THE LIFE COURSE IMPLICATIONS OF YOUTH-ONSET TRAUMATIC BRAIN INJURY IN YOUTH AND EARLY ADULTHOOD

by

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Abstract

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Traditionally, long-term outcome studies of individuals with disabilities followed a medical model, in which impairments were seen as physical or cognitive deficits, relatively independent of socio-cultural or developmental contexts. However, this medical model leads to an incomplete understanding of the individuals’ lived experiences and development. In contrast, typically, life course theories, characterized individuals’ lives in relationship to these contexts, but usually did not focus on individuals with disabilities. Since adolescence-onset traumatic brain injury (TBI) or spinal cord injury (SCI) may result in changes in physical and/or cognitive functioning which may interact with development and socio-cultural context, interviews with individuals with or without disabilities may disentangle some of these issues. This study bridged a gap between medical outcome studies and life course theory, by examining how people narrated their lives and their impairments/disabilities.

The life story narratives of individuals with TBI were compared to the narratives of individuals with traumatic SCI. To highlight the impact of traumatic medical injury on the life course, individuals with no known disability (NKD) also participated. Using qualitative methods, the life-stories were examined for typical and non-typical life course elements, narrative evaluations, and injury/disability stories. Individuals also created a personal time-line and answered the Personal Opinions Questionnaire (Bolton & Brookings, 1998). Since the data were oral, and individuals with TBI may have linguistic impairments, linguistic comparisons on the life stories were done. Another source of linguistic data included a short, verbal fluency task. Participants were also given the Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997).

Sixteen participants, between the ages of 18 and 49 volunteered. Individuals with injuries were injured between the ages of 14 and 24. Individuals with NKD were matched to the TBI sample as much as possible on gender, age, ethnicity, language background, and education. This design permitted the exploration of the narrative and socio-cultural contexts of individual development which enabled a more complex, less decontextualized and less exclusively medicalized understanding of the lives of individuals with disabilities. Given the current emphasis on person-centered planning, this understanding may, in turn, be used to inform service delivery and outcomes measurement.

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I have many favorite stories about Herb. The one that means the most to my current life happened in the Fall of 2008. Just as I had made time to settle down and again attempt to tackle my dissertation, my fifth nonnormative life crises hit. I was ready to quit, after all those years. I didn't see how continuing the struggle would be worthwhile, for me or my family. I don't remember what Herb said. All I do remember is that he calmed me down, and we talked about the implications of ABD versus Ph.D. for my future career path. Somehow, I came away from that discussion knowing I wouldn't give up.

Dr. Wayne A. Gordon initially hired me as a research assistant in his Rehabilitation Research and Training Center on TBI. At that time, I was a beginning graduate student, and only knew about TBI from the five books I had read before my job interview. Needless to say, on the job, I learned much more.

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Table of Contents

List of Tables

List of Figures

Chapter 1: Primer on TBI and SCI

Reviews of epidemiological studies (Kraus & McArthur, 1996; Selzer, 1995) have estimated that in the U.S., between one and two million traumatic brain injuries (TBI's) occur each year. In this country, the highest incidence rate occurred for individuals between the ages of 15 and 24 (Jennett, 1996). The majority of these individuals survived (Kraus & McArthur, 1996) and should live for many decades, but we know very little about their long-term development and perceived life outcomes. Using life course and narrative frameworks, this study examined these issues, by analyzing what adolescents and adults with TBI say about their lives. Individuals with spinal cord injury (SCI) or no known disability (NKD) were also included in this study to investigate the roles played by the cognitive, physical, and non-normative nature of the injuries.

Both life course and narrative theories allow for a socio-cultural and historical analysis of individuals' lives. In this study, the life course framework was used to examine the inclusion of the constructs: "location in time and place," "linked lives," "human agency," and "timing" (Giele & Elder, 1998). The narrative framework was utilized to examine how individuals told their stories and evaluated their life courses. Eventually, application of these findings may lead to services which more fully take these theories into consideration.

The study of individuals' lives is an interdisciplinary task. This may include biological, sociological, and psychological perspectives. Therefore, this literature review was broken into two chapters to address these areas. This chapter includes a primer on the biology of TBI and SCI: definitions, epidemiology, and symptoms. This was meant to be an abridged primer in order to discuss issues relevant to this project; it was not meant as a definitive medical text. The primer continues with a review of the medical, rehabilitation, and psychological literature about post-TBI outcomes, including the strengths and weaknesses of various theoretical models for examining these outcomes.

The second chapter reviews the literature concerning life course and narrative theories. These traditions arose from different disciplinary backgrounds and histories, yet both allow for a socio-cultural examinations of lived experience. However, for purely organizational purposes, a somewhat false dichotomy has been utilized. Life course theory is described first; then, narrative theory is discussed. Lastly, the second chapter weaves these areas together to form the research questions.

Traumatic Brain Injury and Spinal Cord Injury Primer

Definition of TBI

According to Selzer (1995), a traumatic brain injury may result from:

> . . .a penetrating body or non-penetrating impact. The former produces laceration and hemorrhage in the track of the missile. However, non-penetrating injuries are by far more common and can produce damage by angular and linear acceleration and deceleration of the brain and its impact against the rough inner surface of the skull (p. 55).

These injuries may be classified as either focal or nonfocal injuries. A gunshot wound is an example of a penetrating, focal injury in which the primary areas of deficit can be specifically traced to the path of the bullet in the brain.

In contrast, as stated above, the majority of traumatic brain injuries are nonfocal and due to momentum, which causes the brain to hit the front and back of the skull. Then, the brain bruises and swells. This type of injury typically results in nonlocalized injuries with multiple sequella which differ based on where the swelling occurred.

Regardless of the type of injury, Selzer (1995) noted that several physiological processes occur as a result of a traumatic brain injury. At the time of injury, there is neuronal death and impaired blood flow. Then, over several days, biochemical processes result in secondary damage to local neurons and blood flow. A portion of this secondary damage may be temporary, which starts the recovery process.

Selzer (1995) also catalogued many of the mechanisms that spur recovery. Neurons may experience plasticity, sprouting, and/or regeneration. Neurons experience plasticity by taking over new tasks; sprouting involves making new dendritic connections between neurons. These mechanisms tend to occur in the short-term and may be responsible for much of the early recovery. However, this author pointed out that complex behaviors may continue to improve for months or years, which may result from adaptations and compensations that the individual learns over time. Some of these behavioral adaptations and compensations may impact individuals’ later outcomes and how they narrate their lives.

Definition of Spinal Cord Injury

As with brain injuries, SCI may result from a penetrating or non-penetrating source (Meyer, Cybulski, Rusin, & Haak, 1995). Often, the non-penetrating injury may result from extreme rotation, bending, extension, and/or compression of the spinal cord (Hanak & Scott, 1993). Spinal cord injuries may result in complete or incomplete quadriplegia or paraplegia. Injuries are judged to be complete if there is a total loss of sensation and paralysis below the level of injury; incomplete injuries result in some residual sensation and possible movement (Hanak & Scott). Quadriplegia occurs when there is damage to the cervical section of the spine which results in impairment of the individual's arms, legs, and trunk. Paraplegia is the impairment of an individual's legs and possibly trunk, but the individual's arms are not affected.

Epidemiology of TBI and SCI

There are several similarities and differences in the population profiles of who is at risk for each type of injury.

TBI

Epidemiological studies tend to capture moderate to severe injuries based on hospital admissions and Glasgow Coma Scale (GCS) scores (Teasdale & Jennett, 1974). Using these types of counts, Kraus and McArthur (1996) reviewed data showing that, in the United States, there are more than 1.5 million emergency room visits, 300,000 hospitalizations, 99,000 disabilities, and 56,000 deaths per year due to TBI. As a result of using hospitalization numbers, these authors write that epidemiological studies may underestimate incidence rates by as much as 85% due to the noninclusion of cases at the least severe end of the spectrum.

Another aspect of TBI to consider is that the etiologies and incidence rates of TBI differ based on age and gender. For example, in a review article, Goldstein & Levin (1987) show that for children under the age of one, falls accounted for more than 60% of hospital admissions for central nervous system injuries. These authors continued that falls were only responsible for 9.7% of similar admissions for 15-19 year-olds, while automobile crashes were responsible for more than 50% of the injuries in this age group.

Although this article Goldstein & Levin (1987) is dated, it has the advantage of reviewing data which grouped children into smaller age ranges than many of the more recent articles (e.g., Langlois, Rutland-Brown, & Wald, 2006) so that changes in developmental abilities and activities can be traced. For instance, the rate of CNS injury from accidents in which the child was a pedestrian was approximately 20% for children ages one to four but jumped to nearly 40% for children ages five through nine, and then declined to approximately 15% for ages 10 to 14 (Goldstein & Levin). Examining this breakdown leads to hypotheses about preventative factors including: the role of strollers; the role of holding an adults' hand when in parking lots or crossing the street; and the role of the visibility of the child, due to increased height with age. As will be described in chapter 3, typical or developmentally-appropriate activities and opportunities led to several participants’ injuries.

In the United States, TBI incidence rates also vary by gender at all ages. For example, between the ages of 15 and 24, the ages of the peak incidence, the male rate is approximately 650 cases per 100,000 population, while for females, the rate is 375 cases per 100,000 population (Jennett, 1996).

Given the social and historical nature of this project, it would be remiss for this epidemiological review not to mention rates of traumatic brain injuries among soldiers (e.g., Ivins, et al., 2003; Okie, 2005). The first study examined the baseline rates of TBI in active-duty paratroopers and non-paratroopers; it found a 23% rate of TBI in regular soldiers, and a rate more than twice as high in paratroopers, which the authors attributed to parachuting accidents. Among soldiers exposed to blasts, Okie found a 59% rate of diagnosis of TBI. Even though participants in the current study were not drawn from this demographic, the sizable number of injured soldiers may, in the future, affect service delivery to and awareness of TBI among soldiers, their families, and civilians.

Taken together, these civilian and military data show that TBI follows a gender-based and developmental pattern; individuals of different ages and genders have various experiences that put them at risk for different types of accidents. These accidents may include falls while learning to walk, car accidents while learning to drive, injuries during military services, or shootings related to gang-membership. Perhaps due to expanding opportunities and gendered activities, adolescent males have the highest rates of injury. Among this population, it has been assumed that inner city males have the highest risk; however, some studies have found even higher rates among Native American males (Langlois et al., 2003), perhaps because of the cultural importance of risk-taking and further distance from hospitals. Adolescents may also have a sense of immortality and use risk-taking as a tool in cultural or identity development (Lightfoot, 1997), which may contribute to this developmental rate increase.

The same factors that put adolescents at risk for TBI also make them an important population to follow. Typically, adolescents begin to break away from their families of origin and begin to search for future adult identities and roles. The experience of a TBI may interact with these developmental tasks, which may color the individuals' perceptions of the remainder of their lives.

SCI

Rates for spinal cord injury also vary developmentally (Zigler & Capen, 1998). According to this review, 82% of this population was male, and the median age at injury for males and females is 25, which is slightly older than for the TBI group. Also, the authors stated that the majority of spinal cord injuries were the result of car accidents, violence, sports, and falls.

Traumatic spinal cord injury had a much lower incidence rate than TBI, with only 8,000-10,000 new injuries per year (Meyer et al., 1995). Zigler & Capen (1998) listed fairly even rates for paraplegia and quadriplegia: 45.9% for paraplegia and 54.1% for quadriplegia.

As with TBI, SCI may also interact with the developmental tasks of adolescence and early adulthood. However, in the case of SCI some of the developmental issues may also be focused on mobility and accessibility.

Why compare individuals with TBI, SCI, or NKD?

There are two methodological issues that arise from the design of this study which compared individuals within and between groups. The first issue was whether individuals within a group are truly similar and should be compared. For instance, was someone with a TBI which has resulted in hemiplegia, vision problems, and memory problems, similar to someone who has “only” experienced memory problems? In this study, this question was made more significant by the lack of access to “medical” records to trace injury sites within the brain. However, within group analyses may highlight certain characteristics, life experiences, and/or identities which are only shared by members within each group.

The second issue was the choice of these three groups for comparison purposes. These groups were chosen because of the potentially intriguing differences in their profiles. For example, individuals with TBI typically live with cognitive impairments, individuals with SCI live with mobility impairments, and individuals without disabilities supposedly function “normally” in both these domains. These differences may impact social relationships and/or long-term outcomes. By conducting within and between group analyses, this study may start to suggest how these similarities and differences may shape long-term outcomes and service delivery.

Impairments vs. Disabilities

Throughout history, there have been various ways of conceptualizing people with disabilities and their experiences. For example, the charity model led to the spread of large-scale institutions for people with disabilities in the 1700's and 1800's (Wolfensberger, n.d.). The current paper will not review disability history and the disability rights movement; however, it is necessary to provide a brief discussion of the current terminology and the prominent theoretical models of disability.

One of the earliest academic stances for conceptualizing the experiences of individuals with illnesses or disabilities was Goffman’s (1963) description of stigma, which arose from the sociological focus on the construct of deviancy. This work started to deal with impression management between people with or without characteristics which carry societal stigma, like people with or without disabilities. Over time, a large literature developed to explore the boundaries of stigma and its management across situations.

According to Sherry (2006), one of the earliest (and most well-known) published formulations of what would become known as the "social model of disability" was by the British Union of Physically Impaired Against Segregation (UPIAS) who, in 1976, created a definition of disability which placed the biological impairment in the person, aligned with the medical view, and the societal oppression of the disability within the physical and social environment. This early definition grew through implicit and explicit usage (e.g., Oliver, 1983; Murphy, 1987; Saxton & Howe, 1987).

Fine & Asch’s article (1998) discussed the “disability as minority-group” model. The authors reviewed this perspective in light of historical and political events of the 1970's and 80's. They stated that even though some individuals with disabilities may not see themselves as a minority-group, this does not necessarily negate the group identity of individuals who may see themselves in this minority role.

Linton (1998) used a social model of disability to counter the traditional medical model, in which the impairment was located in the person and needed to be fixed. Her social model argument examined the use of language, politics, and the environment in shaping the experiences of people with disabilities. She explored how the everyday language of “normality” and “able-bodiedness” shape our cultural expectations of abilities and experiences and result in a discounting of people with disabilities. In the social model, disability does not reside within the individual’s biology; it resides within the physical and social environment which does not fit the individual’s requirements.

Currently, there is some academic discussion of whether, after 30 years of political and theoretical change, the divide between the social versus medical model still serves a purpose in theory and/or practical advocacy (e.g., Shakespeare, 2006).

While these theoretical stances each contribute a major piece to the disability literature, my participants may not have been exposed to any or all of these ideas. However, it is necessary to provide some structure in the literature review for discussing “potential symptoms” arising from TBI or SCI. According to the Institute of Medicine’s 1997 report (Brandt & Pope, 1997) which used a social model, an ***impairment*** is the physiological or biological aspect of a disorder, free of any social context. In contrast, a ***disability*** is the result of the interaction between the impairment and the social context. For example, an individual with TBI could have a speech impairment involving fluency. If the individual’s environment accepts the fluency problem, it remains an impairment. However, if the environment is not accepting, the speech impairment would become a disability. This distinction will be used throughout the rest of this paper.

Since the impairments found in individuals with TBI and SCI vary greatly among individuals, the following descriptions of impairments and disabilities are meant as a general overview. They are neither an exhaustive description of the sample, nor of any specific individual. The methods chapter contains a description of my sample, but it must be noted that given the nature of this project, a complete medical history was not included in data collection. Therefore, individual’s impairments were only noted if self-disclosed during the data collection or if accommodations were arranged prior to the interview.

For the ease of this discussion, TBI-related impairments will be divided into motoric, cognitive, and linguistic domains, while SCI-related impairments will cluster in the motoric domain.

TBI impairments: Motoric

Due to visibility, the motoric impairments that may accompany TBI are often seen as least problematic by the individual and those around him or her (Krefting, 1990). These physical injuries may result from trauma to other areas of an individual's body or damage to the brain that controls specific body parts. For example, during a car accident, an individual may also break his or her arms; if they do not heal completely, the individual may be left with residual impairments. If the TBI involves the part of the brain that controls movement on one side of the body, the individual may experience hemiparesis, weakness on one side of the body, or hemiplegia, paralysis on one side of the body.

SCI Impairments: Motoric

In addition to the partial or complete paralysis of the arms or legs that occurs with SCI, individuals may experience additional physical impairments. If the injury is high enough on the spinal column, the individual may experience ongoing problems with respiration; impairments may also occur in individuals' gastrointestinal/urinary, reproductive, and epidermal systems (Hanak & Scott, 1993).

TBI impairments: Cognitive

Cognitive difficulties may include problems in executive functioning, attention, and/or memory (Lezak, 1995). This author details how impaired executive functioning could include an inability to complete multi-step tasks, monitor one's behavior, and/or be aware of one's limitations. Individuals may also experience slowed processing speed and inability to divide attention across tasks.

While some individuals with TBI experience severe behavioral and emotional dyscontrol issues (Lezak, 1995), in the current study, participants with TBI represent a specific place on the post-TBI outcome continuum. They lived in the community, were able to travel to an interview (alone or with assistance) and were able to participate in a conversational interview; therefore, they might have fewer issues around dyscontrol than a broader sample. Nevertheless, some of them may still have issues at the level of disinhibition and the need to monitor themselves. This impairment may affect social relationships and result in a social disability, which might be reflected in life-stories. Again, data collection was through self-reports, so it might have glossed over problematical social relationships, as a means of protective self-presentation.

Memory problems may be due to encoding or decoding/retrieval problems in interaction with slower processing speed and limited attention (Lezak, 1995). For example, individuals may have difficulty with retrieving and applying information in context. This impairment may affect the types and amounts of information given by the participants with TBI in the self-structured life story section of the interview.

TBI impairments: Linguistic

In conversations, some individuals with TBI may experience receptive, productive, and/or pragmatic language problems (Marshall, 1989). This author described receptive problems that include impairments of: memory for what was said, auditory comprehension, hearing loss, and/or attention. Productive problems may involve vocabulary memory and recall, fluency, stuttering, and/or motor control of speech sounds. He described the pragmatic problems as difficulties in conversation that may be traced to problems with: understanding nonverbal behaviors, knowing how to take speech turns, the maintenance and transition of topics, social appropriateness, and lack of attention to the process of speaking and listening. The ways in which these linguistic impairments might have compromised individuals' storytelling will be discussed in the next chapter, during the review of the narrative literature.

For Marshall (1989), the social/pragmatic aspects of communication are most in need of research because problems in these domains may be the most unexpected, least obvious types of problems. Therefore, these issues may have the most unsatisfactory outcomes for the individual with the TBI and the conversation partner, because the conversation flows neither smoothly nor as expected.

TBI Disability

The disability arising from a brain injury occurs when the physical, cognitive, and/or linguistic impairments of an individual interact with other individuals, social structures, or society. For example, an individual's inability to monitor his/her behavior and/or emotions may lead to socially awkward situations. If the environment is not accepting, this could lead to a social disability.

SCI Disability

Stereotypically, when one pictures the disability arising from an SCI, it involves the physical environment. However, individuals with SCI may also experience social disability, perhaps due to their status as individuals with visible impairments.

Summary and implications of this biological introduction

This background knowledge about the populations and symptoms of TBI and SCI was necessary to build the foundation for this study.

First, by highlighting the developmental characteristics of the majority of the TBI and SCI populations, it becomes evident that adolescents and young adults who experience either type of injury face situations in which their impairments or disabilities may interact with their age-appropriate developmental tasks. By examining what individuals say about their development and life experiences it may become easier to facilitate appropriate services and supports for more individuals.

Second, by understanding that TBI tends to include motoric, cognitive, behavioral, and/or linguistic impairments, while SCI tends to include mainly mobility impairments, it becomes apparent that these individuals will have different post-injury experiences, which may shape their future behaviors, expectations, social environments, and perceptions of their outcomes.

Third, depending on the cognitive impairments of the participants, individuals' impairments may be displayed during the interview or may interact with the methods of data collection. For instance, memory problems that cause an individual to have trouble with putting memories into context may lead to a very sparse life story. In an attempt to meet the needs of participants, this study has several formats which require different cognitive abilities. For example, that same individual may provide more information in the second part of the interview, which includes direct questions and visual cues in the form of icons to be placed on a time-line. These different formats can be thought of as Vygotskian scaffolding (Wood, Bruner, & Ross, 1976), which increases individuals performance by providing support.

Lastly, while participants may not use the terms "disability" and "impairments" in the same way as the literature does, in the interview, the individuals may share experiences in which they perceived that their impairments or disabilities played a role. These types of events, which may shape their future behaviors, would not be found in traditional outcome studies which measure constructs like employment status. However, these incidents may shape the meanings that individuals' attach to themselves, their abilities, and their possible options for the future. As we will see, life course theory and narrative theory are tools for examining these meanings and outcomes.

Outcome studies

This section discusses the theoretical and methodological strengths and weaknesses of various types of outcome studies. Due to methodological issues with outcome studies, which will be discussed below, the earlier biological sections of this paper used biomedical sources to describe possible TBI impairments. In contrast, Table 1.1, lists the range of outcomes measured in 12 studies. These outcomes were measured biologically (e.g., death or disorders of consciousness), functionally (e.g. activities of daily living), and/or psychosocially (e.g., quality of life, employment or marital status.)

Table 1.1 Selected TBI outcome studies

Primary Author	Year	N	Age Injury (yrs)	Time Post	Severity	Outcomes	Type of study
Eiben	1984	42	3-23	1-11 yrs	Not stated; (LOC=0-21+ days)*	Parental reports: 37% judged independent, 49% dependent, 14% died.	Functional
Thomsen	1984	40	15-44	10-15 yrs	PTA>1 month**	Late outcomes still show improvement. Psychosocial sequella most problematic for individuals and their families.	Medical
Berger	1985	37	0-17	6 mo.	“Severe” GCS*** score<8 for at least 6 hrs.	51% judged good recovery/moderate disability, 14% severe disability, 2% vegetative, 33% died.	Medical
Filley	1987	53	0-18	.5-11+ yrs	3.7% LOC<1 day 34% LOC>1 mo	Outcome correlated with type of injury and length of coma.	Medical
Kriel	1988	26	0-17	>2 yrs	LOC>90 days	15.38% Testable IQ>70, 26.92% Functional Communicators, 34.61% Socially Responsive, 23.08% Persistent vegetative.	Functional
Rappaport	1989	55	avg 27.8	5-10.4yrs	Not stated	61% unemployed, 19% married, 27% living with parents. Outcome linked to time between injury and rehab, and severity.	Functional
Boyer	1991	220	0-21	1-3 yrs	Not stated-patients at a tertiary rehab. center	46% walk independently, 36% no communication problems, 21% no/minimal cognitive deficits	Functional
Thomsen	1992	31	15-37	20+	PTA>1 mo	Same participants as 1984 study. Disturbed behavior and insight significant in outcomes.	Medical
Klonoff	1993	159	2.7-15.9	23 yrs	89.3% LOC<30 min.	42.1% had undergone some form of post-secondary education, 59.2% were married, and 80.1% were employed full-time.	Medical
Bogan	1997	31	--	1-5 yrs	post-injury sequellae	age at interview: 14-20 yrs. Wanted more support, better explanations for long-term problems.	Psychosocial
Mazaux	1997	79	0-60	5 yrs	24 mild=GCS≥13 28 mod=GCS 9-12 27 severe=GCS≤8	Cognitive impairments are correlated with lack of social autonomy and lack of return to work.	Psychosocial
Brown	1998	430 TBI	--	1-53	72% LOC>1 day	Used a TBI, SCI, & NKD sample. Outcome was QOL; unmet important needs were largest in the TBI group.	Psychosocial

* LOC=Loss of Consciousness **PTA=Post Traumatic Amnesia ***GCS=Glasgow Coma Scale

It should be noted that measured outcomes rely on an interaction of several forces. First, medical technology at a given point of time is one determinant of who survives and with what level of impairment (Haas et al., 2009). Second, outcomes also depend upon what types of services society provides for individuals during a specific historical time--institutions, personal attendant services, and/or vocational rehabilitation, for example. Third, measured outcomes depend on what outcomes the researchers believe to be possible, as well as which outcomes they believe are worthy of being counted.

Given the wide range of potential measures, there are three traditional lenses for recording potential outcomes for populations with disabilities. Medical outcomes tend to focus on survival and lasting impairments without examining context (e.g., Pickelsimer et al 2006). Functional outcomes usually explore what the individual does, with or without assistance; such studies are more likely to address context (e.g., Boyer & Edwards, 1991). Psychosocial outcomes may measure constructs including employment status, marital status, quality of life, social support, adjustment, coping, or related concepts (e.g., Wood & Rutterford, 2006). Outcome studies may incorporate any or all of these lenses, and may or may not include basic demographic information. Table 1.1 lists 12 selected studies, demographics of the samples, selected outcomes, and which lens is primarily used. This paper argues that life course and narrative frameworks could, theoretically, be used to explore the meaning-making surrounding the life experiences of people with disabilities, guide service delivery, and measure outcomes. This would be in line with the current service delivery model of person-centered planning, which is based on determining possible supports for meeting the needs or desires of the individual.

Medical outcomes: Measuring Impairments

Klonoff, Clark, & Klonoff (1993) was a typical questionnaire study which measured impairments. Table 1.1 described their sample and selected outcomes. In their article, the authors catalogued the physical, cognitive, and emotional symptoms that participants experienced, grouped by whether the individual felt the symptoms were or were not related to the brain injury. These lists include symptoms like musculo-skeletal problems, attention/memory problems, behavioral problems, and psychological problems. These sequellae are simply counted; they are not inserted into the context of what they meant for the individual and his or her life.

At a more contextual level, Klonoff et al. (1993) attempted to explore individuals' lives. However, they solely did this through counts of demographic characteristics like years of schooling, employment status, and marital status. Again, they did not explore the impact of these demographics on individuals. In their sample, 42.1% had taken part in some form of post-secondary education, 59.2% were married, and 80.1% were employed full-time. Unfortunately, this study did not include a matched comparison group. However, when comparing these results with others listed in the table, these rates for marital status and full-time employment seem exceptionally high for a population with TBI. This may be due to the participants' mild injuries and less severe impairments, and/or to their early age at injury, which affected their later development and expectations. These numbers are intriguing, but they do not give the reader a sense of whether these individuals were competently fulfilling their adult roles and responsibilities or whether they were experiencing disability.

A more recent study in this vein was Pickelsimer et al (2006). The researchers conducted in-depth telephone interviews with 2,118 individuals, who were individuals with TBI or their caregivers. In terms of medical outcomes, this study did report on death and physical symptoms. However, it also included functional and psychosocial outcomes. The purpose of including the psychosocial outcomes was merely to see whether services were being provided or were needed. Again, these issues were not given meaning by the participant, and were only viewed in terms of service delivery.

