Investigation of Implementation of Life Care Plans and Impact on the Quality of Life of Individuals with Spinal Cord Injuries

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Abstract

The field of life care planning has been a prolific area of practice for rehabilitation professionals since the early 1980s. Life care planners are responsible for outlining future disability-related goods and services and provide information regarding the funds necessary to provide items in the life care plan. Life care planning literature references the World Health Organization International Classification of Functioning (WHO-ICF) model as the foundation for life care plan development as it considers not only the health condition, but the environmental, personal and activity limitations of the individual. The WHO-ICF theory provided the theoretical foundation for this study as it is applicable to life care planning as well as quality of life, one of the outcome variables measured in this study.

The current research interviewed 55 adults with spinal cord injuries throughout the United States who had a life care plan developed. These individuals were surveyed for receipt of funding for life care plan items, rates of life care plan implementation, as well as quality of life reports as measured by the WHOQOL-Bref. A multivariate analysis of variance (MANOVA) found a significant quality of life difference between those who did and did not receive life care plan funding but did not find a statistically significant difference between those who implemented more than 50% of the items in the life care plan. Additional analyses were undertaken to examine demographic and life care plan related variables that contributed to life care plan implementation.

Chapter I - The Problem

Service planning has always been a central part of rehabilitation services as disabilities typically result in the need for medical and related services (Roessler & Rubin, 2006; Weed & Berens, 2009). Whereas vocational rehabilitation planning focused on employment (Krause, 2003 as cited in Salmons, 2008) and discharge planning focused on post-acute care services, life care planning emerged as a transdisciplinary specialty of practice used to evaluate an individual's personal and environmental lifelong disability-related needs (Weed &

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Field, 1994). Life care planning first developed in response to the need of families of individuals with disabilities to have a long-term plan that comprehensively outlined rehabilitation needs for those who had sustained catastrophic injuries. The goal of the plan is to enhance the implementation of long-term rehabilitative care for these individuals (Deutsch, 2002). The definition of a life care plan is as follows:

> A life care plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized concise plan for current and future needs with associated costs, for individuals who have experienced catastrophic injury or have chronic health care needs (Weed & Berens, 2010, p.3).

Life care planning is a methodology to comprehensively analyze disability and its resulting needs including the frequency, duration and cost of necessary disability-related goods and services. Life care plans typically include an assessment of needs in projected areas including therapeutic evaluations and modalities, diagnostic testing/ educational assessment, wheelchair needs including equipment and maintenance, aids for independent function, orthotics/prosthetics, architectural renovations, medications, supplies, home care, facility care, routine future medical care, transportation, health/ strength maintenance, surgical intervention, orthopedic equipment, and vocational evaluation (Deutsch & Raffa, 1981; Deutsch & Sawyer, 2002; Sutton, Deutsch, Weed & Berens, 2002; Weed, 1998).

Historically, medical management of potential complications and prevention of disability has been the focus of rehabilitation research. However, with the emergence of the disability rights movement, the focus shifted from disability prevention and cure to maintenance of quality of life for individuals with disabilities with some proposing that quality of life should be adopted as the primary, and most comprehensive, rehabilitation outcome criterion (Miller, Chan, Ferrin, Lin, Jacob & Chan, 2008; Roessler & Rubin, 2006; Salmons, 2008; Switzer, 2003; Whiteneck, 1993). Measures of quality of life may include objectively measurable and externally manifested items, including income, employment, or physical function and/or the individual's subjective overall satisfaction with life or with specifically identified aspects of life such as relationship satisfaction or feelings of safety (Miller et al., 2008). Inclusion of both subjective and objective measures may provide a comprehensive picture of the quality of life of people with disabilities (Miller et al., 2008).

The life care plan, driven by prevention of complications, introduced a paradigm shift away from reactive crisis intervention and toward maintaining a satisfactory quality of life for the individual with the disability (Deutsch, 2002; Weed, 2007). By providing a comprehensive, interdisciplinary approach that systematically documents the lifetime needs of an individual with disability, the life care plan sets out criteria to maximize the individual's function, facilitate social independence, minimize the impact of secondary complications, enhance emotional adaptation, and promote reintegration into the community (Blackwell, Krause, Winkler & Steins, 2001).

Life care plans are essentially educational tools. The life care plan is often the only document that educates all interested parties about the various goods and services, along with the cost of service provision, which will be required throughout the person's life expectancy. The plan is developed with the person who has a disability, family members, and treatment team members. Parties interested in adjudication and funding of the client's

disability-related claim review the plan to understand what services are required and what the accompanying costs will be for the services (Weed & Field, 1994).

Life care plans have been successfully used in various public and private sector venues where it is necessary to predict future care needs and costs (Weed, 2002). Life care plans have been utilized for over thirty years in personal injury cases, workers' compensation, insurance reserve setting, estate planning, mediation, discharge planning, long-term managed care, geriatric services implementation, and various other disability related specialty programs, such as the vaccine injury fund and Medicare (Countiss & Deutsch, 2002; International Association of Life Care Planners, (IALCP) 2002; Weed, 1998). Life care plans also serve as financial planning tools to allocate necessary funds for future medical and rehabilitation services. With the aging baby-boomer population and increasing life expectancies for individuals with disabilities, life care planning may expand into additional systems.

Life care planning has evolved into a specialized area of expertise within the field of rehabilitation, and life care plans have been increasingly used since their introduction in the 1980s (Weed, 1998). There are currently several programs of life care planning studies, a professional designation as a certified life care planner (CLCP), a peer reviewed journal, the Journal of Life Care Planning, a code of ethics and standards of practice, six professional life care planning summits that have been held and a life care planning professional organization, the IALCP within the professional organization, the International Association of Rehabilitation Professionals (IARP).

By the 1990s, life care planning literature increasingly addressed quality of life issues for individuals with disabilities (Blackwell, 2001; Weed & Field, 2001). With its comprehensive focus, a life care plan encompasses the environmental, medical, psychological and vocational needs of the person with the disability (Pomeranz & Shaw, 2007). The purpose of the life care plan extends beyond prevention of medical complications and considers the overall functioning of the individual. Life care planning literature has called for the life care plan to be utilized as a case management tool, a living document, with a goal of providing the maximum quality of life for the individual with a disability (Brethauer & Brethauer, 2003; Casuto & Gumpel, 2003, Patterson, Murphy & Masterson, 2004; Weed, 2002). Through implementation, the "LCP will accomplish its mission:... to decrease the frequency and severity of medical complications for a particular (client's) overall quality of life" (Kendall, et al., 2002, p.158-159).

Statement of the problem

While life care planners are in a unique position to create the "big picture" for future needs of the individual with a disability, they rarely know how the life care plan is implemented and how plan implementation, or lack thereof, impacts the quality of the life of the individual with a disability (Marini & Miller, 2007). Although the field of life care planning has roots in case management and developmental psychology, there has been little study of what occurs in the lives of individuals for whom life care plans are prepared following case resolution (Salmons, 2008). Life care planners have long faced questioning about the use of the life care plan, after litigation as well as questioning about how life care plans impact the quality of life for those that we serve (Brethauer, 2003). The purpose of this study is to assess the implementation rates of life care plans developed for individuals with spinal cord injuries, to determine what variables contributed to implementation rates, to see what spe-

cific aspects of their life care plans persons with SCI purchased, and to determine how plan implementation impacted the individual's quality of life. By answering these questions, life care planners will establish an outcome measurement that has heretofore been absent in the life care planning literature.

Significance of Study

Outcome Measurement

Life care planning, as a field, has concentrated more on practice than it has on research. While research has been conducted to establish the reliability and validity of life care plans (Kendall & Casuto, 2005; Kendall & Deutsch, 2002; Sutton, Deutsch, Weed & Berens, 2002), limited research has been conducted to establish the outcomes of life care plan following their development. This void has been a notable absence both to the life care planners involved in plan preparation and to parties involved in litigation using the plans. A commonly asked question of life care planners is what outcome research has been conducted to determine if and how individuals with disabilities actually use their plan following case resolution. This study attempted to answer this question using a nationwide sample of individuals with spinal cord injuries for whom plans were prepared.

Life Care Plans have been used to establish legal damages as a result of injury or illness. Due to the nature of the involvement of the life care planner, they are typically not involved in life care plan implementation and may not know if and how the plans that they develop are used by the individuals for whom they are developed. This often puts the life care planner at a disadvantage in explaining how the inability to implement the life care plan may directly impact the lives of individuals with disabilities. Without this information, life care planners have lacked critical information about how to improve the effectiveness of the life care plan, which is designed to reduce complications and improve quality of life.

As these plans are often used in litigation, life care planners who author the plan are often ask to explain, either through deposition or trial testimony, how they developed the plan and arrived at their conclusions. In such proceedings, questions about implementation of life care plans are often posed. Only a few life care planners have conducted follow-up with their clients to see if and how the life care plans were implemented. This study provides life care planners with nationwide data about life care plan implementation and the resulting effects of the individual's quality of life following plan implementation.

Although life care planning has been a flourishing section of the field of rehabilitation since the 1990s, there has been a dearth of research to explore how clients use the life care plans post-litigation. Marini and Miller (2007) noted that whether or not any aspect of the life care plan was implemented remained empirically unsupported in the field of life care planning. Countiss and Deutsch (2002) noted that ensuring the future of life care planning within the forensic arena was dependent upon validating the life care planning process in the eyes of the court. The Standards of Practice published by the International Association of Life Care Planners include in the goals section the development of measurement tools to analyze outcomes (IALCP, 2002).

Life care planning literature has addressed questions of reliability and validity, concluding that when established procedures are followed, life care plans are reliable and accurate in outlining future care needs (Kendall & Deutsch, 2002; Sutton, Deutsch, Weed &

Berens, 2002). However, only four published works have assessed life care plan implementation following plan completion (Casuto & Gumpel, 2003; Marini & Miller, 2007; McCollom & Crane, 2001; Reavis, 2002). Casuto and Gumpel (2003) indicated that additional outcome surveys should be completed to compare life care planning outcomes across practitioners and geographic areas, and McCollom and Crane (2001) called for further intensive retrospective study to determine the accuracy of assessment and planning.

Life care planning has been a growing rehabilitation specialty since the 1980s. However, to date there have been relatively few outcome studies to question how the life care plans are used by the clients who need them. Studies conducted to date have not used a standardized set of questions, have had small sample sizes (largest sample size was 22) and have not utilized a quality of life measure to determine how plan implementation affected quality of life. This study was the first nationwide study of life care plan implementation designed to answer the question of how life care plans are implemented once they are completed, what factors influence implementation, and how their utilization impacts the quality of life of adults with spinal cord injuries.

Evidence Based Practice

Providing rehabilitation services to individuals with disabilities is the primary responsibility of rehabilitation professionals. Historically, services provision was conceptualized within a medical model of disability and evaluation by individuals receiving services was not solicited. Today, however, individuals with disabilities are involved in service planning, and rehabilitation agencies have come under pressure to demonstrate accountability for their services due to budget cuts in health, education, and social services (Miller, Chan, Ferrin, Lin, Jacob & Chan, 2008). As tightened funding is present in most medical and rehabilitation programs, demonstrating that the rehabilitation services delivered are cost-effective and result in successful outcomes has become relevant to rehabilitation service delivery (Bellini & Rumrill, 2009).

A 2009 National Council for the Dissemination of Disability Research (NCDDR) task force on best practices for disability and rehabilitation stated that evidenced based practice (EBP) is quickly becoming the preferred approach for guiding disability and rehabilitation professionals in providing services to individuals with disabilities (Johnston, Vanderhanden, Farkas, Rogers, Summers & Westbrook, 2009). As the field of rehabilitation becomes more concerned with the need for evidenced based practices, there is a call for the integration of research and practice to provide the best possible services to individuals with disabilities.

The creation of a valid life care plan does not assure that the life care plan recommendations will be implemented (Kendall & Casuto, 2005). Understanding how often and under what conditions life care plan recommendations are implemented following case closure may assist the life care planner in determining the best practice to ensure that the life care plan will identify and plan for services that have been found to correlate with improved quality of life. Identifying what factors mediate plan implementation and how this may impact quality of life adds to the repertoire of evidenced-based practice currently available to life care planners.

