor the theories are discovered as either given in the data or the analysis. Rather, we are part of the world we study, the data we collect, and the analysis we produce. We *construct* our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices" (Charmaz, 2014, p. 17).

Grounded Theory Overview

The introduction of grounded theory by Glaser and Strauss (1967) represented a shift in social science research from using data to test theories to generating theory based on data analysis. In contrast to the current approaches at that time, which focused on generating hypotheses and testing theory, grounded theory offered a means to discover theory from data and explain the underlying social processes shaping interaction and human behavior (Glaser & Strauss, 1967). Key grounded theory characteristics include the use of an iterative process; purposive and theoretical sampling; creating analytic codes and categories from the data; attention to the advancement of theory development throughout; making comparisons at every stage of data analysis; and theoretical density (Hutchison, Johnston & Breckon, 2010).

Unlike other qualitative methods such as case study or ethnography, grounded theory produces abstractions, not descriptions (Glaser, 2007).

Within grounded theory, data collection and analysis occur simultaneously allowing each to inform the other, thereby leading to more focused data collection and deeper analysis as the research progresses (Charmaz, 1990). Constant comparison is the analysis method most frequently associated with grounded theory. The constant comparison method ". . . is concerned with generating and plausibly suggesting (but not provisionally testing) many categories, properties and hypotheses about general problems (Glaser & Strauss, 1967, p. 104). Glaser & Strauss (1967) describe this as a four step process in which incidents are compared to each category, categories are integrated, theory is developed and theory is written. Comparative categories arise through multiple stages of coding. These stages have been described slightly differently within each branch of grounded theory, however all versions guide the researcher in moving from the initial discovery of many categories to narrowing the categories and finding the relationships between codes and categories so that a theory can be developed. Charmaz (2014) labels these stages initial coding, focused coding, and theoretical coding. In initial coding the researcher remains as close as possible to the data. Charmaz (2014) advises researchers to, wherever possible, code for actions rather than concepts thereby avoiding placing labels on participants and decreasing the likelihood of making conceptual leaps before completing the analysis. Initial codes are provisional and can be changed based on further analysis. The second stage of coding, according to Charmaz (2014), is focused coding. This is when the researcher goes back and analyzes and compares the initial codes to determine which have the greatest analytical relevance and power. The final coding stage, in constructivist grounded theory, is theoretical coding in which the categories identified in focused coding are examined for their relationships to each other.

Memos are an essential component of grounded theory because they allow the researcher to stop and analyze data and codes early in the research process (Charmaz, 2014). The act of memo writing allows the researcher to dialogue with the data and move the analysis further (Corbin & Strauss, 2015). Memos may begin as simple summaries of what seems to be appearing in the data and as analysis progresses memos become increasingly analytical. However both Corbin and Strauss (2015) and Charmaz (2014) extol that even early memos may give rise to brilliant discoveries.

The processes described thus far allow for insightful qualitative data analysis but grounded theory methodology requires moving beyond data analysis to theory construction. Theoretical sampling is the bridge between data analysis and the construction of theory. Glaser and Strauss (1967) define theoretical sampling as

> the process of data collection for generating theory whereby the analyst jointly collects, codes and analyses his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges (p. 45).

In theoretical sampling the researcher identifies promising categories based on initial data analysis and then collects more data in order to develop the properties of the categories thereby bringing explicit systematic checks and refinements into analysis (Charmaz, 2014). In order to understand theoretical sampling in grounded theory it is helpful to understand what it is not. Charmaz (2014) lists four types of sampling that are often used in qualitative research and that are sometimes mistaken for theoretical sampling:

- Sampling to address initial research questions

- Sampling to reflect population distributions
- Sampling to find negative cases
- Sampling until no new data emerge (p. 197).

The items above may be useful in some qualitative methods but they are not theoretical sampling. According to Charmaz (2014) the most common misperception about theoretical sampling is the final bullet -- sampling until no new data emerge. She suggests that this error occurs when researchers focus their data gathering on empirical themes rather than theoretical categories. This mistaken belief may have arisen from misunderstandings of the concept of theoretical saturation. Glaser and Strauss (1967) define saturation as the point at which no additional data can be found that contribute to the properties of a category and indicate that that categories must be *sufficiently* dense. Saturation is not meant to be the point at which a hypothesis is verified nor is it meant to be a point where the researcher knows everything, instead saturation occurs when there is enough explanatory power within categories so that a plausible theory can be presented that is grounded in the data (Breckenridge & Jones, 2009).

The final step in grounded theory methodology is the development of theory. Charmaz (2014) states that grounded theory should answer questions about why actions and events occur. Therefore the theory in grounded theory may provide an explanation that theorizes causation or it can more abstractly explain the relationships between concepts. Charmaz (2014) describes theorizing as a practice. "It entails practical activities of engaging the world and of constructing abstract understandings about and within it" (p.233). With this in mind then it follows that theorizing is not limited to specific individuals or situations; it can move to a broader institutional and even societal level. Charmaz (1990) suggests that constructivist grounded theory is well-suited to examine issues such as power and macro forces allowing researchers to explicitly connect antecedents, current conditions and consequences of social processes.

Ecological Momentary Assessment (EMA) overview

Ecological Momentary Assessment (EMA) is a method in which data are captured repeatedly in real world settings. It includes a range of methods such as paper and pencil diary studies, handheld computers, and ambulatory physiological monitoring (Shiffman et al., 2008). Advantages of using EMA include (a) obtaining data in real-world contexts, (b) preventing retrospective memory biases, (c) providing information about social contributors to the phenomenon being studied, and (d) providing information over time (Silk et al., 2011).

Typically EMA is used for quantitative studies. For instance Kikuchi, Yoshiuchi, Inada, Ando and Yamamoto (2015) developed an EMA scale to measure participants' appetite repeatedly over time. Participants wore a watch-type computer and were given a personal digital assistant (PDA) device that they used to keep a food diary. At designated times, as well as when cued by an alarm, participants responded to questions regarding their mood and appetite on the watch device. The researchers credited the use of EMA for giving them more substantial and more accurate data than that which could be gathered through food diaries alone. Similarly Harrell, Epstein and Preston (2014) used EMA to increase the accuracy of their data in examining the relationship between place and drug craving. However they concluded that it would be best to also integrate the use of Global Positioning System (GPS) devices since they felt that self-report of a location was a limitation of their study.

As a grounded theory researcher my quest is not one of verifying accuracy of the data but, rather, to deepen my conceptual analysis (Glaser, 2007). Others have also adapted EMA methods to increase the richness of their data. For example, Plowman and Stevenson (2012) explored the ways toys and technology were integrated into family life through asking parents from eleven families with young children to respond to text prompts at varying intervals, with a picture of their child at that point in time along with a text stating their location, who they were with, and what they were doing. These pictures and responses were then made into laminated cards and used as cues during later interviews with the parents and children when they were asked to reflect upon the day.

The most common qualitative use of EMA is in diary studies. For example Ahmadi, Masson, Lindblad and Hildingh (2014) conducted a qualitative study in which individuals with chronic obstructive pulmonary disease (COPD) were asked to describe their experiences with breathlessness in a written diary each day for a period of seven days. Poppleton, Briner and Klefer (2008) explored work-non-work relationships and the role of context in shaping these relationships. Each day for 14 consecutive days participants provided written narrative responses to questions about events over the past 24-hours. The researchers explained that they chose their selection of diaries as a data collection method because diaries allowed them to capture the dynamic quality of relationships with sufficient detail to "afford new insights into complex phenomena" (Poppleton et al., 2008, p. 485).

My study sought to integrate the immediacy of capturing data in real-time with the rich qualitative aspects of a diary. Therefore in this study the EMA cue was a phone call in which participants were asked to provide narrative answers to a short series of questions about their mood and activity and their perception of their partner's mood and activity at that same point in time.

Philosophical Influences on Methodology

Grounded theory has a rich heritage of being informed by symbolic interactionism due to the educational background of one of grounded theory's founders, Anselm Strauss, who attended the University of Chicago where symbolic interactionism formally began. Symbolic interactionism is a theoretical perspective whose pragmatic tenants can be traced back to John Dewey and William James but whose founder is considered George Herbert Mead (Charmaz, 2014). Mead (1934) suggested that the self is socially emergent based on interactions with others. Mead (1934) posits that we each have two components of self which he termed "I" and "Me". The "I" is the self that acts in the moment and the "me" is the self that is learned through interactions with others. These two parts of our self engage in a process of internal self-dialogue that guides our actions. Therefore we do not react directly to events, rather, our actions are based on our interpretation of the meaning of events.

Herbert Blumer, a student of Mead, is credited with devising the term 'symbolic interactionism' and refining the theory. Blumer categorized objects into three groups based on their properties -- physical objects such as a desk or a shoe; social objects like friends and family; and abstract objects like moral principles and ideas (Aldiabat & Le Navenec, 2011). Within symbolic interactionism the meaning of objects is deemed to arise from social interactions between people and these meanings are then defined and refined through human interaction (Charon, 2010). As I engage with others I develop a sense of who I am based on their reactions to me. I can also take on the role of the other in order to try to understand myself as they see me (Aldiabat & Le Navenec, 2011). Therefore all humans are interdependent and the ways that we interact with each other forms the basis of human society (Charon, 2010).

Symbolic interactionism melds well with constructivist grounded theory methodology because it "assumes process and explains stability . . . and offers an alternative to other social scientific perspectives that assume stability and attempt to explain change (Charmaz, 2014, p. 266). The key philosophical understandings of symbolic interactionism that influenced my research methodology included:

- Recognition of the importance of symbols. Human beings create and communicate through symbols including gestures, words, objects or acts. Symbols allow us to understand our environment rather than just respond to it (Blumer, 1969).
- Understanding that we are constantly thinking in every situation we encounter. Our actions are the results of thoughts that have defined the situation and our goals within the situation (Blumer, 1969). However this does not mean that our thinking is always precise or rationale (Charon, 2010).
- Human beings are understood as social beings. Social interaction is central to our perceptions and our actions. Meanings emerge through interactions with others (Blumer, 1969).

It should be noted that symbolic interactionism has been traditionally characterized as a theoretical perspective which focuses on the individual rather than on macro-level social structures (Dennis & Martin, 2005). However more recently it has been suggested that symbolic interactionism can be used to make linkages between individuals' actions and macro issues of hegemony and power (Burbank & Martins, 2010; Charmaz, 2014).

Symbolic interactionism informed both the design of my study and the analysis of my data. First the use of symbolic interactionism necessitated the inclusion of both individuals with brain injury and their caregivers as participants in the study since neither party can be understood in isolation. Secondly, based on the belief within symbolic interactionism that social life is open-ended and emergent, I chose to use a combination of semi-structured interviews and EMA to explore relationships over time. Third, in my analysis I drew upon ideas from symbolic interactionism such as self, identity, agency, and action. Finally, an understanding of cultural norms as symbols assisted in the development of my grounded theory model.

Participants

Participants were four dyads with one member of the dyad being an individual with a brain injury and the other, one of their paid caregivers. The caregivers were employed by agencies that provided services for Connecticut's Acquired Brain Injury Waiver program. Inclusion criteria specified that both members of the dyad were 18 years of age or older; worked together at least 20 hours per week; able to identify emotions and recall events for at least 30 minutes; able to participate in face-to-face and telephone interviews; and both individuals were also to have access to their own phone during the time that they worked together. Individuals were disqualified from the study if the paid caregiver and care recipient were related to each other or if they were friends prior to the care receiver’s brain injury because this prior relationship would likely influence the dyad's current relationship.

Recruitment

I contacted the Brain Injury Alliance of Connecticut (BIAC), explained the study, and asked for recommendations for their sponsored support groups that may be willing to have me come and talk about my study for a few minutes during a group meeting. Based on BIAC's recommendation I contacted five support groups. I attended three of the groups, explained my study, distributed an IRB approved flyer about the study, and passed around a sign up list for those who were interested so that I could contact them. A fourth support group leader offered to distribute my flyer to her group. Seven individuals signed up and through this I obtained three dyads. The forth dyad was recruited through contact with an ABI waiver provider-agency.

Protection of Human Subjects

This study was approved by the Institutional Review Board at Lesley University. Prior to beginning an interview the informed consent form was reviewed verbally with each subject and participants were made aware that they could refuse to answer any question or withdraw from the study at any time. In situations in which the care receiver had a conservator, the study was explained and the care receiver was asked to obtain a signature from their conservator before beginning the interview. During the first interview individuals were asked to select a pseudonym that they wanted to be used in publication of the study. This pseudonym was used for storing all data relative to the participant. Digital voice recordings of all interviews were downloaded to a password protected computer and most were transcribed by Matchless Transcription LLC, a company that specializes in working with graduate students and specifies that confidentiality of all data is maintained at all times (Matchless Transcription, n.d.).

Data Collection

There were three phases of data collection -- initial interview, EMA, and then a second interview. These are described below.

Initial Interview

The initial interview was conducted by the researcher in a location of the participant's choosing. For all but one dyad, the interviews took place during the hours the dyad were scheduled to be together and the location was chosen by the paid caregiver. These locations included the care receiver's home, a meeting room at a library, and the lobby area of a YMCA. The other dyad was interviewed outside of the hours they were together. For this dyad the caregiver chose to be interviewed at a coffee shop for the first interview and a local park for the second interview, and the care receiver requested to be interviewed at her home. Prior to beginning the interview the purpose of the study and the informed consent form were reviewed. In three cases the care receiver had a conservator. In these instances the care receiver was asked to give the form to their conservator for signature and the initial interview was conducted at a later date. The initial interviews lasted between 25 and 65 minutes. All interviews were recorded using a digital voice recorder and were semi-structured following a general interview guide. The initial and post-EMA interviews were transcribed verbatim by a transcription service and when I received the transcriptions I re-listened to each audio file and made corrections as necessary.

Like most qualitative researchers, when I conducted the interviews I paid attention to both the participants words and the meaning behind the words. However, since I was utilizing constructivist grounded theory I did not enter into the interviews with any preconceived ideas regarding the specific information I was looking for (Charmaz, 2014).

Ecological Momentary Assessment (EMA)

The second phase of data collection was the Ecological Momentary Assessment. Although EMA is not a traditional method used in grounded theory, Corbin and Strauss (2015) noted that grounded theory researchers can chose to use one or several sources of data including observations, videos, diaries, and memoirs, among others. Further, Charmaz (2014) posits that theoretical plausibility is strengthened through broad and deep coverage of emerging categories. EMA allowed me to look both at the daily realities of the interactions between caregivers and care receivers as well as point the way toward the emerging categories that I could then explore more deeply in the second interview.

Initially the EMA interviews were planned to be conducted verbally with the care receiver while the paid caregiver called into a voicemail number and left their answers to the same questions at the exact same point in time, however this procedure was modified after approximately eight EMA phone calls for two reasons. First, due to phone access while the pair were in the community, some dyads needed to share the same phone so that the EMA responses were not occurring simultaneously, and secondly I felt like I was missing important data because the answers left on the voice mail number were often brief and lacked the detail that I felt I could obtain if I was able to probe further during a phone conversation. Therefore all subsequent EMA was conducted by calling either the caregiver or care receiver, requesting that they go to a private location (i.e. bedroom with closed door), asking them the EMA questions and then having them hand the phone to their partner and repeating the sequence.

The EMA was time-based, meaning that assessment occurred at random points in time. It is typical for EMA assessment to occur three to five times per day however this is based on considerations of subject burden and the degree to which the target phenomenon is expected to vary over time (Shiffman et al., 2008). Individuals with brain injury typically function best in routinized environments (Jackson et. al, 2014) and frequent phone calls would have disrupted these routines, caused stress, and impacted the results of the study. In addition there were a number of occasions when I called dyads but they were either not together during regularly scheduled hours, or they were engaged in an activity and chose not to answer the phone (i.e. at an appointment, at the movies, at the gym, or driving). Therefore EMA only occurred sporadically over a six-month period. Although this interval schedule did not allow for full coverage of daily interactions, intermittent sampling over time has been shown to provide representative information in EMA studies (Shiffman et al., 2008).

Second Interview

The third phase of data collection was the follow-up interviews. These interviews were face-to-face, again at a location of the participant's choosing. All locations were the same as the initial interviews except that I met with one caregiver at a park rather than a coffee shop. The follow up interviews ranged from 22 - 55 minutes. An interview guide was developed based on the categories that were beginning to emerge during analysis of the data. This interview guide was used as the basis for the semi-structured interviews with additional questions asked as warranted.

Data analysis

In keeping with grounded theory, my data analysis procedures included initial coding, focused coding, memo writing, theoretical sampling, and theoretical coding in an emergent analysis process (Charmaz, 2014). I began, as suggested by Corbin and Strauss (2015), with reading the entire interview first in order to "enter vicariously into the life of the participants, feel what they are experiencing, and listen to what they are saying through their words and actions" (p. 86). Initial codes were determined through line-by-line coding. Since I was using a constructivist grounded theory approach I coded for "possibilities suggested *by* the data rather than ensuring complete accuracy *of* the data" (Charmaz, 2014, p. 120). This allowed for increased possibilities for analytical comparisons between data sets. For instance this statement

> "It just changes their life tremendously. I mean, here you have -- you know, you or I could be driving, get in a car accident and then your whole life changed."

was coded as *imagining what it is like.* Additionally as seen in this example, I coded with gerunds as much as possible. This allowed me to more closely interact with the data rather than accept participant's statements at face value. Coding for actions rather than coding for topics helps explicate emergent links in the data (Charmaz, 2014). Coding for actions required deeper thought than coding for themes and this did not come naturally to me. I often found myself lapsing into coding for themes and had to go back and re-examine the data.

Following initial coding I moved to focused coding. I had used a web-based qualitative analysis program, Dedoose, to conduct my initial coding and at the end of that I had over 400 codes. I exported these codes to an Excel document and began to group them based on those that seemed related to one another. This resulted in narrowing the data into fourteen categories however a number of these categories were very large and poorly defined (i.e. negative statement made by a participant). It was at this point that I was able to then go back to the excerpts I had coded and begin to compare data within categories as well as compare the data between dyads and within dyads. To assist with this process I re-read the interviews and all EMA contacts with each participant and wrote the longitudinal "story" that this data told. At the same time I extracted excerpts from the interviews and EMA contacts to a Word document and used this as an opportunity to re-examine and compare data. This resulted in a further refinement of my categories so that the excerpt below which was initially coded as *imagining what it was like* became *people with brain injury as "different".*

> "It just changes their life tremendously. I mean, here you have -- you know, you or I could be driving, get in a car accident and then your whole life changed."