While Pickelsimmer et al. (2006) focused on individuals one year post-injury, another feature of the Klonoff et al. (1993) article was the amount of time, 23 years, that had passed since the initial injuries. Very few other studies (e.g., Thomsen, 1992) have investigated impairments or disabilities at similar lengths of time post injury. One consequence is that these later two samples were injured in the late 1960's and early 1970's, when trauma medicine was starting to become more available and more effective, whereas Pickelsimmer’s participants were injured after 1998. Table 1.1 shows the comparison between Klonoff’s sample of mildly injured children, and Thomsen’s sample of severely injured adults. These factors may partially explain the difference in outcomes for the two populations. Due to changes in medical knowledge and technology, when judging outcomes, it is necessary to be aware of the historical timing of the injuries.

Thomsen’s studies (1984, 1992) are interesting for another reason. While the author catalogued symptoms and group outcomes, she also followed her participants as individuals. In addition to her role as researcher, she had an ongoing, clinical relationship with many, if not all, of her participants. Data collection was based on questionnaires. In the 1984 study, the questionnaires were administered to the caregiver and were modified for the individual with TBI. The caregiver's responses were assumed to be more accurate when disagreement occurred. She catalogued the impairments of individuals then, briefly in 1984 and at length in 1992, created sketches of the disability experienced by individuals with extremely positive and extremely negative outcomes. However, she did not necessarily talk with her participants about their own understandings of their situations.

While the time-line section of my study includes demographic data, like employment and marital status, my study moves beyond this in the life story section to examine the meanings that individuals give to these demographics and their life experiences. This level of additional detail allowed painting a picture of the social, historical, psychological, and/or sociological backgrounds of my participants and their life experiences. With the exception of Sherry (2006), this has not been accomplished before with these populations.

Functional outcome studies: Measuring Disability

A functional focus rests more on what an individual actually does rather than the impairments or disabilities that the individual has. Kriel et al.(1988) and Boyer & Edwards (1991) are typical examples of this approach. Kriel et al. compiled data on children actively being seen by hospital staff; data consisted of CAT scans, developmental and intelligence tests, functional assessments, and family/school surveys.

Boyer & Edwards (1991) grouped participants (ages 0-21 years) according to whether they are independent, partially independent, or dependent in 6 activities of daily living (ADLs). These activities are: feeding, dressing, grooming, transfers, bathing, and bowel/bladder control. This grouping would make sense for an adult sample, but Boyer ignores the fact that young children with or without disabilities would not do some of these tasks alone. Similarly, Kriel et al. (1988) includes a table in which the participants are listed individually. For each child, the author lists the severity of their injury, his/her age at injury, his/her cognitive and motor outcomes at discharge, and his/her anticipated living arrangements as adults. Both these authors ignored the fact that developmentally, even children and adolescents without disabilities are dependent on their parents. For a multitude of reasons, including economic ones, in our society, most children are discharged to their parents. Many parents of children with disabilities see having their child at home and meeting his or her developmental needs as a core of parenting (Lalvani, 2008). Also, given the young age of some of the children in this sample, it is problematic to predict their future capabilities and living arrangements. Even though these authors projected into the future, they did not discuss that possible living arrangements might change, given the potential evolution of different systems for providing daily assistance. Also, it is problematic to project abilities for small children over a span of 10-15 years; they may have learned self-care skills. Both these articles fail to consider the role of development in these children's experiences of disability. In contrast, my study highlighted this interplay between development and injury.

Psychosocial outcome studies: Measuring Post-Injury Life

Two articles, Bogan et al. (1997) and Brown & Vandergoot (1998) focus more on life satisfaction than on functional abilities. Bogan et al. examined identity and TBI-related experiences while Brown & Vandergoot examined quality of life (QOL).

In Bogan et al. (1997), the authors administered, to adolescents, a quantitative identity questionnaire, the Offer Self-Image Questionnaire, and a qualitative interview about life with TBI. The authors found that in most identity areas, the adolescents with TBI did not differ from the norms. In their interviews, adolescents talked about their experiences as well as their frustration with lack of information about and support for their long-term impairments. This study was groundbreaking in that it examined the meanings that individuals assigned to their experiences.

Brown & Vandergoot's work (1998) was also groundbreaking in several respects. First, for comparison purposes, the study included individuals with TBI, SCI, or no known disability. Second, it allowed individuals to design their own sense of quality of life by rating whether or not certain areas of life were important and whether or not these life areas were currently fulfilled. While this study did give more voice to the participants, it still did not fully investigate the meaning attached to the fulfillment or lack of fulfillment of these needs. For example, an individual may react to unmet social needs with resignation, anger, confusion, wistfulness, and/or patience, among others. This reaction may shape the impact and meaning of this social need, whether it is deemed important or unimportant. By soliciting individuals' narratives about their experiences, the current study gives participants the space to include their perceptions of their needs, sense of fulfillment, and the meanings they attach to this information. However, it must be noted that participants were not specifically asked, so this information may not be included by all participants.

What are the strengths and limitations of these outcome studies?

As can be seen from the examples above, outcome studies can measure a wide variety of characteristics. However, as a group, they do tend to have several characteristics in common.

First, they tend to focus on group and not individual outcomes. As a result, we cannot easily trace the path that an individual follows over time. Second, the studies tend not to have control or comparison groups. Therefore, base rates of activities are not available for similar non-disabled individuals. Third, the outcome studies tend not to focus on the meaning that individuals give to life events, impairments, or disabilities. Often, the studies simply count the presence or absence of these characteristics.

Fourth, because outcome studies don’t focus on self-created meanings, they don’t examine continuity/discontinuity in individuals’ lives before and after their TBI. In developmental psychology, the tension between continuity and discontinuity results in questions about whether adult behaviors continue childhood patterns. In the TBI field, outcome studies do not reflect whether post-TBI outcomes are simply continuations of previous patterns. For example, if someone has always struggled to form personal relationships, he or she may ignore the additional social disability that may arise from a TBI, whereas another individual may attribute his or her post-injury loss of social contacts to his or her social impairments from the TBI.

Lastly, most outcome studies focus on one event in an individual’s life and trace all other individual characteristics back to that specific event. Now, over the short-term, that may be sensible. However, over the longer term, people may experience other life-altering events, which may have more life-altering impacts. As an admittedly extreme hypothetical example, an individual may experience a mild TBI during his or her teens. Twenty years later, as he or she participates in a TBI outcomes study, the individual may be undergoing treatment for cancer, or perhaps the individual won the lottery. Either way, the person may re-organize the meaning of his or her TBI given these new life circumstances.

Sherry (2006) is not a traditional outcomes study, so it does not have the same drawbacks. Rather, the author describes a program of emancipatory research with a group of individuals with brain injuries. However, he not only describes the research agenda of systems change and empowerment, but also paints a picture of each of his participants as individuals embedded in social systems with their own unique strengths, weaknesses, and identities.

As will be shown in the following chapter, applying life course and narrative approaches to long-term outcome studies may minimize some of the above issues. For this project, life course theory and narrative theory were both used as tools to explore the meanings that individuals attach to the events in their lives.

Chapter 2: Life Course and Narrative Theories

When studying individuals' lives, it is only natural to use socio-cultural frameworks, like life course and narrative approaches, to explore individuals' meaning-making. Because life course and narrative research grew out of different traditions, for organizational purposes, these fields will be described separately. This chapter first reviews the history of life course theory and then moves into a review of narrative theory; it then concludes with the research questions.

Life course theory: What is it?

According to a review by Elder (1994),

> . . .the life course can be viewed as a multilevel phenomenon, ranging from structured pathways through social institutions and organizations to the social trajectories of individuals and their developmental pathways. (p. 5)

This life course perspective examines the impact of historical events, societal reactions, institutional services, normative, expected experiences, and nonnormative, unusual experiences on individuals' development. Applying a life course framework to this study is appropriate, because treatments for traumatic brain injuries have changed drastically over the last 50 years, and may involve several institutions (schools, hospitals, rehabilitation programs, etc.). Additionally, a life course approach may bring a new perspective to outcome measurement.

Similar to Elder's definition, for Clausen (1986), the key feature of life course theory is the "constantly evolving product of the complex interactions among the biological, the psychological, and the sociocultural realms" (p. xiii). Again, this definition focuses on the interaction of the individual with their surroundings, with the understanding that the surroundings shape the individual and vice versa.

Giele & Elder (1998) write that life course theories typically have four characteristics: ***location in time and place, linked lives, human agency,*** and ***timing***. The ***location*** of lives includes the historical, cultural, and geographical patterns for lives. ***Linked lives*** represent the interaction of individuals. ***Human agency*** is the individual's sense of agency, control, or goal-directedness. An individual's ***timing*** is his or her personal timing of life events against the background of historical events. This is the framework and terminology that will be used throughout this paper, when discussing people's life course elements.

The following example illustrates how these elements and their meanings might play a role in an actual life. BT narrated his story when he was 25 (Patti, 1999). He spoke about his pre-injury troubles hanging out with the wrong crowd and experiencing problems with the public school bureaucracy, which made him decide to drop out of school after 9th grade and get a job. He worked a series of manual jobs, and then, when he was 16, he was hit by a subway on his way home from work. He spoke eloquently of learning to walk again,

> --I have a picture of the first time I got out of the wheelchair, with a cane, a quad cane, y'know. But, they [the nurses] took a picture of it. And, (chuckle) I've still got the picture, and I treasure it of course, cuz, y'know, that's a big victory in my life.

Because of his age, he attended a pediatric rehabilitation center, where they focused on community living. As part of his rehabilitation, he talked about the freedom of going to restaurants with other clients. He then mentioned his desire and decision to leave rehab and move back home with his parents and siblings. As he reflected on current events in his life, he discussed his first steps to find a vocation, which show his sense of agency. He also remarked that all of his siblings had left the parental nest, except for him, which was a source of unhappiness for him. At the time of his interview, he was also trying to establish his first post-injury dating relationship.

Ironically, BT's location as a teenager in a peer group that encouraged risky behavior and leaving school early, may have placed him at risk for a TBI, even though his actual TBI happened as he was "responsibly" coming home from work. Because of his historical and geographical location, he did receive trauma services, in-patient pediatric rehabilitation, and a diagnosis of TBI. After rehab, BT's living arrangement with his parents initially was seen as being "on time" and normative, since his older "nonimpaired" siblings were also at home. However, as time passed, and his siblings moved out, BT felt his living arrangement was becoming nonnormative. These perceptions may also play into his social ties to his parents and his attempts to find other significant relationships. BT may have felt that his personal control was limited, because of his interaction with the vocational rehabilitation system, but he was starting to find a career path for himself, at the time of the interview. This extended example shows how BT's life events and the personal meanings he attached to them may have interacted with larger societal factors which may have placed his life on its current course.

BT's situation was a brief introduction to how life course theory could be applied; the current study discusses specific exemplars for each life course element. The construct of linked lives was explored through particpants' mentions of other people in their life stories. Human agency was represented through Bolton and Brookings' (1998) Personal Opinions Questionnaire. Location in time and place was explored by showing how stories of immigration may be similar to stories of disability, as opportunities for negative stress or positive growth (Slota & Peffley, 2005). Timing had 2 exemplars: experiences with educational services and individuals' relationships to the Americans with Disabilities Act (Slota & Peffley, 2004).

This last exemplar requires a brief discussion about its place in our culture and its relationship to individuals with disabilities. At the time of data collection, the 1990 ADA was the law of the land, yet in order for it to be effective, people needed to proactively monitor, seek redress for lack of compliance, and/or prove disability discrimination. At the time of this writing, the 2008 revision to the ADA was passed less than a year ago. It is still too early to tell whether the new law will change the enforcement policies or change society as much as the 1990 ADA did.

David Engel and Frank Munger (2003) explore the connection between identity and the ADA. They collected disability narratives from 1994 through 1997 to ascertain the role of this civil rights legislation in the everyday lives of individuals. In terms of methodology, they interviewed individuals, wrote summaries of the information given, and then shared the summaries with the participants, in order to receive feedback. This feedback was then incorporated into the final work. The authors argue that identity formation, through these narrative constructions, is a key to understanding the complex impact of civil rights legislation on individuals. They write,

> The perception of boundaries wrongly placed is inseparable from the sense of self. The perception that exclusion is appropriate or inappropriate, indeed that awareness that exclusion has occurred, hinges on the way in which individuals and those around them define their identity (p.40).

In the current study, because it was not known if individuals would always mention the ADA in their life story narratives, specific questions relating to the ADA were asked during the "Interviewer-led Subsection" of the "Life Story Section" of the interview.

Over time, the ADA and other disability laws have grown and changed. Similarly, over the last fifty years, many researchers have added various constructs to the field of life course theory. A chronological review will highlight how the field grew, how this growth was shaped by historical forces, and how choice of methods affect findings.

Life course theory: What is its history?

Giele & Elder (1998) trace the foundations of life course theory back to work by W. I. Thomas. Thomas and Znaniecki authored a work entitled <u>The Polish Peasant in Europe and America</u> (1918-1920), which used primary source letters by immigrants to explore the process of immigration and Americanization. They were looking at the meanings behind the experiences, not just simple counts of incidents. Thomas was also instrumental in the formation of symbolic interactionism, a sociological school which states that the meaning an individual gives to an object or event directly affects its impact (G. Handel, personal communication, spring, 1999). Therefore, letters, which discussed events and their meanings, were an appropriate source of data.

However, the timing was not yet right for life course theory to emerge. Elder (1985) wrote that three events occurred in the 1960's which made life course theory possible. First, there was a growing interest in how historical events shaped individual development. Second, many long-term studies which started between 1910 and 1930 were reaching fruition. Third, advanced statistical methods were becoming available for tracing the impact of variables over time.

Neugarten (1968) and Neugarten, Moore and Lowe (1965) made the argument that every society provides age-norms for achieving expected developmental tasks, like getting married or starting a first job, and that other peoples' perceptions of an individual will be shaped by whether the individual fits these age-norms. For the 1965 study, the authors used a questionnaire to elicit responses from 93 middle-class participants about the appropriate ages to reach certain developmental milestones of adulthood, such as marriage or employment. Of course, the methods of eliciting responses, the demographics of the participants, and the historical timing of this study (the turbulent 1960's), all shaped the results. The authors extended these findings to hypothesize that these age-norms may act to regulate the speed of an individual's development, by pushing the individual to accelerate or slow down the completion of developmental tasks. In the above example of BT, as well as from other participants in that study (Patti, 1999), this framework was useful in exploring the self-reports of people with traumatic brain injury-related delays in reaching expected developmental milestones at "appropriate" or "expected" times.

Perhaps the most well-known life course study is Elder's *Children of the Great Depression* (1999), in which he traces the impact of the age/developmental status of children during the Depression on their adult outcomes. He found that younger children had worse outcomes, perhaps due to their more complete reliance on their families, and perhaps due to their age/developmental status at other historical points. Older children were able to help their families during the Depression, and then they garnered further potentially life-altering experiences during World War II. This study was one of the first to examine how historical events interacted with individual development.

Also, during the 1970's, there was an increasing interest in adult development (i.e., Vaillant, 1977; Levinson, Darrow, Klein, Levinson, & McKee, 1978). However, both studies focused on “normal” adults, and normative experiences. In these studies, “normal” adults were typically male, white, and middle or upper class. Vaillant used a cohort of Harvard graduates, while Levinson et al. used a cohort of employed men, most of whom were middle-class. Similarly, Clausen (1986) explicitly mentions an ***expectable life course*** which also tends to focus on normative experiences and typical individuals. The current study shifts this focus to using a framework centered on people with disabilities and their life course experiences.

Elder (1985) discusses the roles of ***trajectories*** and ***transitions*** in shaping the life course. For him, ***trajectories*** are the paths that individuals follow in institutions or social roles. These trajectories may be followed with little or much deviation from the norm. For example, some individuals succeed in the age-graded institution “school,” while others may fall behind, repeat a grade, or drop out. According to Elder, ***transitions*** are experienced when an individual’s trajectory undergoes change; for example, an individual faces a transition between graduating college and starting a career. Because of their involvement with additional services and institutions, people with disabilities may experience more trajectories and transitions in their lives.

Clausen (1986) divides the life course into three time-lines which may overlap and/or interact. First, ***historical time*** is the background of historical events during an individual's life. Second, ***social time*** is the expected timing of events, given one's location. Third, ***chronological time*** is the actual timing of developmental events in an individual's life. Clausen would say that an individual is on-time if their chronological and social time coincide; as discussed above, Neugarten (1968) and Neugarten et al. (1965) would say that the individual is meeting his or her age-norms. Regardless of the terminology in the studies, societal expectations may lead to social pressures when developmental milestones are delayed. The earlier example of BT's experiences with living with his parents illustrate this tension.

Clausen (1993) takes an in-depth look at several case studies of individuals followed since the 1930's. He uses the construct of ***planful competence*** to highlight issues of continuity and discontinuity over the life course. For Clausen, planful competence is the ability to set goals, to determine the steps needed to achieve them, and then to follow through. He has found that the presence or absence of planful competence can be used to separate those people with better or worse than expected life outcomes. The sample size in the current study is too small to show this relationship; however, "personal competence" and "self-determination," which are similar to planful competence, were two subscales on the "Personal Opinions Questionnaire" (POQS) (Bolton & Brookings, 1998). Because choice of methodology affects participants' responses and the conclusions that may be drawn, results of the POQS will not be identical to individual's portrayals of themselves in the "Participant-led subsection" of the life story section of the interview.

Issues Across Life Course Studies

When examining various life course projects, several aspects of the studies should be noted. Sample size, methodology, and choice of subject populations all affect the types of results which are found.

Sample Size

First, many life course studies have focused on group outcomes (e.g., Conger, Lorenz, Elder, Simons, & Ge, 1993; Elder, 1999; Palmer, 1987), while others have focused on individual outcomes (e.g., Clausen, 1993; Handel, 2000). Group findings may not have the same meanings for individuals. For example, Elder's Depression-era children and adolescents did have different outcomes from each other, but would any or many of them have attributed their outcomes to their age or developmental stages during the Depression? Or, would they tell their life stories based on the choices that they made and the people they interacted with? Group or individual findings should not be judged on which is "more valid;" they should be used to complement each other in furthering the development of life course theory. This project will include some group analyses, as well as individual analyses.

Methodology

Second, there are differences in possible results and conclusions between studies that use qualitative or quantitative methods of analysis. Historically, studies like Elder (1999) used quantitative measures, large sample sizes, and statistical analyses to reach conclusions. Recently, qualitative methods have also been used in life course studies (e.g., Laub & Sampson, 1998). These authors used a pre-existing database about juvenile delinquency, and integrated qualitative and quantitative analyses into their re-analysis to create both a richer sense of participants' experiences, as well as a theory about individual persistence in criminal behaviors.

The current project was originally designed with a sample size large enough to yield statistical relationships, yet small enough for an in-depth qualitative analysis, in order to capture the strengths of both types of analyses. However, due to issues with locating participants, the final sample size is not large enough for detailed statistical analyses and statistically significant group outcomes. Instead, the focal analyses will be qualitative in nature and focus on sociocultural aspects of individuals’ life courses, the meanings they create, and how their cognitive impairments may affect what they say and how they communicate during the interview.

Inclusion of individuals with disabilities

As stated above, Vaillant (1977) and Levinson et al. (1978) specifically sampled individuals who were experiencing typical or privileged adult development, and these authors did not see disability as being a component of typical adult development. Similarly, in Clausen’s (1986) definition of expectable life course, he specifically writes,

> A normal, expectable life course includes a number of illnesses, major and minor, but some persons are born with or acquire impairments that make this expectable life course impossible. . . . The courses of their [people with disabilities who now survive] lives are markedly influenced by their

> impairments, but to a considerable extent they are subject to the same general developmental processes as their unimpaired peers (p. 5).

Here, Clausen does not explicitly describe which individuals with disabilities are included in or excluded from typical life course processes. He also does not discuss how disability affects the life course. This is one of the foundations for this dissertation.

One study that does focus on the life course experiences of people with disabilities was Palmer (1987). He did a traditional life course path analysis on life outcomes for 80 adults with "mental retardation," who had an average IQ of 53. He found that although cognitive abilities could be predicted over time, social abilities could not be predicted very well. Perhaps the variability in social abilities is partly due to the inclusion of someone else in the interaction, who might provide scaffolding for the encounter. Palmer's study focused on group outcomes by collecting scores from standardized testing, medical examinations, family demographics, previous school records and employment history, among other sources of data. Although he had multiple data sources, his study did not examine individuals' meanings about their abilities or life experiences.

In contrast, Priestley (2001), collects a variety of life course studies about individuals with disabilities. Some (e.g., Rowlands, 2001) focus on the author's meaning-making surrounding the author's own disability. Kasnitz (2001) showed how life course theory should be applied to the lives of individuals with disabilities. As part of a larger study, leaders in the disability movement (solicited through peer nominations) were interviewed; the data was analyzed using event history analysis. The author found that, often, an "Aha!" moment served as a catalyst for becoming more involved in the movement. For some individuals, another positive catalyst for becoming an activist was being in locations with other people with disabilities, so that a common identity could be forged. This leads Kasnitz to conclude the chapter by asking what the path to leadership will be for the next generation, who have not spent time in specialized settings. The one drawback to Kasnitz's study is that she focused on leaders, so she does not necessarily capture the experiences of the "typical" person with a disability. Typically, leaders in the disability community have formed strong, positive identities around their disabilities. Psychology does not have the large-scale, longitudinal studies to know how common this type of identity is, and how its presence or lack shapes the meaning individuals attach to their disability experiences.

Besides leadership development, another reason for examining the role of disability on the life course is that the population of the United States is aging and chronic illness or disability is more likely to become a normative experience (Albrecht & Levy, 1991). These authors also point out that the developmental and social implications of chronic illness or disability are quite different for adolescents or young adults than older adults, because, in our culture, impairments are often perceived as nonnormative in the younger age-groups. This nonnormative status may affect individuals' interactions with other disabled or nondisabled individuals.

Inclusion of individuals with TBI

There are many potential links between life course theory and the lives of individuals with TBI. First, a life course perspective can be used to examine the role of historical factors in individuals' lives. For example, in the current study, two of my participants with TBI were injured in the 1970's when the diagnosis of "traumatic brain injury" did not exist. One participant, ES, was seen as a "miracle" of survival by her family, friends, and doctors. In contrast, another participant, LS, was not given a diagnosis of TBI until more than a decade after her injury. She discusses the impact on her sense of identity, of relatives and friends who did not believe that she had impairments, and her resulting attempts to function in the world as if she did not have impairments (Slota, 2006). By utilizing a method in which participants have primary control of their narratives, they can volunteer the meanings that they have attached to their historical placement an how it affected their lives.

Second, many individuals with TBI participate in mainstream and/or specialized social institutions, like work or rehabilitation services, which may affect the individuals' experiences. An individual's successful or unsuccessful trajectory in a social institution may determine which other social institutions the individual will participate in later in the life course. For example, another participant in the current study, SV, was injured at age 17, and entered the system of homeless shelters at age 18, possibly because his parents didn't know about other available services (Slota, 2006). Eventually, this led him to vocational rehabilitation services and a residential placement.

Third, Clausen's social, historical, and chronological time can be used to see which normative, developmental experiences occur, and whether they occur at expected times, given the individuals' location. Many of the outcome studies (e.g., Rappaport et al., 1989) would predict that normative experiences like living independently do not happen, or happen later, for individuals with TBI. This fits with the earlier example given of BT's changing feelings toward living at home with his parents; when his older siblings were still at home, he wanted to; when they left, he felt left behind (Patti, 1999).

Fourth, a life course perspective allows the inclusion of multiple, nonnormative, life-altering events, which many outcome studies overlook. For example, one participant, TD, tells of three traumatizing events in her life: being kidnapped as a child, experiencing her brain injury and rehabilitation, and facing disability discrimination in graduate school. As she was telling her story, she concluded that the most traumatizing event was graduate school! This may have occurred for many reasons, including, but not limited to: graduate school was the most recent event, it made her question her student identity, it shook her sense of her academic ability, it was unclear to her if her academic abilities had been affected by her injury, and possibly, it made her question whether she could have the career she desired (Slota, 2006).

Fifth, a large-scale life course study of individuals with TBI could start to answer the call in Ragnarsson (2006) for an examination of the "duration, natural history, and life course manifestations (neurological, cognitive, social, psychological, economic, etc) of mild, moderate, and severe TBI" (p. 382). This article catalogued the next steps for TBI research and treatment, some of which may be fulfilled through life course research.

Lastly, since TBI and SCI may differently affect an individual’s biology, psychology, and social relationships, a life course perspective, which focuses on the interplay of these elements, is well-suited for research with these populations.

Life Course Theory & Narratives

Many life course studies (e.g., Karweit & Kertzer, 1998) have utilized government documents, like birth, marriage, and death certificates to form an historical, “factual,” documented sense of the life course in certain geographical locations. These studies treat life course events as documented fact; they do not allow room for personal reflection or meaning-making. In contrast, Cohler (1982) discusses how the life course can be construed as a series of narrative constructions, which change over time to fit an individual’s needs. Cohler links these changes to personal events and chronological life-stage changes, like middle childhood and adulthood, which contribute to societal and personal expectations about an individual’s role in society. Cohler argues that personal narratives are one way in which meaning can be attributed to life course events. As such, the next part of this paper will briefly review the narrative literature.

What are narratives?

How a "narrative" is defined depends upon the professional background of the investigator. Researchers in linguistics, literature, psychology, and sociology, have different, yet sometime overlapping, definitions of and uses for "narratives" (Daiute & Lightfoot, 2004). In literature, one concern is form, as seen through the device of plot (e.g., Couser, 1997), whereas in sociology, the intent of narratives is to pass on the important cultural aspects of an experience (e.g., Fisher & Goodley, 2007).

The field of linguistics defines narratives as one type of speech sample in which ideas are joined together to create a story with characters (e.g., Chapman, 1995). In linguistic studies in this vein, narratives are typically evaluated for content, cohesion, clarity, and complexity (e.g., Biddle, McCabe, & Bliss, 1996; Chapman et al., 1992; Cherney, Shadden & Coelho, 1998). As will be discussed below, there is some evidence that people with TBI may lack some content, cohesion, clarity, and complexity in their narratives, with the implication that what gets told is either not a narrative, or at best, is an incomplete narrative (e.g. Tucker & Hanlon, 1998). Linguistically, this distinction may not be important; cognitively, it may be a marker for the biological impairment;

psychologically, this interaction between cognitive impairments and linguistic abilities may affect one's ability to attach meaning to his or her experiences, social relationships, and sense of self.