Role of individual with a disability

Many rehabilitation professionals have long believed that clients should play an increased role in decision-making (Murphy & Reid, 2003). Increasing attention in rehabilitation literature has been dedicated to the role of the person with a disability in rehabilitation planning. Many current best practices emphasize the importance of consumer participation, social networks, new technologies and choice for individuals with disabilities (Dennis, Williams, Giangreco & Cloninger, 1993). The World Health Organization's International Classification of Functioning, Disability and Health (ICF) model provides the theoretical basis of this study (World Health Organization, 2001). The ICF model asks individuals with disabilities for their own view of their well being. Over the last several decades, rehabilitation and healthcare have moved along a continuum from isolation and institutionalization toward mainstreaming, home care and inclusion of individuals with disabilities as part of the health caring team (Brethauer, 2001 as cited in Bretheuer & Bretheuer, 2003). A critical component to life care plan creation is consultation with the individual with a disability. Examination of how the inclusion of the individual with the disability in the life care planning process impacts post life care plan quality of life will provide life care planners new information about the role of the person with a disability in the life care planning process. This is consistent with the ICF framework and goals of client centered planning.

Quality of Life and Disability

Quality of life is a term that has been difficult to define (Bellini & Rumrill, 2009), yet is of great importance to individuals in society, both with and without disabilities. Arguments in rehabilitation literature have been made that quality of life should be our primary rehabilitation outcome criterion (Roessler & Rubin, 2006; Salmons, 2008). Quality of life must be defined or quantified and rehabilitation researchers have begun to asses this both qualitatively and quantitatively (Bellini & Rumrill, 2009). In general, subjective quality of life is assessed by individuals comparing what they have against what they believe that they deserve and what they value (Roessler & Rubin, 2006; Bishop, 2005). Correlates of quality of life for individuals with disabilities include employment, leisure time, health, social relationships, and level of resources (Roessler & Rubin, 2006). Within the framework of the disability centrality model (Bishop, 2005), the areas of one's life most consistently identified as factors in quality of life include physical health, psychological or emotional health, social support, employment or other productive activity, and economic or material well-being.

Care coordination

The field of life care planning emerged from rehabilitation practice but has had far reaching impact on a number of public and private systems including insurance companies, setting reserves for insurance claims, financial and trust entities, the judiciary and governmental bodies including the post-911 commission and vaccine injury compensation fund. The field of life care planning is unique within the field of rehabilitation in that it traverses both public-private sectors. Multiple establishments, including banks, state and federal courts and legislative entities have influence on the field of life care planning. Financial institutions use the life care plan to establish and administer trusts or other settlement products following care resolution. As life care plans often use state-regulated fee schedules, decisions

made by the state legislature impact the costs used in some life care plans. Federal agencies, including the federal September 11 Victim Compensation Fund and the Vaccine Injury Compensation Trust Fund administered by the United States Health and Human Services Health Resources and Services Administration have utilized life care plans to establish damages for individual's injured covered by these programs. Finally, the field of life care planning has been impacted by both state and federal judicial decisions, most notably *Daubert v. Merell Dow Pharmaceuticals*, Inc., 43 F.3d 1311 (1995).

As individuals live longer with their disabilities, the need for accurate, comprehensive lifelong care planning will become increasingly important. Providing empirical support for developing life care plans that enhance the quality of life for individuals with disabilities should enhance the credibility of the life care plan in the eyes of the court and may encourage life care planning to be seen as a valuable tool in healthcare planning. With an aging population and increased concern about healthcare cost factors, life care planning may be utilized as a mechanism for disability related budgetary planning. Concurrent with an aging population, however, is the emergence of the consideration of quality of life factors. Life care planners consider for inclusion in the life care plan items that are both medically necessary and items that enhance one's quality of life.

Social justice

A foundational ethical principal within rehabilitation counseling is the notion of justice. Justice implies that resources and services are disbursed fairly without regard to status or privilege (Bellini & Rumrill, 2009). However, unequal access to resources is often seen among people with disabilities. Individuals with disabilities are disproportionately represented in those living under the poverty line in the United States (Erickson & Lee, 2008), residing in more sparsely populated areas (Waldrop & Stern, 2003), and having lower levels of education (Erickson & Lee, 2008). Interfacing these characteristics with a healthcare system that is increasingly specialized, complex, and centered in metropolitan areas presents multiple access barriers for individuals with disabilities. Additionally, inequity within the legal system has been noted on the basis of race, gender and socioeconomic status of the plaintiff who sustains injury and seeks legal remedies (Chamallas, 2005). This study examined the relationship between education, geographic area, and financial resources on an individual's implementation of the life care plan and quality of life outcomes. Unequal access to resources was examined to determine if and how this factor impacted life care plan implementation.

Summary

Since 2001, the field of life care planning has called for intensive study of the outcomes for life care planning clients. Several life care planners have conducted such studies; however they were limited to relatively small sample sizes. This study was the first nationwide study to examine outcomes for a significant number of individuals with spinal cord injuries. This study is important in a time of increased concern about healthcare planning because the life care plan process places the individual with a disability at the center of the life care planning process. Their participation is essential in plan development, which is a paradigm that stands in contrasts to many current healthcare planning processes. This study provides life care planners with evidence about how life care plans are implemented,

what factors are associated with plan implementation and how life care plan implementation affects the quality of life for adults with spinal cord injuries.

Assumptions Underlying the Study

Several assumptions underlie this study. First, it is assumed that each respondent completed the survey only one time. Second, data was collected through self-report methods and that the individual's self-report is an accurate reflection of the individual's experience. Third, it is assumed that quality of life for individuals with disabilities consists of the same elements as quality of life for individuals without disabilities. Fourth, it is assumed that study participants are a representative sample of adults with spinal cord injuries for whom life care plans were developed. Finally, it is assumed that life care plans developed for adults with spinal cord injuries contain the same or similar areas of items and services.

Theoretical basis of study

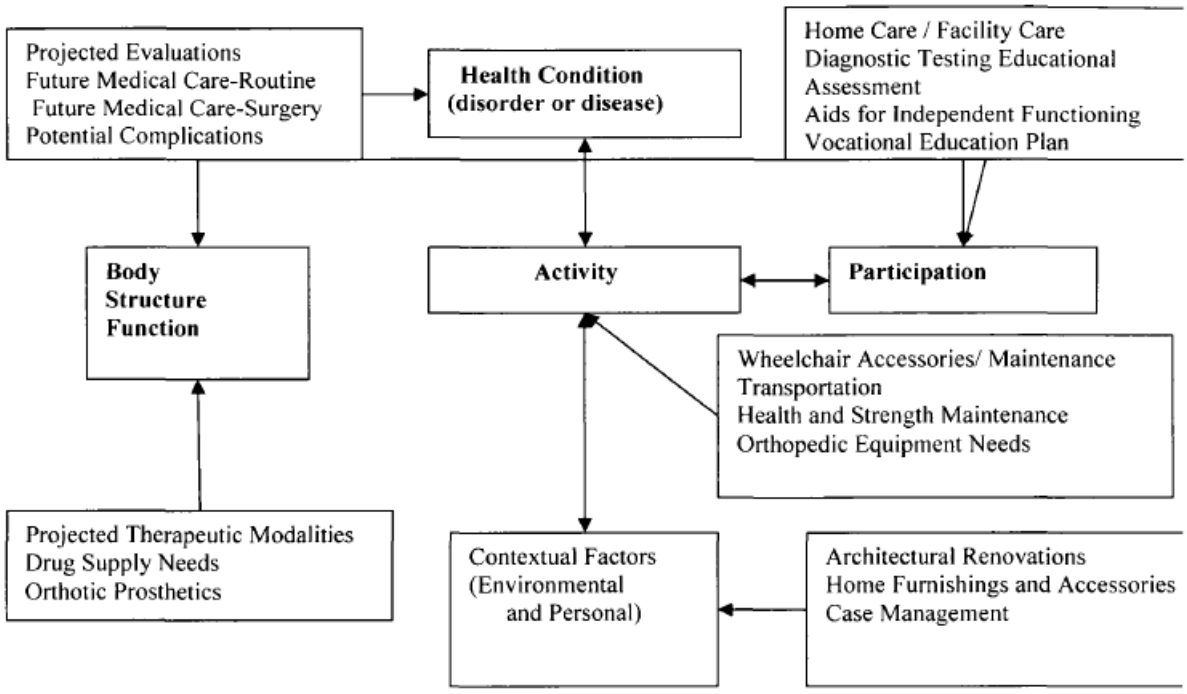
The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) provided the foundation for this study (WHO, 2001). The ICF is a biopsychosocial model of disability that incorporates elements of the individual's bodily functions, engagement in activities, participation restrictions, and environmental factors that interact with disability. The ICF model shifts the focus of disability from impairment (medical model) to a concept of functioning within societal context whereby disability management requires environmental modification, social action and ideological changes (World Health Organization, 2001). With its inclusion of environmental barriers and facilitators, and its shift from cause to impact of disability, this model provides guidelines to better understand how environmentally based factors can improve the functioning of individuals with disabilities. The ICF model is perhaps the international authority for disability conceptualization (Murphy & Reid, 2003).

Pomeranz and Shaw (2007) noted that the method used by life care planners to evaluate disability is consistent with the ICF model. As life care planners analyze medical, psychological, social and environmental components of the lives of their life care planning clients, the ICF model provides a theoretical framework to view life care plan development and implementation. The ICF model can be useful in explaining life care planning concepts and has been effective in identifying and measuring effectiveness of rehabilitation services (Peterson & Kosciulek, 2005 as cited in Pomeranz & Shaw, 2007). The life care planner consults with the individual who has the disability and his or her family, treatment team members of various specialties including medical, psychological, and specialized therapies, as well as individuals familiar with local community resources including local building codes. The unique position of the life care planner to consider physical, psychological, social and environmental aspects of the individual's life is reflected in this model of disability. Pomeranz and Shaw (2007) developed a model of ICF-Life Care Planning that outlines corresponding life care plan areas with the areas of disability in the ICF model. This is shown in Figure 1. The World Health Organization Quality of Life (WHOQOL) measure was used in this study to collect data on the individual's perceived quality of life. The instrument assesses the individual's perceptions within a cultural context including one's personal goals, standards and concerns. The WHOQOL-BREF is comprised of twenty-six items that measure the following broad do-

Figure 1

ICF-Life Care Planning Model

Reprinted with permission of authors and journal editors. Pomeranz, J.L. & Shaw, L.R. (2007). International classification of functioning disability and health: A model for life care planners. Journal of Life Care Planning, 16(1-2), 15-24.



mains: physical health, psychological health, social relationships, and environment (Murphy, Hawthorne, Pinzone & Evert, 2000). These domains are consistent with those assessed by the life care planner. Facets within the domain of physical health include activities of daily living, dependence on medicinal substances and aids, energy and fatigue, mobility, pain/ discomfort, sleep/rest and work capacity. Facets within the psychological domain are body image, negative and positive feelings, self-esteem, religion/ spirituality and thinking/ learning, memory and concentration. Facets within the social relationships domain include personal relationships, social support, and sexual activity. Facets within environment domain include financial resources, freedom, physical safety and security, access and quality of health and social care, home environment, opportunities for acquiring new information, participation in recreation/ leisure, physical environment and transportation (Murphy, et al., 2000). Many of the facets within the four domain areas are considered as part of life care plan development. Therefore, the ICF model provides an appropriate theoretical model within which life care planning can be analyzed.

Research Questions

Based upon the ICF-Life Care Planning model and past life care planning research, questions for this investigation included:

1. What percentage of individuals with spinal cord injuries (SCI) implements key elements of the Life Care Plan (e.g., attendant care, home modifications, transportation) following case resolution?

2. What domains of quality of life are different for individuals who implement the life care plan when compared to those who do not?

3. Are there differences in life care plan implementation for those who receive settlement or jury award and those who do not? How does this impact quality of life reports?

4. Are there differences among demographic variables (e.g. geographic area of residence, pre-injury education level, ethnicity, severity of injury) for individuals who implement the life care plan when compared to those who do not implement the plan?

5. Does life care plan implementation impact the employment of individuals with spinal cord injuries?

Limitations

Due to the individualized nature of life care plans, caution should be used when generalizing the results of this study. Due to the unique set of factors associated with spinal cord injuries, life care plan implementation rates in this study may not be generalizable to other life care plan populations including those with traumatic brain injury, amputation, or developmental disabilities. Participants with co-morbid conditions with spinal cord injury were not included in the study results.