The next step of my data analysis was theoretical sampling -- I developed properties of my categories until no new properties emerged allowing me to sort them into an integrated theoretical statement (Charmaz, 2014). Theoretical sampling may lead a researcher to going back into the field and gathering more data but does not necessitate this. Charmaz (2014) states theoretical sampling can be conducted through studying documents to elaborate the meaning of categories and explore the variations within them, focusing on certain actions, experiences, events, or issues rather than individuals to define the specific properties of each. To do this I examined each of the excerpts I had pulled earlier into the categorized Word document for its properties relative to its category and moved each into a new excel document. This resulted in a spreadsheet of 378 excerpts that could be sorted by category and property. The excerpt

> "It just changes their life tremendously. I mean, here you have -- you know, you or I could be driving, get in a car accident and then your whole life changed."

was categorized as *Conceptualizing Diagnosis* and was refined through the property of *underlying beliefs*. This was in contrast to other statements such as

> "You know, people have labeled me lazy and it’s not I’m lazy, it’s just when I get overwhelmed, I shut down"

which also was sorted into the category *Conceptualizing Diagnosis* but whose property was more appropriately described as *outside influences.*

Simultaneously during theoretical sampling I began diagramming the connections between categories and properties and it became apparent to me that rather than each category having unique properties, as is often seen in grounded theory, my properties appeared to persist across multiple categories and, in addition, there were micro and macro-level processes at play leading to the conceptualization of the model which will be presented in Chapter 4. To assure credibility of the model I went back to the "longitudinal stories" that I had written earlier to see if the model fit with the stories that this data told.

The analytical process described above was not the linear, efficient process of data analysis that I had envisioned when I began this project. Moving from Dedoose to Excel to Word and then back to Excel was a much messier path than I would have chosen however the move to each program allowed me to continuously re-examine, sort, and think about my data in new ways at increasingly abstract levels, raising the conceptual levels of my categories in a way that, I believe, explains the experiences of my participants.

Issues of Trustworthiness

The purpose of data collection in grounded theory is to advance theoretical analysis therefore Charmaz (2014) recommends attending to four theoretical concerns -- theoretical plausibility, direction, centrality and adequacy. Theoretical plausibility is met through assuring that data collection methods contribute to and allow for eventual theory development. Broad, deep coverage through substantial data collection increases theoretical plausibility (Charmaz, 2014). In order to assure broad, deep coverage I used four dyads and collected data from each individual in the dyad over a period of six months. This included an initial and follow-up interview and phone contacts allowing me to analyze data within each participant, within each dyad, and between each dyad.

Theoretical direction evolves from the analysis of the data as some interview responses stand out or cluster, and patterns emerge. Theoretical direction is supported through the use of an emergent research structure. Keeping this in mind, even though I developed an interview guide for the EMA portion of this study, as I explained earlier in this chapter, I ultimately changed the format of phone calls based on analysis of the early EMA data. In addition theoretical direction was supported through the use of a second interview guide that was developed based on the categories that were beginning to emerge during data analysis.

Theoretical centrality is similar to theoretical direction in that it is prefaced on an emergent, reflexive response to the analysis of data (Charmaz, 2014). In order to achieve theoretical centrality the researcher must be open to adjusting lines of inquiry based on codes and tentative categories. In order to maintain this responsiveness the final interview guide was not developed and the interviews were not conducted until all prior data had been collected and initially analyzed.

The final theoretical concern is theoretical adequacy of the categories -- meaning the categories are plausible, with an underlying logic that is representative of the data across settings or individuals (Dey, 2007). This necessitates thoughtful, robust analysis of the data. This was achieved through the utilization of the constant comparative process and the use of memos and a research journal throughout data collection and analysis

Chapter 4: Findings

In this study I investigated the relationships between individuals who have had a brain injury and their paid caregivers. I sought to understand how the individual perceptions of the paid caregiver and the care receiver influenced their relationship and how the learning that occurred both outside and within the relationship, impacted the interactions between the individuals. In this chapter I provide the findings from the study. These findings came from 34 interviews with eight participants. All participants were either a paid caregiver or a care receiver within Connecticut's Acquired Brain Injury (ABI) Medicaid Waiver program. As described in Chapter 1, the ABI Waiver program provides supportive services for qualifying individuals so that they can live in the community rather than an institutional setting. Inclusion criteria for the study specified that each member of the dyad be at least 18 years old, able to identify emotions and recall events for at least 30 minutes, able to participate in face-to-face and telephone interviews, and the dyad must work together at least 20 hours per week. Individuals were disqualified if they were related to each other or were friends prior to the care receiver's brain injury. The interviews included two face-to-face interviews as well as multiple short Ecological Momentary Assessment (EMA) interviews over a six-month period. The tables below display the demographic data for each paid caregiver, care receiver, and combined paid caregiver/care receiver dyad in the study. Each participant was invited to provide their own pseudonym or, if they preferred, have a pseudonym assigned to them. All but one of the care receivers self- identified a pseudonym while only one of the paid caregivers did so, and thus had a pseudonym assigned to them.

Table 2: Caregivers Demographics

Name	**Sex**	**Age**	**Race**	**Highest Grade Completed/Major**	**Time working in Waiver**	**ABI Waiver Designation**
Scarlet	Female	55	White	High School	16 years	ILST
Barry	Male	33	Asian	Bachelors/English & Philosophy	1 year	Companion/ILST
Caitlin	Female	48	White	Some College/Human Services	8 years	ILST
Doug	Male	60	White	Some Graduate School/Social Work	4.5 years	ILST

Table 3: Care Receiver Demographics

Name	**Sex**	**Age**	**Race**	**Highest Grade Completed/Major**	**Age brain injury occurred**	**Time receiving Waiver services**
Lauren	Female	52	White	Some College/Accounting	19	10+
Chailya	Female	33	White	Bachelors/Liberal Arts	3	7 years
Siobhan	Female	26	White	High School	10	3 years
Mike	Male	41	White	11th grade	17	10+

Table 4: Dyad Demographics

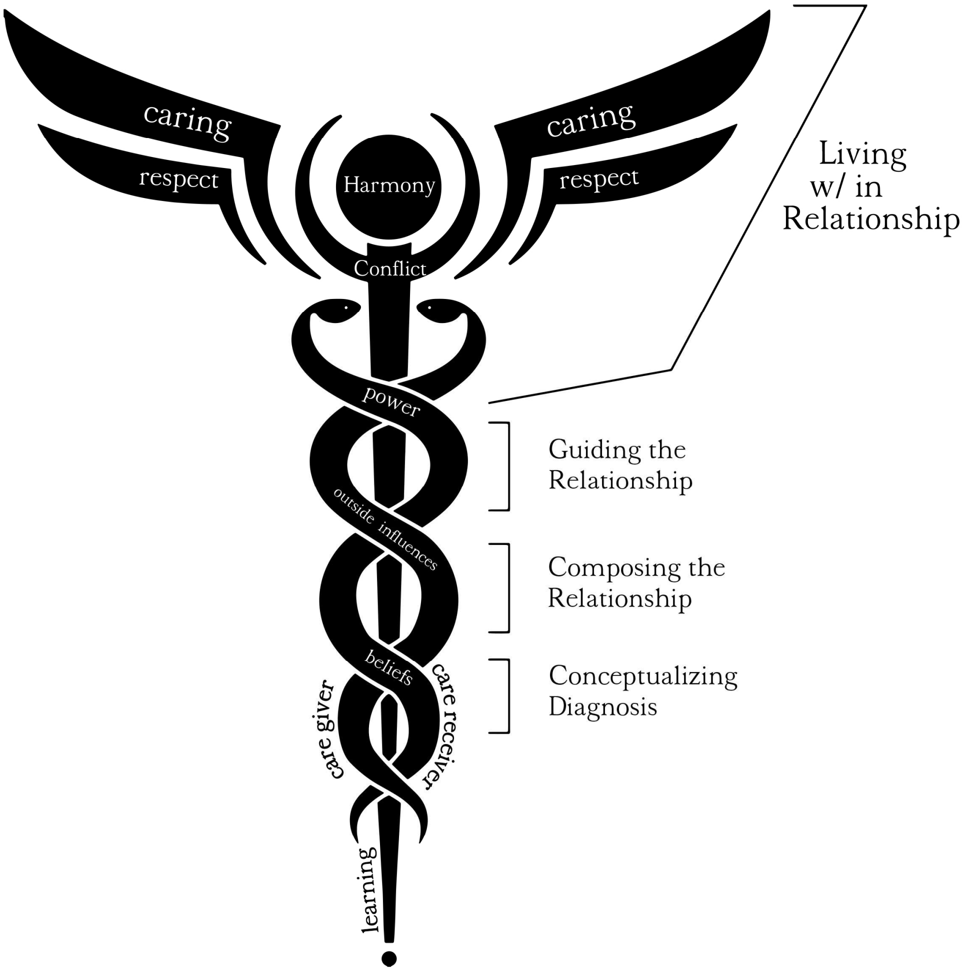
Names	**Time working together (at beginning of study)**	**# of hours together weekly**
Scarlet & Lauren	8 years	32
Barry & Chailya	4 months	24
Caitlyn & Siobhan	2.5 years	40
Doug & Mike	3 years	40

I have chosen not to present additional background information about each participant for a number of reasons. First, the ABI Waiver program in which all participants are involved as either a paid caregiver or care receiver is a relatively small program and I want to respect and protect each participant's confidentiality. Secondly, I do not want to further position the care receiver participants as "other" by describing the way they sustained their brain injury or the "impairments" that have resulted from the injury. Finally, because this is a grounded theory study the focus of the findings is on the theoretical categories that have arisen from the data rather than each individual's story (Glaser & Strauss, 1967). Likewise, in the results below I have made judicious decisions regarding the attribution of quotes and statements to participants in order to strike a balance between revealing the participants' individual voices and protecting their anonymity.

Overview

The factors and perceptions that influenced the day-to-day interactions between individuals with brain injury and their paid caregivers are represented by a conceptual model (Figure 2) in which an intersecting, multi-component process between the paid caregiver and care receiver is seen as embedded in the medical system which is represented by the use of the caduceus, a symbol of medical practice. This conceptual model illustrates four major categories that emerged through analysis of paid caregiver and care receivers' interviews and EMA phone calls. These categories are *Conceptualizing Diagnosis*, *Composing the Relationship*, *Guiding the Relationship,* and *Living within the Relationship.* The properties of the categories, or the conditions through which they arise, are *underlying beliefs, outside influences, power, and respect and fondness.* The core category, which serves to integrate all parts of this model, is Learning, that is, the ways in which the social exchange between the paid caregiver, care receiver, and the broader sociocultural community shapes the ongoing learning within this relationship.

Figure 2



Next I will fully describe the findings that led to the model. This model illustrates an integrative process that, at varying times, can lead to conflict or harmony. I will begin with a discussion of the three underlying categories of *Conceptualizing Diagnosis, Composing the Relationship, and Guiding the Relationship* and, within each, their associated properties, and then discuss *Living within the Relationship* and its associated properties. Next I will explore the ways in which the medical model infiltrates each category and conclude the chapter with a discussion of learning as a unifying concept within this grounded theory.

Conceptualizing Diagnosis

Although the term "brain damaged" is no longer used in the literature, both the paid caregivers and care receivers viewed individuals who have had a brain injury as damaged -- the individual with a brain injury is now lesser than they were or they could have been. For instance one paid caregiver in referring to their care receiving partner, states "she would have pretty much been a lethal entrepreneur if she had all her faculties". Mike, a care receiver indicates that he is unable to do "normal stuff" like go to parties with his friends or find a girlfriend. Other care receivers referred to themselves as being "kicked to the curb by their friends" "screwed up" or as being a "pain in the ass".

Additionally there is a perception that brain injury leads to stagnation. The impression is that people can become "stuck" in the developmental stage at which the brain injury occurred. For instance one of the paid caregivers, Scarlet, described how a brain injury can cause people to remain childlike -- "you have those that are stuck in that in between realm, and that's the worst, I think, where they want to grow up but they can't grow up", and Siobhan, a care receiver, states that she believes that brain injury stunts "personal growth -- emotional and otherwise."

However in addition to perceiving their brain injury as "damage", the care receivers also viewed their brain injury as making them unique. Chailya described how her injury, at age three, has led her to see the world in a different way:

> I get frustrated and stuff like that but every morning I wake up and I am so thankful that I can walk, talk, think, sing, dance and I can use one of my hands . . . I've adapted to my surroundings and everything like that and I love my life.

Siobhan stated that her brain injury has made her different than others but she is who she is and if "people don't like me because they think I am weird then they can just kiss my weird ass". Mike, another care receiver, shared how others in his gym approach him and tell him that he inspires them. Mike is proud and happy that he is making a difference in people's lives.

On the other hand, paid caregivers viewed brain injury as completely tragic. Caitlyn summed up the perspective about brain injury that was expressed in various ways by all the caregivers:

> It just changes their life tremendously. You know, you or I could be driving, get in a car accident and then your whole life changes. The person is very angry. Everybody I’ve worked with is very angry that they have their brain injury and they can’t do things they used to do.

One way that the care receivers develop a view of themselves as damaged is through their interactions with others. For instance Chailya explained how the first time she meets someone they give her, what she refers to as, the "x-ray look":

> So they start at my head and they work their way, just their eyes, and they look like they give you like a once-over going down and then going up because I walk with, you know, my gait problem and everything like that.

Siobhan shared that when she first meets a new person she tries to make a joke because "it is better to make people laugh with you before they laugh at you".

During day-to-day interactions in the community it is apparent to the care receivers that they are viewed differently than the paid caregivers. Lauren stated that people treat her as if her paid caregiver is her mother even though Lauren is 52 years old and is clearly not a child. Mike recounted how people rush to open doors for him because he uses a wheelchair and "they think something is wrong with me." Chailya described that when she tells people that she graduated from college magna cum laude they are "shocked". These experiences provided a constant source of data to the individuals with brain injury that, in the eyes of others, they are "damaged".

Paid caregivers chronicled their experiences of needing to justify to their friends and family why they would choose to work with individuals with brain injury because it is assumed to be a job that would be unrewarding and difficult. Friends and family tell the paid caregivers that they must be a "saint", compare them to "Mother Teresa" and exclaim that they must have a lot of patience. These messages illustrate the commonly held view in the community -- people with brain injury and the caregivers that work with them are different than others. These differences lead to pity for the individuals with brain injury and admiration for the individuals that care for them.

Both the paid caregivers and care receivers describe brain injury as an individualized experience. Chailya states she equates brain injuries to snowflakes -- everyone is different. Doug explains:

> What's really important is that we have to acknowledge that it's individual based, we can't treat it as you might the common cold, you know, and give them the same prescription for an antibiotic, [we must] treat each individual in an individual way.

The care receivers also made it clear that it is impossible for someone to really understand brain injury if they don't have one. Chailya comments that people don't realize how lucky they are to have two working hands, and Siobhan asserts that even people "who study brains and everything, don't have a darn clue about what TBIs actually do to a person."

The individuals with brain injury talked about the life philosophies to which they ascribe. There was a belief among all care receivers that, "just because you had a life altering event happen to you it does not mean that life stops." The idea that brain injury was an event that happened rather than a defining diagnosis underlies the beliefs of all care receivers. As Lauren noted, her brain injury affected some things about her but definitely not everything. Chailya stated. "You look at yourself and you say, you know what, this is what happened, do I let it take over my life or do I figure out how to deal with it the best I can."

Mike explained:

> I got in a real bad car accident but if I felt bad about myself I would never get anywhere and would just be sitting home feeling bad about myself, and waste away, and I wouldn't be able to do anything. So when I get up in the morning I always feel happy. I am in a good mood. Every day.

Paid caregivers tried to imagine what it might be like to have a brain injury. Barry described how when he first started working with Chailya he bound one of his arms and then tried to prepare and eat breakfast in order to see what it might feel like to live with the use of only one arm. Other caregivers speculated about how angry they may feel in particular situations. As one paid caregiver expressed:

> When she tells me "no", it's okay, and I don't blame her. Someone coming in their home, I don't know if I could do it. Being honest, I'd be telling them get the hell out, you know –

These attempts by paid caregivers to imagine what they personally might feel like if they had a brain injury had a significant impact on their beliefs about brain injury. All paid caregivers believed that individuals with brain injury are, as a rule, consistently frustrated by the things that they can't do and when there is a lack of frustration it is believed to be due to an unawareness on the part of the individual with brain injury as to the extent of their impairments.

This discrepancy between the care receivers' and paid caregivers' perceptions of living with brain injury was particularly apparent in the final individual interviews when all participants were asked if they felt good about themselves on most days and if they felt like their partner (care receiver or paid caregiver) felt good about themselves on most days. All participants, both paid caregivers as well as care receivers, stated that they felt good about themselves on most days however they were uncertain, or provided a caveat, regarding their partner's happiness. This was equally true for paid caregivers and care receivers. Paid caregiver's statements regarding their partner with brain injury included the fact that the individual with brain injury was happy on most days because the paid caregiver made an effort to always keep things positive. Another believed that their partner was happy most days because, due to participation in the ABI Waiver program, the individual was in the community surrounded by people everyday. A third paid caregiver believed that the care receiver was generally happy but often got frustrated, and the forth paid caregiver indicated that she would like to believe that the individual she worked with was happy, but she did not really think this was true. In fact, however, all the care receivers indicated that they felt good about themselves on most days but they were less certain if the caregiver was happy. Issues such as family illness and outside pressures were cited by care receivers as impacting the paid caregiver's happiness.

Although faced with consistent feedback from others that they are damaged, individuals who have had a brain injury do not solely define themselves by their diagnosis and, in fact, report feeling good about themselves on most days. Paid caregivers, on the other hand, assume that anyone with a brain injury would be unhappy and would want to change. This belief serves as the basis for the relationship between paid caregiver and care receiver and contributes to the day-to-day interactions that will be discussed in the next category.