In contrast to the linguistic definition, Daiute & Lightfoot (2004) define narratives as,

> . . .more than words or windows into something else. Narrative discourses are cultural meanings and interpretations that guide perception, thought, interaction, and action. Narrative discourse organizes life—social relations, interpretations of the past, and plans for the future. The way people tell stories influences how they perceive, remember, and prepare for future events (pp. x-xi).

Similarly, for Polkinghorne (1991) and other narrative theorists (e.g., Daiute & Lightfoot, 2004; Daiute & Nelson, 1997; Josselson & Lieblich, 1993; Spence, 1982), we are the narratives, or stories, that we tell about ourselves. Narrative theory posits that life experiences only become meaningful as they are narrated and integrated into one's life narrative. According to this theory, this meaning, not the experience itself, serves as the psychological foundation for individuals' identities and their lives (e.g., Daiute & Lightfoot, 2004). However, before this level may be explored, let us start at the lower, linguistic level.

TBI impairments and linguistic aspects of narratives

Using the linguistic definition of narrative, many studies have found differences in the narrative speech of individuals with and without TBI (e.g., Tucker & Hanlon, 1998; Chapman, Levin, Matejka, Harward & Kufera, 1995; Mentis & Prutting, 1987; Cherney, Shadden & Coelho, 1998). For example, Mentis and Prutting (1987), found that stories produced by individuals with brain injuries had less cohesion and transition, as compared to those by individuals without injuries, in both storytelling and conversational contexts. Similarly, Chapman et al. (1992), found that children and adolescents with brain injuries told disorganized stories when given story stimuli.

However, the above studies share several characteristics. First, the samples were often hospital-based, meaning that the injuries occurred relatively recently, so the individual is still undergoing the early stages of cognitive recovery. Therefore, results may not be representative of individuals' long-term performance. Second, because the studies were hospital-based, they assumed a medical model of impairment, in which the injured biology created linguistic deficits which needed to be repaired, regardless of the social environment surrounding individuals. Third, these studies were not examining real-world conversational interactions, so they did not necessarily capture the interactional nature of everyday story-telling. Fourth, the story-telling stimuli were novel; often, participants were given one or more pictures to tell a story about. Someone with a brain injury may face more challenges complete new tasks, so this activity may under-represent their linguistic abilities. Fifth, fictional, non-autobiographical storytelling based on a stimulus picture may or may not be a typical "school task" for children learning to read or learning to increase their reading comprehension. This again reflects the novelty and difficulty of the task. For adults, this fictional, non-autobiographical storytelling in response to a picture is not typically a daily task, which again may increase the difficulty.

My study has overcome some of these methodological design flaws. My participants with TBI were further post-injury and recovery. They were living in the community and were not receiving hospital-based rehabilitation services. Also, each participant was asked to tell his or her life story, which should be neither abstract nor novel. Additionally, fictional story telling data were collected (Slota, n.d.), so that future analyses can be conducted to compare these individuals' performances of autobiographical stories with their performances on a picture-based storytelling task.

The potential linguistic differences in linguistic productivity, cohesion, and complexity may have broader implications for social relationships (Marshall, 1989), because these differences may affect an individual's ability to form social relationships, which are often based on the sharing of narratives.

Qualitative studies are often interdisciplinary in nature. As such, they draw from multiple disciplinary approaches. As mentioned earlier, in order to study the meanings people give to their life experiences, this study uses information from the fields of medicine, sociology, linguistics, disability studies, and several subfields of psychology. These disciplinary frameworks often overlap, but for purposes of clarity and organization, they are being discussed separately. While this section of the paper focused on various definitions of narratives, the following sections detail various socio-cultural uses of narratives as meaning-making.

Narrative as Meaning-Making

People of all ages and developmental stages use oral or written narratives to explain or make sense of their experiences (e.g., Nelson, 1989; Daiute, 1995; Brubaker & Wright, 2006; Howie, Coulter, & Feldman, 2004). For example, Nelson examined how a young child would make sense of daily events by creating oral narratives before she slept each night; Daiute studied how elementary students integrate written conventions into their blossoming ability to use narratives to express themselves. Brubaker & Wright examined the narratives of teen mothers for narrative repair, to see how participants strengthened their identities for their new roles. Lastly, Howie, Coulter, and Feldman looked at the narratives of older adults and how they made sense of their vocational and avocational interests.

As seen in the above examples, it is not simply the age of the speaker or writer, but also the narrative form and focus which develops. Nelson’s “Emily” (1989) orally focused on recent events-past or future, while Daiute’s (1995) students who were already able to tell oral narratives, were learning, in the social setting of school, to apply their skills to a written format within this specific setting with its own expectations. The other two studies assumed that their participants “knew” the narrative format, and could use it to focus on reframing challenging developmental events—teen pregnancy or positive aging.

In all these studies, the narratives serve to construct meaning out of the events experienced by the individual. For example, in the Brubaker and Wright (2006) study, one of the tasks faced by individuals was to construct a positive, agentic, resilient, identity to counter the societal stereotype of teen mothers as ineffective or “bad” mothers. This task of turning a stereotypically negative event into something positive may also be experienced by individuals with adolescence-onset injuries.

Similarly, Solis (2004) examined change in identity status and agency of individuals as they developed from seeing themselves as “illegal” immigrants to "undocumented" immigrants. She used grounded theory to explore oral, written, and pictorial texts for the meaning-making that individuals experienced as they became more involved in a community organization, which, for some individuals, led to political activism.

Illness Narratives: Why and how do people with illnesses talk about their lives?

Strauss (1990) described three commonly researched uses of narratives about illness or disability. First, they may convey the experiences of being ill or disabled. Second, they may describe the daily tasks associated with living with the impairment, and, third, they may discuss identity work surrounding the illness. These uses can be thought of as a type of meaning-making and as a way to reproduce the illness experience for others.

One example of illness identity work using narratives, was done by one of Strauss' students, Charmaz (Charmaz, 1983; Charmaz, 1987; Charmaz, 1990). She used a grounded theory approach to examine narratives for identity issues in individuals with chronic medical illnesses. She found that, at any time, individuals tended to have one of four identities: supernormal, restored, contingent, or salvaged. The identities differed in terms of current and future expectations of activity level. For example, an individual with a supernormal illness identity was striving to do more tasks than would be expected of someone without a disability or illness.

In contrast to Charmaz's use of a medical sociology framework to explore identity status, Kameny and Bearison (2002) used a health psychology framework, to explore the themes of control, coping, social support, and identity development throughout treatment.

These authors analyzed narratives from adolescents and young adults with various cancer diagnoses, and found that the narratives did successfully address these issues, which have practical implications for service delivery.

The illness narratives literature is important for this study, because it illustrates how narratives are an appropriate method for collecting information about non-normative experiences with illness or disability. However, one drawback to this literature is that it tends to forefront the person's illness or illness identity, without examining other life events or identities. The current study examines how individuals with disabilities integrate disability experiences into their over-all life experiences.

What are "narrative" studies of individuals with cognitive impairments?

While there is a tradition of using qualitative or narrative methods with individuals with chronic medical illnesses or physical impairments (e.g., Gerhardt, 1990; Strauss et al., 1985), "narrative" research has rarely been used with individuals with cognitive impairments or disabilities. A literature search of PsycINFO articles conducted in August 2007, using the descriptors "mental retardation" and "narratives" located only 12 citations for articles about narratives or narrative research and individuals with "mental retardation." The term "mental retardation" was used because, that was the indexed term in the database. All of these articles were published from 1998 onward; earlier articles focused on teaching children with developmental disabilities how to understand fictional narratives.

Similarly, a literature search located few "narrative" research projects with individuals with brain injury. However, of these studies, only three sets of data (Crisp, 1993; Crisp, 1994; Nochi, 1997; Nochi, 1998a; Nochi, 1998b; Nochi, 2000; Chamberlain,

2006) elicited actual narratives from individuals with brain injury. Another article (Price-Lackey & Cashman, 1996), was a narrative retelling of the second author's vocational interests before and after her brain injury. Another two studies, Carson (1993) and Krefting (1990), used ethnographic methods and/or interviews to examine the familial relationships in families where one person has a brain injury. However, both of these studies focused more on the non-injured members than on the injured member. The last study (Morris, 2004) was not based on a research project; instead, it made the case for narrative therapy for individuals with traumatic brain injuries.

This paucity of studies about the narrative meaning-making by individuals with TBI may be due to several factors, which will be minimized in this study. First, individuals with TBI are often medicalized, only seen as patients, and narrative methods have not been fully integrated into medical research methodologies. Second, individuals with TBI may be stereotypically perceived as unable to participate in or unworthy of participation in narrative studies. Lastly, some individuals with TBI may have linguistic or cognitive impairments that may actually affect their data output in narrative conditions. In an attempt to minimize the role of potential impairments, this interview includes sections which draw upon different linguistic capabilities. For example, the life story section lessens the need for pragmatics like turn-taking, while the question-and-answer section and time-line sections increase pragmatics but lessen the individual's need to organize their speech, because the structure is provided in the questions or icons. Nevertheless, linguistic analyses will be carried out to investigate whether linguistic impairments may impact the data.

Summary & Synthesis

This literature review has proceeded from reviewing the medical aspects of traumatic brain or spinal cord injury, to a review of outcome studies, to the importance of using the sociocultural frameworks of life course and narrative theories to investigate the meanings people give their life experiences. This integration of life course and narrative frameworks will allow researchers to move from simply counting the presence or absence of an impairment, skill, or psychological construct for a large group of individuals, to focusing on the meaning given to the characteristic or its lack by the individual. This will yield a study of both group outcomes and individual's experiences through a lens of his or her current context, with links to the past and the future.

Research Questions

This study examined how people with or without disabilities constructed meanings around their life experiences. Although this endeavor requires integration, for purposes of organization, the research questions will first break this issue into pieces for analysis, and then the findings will be synthesized.

1. Are there within or between group relationships in the following measures: the time-line co-constructions, the Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997), linguistic productivity, and the Controlled Oral Word Association Test (Benton & Hamsher, 1978)?

2. How do individuals with TBI, SCI, or NKD use evaluative devices in their narratives? Specifically, how are causality, emotions, cognitions, perceptions, and conversations included? Does this vary within and between groups? If so, how?

3. How are life course elements (linked lives, human agency, location in time and place, and timing) incorporated into individuals' narratives? Does this vary between and within groups?

4. How do individuals with TBI or SCI narrate their injuries/disabilities within the framework of their lives?

Answers to these questions may start to illustrate how cognitive impairments may interact with or be reflected in narrative structure, meaning-making, and life experiences. This information may eventually help shape service provision in the areas of cognitive rehabilitation, community living, and outcomes measurement.

Chapter 3: Methods

This chapter outlines the methods for locating and recruiting participants. It then describes data collection and analysis.

Locating Participants

Attempts to locate participants occurred through many venues. Within Mount Sinai Hospital in New York City, if participants met criteria and had already participated in research conducted through the Rehabilitation Research and Training Center on TBI, they were called to see if they were interested in participating in the current study. Several colleagues also posted or gave flyers to potential participants. If the individuals then made or agreed to an explanatory phone call with the investigator, contact was made. Flyers were also distributed to members of the Women's TBI Support Group at Mount Sinai, and a flyer was hung in the Rehabilitation Research and Training Center on TBI, as well as in the out-patient rehabilitation clinic at Mount Sinai. Additionally, colleagues involved in the TBI community were asked if they would make initial contact with any of their friends who qualified for the study. If interest was expressed, this contact was followed by an explanatory phone call from the investigator.

Also, several organizations focused on individuals with traumatic brain injury (TBI), spinal cord injury (SCI), or adaptive athletics were contacted. Most organizations were willing to distribute flyers or hang them on walls; however, few individuals responded to the flyers. Similarly, the offices for students with disabilities at several City University of New York campuses were contacted; again, no participants were located. However, through one of these offices, contact was made with a student who ran an hour on public radio in New York City focusing on issues for people with disabilities. As a result, the investigator went on the radio show. Several people who heard the show did contact the investigator; none of them met the criteria.

Individuals with SCI who met criteria and received treatment through the SCI model systems clinic at Mount Sinai, were called to see if they were interested in participating. Postings were also made to web-based support groups, after getting approval from the moderator of each group. Some of these groups were national in scope, some of them were more local.

For several semesters, flyers for participants with disabilities were also distributed to the investigator’s students on the last day of class; students were told that they did not meet criteria for the study, but they could distribute the flyer to friends or relatives. Again, while some contact was made, the individuals did not meet the criteria.

For potential participants with no known disabilities (NKD), who needed to be matched linguistically and educationally to participants with TBI, initially, an announcement was distributed through a school list-serve. In 2004, IRB approval was granted through Hunter College, for flyers to be distributed to potential participants in courses in the Psychology and Educational Foundations departments. Contact was made with individual instructors; willing faculty were given flyers to distribute at the end of the semester. Over 1,000 flyers were distributed. Four students responded and were included.

As a result of these diverse efforts, 16 participants were enrolled.

Table 3.1 Participants located through each source

Source	Number of Participants Located
Previous Research at Mount Sinai	3 individuals with TBI
Women's TBI Group at Mount Sinai	3 individuals with TBI
From Colleagues	2 individuals with TBI
Sinai Clinical Services	1 individual with SCI
Local On-line Support Group	2 individuals with SCI
Graduate Center List-Serve	1 individual with NKD
Distribution of flyers at Hunter College	4 individuals with NKD

Participants

At the time of the interview, all 16 participants were between the ages of 19 and 49, and lived in the New York metropolitan area. All participants were able to communicate in English, and they were able to travel, alone or with assistance, to an interview in one of the investigator's offices in New York City. As such, the participants represent specific subpopulations of individuals with TBI, SCI, or NKD.

Participants' demographics can be found in Table 3.2, below. This table lists which group the individual belongs to, his/her gender, race/ethnicity, language status, education level, and age at interview. Race/ethnicity was coded as in the Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997). Where appropriate, age at injury and whether he/she has a demographic match are also listed. The listed order of participants is consistent in the graphs and tables throughout this paper.

Table 3.2 Sample Demographics

Panel	ID	Gender	Race	Language	Education	Age @ Interview	Age @ Injury	Matched to
TBI	DI	Male	2	English	H.S.	24	18	No match
TBI	TT	Female	2	English	Some College	29	17	No match
TBI	FT	Male	3	Spanish/ English	HS/GED	24	18-19 (no exact date)	KT
TBI	SV	Male	2	English	Some HS	23	18	No Match
TBI	TD	Female	1	Spanish/ English	Graduate School	28	24	MB
TBI	FC	Female	1	Russian/ English	Some College	21	16	DT, KH
TBI	LS	Female	1	English	MA	43	18	VZ
TBI	ES	Female	1	English	HS, some college @ same time	47	17	No match
SCI	KI	Male	3	Spanish/ English	Some College	20	14	N/A
SCI	KD	Female	1	English	HS	49	17	N/A
SCI	BQ	Male	1	English	College	43	18	N/A
NKD	KT	Male	3	Spanish/ English	Some College	20		FT
NKD	DT	Female	1	Russian/ English	Some College	19		FC
NKD	MB	Female	3	Spanish/ English	Some College	25		TD
NKD	VZ	Female	1	English	MA	41		LS
NKD	KH	Female	1	Polish/ English	Some College	19		FC

1=White, Caucasian 2=Black, African, African-American 3=Hispanic, Latino, Latina

As part of the criterion for participation, individuals with impairments were injured between the ages of 14-24, and were at least one year post injury. This cut-off was used because the first year after injury may be stressful, filled with health care appointments, and unrepresentative of what life will be like in the future. Also, before being accepted into the project, individuals with TBI were screened for a self-reported loss of consciousness (LOC) of at least 1 day. In contrast, before acceptance, potential participants with SCI or NKD were screened to exclude any participants with more than a brief loss of consciousness. However, this information was not always consistent between the screening discussion and the actual interview, so the groups may not be as separate as was assumed during data collection. Individuals with SCI were screened for a self-report of either paraplegia or quadriplegia and the use of wheelchairs for mobility.

Since the developmental variations between individuals who are 14 to 24 years old may be quite extreme, individuals with injuries were screened concerning their developmental status prior to their injuries. Individuals who were not completely independent from their families of origin before their injuries, were given preference. As can be seen on the table, 10 of the 11 individuals with disabilities were injured between the ages of 14 and 19. The one outlier at age 24 was a first semester graduate student, who, at the time of her injury, had not established complete independence from her family.

Individuals with no known disability (NKD) were matched to individuals with traumatic brain injury (TBI) on as many of the following criteria as possible: gender, language background, race/ethnicity, educational level, and age, in that order. As a result, 5 participants with NKD were matched to 4 participants with TBI.

Interview Procedures

For ease of discussion, the description of the procedures will trace participants from their first contact with the interviewer through the interview.

Pre-Interview Procedures

After learning of the existence of this project, potential participants contacted me through telephone calls, or if they had given verbal approval to a colleague for me to call them, I initiated the call. During this conversation, I explained the interview and screened them for whether they met project criterion. They were told that the interview would be a one-on-one, audio-taped, in-person interview at whichever of my available offices they selected. They were informed it should take approximately 4 hours, with a follow-up 15 to 30 minute phone call a day or two after the in-person interview. Participants were informed that these times were estimates, and that it could vary based on their interest and involvement.

During the initial phone conversation, I also informed them that they would be paid $25 for participating, and I explained their rights as participants (see Appendix A for the telephone script). For participants who were able to write and were their own legal guardians, if they decided to participate, they signed the consent form the day of the interview. If the individual was not his/her own legal guardian (as in one case), and he/she decided to participate, I told the participant that I would mail them the consent form for signatures; only after the form was returned to me, was the individual scheduled to participate. If a participant couldn't write, oral consent was taped. If, after hearing all the project information, the individual mentioned that he or she would like to participate but could not travel alone, I asked them if someone could accompany them. If the person was a family member or friend, I offered to pay that individual another $25 for his/her effort.

If an individual agreed to participate, an interview appointment was scheduled. If time permitted between the phone conversation and the scheduled appointment, I mailed participants a reminder letter, which included the time and date of their interview, as well as directions on how to get to the appropriate office. Also, the day before the appointment, I made a reminder call. If rescheduling was necessary, it was accomplished at that time.

Interview Procedures

Interviews were held in 1 of 5 offices, depending on availability and each participant's geographical preference. Two offices were at Mount Sinai, at 98th Street in Manhattan, one office was at Hunter College, at 68th Street, and 2 offices were at the Graduate School, at 34th Street. All the offices were similarly outfitted with at least 1 desk or table, a telephone, and a bookshelf or filing cabinet. None had external windows.

When the participant arrived for the interview, he or she was given the consent form to sign. If the individual was escorted to the interview, as happened in one case, the escort, who was a family member, was given $25 and waited in a separate lounge area.

Because the interview could be extremely lengthy, participants were encouraged to request breaks. If needed, which it was in two cases, the interview was completed on two separate days. In one case, this was done to work around class schedules; in another, it was due to fatigue issues. Also, breaks were scheduled between the sections of the interview. Water and sodas were provided by the interviewer, and several participants brought snacks with them or took breaks for lunch.

Interview Sections and Instruments

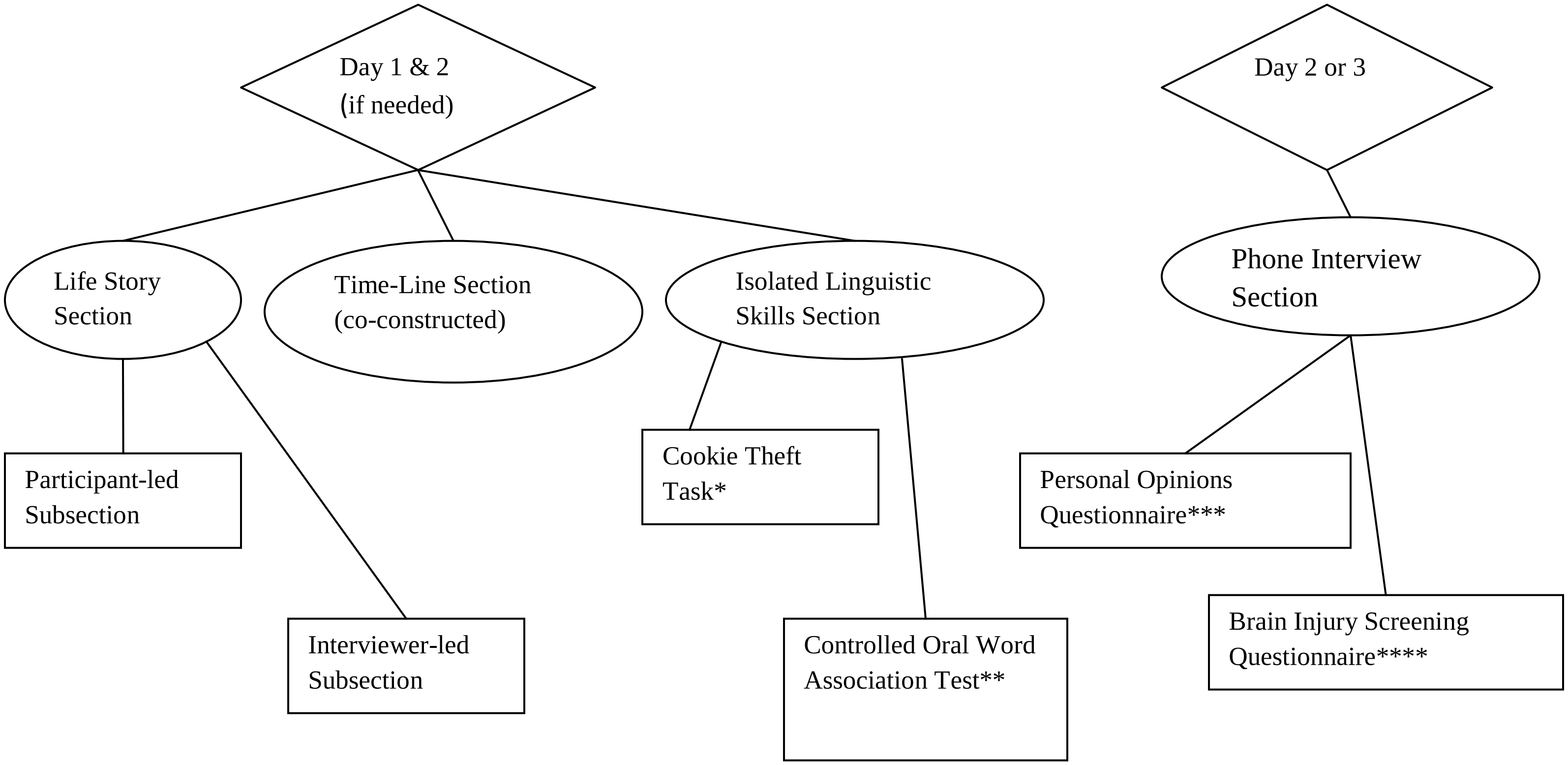
The interview had 4 major sections, with a total of 6 subsections. The main sections were:

- The “Life Story” section,
- The “Time-line” section,
- The “Isolated Linguistic Skills” section,
- The “Phone Interview”.

Figure 3.1 shows these major sections as well as the subsections. As can be seen in the figure, the “Life Story” section was composed of two subsections, the “Participant-led” subsection, and the “Interviewer-led” subsections (see Appendix B for the interview script). Although the entire interview could be seen as a “life story interview,” this section was given this title for ease of discussion, and to differentiate it from the time-line section. Similarly, although all conversation is dyadic, and who has control often switches between conversational partners, the terminology of “Participant-led” or “Interviewer-led” subsections was used to signify that, due to the methodology used, either the participant or the interview was assumed to be more directive.

The “Participant-led” subsection was based upon the technique developed by Rosenthal (1993). In her study, she interviewed people who were growing up in Germany in the 1930’s and 1940’s. She asked them to describe how the National Socialism movement affected the individual's life experiences. She then let the participant speak, with minimal interruption, until he or she was finished. Given that she

Figure 3.1 Sections and Subsections of the Interview



*Goodglass & Kaplan, (1983)   **Benton & Hamscher (1978)   ***Bolton & Brookings, (1998) **** Gordon, Brown, & Hibbard (1997) was of a different generation, Rosenthal believed that this technique minimized the possible contamination from her own ideas, perspectives, and questions. However, in her article, she does mention, without giving examples, that she made socially appropriate responses, when required. Her paper describes the experiences of one man, who was of the appropriate age to join Hitler Youth, and then fight in World War II. He starts by saying he doesn't know what to say, and that Nazism didn't affect his life. However, he then gave the longest interview of any of her participants, and gave examples of how his timing affected his post-war job opportunities and life. The current study adopted Rosenthal's technique for the above reasons, as well as reasons related to individuals' cognitive abilities. Some individuals with TBI may experience difficulties with the two-way nature of communication, due to the need to use pragmatic, conversational rules or short-term memory overload. For these individuals, an unstructured interview, which has some features of a monologue, may be most comfortable and productive.

If, at the start of this subsection, participants asked questions about how they should frame their stories or whether to include certain incidents, the interviewer encouraged them to make their own decisions, because they were describing their own lives. If participants were still unsure, the interviewer asked a probe question about childhood or suggested a chronological approach; this was typically enough encouragement.

In the second subsection, the "Interviewer-led" subsection, the interviewer asked some clarification questions and also several standard questions. Clarification questions focused, in part, on idiosyncratic issues mentioned in the interviews, such as participants' bilingualism and acquisition of spoken English. The standard questions (see Appendix B for the interview script) included several topics, such as the participant's contact with people with disabilities before and after his/her injury, and his/her knowledge of the Americans with Disabilities Act

The second section of the interview, the Time-Line Section, had no subsections. It involved a co-construction, between the interviewer and participant, of the participant's time-line. Although a time-line may include stories about individuals' lives, the name of this section reflects that a paper-and-pencil time-line was created. This activity was included in the study, because it built on different cognitive and linguistic abilities than the "Life Story" section. Here, the influence of the participant's two-way conversational abilities and memory may have been be more apparent. However, the individual was given visual cues, in the form of icons, to be placed on the time-line (see Appendix C). These visual symbols were based on Bruckner & Mayer (1998), to cue for the following issues: family, friends, significant romantic relationships, education, hospitalizations, non-normative life events, housing, and jobs (paid or volunteer). (See Appendix C for pictures of the visual icons.) In terms of providing structure for the participant, the interviewer made suggestions, such as completing all schooling icons before moving to the next set of icons.