Information collected in this study was primarily collected by mail, telephone and internet surveying and different results may be generated by in-person interviews. Life care plan implementation rates were collected via self-report format and the life care plan was not always available for review at the time of survey completion. The respondent may have been unaware of all of the items that were included in the life care plan. Bellini & Rumrill (2009) note that self report methods of data collection can introduce error as study participants must rely on their memory to reconstruct experiences. Additionally, if a surrogate responder is completing the survey with the individual with SCI, the participant may mask depressed quality of life reports.

Due to the temporal nature of quality of life, it is noted that longitudinal assessment of quality of life may be a better measure of quality of life. This research is not longitudinal in nature and therefore only provides a snapshot of the individual's evaluation of their quality of life. Finally, it is noted that the subjective nature of quality of life may be difficult to assess within a quantitative framework.

Definitions and Operational Terms

Life care plan

A life care plan is a dynamic document based upon published standards of practice, comprehensive assessment, data analysis and research, which provides an organized, concise plan for current and future needs with associated costs for individuals who have experienced catastrophic injury or have chronic healthcare needs. This definition is published in the *Life*

Care Planning and Case Management Handbook (Weed & Berens, 2010) and endorsed by the International Association of Life Care Planners.

- A life care plan typically consists of a narrative report, a tables section outlining future goods and services and a vocational worksheet may be included. Areas for consideration in the life care plan tables section include:
- Projected Evaluations: These are typically non-physician evaluations such as physical, occupational, or speech therapy, nutritional, vocational rehabilitation, and recreational therapy, depending upon the needs of the client.
- Projected Therapeutic Modalities: These are modalities that result from evaluations including physical, occupational or speech therapy sessions, counseling, case management, etc.
- Diagnostic Testing/ Educational Assessment: This area includes testing or supplemental educational services.
- Wheelchair Needs: Wheelchair needs may include manual, power, shower or specialized wheelchairs.
- Wheelchair Accessories and Maintenance: Accessories such as wheelchair cushions, bags, trays, etc are included as well as maintenance required for each chair.
- Aids for Independent Functioning: This area may include items such as reachers, bath or eating aids or aids that promote environmental navigation.
- Orthotics/ Prosthetics: This includes any braces, prosthetics, etc that are required as well as any supplies or maintenance required by the prostheses.
- Home Furnishing/ Accessories: This area includes lifts, beds or other large items that will be necessary in the client's home for proper care.
- Drug/ Supply Needs: Medications including dosage and frequency are outlined in this area as well as bladder, bowel or skin care needs.
- Home Care/ Facility Care: This area includes attendant care including level and number of hours of care provided in the home as well as a facility care option (if appropriate) at the current time and as the client ages.
- Future Medical Care- Routine: Routine physician visits, tests and laboratory monitoring will be included in this area.
- Transportation: A specialized van including vehicular modifications and required maintenance are outlined in this area.
- Health and Strength Maintenance: This area includes items needed for recreational and exercise endeavors.
- Architectural Renovations: Modifications necessary for the home are included here and may include ramps, door widening, attendant room, floor coverings, etc.

- Surgical Intervention/ Aggressive Treatment: This area includes an outline of surgical procedures, injections, etc. that may be required in the future.
- Orthopedic Equipment: Items including walkers, tables, etc. are included in this area.
- Potential Complications: Complications common to the particular diagnosis are included in this section.
- Vocational/ Educational Plan: Costs of a vocational rehabilitation plan are typically included in this area.

While the items included in each section vary depending upon the particular client and his or her diagnosis, these areas should be considered to ensure adherence to current standards (Weed, 1998). Due to the large number of possible items included in the life care plan, the following items and services were queried in the life care plan survey developed for this study:

Counseling Services	General Practitioner Visits
Physical Therapy Services	Physiatrist Visits
Occupational Therapy Services	Urology Visits
Nutritional Counseling	Attendant Care Services
Case Management	Emergency Room Visits
Manual Wheelchair	Van/Vehicle Modifications
Power Wheelchair/Scooter	Lift Devices
Horne Modifications	Exercise Equipment
Seating for Wheelchairs	Bed/Mattress System
New, Accessible Housing	

Spinal Cord Injury

Traumatic spinal cord injury (SCI) is defined as an acute, traumatic lesion of the spinal cord resulting in any degree of sensory or motor deficit or paralysis, including injury to the nerve roots or cauda equina (Lin, Chen, Chiu, 2007). Participants in this study were adults with various levels of spinal cord injury. They were selected for inclusion by the life care planner who prepared their life care plan.

Quality of life

The World Health Organization (2001) defines quality of life as "an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (WHO, 1999 as cited in Wood-Dauphinee, Exner & the SCI Consensus Group, 2002). Quality of life is affected by the

person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.

Disability

The World Health Organization defines disability as "an umbrella term for impairments, activity limitations and participation restrictions." (WHO, 2001, p. 4). It denotes negative aspects of the interaction between the person and the overall context in which a person lives (WHO, 2001). Disability and functioning are viewed as interactions between health conditions and contextual factors the environment of the individual.

World Health Organization Quality of Life-BREF

The World Health Organization Quality of Life (WHOQOL) project was initiated in 1991 to develop an international cross-culturally comparable quality of life assessment instrument. The World Health Organization, with 15 worldwide collaborating centers, developed two instruments for measuring quality of life (WHOQOL-100 and WHOQOL BREF). The WHOQOL-BREF was developed using data from the field-trial version of the WHOQOL-100 and domain scores have been found to correlate at around .9 with the WHOQOL-100 domain scores (Murphy, et al., 2000). The WHOQOL-BREF is a 26-item self report questionnaire. It can be self administered or interviewer administered. It is a shorter version of the WHOQOL-100 and has been shown to have good discriminant validity, content validity and test-retest reliability (.76-.80), internal consistency (.70-.77) (Lin, Swang, Chen & Chiu, 2007). The overall quality of life score is comprised of environmental, physical, social and psychological domains. Miller, Chan, Ferrin, Lin and Chan (2008) validated the instrument for use with individuals with spinal cord injuries and suggest that the WHOQOL-BREF be used by rehabilitation researchers as a measure of subjective quality of life.

Environmental Quality of Life Domain

Facets within environment domain include financial resources, freedom, physical safety and security, access and quality of health and social care, home environment, opportunities for acquiring new information, participation in recreation/ leisure, physical environment and transportation (Murphy, et al., 2000).

Physical Quality of Life Domain

Facets within the domain of physical health include activities of daily living, dependence on medicinal substances and aids, energy and fatigue, mobility, pain/ discomfort, sleep/rest and work capacity (Murphy et al., 2000).

Psychological Quality of Life Domain

Facets within the psychological domain are body image, negative and positive feelings, self-esteem, religion/ spirituality and thinking/ learning, memory and concentration (Murphy et al., 2000).

Social Quality of Life Domain

Facets within the social relationships domain include personal relationships, social support, and sexual activity (Murphy et al., 2000).

Implementation Rate

Implementation rates were measured by self-report methods of the percentage of items implemented by the individual. Calculations were conducted to estimate the number of individuals who implemented none of the items included in their life care plan; those who implemented 1-25% of the items in the plan; those who implemented 26-49% of items in the life care plan; those whom implemented 50-74% of items in their plan; and those who implemented 75% or more of the items in the plan.

Life care plan outcome survey

A review of literature was conducted to identify all published life care plan outcome surveys and no standardized survey was located. Additionally, life care planners throughout the United States were asked to notify the author of any existing surveys developed for this purpose. As a result, three surveys were collected. A review of the surveys concluded that the following areas were consistently queried about life care plan implementation:

1. Physician visits
2. Home modifications
3. Vehicle/ transportation needs
4. Complications or hospital treatment
5. Medications
6. Personal care attendant needs
7. Training/ educational endeavors
8. Employment
9. Wheelchair needs.

As a result of this analysis, these items were included in a life care plan survey developed by the author to measure life plan implementation.

Summary

While rehabilitation planning has long been part of the job function of rehabilitation professionals, the advent of life care planning in the 1980s ushered in a new paradigm of lifelong, comprehensive planning for individuals with disabilities. As the field has continued to grow, empirical support for the reliability and validity of the life care plan has been researched and established. However, one area that life care planners have been unable to empirically support is how the plans that they develop are used after they are developed. A

review of previously developed life care plan outcome surveys found overlap in various life care plan areas, which were consolidated into a life care plan survey used for the current study.

This study surveyed individuals with spinal cord injuries nationwide for whom life care plans were developed. Information was collected to determine if pertinent areas of the life care plan were implemented and what factors may have influenced life care plan implementation. Finally, this study sought to determine what factors impacted life care plan implementation and how the resulting implementation affected the individual's quality of life. With this information, life care planners will be provided with evidenced based practice guidelines on which to base their life care planning practice.

Chapter II - Literature Review

Life care planning has been employed as a tool of rehabilitation professionals since the 1980s. Research on methodologically sound procedures for life care plan development has been the focus of the research previously conducted in this area. Historically, less attention has been focused on what occurs after the plans are developed (Marini & Miller, 2007). Although life care planners recognize the contribution that life care plans make in the lives of individuals with disabilities, there has been little empirical investigation into this phenomenon (Salmons, 2008). Specifically, there has been no investigation into the impact that life care plans have on the quality of life for individuals with spinal cord injuries. This chapter reviews pertinent literature on these topics. Consistent with the objectives of this investigation, the review of relevant literature addresses: (a) the impact of spinal cord injury in America (b) the emergence of the field of life care planning (c) quality of life as an outcome measurement and (d) the International Classification of Functioning as a disability model.

Spinal Cord Injury in America

Previous life care planning outcome studies have surveyed individuals with various disabilities including cerebral palsy (Casuto & Gumpel, 2003), traumatic brain injury (Reavis, 2002) and spinal cord injuries (McCollom & Crane, 2001; Marini & Miller, 2007). To better understand the prevalence of spinal cord injury, a review of spinal cord injury literature was made.

Over the last 50 years, there has been a 2000% increase in the post-SCI life expectancy for individuals (Kemp & Krause, 1999), but overall life expectancy for individuals with SCI continues to remain below the life expectancy for the general population, ranging from 73 years for SCI onset at age 20 to 78 years for SCI onset at age 60 (The National SCI Statistical Center, 2009). Common causes of death specific to the SCI population include pneumonia, pulmonary emboli, and septicemia (The National SCI Statistical Center, 2009).

The spinal cord consists of the major bundle of nerves that transmits impulses to and from the brain and body and it lies within the spinal canal created by the vertebrae in the spinal column (Blackwell, Krause, Winker, & Stiens, 2001). Thirty pairs of sensory and motor nerves originate in the spinal cord - 8 cervical (neck), 12 thoracic (chest), 5 lumbar (lower back), and 5 sacral (tailbone) - and exit between adjacent openings in the vertebrae (Blackwell et al., 2001). An injury to the spinal cord can cause various degrees of neurological

(motor and sensory) impairment depending upon where and to what extent (e.g. incomplete or complete lesion) the spinal cord is injured (Blackwell et al., 2001).

A review of spinal cord injury statistics from The National Spinal Cord Injury (SCI) Statistical Center (February 2010) indicates that approximately 12,000 new spinal cord injuries are sustained each year. Of these, 81% of individuals who sustain these injuries are male and since 2005, the average age at injury was 40.2 years. Population ethnicity breakdowns since 2005 are 66% Caucasian, 27% African American, 2% Asian, 8% Hispanic. The most commonly reported SCI causes include motor vehicle accidents 41%, falls 27%, violence 15%, sports 8%, and other 9%. One year following SCI, 12% individuals with SCI are employed and by 20 years post SCI, 35% are employed (The National SCI Statistical Center, 2009). Fifty-two percent of individuals who sustain SCI are single when injured and the likelihood of a marriage remaining intact following SCI is slightly lower than the general population. The likelihood of getting married after injury is also reduced (The National SCI Statistical Center, 2009). Eighty-eight percent of individuals with spinal cord injuries are discharged to a private residence, typically their pre-injury home.

As individuals with spinal cord injuries leave rehabilitation facilities and return to private residences, they require environmental modifications to allow accessibility for wheelchair use. The modifications may include acquisition of equipment and supplies, as well as modification of existing structures and employment of attendant care providers. Life care planners are involved in assessment of each of these disability-related areas. The life care plan will outline the needs of the individual within these areas, as well as research the costs of these goods and services in the individual's geographic area of residence.