Composing the Relationship

The category *Composing the Relationship* captures the day-to-day functioning of the caregiver/care receiver dyad. All dyads had a regular routine of activities that they did together. For Mike and Doug this was working out, eating, and socializing at a local YMCA. Siobhan and Caitlin regularly took walks, went to the library, attended support group meetings and appointments, and spent time talking, singing, and playing games. Chailya and

Barry often worked on various projects related to the art Chailya sold at craft fairs, and Lauren and Scarlet divided their time between household tasks and leisure activities.

The ABI Waiver program is a unique work setting for caregivers. Unlike institutional settings, there are no other on-site staff or supervisors during a paid caregiver's work hours. All of the paid caregivers disclosed that they really enjoyed the autonomy that this afforded them, expressing opinions similar to Caitlin's statement:

> you don't have a boss over you all the time which is nice. I like that you could do your own thing and you don't have to go to her every time [and say] "well, I want to do this and that, what do you think?"

The significance that the paid caregivers placed on autonomy is seen in their efforts to allow their care receiving partner choice and control within their day-to-day activities. All paid caregivers talked about consciously providing the care receivers choice such as choosing what to have for breakfast, the order of the daily activities, or what time to eat dinner.

Beliefs about autonomy became more complicated, though, within the context of the care receiver's behavior. Paid caregivers struggled with what they have been told about the impact of brain injury on behavior, and what they believed to be true about an individual's control over their own behavior. Most paid caregivers talked about this on numerous occasions. The following quote illustrates this struggle:

> I know that they have impulse control [issues] and all that but I think that to some extent, they can control that. You know, some people think maybe not but I think that – I mean, because [care receiver] had no impulse control in the beginning and now she does. So if you are really working hard towards your goals, then yes, you can do it.

Paid caregivers talked about care receivers choosing to behave in particular ways because they didn't want to do something, or using behavior as a ploy to get attention from others. At the same time, though, all paid caregivers expressed that they tried to find an outside reason for the care receiver's actions. For instance one caregiver questioned, "Is it a food that can cause her to do that? You don't know, we don't know where the mind shuts down. Is it the smoothies, is it the yogurt, is it this?" Another paid caregiver hypothesized "her sister moved out and got engaged and [care receiver] feels she should have done this already so that is what I am thinking is happening."

This reasoning assumes that determining the environmental cause of the behavior and/or providing the care receiver with a better behavioral response can resolve the issue; therefore the paid caregivers tended to see themselves as teachers. For instance, one paid caregiver described how she has tried to teach social strategies so that the care receiver does not embarrass herself in public. Another talked about how if you teach something "often enough, on a regular basis, they'll remember". This belief in the power of repetition was prevalent among the paid caregivers as seen by a caregiver who expressed frustration with the fact that the care receiver did not cover their mouth when coughing even though they had been working on this for weeks; and in the strategy, described by another paid caregiver, who stated that rather than constantly correcting the care receiver's behavior, she will ask the care receiver to tell her the protocol for the activity prior to beginning.

Although paid caregivers perceived themselves as teachers, care receivers did not perceive themselves as students. While they all felt that they learned things from their paid caregivers, they perceived the paid caregiver's primary role as being their "helper". For instance, Mike described Doug's role with him as " to bring me to the gym and make sure I get on the machines safely and make sure I walk safely and don't hurt myself". Another care receiver similarly expressed that her paid caregiver drives her around and protects her from doing bad things and talking to strangers. While another care receiver talked about how much she appreciated her paid caregiver's help in assisting her with breaking down tasks into manageable chunks.

This incongruity between the paid caregivers and care receivers regarding the paid caregiver's role, while not explicitly recognized by the paid caregivers, did appear to be sensed by some. As one paid caregiver expressed when asked how others viewed his job, "I'm not sure they understand. Hell, I don't even understand exactly what my job is". Another wondered aloud if he was simply there as "sort of a placeholder" until the next staff comes along to work with the individual on the same things. He went on to explain that the care receiver has a t-shirt that reads, "I see you speaking but all I hear is blah, blah, blah". He laughed as he told this story, but this tension between wanting to make a difference in a care receiver's life and the uncertainty that this was occurring was expressed by most of the paid caregivers.

This pressure was heightened by the messages that paid caregivers received from others. Although none of the dyads spent significant time with the care receiver's family members, family dynamics appeared to heavily influence the relationship between the paid caregiver and care receiver. For instance one paid caregiver stated:

> At the beginning there's always a tense period of trying to produce results for the mom or the conservator and there's pressure on my part to keep the day going and progressing and I found that counterproductive because it raises the tension level of our day.

Both the paid caregivers and care receivers expressed that past and present interactions with family members had an effect on later interactions between the pair. In the two cases where the care receiver lived with family members, the paid caregiver and care receiver were asked to be out of the home for most, or all of the day, in order to give the family "a break". In another case a paid caregiver described how when the care receiver's parent calls the home while they are together it "triggers" the care receiver and affects the rest of the evening.

Care receivers also expressed that their family member's perceptions affected the relationship between them and their caregiver. For example one care receiver stated that she would like to have a boyfriend but she is only allowed out of the house with her paid caregiver and "my family thinks I am too screwed up to get a man". Another care receiver remarked on her mother's views of her paid caregiver, which appeared to color her own views of the paid caregiver.

In addition, the paid caregiver's experiences within their own family, particularly with their parents, had an effect on the way the paid caregiver interacted with the care receiver. Most paid caregivers described their interactions with the care receiver as very similar to the way their parents had interacted with them. For instance one paid care giver stated "there have been times when I have to step back because the first response that was coming -- I could just identify this as something my parents would say". Another expressed that her mother had instilled in her a philosophy of always looking for the positive and now she was trying to instill this same attitude in the care receiver.

Another significant outside influence on the relationship between paid caregivers and care receivers was the paid caregiver's employer within the ABI Waiver program. Most paid caregivers reported that their employer was a source of support and encouragement to them.

For instance one paid caregiver described how after a difficult first day with a care receiver she called her employer to tell her "I can't do this, I don't want to" but her employer encouraged her to stay and told her that she had specifically selected her for this case because she knew the paid caregiver could handle it and so the paid caregiver stayed. Other paid caregivers also talked about feeling supported and validated by their supervisors. Even though most of the paid caregivers in this study were seasoned employees within the ABI Waiver program they liked knowing that there was outside support available when they felt discouraged. The care receivers generally did not interact with these agencies although they were aware that their paid caregivers and family members did so and they were also aware that these agencies held power over their relationship with the paid caregiver.

A third outside influence on the relationship between paid caregivers and care receivers were others that the pair encountered in the community. One paid caregiver explained that he can never leave the care receiver alone, even for a minute, because of an incident that occurred a year ago. Following this incident the pair were told that if the same thing ever happens again they would never be allowed to return to the facility. Another paid caregiver describes how she has to always be on guard to prevent the care receiver from saying something offensive to others in the community. However not all community interactions were negative. Paid caregivers and care receivers also described situations in which care receivers were embraced by the community and formed friendships with others. For instance Siobhan proudly shared that the pastor at her church complained to her that the service is just not as joyous sounding when she was not there to sing; Scarlet described how others in Lauren's apartment complex will frequently drop by to visit Lauren; and Doug recounts how "where ever we go people just throw their love at Mike".

A final outside influence on the day-to-day relationship between paid caregiver and care receiver is the paid caregiver's life outside the context of work. Within the six months the interviews took place, the paid caregivers experienced family illnesses, deaths, financial difficulties, changes in personal commitments, disagreements, and other life stressors. Although the paid caregivers expressed trying to leave their outside life "at the door" almost all of the care receivers perceived that there were times when the paid caregiver was stressed due to outside circumstances.

Beliefs about autonomy, the role of the paid caregiver and care receiver in the ABI Waiver program, and interactions with others outside the dyad affected how the members of the caregiving dyad felt, how they spent their time, and how they perceived themselves and each other on a day-to-day basis.

Guiding the Relationship

The category *Guiding the Relationship* is used to capture the aggregate beliefs that impacted the relationship between the care receiver and paid caregiver. These broader concepts, combined with the beliefs and influences discussed in the other categories have a significant impact on the final category, *Living within the Relationship,* leading to either conflict or harmony within the relationship.

One consistent belief among the paid caregivers and, to a lesser degree, among the care receivers was the idea that things happen for a reason or, concomitantly, that positive outcomes can be found in most situations. One way the paid caregivers expressed this belief was in relationship to becoming employed within the ABI Waiver program. All paid caregivers described how they happened to stumble upon the opportunity to work as a paid caregiver but now they feel like it was "meant to be" because they have learned things that have helped them in other parts of their lives.

The care receivers did not believe that their brain injury was "meant to be" but most have attempted to find meaning in the incident. For example Siobhan expressed "the good Lord kept me alive for one reason or another . . . and I am going to try to find out what that reason is. . . every set back is actually a set up for a comeback." Chailya explained that having the opportunity to work with so many different paid caregivers has made her life more diverse and richer, and Mike talked about how his accident ended his dangerous partying lifestyle.

Another prevalent belief among both paid caregivers and care receivers was a belief in the value of progress. The ABI Waiver program requires that all participants within the program have designated goals and that care providers report monthly progress toward these goals so there is an explicit requirement for caregivers to demonstrate progress. The caregivers did not question this aspect of the ABI Waiver program and shared this belief in the importance of progress. Caitlin conveyed a view expressed in different ways by all of the paid caregivers:

> I've always been a helping person, I want to help. It just brings me joy and it just makes – seeing the difference that you make in somebody's life, you know, progress . . . it's challenging but rewarding.

But as Doug explains, in comparison to his previous career in the business field, measuring progress in the ABI Waiver program can be difficult. "With [business], it could be easily done by producing a particular number of [contacts] per week but in this job, it's difficult to elicit that type of result." This is particularly true when the care receivers and paid caregivers have different concepts of progress in mind.

The care receivers all viewed progress as a tangible outcome -- walking better, losing weight, accomplishing tasks, moving out of their parent's home -- whereas the paid caregivers measured progress as a change in an individual's behavior.

This perception regarding the need to change the care receiver's behavior arose from innate beliefs about progress but there were variations in the caregivers' definitions of progress. For instance one paid caregiver explained progress as helping the individual "get better":

> We're not here to just be the friends or to give them something because oh, they have a brain injury and you know, it's okay. No. We're here to do a job and make sure we stick to it and that's the only way they're going to get better, the only way. And it's not easy.

Another paid caregiver described the need to build healthy relationships as the basis for progress:

> . . . if you want to move forward in your life, your relationships have to be healthy. So you know, we talk a lot about that -- you need to start with yourself first and start with home and with your family and then go out into the community.

The third paid caregiver discussed progress as a biological change:

> If she forgets, it is actually good for her to get up and walk to the other room again and bring it back. She does it often enough, she will stop forgetting so

> much. It's more and more. Really, there is a very clear connection between muscle and memory, muscular movement and memory.

And the fourth paid caregiver described progress as increased independence:

> I would love to have [care receiver] exhibit as much independence as possible and I push [care receiver] to do a lot of the hard work himself so that's a major goal.

Although there was variation between each of the paid caregivers' descriptions of progress, there was agreement among all of the paid caregivers about how to achieve progress. Every paid caregiver expressed the importance of being "strict" or being a "task master". This belief can be seen in the descriptions of progress above as well as the quote from a paid caregiver below:

> . . . it’s like 24/7 on her like that, you know? And when I train people, I’ve said "you may think that I’m mean or I’m strict. I’m really not (laughs), but this is what I have to do with [care receiver] because this is how she’s turned around.

Although some of the paid caregivers believed that others viewed these interactions negatively, they were convinced that this approach was necessary. Paid caregivers worried about what would happen if the care receiver did not have someone in their life that held them accountable:

> I think she would just sit there and... I think, how would I say this? I think her life would just be, she would be nothing. She wouldn't have the skills that she needs when going out [in the community].

All of the paid caregivers explained that their ultimate goal was to improve the quality of the care receiver's life. As one paid caregiver expressed:

> I am here to assist him in getting from point A to point B, you know, at 1/4 mile an hour -- safely and with appropriate behavior, and hopefully with an improvement in his quality of life.

Another paid caregiver described her role as teaching the care receiver "how to live her life on a daily basis with as much happiness as I can".

Both the paid caregivers and care receivers believed in the potential for progress. One care receiver described her brain as still being "elastic and bendy" and, therefore, able to learn new things. Another tells how he puts his mind to good use through volunteering with a local organization which counts on his ability to learn how to do a job correctly, and a third care receiver talked about the fact that she is an "outside the box" type thinker who loves taking on more and more responsibility.

Paid caregivers remarked that progress was slow. They described their care receiver as "a work in progress" and some found themselves trying to help the care receiver's family members see the progress that they were making:

> One sister really thinks [care receiver] needs to be put in a home. Because she's like she never...there's no improvement. There isn't. But there is. There's so much improvement from when I first came here.

These overarching beliefs about why things happen and the nature of progress implicitly contribute to the interactions between the paid caregivers and care receivers. From the caregiver's perspective the care receiver needs "fixing" and it is their duty to reform them, while the care receivers want to achieve their goals and live their lives.

Living within the Relationship

It is not uncommon for paid caregivers and care receivers in the ABI waiver program to work together for years. At the beginning of this study the participants had worked together between four months and eight years. Therefore, it is not surprising that during the six-month period of the study the paid caregivers and care receivers experienced harmonious times as well as conflict. As described in earlier sections, there was some discrepancy between paid caregiver and care receiver beliefs in terms of the nature of brain injury, the purpose of the ABI Waiver program, and perceptions of progress. These differences were generally mediated by respect and fondness for the other individual so that harmony was maintained within the relationship. However, from time to time, these differences clashed and power struggles arose. This category, *Living within the Relationship*, will examine these dynamics.

Most conflicts within the relationship between a paid caregiver and care receiver appeared to be related to, or affected by, the power differential within the relationship. This power differential is not as straightforward as one might expect where it would be assumed that the paid caregiver holds all of the power. In fact, in the on-going relationship within the ABI waiver program, the care receiver holds a significant amount of power. There are two primary reasons for this. The first is that the care recipient, or more typically, their family member, is considered the employer of the paid caregiver. This means that if a family is unhappy with the paid caregiver's performance they can request a new paid caregiver or even a new agency. This was a well-known fact among both care receivers and paid caregivers. A number of participants talked about "firing" past paid caregivers who they were unhappy with and suggested that if a particular agency didn't meet the care receiver’s needs the care receiver will switch to a new agency.

The second way the care receiver holds power is predicated on the paid caregiver's beliefs. As described earlier, most paid caregivers believe that the care receivers can control their behavior if they want to. They also believe that it is their responsibility as caregivers to teach the care receiver appropriate behavior and to demonstrate to others that the care receiver is changing. When the care receiver behaves in a way that is deemed inappropriate then the paid caregiver feels personally responsible for these actions. One paid caregiver described how she would sometimes cry in her car on the way home because she would be so frustrated.   The most common response though, when a care receiver behaved in a way that the paid caregiver deemed wrong, was anger -- initially at the care receiver for not behaving, and then at himself or herself.   Almost all paid caregivers talked about situations where they had to take a "time out" to get their emotions under control. None of the care receivers expressed this same level of emotional distress in regard to their relationship with the paid caregiver although some did disclose anxiety in regard to the potential that the paid caregiver may leave them.

An important component of the relationship between caregivers and care receivers was trust and matters of trust often were intertwined with the issues of power described above. Some care receivers shared situations in which they were made promises by paid caregivers that weren't kept and some paid caregivers talked about incidents where they felt like the care receiver behaved in ways that betrayed their trust. These situations generally led to confrontations between the paid caregiver and care receiver, interactions with the employer agency, and threats regarding termination of the relationship.

A component of the relationship in which a power struggle might be anticipated is the reaction of the care receivers to what the paid caregivers described as "being strict". However, in fact, none of the care receivers commented on this and the partners of the paid caregivers who most frequently talked about being strict appeared to have particularly close bonds with their caregiving partner. This seemed to be due to respect and fondness between the paid caregiver and care receiver. It appeared that the care receivers viewed “strictness” as the paid caregiver's belief in their capabilities and respect for them.

The respect that paid caregivers had for the care receiver arose, at least in part, from their beliefs about brain injury. As explained earlier, the paid caregivers often tried to imagine what it might be like to have a brain injury and many remarked on the care receiver's strengths in comparison to others or what they imagined themselves to be like if they were in the same situation. For instance Barry described Chailya as having " a really good sense of humor and an awesome view on life." Caitlin expressed that Siobhan is intelligent and smart and that she learns something from Siobhan every day. Scarlet states that she is always touched by Lauren's empathy for her, and Doug expressed admiring and learning from Mike's upbeat attitude and outgoing personality.

This empathy and respect led to thoughtful interactions with the care receiver. As one paid caregiver stated "I try to be sensitive to the fact that he can't play sports or have much of a social life". Another explained how she is really careful regarding the way she provides cuing to the care receiver when they are in public so that she does not embarrass her. A third describes how she makes a point to always treat the care receiver as an adult.

The care receivers have respect for their paid caregivers as well. One care receiver was appreciative that his paid caregiver taught him "how to respect people and make people think good about you because you don't say nothing stupid to get them mad". Another expressed that she had changed for the better since working with her paid caregiver and a third expressed how her caregiver "gets" her and worked with her in a way that was helpful while the fourth stated that her paid caregiver had done so much for her that she thinks the caregiver should get a raise in pay.

The final critical factor in the relationship between the paid caregiver and care receiver is the level of fondness that developed between the dyad over time. This was particularly evident in the pairs that had been together for years. Paid caregivers and care receivers used words like "love" and "friends" when describing their relationship and talked about special routines, private jokes and nicknames. For instance a paid caregiver described that every morning when she arrives at the care receiver's home "I say hello Mushamoo and she says hello my Mushamoo". Another paid caregiver talked about special events that she and the care receiver plan together each week. One of the care receivers described how she felt more comfortable talking to the paid caregiver about things in her life than with any other person. Another care receiver, in describing her relationship with her paid caregiver, stated "I feel like my world is bigger because of working with him." It appears that this fondness for each other, which grows out of trust and respect, is a major component for maintaining a harmonious relationship.