The purpose of the "Isolated Linguistic Skills" Section was to examine some of the specific language characteristics that might influence the content and structure of the stories in the first two parts of the interview. The "Cookie Theft Picture" from the Boston Diagnostic Aphasia Examination (Goodglass and Kaplan, 1983), was used to examine how individuals tell a story when given the same stimuli (Slota, unpublished data, n.d.). The Controlled Oral Word Association Test (Benton & Hamsher, 1978), a verbal fluency task, was used to assess verbal ability, in order to see if this ability was related to other aspects of individuals' life stories. Benton and Hamsher were the original creators of this task; others have created norms for similar tests.

At the end of the "Isolated Linguistic Skills" section, participants had an opportunity to ask follow-up questions they had about the study, and they scheduled a follow-up phone call to complete the two questionnaires.

One or two days later, at the prearranged time, the fourth, follow-up section, was administered via a phone call. Participants were asked whether the call could be taped, and they were told that it should take 15 to 30 minutes, but that this was an approximation. This call also verified that participants did not experience harm from the initial interview. It completed the study, by administering the Personal Opinions Questionnaire (POQ), a measure of intrapersonal empowerment (Bolton & Brookings, 1998) and the Brain Injury Screening Questionnaire (Gordon, Brown & Hibbard, 1997). These instruments were administered last, so that they would not influence other sections of the interview.

The empowerment questionnaire allowed for triangulation between data sources, about identity and sense of agency gathered from the first three parts of the interview. Bolton & Brookings' (1998) questionnaire has four identity subscales: personal competence, group orientation, self-determination, and positive disability identity. Personal competence is one's belief in his or her ability to complete tasks in their lives; there were 24 items on this subscale. Group orientation is whether the person perceives that he or she accomplishes tasks better in individual or group activities; there were 15 items on this subscale. Self-determination is defined as the ability to chose one's future goals and directions; there were 14 items on this subscale. Positive disability identity is the belief that one has a positive sense of him or herself, in relation to his or her disability and daily life activities; there were 11 items on this subscale. Each subscale had items that were written positively or negatively. All four subscales were administered to individuals with disabilities; nondisabled individuals were given the first three subscales.

The Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997), collected data about an individual's history of hits to or on the head, periods of unconsciousness or confusion, and frequency of cognitive symptoms that have been problematical in the current month. Although this instrument is a self-report of symptoms, not a comprehensive review of an individual's medical files, it was necessary in order to collect similar data about everyone's symptoms, which participants may not have always included during the "life story" section of the interview. Throughout the phone interview and after the questionnaires were completed, participants had another opportunity to ask any questions they had about the study.

Transcription

Transcripts of the interviews were formatted to focus on word-level information. Therefore, pauses were noted, but not timed. Similarly, phonetics and stuttering were not noted. However, false starts and changes in mid-sentence were noted. Sentences were formed when intonation, pauses, or subject changes made it fairly obvious to the investigator, a native English-speaker, that a new thought was being introduced. To check accuracy, transcripts were listened to a second time; any necessary corrections were made.

Levels of Analysis

For the purposes of this project, there will be four levels of analysis (listed from largest to smallest): interview sections, interview subsections, events, and T-units (Hunt 1965, 1970 cited in Cherney, Shadden & Coelho, 1998). Table 3.3 below summarizes the definitions and gives examples of these levels.

The unit of analysis of the interview section was used primarily for the length analyses. Due to participant characteristics, length analysis, which was measured by time audiotaped, was important in determining if group membership affected the amount of data. Although this simple time measurement may disguise group differences because of differing rates of speech, a more detailed length analysis is not needed until in-depth linguistic analyses are carried out, since the two issues may be inter-related.

The interview subsections were utilized in the analyses in several ways. For example, an individual's (or a group's) performance could be tracked across subsections, to see if one method of data collection worked differently than the others. Also, several analyses were conducted solely within one subsection. For example, linguistic productivity was calculated within the “Participant-led” subsection, because that was where the participant controlled the discussion.

Given that time-lines record events, I created the construct of events, for my master’s thesis (Patti, Unpublished), in order to compare pieces from the narrative and time-line sections. Events are happenings in the life story, which may or may not be fully described, and which could appear on a time-line (Appendix D). I chose to avoid the terminology of “episode,” because that construct carries some literary assumptions about

Table 3.3 Levels of Analysis and examples

Level of Analysis (Source)	Definition	Examples from my 2nd year project
T-unit (Hunt, 1965, 1970 cited in Cherney, Shadden, & Coelho, 1998)	"... one main clause plus any subordinate clauses or nonclausal structures attached to or embedded in the main clause" (p. 22).	1 T-unit: **I got hit by the car.** 1 T-unit: **and then, when I was eight months old, in the middle of a blizzard, we moved to the house where I was lived (sic) for the next 14 years.** 2 T-units: **And in 1986 all my friends graduated high school,** *and I didn't.*
Events	"... any action by self or others that happened, with or without further elaboration. The event can be as small as one clause or as large as many clauses (even over sentence boundaries), as long as the clauses provide topical cohesion and/or elaboration. Topical cohesion means that several actions that are thematically related can be part of 1 event. The elaboration may include: evaluation, description, references to time, outcome, and causal attributions. Event boundaries occur between clauses or between sentences where a shift in topic occurs."	1 Incident: **... then I was sent home and was coming for outpatient visits, to M- a couple days a week,** 1 Incident:**. . . And I grew up here in E-, Q-. And, um, I'm the youngest of five children--two brothers, two sisters. And um, growing up, we had, on our block, we had like a lot, a lot of kids, and we were the only ones who weren't Hispanic, but y'know whatever.**
Interview Subsection	This is based on the structure of my interview.	The subsections are: Participant-led, Interviewer-led, Cookie Theft, Controlled Oral Word Association Test, Personal Opinions Questionnaire, and the Brain Injury Screening Questionnaire.
Interview Section	This is based on the structure of my interview.	These are: Life Story, Time-Line, Isolated Linguistic Skills, and Phone Interview.

the form or structure of the retelling, which may or may not be true for some of the events narrated by my participants. Similarly, while events may share some characteristics with “focal points” or “turning points,” these terms imply a certain construction, usage, and importance, which may or may not be present in the speech of my participants.

A T-unit, or minimal terminal unit, is the smallest linguistic unit which carries meaning and can be punctuated as a simple or complex sentence. As shown in Table 3.3, a T-unit can be a simple sentence with one independent clause (noun + verb) or a complex sentence (noun + verb + subordinate clause). Compound sentences, which are made of two main clauses, count as 2 T-units. In my master’s thesis (Patti, 1999), I counted clauses instead of T-units. However, this clausal system gave equal weight to independent, stand alone, clauses and dependent clauses; this may have camouflaged differences in linguistic structure, since individuals without linguistic impairments may use more independent clauses, while individuals with linguistic impairments may improperly use dependent clauses as stand-alone clauses. T-units make this discrimination. As discussed later in this chapter, T-units are integral building blocks for several linguistic analyses.

Due to copyright, Appendix E outlines only the changes required to the system found in Hunt, (1965, 1970 cited in Cherney, Shadden, & Coelho, 1998) for operationalizing T-unit boundaries. The changes were needed because of overlapping speech or speech that was unintelligible and could not be transcribed, among other issues..

As shown in the chart above, I did not include “narrative” as a unit of analysis. This is due to findings in the linguistic literature that some people with TBI create and tell incomplete or impoverished narratives (e.g., Mentis & Prutting, 1987). Since this potential group difference could complicate the operationalization of smaller narratives within the full life narrative, and it could complicate the comparisons of "narratives" across groups, it did not make sense to compare units of analysis called "narratives." For example, if the definition of narrative includes resolution of the incident being described, individuals with TBI might not resolve their incidents, so therefore the boundaries of "narratives" would be inconsistent across groups. Although all the participants were cognitively able to complete the various sections and subsections of the interview, there were variations in how this was done. Initially, several participants were unsure where to start. Most decided within the first two minutes, and then they continued to talk without significant prompting. However, a few needed more structure, so that their "Participant-led" subsection became more conversational in nature, with the interviewer both asking and answering questions. The field of linguistics might say that these individuals were unable to form full narratives that carried meaning; I would argue that conversations about the success or failure in making Jello, driving a car, and playing on a high school basketball team, among other topics, do convey meaning about the individual's identity and what is important to the individual.

Additionally, the purpose of this study was not to examine whether or not both groups had "complete narratives;" it was to examine how people create meaning. Therefore, it was more useful to break all the interviews into "events" (see Appendix D) and then examine the linguistic characteristics of "events" within and between groups. As will be seen in the next chapter, there were group differences in which details were included in the description of events.

As noted in the table, it is assumed that: events are constructed from 1 or more T-units, an event may be a complete or incomplete narrative, interview subsections are constructed from multiple events, and interview sections themselves may contain complete or incomplete life story narratives. While this sounds confusing, it may be easier to visualize these relationships. The row of blocks, below, represents an individual's "life story" or "time-line" section of his or her interview. Each block represents a T-unit. The groups of T-units enclosed in darker outlines represent events, and multiple events are included in one interview subsection. Depending on the individual, these events may or may not form a prototypical narrative.

Figure 3.2 T-units and events

Length Analyses

Before substantive analyses were conducted, within and between group length analyses were conducted. This was necessary, because group differences in length could affect the amount of data across groups, which might skew the comparisons for the research questions. As mentioned above, length was measured as a function of time. Additionally, for the "Participant-led" subsection, length was also described as number of events narrated and number of t-units. While all three of these measures are correlated, there is also individual variability in rate of speech, amount of details in events, and length of t-units, among other issues.

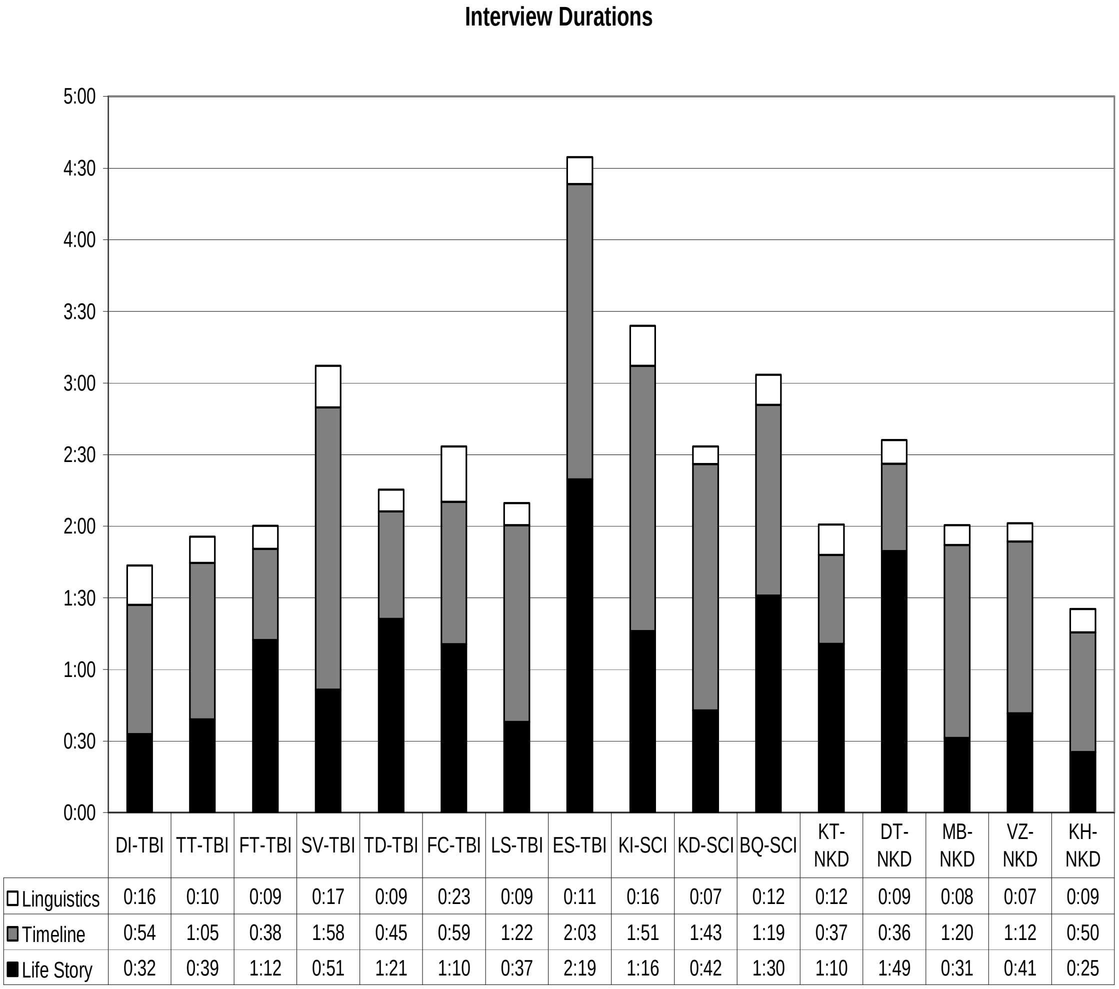
Descriptive statistics on time spent per section were as follows:

Table 3.4 Interview length as a measure of time in minutes

Interview Section	Statistic	TBI	NKD	SCI
Life Story Section	Mean	65	55	52
	Median	61	41	42
	St. Dev.	35.0	34.7	33.7
Time-Line Section	Mean	74	55	77
	Median	62	50	79
	St. Dev.	32.5	20.1	26.5
Isolated Linguistic Skills Section	Mean	11	9	9
	Median	10	9	9
	St. Dev.	3.3	1.9	2.5

This table shows few differences between groups, yet there are relatively wide standard deviations, meaning outliers had an effect. Each group had individuals who talked for less time, as well as individuals who talked for more time. Figure 3.3 below shows individual lengths of time, so the inter-individual variability can be seen.

Figure 3.3 Interview Durations by Individual



	DI-TBI	TT-TBI	FT-TBI	SV-TBI	TD-TBI	FC-TBI	LS-TBI	ES-TBI	KI-SCI	KD-SCI	BQ-SCI	KT-NKD	DT-NKD	MB-NKD	VZ-NKD	KH-NKD
□ Linguistics	0:16	0:10	0:09	0:17	0:09	0:23	0:09	0:11	0:16	0:07	0:12	0:12	0:09	0:08	0:07	0:09
▨ Timeline	0:54	1:05	0:38	1:58	0:45	0:59	1:22	2:03	1:51	1:43	1:19	0:37	0:36	1:20	1:12	0:50
■ Life Story	0:32	0:39	1:12	0:51	1:21	1:10	0:37	2:19	1:16	0:42	1:30	1:10	1:49	0:31	0:41	0:25

Similarly to length as a function of time, length of the Participant-led subsection can be measured through number of events or number of t-units. Table 3.5 below, shows the descriptive statistics for events, and Table 3.6 shows the descriptive statistics for t-units.

Together, these tables hint at the variation within and between groups. Because of outliers, the means may be skewed and not as robust as the medians. For example, the median number of events for the TBI group seems to be substantially shorter than the medians for the other groups, which means the narratives created by individuals with TBI

Table 3.5 Number of Events by Group

	Statistic	TBI	NKD	SCI
Number of Events in the Participant-Led Subsection	Min	23	34	74
	Max	114	108	104
	Mean	56.38	64.8	86
	Median	35	61	80
	Standard Deviation	38.18	28.42	15.87

Table 3.6 Number of T-Units by group

Statistic	TBI	NKD	SCI
Min	116	163	432
Max	1925	902	860
Mean	525.38	465.40	699.67
Median	315	406	807
Standard Deviation	604.88	307.87	233.32

have fewer events. However, because of ES's role as an outlier in terms of length of time spent on the interview, the standard deviation for the TBI group is significantly larger than the group's mean.

Table 3.6 shows the variations in t-unit counts within and between groups. The number of t-units is indirectly related to meaning-making, because if a participant speaks more, he or she may have more opportunity to create shared meanings. However, a participant may speak t-units that are very unproductive; therefore, they wouldn't include much information for creating meaning.

Now that the length analyses have been discussed, the methods for answering the research questions can be outlined. As mentioned previously, this study examined how people with or without disabilities constructed meanings around their life experiences. Although this endeavor requires integration, for purposes of organization, the research questions will first break this issue into pieces for analysis, and then the findings will be synthesized.

Research Question 1: Are there within or between group relationships in the following measures: the time-line co-constructions, the Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997), linguistic productivity, and the Controlled Oral Word Association Test (Benton & Hamsher, 1978)?

In examining the data from this project, it became clear that one variable internal to this study seemed to capture the individuals who might stereotypically be identified as "lower-functioning." This variable related to how individuals completed the time-line section of the interview (Slota & Peffley, 2007). As mentioned above, the time-line utilized 8 icons, which each included standard questions about that area of life (see Appendix C for the icons). Within the TBI group, individuals could be broken into subgroups: “Individuals with Full Icon Usage” or “Individuals with Partial Icon Usage.” What these terms mean, is that some individuals with TBI either indicated that they had none of that area in their lives (e.g., significant romantic relationships), or that they didn’t want the topic included on their time-lines. The next chapter goes into more details about these two groups of individuals, and how they performed in other aspects of this study.

One measure of cognitive impairment used in this study was the Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997). The BISQ is a self-report of cognitive symptoms that have recently caused difficulty. Performance on this questionnaire will also be compared to the results of the other research questions. All of these analyses will be compared within and between groups. Again, this research question measures various cognitive abilities in order to examine whether they may play a role in the individual’s performance in the remainder of the interview, and whether these abilities may interact with the individual’s meaning-making. This research question sets the foundation for examining whether various cognitive measures differ within or between groups. If inter-group variability does exist, then these measures may serve as proxies for examining if, or how, cognitive abilities interact with how individuals create meaning in their lives.

In order to measure linguistic productivity, several foundational analyses were required. First, the text needed to be broken into t-units. This was done solely for the Participant Constructed Subsection. Appendix E outlines the changes made to Hunt’s paradigm for deciding on t-unit borders. Then, linguistic productivity was calculated. Productivitiy is an indication of how many false starts, tangents, and/or interruptions that a speaker makes, which may interfere with the listeners’ comprehension. It is calculated as the percentage of edited words/total words (Shadden, 1998). For expediency, and because the length of the Participant-led subsection varied between individuals, it was decided to calculate productivity on the first 1,000 words. Not all participants had t-unit breaks at word number 1,000, so the calculation included the full t-unit above word 1,000. The rules for editing out empty, unimportant, and/or extraneous words came from (Shadden). This productivity level was important, because it might show whether there is a difference, between groups, in how smoothly language proceeds.

Linguistic productivity was then compared to several other measures in this study. For example, it was compared to the length of the Participant-led subsection, amount of codes in the Participant-led events, and scores on the Controlled Oral Word Association Test (Benton & Hamsher, 1978), a verbal fluency task.

For the COWAT, participants brainstorm words starting with 3 different letters. The COWAT was scored using the 2nd edition of the norms, which only divide individuals based on educational level and race Performance on this task was also compared to the results in the other sections, to see if they explain some of the individual differences in performance.

Research Question 2: How do individuals with TBI, SCI, or NKD use evaluative devices in their narratives? Specifically, how are causality, emotions, cognitions, perceptions, and conversations used? Does this vary within and between groups? If so, how?

As stated earlier, each individual’s entire Participant-led subsection was broken into events. Based on Daiute (1995), each event was coded for use of evaluative devices: causality, emotion words, words representing cognitions, words representing perceptions, and examples of having specific “characters” speak within the event (see Appendix F).

As an example of the last category, some participants' told stories in which, "He said to me. . . ," and "I said to him. . . ." It was thought that this is a fairly complicated cognitive task, so this set of codes may show group differences, because it may require a participant to have a certain amount of memory for the event, to have the ability to take another's view, and/or to have a complex story grammar. Additionally, events were coded as to whether this "speech" was internal or external. For example, "I said to myself. . . ," "he said to me. . . ,"or very infrequently, "He said to himself. . . ."

These codes form a foundation for examining how individuals assign meaning to their experiences, and whether there are group differences, in either frequency of usage or types of devices used.

Research Question 3: How are life course elements (linked lives, human agency, location in time and place, and timing) incorporated into individuals' narratives? Does this vary between and within groups?

As outlined in the literature review, there are many investigators who have each constructed their own life course theory and constructs. However, as stated earlier, Giele & Elder (1998) wrote that life course theories typically share four characteristics: location in time and place, linked lives, human agency, and timing This project focused on a few aspects of each of these constructs.

Linked lives were coded in terms of whether parents, nondisabled friends, friends with disabilities, significant others, or "miscellaneous others" were mentioned in each event (see Appendix G). For each category, except the miscellaneous category, the person who was mentioned was coded for a positive, negative, or neutral valence, as described in the event. Additionally, whether or not the research participant mentioned the other's perspective in the event was coded. Given that perspective-taking is a fairly complicated cognitive task, it was believed that the inclusion of perspective-taking might be related to group membership and/or cognitive abilities.

One aspect of location that was investigated was the role of institutions in individuals’ lives. Events were coded specifically for mentions of school, work, rehabilitation/hospitals and “other institutions.” These mentions were about the cultural, institutional role of various locations; they were not about individual teachers, bosses, etc., which were coded under “linked lives.” Institutional mentions of school, work, and rehabilitation/hospitals were also coded for valence: positive, negative, or neutral, as well as whether the participant linked it to a previous event.

As another feature of location, immigration stories were also analyzed (Slota & Peffley, 2005). Over half the participants told these stories, whether it involved themselves or their parents. Given that immigration, like disability, is often seen in as a negative, stressful, life event, it was theorized that successful immigration could be used as a stepping-stone to help individuals see that they can cope with the “stressor” of a new disability.

Human agency was initially coded, within each t-unit, by whether the main verb was in active or passive voice. However, perhaps because the use of passive voice may be more cognitively complex than the use of active voice, or because of the nature of this interview task, or other issues, initial counts of passive voice were too low to yield enough data for comparison. Instead, human agency was scored using the 4 subscales of the Personal Opinions Questionnaire (Bolton & Brookings, 1998): Personal Control, Goal Orientation, Self-Determination, and Positive Disability Identity. As mentioned above, together these subscales measured a construct called “intrapersonal empowerment," which seems to reflect whether the person feels a sense of agency or control over his or her life and life decisions.

Timing was explored through 2 exemplars. First, individuals' experiences with the Americans with Disabilities Act, were analyzed to examine whether participants knew their rights and whether participants used them. Second, participants' school experiences with "special education" or college "accommodations" were examined. For each person with an injury, their years of schooling were coded for regular or special education, and accommodations or no accommodations. Schooling was used as an exemplar for timing, because it does imply a normative sequence. Also, given that my sample was injured between the 1970's and the 1990's, schooling may show cohort or timing effects, partly because of changes in educational laws.

Research Question 4: How do individuals with TBI or SCI narrate their injuries/disabilities? Are there differences within and between groups?

After dividing individuals' Participant-led Subsections into events, each event was coded as to whether it mentioned or described the initial injury and the hospitalization until the person "woke up," or personal stories of hospital life, rehabilitiation, and the after-effects of the injury/post-injury limitations. Individuals' patterns were then explored for similarities and differences, as well as the meanings they assigned to the role of their injury in their life experiences.

Reliability, Validity, Predictability, and Generalizability

Now that an overview of the analyses has been given, several issues need to be addressed. Just as rigorous quantitative studies must meet criterion for reliability, validity, predictability, and/or generalizability, there are techniques to increase these features in qualitative or mixed research designs. Because my study will examine the process that people use in telling their stories, this project may never be predictive of group outcomes in the lives of people with brain injuries; however, by providing a snapshot, it will raise questions for future investigations with larger populations.

Reliability

In qualitative psychology, several methods have been used to try to overcome the criticism that the results are based on a single researcher's unreliable, privileged relationship with the data. To overcome this sense, I included a traditional reliability coder for my content analyses. My coder and I achieved an overall agreement of 90.52% for the evaluative codes, linked lives, and location codes.

Validity

I had several methods for ensuring validity. First, I had several sources for triangulating the data. I had the life story and time-line sections of the interview for partially triangulating life events, when events were mentioned in multiple sections of the interview. Second, I also had linguistic measures and the Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997) to catalogue symptoms and abilities, which might affect performance in the other sections. Lastly, the study included the Personal Opinions Questionnaire (Bolton & Brookings, 1998), to support the face validity of individuals' sense of themselves across types of data.

Generalizability

I dealt with generalizability by focusing on themes that run ACROSS individuals, instead of focusing on individual differences. Even though I will not be able to predict which individuals in the larger population would have these themes, I would be able to say that it's not just a theme based on one individual.

Tying the Analyses Together

It may seem that the distinctions between the above research questions and analyses are somewhat arbitrary and therefore, lose their ability to create meaning through an overarching framework. However, in the results and discussion chapters, these disparate results will be incorporated into each other, so that a framework is formed to show how this sample of individuals with or without cognitive disabilities speaks about themselves, their lives, and their injuries. These findings will point towards new research areas and areas for service improvement.

Chapter Four: Results

This chapter outlines findings for each of the research questions, and then integrates the results, to illustrate individuals' meaning-making.

Research Question 1: Are there within or between group relationships in the following measures: the time-line co-constructions, the Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997), linguistic productivity, and the Controlled Oral Word Association Test (Benton & Hamsher, 1978)?

As mentioned in the previous chapter, there was one variable internal to this study which seemed to reflect a mixture of cognitive and social functioning (Slota & Peffley, 2007). This variable was whether individuals incorporated all 8 areas of life represented by the time-line icons (housing, relatives, schooling, friendships, romantic relationships, jobs, medical events, and life events), into their personal time-lines. "Individuals with Full icon usage" incorporated all 8 types of icons on their time-lines. This group consisted of all individuals with SCI and NKD, and half the individuals with TBI.

The other half of the TBI group were "Individuals with Partial icon usage," who did not nominate all 8 areas of life. Intriguingly, none of the individuals in this group neglected only one area of life; they were all "missing" 2 or 3 areas of life. These missing areas were social in nature: jobs, friendships, romantic relationships, and miscellaneous life experiences. However, cognition may have played a role in several ways. First, individuals may have lacked the memory of the occurrence of the icon in their lives. Second, there is cognition involved in discussing and placing the icons on the time-line; this is especially true of the miscellaneous category, which was meant to capture the unique and nonnormative experiences people have had. Third, these individuals may perceive themselves, or be perceived by others, as not being able to participate in the social experiences represented by the icons.

Most “Individuals with Partial Icon Usage” said that they had nothing in a specific area (like they had never been in a romantic relationship). In some of these cases, information from other sources or earlier/later parts of the interview did not support their statements. In these cases, the missing icon might, partially, be a result of memory issues. In other cases, the individual actively declined icons, even though they might have mentioned the topic in their life story section.