Emergence of Life Care Planning

The term "life care plan" was introduced in 1981 by Drs. Paul Deutsch and Fred Raffa in the publication Damages in Tort Actions and in 1985, the classic Guide to Rehabilitation introduced the rehabilitation community to the life care plan (McCollom & Weed, 2002). The life care plan was introduced as a case management approach to disability that provided an organized, standardized, consistent, time efficient and comprehensive method for providing the framework of goods and services that resulted from the onset of disability, typically from a traumatic event (Weed & Field, 1994). Life care planning developed in response to a number of multiple professional concerns including:

1. Persons with disabilities and their families need a concise summary to plan for future needs;

2. A communication tool is needed with which all parties involved in a catastrophic injury case will be informed of these needs;

3. A planning approach in the field is needed rather than the traditional reactionary approach;

4. Disabilities could be broken down into basic components to more carefully identify complex concerns;

5. Concerns specific to the person with the disability and their family, such as geographic location, preferences, and personal goals need to be incorporated into a plan of care to ensure a realistic implementation (Weed & Berens, 2010, p. 834).

The life care plan, in addition to addressing ongoing medically related goods and services, also addressed quality of life issues, long-term needs of the patient and family, and non-medical disability-related needs including transportation and architectural renovations (Weed & Field, 1994). Following the introduction of the life care plan to the rehabilitation community in 1985, one of the first life care planning educational conferences was held in 1986 and in that same year the first peer-reviewed rehabilitation journal article on life care planning was published in the Journal of Private Sector Rehabilitation (McCollom & Weed, 2002). By 1992, a comprehensive life care planning curriculum had been developed, comprised of eight two and one-half day training seminars, which was followed by the introduction of a certificate in life care planning in 1996 (McCollom & Weed, 2002). By 1996, the first professional association specific to life care planning was also formed which evolved into the International Academy of Life Care Planners (McCollom & Weed, 2002). A series of life care planning summits was launched in 2000 and have continued through 2010.

Today, life care planners comprise a vibrant portion of the private rehabilitation service industry. They have a professional certification, ongoing continuing education seminars and a peer-reviewed journal, *The Journal of Life Care Planning*. A 2003 study of accredited graduate rehabilitation counseling programs revealed that two-thirds offer life care planning training (Isom et al., 2003 as cited in Weed & Berens, 2009). The 2008 Council on Rehabilitation Education (CORE) accreditation manual identifies life care planning as a required knowledge area (Weed & Berens, 2009). Life care planning has emerged as the most comprehensive and widely accepted process for identifying needs and the accompanying economic projections associated with complex medical impairments and catastrophic injuries (Weed, 2007).

The life care plan was introduced as a case management tool, with the assumption that the recommendations outlined in the plan, when implemented, would succeed at reducing the rate of secondary complications and improving the quality of life for individuals with disabilities (Riddick & Rougham, 1992). Without the care outlined in the plan, the individual with the disability may have increased costs as a result of disability-related complications (Weed, 2002).

To ensure that the recommendations in the plan are followed, case management services are often included as a recommended service to ensure that client services do not "fall through the cracks" (Weed, & Berens, 2010). Both case management and life care planning involve a problem-solving approach that promotes continuity of care and effective appropriation of services (Weed, 2007). The creation of the life care plan occurs first, followed by initiation of case management services to assist the individual to manage these resources (Blackwell, Krause, Winkler & Steins, 2001). In a study of 239 life care planners, 54 percent indicated that they provided case management services to the client after developing the life care plan (Turner, Taylor, Rubin, May, 2000). In a 2003 study of life care plan outcomes, Casuto and Gumpel (2003) concluded that post life care plan case management services were essential for accurate implementation of the life care plan. While some life care planners believe that follow-up case management services should be provided to the individual following completion of the plan to ensure that necessary services are being provided (Casuto &

Gumpel, 2003; Penberty & Priest, 1989), life care planning standards have advised life care planners to separate the life care planning function and case management function (Reavis, 2002). Reavis (2002) encourages follow-up consultation to ensure that the life care plan is understood but cautions against life care planners assuming decision-making responsibility beyond the scope of their professional discipline.

Life Care Planning Research

Life care planners are often called upon to provide testimony in adjudicated settings regarding damages sustained through various areas of tort law. As such, life care plans are reviewed by jurors, judges, legal representatives, third party payers and injured parties involved in litigation. In 1995, the United States Supreme Court issued a decision in *Daubert v. Merell Dow Pharmaceuticals, Inc.*, 43 F.3d 1311 (1995) that set forth the criteria for the admissibility of expert testimony as follows:

1. whether the theory or technique can be or has been tested
2. whether the theory or technique has been subjected to peer review or publication
3. the known or potential rate of error
4. the general acceptance within the relevant scientific community (Countiss & Deutsch, p. 35).

Since the 1995 *Daubert* decision, life care planners have examined how the life care planning process can meet the above standard, as *Daubert* has been invoked as the yardstick by which life care planners measure their work (Pomeranz & Shaw, 2007). Issues arising from the *Daubert* decision have spurred research in life care planning, primarily to establish the reliability and validity of the life care planning process. Bellini and Rumrill (2009) propose that science is not a set of definitive results but a way of understanding the world, and research is the methodology for establishing knowledge of that world. Research analysis of data and evaluation of care recommendations are key elements life care planning and development of a life care plan requires a commitment to a consistent and unbiased process and reliance on fact, research, and expertise (Weed & Berens, 2009).

Reliability in life care plan development has been defined as a consistent methodological approach and adherence to literature-based and industry standards including standards of practice established by the International Academy of Life Care Planners (Sutton, et al., 2002; Reavis, 2002). A life care plan that is reliable could be duplicated for the client by use of the same methods and tools. As a result of a follow-up study of post life care plan outcomes, Casuto and Gumpel (2003) indicated that assessment of life care plan reliability is an important component of life care planning practice.

In 2002, Sutton, Deutsch, Weed and Berens compared 65 original and updated life care plans to determine reliability over time. Attendant/ facility care and routine medical care areas were chosen for investigation because they are common to all life care plans and often comprise the majority of needs and costs in life care plans. This study concluded that the need for life care plan items remained consistent when analyzed again one to five years after the original life care plan was developed (Sutton et al., 2002).

Life care plan validity pertains to the individual items and services included within each subject area (i.e. future medical care routine), which are determined by consultation with appropriate professionals whose area of practice provides specialized knowledge of the particular area (Sutton et al., 2002). Kendall and Deutsch (2002) examined the issues related to validity in life care planning. Face validity, which refers to whether the life care plan "looks like" it details the individual's needs, is important for those who will review the plan upon completion. Content validity, or the applicability of items included in the plan to address the disability-related needs of the individual is essential.

Reviewing treatment protocols for each diagnosis or consensus guidelines of disability related groups is one way of ensuring that all necessary items are included in the life care plan. To test criterion-related validity, Kendall and Deutsch (2002) recommended interviewing individuals who implemented life care plans to individuals without plans and measuring quality of life differences.

Marini and Miller (2007) indicated that one area of life care planning research that remains unexplored includes the life care planners' knowledge of how, or if, their life care plan has been implemented post-settlement. The authors recommended that follow up research using a survey with commonly recommended items and services be conducted to assess to what extent life care plan recommendations were followed.

Kendall and Deutsch (2002) recommended testing the assumption that life care plan development and implementation would reduce the incidence of complications and increase one's quality of life, by comparing the rates of complications and reports of quality of life for individuals who had versus had not implemented their life care plan. While validity and reliability of the life care planning process have been established, testing for quality of life outcomes based upon implementation rates has not been completed (Kendall and Deutsch, 2002; Sutton, et al., 2002).

Marini and Miller (2007) conducted a pilot study to explore post-settlement life care plan implementation for five life care planning clients with spinal cord injuries (SCI). They found that 75% of respondents purchased a modified van with lift; 50% built a new accessible home; 75% purchased either full-time or part-time personal attendant care; and 50% purchased lifting devices. Despite the fact that 80% of respondents reported that their financial needs were taken care of, 60% of respondents reported a lower quality of life than prior to their injury. Five of five individuals surveyed reported SCI related complications including urinary tract infections, skin breakdown, spasms, deep vein thrombosis and bowel problems. Sixty percent of respondents indicated that they spent their typical day talking or online while 40% reported watching television.

In related research, Casuto and Gumpel (2003) sought to determine if life care plans accurately recognized care needs and what issues affected life care plan use. They surveyed families of twenty-two pediatric life care plan clients and concluded that the families who implemented the life care plan were actively involved in the development of the life care plan, saw plan implementation as their responsibility, and had the education necessary to locate services and resources for their child. Certain components of the life care plan were found to be underutilized including recreation, counseling and use of community resources. The authors concluded that case management services were essential to effective utilization of the plan to improve the child's quality of life (Casuto & Gumpel, 2003).

One year prior to the Casuto and Gumpel study, Reavis (2002) conducted a retrospec-

tive study of one life care plan implemented for an adult female who sustained a traumatic brain injury. In this case, the life care planner and case manager continuously followed the client following life care plan completion. Ten years after development of the life care plan, the plan was being followed and the client's utilization of resources was consistent with the recommendations in the plan. The client was engaged in activities, experienced infrequent complications and her cognitive status had improved since her initial discharge. Life care planning and case management services were believed to have improved the individual's quality of life.

In the first published study, McCollom and Crane (2001) conducted a survey of ten individuals who sustained spinal cord injuries between eight and fourteen years prior to the study and had a life care plan prepared between 1995 and 1998. Details of jury verdict, settlement or funding sources are unknown. Areas of the life care plan were assessed and the implementation rates for each area were as follows: five of ten individuals underwent annual comprehensive physician evaluations; ten of ten individuals experienced complications including urinary tract infection, chronic pain and skin breakdown; six often required hospitalizations; ten of ten individuals required multiple, continuing prescription drugs; ten of ten individuals required ongoing use of supplies outlined in the life care plan; eight of ten individuals required wheelchair repair; eight often individuals were unemployed; three of ten individuals received additional education; ten of ten individuals had modified vehicles and drove independently; ten of ten individuals completed modifications to their homes; and six of ten individuals required assistance with personal care. The authors noted that those who underwent routine comprehensive evaluations reported fewer complications than those who saw a physician as needed. Case management services were needed but not available to eight individuals surveyed.

While life care plans are operationalized to define damages that can be delivered in a cost-effective manner, the primary goal of life care planning is obtaining optimized care to maximize one's potential and improve quality of life (Blackwell, et al., 2001; Bretheuer & Bretheuer, 2003; Casuto & Gumpel, 2003; Patterson, Murphy & Masterson, 2004; Smolarski, 2006). Quality of life, as a primary goal of rehabilitation service delivery, has been examined extensively in rehabilitation literature.

Quality of Life

The concept of quality of life (QOL) emerged from the 1920's notion that decisions could be made about an individual's "worthiness" to society based upon what he offered to the community (Koch, 2000). After World War II, however, judgments of a life's worthiness were replaced by the concept of life quality based upon assessment of the individual's physical and cognitive attributes (Koch, 2000). By the 1980s, quality of life morphed from a phenomenon of social observation into a quantifiable construct that could be used in service planning, including rehabilitation service planning, in systems where resources could be scarce (Koch, 2000).

The construct of quality of life (QOL) is a broad construct that has been plagued by definitional ambiguity (Bellini & Rumrill, 2009; Bishop, 2005; Boswell, Dawson & Henninger, 1998; Dennis, William, Giangreco & Cloninger, 1993; Hallin, Sullivan & Kreuter, 2000; Hammell, 2004; Koch, 2000). To measure quality of life, social science researchers have attempted to quantify quality of life for more than 50 years (Dennis et al., 1993).

The World Health Organization defines quality of life as "individuals' perception of their position in life in the context of the culture and value systems in which they live, and in relations to their goals, expectations, standards and concerns" (WHO, 1996, p.5). In brief, quality of life reflects an individual's overall perception of and satisfaction with how things are in their life (Dauphnee & Exner, 2002).

Quality of life factors have been described as temporal/developmental, subjective and affected by context (Boswell, Dawson & Henninger, 1998; Dennis et al., 1993). Quality of life is described as developmental because it changes as one's life experiences and priorities change (Boswell et al., 1998). To quantify quality of life, the construct has been measured by life satisfaction, function, social interaction, unemployment rate or socioeconomic status, often neglecting the subjective factors of quality of life (Bellini & Rumrill, 2009). By this measurement, quality of life reports for individuals with disabilities were often confounded by disability-related impairments.