As in any long-term relationship, caregivers and care receivers experience times of conflict and harmony. Conflict arises when there is disagreement regarding goals and behavior, and issues of trust and power compound these disagreements. However these issues are counterbalanced by the respect and fondness that both members of the dyad have for each other.

Medical Model

Charmaz (2015) has suggested that constructivist grounded theory methodology is not only useful for examining micro-processes that shape experiences and events, but also the macro-structures that inform these processes. Within the relationship between paid caregivers and care receivers it is clear that the medical model perspective has permeated every category that has been described above.

As I explored the relationships between paid caregivers and care receivers and the beliefs that influenced each category it became apparent that these beliefs were heavily influenced by typical medical model views. The category *Conceptualizing Diagnosis* illuminates the way in which disability is viewed as deviance. Bickenbach (1993) describes this assessment:

> The most commonly held belief about disablement is that it involves a defect, deficiency, dysfunction, abnormality, failing or medical "problem" that is located in an individual. We think it is so obvious as to be beyond serious dispute that disablement is a characteristic of a *defective person*, someone who is functionally limited or anatomically abnormal, diseased or pathoanatomical, someone who is neither whole nor healthy, fit nor flourishing, someone who is biologically inferior or subnormal. The essence of disablement, in this view, is that there are things *wrong* with people with disabilities (p. 61).

The experiences of the care receivers in being evaluated by others through the "x-ray look" and fear of being laughed at, as well as their own conception of themselves as different than "normal" people can be understood as directly arising from the ubiquitous and insidious permeation of the medical model into their lives. So too can the caregivers' assumptions about what it might feel like to live with a brain injury when brain injury is societally understood as being "broken".

Additionally, within the medical model, disability is believed to be a problem that solely resides in the individual and must be "cured". This view is apparent in the caregiver's description of their role within the ABI waiver program as a teacher and the messages received from employers and family members regarding the paid caregiver's responsibility for changing the care receiver's behavior. As one caregiver stated:

> I see high potential for [care receiver] and I let her know that she has high potential. I said "you made gradual progression which is good. You're moving forward, but you need to tap into that high potential". So I'm always pushing her, pushing her, and pushing her, so she does that.

Further, the idea of "progress", as understood by both caregivers and care receivers, represents not only movement toward becoming "normal" but also becoming independent. Within the medical model, as well as Western society, independence and autonomy are understood as markers of success. For instance in describing the purpose of the ABI Waiver program one paid caregiver expressed:

> It's a very practical approach to rehabilitation in the sense that you're just optimizing the processes they can do, or you're helping them figure out how to optimize processes so they don't need help to do it on an everyday basis.

One of the care receivers described his goal as:

> . . . to get away from my walker and get away from my wheelchair and just walk like normal people. Like you are. And just walk by myself without a walker or a wheelchair or without hanging on to something.

Paid caregivers and care receivers also expressed view points outside of the medical model such as the care receivers' understanding of themselves as distinct from their brain injury diagnosis and the paid caregivers' expressed wish for the care receivers to just have a good quality of life, but overall their relational dynamics clearly occur within the medical model paradigm.

Learning

Learning is the core category that integrates all parts of this model. Paid caregivers and care receivers are perpetually learning from each other and the learning that takes place in the context of this relationship influences each person's interpretation of the world in all other contexts. Most caregivers directly expressed this. Their comments included:

> Working with and watching [care receiver] most definitely provided impetus to get sort of like a discipline and order into my own life.

> You really get appreciation that you're blessed, that you're grateful for everything because like I said, anything can happen in a second like that, you know, and that it's been a pleasure working with her. I mean, it's challenging but also it's very rewarding so I think that's humbled me that way, you know?

> I think working here . . . has allowed me to learn more about myself and develop another portion of my self. You know, develop people skills and be more empathetic and not so self centered.

Chailya, one of the care receivers, summed up the dynamic of this relationship:

> I think that life is always evolving, life is always changing and that people come into your life for all different reasons and that some of the things that you teach... that they teach, stay with you throughout your life.

Although one might expect that learning within a relationship would bring a paid caregiver and care receiver to the same end point, in reality this does not necessarily occur because each individual brings their own unique individual experiences with them into each new interaction. This was seen, for example in the category *Conceptualizing Diagnosis*. I have suggested that care receivers see themself as both damaged and unique whereas the paid caregivers view the care receivers as damaged even though the paid caregivers also expressed that every brain injury is unique and all described attributes they admire about the individual they work with. What could explain the different conclusions that the care receivers and paid caregivers reach regarding living with a brain injury? From a learning perspective it is obvious that an individual with a brain injury receives constant messages that they are "damaged". These come through their initial designation as a patient within the medical model as well as their interactions with others including friends who "have kicked them to the curb", strangers who give them "the x-ray look", and the ABI program's goal of rehabilitation. However they also receive feedback from society and others that they are an "inspiration", they survived life threatening injuries "for a reason", and the valued cultural belief that "when life gives you lemons you make lemonade". The paid caregivers, on the other hand, observe, or are aware of all of these same messages yet come to a different conclusion based on personal imaginings of what it might be like to have a brain injury. These imaginings are colored by their own experiences. For instance, one caregiver talked about experiencing bullying earlier in life and, in a separate interview, postulated that individuals with brain injury feel disempowered. Another shared how they experienced a physical injury which impacted the ability to do things that used to be easy and later talked about how pride impacts the ability of an individual with brain injury to change their habits. Personal experiences influenced the paid caregivers perceptions of what individuals with brain injury were thinking and feeling.

Additional underlying beliefs that affected learning in this relationship were the dichotomy between voluntary agency and causal beliefs about behavior. This dichotomy was particularly apparent relative to the meaning that paid caregivers attached to the care receivers' behavior. On one hand the paid caregivers believed that the care receivers can behave in certain ways if they chose to, as evidenced by the fact that the paid caregivers had seen changes in the care receivers' behavior over time based, it was believed, on their interventions. However conversely, the caregivers also frequently searched for outside explanations such as the food the care receiver was eating or events that may be occurring in the care receiver's life. Voluntary agency conjectures that we have free will and can decide our actions from moment to moment. Causal attributions for behavior suggest that individuals behave in certain ways due to external forces. Within this view people can be "educated", "rewarded" or "forced" to change their behavior (Gergen, 2009). The paid caregivers also expressed that they chose to work in the ABI Waiver program because they wanted to "help people" therefore their belief that individuals with brain injury are unhappy would necessitate "fixing" the brain injury.

All of the beliefs described above guided the direct learning that occurred in the relationship between paid caregiver and care receiver. This learning included attempting to understand the expectations of the other person, effective and ineffective ways to get needs met, and the other person's personal perceptions of them. In situations where these items were not in congruence there was conflict. For example, the paid caregivers and care receivers learned what to expect from each other based on their previous experiences together and when one member of the dyad suddenly behaved in an unexpected way there was a sense of betrayal.

As one paid caregiver explained in response to unexpected behavior by the care receiver:

> Okay, I was angry . . . kind of like freaked out, I'm like, what? What did you do? . . . I was upset, crying upset, like this is not going to fly, you know, that was I felt very violated and like I can't believe that she did this. Why would she even do this?

In a different dyad a care receiver talked about how she felt her paid caregiver had been so willing to help her but then suddenly, in her opinion, was refusing to help and she felt very let down by the paid caregiver. Generally, though, the learning that occurred between paid caregivers and care receivers resulted in the two being able to work more effectively together and cultivate a close working relationship in which both individuals respected each other and felt cared about by the other individual.

Chapter Summary

The relationships between the paid caregiver and care receiver dyads in this study were influenced by factors within and outside their day-to-day interactions. These factors included each individual's personal beliefs about living with a brain injury; perceptions regarding the purpose of their relationship; how to measure progress; and impressions of each other. These factors were influenced by implicit and explicit messages from other individuals, personal experiences, cultural beliefs and the medical model. This process was illustrated by the use of a conceptual model which included the categories of *Conceptualizing Diagnosis, Composing the Relationship, Guiding the Relationship* and *Living within the Relationship* and the properties of *underlying beliefs, outside influences, power, respect and fondness.* These categories and properties are all represented as embedded inside the medical model and learning was presented as the core category that integrates all parts of the model.

Chapter 5: Discussion

The purpose of this study was to explore the relationships between individuals with brain injury and their paid caregivers. Specifically, the study examined how the individual perceptions of paid caregivers and care receivers influenced their relationship and how the learning that occurred both within and outside the relationship impacted the interactions between the individuals. An analysis of the data resulted in a conceptual model that illustrates the myriad of interrelated influences on these relationships. This chapter presents an interpretation of the study findings and integrates the findings within the extant literature. I will also discuss implications for research and practice.

Synthesis of the Study

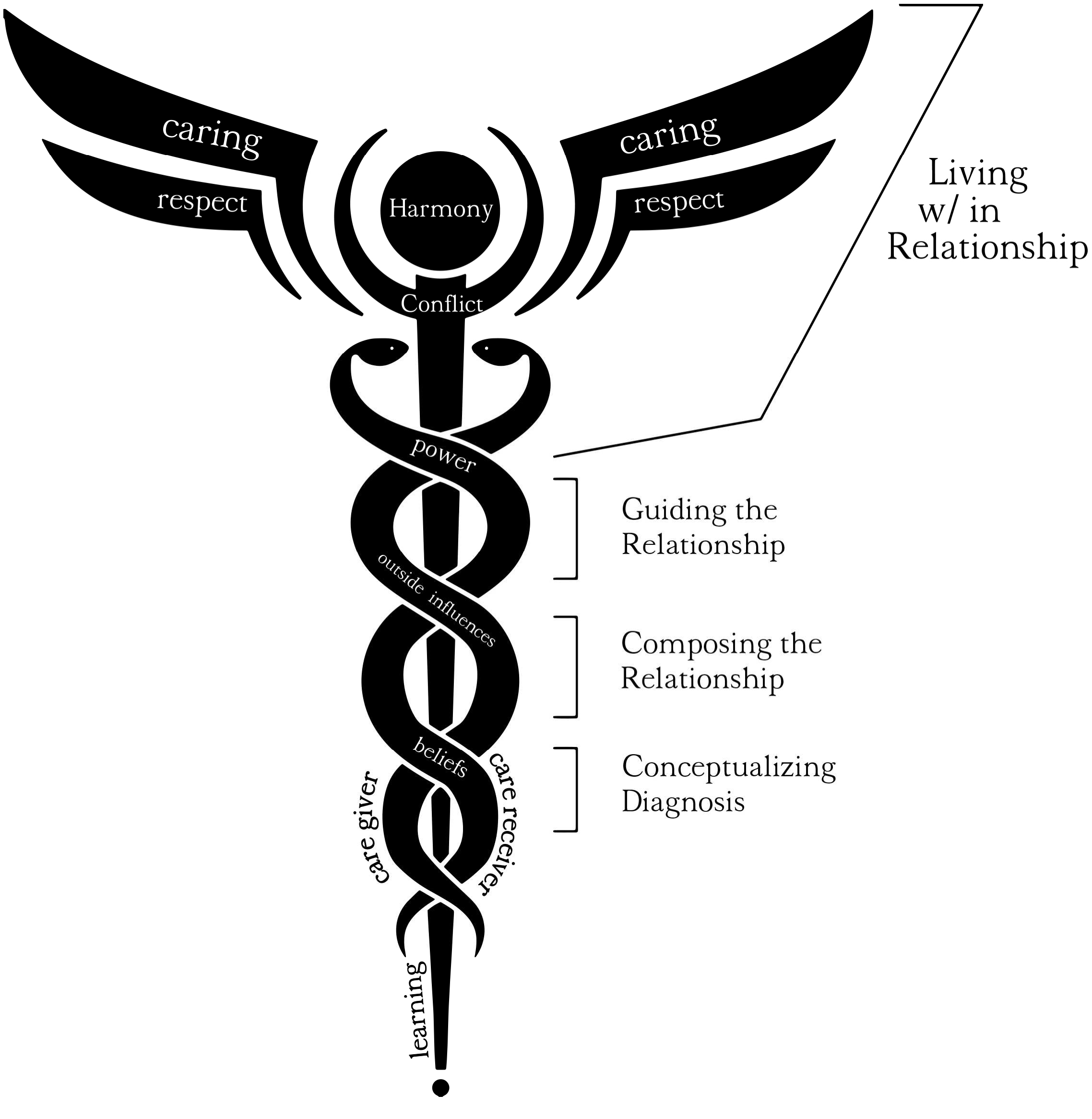
The catalyst for this study was a combination of my personal experience in working with individuals with brain injury, particularly my observations of interactions between paid caregivers and care receivers within Connecticut's Acquired Brain Injury Waiver program, and the scarcity of research regarding paid caregivers in community settings. While there has been research that has examined the experiences of family caregivers with individuals with brain injury, there is a dearth of literature that explores caregiving relationships from the perspective of the individual with brain injury and the paid caregiver in community-based settings. Recent federal rulings have led to an increasing population of individuals with disabilities receiving paid support services in their communities rather than in institutions (Department of Health and Human Services, 2002; Hornbostel, 2005) therefore it is important to develop an understanding of the relationships between paid caregivers and care receivers in community settings. The aim of this dissertation was to illuminate the perceptions between individuals with brain injury and their paid caregivers -- what these perceptions were, influences on these perceptions, and the impact of these perceptions on the day-to-day relationship between the individuals. Guided by Charmaz's (1990, 2014, 2015) constructivist grounded theory approach I analyzed data to develop a model which answered the following questions:

1. What are paid caregivers and care receivers' perceptions of brain injury?
2. What factors influenced these perceptions?
3. How are these factors and perceptions seen in the day-to-day interactions between individuals with brain injury and their paid caregivers?

The development of the model was based on 34 interviews with eight participants over a six-month period. The interviews included two in-depth semi-structured interviews with each participant and, in between these interviews, short phone interviews using an adapted Ecological Momentary Assessment method.

The model (Figure 2) illustrates the four categories -- *Conceptualizing Diagnosis, Composing the Relationship, Guiding the Relationship, and Living within the Relationship* -- as embedded within a macro-level category of the *Medical Model*.

Figure 2


caring
caring
respect
Harmony
respect
Living w/ in Relationship
Conflict
power
Guiding the Relationship
outside influences
Composing the Relationship
beliefs
care giver
care receiver
Conceptualizing Diagnosis
learning

The core concept integrating all parts of the model is Learning. The micro and macro-level categories' relationship to the literature and their relevance to the core category will be discussed below. I begin with discussing the micro-level properties of each category and then will examine the interplay between the medical model and adult learning to explore how these implicit macro-level factors affected the interpersonal relationship between a paid caregiver and care receiver. I will also discuss the usefulness of Ecological Momentary Assessment as a means of data collection with individuals who have a brain injury. Finally, I will detail the limitations of this study and make recommendations for further research and practice based on the results of this study.

Self-image and Quality of Life

This study found that paid caregivers assume that living with a brain injury is frustrating and inferred that individuals would want to regain "normal " functioning. This is consistent with the literature regarding life satisfaction of individuals with brain injury that generally reports decreased life satisfaction and self-efficacy after brain injury. These studies commonly include a comparison between measures of cognitive function, life satisfaction and self-efficacy (see Carroll & Coetzer, 2011; Doering, Conrad, Rief, & Exner, 2010; Gruen, Hawthorne, & Kaye, 2009). The quantitative studies found that individuals who have had a brain injury were more likely to be depressed and to rate their self-concept more negatively when compared to a normative sample.

Actually though, care receivers reported that they felt good about themselves on most days. This finding, that the individuals with brain injury were, for the most part, content, contradicts much of the quantitative literature regarding life satisfaction after brain injury and was quite unexpected. Yet as I examined qualitative studies regarding individuals with brain injury I found themes similar to my findings, particularly in those studies where participants had sustained a brain injury more than five years ago. Like the care receiving participants in this study, the individuals living with brain injury in these qualitative studies had a more nuanced opinion about life after brain injury. They talked about difficult aspects of their lives, particularly in the initial years after the injury, but they also talked about new joys they have discovered. For instance, Levack (2014) found that participants discussed both loss as well as "pride in one's achievements and who one had become after injury" (p. 5). Nochi's (2000) narrative study of ten adults with brain injury found that individuals hold a neutral or positive self image and they, like my participants, asserted that there is a "true" self that brain injury did not affect and that the brain injury enabled the development of positive attributes. Similarly, a major theme that emerged from Shotton, Simpson, and Smith's (2007) qualitative study was "the benefits have far outweighed the consequences" with their participants identifying positive lifestyle and personal changes that arose as a result of their brain injury.

The individuals with brain injury in my study reported feeling good about themselves on most days but also perceived themselves as different than others and "damaged" by their injury. Gelech and Desjardins (2011) suggest that this disparate self-image after brain injury is common. They assert that studies that solely characterize brain injury as a negative loss are overly simplistic. Instead, Gelech and Desjardins (2011) suggest post-injury construction of self is intersubjective and contextual and arises through interactions with others in concert with one's concept of themselves including their individual traits, emotional tendencies, and spiritual beliefs. After a brain injury, individuals can perceive a stable, inner self even when there is a radical change in their public self.

Given their close relationships with the care receivers it is surprising then that the paid caregivers were unsure if their partner felt good about themself on most days or suspected that they only felt good about themself when they were actively engaged with the paid caregiver. It appeared that the paid caregivers based their assumptions about living with brain injury on their own imagined perceptions about what it would be like to have a brain injury. This is consistent with research about potentially negative future events in which those who imagine these events as happening to themself have a distorted estimate regarding the negative outcome of the event (Chen & Williams, 2012; Reinhardt, 2015; Rubin, 2014).