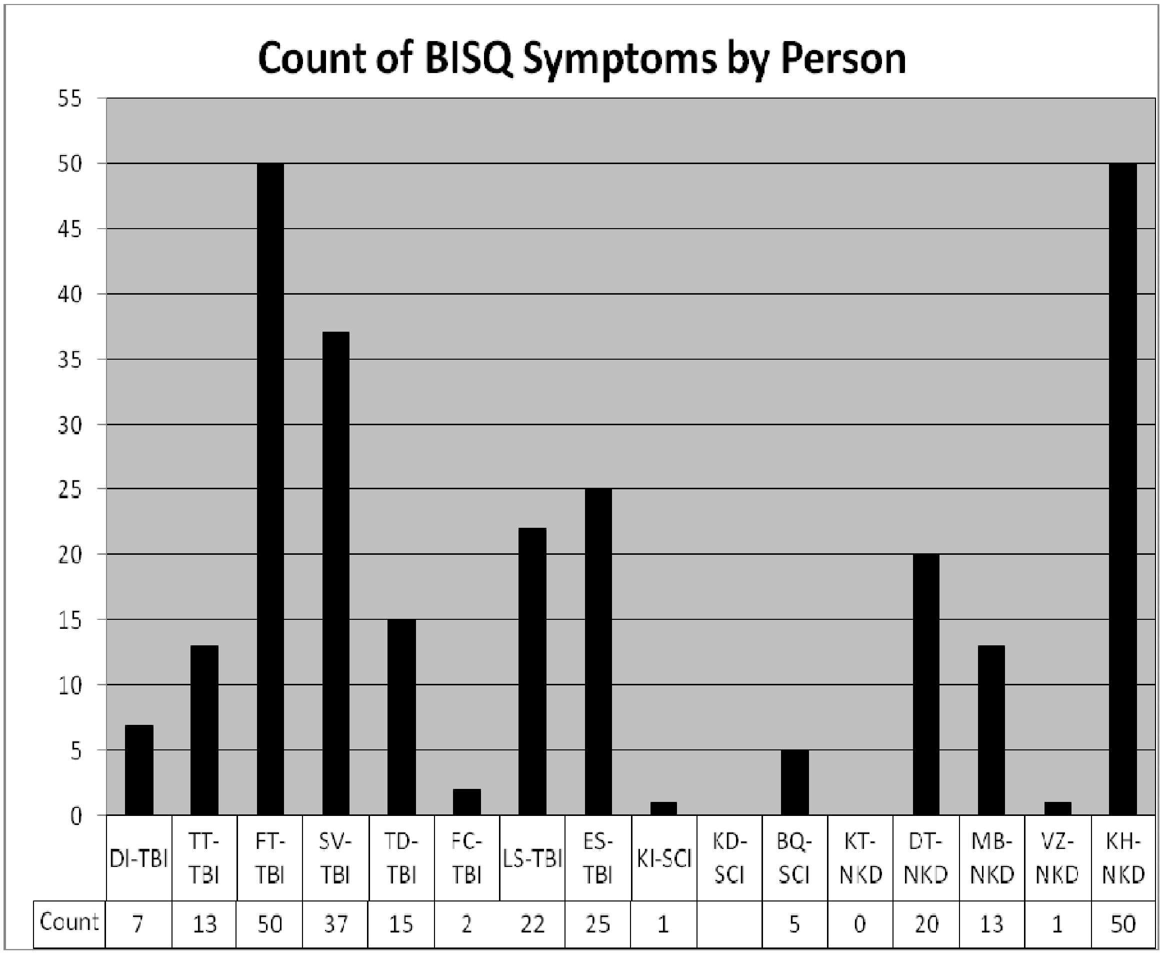
The interviewer’s impression of the group “Individuals with Partial Icon Usage” was that they were living with cognitive impairments which interacted with their ability to find opportunities for socialization, and their actual socialization. Many, but not all, of these individuals were receiving social services, but several individuals with TBI in the full usage group were still undergoing neuropsychological therapy. So, partial icon usage may be a proxy variable for disability caused by the interaction of cognitive skills, social skills, and access to the normative social environment. In the following analyses, the performance of “individuals with partial icon usage” will be highlighted, because it is the impact of cognitive disability on an individual’s meaning-making that is under examination in this study.

Due to the nature of this study, in which subjective perceptions were primary, individuals’ medical records were not reviewed. Therefore, the interviewer’s knowledge of participants’ symptoms was based on disclosures during the “life story” and “time-line” sections, informal observations of the individual in the setting of the study, requests for accommodations, such as a larger copy of the “Cookie Theft” picture, and participant’s answers on the Brain Injury Screening Questionnaire, (BISQ) (Gordon, Brown, & Hibbard, 1997).

As mentioned earlier, the BISQ asks participants about their history of head hits and cognitive symptoms which were a problem in the past month. If all participants are included in the analyses, there are no statistically significant group differences in scores on the BISQ. However, an examination of Chart 4.2, below, shows individual variability and individual outliers. The TBI group affirms an average of 21.4 ±15.9 symptoms as being a frequent problem. KH is the only non-TBI individual to fall in the +2 SD range for symptoms, while the remaining SCI and NKD members fall in the -1 and -2 SD ranges. If KH is removed from the “No Known Disability” group on the basis that her history hints at possible cognitive impairments due to childhood epilepsy and street drug use during adolescence, the SCI+NKD vs. TBI group differences do become statistically significant (.05 if 2-tailed, .02 if 1-tailed). Although the sample size in this study is extremely small for conducting statistical analyses, this finding suggests that the BISQ may screen for potential cognitive impairments, regardless of the source.

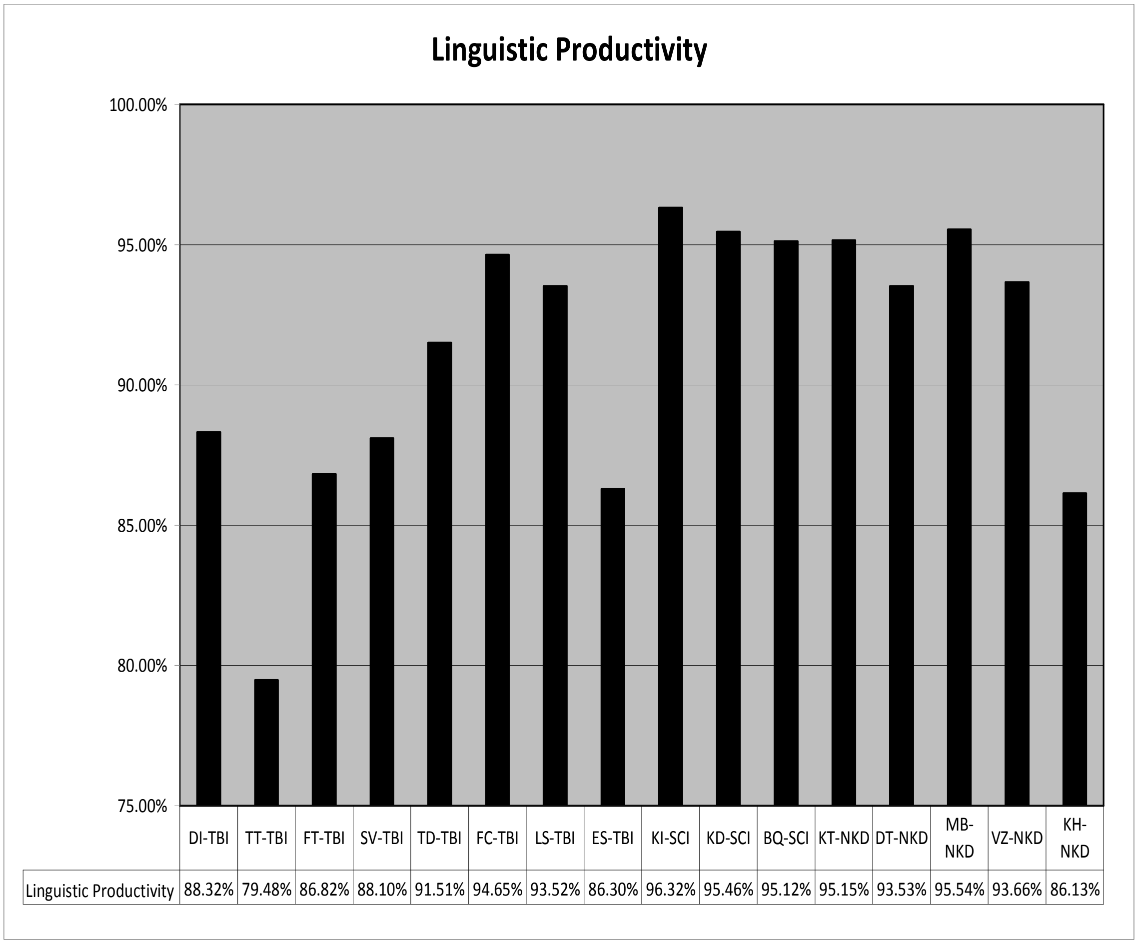
The four individuals in the “Partial Icon Usage” group were DI, FT, SV, and TT. Their demographic details can be found in table 3.1. Examining their BISQ symptoms, FT and SV reported the highest number of symptoms in the TBI group, and DI and TT reported fewer symptoms. This may again reflect cognitive abilities, because in order to nominate a symptom, one has to recognize that it exists and whether it is a problem, given one’s life activities. If one’s life activities have been simplified, then fewer cognitive tasks are likely to be problematical, because the individual is not responsible for doing the tasks. So, just as the time-line captured a potential interaction between cognitive skills and social opportunities, the BISQ may capture a potential interaction between cognitive skills and life activities, which may affect how individuals view their lives.

Figure 4.1 BISQ SYMPTOMS



Another cognitive measure included in this study was "Linguistic productivity." This measures the percent of words in a t-unit which actually convey the syntax and/or semantics of the clause. As stated in chapter 3, linguistic productivity scores were based on the t-unit boundary above the first 1,000 words in the Participant-led Subsection of the interview. Chart 4.1 below shows each individuals' scores, which reveal between-group differences. The full TBI group average was 88.59%±4.8%, which t-tests showed to be significantly different (p=.024) from the combined SCI and NKD groups' scores (93.86±3.26). All four of the "Individuals with partial icon usage" scored below the TBI average, but that was also true for ES. The only non-TBI individual who fell below the TBI average was KH. More will be mentioned later about the profiles of ES and KH, because they are both outliers on multiple measures in their respective groups.

Figure 4.2 Linguistic Productivity in the first 1,000 words



Linguistic productivity may have a fairly direct impact on the difficulty a the participant has in creating their narrative, as well as the difficulty the listener has in understanding the narrative. For example, one early piece of TT's "Participant-led" subsection is: "I um, (pause), in, in um, 1981, my mother, my brother, um, and my father, we moved to where I live in now, um, I started, I started, um, June-, no, I started, I think, I was in, I was either in the 4th or the 5th grade,. . ." As this shows, she repeats words or phrases, has false starts, and doesn't give much detail about the event of moving or being in a new school.

In contrast, KD starts her narrative with, "well, I um was born in New Zealand. I lived on a, a small dairy farm. It was about 250 acres, and we lived in the country. I had, I have a twin sister, I have two older sisters, and had mom and dad, two parents. . ." KD's narrative has fewer false starts and conveys more information than TT's. As these examples show, linguistic productivity does seem to impact how people are able to convey meanings through their narratives. Lower productivity does not necessarily mean that individuals cannot convey meanings; it may simply mean that the individual and his/her listener need to work harder by paying more attention and structuring the conversation.

Another non-narrative measure of linguistic ability which was included in this study was the Controlled Oral Word Association Test (COWAT) (Benton & Hamsher, 1978). This measure did not show group differences.

Now that the basics of each instrument have been discussed on a group basis, how might they interact with individuals' narratives? As mentioned throughout this section, two individuals, KH and ES, seem to be outliers, from their respective groups, on several measures. KH was enrolled as a member of the "No known disability" group. However, while KH saw herself as an individual without a disability or traumatic brain injury, her life story revealed a history of childhood epilepsy and use of street drugs at an early age. By the end of the interview process, she had decided to explore her potential cognitive issues with her therapist.

As mentioned above, KH scored more like the individuals in the TBI group on both BISQ symptoms and linguistic productivity. Her COWAT T-score was 46, which may explain why she had not realized the extent of some of her cognitive issues. She may have used this relative strength to compensate for her cognitive symptoms and conversational profile of low productivity. As will be seen below, she also displays a pattern similar to individuals with TBI when talking about life course elements in her narrative.

ES, an individual with a TBI, was also an outlier on several measures. First, she was the participant who spent the most time on the interview, talking until fatigued on two days (see figure 3.3). As such, the amount she spoke reflects this longer duration. She used 1,925 t-units, whereas the next highest number of t-units in any group was 902, and the highest for the TBI group was 704. Intriguingly, her number of events was not similarly elevated; she had 103 events, while the highest number of events in the TBI group was 114. Therefore, one of her differences was the length of her events; the average number of t-units for the remaining members of the TBI group was 6.5 per event; hers was 18.7, and her longest event had 95 t-units. In contrast, 3 individuals with TBI told their entire Participant-led subsection with less than 200 total t-units. The boundaries for ES' events were not decided differently; throughout her event, she might go off on a tangent, but she did put it back into the larger context, so that it could not simply be a stand-alone event.

In terms of ES’ linguistic profile, she was too fatigued to go through the COWAT, but her linguistic productivity is worth mentioning in the context of the size of her events. As seen in Figure 4.2, for her first thousand words, ES had a productivity level of 86.30%, which was third lowest in any group. Only one other individual with TBI and KH had lower productivity. This may partially explain why ES talked at such length; she may have realized that she constantly revises her speech as she is talking. In some ways, if this is a compensatory strategy, it does work. She is narratively able to get her point across and convey information about herself, even if her stories are longer and have more tangents. One price she may pay is fatigue; she took 2 days to participate in the in-person portions of the interview.

Research Question 2: How do individuals with TBI, SCI, or NKD use evaluative devices in their narratives? Specifically, how are causality, emotions, cognitions, perceptions, and conversations included? Does this vary within and between groups? If so, how?

T-tests showed few statistical differences between the combined SCI/NKD groups and the full TBI group; these were probably due to chance, because of the multiple tests performed. In the three groups, on average, the combined average usage of all the evaluative devices was 14.69% to 21.49% of the time. Events might have multiple codes, so this is not truly 15-22% of the events. These findings support no meaningful group differences.

However, there seems to be a slight difference in whether or not specific evaluative devices are used within an individual’s Participant-led subsection. Among the SCI and NKD groups, only 2 of the 8 categories were not used by everyone. One person did not include perceptions (e.g., “I believe that. . . ”), and 7 of the 8 individuals did not use internal speech by a character other than oneself (e.g., “He said to himself. . .”). This may reflect that, typically, we do not know what others say to themselves, so we rarely include it in stories.

In contrast, among the TBI group, 5 of the 8 categories were not used by at least one individual. The three categories which were universally used were cognitions, perceptions, and causality. To some extent, these may be the “easier” cognitive evaluations. For example, “I think,” “I believe,” or “because,” may serve as foundations for stories in a way which emotion words and conversational speech may not.

In terms of evaluative devices, the TBI group, as a whole, ranged from using 3 to 8 categories. The “Individuals with Full Icon Usage” used 5 to 8 evaluative categories, whereas the “Individuals with Partial Icon Usage” used 3 to 8 categories. So, this is not a large difference; a larger sample may have shown a stronger pattern between the groups. Nevertheless, there is a sense that some individuals with TBI will narrate events without including much evaluation beyond the basics of “I know that . . . because. . . .” Naturally, this has implications for what individuals say in their stories and how they say it.

Research Question 3: How are life course elements (linked lives, human agency, location in time and place, and timing) included in individuals’ narratives? Does this vary between and within groups?

Results—Linked Lives

Linked lives represent the interaction of individuals with other people in their lives and environments. Events were coded to explore who was mentioned in participants’ stories. The people of special interest were parents, friends without disabilities, friends with disabilities, romantic significant others, and miscellaneous others.

The combined SCI and NKD groups, on average, mentioned slightly more than one person (1.06) in each event, while individuals with TBI had less than one person (.82) per event. This could partly be due to a real difference in exposure to other people, partly due to the nature of the cognitive task of including people in narratives, or an interaction of these and other factors.

Again, ES and KH complicate the group profiles. KH nominated approximately .6 people per event, while ES nominated the highest quantity of any participant—1.65. This variation from the other group members yields a nonsignificant t-test, if both of them are included. However, if one or both are excluded from the analyses, then significance is reached (.059 if KH is excluded; .0044 if ES is excluded, and .0006 if both are excluded).

In all but one case, the “miscellaneous other” category was the most frequently used, which makes sense because it has the widest inclusion rules; it is everyone except parents, friends, and significant others. So, it may include people like a bus driver, but it would also include a participant’s favorite teacher or a helpful doctor. In MB’s case, her “romantic significant other” category was her highest category; at the time of the interview, this relationship was in the midst of dissolution. For 12 participants, the highest “non-miscellaneous other” category was parents. This was regardless of the participant’s panel, age, educational level, marital status, whether the relationship was untroubled, or whether the parent was deceased or having health issues. For two of these participants, nomination of parent was tied with that of friends. Of the remaining 3 participants, two nominated friends, while one nominated romantic significant other as the most mentioned. Taken together, these findings hint at the central position of parents in many individuals' lives and narratives.

When the "Individuals with Partial Icon Usage" were first described, it was stated that some individuals decided not to utilize certain icons. In one case, TT had talked in her "Participant-led" subsection, about 3 close, childhood friends, who ended their friendships after her injury. She chose not to put them on her time-line at all—either at the points where they were important to her in a positive direction, or when they ended their friendships, which was still a sensitive area for her even after 12 years. Yet she didn't nominate that as an important life event, either. This may reflect problems with high-level cognitive issues involved in task completion of the time-line, but it may also reflect how we view and talk about the presence or absence of other people in our lives.

There is a possibility that people with TBI are simply exposed to fewer people. Or, perhaps, the between group variations imply that including space for others in our stories is partly a cognitive task—we must realize others' presence and roles in our lives and our stories, and then we must credit them by putting them in our stories.

Results—Human Agency

Human agency is the individual's sense of his/her ability to make decisions and changes in his/her environment. This seems to fit with Bolton & Brookings (1998) construct of empowerment, with the four subscales on the POQ being: personal competence, group orientation, self-determination, and positive sense of identity as a person with a disability. Face validity would imply that someone who is consistent in their scores across subscales would be more stable in their sense of empowerment or agency. However, stability could be at high, medium, or low levels, so the full meaning would depend on the individual’s profile.

In the current study, because of small sample size, no clear patterns could be found between the groups and the subscales. However, when individuals with disabilities were grouped together, the average range between highest and lowest subscale, between the 4 subscales, was 38.3 percentiles; in contrast the average range for individuals without known disabilities was 24.8, on their 3 subscales. Although her score was only slightly above the group average for people with disabilities, KH again followed the pattern of being similar to individuals with disabilities. In other words, individuals without disabilities had more consistent beliefs about their agency across the subscales, while individuals with disabilities had more variability, regardless of time since injury or education level.

It should also be mentioned that Bolton and Brookings (1998; 2000), have published two sets of norms for the POQ. The earlier norms were based on a sample of 156 veterans and college students with disabilities. The second norms were based on a sample of 473 people with disabilities receiving vocational rehabilitation services. Due to the age of the sample in the current study, that 7 of the 11 individuals with disabilities were in college or had some history of college attendance, and few were involved in vocational rehabilitation services at the time of the interview, it was decided to use the norms from the study of college students and veterans. A comparison showed that the second, vocational rehabilitation, set of norms tended to rate the same raw scores as higher relative to the first set of norms, and showed less variation between subscales, which may simply say something about the identity tasks of college students who are exploring their abilities and opportunities to impact their world.

Results—Location in Time and Place

Location includes the historical, cultural, and geographical patterns for lives. Because this study required in-person interviews, the entire sample was from the NYC metropolitan area. Therefore, they are a highly diverse and urbanized population. This is reflected in their stories when they talk about many aspects of daily life, including access to public transportation and being able to choose rehabilitation/medical specialists.

In this study, participants were not specifically asked to focus on their ethnicity; however, ethnicity is a part of one's life story. As an exemplar of this aspect of location, 9 out of 16 (3 individuals with TBI, 2 with SCI, and 4 with NKD) participants told stories about their own or their parents' immigration (Slota & Peffley, 2005). Participants often focused on positive aspects of immigration, not simply the stressors. Some stories were told very simply. For example, one participant's, (KT) story was summed up in his comment, "Um, according to my mom, I was very attached to my dad - more attached to my dad than my mom, and he came to the United States, y'know, in search of a new life, blah-blah-blah the whole story." Other stories were told more elaborately.

Of the six participants who supplied reasons for the immigration, they fell, in equal numbers, into 3 categories: a need for medical care, in search of "a better life," or personal preference.

For example, one participant (SV) spoke of the immigration that began subsequent to a sibling's illness. He said,

> “I was born in um, Belize, which is located in Central America, okay, I was there with my father, . . . my other brother J- which is an older brother, he got very sick, so my mother brought him here to America, to the hospitals here, because the hospital there couldn’t y’know take care of him or whatever good enough for him to get better. . . .Like I was saying, when I was about 4, my mom came back to Belize, we haven’t seen her for all those years, y’know, she came back to Belize to get us, me and my two brothers and my father, who came here to America.”

In contrast, another participant (KI) noted the effect on his worldview of his family’s decision to move to Puerto Rico. He said,

> “um, I think I was like, 7, 7 or 8, my family actually decided to move to Puerto Rico….I lived there for a couple years, life is totally different over there. y’know, it’s hot, it’s one. it’s always hot. Kids walk around with no sneakers, no shoes, just walk around, and y’know, ride bike all day, eat food off the tree. that’s y’know an experience I’ll never forget--eating food off the tree.”

Because all but one of the immigration stories happened before people's experiences of injury, in this sample, the two events did not overlap, except in KD's case. She explains,

> So, I went home and I got out a map, and I looked at Australia, and I chose a place which I thought would be the climate that would suit me, because I hated the cold weather in New Zealand. and I chose ---, which is subtropical, and I wrote a letter to Public Relations, in ---, and somehow my letter got to this independent living place, . . . and it's really independent living, it's not like the centers you have here, these were like apartments or houses, sort of like a . . . they're sort of like a halfway home between um hospital and living in your own apartment in a community, so they have a person there who y'know, helps you with anything, it's not, they don't give you full care or anything, and most of us were independent people, but y'know, like I never had to cook for myself, or anything. So, um, somehow my letter got delivered to these people, and they wrote back and said they had this place, they had a room, and just give them a call when I came over.

Others told stories that reflected their age or developmental stage at the time of immigration. The following story arose from an immigration-related separation from parents. At the time, DT was in early elementary school and had only been in the US for approximately one year,

> That was pretty funny, our reunion. They were upstairs in the apartment, and somebody drove, I can't remember who, somebody drove us back home, and there's this big puddle, and I didn't see it, and I just saw my

> parents, and I was flying towards them, and I tripped over something and flew right into THAT puddle! (both laughing) My parents saw, they ran downstairs! I was soaking wet, but 6 months I didn't see my parents, what do I care?"

All of the above excerpts show people's positive, age-appropriate, narratives about their experiences with immigration and their ability to adapt and change to potentially challenging circumstances.

One implication of this finding is that counselors may be able to help clients see the parallels between immigration and disability. Counselors may be able to help the client make the link that he/she was socially successful in geographically relocating to a new country, and that a new disability can be handled successfully, through relocating biopsychosocially.

Results--Timing

As discussed in chapter 2, location was related to geography; in contrast, timing was related to an individual's personal timing of life events against the background of history. Two examples which will be discussed are the role played by the Americans with Disabilities Act (ADA) in individual's lives (Slota & Peffley, 2004) and the historical-embeddedness of their schooling experiences.

As mentioned in Chapter 2, Engel and Munger (2003), theorized a link between use of the ADA and disability identity. Therefore, in this analysis, only the responses of individuals with disabilities were included. Five individuals were injured pre-ADA, and

6 were injured post-ADA. In support of Engel & Munger's assertions, one respondent in the current project, who was only given her diagnosis of a traumatic brain injury roughly 20 years post-injury, was asked if the ADA changed things for better or worse. She replied, "Not to me personally, no." And then she asks, "What is it?" Upon learning about the ADA, she replied,

> I actually could have used that to my own advantage, but I didn't, 'cause I was in denial. Can't use it if you are in denial ... But even if the accommodations had been presented to me, "Hey would you like to use this? I would have said, "No, I don't need that! I'm not brain injured.

Knowledge of the ADA

Of the 11 individuals with disabilities, 5 individuals were unaware of the ADA (all have TBI), and the remaining 6 individuals were aware.

Of those 5 individuals who claimed unawareness, it is not a simple dichotomy of ignorance vs. knowledge; rather, it is a continuum. One of the 5 "don't knows" showed a complete lack of knowledge; as we've heard, 1 was a "could've used it" but "couldn't because of denial." Another 2 participants didn't know about it, but wanted to learn, because it applied to their lives, and 1 said she didn't know, yet talked about her college accommodations.

Of the 7 individuals who claimed awareness of the ADA, 3 were individuals with SCI, and the remaining 3 were individuals with TBI. So, while 100% of the individuals with SCI were aware of the ADA and could talk about the law, only 37.5% of the individuals with TBI were aware. Given that these interviews were conducted 11 to 13 years after the passage of the ADA, this lack of awareness is troublesome.

In this study the question of if or how identity and the ADA relate, can be examined in several ways. First, the time-line section was designed with a “life events” icon to capture any event that did not fall into the other 7 categories, so the ADA could have been put on an individual’s time-line. Even though the questions about the ADA were in the subsection of the interview immediately preceding the time-line construction, none of the participants saw the ADA as being something to put on their individualized time-lines. This opportunity was not explicitly mentioned to them; however, if any of them had asked to place it on their time-lines, it would have been possible.

Second, the Bolton & Brookings (1998) Personal Opinions Questionnaire had four subscales, one of which was called “Positive Disability Identity.” While the instrument was not designed to measure specific knowledge or usage of the ADA, if positive disability identity and knowledge of the ADA are linked, it could be hypothesized that someone with a high score on the positive disability identity subscale would be in the “aware” group, and might possibly even provide examples of how they have used the ADA in the past. However, in this study, awareness and positive disability identity, as defined by Bolton & Brookings, did not seem to be related.