The pursuit of quality of life by people with disabilities is as complex as it has been for all individuals over time (Dennis et al., 1993). Instruments that purported to measure the quality of life for individuals with disabilities often discounted the contextual factors that are unique to the lives of individuals with disabilities (Bellini & Rumrill, 2009; Koch, 2000). Hammell (2004) notes several problems that have plagued the conceptualization and measurement of quality of life in individuals with disabilities. First, assessments of quality of life have been based upon the values of the dominant culture, rather than quality of life factors reported directly from the individual with the disability. The result of this has been reports of lower quality of life for individuals with disabilities than without disabilities, a phenomenon not observed when subjective measures are employed (Hammell, 2004). Additional limitations in measuring quality of life for individuals with SCI include the myriad of instruments employed to measure QOL, and the conceptual ambiguity for the concept of quality of life to include 'life satisfaction', 'well-being', and quality of life (Hammell, 2004).

Quality of life and Disability

As late as 1998, there was virtually no literature describing quality of life through responses obtained directly from adults with physical disabilities (Boswell, et al., 1998). Surveys whose design was founded in the medical model of disability, often measured the "disease burden", rather than the individual's state (Koch, 2000). Over the last two decades, the study of quality of life has advanced in several important ways:

1. Viewing the concept of quality of life from a multidimensional perspective
2. Using methodological pluralism and multivariate research designs to study the contextual nature of the quality of life construct
3. Shifting our evaluation focus to person-referenced outcomes (Schalock, Bonham, & Marchand, 2000).

Koch (2000) proposed that a self-perceived healthy and rich life results from the individual's embeddedness in his surroundings; communal and familial support including a treatment team that conceives of disability as a physical difference rather than a deficiency; and supportive devices and accommodation. Dennis et al. (1993) identified five areas that

comprised quality of life including community presence, choice, competence, community participation, and respect.

Bishop (2005) proposes what he calls the disability centrality model. In this model, Devins' illness intrusiveness approach is extended to conceptualize how quality of life varies following onset of illness or injury. Quality of life is defined as the subjective sense of overall well-being that results from an individual's evaluation of satisfaction with an aggregate of personally or clinically important domains (Bishop, 2005). Among the most consistently identified domains are physical health, psychological or emotional health, social support, employment or other productive activity, and economic or material well-being. Within the disability centrality model, an initial reduction in overall quality of life follows the onset of disability or illness. However, because overall QOL is disproportionately influenced by satisfaction in more important domains, the overall reduction in QOL is dependent upon the degree to which domains most valued by the individual are affected (Bishop, 2005).

Quality of Life and Spinal Cord Injury

As the life expectancy for individuals with spinal cord injuries has continued to increase, quality of life issues for those living with SCI have become increasingly important (Barker, Kendall, Amsters, Pershouse, Haines, & Kuipers, 2009; Boswell, Dawson & Heininger, 1998; Chase, Camille, & English, 2000; Dijkers, 1999; Hammell, 2004; Kemp & Krause, 1999; Krause & Reed, 2009; Kreuter, Siosteen, Erkholm, & Brown, 2005; Lucke, Coccia, Goode & Lucke, 2004; Sioseteen, Sullivan et al., 1997; Lundquist, Sullivan, Blomstrang, Lind, & Sullivan, 1997; Mortenson, Noreau, & Miller, 2010; Salmons, 2008; Wood-Dauphinee, Exner & the SCI Consensus Group, 2002). To better understand the construct of quality of life for individuals with SCI, Boswell, Dawson and Henninger (1998) conducted a qualitative study to examine the meaning of QOL as defined by adults with paraplegia and quadriplegia. Participants defined quality of life as satisfaction with life, or how closely one comes to meeting life goals (Boswell et al., 1998). Participants described the onset of disability as an instrument of change in quality of life perceptions, particularly in attitudinal changes (Boswell et al., 1998). They described the three most important domains in quality of life to be attitude toward life, work opportunities, and level of resources (Boswell et al., 1998). However, they described resources as the foundation for quality of life as it enabled them to participate in other activities that enhanced life satisfaction (Boswell et al., 1998). Recent studies have expanded quality of life issues to include environmental (Dennis et al., 1993; Kemp & Krause, 1999; Lucke, et al., 2004) and social (Chase, et al., 2000; Kemp & Krause, 1999) aspects of quality of life.

Previous quantitative studies of post SCI quality of life have shown positive correlations between quality of life/life satisfaction and self-assessed health, perceived social support, social functioning/integration, mobility, accessibility (home health care) preferred living situation, adequate income, perceptions of having control over one's life, marital status, satisfaction with relationships, community access/participation and satisfaction with occupational engagement and/or employment (Hammell, 2004). Quality of life has been reported to be negatively correlated with rehospitalizations/perceptions of poor health, pain, spasticity, inadequate income, reduced life opportunities, reduced social interaction, loneliness and boredom, unemployment or dissatisfaction with occupation, reduced mobility, residence in a nursing home, and perceptions of having reduced control over one's life (Hammell, 2004).

Quality oflife differences for individuals of various ethnic and racial groups have been examined. Kemp and Krause (1999) reported that cross cultural reports of quality of life include strong social supports. They examined racial/ ethnic differences in subjective well being following SCI. The majority of racial and ethnic differences in subjective well being related to specific life areas (e.g., economics, employment), rather than more global outcomes (e.g., engagement, health), with Whites generally reporting the best outcomes, followed by African Americans. Differences in subjective well being appeared to be most pronounced in areas where societal participation was likely diminished by both racial and disability barriers. It appears that where there is an interaction of racial barriers (racism) and disabilities (ableism), there are lower quality of life reports. This may reflect what has been referred to as the "plus one" factor where the barriers associated with minority status and disability combine resulting in lower participation rates in education and the labor force (Hanna & Rogovsky, 1991).

Quality of life has been conceived of either positively (high life satisfaction) or negatively (distress and depression) (Kemp & Krause, 1999). A meta-analysis of 18 studies examining life satisfaction in individuals with SCI revealed that 10 of 12 reported that life satisfaction was higher in the non-disabled group, while two showed no difference (Kemp & Krause, 1999). Regarding a negative quality of life, suicide was found to be five times higher among individuals with SCI, presumably reflecting a depressed quality of life (Kemp & Krause, 1999). Depression and life satisfaction both appeared to be related to handicap (i.e. community activities and social participation), but not to educational level (Kemp & Krause, 1999). Individuals with disabilities in these studies reported levels of life satisfaction that were often below that of their non-disabled counterparts. The authors suggest that the longer one lives with SCI, the more satisfied they become with life, but that social support appeared to be a more important determinant of life satisfaction than duration of disability (Kemp & Krause, 1999). Dijkers (1999) analyzed life satisfaction correlates in 2,183 individuals with SCI and concluded that age had no effect on life satisfaction while gender had a minor one.

In a 2004 study 91 individuals with SCI lesions at C4 or above, 92% of the study participants reported to be glad to be alive (Hammell, 2004). Eighty-three percent of individuals who were ventilator assisted rated their quality oflife as excellent or good, as did 72% of the respirator independent group. An individual's activity level was significantly correlated with both QOL and self-esteem.

The first aspect of quality of life that is addressed following SCI onset is the physical domain. Many studies have examined the role of health in quality of life (Chase, Comille & English, 2000; Jain, Sullivan, Kazis & Tun, 2007; Kemp & Krause, 1999). The goals of acute treatment and subsequent rehabilitation are to improve function, often referred to as health-related quality oflife (HRQoL) (Jain et al., 1997). Functional outcome is one of the main aspects of determining quality of life in individuals with SCI (Wood-Dauphinee, Exner, & SCI Consensus Group, 2002). In an investigation of the health-related quality of life estimates of 356 individuals with spinal cord injuries, factors including age, employment status, lesion level and completeness of injury and mobility were significantly associated with HRQoL, with 13.5%-44& of variance in HRQoL explained (Jain et al., 1997). The authors found that older participants reported lower HRQoL than did younger individuals and higher HRQoL were related to the ability to get around independently. Based upon the proportion of variance explained by the factors, the authors conclude that there are additional factors

that contribute to HRQoL (Jain et al., 1997).

Chase, Comille and English (2000) conducted a review of life satisfaction in 158 individuals with spinal cord injuries and found that life satisfaction was significantly related to perceived control, communication skills, satisfaction with personal assistance, marital status, and handicap. Life satisfaction was defined as a psychological state associated with psychological well being (Chase et al., 2000). Perceived control and marital status were the strongest predictors of life satisfaction, while no significant group differences were found based upon level of lesion (Chase et al., 2000).

In a 2005 study of quality of life in individuals with spinal cord injuries, quality of life was found to be influenced by factors including physical, psychological and emotional function, ability to work, ability to perform leisure activities and relations to other people and society (Kreuter, Siosteen, Erkholm, Bystrom & Brown, 2005). In this study, lower levels of SCI lesion and higher levels of education correlated significantly with the persons' perceived QOL. Other variables including age, age at lesion, completeness of lesion, occupation and marital status were not significantly correlated with global QOL (Kreuter et al., 2005).

Barker, Kendall, Amsters, Pershouse, Haines and Kuipers (2009) conducted an Australian study of 270 individuals who sustained SCI to compare their quality oflife reports to their able-bodied peers, utilizing the WHOQOL-Bref. They found that QOL reports were significantly lower for people with SCI compared to the general population, irrespective of age or time since injury. However, they note that lower quality oflife reports were primarily associated with secondary impairments, activity limitations and participation restrictions but not with neurological level, age or time since injury. The most important predictor of QOL was secondary impairments, with more than 32% of the unique variance in QOL accounted for by this one predictor. Participation ranked as the second most important predictor (Barker et al, 2009).

Role of Resources in SCI Quality of Life

Salmons (2008) inquired about the impact of financial settlement on quality of life for twenty-one individuals with spinal cord injury for whom life care plans were developed. He examined the relationship between demographic variables including age, gender, marital status, ethnicity, educational level, work status and date of injury, financial settlement and quality oflife. It is noted that the role of the life care plan was not considered in this study. Based upon a correlational analysis, he found no significant relationship between the demographic variables or financial settlement and quality of life reports (Salmons, 2008).

Krause (2002) notes that individuals who prevail in litigation typically have resources available to meet their healthcare needs. In contrast, he noted that individuals with SCI who had Medicaid or Medicare as a primary paying source had a 1.47 to 2.31 times greater likelihood of mortality than individuals who had other types of coverage. Individuals with SCI whose income was less than $25,000 per year had a 4.5 times greater odds of mortality compared with individuals whose net family income exceeded $75,000 per year. He concluded that income is a major factor in predicting post SCI life expectancy.

In a 2000 study of the relationship among aging, gender, ethnicity, socioeconomic status and depression following SCI, 1,391 adults with spinal cord injuries were surveyed (Krause, Kemp & Coker, 2000). Income was found to be the most powerful predictor of depressive symptoms with individuals earning less than $15,000 per year being 2.84 times more

likely to report clinically significant symptoms and 5.31 times more likely to report probable major depression than those earning $75,000 or more per year. Depression symptoms were found to correlate positively with age and age at injury onset but the highest levels of depressive symptoms were found in those with the least and most years since injury. No gender differences were observed. Individuals with SCI who belonged to an ethnic minority were found to be at greater risk for depression, particularly women, but this was in part due to education and income (Krause et al., 2000).

Miller et al. (2008) examined correlations between WHOQOL-Bref factors and demographic variables. They found that household income improved physical, social and environmental domains of quality of life. Additionally, education was positively associated with the four domains included in the WHOQOL-Bref.

Individuals who are involved in a litigation process may be awarded damages as a result of injury sustained in an accident. Like those documented in criminal legal proceedings, there have been documented inequities in the distribution of jury awards or settlement figures (Chamallas, 2005; Rose & Vidmar, 2002). The process for evaluating the amount of monetary damages due an injured party is infected by racial and gender bias (Chamallas, 2005). Juries and judges have significant discretion in computing damages and the measurements that are utilized are often based on a market that is infused with general and racial biases (Chamallas, 2005). The result may be individuals from poor or working class backgrounds, women and racial minorities recovering less than white males or individuals from upper-class groups (Chamallas, 2005).