There is a belief that interaction between disabled people and non-disabled individuals will reduce the stigma and fear of disability. Research has demonstrated this to be true in the general population (Corrigan et al., 2001; Heslin, Singzon, Aimiuwu, Sheridan, & Hamilton, 2012) but not necessarily in healthcare workers who are regularly exposed to people with disabilities (Bates & Stickley, 2013; Ross & Goldner, 2009; Ungar & Knaak, 2013). This is consistent with my findings among the paid caregivers who spent a great deal of time in contact with their care receiver but who appeared to fear that they or a loved one would sustain a brain injury. As one caregiver stated:

> I can’t imagine, you know, having that happen to my daughter, so I feel for the family in that aspect. I just can’t imagine – everybody that I’ve worked with, just can’t imagine, you know, that. So I really have respect for her for that, and the family, because that’s – that’s got to be tough. I just can’t even imagine, you know?

Paid Caregiver Role

The paid caregivers and care receivers in this study had different perceptions of the paid caregiver's purpose. The care receivers perceived their paid caregiver's role as a helper and paid caregivers envisioned their role as a teacher. Pryor and O'Connell (2009) found a similar inconsistency between nurses in rehabilitation hospitals and their patients. The nurses viewed their role as facilitating the patients' independence and patients believed that the "nurse is someone who '*does for' the* client" (p. 1769). These findings were collaborated in a systematic review of nurses' and patients' perspectives of caring behaviors by Papastavrou, Efstathiou and Charalambous (2011) which found significantly different perceptions of caring between nurses and patients, with patients valuing the technical aspects of caregiving, while the nurses perceived the psychosocial aspects of caregiving to be the most important. In addition, as described in Chapter 4, the care receivers' perspective is that paid caregivers are employees, which contributes to the perception that the purpose of the paid caregiver is to serve the care receiver. However this viewpoint was complicated by whether the care receiver saw himself or herself as the employer of the paid caregiver, or if the care receiver viewed their family member as the paid caregiver's employer. In my study only one of the care receivers viewed herself as the employer, whereas the others perceived their family member as the employer of the paid caregiver. In these instances, the care receivers still saw the paid caregiver as an employee, but one who was beholden to their family member's wishes --carrying out duties as assigned to them by their family member.

Challenging behavior & conflict

I found incongruity between what the paid caregivers stated they had been told about the biological basis for behavior change after brain injury and what they believed to be true about their care receiver's behavior. Most of the paid caregivers believed that the care receiver could behave in a socially acceptable manner if they chose to however at the same time they often looked for additional outside explanations for the care receiver's behavior. This belief is in accord with research suggesting that adults have an implicit bias to infer intention in all behavior (Guglielmo, Monroe, & Malle, 2009; Rosset, 2008) but in making moral judgments about wrong-doing they attempt to seek out alternative explanations (Monroe, Reeder, & James, 2015; Uhlmann, Pizarro, & Diermeier, 2015; Woolfolk, Doris, & Darley, 2006).

The paid caregivers reported attempting to reduce undesirable behavior by being "strict", "a task master" and constantly "on" the care receiver in order to mold the care receiver's behavior. Surprisingly, none of the care receivers mentioned these types of interactions with the paid caregivers in any of their multiple interviews. Instead, all care receivers described a warm, respectful relationship with their caregivers. Most dyads experienced some conflict within their relationship during the 6-month period of the study but this conflict did not appear to be rebellion against the caregiver's strictness. This was a very unexpected finding. Like the gentleman quoted earlier in my literature review who was envisioning what it would be like to have a paid caregiver I couldn't imagine " having to deal with somebody telling [me] what to do for the rest of [my] life" (Nichols & Kosciulek, 2014, p. 27). I had not expected that being "strict" or a "task master" would be a positive attribute. There is little in the brain injury literature to explain this finding. Research regarding behavior after brain injury is generally related either to the prevalence of challenging behaviors or the evaluation of behavior management programs; there appears to be little research that has explored perceptions of individuals with brain injury relative to these behavior management programs or techniques. However research in the school setting indicates behavioral compliance is dependent upon whether students view the rules and teacher authority as fair and legitimate (Way, 2011). Since the care receivers in this study appeared to perceive their paid caregivers as caring and well intentioned, the care receivers may have been more accepting of the "strict" caregivers. Additionally it seemed that the care receivers viewed paid caregiver strictness as a sign of caring. In fact when one paid caregiver became less directive, conflict increased within the relationship because the care receiver felt like she was being ignored.

Strictness alone, though, was not the key to a positive relationship between the paid caregiver and care receiver. The paid caregivers described their strictness as being tempered by respect and thoughtfulness in the way they interacted with the care receiver. A paid caregiver described this as "volleying power". Although all care receivers and paid caregivers had unique personalities and relationships, there was a sense of mutual respect and caring between each pair that allowed for "strictness" without rebellion. For example one care receiver shared why she gets angry when her family asks her to do something but does not get angry when her paid caregiver asks her to do the same thing: "because they are condescending and bark it out and [paid caregiver] talks it out with me. My dad is a barker and [paid caregiver] is a discusser."

Looking for meaning

There was a common search for meaning among individuals with brain injury and their caregivers to explain their individual circumstances. All of the caregivers described discovering their current caregiving jobs due to happenstance and all believed that discovering this work was, to some degree, "meant to be" because they had gained skills that they were able to use in other aspects of their lives. Although none of the caregivers appeared to look for meaning in their care recipient's injury, they did all attempt to find meaning in their own work with individuals with brain injury believing that there "was a reason" they became paid caregivers for individuals with brain injury. This type of reasoning has been found to be a prevalent sociocultural belief (Banerjee & Bloom, 2014) and this view that "things happen for a reason" may implicitly impact a paid caregiver's beliefs about the care receiver. Individuals who believe that life events have a deeper meaning are more likely to believe that good events are the result of living a virtuous life while bad events are punishments for prior wrong doing (Banerjee & Bloom, 2014). To be clear -- none of the caregivers implied that divine will was the cause of the care recipient's brain injury but this social cognitive bias has been suggested in recent research with children and adults (Banerjee & Bloom, 2014; Järnefelt, Canfield, & Kelemen, 2015; Kelemen & Rosset, 2009).

The individuals with brain injury were less fatalistic in their perception of their circumstances but most also attempted to find meaning in their brain injury. The search for meaning after an individual undergoes a traumatic event is well documented (Dibb, Ellis-Hill, Donovan-Hall, Burridge, & Rushton, 2014; Holland, Currier, & Neimeyer, 2006; Stiegelis et al., 2003) and it has been suggested that the effort to find meaning in one's adversity is important for cognitive adaptation because it provides a sense of control over life events (Landau, Kay, & Whitson, 2015; Taylor, 1983). However one can also assume that like the paid caregivers, the individuals with brain injury were also likewise influenced by the popular cultural discourse that "things happen for a reason" and so were compelled to find meaning in their injury.

Medical model

Underlying all of these findings is the perception by paid caregivers that individuals with brain injury want to regain "normal" functioning. This view of brain injury is prevalent in the literature. The focus on rectifying impairment in the literature is not surprising when it is understood that much of the research comes from the perspective of brain injury rehabilitation, which is inherently a problem-driven approach. However this medical model stance has also seeped into community based programs.

As a Medicaid waiver program, the ABI waiver automatically situates caregivers and care receivers within the medical model framework and requires the establishment of short-term and long-term goals with regular reporting of progress towards these goals. The caregivers within this study were all classified as Independent Living Skills Trainers (ILSTs). Independent living skills training is defined in Connecticut's ABI Waiver as "a teaching service designed and delivered to an individual or a group to improve an individual's ability to live independently in the community and to carry our strategies developed in cognitive or behavioral programs " (Connecticut Department of Social Services, 2013, p. 15). Therefore the paid caregivers are required to ensure that the care receiver demonstrates increased levels of independence and improved cognition and behavior.

The ABI waiver program is characterized as "person-centered". Person-centered care is defined as care based on the needs of a person rather than on the efficiencies of the care provider, and is care that honors the individual's values, choices and preferences (Daley, 2012). This presents a dilemma for paid caregivers because, on one hand, they are required to increase the care receiver's independence, cognitive, and behavioral functioning, yet, on the other hand, they are asked to do this in a person-centered way. The paid caregivers attempt to integrate these conflicting requirements through providing autonomy as possible as illustrated by the following quote from a paid caregiver:

> What I try to do is to prompt [care receiver] to complete the activities that his health professionals would like to see done, what his mom would like to see done and, if enough time, then allow him free reign to choose what it is he wants to do.

In addition, the paid caregivers suggest to the care receiver that they will be happier if they achieve their goals and are more independent. For example one of the paid caregivers explained the reaction to a care receiver's behavioral incident as "the team and everybody explained to her that you need to just worry about yourself and work on yourself and your goals and move forward" and another paid caregiver concretely stated, "I guide [choice] but offer [choice]".

This approach is echoed in the literature. For instance Van Hooren et al's (2002) study of caregivers working with individuals with Prader-Willi syndrome indicated that complete freedom of choice was never given by caregivers. Instead the caregivers guided discussions with the care receivers so that the care receivers reformulated their goals and aspirations. A similar dynamic was noted by Wullink et. al (2009) in their review of autonomy among people with intellectual disability.

This dichotomy between revering independence and autonomy while at the same time controlling choice is not unique to the ABI waiver program. It is seen throughout medical model contexts. Within the ABI waiver program the professionals are deemed to be those who know "what is best" for the individual. This paternalistic treatment has been noted in assistive living settings (Sheehan & Oakes, 2003), community-based mental health practice

(Campbell & Davidson, 2009), and public health (Wiley, Berman, & Blanke, 2013), and is rationalized based on the need to maintain an individual's safety and well-being.

Paid caregivers and care receivers in the ABI Waiver exist in a context of competing desires. There is the strong desire, promoted by the ABI Waiver program, family members, and the implicit infiltration of the medical model, to change the care receiver so that they conform and function within the narrow category of "normal". On the other hand, care receivers just want to live fulfilling lives. Individuals with brain injuries in our medical and social systems are expected to learn and make progress toward designated goals and are not encouraged to challenge what is expected of them. A paid caregiver's "job" is to teach their charge how to conform to expected societal norms. In their discursive study of the co-construction of identity for individuals who had sustained a severe brain injury, Cloute, Mitchell and Yates (2008) found that the medical model discourse positioned individuals with a brain injury as "patients" and the researchers suggested that this forces individuals who have a brain injury into a dependent role in their relationships with others. We are embedded in a culture that values autonomy and independence -- requiring help automatically categorizes an individual as "lesser". Although caregivers and care receivers developed a fondness for each other, in the end, the relationship was most influenced by the underlying dynamic that one person is considered flawed and the other is their caretaker.

Learning

Clearly the relationship between paid caregivers and care receivers can be understood as highly influenced by the medical model but we can also take one step further back and examine how paid caregivers and care receivers learn within their relationship and the outside forces that shape this learning. Experiential learning theories posit that we learn through experience. Therefore it can be assumed that paid caregivers and care receivers have learned things directly through their experiences with each other. Indeed, when asked if they had learned anything from their paid caregiver, the care receivers reported that they had learned skills such as how to read better, walk straighter, cook new recipes, and interact with people. However for adults many theorists consider reflection to be the key component in experiential learning. For example Kolb (1984) described adult learning as a cycle in which concrete experience is followed by reflection, modification of previous knowledge, and then "testing" of new ideas and concepts. Mezirow (1991) also positions reflection as a critical component for deep "transformative" learning. When the paid caregivers were asked what they learned from working in the ABI Waiver program they shared examples of learning indicative of reflection. The caregivers stated that they learned to have more patience, learned to relax their expectations, and learned to have empathy rather than sympathy for their care receiver. It appears that through reflection the paid caregivers integrated their experiences in working with the care receivers with their past life experiences to arrive at a new way of being in the world.

Although the care receivers did not provide examples of reflective learning when they were directly asked what they had learned, in other parts of their interviews most did show evidence of reflection remarking for instance "I'm not the same person that I was 1 year ago, five years ago . . . I evolved". Another individual talked about how he acts differently when he is with his caregiver than when he is as home because the expectations are different. Therefore it appears that the individuals with brain injury were using reflection as part of their learning.

There is a lack of research regarding the use of adult learning principles with individuals who have a brain injury, instead many programs are based on the assumption that individuals with brain injury require reward-based operant learning strategies in order to learn new skills (Hanley, Iwata, & McCord, 2003; Wood & Alderman, 2011; Ylvisaker et al., 2007). However in this study it appears that the individuals with brain injury, like other adults, have learned from their experiences. Critics of reflection-based learning theories complain that these theories are too narrowly focused on individual learning and do not adequately take into account context and social politics (Fenwick, 2000; Sandlin, Wright, & Clark, 2011). Consequently, while experiential learning theory can be used to explain the conscious perceptions of learning described by the paid caregivers and care receivers it does not fully capture the innate learning that influences the relationship between the paid caregiver and care receiver.

Much of the innate learning about disability and brain injury is rooted in cultural discourse. As Fenwick (2003) points out . . . who we are and how we think about who we are, emerges through our engagement within the practices, discourses, moralities, and institutions that give significance to events in our worlds" (pp. 17-18). One particularly important concept relative to adult learning and adults who have a brain injury is how society defines adulthood. A number of theorists such as Erikson (1968), Piaget (1972), and Levinson (1978) have suggested that development occurs in terms of stages. This view of development has become part of our cultural lexicon (Riediger, Voelkle, Schaefer, & Lindenberger, 2014). Tennant and Pogson (1995) suggest that development is believed to occur when an individual demonstrates growth in qualities that we as a society value, such as becoming more autonomous or better at problem solving, and therefore development can be understood as a social construct.

All of the paid caregivers in this study provided some indication that the care receiver was not viewed as fully adult. Two paid caregivers specifically stated that the care receiver, at times, acted "like a child", another described how some days caregiving felt like "babysitting work," and a fourth paid caregiver described childlike treatment of an individual -- indicating that he had been directed to withhold a daily treat if the care receiver did not comply with what was asked. In addition, the paid caregivers described how they found themselves interacting with the care receiver in a manner similar to how they were treated as children; alluding to the development of a parent/child caregiving relationship.

The Western view of adulthood idealizes independence, strength, control, self-mastery, and struggle (Kudlick, 2003). When an individual cannot meet all the requirements of full adulthood they are assumed to still be childlike and children do not have the same societal rights regarding autonomy and decision-making as adults do. Therefore this implicit learning regarding the definition of adulthood reinforces and condones the paternalism inherent in the medical model resulting in a cycle of justification for erosion of privacy and autonomy for individuals with disability and complicity on behalf of the care receivers who have implicitly learned this same cultural discourse.

Discussion of methodological approach

In this study, in addition to the two semi-structured interviews with each participant, I utilized a modified Ecological Momentary Assessment (EMA). Traditionally EMA studies collect quantitative data asking participants, when cued, to rate self-perceptions of, for example, mood (Kanning & Schlicht, 2010) , cravings (McCarthy, Minami, Yeh, & Bold, 2015), or hunger (Kikuchi et al., 2015) on a Likert-type scale. The advantage of EMA is that it occurs repeatedly in real-time thereby minimizing recall bias and it allows for the study of behavior over time in the participant's natural environment (Shiffman et al., 2008).

Since impaired short term memory is one common consequence of brain injury I believed that EMA would enable the care receivers to fully participate in this study without requiring them to recall what they were doing or feeling at some past point in time. In addition, I believed that modifying the EMA approach by using open-ended questions rather than Likert-scale type questions would allow me to obtain more meaningful data.

During the data collection phase of the study paid caregivers and care receivers were called periodically during the time they were together and asked to respond to a short series of questions. Initially I asked the caregivers to call in to a voice mailbox and record their answers to each of the questions while I was on the phone with the care receiver verbally asking the same questions. However when I reviewed the responses after the initial phone calls it quickly became apparent that the data I was obtaining during the in-person calls with the care receivers was much richer than the data that the paid caregivers were leaving in their voicemail responses. Therefore I began doing the EMA data collection for both the care receivers and the paid caregivers through direct phone contact.

There were some challenges to using this method. Because I called the dyads at random, there were many times that the dyad did not answer the phone because they were not in a location where they could easily speak on the phone or they were engaged in an activity and chose not to answer the phone. In addition, although the participants were instructed that they were supposed to answer their questions in a private location, once I changed the procedure so that I was speaking with each individual directly I suspect that not all the participants had the opportunity to answer the questions in private.

However, I believe that using EMA significantly enhanced my study findings. I gained several insights from using a modified EMA approach in this study. First, it allowed me to see the ebb and flow of the relationship between the paid caregiver and care receiver over time. Second, it provided the individuals with brain injury "voice" throughout the process rather than solely requiring them to recall events that happened at some earlier time. A third insight gained was that EMA enhanced the relationship between the study participants and myself. The repeated phone contact allowed for the development of a sense of familiarity with the participants so that by the time we met for the second face-to-face interview the participants appeared very relaxed and open with me. Finally the EMA data was extremely useful in guiding the development of the questions for the second face-to-face interview and during that interview I was able to use the data previously gathered to assist the care receivers with recalling prior events and feelings. These findings suggest that EMA can be a valuable approach to conducting research with individuals who have a brain injury.

Limitations

This study focused on the relationship between individuals with brain injury and their paid caregivers within the context of Connecticut's Acquired Brain Injury Medicaid Waiver program. Rich data emerged from this qualitative research that may assist in understanding the complexities and dynamics inherent in these relationships however there is no assumption that the findings can be generalized.

This study design required both an individual with brain injury and their caregiver to participate. If either party refused they were unable to participate in study. Therefore my findings may underrepresent dyads in which there is conflict within the dyad and may not reflect the experiences of all paid caregivers and care recipients in the ABI waiver program.

In addition the results of my study may be skewed because all participants in my study received services through Connecticut's ABI Waiver program. This program afforded these individuals the opportunity to interact with others and within the community on a regular basis. Social support and social participation have been found to be a source of life satisfaction for individuals with brain injury (Douglas, 2012; Jones et al., 2010). Therefore my participants' self-reported sense of well-being may be attributed to their participation in the ABI Waiver program.

Recommendations for Future Research

Dynamics between family caregivers and paid caregivers

This study explored the dynamics of the relationship between individuals with brain injury and their paid caregivers, however it became apparent that even in situations where there is a paid caregiver, family caregivers still have a strong role. This is particularly true because even though the paid caregivers were employed by a separate provider agency; the family caregivers were typically understood to be the "employers" of the paid caregiver for a particular case. It is recommended that future researchers examine the perspectives of family caregivers in addition to those of paid caregivers and care receivers in order to develop an understanding of the relationship dynamics between these three parties.