Perhaps a more authentic way to investigate the link between identity and knowledge of the ADA is to listen to what individuals actually say about themselves. For brevity, the following is an edited example from one man with a spinal cord injury since the 1970's, who goes on at length about his views of himself and the ADA:

. . . first of all, I know some people that are advocates that fight when things don't get followed by the ADA, and they're pretty radical, which is okay. . . And then there's the activists that go to Albany and go to Washington, and say, "here, call the lawmakers and their politician is so-and-so; you're councilperson is so-and-so." Now, if I feel like signing a petition, I will; if I feel like calling somebody I will, but to me, it's like throwing money into the wind, or throwing my opinion. On a more personal level, though, if I find a movie theater that doesn't have access or discrimination, [I will take action]. An example, this is a really short example, I was going to N- and I wanted to impress this girl, so I took her out on a Friday night, dinner and a movie, y'know. And we go to the movie and the guy says that I'm a fire hazard, that I have to be transferred into a seat, . . . two little idiots, are assigned to evacuate me in the case of an emergency. I said, "Listen, pal, this chair is souped up, it's got zoom speed on it, if a fire breaks out, I'll be out there before the smoke even hits the back row. I said, "I'm not a fire hazard. Don't give me that crap." He said, "Well, I used to be a fire marshal." I said, "Well, I used to walk. So what?" And, uh, y'know, so, I sat in front of the box office, and I said, "Do not buy tickets from this man; he discriminates; he's an asshole; he hates disabled people and he won't sell me a ticket. Don't buy tickets." And, some people are like, "Get out of the way, I wanna buy a ticket" other people are like, "Really? He did that? Aw, man, I'm outta here." So, the guy's (motioning) "c'mon, c'mon to the lobby." He goes, "Listen,

> man, I can't sell tickets with you in the way." I said, "well, then, sell me a ticket and I won't be in your way; I'll be one of your customers." So, he said, "Alright, if you sit in the back." I said, "Where else am I gonna sit, idiot, you didn't make any wheelchair accessible seating." "An', uh, I'll let you in." I said, "Sounds like you're doing me a favor, man. I don't want an apology, just, get your theater fixed up." And, I went in and saw the movie, but I was pissed.. . . So, while I can make change on a personal level, and for other people, it feels good.

As his words show, this man has an active knowledge of the ADA, which he integrates into his daily interactions with the community at large, even though he denies an activist identity and scored at the 60th %tile for postive disability identity on the POQ .

ADA Usage

Several participants also discussed the educational, employment and/or architectural accessibility aspects of the ADA. It is somewhat notable that while several participants talked about work accommodations, because of the varied work histories and/or young age of my participants, these discussions were typically hypothetical.

One college student with a TBI, who, at the time of the interview, was one semester away from graduation, discussed her views of school and work accommodations:

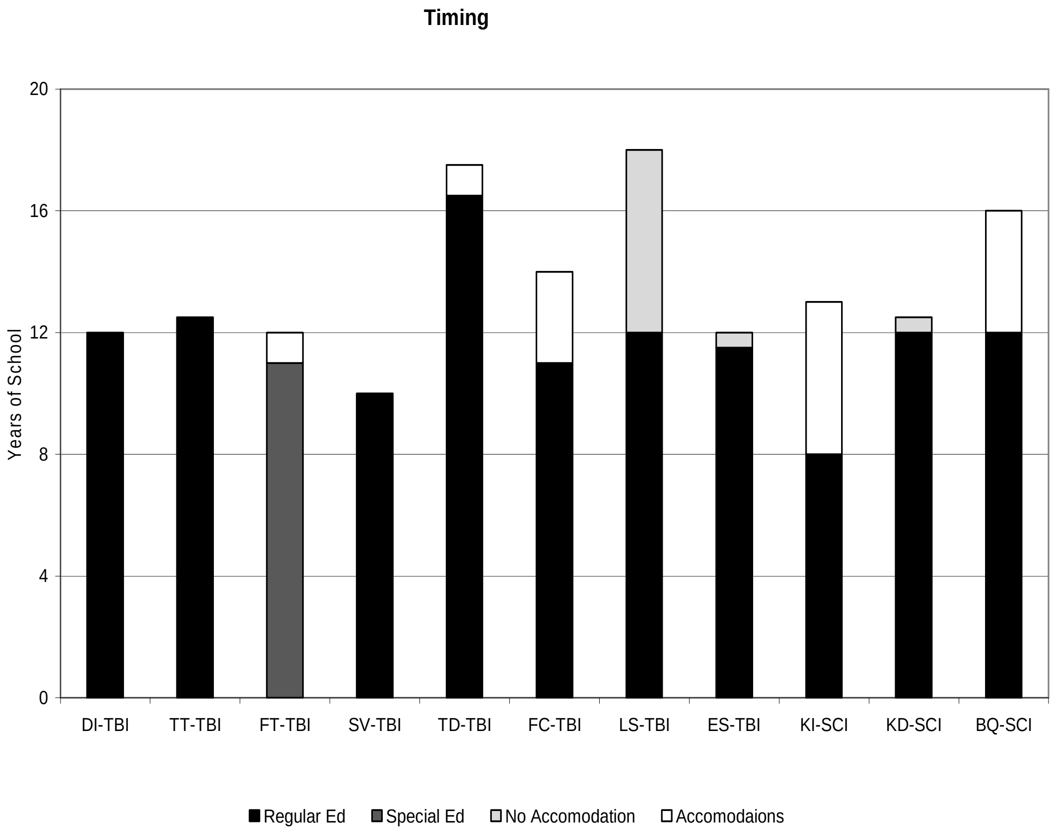
> When I was at [school], I went to register with disability. With disability [I] used to get priority registration, I did that for about two years. Until this past semester, [when] they stopped doing it, because, you know, everybody started taking advantage of priority registration, which is fine

> with me, because [it] left when I think I was junior - I didn't really care, because I'd get my classes anyway. So, I took advantage of it in terms of getting classes. I also get extended time on tests. . . Sometimes I do use the extended time, sometimes I don't. The thing is, if I feel like, I have only like a little bit of time, and I have so much to do, that I just kinda shut down. But, if I know that I'm going to have, like, unlimited time, I go through it calmly, whatever, and I finish it on time. Maybe like about 10 minutes over, not much.
>
> I went for several [job] interviews, I don't disclose [that I have a TBI]. because the thing is I don't need um, a special computer, I don't need anything like that. Basically, I don't really need any of that, and if I do need like, some extra time, then, I'll just get it from lunch. [You] know, I'll just work a little bit longer and have less of a lunch, or whatever it is, that's not a problem. So, I mean, if you do--what I've found is that if you do disclose things like that, it may kinda turn employers, like you know, so it's better [to] let them get to know you first, and then tell them.

For those who did know of the ADA, many used it in some form and within various realms, most notably in school, employment and architectural accessibility. Sadly, others equated "leveling the playing field" with charity or dishonesty. Still others – too many people – said that they were unfamiliar with the ADA. Fortunately, these people indicated that they were interested in learning about the law. The implication of this is that they may be able to use their rights, once they are aware.

Although use of the ADA takes awareness on the part of the individual, the individual him/herself, depending on age, may or may not be involved in decisions about schooling, special education, and/or accommodations. Given the historical location of my participants who were injured between the 1970's and 1990's, schooling falls under timing, because of the special education laws and the ADA. The first federal special education law was PL 94-142, The Education for All Handicapped Children Act, which was then superseded by IDEA, the Individuals with Disabilities Education Act and its various reconfigurations and re-authorizations. Figure 4.3 below, shows individuals' experiences with schooling, services, and completion.

Figure 4.3 Timing of School Services



First, the individuals whose initials are asterisked, were injured in the 1970's, around the time of the original law. However, KD was not in America, at that stage in her life. At the time of their injuries, three had recently graduated high school; the remaining individual was taking a college class while in high school. Of these four, three continued their education at some point post-injury, and only one used accommodations. BQ mentions that, in the 1980's, his accommodations were informal; he would get his female classmates to be his notetakers and readers.

In terms of the cohort who were injured more recently, three (DI, SV,TT) did not get accommodations and did not go further. They did not go back to school after their injuries. TT experienced an aneurysm in her first semester of college; DI was injured during his high school graduation week, so his mother was given his diploma while he was in a coma, and SV had stopped regularly attending high school before his injury. As far as could be ascertained from the data from these three individuals, educational services were never offered or pursued, even though they might have been available, given their ages at injury.

In contrast, KI, FC, FT, and TD did receive formal accommodations which permitted them to finish the educational level they were pursuing at the time of their injuries. FT, who had received special education services before his injury, received accommodations and special education after injury; he graduated. KI and FC used accommodations in high school, and then continued them into college. At the time of the interview, they were still college students. TD was injured in her first month of graduate school; when she reapplied, she received accommodations. Like KI and FC, she was also still in school.

Therefore, for my small sample, individuals were more likely to finish or continue their educations if they received “special education” services or accommodations, which shows the importance of ensuring that students receive services, whether they are injured in their first or last week of school.

In addition to the reasons listed above concerning why students did or did not receive services, it may also be possible that there was a disconnect between their hospitals and schools. All of this current sample was treated in adult hospitals and rehabilitation centers; none of them mentioned their rehabilitation services reaching out to their schools. It may have happened, but not been reported. However, in Patti (1999), half of that small sample had been in pediatric units and they did mention that their cases were transitioned back to their schools with services.

Research question 4: How do individuals with TBI or SCI narrate their injuries/disabilities?

How are the initial mentions of individuals’ injuries framed? Table 4.1 shows the first or first several t-units for each person’s initial mention of their injury. These are not the complete events; they are simply the introduction. Several individuals give the date, or fumble over the date. Others focus on how old they were, or what they were doing. Two mentioned negative peer influences prior to their injuries, but neither of them were doing something exceptionally risky at the time of their accidents. So, individuals do attach some type of meaning to the introduction of their injury into their life story. They then varied in how much detail they gave about the injury and its after-effects.

Table 4.1 Introductions of Injury

ID Letters	Quote
BQ	I was born in the [year], in [month, date], on [month, date]. I got hurt [month, date, year], which was right in the middle of, oh my, I think I was 18, I remember it as 17, but I was 18 turning 19, whatever,
KI	um, then um, my injury, when, well, before that, I started to realize that I was on the wrong track,
KD	so we[she is a twin] started falling with the wrong crowd, and not too long after we fell in with a wrong crowd, I had an accident, which y'know, where I broke my neck in a diving accident, so next change in life was um going away from my town [for medical treatment]
FC	And somewhere in between, I was hit by a car and had a brain injury
LS	I was 17, I graduated from high school, and I was also an organist and a gymnast, and had already taken a semester in college, so I was--I was charging into the world. And, a week later, I was in a hospital in Philadelphia, totally unconscious,
ES	and then, November [date], I had the accident. . . no, not November [date], yes, November [date+1]. God, I should remember. November [date+1], I had the accident.
FT	um, (pause) my injury. I was about 19, 18, 19, when it happened, '96, about 18, yeah.
SV	on [Month, day] of [year], I can never forget that date, that's the day my life changed.
TD	So, [Month, day, year], I was running and crossing a street, I was hit by a car. [she was training for a marathon.]
TT	I took some summer classes and then in October, I think, it was either the [date] or [date+1], I had my aneurysm.

Table 4.2 below, lists the numbered events from the Participant-led subsection. As stated in chapter 3, the "Participant-led" subsection was broken into units called

Table 4.2 Mentions of Injury and Injury After-effects

BQ	KD	KI	SV	DI	FT	TT	ES	FC	TD	LS
1 2 3-18 19-20 **21-22** 23 **24** 25 **26-27** 28 **29-33** 34 **35-38** 39 **40** 41 **42-48** 49-53 **54-56** 57 **58-63** 64 **65-66** 67-70 **71-72** 73-74 **75-79** 80 **81** 82-86 **87-89** 90-92 **93-103** 104	1-8 9 **10-13** 14 **15-16** 17-18 ***19** 20-23 **24** 25-26 **27** 28 **29** 30 **31-32** 33-34 **35** 36 **37** 38-42 **43** 44-46 **47** 48-51 **52** 53-59 **60-61** 62-63 **64** 65-80	1-26 27 28-45 46-49 **50-51** 52 53-55 **56** 57 **58-65** 66 **67-68** 69-74	1-7 8 9 10-23 **24** 25-27 **28-31** 32-38	1-26 (No mention of injury or after-effects.)	1-24 **25** 26-27 **28** 29-37 38-44 **45** 46 **47-50** 51 **52** 53-55 **56-58** 59-61 **62** 63-79 **80** 81-87	1-5 6-11 12 **13-21** 22 **23-26** 27-28	1-28 29 **30** 31-38 39 **40** 41-46 **47** 48-50 51 **52-59** 60-61 **62-64** 65 **66** 67-69 **70** 71 72 **73-74** 75 **76-78** 79 **80** 81 **82-83** 84-87 **88-91** 92-94 **95** 96-97 **98** 99-101 **102** 103	1-17 18 19-26	1-24 25 26 27-38 **39-45** 46-48 **49-50** 51 **52-54** 55-61 **62-63** 64-68 **69** 70-71 **72** 73 **74** 75 **76** 77-80 **81** 82-83 **84-85** 86-89 **90** 91-95 **96** 97-101 **102** 103 **104-107** 108-113 **114**	1-5 6 **7-10** 11 **12-13** 14 **15** 16 **17-19** 20 **21-27** 28 **29-30** 31 **32**

"events," because they may or may not have fit other traditional narrative terminology like episodes, turning points, etc. In order to examine the flow of events between those that discussed the initial injury and hospitalization, those that explained rehabilitation or the after-effects of the injury, or those that did not refer to the injury/disability, each type of event was given a font. Events not related to the injury or disability were coded in black type. Events related to the initial injury and hospitalization were coded by underlining. Lastly, stories about rehabilitation or after-effects of the injury were coded in bold.

This analysis is more interested in the flow between mentions, than the actual content of the mentions. For example, 1 individual (DI) never explicitly mentioned his injury or connected it to his current life, in which he participated in a day program for adults with disabilities. Similarly, FC only mentioned her injury once. As stated above, FC simply said, “And somewhere in between, I was hit by a car and had a brain injury.” She did not go into more detail until later, in the Interviewer-led subsection, when she was given the broad prompt of, “Um, do you want to tell me about your accident, or not yet?” She then proceeded to go into much detail about her accident, hospitalization, recovery, and rehabilitation. However, these details were not put into the spontaneous narrative that she controlled and constructed; they were only volunteered when probed.

Perhaps because most individuals used a rough chronology when telling their life-stories, only one talked briefly about after-effects before discussing the initial injury. As can also be seen, some individuals described the details of their injury and initial hospitalization using few events, while others used more detail and multiple events. Similarly, some individuals consistently linked after-effects to later events, whereas others chronologically discussed after-effects and then recent events in which their disability was not mentioned. Whichever sequence an individual followed, it does illuminate his/her sense of what health psychologists would call “illness cognitions,” in which the individual makes links about causes, timing, and severity of symptoms.

Participants' and Others' Life Course Perceptions

One of the original intentions of this project was to investigate if or how individuals' life courses changed after injury. This becomes a two-part question: how do individuals' view their own lives, and how do other people view the participants' lives. For my participants, sometimes these views were the same, or at least parallel; at other times, these views were diametrically opposed to each other.

FC, who was injured before her senior year of high school and was a college senior at the time of her interview, viewed her injury as one chapter in her life. She did not discuss major changes to her career aspirations. She felt that she was able to successfully function and keep up with the nondisabled students at her very competitive university. When other individuals would examine her life experiences would probably agree that, at least during her schooling, she was experiencing a privileged, but culturally- and developmentally-appropriate, life course. Similarly, ES would endorse that her goal and dream of traveling around the world as a professional dancer had been reached, but she would also point out that her belief was that reaching her goal took somewhat different strategies and was more of a struggle.

Both BQ and KD who, respectively, had spinal cord injuries 25 and 32 years previously, would probably endorse that while their life courses had changed, and in some ways drastically, not all their experiences had been negative. For example, BQ said,

> I still am angry about what I can't do, y'know, taking away my sex life, taking away my walking and, and stuff. I never got any good answers, I never, I was always asking "why me?" and I, I finally answered the question, "Why not you?" y'know and, I've learned a lot of things that

> sped up my development, because of my accident. I had to find the pros to being disabled, and it's like, you don't take, I, me, I don't take any shit from anybody, I don't waste time with small talk, I mean, I-I have small talk, but life is too short.

He then goes on to describe how he and a group of other people with spinal cord injuries visit newly injured individuals in the hospital to give them, "the insider's view of what it's like to be living disabled in New York."

Similarly, KD talks about getting involved in wheelchair sports when she was injured, how her coach mentored her in life and swimming, how the road trips to competitions taught her independent living skills and gave her an outlet for socialization when she was in her early 20's. Her sporting career culminated with a Commonwealth Gold Medal. However, she ended her involvement when she moved out of her mother's house and started living independently in a new country.

LS, who after injury earned her bachelor's degree and a master's degree in speech therapy, would agree that her injury changed her life negatively, both in terms of her relationships with her family, her career choice, as well as in how much effort it took to lead her life.

Three participants, TT, TD, and KI would say that their injuries affected their schooling, and, therefore, their lives. TT did not return to college after her injury; KI received at-home tutoring after his spinal cord injury, so as a freshman in college, he felt he did not have the social skills. TD felt her identity as a "good student" had been shaken by the interaction of her injury and her graduate program. At the time of the interview, she had recently transferred to a different program and was regaining her sense of academic mastery.

DI, the participant who attended a day program for adults with disabilities, might sometimes recognize that his life was not the life he and his family had planned; other observers certainly would. His injury happened in his last week of high school, when he had already received a college scholarship to a prestigious school. From both his statements and those of his mother, she was helping him to keep his memories of high school alive.

The last two participants with injuries, FT and SV, would both agree that their injuries had radically changed their life courses. Their injuries were caused by street violence; both believed that their injuries changed their status within their original group, and both struggled with their new place in their communities. An outside observer might assume that in some ways, getting injured and surviving might lead to a more positive outcome than other possible futures, such as incarceration or death. However, that is a value judgement. In the next chapter, SV's perceptions of his life are examined in more detail.

Chapter Summary

Based on the four research questions, this chapter has reported some initial findings about the abilities of individuals with TBI to participate in narrative interviews. Of course, these participants represent a specific "slice" of the TBI community; they were living in the community and were able to travel (alone or with assistance), yet they did self-report a loss of consciousness longer than 24 hours, which can be used as an indicator of severity. Nevertheless, it became clear, that if someone was willing to listen, these participants were willing and able to speak about their life experiences. They were able to tell stories and create meanings. Some individuals with TBI had somewhat constricted content in one or more area, such as icon usage, creating conversations within the narratives, using other evaluative terms, linguistic productivity, and/or fewer mentions of other people within the participants' stories. However, individuals were able to make and convey meanings, even with these constricted choices. Some of the events might not be embedded in a "traditional" or "complete" narrative from the linguistic point of view, but psychologically, these narratives served to create shared meanings.

This study cannot solve the issue of whether these abridged stories are due to cognitive/memory impairments, linguistic impairments, social disability, environmental factors, or an interaction of these or other variables. That is an important question, and it has implications for theory and service-provision. For example, should interventions focus on learning to compensate for memory impairments, teach the individual skills to help him or her deal with social disability, or model other skills?

However, this study was designed to examine how specific life course elements are integrated into an individual's narrative. As was seen above, individuals did include the four main life course areas: linked lives, location, agency, and timing. One important life course element that differed across groups was the number of social others who were included in the participants' narratives. This has implications for social relationships. In general, people want to know that they are valued and are part of each other's lives. In order to potentially strengthen social relationships, interventions could include teaching individuals with TBI to monitor their stories for inclusion of their closest relationships, and/or teaching the friends/family members that their exclusion is perhaps due to difficulty with the cognitive nature of the task, and not necessarily a personal affront. Otherwise, the friends/family members may make faulty social attributions, which might hinder the continued growth or existence of the relationship.

One question that arises from these linked lives data, is whether individuals with TBI are truly more socially isolated. An alternate explanation could be, that social others are present, but “taken for granted” and assumed to be constants, so they do not need to be mentioned. Again, this would be an important research question, because it could lead to services which would focus on meeting additional social others, in order to build friendships.

The above paragraphs have outlined findings based on each research question. However, these research questions do form a cohesive whole. For example, individuals’ cognitive profiles, as self-reported on the Brain Injury Screening Questionnaire (Gordon, Brown, and Hibbard, 1997) and the Controlled Oral Word Association Test (Benton & Hamsher, 1978), may have impacted how people narrated themselves, their injuries, the life course elements in their lives, and how all of these issues are evaluated. The next chapter shows how these issues play out in one individual’s narrative.

Chapter Five: Case Study

This chapter is a case study of SV's life course experiences and the meanings he creates for himself. At the time of the interview, SV is a 23-year old man who self-identified as "Black, African, African-American" on the demographic section of the Brain Injury Screening Questionnaire (Gordon, Brown, & Hibbard, 1997). He added that he was born in Belize, and his "home languages" were the local Creole and Spanish. At 23, he still uses his Creole, Spanish, and English, depending on whom he is talking to.

In the "participant-led subsection," SV tells his story fairly chronologically; he reaches 18, discusses his injury, and then his life post-injury. As he's summarizing the first part of the interview, SV relates,

> Now, that's when I was 17. [He's referring to his injury, which happened at 18 years, 1 month.] So, just imagine through the years of 17 and now. Now I'm 23, so this, imagine how those years were like, from 17, still a young boy, to 23, I've-I've been through, I've been through hell, so I call it, so I feel."

As will be shown, SV relates many issues that he feels he has struggled with during this time, including his identity as a person with a visible disability and his housing situation.

SV spends approximately the average amount of time on his "Life story section," but his "Time-line Section" is the second longest, at almost 2 hours. Partly, this may have occurred because he tells additional stories about his post-injury life that he did not relate in the first section of the interview. For him, the time-line section was not simply about filling out icons; it was also about telling detailed stories related to the icons.

Linked Lives

Before his injury, SV discusses his parents, siblings, and friends who were part of the street culture in his neighborhood. He describes his parents as “strict” and attributes this to their cultural patterns from Belize. He doesn’t go into detail about when he and his two older brothers were children. He mentions that his oldest brother was “sick” as a child, so their mother brought that brother to the United States for treatment, while he, his other brother, and his father stayed in Belize. The family reunited and came to the United States when SV was approximately 4.

SV talks about “hustling” and being part of the “street culture” in his neighborhood. When he talks about others who were also involved in that life, sometimes he calls them “friends,” but he also wonders if he is being used by them or if they are “real friends.” For example,

> . . . before my injury, I had like, well, I guess they weren’t friends now that I think—really friends, now that I think about it, I had so much social contact with, it was like, with whoever I wanted whenever I wanted, y’know. I’m talking about male and females, y’know, friends that wanted to hang out with me, y’know, and all that stuff, and then, when I got shot, they just started dropping like flies. . .

He attributes their behavior to the visible after-effects of his injury. He was shot in the head, which led to “. . .my eye was closed because of the nerve in my eyelid, it closed down.” He talks about losing these friends because of the visibility of his injury,

> . . . y'know it's um, it's crazy, because I'm a normal person; I'm not saying that individuals with disabilities are not normal, because they are, too, but when I say that is that, it's only a physical thing with me, y'know, I still can talk to you, intellectually, y'know I can still, we can still laugh and talk and joke around, I'm just a normal per-I'm so normal, it's just the physical aspect, is what chases people away or scares people away, with the physical aspect of it, and that hurts. It hurts a lot, because, I'm, I'm human too. I have feelings, y'know. . ."

In this quote, there is also a tension about whether he self-identifies as being an individual with a disability; he clearly gives personhood to "them," yet, he is not including himself.

He also mentions this tension of group membership when answering a question about his current job. He is a secretary at an agency that advocates for "individuals with mental and physical disabilities." He explains,

> I'm a secretary there, at the agency, and there's individuals like that there, that I see every day, y'know, or that I talk to every day, or I laugh, and I feel comfortable there, because being that I have a physical disability, y'know, I just feel comfortable around those people, and they feel comfortable around me, and sometimes we talk, and we share experiences, and try to give each other some ah,points on ways that we can improve our life, y'know, make it better, try to hang, I hang out with them, I talk with them, if they're just sitting around, I'll go over to them and cuz I can just imagine what's going through their mind and how they're feeling, y'know,

> I feel it too, so I will just go to them and just smile or talk, “How ya doing today?” y’know, “How ya feeling?” “Is everything alright?” “Anything you want to talk about?” And I fin-, I find that a lot, a lot of individuals there do want to talk, like “Sure,” “As a matter of fact, are you busy? I wanna talk to you for a” and we just sit there and we talk and we talk.

Here, the tension shows itself through his mentions of “individuals like that” but also“being that I have a physical disability, y’know I just feel comfortable around those people. . . ” When he talks about his role in the organization, he positions himself as listening to the clients, trying to help them, and empathizing with them. Yet, he also describes a reciprocal relationship of sharing experiences, as well as getting and giving pointers for daily life.

At another point in the interview, when SV is directly asked if he has friends with any type of disability, he replies,

> no, I wish. I wish, I got I think what it is is because I’m not I’m not putting myself out there to be surrounded I was telling you earlier, with that type of crowd. With the crowd, y’know that I can relate to, that can relate to me, I’m busy out there with other individuals who have their health and everything, and those are, I don’t understand it, and those are the ones that hurt me. y’know, verbally and use me and so on, but, the people that can relate to me and would understand me, and feel the same, I just feel, I don’t know, I-I don’t know, I can’t understand it, sometimes I feel bad that I’m like I’m, like I’m a traitor, y’know, I cannot understand it.

Here, he goes so far as to call himself a traitor, simply because he is still uncomfortable with his post-injury status. He does realize his resultant isolation, but he is not ready to reach out or change his pattern of socializing.

SV does discuss several significant romantic relationships. The first was a pre-injury, adolescent dating relationship of two years duration. According to SV, she had been trying to get him to leave the street life; when he was shot, probably because of parental pressure, she broke up with him, while he was in the hospital.

The second significant romantic relationship he discusses was with an older neighbor in the same apartment building that he lived in with his parents. SV moved in with this significant other, but eventually, the relationship dissolved and he asked to move back in with his parents. His parents told him that they had warned him, and that he now had to live with the consequences, which was that he was not allowed to live with them. He tells the story of making the call to find services, and traveling with his father to a homeless shelter.

This brings us to SV's social relationships with several of the men at the shelters. He talks about one man who hassles him about a sports jersey, but mentions that other men stepped in to resolve the issue. One man, in particular, had taken SV under his wing, such that "I guess eventually that other guy put the word around that everyone was looking out for me. I was like the brother of that shelter, the little brother." Eventually, he is moved from the general shelter to an accessible shelter for men with disabilities. Here, he befriends and helps one of his roommates who is blind, with activities of daily living and errands.

All of these friendships and relationships show the variety of SV's social ties in a wide range of settings. He sees himself as a son, brother, friend, boyfriend, and member of the shelter system. He uses these relationships to stay connected to the world and to cope with the range of environments he finds himself in.