Barriers to Quality of Life

Barriers within the WHO-ICF model are "factors in a person's environment that, through their absence or presence, limit functioning and create disability" (WHO, 2001 p.192). These may include inaccessible physical environment, lack of technology, negative attitudes of individuals and policies that limit involvement of individuals with disabilities (WHO, 2001). While research about quality of life following spinal cord injury has been widely conducted, there has been a paucity of research examining the contribution of environmental factors on quality of life following SCI (Whiteneck, et al., 2004). However, access to and full participation in community activities is equally important for individuals with SCI (Blackwell et al., 2001). Unfortunately, the medical model of disability has caused demographic and injury related variables to receive much more research attention as correlates of quality of life, than environmental factors (Mortenson, et al., 2010).

An examination of the role of environmental influence on quality of life has emerged with the adoption of the biopsychosocial model of disability. NIDRR's New Paradigm of Disability was to focus attention on environmental modifications to improve the life of individuals with disabilities (Whiteneck et al., 2004). Consideration of environmental variables is key to adequately understanding the long-term consequences of disease and trauma (Fougeyrollas, Noreau & Boschen, 2002). Hammel (2004) found the availability of resources (including attendant care, transportation and adequate income) to be at the foundation of QOL.

In America, individuals with disabilities who reside in rural areas may disproportionately experience limited access to healthcare and other services as well as limitations in accessible transportation (Hagglund, Clay, & Acuff, 1998). While historically few attempts

have been dedicated to documenting problems for individuals with SCI living in rural America, it is estimated that approximately 57,500 individuals reside in rural America with spinal cord injuries (Hagglund et al., 1998). In a 1996 report, The National Council on Disabilities reported that only 35% of rural, fixed-route vehicles were accessible to people with disabilities, whereas 60% of urban buses were accessible (Hagglund et al, 1998). This is particularly troubling when 20 percent of rural survey respondents with SCI purchase and/or obtain service for their mobility aides between 36 and 50 miles from their home; for 18% this service was 51 to 100 miles away; and for 24%, it was 101 or more miles away (Hagglund et al, 1998).

Lack of accessible, reliable, and affordable transportation in rural areas is a significant barrier to obtaining adequate health care, for people with SCI and may indirectly contribute to the development of secondary complications, which are estimated at an average of thirteen per year for individuals with SCI residing in rural areas (Hagglund et al, 1998). When psychological and social needs of individuals with SCI go untreated, quality of life and medical status worsen, and health care costs are often significantly increased, particularly for those in rural areas (Hagglund et al, 1998).

In addition to limitations in transportation, individuals with SCI report limited access to healthcare practitioners skilled in treating spinal cord injuries. A survey of farmers and ranchers found that more than 58% of respondents had to travel at least 26 miles to obtain rehabilitation services and 33% traveled at least 51 miles (Hagglund et al., 1998). Clearly, there is a documented under supply of physicians trained in physiatry, rehabilitation hospitals equipped to care for individuals with spinal cord injuries as well as limited numbers of skilled caregivers for individuals residing in rural America.

A 1990 survey of 149 farmers/ranchers with SCI from 32 states and four Canadian provinces found that at least 40% of churches, local parks and recreation areas, county office buildings, libraries, and post offices were only partially accessible or not accessible (Hagglund et al, 1998). In addition to public areas, study participants reported that most rural housing was inaccessible, older, and difficult to modify. Accessible housing options were reported to be limited with nursing homes often the only available accessible residence in rural areas (Hagglund et al, 1998). As a result, the choice for accessible housing following rehabilitation includes relocation to an urban area with accessible housing options or placement in a nursing home.

As a result of the documented need for increased services to the 25% of Americans who reside in rural areas, The Office of Rural Health Policy (ORHP) of the Department of Health and Human Services has been established to study the needs of individuals with disabilities who reside in rural areas.

Lucke et al., 2004 conducted a longitudinal study with ten adults with SCI and their caregivers. They note that QOL for individuals with SCI involves a complex link between social, physical and environmental factors that contribute to QOL (Lucke et al., 2004). In Sweden, where environmental barriers are less of a concern than in other countries, QOL reports by individuals with SCI are comparable to the non-disabled population, stressing the relevance of assessing environmental quality of life within the SCI population (Lucke et al., 2004).

In a study of 2,762 individuals with disabilities in the Model Spinal Cord Injury System, 80% reported environmental barriers, the top four of which were barriers in the natural environment transportation, help at home, health care, and government policy. Fewer bar-

riers were reported by the study's oldest and youngest participants, males, members of an ethnic majority, and married individuals (Whiteneck, et al., 2004).

In a Canadian study examining the impact of personal, participation and environmental factors on post-SCI quality of life, Mortenson, Noreau and Miller (2010) found that personal factors including age and impairment level had only a minor effect on quality of life. Income and marital status had no impact on quality of life. However, it is noted that the availability of publicly funded healthcare in Canada may have impacted outcomes in this study.

Environmental barriers experienced by individuals with disabilities may limit participation in activities, such as employment, that correlate with higher quality of life reports. Employment, for example, can only be accomplished when personal care, mobility, and transportation barriers can be overcome (Fougeyrollas, et al., 2002).

In a 2009 study of 1,543 individuals with spinal cord injuries, Krause and Reed (2009) found that the environmental factor of quality of life did not load with any of the original factors in the survey, suggesting that environmental variables make a unique contribution to one's quality of life. Incorporating environmental factors in assessment of quality of life will provide policy makers information about the need for reducing or eliminating environmental restrictions to increase participation of individuals with SCI. Unfortunately, however, there is much more literature available pertaining to post-SCI impairment and function limitation as the barrier to participation (Fougeyrollas, et al., 2002). Adjustment to disability, it is argued, is not so much a psychological process but a process of adjusting to changes in others' perceptions, economic and social opportunities (Hammell, 2004).

International Classification of Functioning, Disability and Health (ICF) Model

Previous research shows that quality of life for individuals with SCI is based upon a combination of intrapersonal and societal factors. The International Classification of Functioning, Disability and Health model, developed by the World Health Organization in 2001, encompasses these factors in its concept of health. This model was used as the theoretical framework for the current study.

In 1980, the World Health Organization published the first International Classification Disability and Handicap (ICFDH) model outlining variables associated with disability including disease, impairment, disability and handicap (World Health Organization, 2001). This model attributed disease to abnormal etiology of physiological or biological abnormalities and failed to ascribe disability to environmental factors.

The ICF model allowed for movement along a continuum of function and abandoned the medical model of disability in favor of a biopsychosocial approach (World Health Organization, 2001). In 2001, the model was revised and renamed the International Classification of Function (ICF). Revisions were developed in reaction to a paradigmatic shift of defining disability within a medical framework towards one reflecting social dimensions of disability (Pomeranz & Shaw, 2007). To define health, disability and impairment, the WHO adopted the component of a health classification system, in contrast to the consequence of disease framework used in the 1980 model (World Health Organization, 2001). The revised 2001 model recognizes aspects of health states in all people, not only those with impairments or disabilities, including health condition, body structures, body functions, activity, participation and

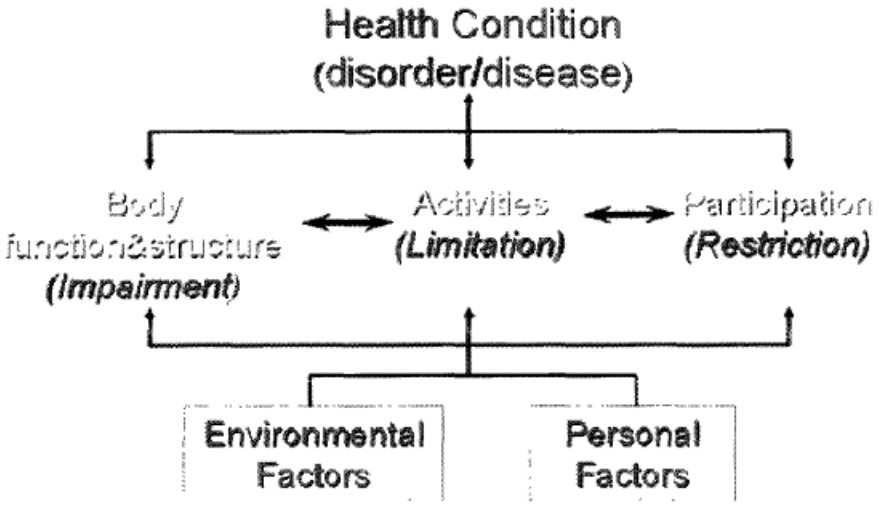
environmental factors (Fougeyrollas, et al., 2002; World Health Organization, 2001). It offers a conceptual framework applicable to health care as well as the improvement of societal participation through removing hindrances and encouraging support (World Health Organization, 2001).

In the ICF model, disability is defined as "an umbrella term for impairments, activity limitations or participation restrictions" (WHO, 2001 p. 3). Disability within this model may result from variables in the physical, social, psychological or environmental domains. Assessing one's disability related needs includes both the individual's health and the context of their social, economic, and psychological factors.

The ICF is made of two parts, each of which has two components, which may be expressed in both positive or negative terms. The first part, functioning and disability, consists of body functions and structures and participation (World Health Organization, 2001). The second part, contextual factors, consists of environmental and personal factors (World Health Organization, 2001). ICF model is context inclusive and is interactive, not linear or progressive.

Figure 2

Interactions between the components of ICF (World Health Organization, 2001)



ICF-Life Care Planning Model

Pomeranz and Shaw (2007) applied the ICF model to the life care plan and concluded that the ICF model was a satisfactory theoretical model to explain the approach used in creating a life care plan. The intent of the ICF model was to provide a mechanism of communication, particularly with respect to rehabilitation (Pomeranz & Shaw, 2007). This, too, is a common use of life care plans. Like the ICF model, life care plans go beyond the medical needs of the individual and address the psychological, environmental and social needs of an individual. The World Health Organization notes that management of a disability includes intervention at an individual level but also at the environmental, social and ideological lev-

els (WHO, 2001). The life care planner, who is often in the role of educator, can invoke the ICF model to disseminate information about the impact of disability from both a medical and social perspective and may use the model to substantiate recommendations included in the plan (Pomeranz & Shaw, 2007).

Key Life Care Planning Items

While the items included in any one individual's life care plan are specific to his or her needs, there are certain items that appear in virtually all life care plans. These items, including attendant care, accessible home modifications, transportation, and employment are items that have been documented in the literature as items that contribute to independent and community integration. A review of literature was made of these commonly included life care planning items and how they impact an individual's quality of life.

Attendant Care in Life Care Plans

One of the most critical and costly services included in the life care plan is the provision of personal attendant care services (Harrell & Krause, 2002, Deutsch, Weed, Kitchen & Sluis, 1989; Pomeranz, Shaw, Sawyer & Velozo, 2006; Weed, 1998). Personal attendant care services are defined by the World Institute of Disability as "assistance, under maximum feasible user control, with tasks aimed at maintaining well-being, personal appearance, comfort, safety, and interactions within the community and society" (Kennedy 1997 as cited in Pomeranz, Shaw, Sawyer & Velozo, 2006 p. 8). In a 1998 study of descriptions of quality of life factors in individuals with spinal cord injuries, attendant care was the most frequently cited basic need related to quality of life (Boswell, Dawson & Henninger, 1998). Most people who have sustained a traumatic SCI do not have the resources to pay for personal assistance (Harrell & Krause, 2002). It is estimated that this one item can comprise up to 44% of the total recurring rehabilitation costs for individuals with spinal cord injuries (Havey, Wilson, Greene, Berkowitz & Stripling, 1992 as cited in Harrell & Krause, 2002; Pomeranz, Shaw, Sawyer & Velozo, 2006). As this is often the most costly portion of the life care plan, it is often one that is debated within the litigation arena with one party often arguing that family members are available to provide attendant care services, negating the need for paid assistance. As some government programs do not provide in home care and others require indigent status to qualify for services, the cost for in-home care can be surprising. Life care planners, as a result, spend a significant amount of time researching the need for services and educating the parties involved about the availability and costs for these services. While the literature reveals that when family members provide personal attendant care services to the individual with a disability, disruption in the natural family relationship can occur (Harrell & Krause, 2002) the life care planner is often responsible for explaining the discrepancy between care recommended in the life care plan and what is currently being provided to the client.

While life care planners are knowledgeable about the availability of local attendant care resources and how individuals may qualify for local programs, they are less knowledgeable about how the availability of attendant care affects the quality of life for individuals for whom life care plans are developed. The provision of attendant care services, according to Harrell and Krause (2002), is impacted by housing, social support, proximity to caregivers, financial resources, availability of family members and geographic location. A quantitative

life care planning follow-up study conducted by Kendall and Casuto (2005), found that attendant care was implemented consistently at the level that was recommended in life care plans. Attendant care, an item that was recommended for all individuals in the study (n=15), was received by 86.7% of study participants.