Care receivers' perceptions of behavior management programs

This study found that the caregivers described themselves as being very strict in regard to molding the care receiver's behavior however none of the care receivers remarked on this and, in fact, seemed to perceive this attention as a sign of caring. While there have been studies that have evaluated the effectiveness of behavioral intervention strategies with individuals with brain injuries there has been little attention paid to the perceptions of individuals with brain injury regarding these interventions. Further study regarding care receiver's perceptions of behavioral programming as well as their perceptions of the caregivers who conduct these behavioral interventions is warranted.

Life satisfaction

Another unanticipated finding was the perception by both the paid caregivers and the care receivers that while they felt good about themself on most days, they were less certain if this was true of their partner. This was an interesting finding in light of the quantitative studies that typically find a decrease in life satisfaction after brain injury as well as the perception among some of the care receivers that their paid caregivers were not satisfied with their lives.

Implications for Practice and Recommendations

This study revealed the micro and macro systems that affected the beliefs and day-to-day interactions between individuals with brain injury and their paid caregivers. There were a number of areas of divergence amongst the perceptions of the paid caregivers and care receivers. First, both the paid caregivers and care receivers believed that the brain injury impaired the care receiver's functional abilities and changed their life, but the individuals with brain injury perceived the brain injury only as an event in their lives, not a defining characteristic of who they are whereas the caregivers believed the results of the brain injury were the central aspect of the care receiver's life. Another conflicting perception was in relation to the role of the paid caregiver. The care receivers perceived that the role of the paid caregiver was as their helper whereas the paid caregivers believed that it was their role to promote progress towards social norms and independent functioning. At times these differences led to conflict within the relationship, particularly when the caregiver or care receiver felt like their trust in their partner was betrayed. However typically, in spite of these differing perspectives, the relationship between the caregiver and care receivers was one of respect and caring.

Though this data is specific to paid caregivers and care receivers within Connecticut's ABI Waiver program my findings suggest that there is a constant interplay between micro-level and macro-level beliefs. The care receivers' experience of living with a brain injury and the paid caregivers' experiences are unique to each individual but each has been shaped by larger cultural forces.

Snyder and Mitchell (2006) have suggested that because individuals with disabilities are subjected to the same medical model discourse as the rest of society, "client-centered care", in which individuals with disabilities are asked about their goals may not really capture the factors that would lead to long-term life satisfaction. I concur with this suggestion.   An approach to community supports for individuals with brain injury is needed that recognizes that independence may not be the best measure of community reintegration. The individuals with brain injury in the ABI waiver program may be better served by an approach that focuses on quality of life rather than progress toward independence. Doble and Santha (2008) have suggested that one way of conceptualizing life satisfaction is through examining components of what they term "occupational well-being". Doble and Santha (2008) posit that individuals experience occupational well-being when they are able to choose and engage in activities that meet their needs for accomplishment, affirmation, agency, coherence, companionship, pleasure and renewal. Accomplishment is experienced when an individual masters or perceives progress in the performance of a meaningful activity, produces a tangible outcome, or helps others. Affirmation may be external or self-generated but in either situation, contributes to an individual's sense of self-worth. Agency occurs when an individual has a sense of control over the activities they engage in and how, when, where, how often, and with whom they participate in these activities. When an individual feels a connection between their past, present and future activities they experience coherence. The need for companionship is met when individuals share common experiences, interests, values, and goals with others in a social context. Pleasure includes contentment, happiness and joy that occurs as the result of participation in activity. Finally, renewal is the sense of mental and physical rejuvenation that exists when individuals are able to deeply engage in meaningful activity. I believe that these constructs may serve as more helpful measures of outcomes in the ABI Waiver program.

I believe the aim of community supports should be to promote an individual's quality of life. If the goal is quality of life, what would the relationship between paid caregiver and care receiver look like? From the outside it might look very similar to the existing relationships seen in this study. Paid caregivers and care receivers might go to the gym, go to the library, work on tasks, and participate in leisure and household activities. However the learning that occurs within the relationship will become different. Rather than caregivers being responsible to "fix" the individual with brain injury they would assist the care receiver in negotiating the social and cultural institutions in which they live. With this as the goal paid caregivers would become the helpers that the care receivers envision and caregivers can help the care receivers to change their lives without necessitating changing who they are.

References

Ahmadi, N. S., Månsson, J., Lindblad, U., & Hildingh, C. (2014). Breathlessness in everyday life from a patient perspective: A qualitative study using diaries. *Palliative & Supportive Care*, *12*(3), 189–194. doi:http://dx.doi.org/10.1017/S1478951512001095

Aldiabat, K. M., & Le Navenec, C.-L. (2011). Philosophical Roots of Classical Grounded Theory: Its Foundations in Symbolic Interactionism. *Qualitative Report*, *16*(4), 1063–1080. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=sih&AN=67335012&site=ehost-live&scope=site

Altman, I., & Taylor, D. (1973). *Social penetration: The development of interpersonal relationships*. New York, NY: Holt.

American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain & process (2nd ed.). *American Journal of Occupational Therapy*, *62*, 625–683.

American Occupational Therapy Association. (2014). About occupational therapy. Retrieved from http://www.aota.org/About-Occupational-Therapy.aspx

American Psychiatric Association DSM-5 Task Force. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Washington, D.C.: American Psychiatric Association.

Anderson, S. L., & Lehman, S. S. (2014). Treating the visual consequences of traumatic brain injury. *OT Practice*, *19*(20), 7–11. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://search.proquest.com/docview/16263

57696?accountid=13381

Ashman, T. A., Gordon, W. A., Cantor, J. B., & Hibbard, M. R. (2006). Neurobehavioral consequences of traumatic brain injury. *Mount Sinai Journal of Medicine*, *73*(7), 999–1005. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=aph&AN=23913439&site=eds-live

Banerjee, K., & Bloom, P. (2014). Why did this happen to me? Religious believers' and non-believers' teleological reasoning about life events. *Cognition*, *133*(1), 277–303. doi:http://dx.doi.org/10.1016/j.cognition.2014.06.017

Bates, L., & Stickley, T. (2013). Confronting Goffman: How can mental health nurses effectively challenge stigma? A critical review of the literature. *Journal of Psychiatric and Mental Health Nursing*, *20*(7), 569–575. doi:10.1111/j.1365-2850.2012.01957.x

Bender, A., Bauch, S., & Grill, E. (2013). Efficacy of a post-acute interval inpatient neurorehabilitation programme for severe brain injury. *Brain Injury*, *28*(1), 44–50. doi:10.3109/02699052.2013.850177

Bickenbach, J. E. (1993). *Physical disability and social policy*. Toronto, Canada: University of Toronto.

Bigler, E. D. (2013). Traumatic brain injury, neuroimaging, and neurodegeneration. *Frontiers in Human Neuroscience*, *7*, 395. doi:10.3389/fnhum.2013.00395

Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. (U. of C. Press, Ed.). Berkeley, CA.

Boake, C., & Diller, L. (2005). History of rehabilitation for traumatic brain injury. In W. M. High, A. M. Sander, & M. A. Struchen (Eds.), *Rehabilitation for traumatic brain injury* (pp. 3–13). New York, NY: Oxford University Press.

Boycott, N., Yeoman, P., & Vesey, P. (2013). Factors associated with strain in carers of people with traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *28*(2), 106–115.

Brain Injury Association of America. (2012). About brain injury. Retrieved from http://www.biausa.org/about-brain-injury.htm

Brain Injury Association of America. (2014). Media center. Retrieved from http://www.biausa.org/bia-media-center.htm

Breckenridge, J., & Jones, D. (2009). Demystifying theoretical sampling in grounded theory research. *Grounded Theory Review*, *2*(8).

Brookfield, S. (2012). Critical theory and transformative learning. In E. W. Taylor, P. Cranton, & Associates (Eds.), *The handbook of transformative learning* (pp. 131–146). San Francisco, CA: Jossey-Bass.

Brundage, S. B., Bowers, M. L., Garcia-Barry, S. K., & Schierts, M. M. (2006). An analysis of clinicians' verbal behaviors in a community reintegration program for traumatic brain injury survivors. *Journal of Allied Health*, *35*(2), 81–88.

Burbank, P. M., & Martins, D. C. (2010). Symbolic interactionism and critical perspective: divergent or synergistic? *Nursing Philosophy*, *11*(1), 25–41. doi:10.1111/j.1466-769X.2009.00421.x

Bylund, C. L., Peterson, E. B., & Cameron, K. A. (2012). A practitioner's guide to interpersonal communication theory: An overview and exploration of selected theories. *Patient Education and Counseling*, *87*, 261–267.

Campbell, J., & Davidson, G. (2009). Coercion in the community: A situated approach to the examination of ethical challenges for mental health social workers. *Ethics and Social Welfare*, *3*(3), 249–263. doi:10.1080/17496530903209469

Capitanio, J. P. (2008). Personality and disease. *Brain, Behavior, and Immunity*, *22*(5), 647–650. doi:http://dx.doi.org/10.1016/j.bbi.2008.02.002

Carroll, E., & Coetzer, R. (2011). Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological Rehabilitation*, *21*(3), 289–305. doi:10.1080/09602011.2011.555972

CDC Division for Heart Disease and Stroke Prevention. (2014). Stroke fact sheet. *Data and Statistics*. Retrieved from http://www.cdc.gov/dhdsp/data_statistics/fact_sheets/fs_stroke.htm

Centers for Disease Control and Prevention. (2014). Traumatic brain injury in the United States: Fact sheet. *CDC Injury Center: Get the Facts*. Retrieved from http://www.cdc.gov/traumaticbraininjury/get_the_facts.html

Centers for Medicare and Medicaid Services. (n.d.). 1915(c) Home and community-based waivers. *Medicaid.gov*. Retrieved from http://www.medicaid.gov/medicaid-chip-program-information/by-topics/waivers/home-and-community-based-1915-c-waivers.html

Chan, V., Zagorski, B., Parsons, D., & Colantonio, A. (2013). Older adults with acquired brain injury: Outcomes after inpatient rehabilitation. *Canadian Journal on Aging*, *32*(3), 278–286.

Chapparo, C., & Shepherd, B. (2010). When work happens in the house: Perceptions of how residential care staff choose to spend work time in transitional living units for people with brain injury. *Work*, *36*(2), 239–247. doi:10.3233/WOR-2010-1024

Charmaz, K. (1990). Constructivist and objectivist grounded theory. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 509–535). Thousand Oaks, CA: Sage Publications.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage Publications.

Charmaz, K. (2015). Progressing with grounded theory. University of North Carolina, Chapel Hill: Qualitative Research Summer Intensive.

Charon, J. M. (2010). *Symbolic interactionism* (10th ed.). Boston, MA: Prentice Hall.

Chen, Z., & Williams, K. D. (2012). Imagined future social pain hurts more now than imagined future physical pain. *European Journal of Social Psychology*, *42*(3), 314–317. doi:10.1002/ejsp.1861

Cloute, K., Mitchell, A., & Yates, P. (2008). Traumatic brain injury and the construction of identity: A discursive approach. *Neuropsychological Rehabilitation*, *18*(5-6), 651–670. doi:10.1080/09602010701306989

Connecticut Department of Social Services. (2013). Acquired brain injury waiver program. State of Connecticut. Retrieved from http://www.ct.gov/dss/lib/dss/pdfs/abi/abiwaiverregs.pdf

Corbin, J. A., & Strauss, A. L. (2015). *Basics of qualitative research* (4th ed.). Thousand Oaks, CA: Sage Publications.

Corrigan, J. D. (1994). Community integration following traumatic brain injury. *NeuroRehabilitation*, *4*, 109–121.

Corrigan, J. D., Cuthbert, J. P., Harrison-Felix, C., Whiteneck, G. G., Bell, J. M., Miller, A. C., … Pretz, C. R. (2014). US population estimates of health and social outcomes 5 years after rehabilitation for traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *29*(6), E1–E9.

Corrigan, P. W., River, L. P., Lundin, R. K., Penn, D. L., Uphoff-Wasowski, K., Campion, J., … Kubiak, M. A. (2001). Three strategies for changing attributions about severe mental illness. *Schizophrenia Bulletin*, *27*(2), 187–195. Retrieved from http://schizophreniabulletin.oxfordjournals.org/content/27/2/187.abstract

Creswell, J. W. (2007). *Qualitative inquiry & research design* (2nd ed.). Thousand Oaks, CA: Sage Publications Ltd.

Csikszentmihalyi, M., & Csikszentmihalyi, I. S. (Eds.). (1988). *Optimal experience: Psychological studies of flow in consciousness*. New York: Cambridge University Press.

Cummins, S., Curtis, S., Diez-Roux, A., & Macintyre, S. (2007). Understanding and representing "place" in health research: A relational approach. *Social Science & Medicine*, *65*(9), 1825–1838.

Curran, C., Dorstyn, D., Polychronis, C., & Denson, L. (2014). Functional outcomes of community-based brain injury rehabilitation clients. *Brain Injury*, *29*(1), 25–32. doi:10.3109/02699052.2014.948067

Daley, K. A. (2012). Person-centered care - What does it actually mean? *American Nurse*, *44*(6), 3. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=2012247773&site=ehost-live&scope=site

Demery, J. A., Larson, M. J., Dixit, N. K., Bauer, R. M., & Perlstein, W. M. (2010). Operating characteristics of executive functioning tests following traumatic brain injury. *The Clinical Neuropsychologist*, *24*(8), 1292–1308. doi:10.1080/13854046.2010.528452

Dennis, A., & Martin, P. J. (2005). Symbolic interactionism and the concept of power. *The British Journal of Sociology*, *56*(2), 191–213. doi:10.1111/j.1468-4446.2005.00055.x

Denzin, N. K., & Lincoln, Y. S. (2005). Introduction: The discipline and practice of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 1–32). Thousand Oaks, CA: Sage Publications.

Department of Health and Human Services. (2002). *Delivering on the promise: U.S. Department of Health and Human Services self-evaluation to promote community living for people with disabilities. Report to the President on Executive Order 13217*.

Dewey, J. (1916). *Democracy and education*. New York, NY: Macmillan.

Dibb, B., Ellis-Hill, C., Donovan-Hall, M., Burridge, J., & Rushton, D. (2014). Exploring positive adjustment in people with spinal cord injury. *Journal of Health Psychology* , *19* (8), 1043–1054. Retrieved from http://hpq.sagepub.com/content/19/8/1043.abstract

Dikmen, S. S., Corrigan, J. D., Levin, H. S., Machamer, J., Stiers, W., & Weisskopf, M. G. (2009). Cognitive outcome following traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *24*(6), 430–438.

Dillard, J. P. (1990). A goal-driven model of interpersonal influence. In J. P. Dillard (Ed.), *Seeking compliance: The production of interpersonal influence messages* (pp. 41–56). Scottsdale, AZ: Gorsuch Scarisbrick.

Doble, S. E., & Santha, J. C. (2008). Occupational well-being: Rethinking occupational therapy outcomes. *Canadian Journal of Occupational Therapy*, *75*(3), 184–190.

Doering, B. K., Conrad, N., Rief, W., & Exner, C. (2010). Living with acquired brain injury: Self-concept as mediating variable in the adjustment process. *Neuropsychological Rehabilitation*, *21*(1), 42–63. doi:10.1080/09602011.2010.525947

Doig, E., Fleming, J., & Tooth, L. (2001). Patterns of community integration 2-5 years post-discharge from brain injury rehabilitation. *Brain Injury*, *15*(9), 747–762. doi:10.1080/02699050119845

Douglas, J. M. (2012). *A social cure: Identity, health and well being*. (J. Jetten, C. Haslam, & A. S. Haslam, Eds.). New York, NY: Psychology Press.

Dubouloz, C.-J., King, J., Paterson, B., Ashe, B., Chevrier, J., & Moldoveanu, M. (2010). A model of the process of transformation in primary care for people living with chronic illnesses. *Chronic Illness* , *6* (4), 282–293. doi:10.1177/1742395310383340

Dubouloz, C.-J., Vallerand, J., Laporte, D., Ashe, B., & Hall, M. (2008). Occupational performance modification and personal change among clients receiving rehabilitation services for rheumatoid arthritis. *Australian Occupational Therapy Journal*, *55*(1), 30–

38. doi:10.1111/j.1440-1630.2006.00639.x

Eiken, S., Sredl, K., Gold, L., Kasten, J., Burwell, B., & Saucier, P. (2014). Medicaid expenditures for long-term services and supports in FFY 2012. *Medicaid.gov*.

Erikson, E. H. (1968). *Identity and the life cycle: Selected papers*. New York, NY: International Universities Press.

Ernst, W. J., Trice, A. D., Gilbert, J. L., & Potts, H. (2009). Misconceptions about traumatic brain injury and recovery among nursing students. *Journal of Head Trauma Rehabilitation*, *24*(3), 213–220.

Fenwick, T. (2010). Workplace learning: Emerging trends and new perspectives. In S. B. Merriam (Ed.), *Third update on adult learning theory : New directions for adult and continuing education, Number 119* (3rd ed.). http://www.interscience.wiley.com: Wiley. Retrieved from http://www.interscience.wiley.com

Fenwick, T. J. (2000). Expanding conceptions of experiential learning: A review of the five contemporary perspectives on cognition. *Adult Education Quarterly*, *50*(4), 243–272. Retrieved from http://aeq.sagepub.com/content/50/4/243.abstract

Fenwick, T. J. (2003). *Learning through experience: Troubling orthodoxies and intersecting questions*. Malabar, FL: Krieger Publishing Company.

Fine, M., & Weis, L. (2005). Compositional studies, in two parts. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (third., pp. 65–84). Thousand Oaks, CA: Sage Publications.