Human Agency

Agency is the sense that one has control over one's life, the power to make one's own decisions, and the ability to carry through on those decisions. SV talks about his spiritual beliefs as one way to find answers. For example,

> I believe, I believe in my heart that there's a purpose for me here on earth, but I feel like I'm ignoring that purpose, but I don't know what it is, if I knew what it is, I--I beg the Lord every night to tell me what this reason is, if I knew what it was, I would walk in that path, y'know, but, I don't, so I just continue to live and pray and hope that one day, I will just walk into the reason, . . .

One decision SV is struggling with is whether he is still involved in street culture or how he could exit that culture. Again, he looks to his spirituality for answers:

> . . . I pray every night for the Lord to help me understand this, y'know. Sometimes I feel that I'm still in the life that I came from, the way I dress, y'know the way I talk, the individuals that um, that I hang out with, y'know, I feel like I'm still in this life, when I know it's wrong, and I shouldn't be, but it feels like I can't. . .

In other parts of the interview, he talks about the suggestions, advice, and nagging he receives from his parents about his inability to leave the street behind and become more involved in other aspects of the community. Nevertheless, at the time of the interview, he is still struggling to find his place in society and to figure out how to get there.

Location in Time and Place

As has already been mentioned, SV immigrated to the United States as a young child. His place as an immigrant to New York City may have shaped where he lived as a child and adolescent. The lure of street culture may have been seen as one developmental pathway, ". . . I was drinking, you know what I mean, and um, I was smoking, so I was, y'know, I was like the average teenager out there, y'know." As mentioned above, several years after his injury, SV is still torn between being a part of that group, or finding a way to part from it.

SV's account of his injury can be linked to his location as a youth involved in street culture. He narrates his injury story by saying it was a life-changing event, starting to describe it, then saying he has to skip to waking up, because he can't remember the actual incident. When he wakes up, his parents tell him he was in a car accident. SV narrates that he doesn't remember being in a car that day. A short time later, he has a visit from a friend from the neighborhood,

> and he said, "What's up?" to me, and I said, "What's up?" And he said-he said, "Yo, we're gonna get the person that shot you" and, if you read in between the lines, just fifteen minutes before that my father told me I was in a car accident, so when he said, "we're gonna get the person that shot you," I stopped him immediately. And I said, "shot me?" So, now I'm

> knew it, well, I didn't know if, if that person was lying, or if I was just confused.

When the friend leaves and his parents return, he questions their story. His father admits that SV was robbed and shot., as a result of his activities.

These examples show how SV's location as a youth involved in street culture may have contributed to his injury. However, being in the metropolitan area, he was also transported to a local hospital which was able to meet his medical needs.

Timing

As mentioned in the previous chapter, participants were specifically asked about their knowledge of the Americans with Disabilities Act. SV was one of the participants who claimed to have no knowledge of the Act, and to never have been taught about it when he was receiving rehabilitation or vocational services. He was interested in learning more and indicated that he would do some internet searching based on the referral sheet he was given at the start of the interview.

His discussion of the ADA finishes with:

> I knew that they, there were, tha-that I had rights, I just knew that because I am still an individual, y'know, so I was looking at it like that. I knew there were rights, but I never knew--and I also knew that there were specific or special y'know rights and so on for indiv-for an individual like myself, but um, I never knew specifically, or never read anything, or actually heard, talked to anyone that explained this to me

Here, he recognizes that individuals have rights, and, even though he still has trouble calling himself disabled, he is interested in learning more, to see if the law directly impacts his current life.

Timing also covers the interaction of SV's developmental status with his entry into the New York City system of homeless shelters. By SV's account, although he was not actively attending 11th grade before his injury, he was 18 when he started his stint in the homeless system. New York law states that parents are legal guardians until the child's 21st birthday. Therefore, it is this author's contention that, as an 18 year old with a disability, he might have qualified for a foster home or group home for teenagers. Therefore, this example of timing becomes even stronger, because it is not simply one of being the youngest in the shelter, but also being in a shelter even though other alternatives might have existed, and his family may have been unaware, given their location. These issues may have all contributed to his placement in the shelter system.

Conclusion

This examination of SV's story shows the multiplicity of interactions between the four life course elements of linked lives, agency, location, and timing. It also shows one individual's awareness of and complex relationships with his social support system, his physical and social environment, his access to services, and his struggles to find his identity, which is often a complex task at th age of 23.

Chapter Six: Discussion and Implications

One of the most basic findings of the current study was that all the participants in this study, representing a specific place on the spectrum of individuals with TBI, could tell their own life stories. The stories may or may not have the prototypical structure of "life stories," yet even stories about learning to drive or making Jello tell inform us about the participant's cultural expectations and geographical location. This is significant because the life courses of individuals with severe injuries have not been previously studied in this way. This study shows the feasibility of using life course and narrative frameworks to examine the life experiences of individuals with disabilities. Little is known about the long-term outcomes of individuals with severe brain injuries. Given the current military situations, knowledge about the long-term outcomes for individuals with TBI is extremely important for planning treatment and services.

When examining group results about individuals' use of narrative evaluative devices, if an individual used an evaluative device, the frequency of use was similar across groups. However, as with icon usage, the difference between the TBI and other groups was whether a device was used. This may mean that for individuals with full evaluative device usage, their ability to narrate and convey meaning about their lives is not compromised. However, for individuals with partial evaluative device usage, it may be more difficult to convey meaning. Partial or full device usage was not highly correlated with linguistic productivity, therefore, individuals' might have impaired communication at one or both levels, of speech production or communicative meaning-making, which might affect social relationships.

Although this paper has, for organizational purposes, tended to discuss narrative evaluations and life course elements separately, the two areas are intertwined. The evaluations tied to an event shape how the experience is conveyed to others, which affects how the social meanings of the experience are created. It also affects the individual's understanding of that event.

The quantitative measures in this study, linguistic productivity and the Brain Injury Screening Questionnaire (Gordon, Brow, & Hibbard, 1997) seemed to reflect variation among groups fairly well. Linguistic productivity was lower for individuals in the TBI group. Similarly, KH, the outlier in the nondisabled group, who may have had cognitive impairments had relatively low linguistic productivity. She also had a high score in her self-report of cognitive symptoms on the BISQ, which suggests that this instrument may have face validity for screening populations with cognitive impairments, regardless of the cause of the impairments.

Life course theory with its focus on location, linked lives, agency, and timing is a useful theoretical tool for exploring the life experiences of individuals with disabilities. This framework was originally created to explore typical development; it initially ignored issues around disability. However, as seen in the current study, using life course theory with people with or without disabilities, does highlight the similarities and differences in the life experiences of some individuals with disabilities. For instance, everyone did mention institutions like schools and hospitals, as being sites in their lives. In contrast, only some individuals had interactions with organizations like the New York Vocational and Educational Services for Individuals with Disabilities (VESID). These services may shape an individual’s later life, by providing job-training or money for college. As a result, the individual’s life course may change.

This study also examined specific examples of life course elements in the lives of people with or without disabilities. For example, immigration stories, knowledge of the Americans with Disabilities Act, and schooling experiences were explored. These are simply three exemplars of various areas that can be subsumed under life course theory.

In addition to exploring the presence of life course elements, the current study used narrative methods to yield various types of personal meanings about which events were life-altering, as well as what the individual considered important life outcomes for himself or herself. The experiences of four individuals will be discussed, in order to discuss the tension between group outcomes, individual outcomes, and meaning-making.

For example, as seen in the previous chapter, SV stereotypically fills our expectations about the life-altering aspects of TBI when he speaks of “August 26, of 1996, I can never forget that date, that’s the day my life changed.” He tells the story of the gunshot wound that changed his life, at age 17. When he tells his narrative, he speaks of his current housing and his current job. He does not tell the story of how he arrived in those situations. Only in the time-line section does he chronicle his parents’ refusal to let him live at home at age 18, after he had previously moved out. As a result, possibly because of his age, and possibly because his parents didn’t know the various services available in the US, he spent about two years in a series of homeless shelters. For him, he traces his life difficulties directly back to his injury. He did not believe he would have been in the shelters if he had not been disabled.

As mentioned in chapter 1, LS received her brain injury in 1976, and she similarly believes that it did alter her life. She lived for many years without the proper diagnosis and treatment, with everyone telling her that “the rapist didn’t rape you” and that she should move on with her life. In New York City, professional knowledge of TBI blossomed in the late 80's to 90's, so many people with earlier impairments were finally receiving the label of TBI, which accompanied an explanation of why individuals had struggled with cognitive tasks for years or decades, without being believed by those around them. LS mentions several turning points in her life--her injury, her first Overeater’s Anonymous meeting for bulimia, her first TBI support group, speaking about living with TBI to a prominent newspaper, her first evaluation by a neuropsychologist, and leaving work to go on disability. She says of starting the evaluation process,

> I didn’t want the neuropsychologist to tell me all of my deficits, and when they did, I remember the guy was sitting across the table and he, he just kept shaking his head and saying, “I don’t understand how you’ve been working for 20 years. I don’t understand.” And I said, “Denial.”

At the time of the interview, LS was finally content with her understandings of her self, her limitations, and her identity. She had stopped working and had moved out of the city. After years of struggling, she was becoming comfortable with her experiences.

As mentioned in chapter 4, FC, closes her story with “So, that’s basically my life until now. In a nutshell. And somewhere in between, I was hit by a car and had a brain injury.” She compartmentalized her TBI experience as 1 chapter in her life story, which had resolved. As a college student, she was busy looking ahead, not looking back.

TD speaks of three major life events--being abducted for approximately 24 hours at age 13, experiencing her brain injury at 24, and having issues at her first graduate school for speech pathology at age 27. In terms of impact, she says,

> because it was my abduction, which, thank God, didn’t have as lasting an effect on me as the others. My traumatic brain injury, and then [name of grad school] and I think the [school name] one is going to be the most lasting, because I was always very academically inclined.”

One of her stock phrases is “beyond traumatic;” she uses traumatic for her brain injury and her abduction; “beyond traumatic” is for her graduate school fiasco which included incidents of disability discrimination. She implies that part of her issues with the school were disability-based, but that some of it was also curricular. She transferred to a different school; at the time of the interview, she was waiting for her first midterm results. She is a good example that many people have multiple important life events, which can influence the meanings and significance a person gives to each event.

DI was in his late twenties at the time of his interview, and experienced his brain injury in June of his senior year in high school. He told his story by focusing on high school, and then moving backwards through his childhood. For him and his family, the physical and cognitive impact of his injury was so significant and life-altering that the focus was on who he was before his injury and in helping him to keep those memories of himself alive.

For all of these individuals, it is less about their shared experience of TBI and more about the various meanings they have given to their individual experiences. Therefore, trying to force these individuals into one box for a traditional outcome study is inappropriate. It does them and their experiences a disservice. Grouping these people together, typically renders the traditional medical outcomes studies as statistically significant, yet practically meaningless. So, the question then becomes, in the future, how should individual outcomes for people with or without disabilities be measured? Another participant, ES, has the perfect solution. When she is starting to tell her story, she first discussed whether to tell her story chronologically, or in reverse and then decides to go by theme, "ever since I can remember, two things I wanted to do, dance and travel around the world. Those were my two dreams." She then spends the interview talking about her achievement of those dreams.

While measuring achievement of life-long dreams is somewhat utopian, it does grant space to go beyond being a group of "patients" who can or cannot conduct activities of daily living non-independently, independently, or interdependently. It gives room to strive for goals, and in a utopian world, it would serve as a rationale for providing services that truly maximize abilities to reach specific, individual goals, instead of focusing on what a providers think is an easy to provide way to give a generic group of people what they need or want.

In the real world, life course theory could be applied to programs using person-centered planning to help uncover individual's desires and holes in terms of the traditional life course elements. According to O'Brien & O'Brien (2000), one of the roots of person-centered planning was the normalization movement, which aimed to make people with disabilities "normal," by providing services, which tended to follow a fairly standard social work paradigm. The focus was on making people with disabilities into people with "normal" lives.

The current study advocates for using life course theory to explore the lives of individuals with disabilities. Instead of starting from a deficit model and making people normal, a life course framework allows people with disabilities to use a mainstream theory to describe their lives and then explicitly make disability into part of that assumed life course. This is more than just a semantic issue about whether to start from the deficits or to start from individuals' strengths. It is an argument about whether disability is still seen as something stigmatizing and negative that needs to be fixed or if disability is simply another positive or negative factor in how the life course is experienced.

If life course theory is linked with person-centered planning, there are three potential levels of overlap. First, it would allow individuals to see if they have life course "holes." They could then decide whether or not to try to fill these holes. Second, person-centered planning would then design services and provide training to fill those areas. Third, a life course framework could be used to assess outcomes, by examining whether or not the person-centered process was successful. While this sounds like a traditional person-centered planning paradigm, the difference is the assumptions about what filling, why, and what the implications are for the individual's meaning-making. Is he or she seeing it as an attempt to be made "normal," or is the individual seeing it as a way to address the disability-related features of one's own unique life.

Limitations:

As mentioned earlier, this study did have several limitations. First, the most important limitation was that of small sample size and difficulty in locating participants. The original study was planned for 16 participants from each panel, not 16 participants total. Even though the methodology would have still been qualitative, a larger sample may have shown stronger trends or given more indication of generalizability to other groups.

Second, this study reports on cross-sectional information. Therefore, this study lacks the ability to trace issues or changes in life story elements over time. It is hoped that a follow-up study will be able to locate these participants. It would be interesting to see whether the individuals who were attending school actually finished, and what they did with their lives next. This study could also trace whether or how their narratives have changed to address their new situations.

Third, because of the cognitive abilities required in this narrative study and the need to travel to the interview, this project focused on individuals on one part of the TBI spectrum. This study did not include individuals who could not communicate through speech; it did not include individuals who are residing in group homes or institutions, so the findings might not generalize to all individuals with TBI.

Fourth, because this was a study of participants' perceptions about their own lives and their own construction of their life story, this study did not "build in" procedures to check on the factual accuracy of individuals' narratives. At one level, this is unnecessary, because reality is a social construction, understood differently by various theorists, and the phenomenon of interest in this study was individuals' constructions. However, if information had been able to be verified, it might have filled in some gaps in individuals' narratives; there were several participants who rented apartments, and therefore moved frequently. For the most part, those moves were not able to be catalogued, because individuals could not remember when moves happened or where the destination was. As a result of issues like this, the number of icons in a specific category was not reliable, however, if a category was missing, that became a significant proxy for how the individual performed in other areas of the study. Also, this study did not include the perspectives of close friends and relatives to examine the linkages between people's lives.

Similarly, a fifth limitation is that this study did not include a medical chart review. As a result, medical information depended on self-reports from individuals who are likely to have memory impairments. Therefore, the severity of their coma or the time it took to "wake up," may not have been reported accurately, so measures of injury severity are lacking.

Next Steps

In conclusion, this study has shown that narrative and qualitative methods and designs can be used successfully with individuals with TBI. Therefore, as mentioned above, it is hoped that a longitudinal, Time 2 study can be carried out. This follow-up could explore whether individuals finished their educations, reached their life goals, and expanded their social networks. It would also be interesting to examine whether the meanings given to certain life events in the current study had morphed or stayed constant over time.

One of the original goals of this study was to conduct in-depth linguistic analyses on the total interviews, to build complex profiles of the linguistic patterns and abilities of individuals with or without TBI. This analysis was not conducted, but the data still exist. So, in order to supplement the linguistic findings in this study, the remaining linguistic analyses could be conducted. If the results show deficits, a collaborative, interventional project might be possible.

Given the above recommendations about tying life course theory to person-centered planning, an obvious next step would be to partner with a Center for Independent Living or a chapter of the Brain Injury Association to test this combination in the real world.

By advocating for the use of life course theory to examine the experiences of individuals with disabilities, this study attempted to move beyond standard psychosocial outcomes studies. This might allow researchers to hear what people with disabilities say about their whole life experiences; for without that, participants in disability research are simply guinea pigs, patients, clients or consumers. By listening to how people actively construct their life experiences, goals, and dreams, people with disabilities can be seen as friends, neighbors, workers, or in any other way they want to be seen.

Appendices

A. Telephone Script

B. Interview Script

C. Icons

D. Event Rules

E. Changes to Hunt’s T-Unit rules

F. Coding Rules for Evaluative Devices

G. Life Course Codes

A. Telephone Script

Hello, this is Nina Slota calling from Mount Sinai Medical Center's Research and Training Center. I’m returning _______’s call. May I speak with __________?

[NOT HOME] When would be a good time to reach him/her? Thank you for your time.

[YES] Hello, __________, my name is Nina Slota and I'm returning your call to Mount Sinai's Research and Training Center. With the co-operation of the City University of New York and the RTC, I'm conducting a study about how people talk about their life experiences. Do you have a few minutes, so I can describe the study to you and answer any of your questions?

[NO] Would you like me to call at a better time, or are you not interested in the study? Thank you for your time. Goodbye.

[YES] This study is my dissertation for school, but it has also been funded by the federal government. The purpose of this project is to examine how people talk about their lives, and what they say about their lives. I’m going to be talking to young adults who had brain or spinal cord injuries when they were teenagers. I’m also going to be talking to individuals without disabilities. This study is important, because it may show similarities or differences in how people talk about themselves and their lives.

The interview has four sections (3 are during a one-on-one interview, and the other is a follow-up by phone.) There are multiple sections, because some people may find some parts more interesting than others. I expect that the one-on-one interview will take four hours (and the phone call should take 15 minutes). It may take more or less time, depending on how much you enjoy the interview and how much you like to talk about yourself! You'll be paid $25 for your time.

In the first section of the interview, I'll ask you to tell me your life story. While you're talking about your life, I won't interrupt you. I want to hear what you have to say. I won't say anything because I want you to say what you want, without me asking questions or changing the topic. Once you're finished, I may ask you a few questions about what you said.

In the second section, you and I will make a time-line of your life, so far. The time-line will show the important events in your life. There may be parts of your life story that you want to put on the time-line that you've already talked about, or you may remember new things to put on the time-line.

Then, in the third section, we'll do 2 short, oral exercises involving either your verbal memory or stories, because some people are just naturally good story tellers, and other people have to work at it. The first exercise is telling me a story based on a picture, and the second is brainstorming for words. By looking at these results, I may have a better idea about which people are natural storytellers, and who has to work at it. At the end of the interview, we’ll arrange a time that’s convenient for you, so that I can talk to you for an additional 15 minutes. At that time, we’ll complete a questionnaire about how you see yourself, and whether you’ve had any major brain injuries.

As in the previous studies at the RTC, you can take a break at any time, and you can decide not to answer any or all questions. If you want, you can decide to end the interview at any point. The interview doesn't have to be done in one session, but it does need to be an in-person interview at Mount Sinai or the Graduate School of CUNY. The interview and phone call will be taped, and you have the right to listen to the tape after the interview.

Everything you say will be completely confidential, and when I put your responses into the computer, your name won't be attached.

Do you have any questions? Do you think you might be interested?

[NO] Thank you for your time.

[MAYBE] I’ll give you a few days to think about it, and you can get back to me at (212)241-5152, or I’ll call you in a few days. Is that okay with you?

[YES] Since you are interested, let me see if you meet ALL the requirements for this study.

Are you between the ages of 18-40? _____

[If talking to an individual with SCI or TBI] How old were you when you had your injury? _____

Have you ever had a loss of consciousness? ____ How long?____

Will you be able to come to Manhattan for the interview? _____ (If answer is equivocal, go through the rest of the details. Then, if the individual qualifies AND is interested, find out if they could come to the interview with an friend or family member. If so, discuss payment with the participant and the family member.)

[No] I'm sorry, but for this study, I'm specifically looking for ___. However, is it okay with you if I keep your name on file? That way, if the criterion change, I'll be able to give you a call.

[Yes] Great! You fit into the study. Do you have any questions about the study? [After answering questions, explain that if the individual is not their own legal guardian, consents will be sent to them, otherwise consents will be signed the day of the interview. If individuals cannot sign their names, oral consent will be audiotaped.]

Now that you've heard everything, would you still like to participate?

[Yes] Great! Let me get the schedule...(Schedule)

Thank you very much! I look forward to talking with you.

[No] Well, thank you very much for your time. I enjoyed chatting with you today.

B. Interview Script

As we discussed on the phone, the purpose of this project is to examine how people tell stories about their lives, and what they say about their lives.

The interview has four sections, because some people may find some parts more interesting than others. You or I can decide when it's time to start the next section. You can also decide to not answer any question or decide to end the interview at any point.

In the first section, I'll ask you to tell me your life story. While you're talking about your life, I won't interrupt you. I want to hear what you have to say. I won't say anything because I want you to say what you want, without me asking questions or changing the topic. When you're finished, I may ask a few questions.

In the second section, you and I will make a time-line of your life, so far. There may be parts of your life story that you've already mentioned that you want to put on the time-line, or you may remember new things to put on the time-line.

Then, in the third section, we'll do 3 oral exercises, because some people are just naturally good story tellers, and other people have to work at it. Those exercises will wrap up today's interview, but we'll arrange a 15 minute phone call for later in the week, when I'll ask you some questions from 2 questionnaires.

> I expect that today's interview will take four hours, but it may take more or less time, depending on how much you enjoy the interview. You can take a break at any time, and you can decide not to answer any or all questions. The interview

doesn't have to be done in one session, but it does need to be an in-person interview at Mount Sinai. The interview will be taped, and you have the right to listen to the tape after the interview.

Everything you say will be completely confidential, and when I put your responses into the computer, your name won't be attached.

Do you have any questions?

Part I

Take a moment to organize your thoughts, and then, when you’re ready, can you please tell me your life story? (If needed, prompt w/ some people organize their story by time, others by events or themes).

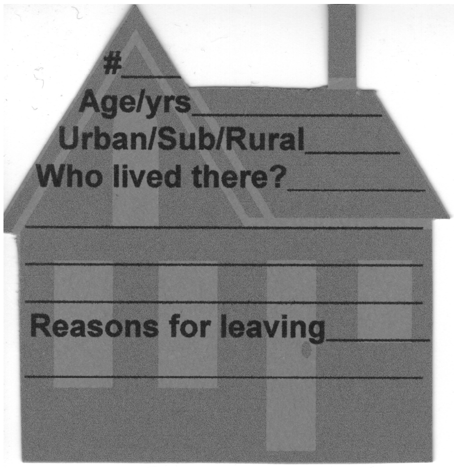
Follow-up questions based on the individual narratives.

Part II

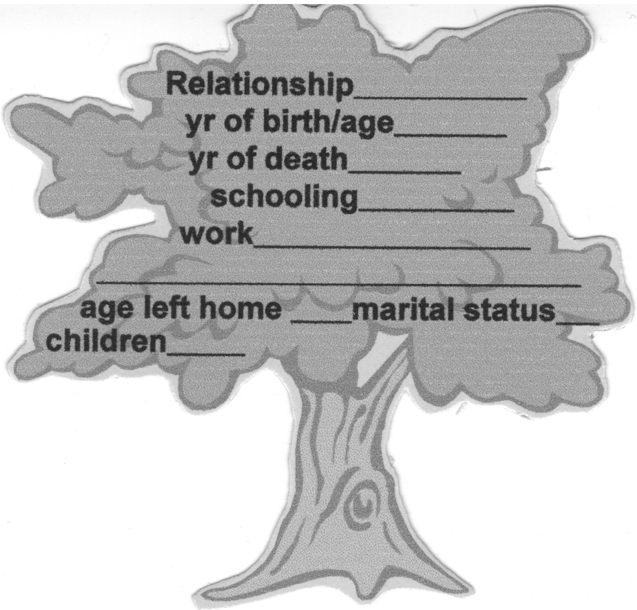
Now we’re going to make a time-line. One way to start the time-line is to pick a few of the events you mentioned when you were telling your story, and grow out from those events.

The interviewer and participant will create a life time-line.

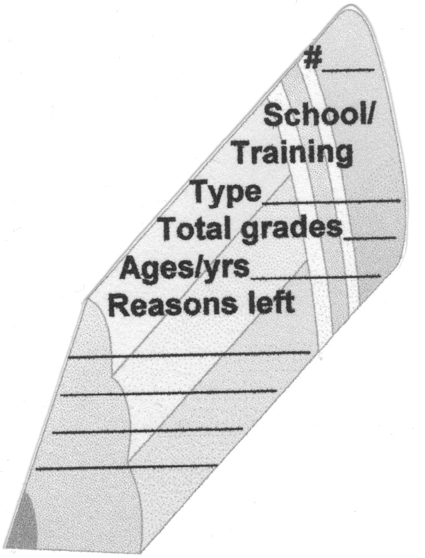
C. Icons



#____
Age/yrs__________
Urban/Sub/Rural______
Who lived there?_________
____
____
____
Reasons for leaving_______
____

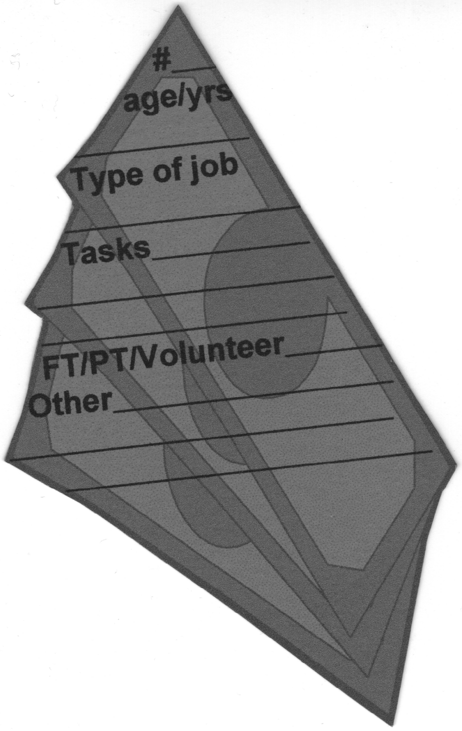


Relationship___________
yr of birth/age_______
yr of death_______
schooling_________
work________________
____
age left home ____marital status___
children_____

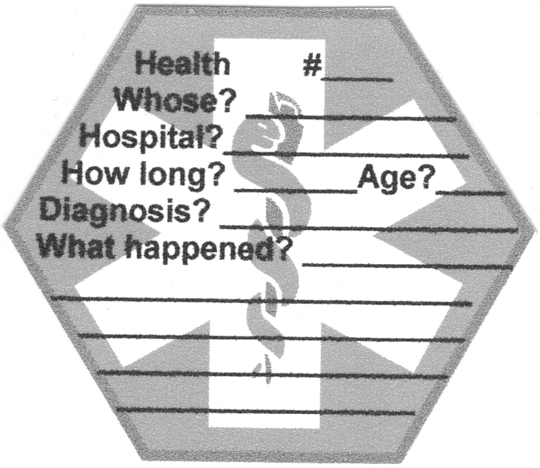


#____
School/
Training
Type________
Total grades___
Ages/yrs_______
Reasons left
____
____
____
____

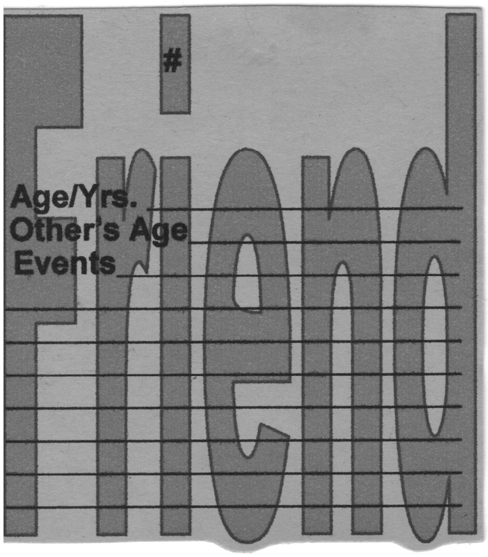
Significant #_______
Relationships
Age/yrs __Other's age__
Relationship events_____
____
____
____
____
____
____



#___
age/yrs
Type of job___
Tasks___
FT/PT/Volunteer___
Other___



Health #____
Whose? ____
Hospital? ____
How long? ____Age?____
Diagnosis? ____
What happened? ____



#
Age/Yrs.___
Other's Age___
Events___

Life Events #____
Age/Yrs____
Event____

D. Event Rules

One goal of this project is to compare the information given by the interviewees in different modalities. By nature, a time-line records events. Therefore, to compare the time-line and other sections of the interview, the other sections must also be broken into events that conceivably COULD be on a time-line.