Harrell and Krause (2002) investigated the impact of the provision of in-home care on the perceived quality of life of individuals with disabilities. An additional line of inquiry regarding attendant care included how the provision of care (i.e. agency versus private hire) impacted quality of life. A review of literature suggests that individuals with spinal cord injuries who manage their attendant care services report fewer preventable complications, hospitalizations and overall better health and life satisfaction than those who rely on agency provided care (Harrell & Krause, 2002; Pomeranz, Shaw & Sawyer, 2006). Attendant care services were found to directly impact quality of life by changing access to community, including work, which has been found to correlate with higher quality of life reports (Arango-Lasprilla, Ketchum, Stevens, Balcazar, Wehman, Forster & Hsu, 2009; Boswell, Dawson & Henninger, 1998; Harrell & Krause, 2002; Krause, 1992; Meade, Lewis, Jackson & Hess, 2004).

Under representation of personal care attendant needs in a life care plan may lead to inadequate services being received, more frequent hospitalizations and painful complications (Weed, 1998). In contrast, over representing personal care attendant needs in the life care plan may result in an inflated and costly plan that is unfair to all parties involved (Weed, 1998). Understanding if, and how, attendant care is implemented following life care plan creation will provide life care planners guidance on how to plan for care that is utilized following case resolution. Further, understanding the relationship between implementation of this life care plan item and quality of life will provide life care planners with information that has never before been researched.

Accessible Housing in Life Care Plans

Particularly for individuals with spinal cord injuries, a second item in the life care plan that can have a significant impact on quality of life is accessible housing. This may be provided either through renovation of the existing

residence, through purchase of new, accessible housing or through building a new accessible residence (Blackwell, Krause, Winkler & Stiens, 2001). As 87.7% of individuals with SCI are discharged to a private home, the life care plan must include modifications that afford the opportunity to accomplish activities of daily living (Blackwell et al., 2001; The National SCI Statistical Center, 2009). A home evaluation may be necessary to determine the individual's accessibility needs. The life care planner also considers housing needs as the individual ages with SCI. To provide the appropriate modifications to make a home environment accessible, Blackwell, Krause, Winkler & Stiens (2001) outlined commonly considered items for life care plan development. These items are outlined in Table 1.

Table 1
Home Modifications Commonly Considered in Life Care Plan

- Installation of ramps (with two exits recommended for safety)
- Widening of doorways and halls

- Removal of thresholds between rooms
- Installation of lift/elevator for getting from one level of the home to the other
- Renovating the kitchen with accessible appliances, shelves, and working spaces
- Modifying the bathroom to accommodate a wheelchair and related needs
- Replacing floor coverings
- Lowering light switches
- Renovating plumbing
- Modifying walks and driveways
- Modifying heating and air conditioning
- Incorporating an environmental control unit (ECU) or other adaptive equipment to maximize independence and safety

Consideration of the above modifications enables the individual with a spinal cord injury to remain as independent as possible and reduce dependence upon others for daily activities (Deutsch & Sawyer, 2002).

Transportation in Life Care Plans

The availability of transportation for an individual with a spinal cord injury directly affects the person's community participation. Transportation is necessary to attend medical visits, work, and social engagements (Winkler & Reed as cited in Weed, 1999). Following a driver's evaluation, many individuals with spinal cord injuries are able to drive independently (Deutsch & Sawyer, 2002). Van Roosmalen, Paquin, and Steinfeld, (2010) examined the role of transportation in community participation of individuals with who utilize scooters or wheelchair for mobility. They note that approximately 25% of individuals in this population drive. Approximately one-third do not reside in an area with access to public transit services. Lack of access to transportation is identified as a key barrier to community participation for individuals with disabilities, particularly for those who reside in rural areas (Roosmalen et al., 201O; Hagglund et al., 1998). As activities of daily living and community participation depend upon access to transportation, lack of transportation may negatively impact access to health care and employment as well as increase social isolation.

One area of the life care plan that can contribute to accessing both medical services and promoting community participation is transportation. Inclusion of accessible transportation may contribute to the overall effectiveness of the life care plan (Weed & Berens, 2009). Transportation needs are often identified through a driving evaluation which can be performed either during rehabilitation or following discharge. Transportation items in the life care may include purchase of equipment either for the individual with SCI to drive or to be transported while in a wheelchair (Weed & Berens, 2009). Properly assessing the individual's ability to drive is critical because independent transportation is required for employment or other community resources (Weed & Berens, 2009).

Employment in Life Care Plans

Employment outcomes for individuals following a spinal cord injury have been widely studied (Arango-Lasprilla, Ketchum, Stevens, Balcazar, Wehman, Forster & Hsu, 2009; Crewe, 2000; Krause, 1992; Krause, 1996; Krause & Reed, 2009; Krause, Saunders & Staten, 201O; Marini, Lee, Chan, Chapin & Romero, 2008; Meade, Lewis, Jackson & Hess, 2004; Murphy & Young, 2005) and have been identified as a central rehabilitation goal (Krause, 1996). Unfortunately, post-SCI employment rates have continued to lag behind that of the non SCI population (Krause & Reed, 2009). Spinal Cord Injury Model Systems Data reveals that while 57.5% of individuals are employed at the time of their SCI, 11.6% of individuals with SCI are employed one year after SCI onset (The National SCI Statistical Center, 2009). Approximately 35% of individuals are employed at 20-30 years following SCI (The National SCI Statistical Center, 2009).

Employment following SCI onset has been identified as a factor in higher post SCI quality of life (Arango-Lasprilla, et al., 2009; Boswell, et al., 1998; Krause, 1992; Meade, Lewis, Jackson & Hess, 2004). Krause (2002) examined the survival rates of individuals with SCI and concluded that individuals who were employed were 2.38 times more likely to have survived over the 11-year study period than those who were unemployed.

Krause (1992) investigated the relationship between work history, biographical status and post-SCI adjustment in 286 individuals with SCI. Younger individuals were found to have higher employment rates than individuals who were never employed. Individuals who were employed had more years of education and more years since SCI onset. He found that individuals with SCI who were employed reported greater general and economic satisfaction, better adjustment and less emotional distress, and fewer health complaints than individuals who had never been employed following SCI (Krause, 1992). While the employed group reported fewer health complaints, there were no observable differences in medical history, suggesting that employment had a greater impact on subjective wellbeing (Krause, 1992).

Rates of post-SCI employment vary. Krause (1992) found that employment rates for individuals with SCI ranged from 3% for individuals with less than 12 years of education to 70% for those with 16 or more years of education. Krause, Kewman, DeVivo, M.J., Maynard, Coker, Roach, & Ducharme, (1999) concluded that post-SCI employment rates peak at 30-35% at approximately 10-15 years post-SCI. Yasuda, Wehman, Targett, Cifu and West (2002) found that age at spinal cord injury onset was the most important return to work predictor (as cited in Marini et al., 2008). Krause, Saunders and Staten (2009) found that the strongest predictor of post-SCI employment was education, followed by injury severity, age at injury, and then race.

Krause, Sternberg, Maides and Lottes (1998) found that individuals who sustain SCI prior to age 18 have employment rates of 69% while those who were injured after age 45 were employed at a rate of 9% (as cited in Marini et al., 2008). In 1996, the Canadian Paraplegic Association study found that individuals with T7 to T12 injury levels were employed at a rate of 73% compared to individuals with C5-C6 injury levels who were employed at a rate of 46% (as cited in Marini et al., 2008).

Crewe (2000) investigated the vocational experiences, including the meaning of work, in the lives of 50 individuals with spinal cord injuries over 20 years after the onset of injury. In her sample, 86% of respondents were employed at some point post-injury and 24 of the

respondents were engaged in advanced education and work for all of the years since their discharge to the first survey in 1994. She identified a strong work ethic, receipt of rehabilitation services and loyalty in employment as salient features of the vocational experiences of this group of individuals.

In 2008, Marini, et al. studied vocational rehabilitation service patterns relating to successful competitive employment outcomes of individuals with SCI. They examined the rehabilitation patterns of 10,901 individuals with spinal cord injuries whose rehabilitation files were closed by state vocational rehabilitation agencies. They found that women were employed at a higher rate than men (55% vs. 53%). Asian Americans and European Americans demonstrated higher employment rates (56% and 53%) when compared with Latinos (53%), Native Americans (50%) and African Americans (49%). Individuals with at least some college had an employment rate of 60% versus those who had at least a high school diploma (53%) or less than a high school diploma (46%). Individuals who were married demonstrated higher employment rates (58%) than did those who were never married, widowed, divorced or separated (51%). Job placement services were the most significant predictor of employment, while the second most important factor was case expenditures (Marini et al., 2008). Case expenditures were likely associated with post-SCI educational training, which has been found to predict successful employment in this population. The authors concluded that individuals with no financial disincentives, transportation problems, need for physical or mental restoration and who were better educated demonstrated higher employment rates.

Krause (1996) studied the relationship between post-SCI adjustment and employment in 142 individuals over an 11-year interval. He noted that many individuals engage in employment following SCI, however less than 50% are employed at any given time. Post SCI employment was found to correlate with post-SCI training, training geared toward acquiring skills compatible with the individual's physical limitations. While post-SCI individuals with chronic unemployment were similar demographically to those with greater employment rates, those who pursued additional education following the SCI showed higher employment rates (Krause, 1996). The "spread effect" of employment on overall post-SCI adjustment was noted, in that transition to employment enhanced other areas of life adjustment.

Krause and Reed (2009) examined the relationship between post-SCI employment and pre and post injury education. They reviewed SCI model systems data and found that those with higher level lesions (Cl to C4) had lower employment rates than did those with the lower level lesions (ASIA D) at lower levels of education (less than high school diploma or high school diploma) but not at the highest levels of education (master's or doctoral degree). They found that with the exception of a high school certificate, completing educational milestones post-SCI was associated with higher odds of post-SCI employment. They concluded that post-SCI completion of educational milestones was highly correlated with post-SCI employment and that completion of each successive educational milestone (i.e. high school, technical certificate, associate's degree, bachelor's degree) improved employment rates. They concluded that even with high levels of pre-injury education, post-injury education and training may be needed to maximize post-injury SCI employment.

Arango-Lasprilla, et al. (2009) found that successful post-SCI employment was associated with better health, greater longevity, higher levels of participation and life satisfaction and quality of life following SCI. Variables that affected post-SCI employment rates included gender, age, injury severity, education and time since injury.

Racial/ethnic differences in post-SCI employment have also been examined (Krause, Saunders & Staten, 2009; Arango-Lasprilla, et al., 2009; Meade, Lewis, Jackson & Hess, 2004). Arango-Lasprilla, et al., 2009 studied racial/ethnic disparities in employment rates between Hispanics and Caucasians one year after SCI. Consistent with previous literature, the authors concluded that race/ ethnicity significantly affects employment status one year following SCI, after adjusting for age, gender, marital status, education level, employment status at admissions, cause of injury, SCI level, and ASIA impairment scale. They note that individuals of ethnic minorities are less likely to return to their pre-injury jobs, have less opportunity for skill development, and have lower reports of financial and career well being than do Caucasians (Arango-Lasprilla et al, 2009).

Variations in employment rates for individuals with SCI of various races have been examined (Krause et al., 2010; Meade, Lewis, Jackson & Hess, 2004). Meade et al. (2004) examined disparities in employment between Caucasians with SCI and African Americans with SCI, finding significant racial disparities in employment for individuals of various races at one, five, ten, fifteen and twenty years post-SCI, even when education and injury-related variables were controlled. Participants in their study reported reasons for not working to include physical inability to perform the same type of work post injury (60%); poor health, stamina, or endurance (28%); loss of benefits (28%); not feeling physically capable of working (27%); inaccessibility of the workplace (23%); and lack of transportation. Employed individuals in the study demonstrated higher levels of economic self-sufficiency, social integration, and satisfaction with life than those who were not employed. Race was identified as the factor most consistently associated with low SCI employment rates (Meade et al., 2004).