Fleming, J., Riley, L., Gill, H., Gullo, M. J., Strong, J., & Shum, D. (2008). Predictors of prospective memory in adults with traumatic brain injury. *Journal of the International Neuropsychological Society : JINS*, *14*(5), 823–831. doi:http://dx.doi.org/10.1017/S1355617708080971

Fowler, M., & McCabe, P. C. (2011). Traumatic brain injury and personality change. *National Association of School Psychologists. Communique*, *39*(7), 4–10. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://search.proquest.com/docview/867665184?accountid=13381

Gantert, T. W., McWilliam, C. L., Ward-Griffin, C., & Allen, N. J. (2008). The key to me: Seniors' perceptions of relationship-building with in-home service providers. *Canadian Journal on Aging*, *27*(1), 23–34.

Gelech, J. M., & Desjardins, M. (2011). I am many: The reconstruction of self following acquired brain injury. *Qualitative Health Research*, *21*(1), 62–74. doi:10.1177/1049732310377454

Gentleman, D. (2001). Rehabilitation after traumatic brain injury. *Trauma* , *3* (4), 193–204. doi:10.1177/146040860100300401

Gergen, K. J. (2009). *Relational being: Beyond self and community*. New York, NY: Oxford University Press.

Gibson, B. E., Secker, B., Rolfe, D., Wagner, F., Parke, B., & Mistry, B. (2012). Disability and dignity-enabling home environments. *Social Science & Medicine*, *74*(2), 211–219. doi:http://dx.doi.org/10.1016/j.socscimed.2011.10.006

Giles, H. (2008). Communication accomodation theory. In L. A. Baxter & D. O. Braithwaite

(Eds.), *Engaging theories in interpersonal communication: Multiple perspectives* (pp. 161–173). Los Angeles, CA: Sage Publications.

Glaser, B. (2007). All is data. *The Grounded Theory Review*, *6*(2), 1–22.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory*. Chicago, IL: Aldine Publishing Company.

Goodley, D. (2013). Dis/entangling critical disability studies. *Disability & Society*, *28*(5), 631–644. doi:10.1080/09687599.2012.717884

Gouick, J., & Gentleman, D. (2004). The emotional and behavioural consequences of traumatic brain injury. *Trauma*, *6*(4), 285–292. doi:http://dx.doi.org/10.1191/1460408604ta323oa

Grue, J. (2011). Discourse analysis and disability: Some topics and issues. *Discourse & Society* , *22* (5), 532–546. doi:10.1177/0957926511405572

Gruen, R. L., Hawthorne, G., & Kaye, A. H. (2009). Traumatic brain injury and long-term quality of life: Findings from an Australian study. *Journal of Neurotrauma*, *26*, 1623+. Retrieved from http://go.galegroup.com/ps/i.do?id=GALE|A211707675&v=2.1&u=a13qu&it=r&p=HRCA&sw=w&asid=75e56e0ac83adb75d80931d796fa475e

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In E. G. Guba & L. Y. S. (Eds.), *Handbook of qualitative research* (pp. 105–117). Thousand Oaks, CA: Sage Publications.

Guglielmo, S., Monroe, A. E., & Malle, B. F. (2009). At the heart of morality lies folk psychology. *Inquiry*, *52*(5), 449–466. doi:10.1080/00201740903302600

Gynnild, A. (2011). Book review: Grounded theory: A practical guide (Birks & Mills, 2011). *Grounded Theory Review*, *10*(3).

Hanley, G. P., Iwata, B. A., & McCord, B. E. (2003). Functional analysis of problem behavior: A review. *Journal of Applied Behavior Analysis*, *36*(2), 147–185. doi:10.1901/jaba.2003.36-147

Harrell, P. T., Epstein, D. H., & Preston, K. L. (2014). Place and drug craving: An ecological momentary assessment study. *Drug and Alcohol Dependence*, *140*(0), e80. doi:http://dx.doi.org/10.1016/j.drugalcdep.2014.02.237

Herron, L., Turner, J. A., Ersek, M., & Weiner, P. (1992). Does the Millon Behavioral Health Inventory (MBHI) predict lumbar laminectomy outcome? A comparison with the Minnesota Multiphasic Personality Inventory (MMPI). *Journal of Spinal Disorders*, *5*(2), 188–192.

Heslin, K. C., Singzon, T., Aimiuwu, O., Sheridan, D., & Hamilton, A. (2012). From personal tragedy to personal challenge: Responses to stigma among sober living home residents and operators. *Sociology of Health & Illness*, *34*(3), 379–395. doi:10.1111/j.1467-9566.2011.01376.x

Holland, J. M., Currier, J. M., & Neimeyer, R. A. (2006). Meaning reconstruction in the first two years of bereavement: The role of sense-making and benefit-finding. *Omega: Journal of Death & Dying*, *53*(3), 175–191. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=tfh&AN=22848184&site=eds-live

Holroyd, K. A., & Coyne, J. (1987). Personality and health in the 1980s: Psychosomatic medicine revisited? *Journal of Personality*, *55*(2), 359–375. Retrieved from 10.1111/1467-6494.ep8970768

Hooper, S. R. (2006). Myths and misconceptions about traumatic brain injury: Endorsements by school psychologists. *Exceptionality*, *14*(3), 171–182. doi:10.1207/s15327035ex1403_5

Hooren, R. H. van, Widdershoven, G. A. M., Borne, H. W. van den, & Curfs, L. M. G. (2002). Autonomy and intellectual disability: The case of prevention of obesity in Prader–Willi syndrome. *Journal of Intellectual Disability Research*, *46*(7), 560–568. doi:10.1046/j.1365-2788.2002.00426.x

Hornbostel, R. (2005). The realpolitik of deinstitutionalizing long-term care: Olmstead meets reality. *Ethics, Law and Aging Review*, *11*, 43–56. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://search.proquest.com/docview/205268371?accountid=13381

Hux, K., Bush, E., Evans, K., & Simanek, G. (2013). Misconceptions about traumatic brain injury among students preparing to be special education professionals. *Support for Learning*, *28*(3), 109–114. doi:10.1111/1467-9604.12028

Hux, K., Schram, C. D., & Goeken, T. (2006). Misconceptions about brain injury: A survey replication study. *Brain Injury*, *20*(5), 547–553. Retrieved from 10.1080/02699050600676784

Järnefelt, E., Canfield, C. F., & Kelemen, D. (2015). The divided mind of a disbeliever: Intuitive beliefs about nature as purposefully created among different groups of nonreligious adults. *Cognition*, *140*, 72–88. doi:http://dx.doi.org/10.1016/j.cognition.2015.02.005

Jones, J. M., Haslam, S. A., Jetten, J., Williams, W. H., Morris, R., & Saroyan, S. (2010). That which doesn't kill us can make us stronger (and more satisfied with life): The contribution of personal and social changes to well-being after acquired brain injury. *Psychology & Health*, *26*(3), 353–369. doi:10.1080/08870440903440699

Jumisko, E., Lexell, J., & Soderberg, S. (2005). The meaning of living with traumatic brain injury in people with moderate or severe traumatic brain injury. *Journal of Neuroscience Nursing*, *37*(1), 42–50.

Kaiser Family Foundation. (2012). Distribution of Medicaid spending on long term care. *State Health Facts*. Retrieved from http://kff.org/medicaid/state-indicator/spending-on-long-term-care/

Kanning, M., & Schlicht, W. (2010). Be active and become happy: An ecological momentary assessment of physical activity and mood. *Journal of Sport & Exercise Psychology*, *32*(2), 253–261. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=s3h&AN=49040370&site=ehost-live&scope=site

Kelemen, D., & Rosset, E. (2009). The human function compunction: Teleological explanation in adults. *Cognition*, *111*(1), 138–143. doi:http://dx.doi.org/10.1016/j.cognition.2009.01.001

Kessler, D., Dubouloz, C.-J., Urbanowski, R., & Egan, M. (2009). Meaning perspective transformation following stroke: The process of change. *Disability and Rehabilitation*, *31*(13), 1056–1065. doi:10.1080/09638280802509512

Kikuchi, H., Yoshiuchi, K., Inada, S., Ando, T., & Yamamoto, Y. (2015). Development of an ecological momentary assessment scale for appetite. *BioPsychoSocial Medicine*, *9*. doi:http://dx.doi.org/10.1186/s13030-014-0029-6

Kitchenham, A. (2008). The evolution of John Mezirow's Transformative Learning Theory. *Journal of Transformative Education*, *6*(2).

Klein, A.-M., Howell, K., Vogler, J., Grill, E., Straube, A., & Bender, A. (2013). Rehabilitation outcome of unconscious traumatic brain injury patients. *Journal of Neurotrauma*, *30*(17), 1476–1483. doi:http://dx.doi.org/10.1089/neu.2012.2735

Kolb, D. (1984). The process of experiential learning. In *Experiential learning: experience as the source of learning and development* (pp. 20–38). Englewood Cliffs, NJ: Prentice Hall.

Kolb, D. A. (1976). *The learning style inventory*. Boston, MA: McBer.

Konrad, C., Geburek, A. J., Rist, F., Blumenroth, H., Fischer, B., Husstedt, I., … Lohmann, H. (2011). Long-term cognitive and emotional consequences of mild traumatic brain injury. *Psychological Medicine*, *41*(6), 1197–1211. doi:http://dx.doi.org/10.1017/S0033291710001728

Kudlick, C. J. (2003). Disability history: Why we need another "Other." *The American Historical Review*, *108*(3), 763–793 CR – Copyright © 2003 American Histor. doi:10.1086/529597

Lagace, M., Tanguay, A., Lavallee, M., Laplante, J., & Robichaud, S. (2012). The silent impact of ageist communication in long term care facilities: Elders perspectives on quality of life and coping strategies. *Journal of Aging Studies*, *26*(3), 335–342.

Lakoff, G., & Johnson, M. (1980). *Metaphors we live by*. Chicago, IL: University of Chicago Press.

Landau, M. J., Kay, A. C., & Whitson, J. A. (2015). Compensatory control and the appeal of a structured world. *Psychological Bulletin*, *141*(3), 694–722. doi:10.1037/a0038703

Levack, W. M. M., Boland, P., Taylor, W. J., Siegert, R. J., Kayes, N. M., Fadyl, J. K., & McPherson, K. M. (2014). Establishing a person-centred framework of self-identity after traumatic brain injury: A grounded theory study to inform measure development. *BMJ Open*, *4*(5). doi:10.1136/bmjopen-2013-004630

Levinson, D. J., Darrow, C. N., Klein, E. B., Levinson, M. H., & McKee, B. (1978). *The seasons of a man's life*. New York, NY: Ballantine.

Linden, M. A., & Redpath, S. J. (2011). A comparative study of nursing attitudes towards young male survivors of brain injury: A questionnaire survey. *International Journal of Nursing Studies*, *48*(1), 62–69. doi:http://dx.doi.org/10.1016/j.ijnurstu.2010.05.011

Linder, J. (2000). Does personality or psychopathology predict disability in chronic pain patients? *Disability and Rehabilitation*, *22*(6), 281–287. doi:10.1080/096382800296746

Mahar, C., & Fraser, K. (2012a). Barriers to successful community reintegration following acquired brain injury (ABI). *International Journal of Disability Management*, *6*, 49–67.

Mahar, C., & Fraser, K. (2012b). Strategies to facilitate successful community reintegration following acquired brain injury (ABI). *International Journal of Disability Management*, *6*, 68–78.

Marsh, N. V., Kersel, D. A., Havill, J. H., & Sleigh, J. W. (1998). Caregiver burden at 1 year following severe traumatic brain injury. *Brain Injury*, *12*(12), 1045–1059. doi:10.1080/026990598121954

Marsick, V. J., & Watkins, K. E. (2001). Informal and incidental learning. *New Directions for Adult and Continuing Education*, *2001*(89), 25–34. doi:10.1002/ace.5

Martin, C. E., Johnson, E., Wechter, M. E., Leserman, J., & Zolnoun, D. A. (2011). Catastrophizing: A predictor of persistent pain among women with endometriosis at 1 year. *Human Reproduction*, *26*(11), 3078–3084. doi:10.1093/humrep/der292

Matchless Transcription. (n.d.). FAQ. *Matchless Transcription*. Retrieved January 31, 2015, from http://matchlesstranscription.com/faq/

Matsuda, S. J., Clark, M. J., Schopp, L. H., Hagglund, K. J., & Mokelke, E. K. (2005). Barriers and satisfaction associated with personal assistance services: Results of consumer and personal assistant focus groups. *OTJR*, *25*(2), 66–74. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://search.proquest.com/docview/220300629?accountid=13381

McCann, T. V., & Baker, H. (2001). Mutual relating: Developing interpersonal relationships in the community. *Journal of Advanced Nursing*, *34*(4), 530–537.

McCarthy, D. E., Minami, H., Yeh, V. M., & Bold, K. W. (2015). An experimental investigation of reactivity to ecological momentary assessment frequency among adults trying to quit smoking. *Addiction*, *110*(10), 1549–1560. doi:10.1111/add.12996

McColl, M. A., Carlson, P., Johnston, J., Minnes, P., Shue, K., Davies, D., & Karlovits, T. (1998). The definition of community integration: Perspectives of people with brain injuries. *Brain Injury*, *12*(1), 15–30. doi:10.1080/026990598122827

McKinney, M., Mcllvain, H. E., Hofschire, P. J., Collins, R. E., Somers, J. A., Ruddel, H., … Eliot, R. S. (1987). Cardiovascular changes during mental stress: Correlations with presence of coronary risk factors and cardiovascular disease in physicians and dentists. *Journal of Human Hypertension*, *1*(2), 137.

Mead, G. H. (1934). *Mind, self, and society*. Chicago, IL: University of Chicago Press.

Merriam, S. B., & Bierema, L. L. (2014). *Adult learning: Linking theory and practice*. San Francisco, CA: Jossey-Bass.

Merriam, S. B., Caffarella, R. C., & Baumgartner, L. M. (2007). *Learning in adulthood*. San Francisco, CA: Jossey-Bass.

Mezirow, J. (1991). *Transformative dimensions of adult learning*. San Francisco, CA: Jossey-Bass.

Mezirow, J. (2009). Transformative learning theory. In J. Mezirow, E. Taylor, & Associates (Eds.), *Transformative learning in practice* (pp. 18 –32). San Francisco, CA: Jossey-Bass.

Millis, C., Rosenthal, M., Novack, T. A., Sherer, M., Nick, T., Kruetzer, J. S., … Ricker, J. (2001). Long-term neuropsychological outcome after traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *16*(4), 343–355.

Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods*, *5*(1), 1–10.

Minnes, P., Harrick, L., Carlson, P., & Johnston, J. (1998). A transitional living environment for persons with brain injuries: Staff and client perceptions. *Brain Injury*, *12*(11), 987–992. doi:10.1080/026990598122034

Mintz, S. B. (2002). Invisible disability: Georgina Kleege's sight unseen. *National Women's Studies Association Journal*, *14*(3), 155–177.

Mollayeva, T., Kendzerska, T., Mollayeva, S., Shapiro, C. M., Colantonio, A., & Cassidy, J. D. (2014). A systematic review of fatigue in patients with traumatic brain injury: The course, predictors and consequences. *Neuroscience & Biobehavioral Reviews*, *47*(0), 684–716. doi:http://dx.doi.org/10.1016/j.neubiorev.2014.10.024

Monroe, A. E., Reeder, G. D., & James, L. (2015). Perceptions of intentionality for goal-related action: Behavioral description matters. *PLoS One*, *10*(3). doi:10.1371/journal.pone.0119841

Murdock, S. (2013, July 26). North Carolina eugenics: Sterilization program victims offered funds. *Huffington Post*. Retrieved from http://www.huffingtonpost.com/2013/07/26/north-carolina-eugenics-sterilization-victims-offered-funds_n_3657982.html

My Place CT. (2014). Connecticut Medicaid program. Retrieved from http://www.myplacect.org/

National Alliance for Caregiving. (2009). *Caregiving in the U.S.* Retrieved from http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf

Nichols, J. L., & Kosciulek, J. (2014). Social interactions of individuals with traumatic brain injury. *Journal of Rehabilitation*, *80*(2), 21–29.

Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science & Medicine*, *51*(12), 1795–1804. doi:http://dx.doi.org/10.1016/S0277-9536(00)00111-8

Novack, T. A., Bergquist, T. F., Bennett, G., & Gouvier, W. D. (1991). Primary caregiver distress following severe head injury. *Journal of Head Trauma Rehabilitation*, *6*(4), 69–77.

O'Day, B., & Killeen, M. (2002). Research on the lives of persons with disabilities: The emerging importance of qualitative research methodologies. *Journal of Disability Policy Studies*, *13*(1), 9–15. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://search.proquest.com/docview/211250454?accountid=13381

Oudshoorn, A., Ward-Griffin, C., & McWilliam, C. (2007). Client-nurse relationships in home-based pallitive care: A critical analysis of power relations. *Journal of Clinical Nursing*, *16*, 1435–1443.

Papastavrou, E., Efstathiou, G., & Charalambous, A. (2011). Nurses' and patients' perceptions of caring behaviours: Quantitative systematic review of comparative studies. *Journal of Advanced Nursing*, *67*(6), 1191–1205. doi:10.1111/j.1365-2648.2010.05580.x

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage Publications.

Perlesz, A., Kinsella, G., & Crowe, S. (2000). Psychological distress and family satisfaction following traumatic brain injury: Injured individuals and their primary, secondary, and tertiary carers. *Journal of Head Trauma Rehabilitation*, *15*(3), 909–929.

Peterson, M., & Greenwald, B. D. (2015). Balance problems after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, *96*(2), 379–380. doi:http://dx.doi.org/10.1016/j.apmr.2013.06.012

Petrella, L., McColl, M. A., Krupa, T., & Johnston, J. (2005). Returning to productive activities: Perspectives of individuals with long-standing acquired brain injuries. *Brain Injury*, *19*(9), 643–655.

Phelan, J. C., Lucas, J. W., Ridgeway, C. L., & Taylor, C. J. (2014). Stigma, status, and population health. *Social Science & Medicine*, *103*(0), 15–23. doi:http://dx.doi.org/10.1016/j.socscimed.2013.10.004

Piaget, J. (1972). Intellectual development from adolescence to adulthood. *Human Development*, *15*, 1–12.

Plowman, L., & Stevenson, O. (2012). Using mobile phone diaries to explore children's everyday lives. *Childhood*, *19*(4), 539–553.