An incident is any action by self or others that happened, with or without further elaboration. The event can be as small as one clause or as large as many clauses (even over sentence boundaries) as long as the clauses provide topical cohesion and/or elaboration. Topical cohesion means that several actions that are thematically related can be part of 1 event. The elaboration may include:

Evaluation
Description
References to time (social, historical, developmental)
Outcome
Causal attributions

Event boundaries occur between clauses or between sentences where a shift in topic occurs. This shift may be signaled by a change in time, place, or person.

For example:

Event 1

. . . And I grew up here in Elmhurst, Queens. And, um, I'm the youngest of five children--two brothers, two sisters. And um, growing up, we had, on our block, we had like a lot, a lot of kids, and we were the only ones who weren't Hispanic, but y'know whatever.

Event 2

And, um, --

used to play around a lot--y'know, they'd play handball, baseball, football, all that, y'know. And I sucked at sports, y'know, I was really bad with sports. And it was messed up. So, a lot of times they wouldn't let me play, cuz I held things back, brought everything down, and, um, that pissed me off a lot.

These are separate events signaled by changes in topic, person, and place.

A less elaborated example from another speaker follows:

Event 1

.. . .then I was sent home and was coming for outpatient visits, to M-S- a couple days a week,

Event 2

then, um, I started this other program, ICD, the I-C-D, and I was, I was there for about two years, I graduated the cognitive rehabilitation program, and from there, what I do from there?

This split is signaled by changes in location and type of program.

E. Changes to Hunt’s T-Unit rules

T-units were operationalized based on Hunt’s (1965, 1970) rules as cited in Cherney, Shadden & Coelho (1998).

Due to the conversational nature of the transcripts, t-unit borders were also created when:

- there was an interruption by the interviewer
- unintelligible speech.

In cases of overlapping speech, the interviewer’s words were ignored, and nothing different was done in creating the participant’s t-unit boundaries.

F. Coding Rules for Evaluative Devices

Based on Dauite's (1995) evaluation devices.

For my project, I simply measured the presence or absence of at least one example per event.

Internal States

Cognitions-Explicit statements like "I think" "I don't know why. . ."

Perceptions-Explicit statements.

Emotions-Use of emotion words like happy or sad.

Speech-Internal or external speech of self or others.

Adjectives-Any adjective in the event.

Causality-Signalled by words like "because."

From this model, the categories of relationships, social conventions, intensity, and written conventions were not used. Written conventions were not used, because the task was oral. Intensity was not used because repetitions and exaggerations could be viewed as either narrative devices or cognitive problems of the TBI.

G. Initial Life Course Codes

Units of analyses:

T-units--independent clauses and their dependent structures

Events--same definition as in my 2nd year project; the elaborated or unelaborated description/discussion of something that happened. Depending on the participant's verbal style, it may be (but doesn't have to be) a complete episode, as in story-grammar theories and other similar theories.

Interview Section--Each task specific part of the interview: Narrative, Time-line, & Linguistic, and Follow-Up.

At the event level, coding has five areas: contexts, relationships, timing, impairment/disability related features, and task-related features.

Life Course Features:

Locations:

School
Work
Family
Religion
Rehab/Hospitals
Hobby-related (sports, arts, etc.)
Volunteer Organizations

Social Ties:

Parents
Siblings
Other Relatives
Friends

	Significant Others
	School Personnel
	Co-workers & Bosses
	Rehab. Personnel
	Misc. Others
Timing:	Ahead of expected
	On-time
	Delayed timing
Impairment/ Disability	Before/After
	Limitations
	Hypotheticals
	Emotion
	Agency
Task-related:	Before/After
	Limitations
	Hypotheticals
	Emotion
	Agency

The following page describes the meanings of the above codes and their sub-codes. The Impairment/Disability (I/D) and Task-related codes are the same, except I/D only refers to the injury and its sequella, while the other focuses on the use of these constructs in other contexts as story-telling devices. The Task-related codes will be applied to individuals in all 3 groups.

What do the codes mean?

Locations: These are the institutional and societal-level institutions. Potential examples include: School, Work, Religion, Rehab/Hospitals, Hobby-related (sports, arts, etc.), and Volunteer Organizations. Depending on participants' story styles in my sample, potential subcodes may include: marked positive/negative/neutral valences, and/or how previous experiences are perceived as shaping later decisions.

Social Ties: These are the people who enter into the life story. Potential examples include: Parents, Siblings, Other Relatives, Friends, Significant Others, School Personnel, Co-workers & Bosses, Rehab. Personnel, and Misc. Others. While it is important to note who appears in the narrative, it is more important to note the valence of each reported interaction, as well as whether the other person's perspective is marked in the interaction.

Timing: This code examines whether individuals have completed culturally-expected tasks at expected ages, or earlier or later than normal. Some sociological theories (like Neugarten et al.) posit that pressure is put on individuals to meet societal expectations at the expected times; however, some sociological theories (like Parson's sick role) also posit that individuals with disabilities would be "excused" from these pressures due to their disabilities. Depending on the data, subcodes may be needed to examine how the individual feels about this pressure or lack of pressure.

Impairment/Disability: This is how the injury/impairment/disability is portrayed in the narrative. Potential examples include: Before/After, Limitations, Hypotheticals, Emotions, Causality, and Agency. Before/After and hypotheticals are self-explanatory, and should not require any sub-codes. Limitations, which were taken from 1 of 2nd year project participants, include the perceived effects of past, present, and future limitations. Emotions will be coded for emotions at the time of injury and also current emotions looking back. Agency will be coded using linguistic markers, like active voice and word choice.

Task-related: Since this is a narrative interview, the task may force or push participants to use certain story-telling devices. For the purposes of this project, the story-telling devices that will be examined are the same as the impairment/disability codes, except these codes will be applied to all the situations that do NOT refer to the injury/impairment/disability. For comparison purposes, it is projected that the same subcodes will also be used.

References

Albrecht, G., & Levy, J. (1991). Chronic illness and disability as life course events. In G. Albrecht & J. Levy (Eds.), *Advances in medical sociology: A research annual* (Vol. 2, pp. 3-13).

Benton, A., & Hamsher, K. (1978). Multilingual Aphasia Examination. Iowa City: University of Iowa.

Berger, M., Pitts, L., Lovely, M., Edwards, M., & Bartkowski, H. (1985). Outcome from severe head injury in children and adolescents. *Journal of Neurosurgery, 62*, 194-199.

Biddle, K. R., McCabe, A., & Bliss, L. S. (1996). Narrative skills following traumatic brain injury in children and adults. *Journal of Communication Disorders, 29*, 447-469.

Bolton, B. & Brookings, J. (1998). Development of a measure of intrapersonal empowerment. *Rehabilitation Psychology*. 43(2), 131-142.

Brookings, J. & Bolton, B. (2000). Confirmatory factor analysis of a measure of intrapersonal empowerment. Rehabilitation Psychology 45(3). 292-298.

Bogan, A. M., Livingston, M. G., Parry-Jones, W., Buston, K., & Wood, S. (1997). The experiential impact of head injury on adolescents: Individual perspectives on long-term outcome. *Brain Injury, 11*(6), 431-443.

Boyer, M., & Edwards, P. (1991). Outcome 1 to 3 years after severe traumatic brain injury in children and adolescents. *Injury: The British Journal of Accident Surgery, 22*, 315-320.

Brandt, E., & Pope, A. (Eds.). (1997). *Enabling America: Assessing the role of rehabilitation science and engineering.* Washington, DC: National Academy Press.

Brown, M., & Vandergoot, D. (1998). Quality of life for individuals with traumatic brain injury: Comparison with others living in the community. *Journal of Head Trauma Rehabilitation, 13*(4), 1-23.

Brubaker, S. J., & Wright, C. (2006). Identity transformation and family caregiving: Narratives of African American teen mothers. *Journal of Marriage and Family*. 68(5), 1214-1228.

Bruckner, E. & Mayer, K. (1998). Collecting life history data: Experiences from the German Life History Study. In J. Z. Giele & G. H. Elder (Eds.), *Methods of life course research* (pp. 152-181). Thousand Oaks: Sage.

Carson, P. (1993). Investing in the comeback: Parent's experience following traumatic brain injury. *Journal of Neuroscience Nursing, 25*(3), 165-173.

Chamberlain, D. J. (2006). The experience of surviving traumatic brain injury. *Journal of Advanced Nursing*. 54(4), 407-417.

Chapman, S. (1995). Discourse as an outcome measure in pediatric head-injured populations. In S. Broman & M. Michel (Eds.), *Traumatic head injury in children*. NY: Oxford University Press.

Chapman, S., Culhane, K., Levin, H., Harward, H., Mendelsohn, D., Ewing-Cobbs, L., et al. (1992). Narrative discourse after closed head injury in children and adolescents. *Brain and Language, 43,* 42-65.

Chapman, S. B., Levin, H. S., Matejka, J., Harward, H., & Kufera, J. A. (1995). Discourse ability in children with brain injury: Correlations with psychosocial, linguistic, and cognitive factors. *Journal of Head Trauma Rehabilitation, 10*(5), 36-54.

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health and Illness, 5*(2).

Charmaz, K. (1987). Struggling for a self: Identity levels of the chronically ill. *Research in the Sociology of Health Care, 6*, 283-321.

Charmaz, K. (1990). 'Discovering' chronic illness: Using grounded theory. *Social Science & Medicine, 30*(11), 1161-1172.

Cherney, L., Shadden, B., & Coelho, C. (Eds.). (1998). *Analyzing discourse in communicatively impaired adults*. MD: Aspen.

Clausen, J. A. (1986). *The life course: A sociological perspective*. NJ: Prentice-Hall.

Clausen, J. A. (1993). *American lives: Looking back at the children of the Great Depression*. NY: Free Press.

Cohler, B. (1982). Personal narrative and life course. In P. Baltes & O. Brim (Eds.), *Life-span development and behavior* (Vol. 4). NY: Academic Press.

Conger, R. D., Lorenz, F. O., Elder, G. H. J., Simons, R. L., & Ge, X. (1993). Husband and wife differences in response to undesirable life events. *Journal of Health and Social Behavior, 34*(March), 71-88.

Couser, G. (1997). *Recovering bodies: Illness, disability, and life writing*. Madison, WI: University of Wisconsin.

Crisp, R. (1993). Personal responses to traumatic brain injury: A qualitative study. *Disability, Handicap & Society, 8*(4), 393-404.

Crisp, R. (1994). Social reintegration after traumatic brain injury impairment: A qualitative analysis. *Journal of Applied Rehabilitation Counseling, 25*(4), 16-21.

Daiute, C. (1995, June). Imposing the self on school. Paper presented at the 25th annual symposium of the Jean Piaget Society. Berkeley, CA.

Daiute, C. & Lightfoot, C. (Eds.). (2004). *Narrative Analysis: Studying the development of individuals in society*. Thousand Oaks, CA: Sage.

Daiute, C., & Nelson, K. (1997). Making sense of the sense-making function of narrative evaluation. *Journal of Narrative and Life History, 7*(1-4), 207-215.

Eiben, C., Anderson, T., Lockman, L., Matthews, D., Dryja, R., Martin, J., et al. (1984). Functional outcome of closed head injury in children and young adults. *Archives of Physical Medicine & Rehabilitation, 65*, 168-170.

Elder, G. H., Jr. (1999). *Children of the Great Depression: Social change in life experience* (25th Anniversary ed.). Boulder, CO: Westview Press.

Elder, G. H., Jr. (Ed.). (1985). *Life course dynamics: Trajectories and transitions, 1968-1980*. Ithaca: Cornell.

Elder, G. H., Jr. (1994). Time, human agency, and social change: Perspectives on the life course. *Social Psychology Quarterly, 57*(1), 4-15.

Engel, D. & Munger F. (2003). *Rights of Inclusion: Law and Identity in the Life Stories of Americans with Disabilities*. Chicago: The University of Chicago Press.

Filley, C., Cranberg, L., Alexander, M., & Hart, E. (1987). Neurobehavioral outcome after closed head injury in childhood and adolescence. *Archives of Neurology, 44*, 194-198.

Fine, M., & Asch, A. (1988, Spring). Disability beyond stigma: Social interaction, discrimination, and activism. *Journal of Social Issues, 44*(1), 3-21.

Fisher, P. & Goodley, D. (2007). The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. Sociology of Health & Illness, 29(1), 66-81.

Gerhardt, U. (1990). Patient careers in end-stage renal failure. Social Science & Medicine. 30(11), 1211-1224.

Giele, J. Z., & Elder, G. H. (1998). Life course research: Development of a field. In J. Z. Giele & G. H. Elder (Eds.), *Methods of life course research* (pp. 5-27). Thousand Oaks: Sage.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. NJ: Prentice-Hall.

Goldstein, F., & Levin, H. (1987). Epidemiology of pediatric closed head injury: Incidence, clinical characteristics, and risk factors. *Journal of Learning Disabilities, 20*(9), 518-525.

Goodglass, H., & Kaplan, E. (1983). *The Boston Diagnostic Aphasia Examination* (2nd ed.). Boston: Lea & Febiger.

Gordon, W., Brown, M., Hibbard, M. (1997). Brain Injury Screening Questionnaire. NY: RTC on Community Integration of Individuals with Traumatic Brain Injury, Mount Sinai School of Medicine.

Haas, B., Jurkovich, G., Wang, J., Rivara, F., Mackenzie, E., Nathens, A. (2009). Survival advantage in trauma centers: Expeditious intervention or experience? *Journal of the American College of Surgeons, 208*(1), 28-36.

Hanak, M., & Scott, A. (1993). *Spinal cord injury: An illustrated guide for health care professionals* (2nd ed.). New York: Springer.

Handel, G. (2000). *Making a life in Yorkville: Experience and meaning in the life-course narrative of an urban working-class man*. CT: Greenwood Publishing Group.

Howie, L., Coulter, M. & Feldman, S. (2004). Crafting the self: Older persons' narratives of occupational identity. *American Journal of Occupational Therapy*. 58(4), 446-454.

Ivins, B., Schwab, K., Warden, D., Harvey, L., Hoilien, M., Powell, C., et al. (2003). Traumatic brain injury in U.S. Army paratroopers: Prevalence and character. *The Journal Of Trauma*, *55*(4), 617-621.

Jennett, B. (1996). Epidemiology of head injury. *Journal of Neurology, Neurosurgery, and Psychiatry, 60*(4), 362-369.

Josselson, R., & Lieblich, A. (Eds.). (1993). *The narrative study of lives* (Vol. 1). Newbury Park: Sage.

Kameny, R., & Bearison, D. (2002). Cancer narratives of adolescents and young adults: A quantitative and qualitative analysis. *Children's Health Care*, 31(2), 143-173.

Karweit, N., & Kertzer, D. (1998). Data organization and conceptualization. In J. Giele & G. Elder (Eds.), *Methods of life course research: Qualitative and quantitative approaches*. CA: Thousand Oaks.

Kasnitz, D. (2001). Life event histories and the US independent living movement. In M. Priestley (Ed.), *Disability and the life course.: Global perspectives* (pp. 67-78). UK: Cambridge University Press.

Klonoff, H., Clark, C., & Klonoff, P. S. (1993). Long-term outcome of head injuries: A 23 year follow up study of children with head injuries. *Journal of Neurology, Neurosurgery, and Psychiatry, 56*, 410-415.

Kraus, J., & McArthur, D. (1996). Epidemiologic aspects of brain injury. *Neurologic Clinics*, 14(2), 435-450.

Krefting, L. (1990). Double bind and disability: The case of traumatic head injury. *Social Science & Medicine, 30*(8), 859-865.

Kriel, R., Krach, L., & Sheehan, M. (1988). Pediatric closed head injury: Outcome following prolonged unconsciousness. Archives of Physical Medicine & Rehabilitation, 69, 678-681.

Lalvani, P. (2008). Mothers of children with Down syndrome: Constructing the sociocultural meaning of disability. *Intellectual & Developmental Disabilities. 46*(6), 436-445.

Langlois, J. A., Kegler, S., Butler, J., Gotsch, K., Johnson, R., Reichard, A., et al. (2003, June 27). Traumatic brain injury-related hospital discharges: Results from a 14-state surveillance system, 1997. *MMWR Surveillance Summaries, 52*(4), 1-24.

Langlois, J. A., Rutland-Brown, W., & Wald, M. M. (2006). The epidemiology and impact of traumatic brain injury: A brief overview. *The Journal Of Head Trauma Rehabilitation, 21*(5), 375.

Laub, J., & Sampson, R. (1998). Integrating quantitative and qualitative data. In J. Giele & G. Elder (Eds.), *Methods in life course research: Qualitative and quantitative approaches* (pp. 213-230). CA: Sage.

Levinson, D., Darrow, C., Klein, E., Levinson, M., & McKee, B. (1978). *The seasons of a man's life*. NY: Knopf.

Lezak, M. (1995). Neuropathology for neuropsychologists. In M. Lezak (Ed.), *Neuropsychological assessment* (3rd ed.). NY: OUP.

Lightfoot, C. (1997). The culture of adolescent risk-taking. New York: Guilford.

Linton, S. (1998). *Claiming Disability: Knowledge and Identity*. NY: New York University Press.

Marshall, R. C. (1989). Evaluation of communication deficits of closed head injury patients. In M. D. Lezak (Ed.), *Assessment of the behavioral consequences of head trauma* (pp. 87-112). NY: Liss.

Mazaux, J., Masson, F., Levin, H., Alaoui, P., Maurette, P., & Barat, M. (1997). Long-term neuropsychological outcome and loss of social autonomy after traumatic brain injury. *Archives of Physical Medicine & Rehabilitation, 78,* 1316-1320.

Mentis, M., & Prutting, C. (1987). Cohesion in the discourse of normal and head-injured adults. *Journal of Speech and Hearing Research, 30*, 88-98.

Meyer, P., Cybulski, G., Rusin, J., & Haak, M. (1995). Spinal cord injury. In R. Young & R. Woolsey (Eds.), *Diagnosis and management of disorders of the spinal cord* (pp. 103-134). Philadelphia: Saunders.

Morris, S. D. (2004). Rebuilding identity through narrative following traumatic brain injury. Journal of Cognitive Rehabilitation. 22(2), 15-21.

Murphy, R. (1987). *The body silent*. New York: Holt.

Nelson, K., (Ed.), (1989). Narratives from the crib. Boston: Harvard University Press.

Neugarten, B. (1968). Adult personality: Toward a psychology of the life cycle. In B. Neugarten (Ed.), *Middle age and aging: A reader in social psychology*. Chicago: University of Chicago.

Neugarten, B., Moore, J., & Lowe, J. (1965). Age norms, age constraints, and adult socialization. *American Journal of Sociology, 70*, 710-717.

Nochi, M. (1997). Dealing with the “void”: Traumatic brain injury as a story. *Disability & Society, 12*(4), 533-555.

Nochi, M. (1998a). “Loss of self” in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science & Medicine*, *46*(7), 869-878.

Nochi, M. (1998b). Struggling with the labeled self: People with traumatic brain injuries in social settings. *Qualitative Health Research*, *8*(5), 665-681.

Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science & Medicine*, *51*(12), 1795-1804.

O’Brien, C., & O’Brien, J. (2000) The origins of person-centered planning: A community of practice perspective. Responsive Systems Associates.

Okie, S. (2005). Traumatic brain injury in the war zone. *The New England Journal Of Medicine, 352*(20), 2043.

Oliver, M. (1983). *Social work with disabled people*. Basingstoke: Macmillan.

Palmer, R. (1987). Courses of development in mentally retarded persons. *Upsala Journal of Medical Science Supplement, 44*, 212-216.

Patti, N. (1999). *A methodological comparison of two life story methods used with individuals with traumatic brain injury.* Unpublished master’s thesis, City University of New York.

Pickelsimer, D., Selassie, A., Gu, J., Langlois, J. (2006). A population-based outcomes study of persons hospitalized with traumatic brain injury: Operations of the South Carolina Traumatic Brain Injury Follow-up Registry. *Journal of Head Trauma Rehabilitation*, *21*(6), 491-504.

Polkinghorne, D. (1991). Narrative and self-concept. *Journal of Narrative and Life History, 1*(2 & 3), 135-153.

Price-Lackey, P., & Cashman, J. (1996). Jenny's story: Reinventing oneself through occupation and narrative configuration. *American Journal of Occupational Therapy, 50*(4), 306-314.

Priestley, M. (Ed.) (2001). *Disability and the life course: Global perspectives*. UK: Cambridge University Press.

Ragnarsson, K. T. (2006). Traumatic brain injury research since the 1998 NIH consensus conference: Accomplishments and unmet goals. *The Journal Of Head Trauma Rehabilitation, 21*(5), 379.

Rappaport, M., Herrero-Backe, C., Rappaport, M., & Winterfield, K. (1989). Head injury outcome up to ten years later. *Archives of Physical Medicine & Rehabilitation, 70,* 885-892.

Rosenthal, G. (1993). Reconstruction of life stories: Principles of selection in generating stories for narrative biographical interviews. In R. Josselson & A. Lieblich (Eds.), *The narrative study of lives* (Vol. 1, pp. 59-91). Newbury Park: Sage.

Rowlands, A. (2001). Breaking my head in the prime of my life: Acquired disability in young adulthood. In M. Priestley (Ed.), *Disability and the life course.: Global perspectives* (pp. 179-191). UK: Cambridge University Press.

Saxton, M., & Howe, F. (Eds.). (1987). *With wings: An anthology of literature by and about women with disabilities*. New York: Feminist Press.

Selzer, M. (1995). Introduction: Epidemiology and pathophysiology of traumatic brain injury. *Journal of Neurologic Rehabilitation, 9,* 55-60.

Shadden, B. (1998). Obtaining the discourse sample. In L. Cherney, B. Shadden, & C. Coelho (Eds.). (1998). *Analyzing discourse in communicatively impaired adults* (pp. 9-34). MD: Aspen.

Shakespeare, T. (2006). *Disability Rights and Wrongs*. London: Routledge.

Sherry, M. (2006). *If I only had a brain: Deconstructing brain injury*. New York: Routledge.

Slota, N. (2006, June). Re-imagining outcome studies: The possibilities of life course research with individuals with traumatic brain injuries. Paper presented at the annual meeting of the Society for Disability Studies. Washington, DC.

Slota, N. (n.d.). [Fictional vs. autobiographical story-telling performance.] Unpublished raw data.

Slota, N. & Peffley, K. (2004, June). Gateway to action: Knowledge of the ADA by individuals with or without disabilities. Paper presented at the meeting of the Society for Disability Studies, St. Louis, MO.

Slota, N. & Peffley, K. (2005, June*)*. Disability and ethnic identity: The role of language and immigration in disability narratives. Paper presented at the annual meeting of the Society for Disability Studies, San Francisco, CA.

Slota, N. & Peffley, K. (2007, July). Triangulating qualitative data: The co-construction of visual time-lines with individuals with traumatic brain injuries. Paper presented at the Fifth Biennial Conference of the International Society of Critical Health Psychology, Boston, MA.

Solis, J. (2004). Narrating and counternarrating illegality as an identity. In C. Daiute & C. Lightfoot, (Eds.), *Narrative analysis: Studying the development of individuals in society* (pp. 181-200). Thousand Oaks, CA: Sage.

Spence, D. P. (1982). *Narrative truth and historical truth*. NY: Norton.

Straus, A. et al. (1984). *Chronic illness and the quality of life.* St. Louis, MO: Mosby.

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

Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness. *Lancet, 2,* 81.

Thomas, W. I., & Znaniecki, F. (1918-1920). *The Polish peasant in Europe and America*. Chicago: University of Chicago.

Thomsen, I. V. (1984). Late outcome of very severe blunt head trauma: A 10-15 year second follow-up. *Journal of Neurology, Neurosurgery, and Psychiatry, 47*, 260-268.

Thomsen, I. V. (1992). Late psychosocial outcome in severe traumatic brain injury. *Scandinavian Journal of Rehabilitation Medicine, Supplement 26*, 142-152.

Tucker, F., & Hanlon, R. (1998). Effects of mild traumatic brain injury on narrative discourse production. *Brain Injury, 12*(9), 783-792.

Vaillant, G. (1977). *Adaptation to life*. Boston: Little, Brown.

Wolfensberger, W. (unpublished). Some historical roots of human service institutions: Notes on lectures by Wolf Wolfensberger, April, 1982, Significantly annotated by David A. Goode, College of Staten Island, CUNY. Unpublished manuscript.

Wood, D., Bruner, J., & Ross, G. (1976). The role of tutoring in problem solving. *Journal of Child Psychology and Psychiatry, 17*(2), 89-100.

Wood, R., & Rutterford, N. (2006). Psychosocial adjustment 17 years after severe brain injury. *Journal of Neurology Neurosurgery & Psychiatry, 77*, 71-73.

Zigler, J. E., & Capen, D. A. (1998). Epidemiology of spinal cord injury: A perspective on the problem. In A. Levine, F. Eismont, S. Garfin & J. Zigler (Eds.), *Spine trauma* (pp. 2-8). Philadelphia: Saunders.