Ponsford, J., Sloan, S., & Snow, P. (2012). *Traumatic brain injury: Rehabilitation for everyday adaptive living* (2nd ed.). Taylor & Francis.

Poppleton, S., Briner, R. B., & Kiefer, T. (2008). The roles of context and everyday experience in understanding work-non-work relationships: A qualitative diary study of white- and blue-collar workers. *Journal of Occupational and Organizational Psychology*, *81*(3), 481–502. doi:10.1348/096317908X295182

Pryor, J., & O'Connell, B. (2009). Incongruence between nurses' and patients' understandings and expectations of rehabilitation. *Journal of Clinical Nursing*, *18*(12), 1766–1774. doi:10.1111/j.1365-2702.2008.02322.x

Ralston, D. C., & Ho, J. (2010). Introduction: Philosophical reflections on disability. In D. C. Ralston & J. Ho (Eds.), *Philosophical reflections on disability*. New York, NY: Springer.

Reinhardt, G. Y. (2015). Imagining worse than reality: Comparing beliefs and intentions between disaster evacuees and survey respondents. *Journal of Risk Research*, 1–26. doi:10.1080/13669877.2015.1017827

Riddell, S., & Watson, N. (2014). Disability, culture and identity: Introduction. In S. Riddell & N. Watson (Eds.), *Disability, culture and identity* (2nd ed., pp. 1–16). New York, NY: Routledge.

Riediger, M., Voelkle, M. C., Schaefer, S., & Lindenberger, U. (2014). Charting the life course: Age differences and validity of beliefs about lifespan development. *Psychology and Aging*, *29*(3), 503–520. doi:10.1037/a0036228

Ross, C. A., & Goldner, E. M. (2009). Stigma, negative attitudes and discrimination towards mental illness within the nursing profession: A review of the literature. *Journal of Psychiatric and Mental Health Nursing*, *16*(6), 558–567. doi:10.1111/j.1365-2850.2009.01399.x

Rosset, E. (2008). It's no accident: Our bias for intentional explanations. *Cognition*, *108*(3), 771–780. doi:http://dx.doi.org/10.1016/j.cognition.2008.07.001

Rubin, D. C. (2014). Schema-driven construction of future autobiographical traumatic events: The future is much more troubling than the past. *Journal of Experimental Psychology: General*, *143*(2), 612–630. doi:10.1037/a0032638

Salmond, C. H., & Sahakian, B. J. (2005). Cognitive outcome in traumatic brain injury survivors. *Current Opinion in Critical Care*, *11*(2), 111–116.

Sander, A. M., Clark, A., & Pappadis, M. R. (2010). What is community integration anyway?: Defining meaning following traumatic brain injury. *Journal of Head Trauma Rehabilitation*, *25*(2), 121–127.

Sandlin, J. A., Wright, R. R., & Clark, C. (2011). Reexamining theories of adult learning and adult development through the lenses of public pedagogy. *Adult Education Quarterly*, *63*(1), 3–23. doi:10.1177/0741713611415836

Segerstrom, S. C., & O'Connor, D. B. (2012). Stress, health and illness: Four challenges for the future. *Psychology & Health*, *27*(2), 128–140. doi:10.1080/08870446.2012.659516

Shakespeare, T. (2013). Facing up to disability. *Community Eye Health Journal*, *26*(81), 1–3.

Shanmugasegaram, S., Flett, G. L., Madan, M., Oh, P., Marzolini, S., Reitav, J., … Sturman, E. D. (2014). Perfectionism, Type D personality, and illness-related coping styles in cardiac rehabilitation patients. *Journal of Health Psychology* , *19* (3), 417–426. doi:10.1177/1359105312471571

Sheehan, N. W., & Oakes, C. E. (2003). Bringing assisted living services into congregate housing: Residents' perspectives. *The Gerontologist*, *43*(5), 766–770. doi:10.1093/geront/43.5.766

Shiffman, S., Stone, A. A., & Hufford, M. R. (2008). Ecological momentary assessment.

Annual Review of Clinical Psychology, *4*, 1–32.

Shotton, L., Simpson, J., & Smith, M. (2007). The experience of appraisal, coping and adaptive psychosocial adjustment following traumatic brain injury: A qualitative investigation. *Brain Injury*, *21*(8), 857–869. Retrieved from 10.1080/02699050701481621

Silk, J. S., Forbes, E. E., Whalen, D. J., Jakubcak, J. L., Thompson, W. K., Ryan, N. D., … Dahl, R. E. (2011). Daily emotional dynamics in depressed youth: A cell phone ecological momentary assessment study. *Journal of Experimental Child Psychology*, *110*(2), 241–257. doi:http://dx.doi.org/10.1016/j.jecp.2010.10.007

Simmons, O. E. (2010). Is that a real theory or did you just make it up? Teaching classic grounded theory. *Grounded Theory Review*, *9*(2).

Smart, J. (2009). *Disability, society and the individual* (2nd ed.). Austin, TX: Pro-ed.

Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Kennedy, G., Burwell, B., … Williams, L. (2000). Understanding Medicaid home and community services: A primer. *U.S. Department of Health and Human Services*. Retrieved from http://aspe.hhs.gov/daltcp/reports/primer.htm

Snyder, S. L., & Mitchell, D. T. (2006). *Cultural locations of disability*. Chicago, IL: University of Chicago Press.

Stiegelis, H. E., Hagedoorn, M., Sanderman, R., Van der Zee, K. I., Buunk, B. P., & Van den Bergh, A. C. M. (2003). Cognitive adaptation: A comparison of cancer patients and healthy references. *British Journal of Health Psychology*, *8*(3), 303–318. doi:10.1348/135910703322370879

Strauss, A. L., & Corbin, J. A. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Newbury Park, CA: Sage Publications.

Taylor, E. W., & Snyder, M. J. (2012). A critical review of research on transformative learning theory 2006 - 2010. In E. W. Taylor & P. Cranton (Eds.), *The handbook of transformative learning* (pp. 37–55). San Francisco, CA: Jossey-Bass.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. *American Psychologist*, *38*(11), 1161–1173. doi:10.1037/0003-066X.38.11.1161

Tennant, M., & Pogson, P. (1995). *Learning and change in the adult years*. San Francisco, CA: Wiley Bass.

Uhlmann, E. L., Pizarro, D. A., & Diermeier, D. (2015). A person-centered approach to moral judgment. *Perspectives on Psychological Science*, *10*(1), 72–81. Retrieved from http://pps.sagepub.com/content/10/1/72.abstract

Ungar, T., & Knaak, S. (2013). The hidden medical logic of mental health stigma. *Australian and New Zealand Journal of Psychiatry* , *47* (7), 611–612. Retrieved from http://anp.sagepub.com/content/47/7/611.short

United States Census Bureau. (2012). *Americans with disabilities: 2010*. Retrieved from http://www.census.gov/people/disability/

van de Ven, L., Post, M., de Witte, L., & van den Heuvel, W. (2005). It takes two to tango: the integration of people with disabilities into society. *Disability & Society*, *20*(3), 311–329. doi:10.1080/09687590500060778

Van Dyke, D. J., & Hovis, R. (2014). Systemic critique of the DSM-5: A medical model for human problems and suffering. *Journal of Psychology and Christianity*, *33*, 84+. Retrieved from http://libraryproxy.quinnipiac.edu/login?url=http://go.galegroup.com.libraryproxy.quinnipiac.edu/ps/i.do?id=GALE%7CA369549883&v=2.1&u=a13qu&it=r&p=AONE&sw=w&asid=fee8c8d7948e7460311baa893ee5e569

Wappett, M., & Arndt, K. (2013). *Foundation of disability studies*. Palgrave Macmillian.

Way, S. M. (2011). School discipline and disruptive classroom behavior: The moderating effects of student perceptions. *The Sociological Quarterly*, *52*(3), 346–375. doi:10.1111/j.1533-8525.2011.01210.x

Wells, R., Dywan, J., & Dumas, J. (2005). Life satisfaction and distress in family caregivers as related to specific behavioural changes after traumatic brain injury. *Brain Injury*, *19*(13), 1105–1115. doi:10.1080/02699050500150062

Wheatley, D. (1984). Psychological stress and cardiovascular diseases. *Scandinavian Journal of Work, Environment & Health*, *10*(6), 415–417. doi:10.2307/40965108

Wiley, L. F., Berman, M. L., & Blanke, D. (2013). Who's your nanny?: Choice, paternalism and public health in the age of personal responsibility. *The Journal of Law, Medicine & Ethics*, *41*, 88–91. doi:10.1111/jlme.12048

Wood, R., & Alderman, N. (2011). Applications of operant learning theory to the management of challenging behavior after brain injury. *Journal of Head Trauma Rehabilitation*, *26*(3), 202–211.

Woolfolk, R. L., Doris, J. M., & Darley, J. M. (2006). Identification, situational constraint, and social cognition: Studies in the attribution of moral responsibility. *Cognition*, *100*(2), 283–301.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health*. Geneva.

Wortzel, H. S., & Arciniegas, D. B. (2014). The DSM-5 approach to the evaluation of traumatic brain injury and its neuropsychiatric sequelae. *NeuroRehabilitation*, *34*(4).

Wullink, M., Widdershoven, G., Van Schrojenstein Lantman-de Valk, H., Metsemakers, J., & Dinant, G.-J. (2009). Autonomy in relation to health among people with intellectual disability: A literature review. *Journal of Intellectual Disability Research*, *53*(9), 816–826. doi:10.1111/j.1365-2788.2009.01196.x

Ylvisaker, M., Turkstra, L., Coehlo, C., Yorkston, K., Kennedy, M., Sohlberg, M. M., & Avery, J. (2007). Behavioural interventions for children and adults with behaviour disorders after TBI: A systematic review of the evidence. *Brain Injury*, *21*(8), 769–805. doi:10.1080/02699050701482470

Yuhasz, J. E. (2013). Misconceptions about traumatic brain injury among correctional health care professionals. *Journal of Correctional Health Care*, *19*(2), 135–143. doi:10.1177/1078345812474644

Appendix A: Informed Consent Form

INFORMED CONSENT

Title: How do perceptions of behavior influence day-to-day relationships between individuals with brain injury and their paid caregivers?

Principal Investigator: The principal researcher conducting this study is Barbara Nadeau, a doctoral student at Lesley University (860) 778-3097 or bnadeau2@lesley.edu. Please contact her if you have any questions now or later. If you have questions about your rights as a subject, you may contact the chair of Lesley University's Institutional Review Board, Dr. Terrence Keeney at tkeeney@lesley.edu.

Description and Purpose:

You are being asked to volunteer for a research study because you are either an individual who has a brain injury or a paid caregiver for an individual who has a brain injury.

The purpose of this study is to understand the relationship between individuals with brain injury and their paid caregivers.

Participants in this study will be pairs of paid caregivers/care recipient. There will be six pairs in the study. This study will occur over a four-month period.

Procedures: If you agree to be in this study, you will be asked to participate in two interviews and 6-week phone study. The interviews will be held in a place of your choosing and will each be about 1 hour long. The interview will ask for some general information about you, your experience with brain injury, and your experience with your partner (caregiver or care recipient) who is also participating in this study. The phone study will involve answering a list of 8 short questions two or three times a week for 6 weeks. Each phone call will take about 5 minutes and will ask you to describe your current activity, your mood, you perception of your partner's mood and anything that might be contributing to these moods. The interviews and phone calls will be recorded in order to accurately gather the information.

Voluntary Nature of the Study: Your participation in this study is strictly voluntary. Your decision whether or not to participate will not affect your relationship with the researcher or the ABI Waiver program. You may withdraw from this study at any time.

Risks and Benefits of Being in the Study: There are no risks associated with participating in this study and there are no short or long-term benefits. In the event you experience stress while participating in the interview or phone study you may stop participation. You may also refuse to answer any questions you consider invasive or stressful.

Compensation: There will be no compensation provided for your participation in this study.

Confidentiality:

You have the right to remain anonymous. If you elect to remain anonymous, I will keep your records private and confidential **to the extent allowed by law**. I will use numerical identifiers rather than your name on study records. Your name and other facts that might identify you will not appear when I present this study or publish its results. Research records will be kept in a locked file, and data will be kept in a password-protected computer; only the researcher will have access to the records.

You may keep one copy of this form.

Signatures and names

a) **Investigator's Signature**:

Date	Investigator's Signature	Print Name

b) **Subject's Signature**:

I am 18 years of age or older. The nature and purpose of this research have been satisfactorily explained to me and I agree to become a participant in the study as described above. I understand that I am free to discontinue participation at any time if I so choose, and that the investigator will gladly answer any questions that arise during the course of the research.

Date	Subject's Signature	Print Name

If applicable:

Date	Signature Legally Authorized Representative	Print Name

Appendix B: Study Flyer

Are you currently receiving services through Connecticut's ABI Waiver program?

Or

Do you work with individuals in Connecticut's ABI Waiver program?

If yes, please consider participating in a study to improve understanding of the relationship between individuals with brain injury and their paid support staff.

I am looking for 6 pairs of individuals (person on the ABI waiver & 1 of their staff) who are willing to be interviewed about their experiences.

What are the requirements for participation?

Both members of the pair must be:

*18 years of age or older
* Either a participant or staff member in the ABI Waiver program
* Able to identify emotions & recall events for at least 30 minutes
* Able to participate in face-to-face and telephone interviews
* Work together at least 20 hours per week
* Both individuals will also need to have access to your own phone (mobile or landline) during the time you are together.

Sorry, but you cannot participate in this study if you and your ABI Waiver partner (ABI waiver participant and staff) are related to each other or were friends before the brain injury.

What will I have to do?

There are 3 parts to this study.

1. Interview

This will be a private in-person interview at a location of your choosing. This interview will be about an hour and we will talk about brain injury, you, and your relationship with your ABI Waiver partner (ABI waiver participant or staff).

2. Phone calls

I will call 2-3 times per week for six weeks during the time you are with your ABI Waiver partner. You will be asked to answer a few questions about what you are doing and how you are feeling at that particular point in time. Each phone call will take about five minutes.

3. Interview

After the phone call part of the study we will meet one more time for an interview.

This study is being conducted as part of a doctoral dissertation. The results will be published in the dissertation and may be published, or presented, elsewhere. All participants will remain anonymous. All names will be changed and any information that could potentially identify you will not be included in any report.

I would be very grateful for your participation. Please contact me, Barbara Nadeau, [Phone Number] if you would like more information

Appendix C: Interview Guide for First In-Person Interview

Demographic information:

Alias?

What is the name of the town you live in.

Have you always lived in CT?

If not, where else have you lived?

How old are you?

What is the highest grade of school that you completed? If college, what was your major?

What is your ethnicity?

Factors leading to involvement in ABI Waiver program:

How long have you worked for/been a part of the ABI Waiver program?

Individual with brain injury: questions relative to when and how brain injury was sustained and rehab process

Paid caregiver: questions relative to work history and why chose to work within the ABI waiver program

Brain injury:

Not necessarily thinking about yourself/care recipient, just in general, how do you think brain injury affects most people? Probe as necessary to obtain information about physical, cognitive, behavioral and social effects of brain injury.

[Utilizing information obtained from above question] Is there anything beyond the injury to the brain that you feel causes ________________________

How do you feel your brain injury affected you? (or partner's brain injury him/her)

Other member of dyad:

What is a typical day like for you when you are working with __________________

How would you describe your relationship with caregiver/care recipient?

What things, do you feel, have caused you to feel your relationship is [descriptor used to answer above question]?

What things do you feel you have in common with caregiver/care recipient?

In what ways do you feel you are different from caregiver/care recipient?

Growth and learning:

Do you feel that you have changed in the time you have been involved with the ABI Waiver program? In what ways?

What do you think caused these changes?

What is the biggest thing that you believe influenced your learning?

Do you think that caregiver/care recipient has changed in the time you have known him/her? In what ways?

What do you think caused these changes?

What is the biggest thing that you believe influenced his/her learning

Schedule for working together?

In thinking about my topic of relationships between people with brain injury and their paid caregivers are there any other questions that you think I should have asked or other information that you think would be useful to me?

Appendix D: EMA Questions

Phone call questions

Directions: Barbara will call periodically while you are together and speak with both people. These conversations should take place in a private room with the door closed.

What emotion are you feeling right now?

Why do you think you are feeling that way?

What were you doing just before this phone call?

How would you describe ________________'s emotional state right now?

Why do you think he/she is feeling that way?

What is one negative thing that has happened for you so far today?

What is one positive thing that has happened for you so far today?

Is there any other information you would like to share about the day or how you are feeling?

Appendix E: Interview Guide for Second In-Person Interview

One of the things people talk about when looking at adult learning is transformative learning experiences -- an experience that occurs in your life that changes the way you think about something. Do you feel like you have had any transformative learning experiences in your life?

Do you think you have had any transformative learning experiences in working with ________?

Thinking about the past month -- when were you the happiest?

Thinking about the past month -- when do you think ________ was the happiest?

Behaviors home versus staff -- what do you think it is about your relationship with _______ that causes her behavior to change when she is with you

Do you think you interact differently with ________ than you do with your family? Examples of similarities and differences

Do you think you think working with __________has influenced the way you think about or interact with your family?

What are __________ goals within the ABI Waiver program?

You have mentioned a couple times during our conversations that you have talked to your boss about different things that have come up with __________. Do you think having a boss to talk to has been helpful to you? Why?

[Insert Individualized questions based on EMA data]

Based on my conversations it sounds like you and ___________ have a little routine of things that you do on a regular basis like ______________. Was this routine already in place when you started working with _________ or did you develop it? Are there some things you used to do with _________ when you first started working with her that you don't do anymore

Do you feel it is important for both the person with brain injury and ILST to have similar views about life?

Tell me some things you feel you have learned from working with________________

When you are meeting people for the first time and you tell them about the work you do [or that you have a brain injury] what do they typically say?

There were a few times during our phone conversations when [stressful situation]. Was ________ aware of this? Do you think __________ acts any different when you are under stress?

Do you feel good about yourself on most days? Why?

Do you think _____________ feels good about herself on most days? Why

What do you imagine your life will be like 5 years from now?

What do you imagine ___________ life will be like 5 years from now?