Cross cultural studies of post-SCI employment predictors have also been studied. Research in Australia with 289 individuals with SCI found that demographic variables including gender and psychological variables including work attitude were more related to employment participation than were injury variables (Murphy & Young, 2005). The best predictors of work rate were found to be gender and work attitude, which together accounted for more than half of the reliably explained variance. In a 2003 study by the authors, work attitude accounted for the greatest proportion of variance in employment (Murphy, Young, Brown & King, 2003 as cited in Murphy & Young, 2005).

Conclusion

While there have been various definitions of quality of life, quality of life is clearly a rehabilitation outcome worthy of study. Life care planning literature has identified improved quality of life as a primary goal in life care plan development. Implementation of the life care plan is implicit in its design, as it was developed out of the field of case management. To date, however, only four studies have investigated what happens to life care plans once they are developed.

As spinal cord injuries are a relatively stable condition and the life expectancy for individuals with spinal cord injuries continues to increase, understanding how life care plan implementation can impact quality of life for individuals with spinal cord injuries should be investigated. This study will attempt to provide information about life care plan implementation rates and how quality of life reports for individuals with spinal cord injuries who implement and do not implement their life care plans.

Chapter 5 - Discussion

This chapter includes five major sections: (a) the first a brief summary of the research questions and results, (b) a statement of the limitations of the study, (c) the integration of the results with existing rehabilitation literature and research and (d) the implications of the results for the field of life care planning. This research attempted to answer some previously unanswered questions about if and how individuals with disabilities implement their life care plan following litigation. Between group differences were examined to determine how those who implemented their life care plan differed from those who did not. Factors hypothesized to affect plan implementation including funding, education level, employment status, and availability of case management services were examined in a nationwide study of 55 adults with spinal cord injuries for whom a life care plan was developed.

Statement of the Problem

Since the early 1980s, rehabilitation professionals have actively engaged in a subsection of rehabilitation called life care planning. Life care planners are utilized in numerous venues where funding must be allocated for future disability-related goods and services including insurance reserve setting, post 9/11 victim compensation and in state and federal case adjudication when disability results in litigation. Life care plans outline not only future medical needs resulting from disability but also incorporate disability related environmental and psychological needs of the individual. Although the goal of the life care plan is to maximize function, minimize complications, facilitate independence, enhance emotional adaptation and improve quality of life (Blackwell et al., 2001; Bretheuer & Bretheuer, 2003; Casuto & Gumpel, 2003; Kendall et al, 2002; Patterson, et al, 2004; Smolarski, 2006), very little follow up has been conducted with individuals for whom these plans are developed. Often, the life care planner does not know the outcome of the individual's litigation, funding situation or long-term prognosis, as the life care planner's role is typically limited to plan development, not plan implementation. A literature review revealed only three published follow-up studies that tracked post-litigation follow-up of items and services allocated in life care plans. This study assessed life care plan implementation in plans developed for adults with spinal cord injuries, to assess what variables contributed to plan implementation, and to determine how plan implementation impacted the individual's quality of life. By answering these questions, this research provides life care planners an outcome measurement.

Statement of the Procedures

A sample of 55 adults with spinal cord injuries in the United States participated in this research. These individuals had sustained spinal cord injuries, engaged in litigation and in the course of litigation had a life care plan developed for them. Participants were recruited through 614 life care planners throughout the United States. Six hundred and fourteen life care planners were contacted to refer possible participants from October 2010 until March 1, 2011. Of 614 life care planners contacted, 15 chose to participate, referring a total of 372 possible participants. Approximately 238 of 372 possible participants could not be located. Potential participants were contacted by telephone, email, or mail, depending upon the method of contact information provided by the life care planner. Of the participants who could be located, 11 declined participation and 23 were deceased. Of the remaining 100

potential participants, 55 respondents completed two surveys, the WHOQOL-Bref and a life care plan survey created by the researcher.

The life care plan survey inquired about the types of common goods/ services received by the individual prior to their life care plan being developed, whether or not they received a settlement/ jury award and what items were received after the life care plan was developed. Life care plan implementation was measured by a self-report measure where the individual reported the percentage of life care plan items (0-100%) that they implemented.

Demographic Characteristics of Sample

Respondents in this research were 60% male and 40% female. The majority (85%) were White/Caucasian, with 7% African American, 5% Hispanic and 2% Asian. The average age at injury in this sample was 30.6 (SD14.26). Respondents resided in 18 states throughout the U.S., with over 90% residing in non-rural geographic locations. At time of injury, approximately 50% of respondents had a high school diploma or less, while approximately 50% had attended some college or above. The most frequent cause of injury in the sample was motor vehicle accident, followed by on the job injury and sports related injury.

In comparison to national data, information published by the National Spinal Cord Statistical Center in February 2010, indicates that the average age at injury since 2005 was 40.2, with approximately 80% of spinal cord injuries reported occurring among males. Since 2005, approximately 66% of those with spinal cord injuries are Caucasian, 27% African American, 7.9% Hispanic and 2.0% Asian. In America, motor vehicle crashes are the most common cause of injury, followed by violence and sports. When comparing the sample of respondents in this research to the national sample, the current sample is somewhat younger and includes more females but reflects similar trends to those in the American population. In general, this sample appears to be representative of the population of Americans with spinal cord injuries. Although a small sample, the representativeness of this sample allows for extrapolation of the results of this finding to adults with spinal cord injuries for whom a life care plan has been prepared.

Theoretical Foundation of Study

The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) provided the foundation for this study (WHO, 2001). The ICF is a biopsychosocial model of disability that incorporates elements of the individual's bodily functions, engagement in activities, participation restrictions, and environmental factors that interact with disability (WHO, 2001). As this theory addresses the multifactorial experience of all individuals, it can be applied to the field of life care planning. In fact, in 2007, Pomeranz and Shaw analyzed the congruence between life care plans and the ICF model, concluding that the ICF model can be useful in explaining life care planning concepts. As the life care planner may be the only individual who addresses the needs of the entire person with a disability, including social interaction, environmental modifications, the need for medical treatment, as well as the psychological needs of the individual, life care planners address the individual's needs within each of the four domains outlined by the ICF model.

As late as 1998, there was virtually no literature describing quality of life through responses obtained directly from adults with physical disabilities (Boswell, et al., 1998). Over

time, rehabilitation research has begun to incorporate quality of life reports obtained directly from individuals with disabilities. Consistent with the ICF model, the life care plan development process commences by obtaining the input of the person with the disability about their current status, activities and potential needs. The ICF model is consistent not only with the life care planning model but was designed to consider the needs of those without and with disabilities. Specifically, it is useful in analyzing the needs of those with spinal cord injuries.

WHO Applied to Life Care Plan Implementation

In planning for the medical, environmental, social and psychological needs of individuals with disabilities, the ICF model can provide guidance for areas that life care planners and other rehabilitation professionals routinely assess. Following onset of injury, the individual has an entirely new set of needs that must be assessed including equipment like wheelchairs, disability adjustment psychological processes, medical services and procedures and environmental barriers that have heretofore not existed for the individual. There is often a team of medical professionals who provide treatment in the acute stage of injury but following discharge to the home environment, there continue to be lifelong disability related needs that must be assessed. This is performed only by the life care planner who visits the person's home to assess environmental needs, meets with medical professionals to assess future medical needs and assesses the individual for depression, anxiety or maladjustment to disability, all of the areas encompassed within the ICF model. The life care plan, in tum, is presented to those responsible for funding future disability-related goods and services throughout the person's life expectancy including insurance companies and triers of fact (e.g. judges or juries) who adjudicate liability related claims for future damages. These individuals may provide no monies for future services, partial necessary funding or full funding for the items and services outlined in the life care plan.

In this study, follow-up interviews were conducted with individuals who sustained spinal cord injuries, had a life care plan developed and either did or did not receive the funding necessary to purchase the necessary disability related goods and supplies that were outlined in their life care plan. What was discovered is that those who did and did not receive funding implemented their plans in noticeably different ways and had significantly different quality of life reports. What was not found, however, were significant differences in quality of life reports for those who did and did not implement their life care plans. There were no measurable differences in resulting quality of life for these two groups. Specific implementation information is outlined below.

SCI Related Item and Service Consumption

In this research, respondents were queried about medically based services as well as disability-related goods that they received both prior to and after life care plan development. In comparing pre and post life care plan services, consumption of all medical services other than urological consultation, decreased as expected over time. In general, fewer respondents reported receiving medical services and therapeutic modalities after their life care plan was completed. This reflects the movement away from acute SCI management to a health maintenance focus over time.

However, it is noteworthy that most individuals in this sample reported infrequently seeing a specialist in spinal cord medicine. Respondents were 2.5 times more likely to see a general practitioner than a physiatrist prior to life care plan development and four times more likely to see a general practitioner than a physiatrist after their life care plan is developed. As physiatrists have special training in spinal cord injury, they may be better able to design medical regimens to prevent health related complications specific to spinal cord injury.

In studies of quality of life in individuals with spinal cord injuries, rehospitalizations and health related complications have been cited as a correlate to lower QOL reports, accounting for over 30% of the variance in quality of life scores (Barker et al, 2009). In this study, respondents were asked to report the number of post-SCI hospitalizations and complications experienced. In this sample, approximately 60% of respondents experienced one to six hospitalizations since their initial discharge. It is noted that some respondents were over 20 years post injury, while others were within several years.

Almost 90% (88%) of respondents reported experiencing bladder infections since the SCI event and the most commonly consumed post-life care plan medical service was urology visits (65%). Urological complications have historically been the complication most likely to cause death in the American SCI population. The alarming number of respondents reporting bladder infections as well as the increase in urological consultation over time suggests that there was not adequate urological care being provided following life care plan development. Perhaps with care provided by physiatrists trained in spinal cord medicine, urological complications would be less frequent over time.

Pre and post life care plan equipment consumption remained relatively consistent in this sample. Respondents reported consuming manual and power wheelchairs, lifts, beds and exercise equipment at relatively similar rates pre and post plan development.This is expected as equipment needs remain relatively stable over one's lifetime. Slightly more individuals in this sample consumed power wheelchairs and Hoyer lifts post the life care plan while fewer respondents received manual wheelchairs post-life care plan development compared with prior to life care plan development. Pre and post life care plan consumptions rates are shown in Figure 3.

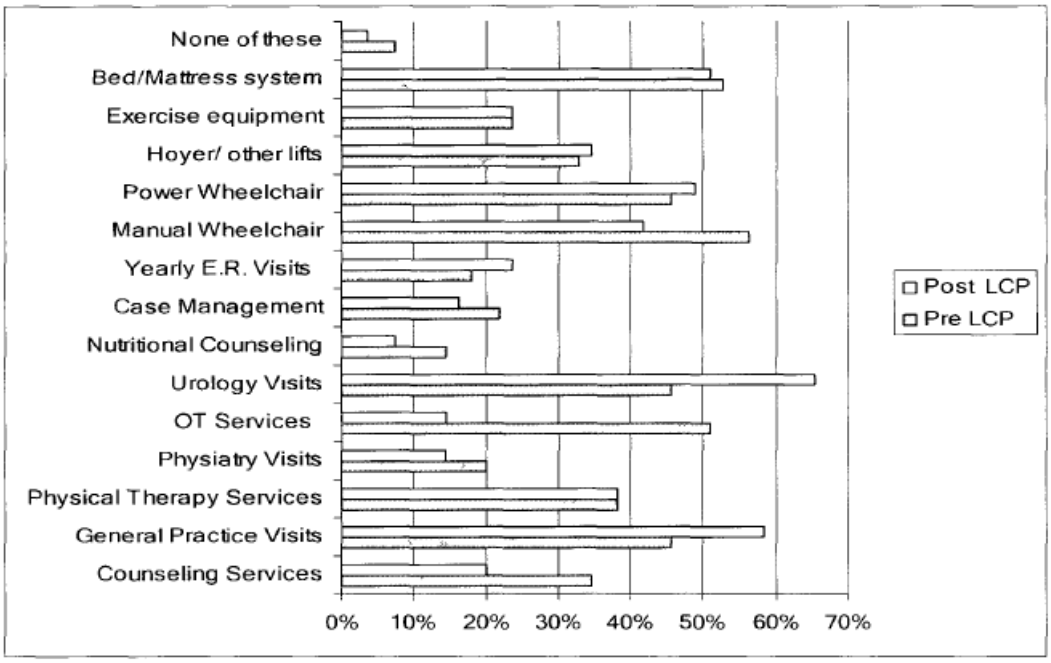
Key Life Care Plan Item Consumption

In depth questions were posed to respondents about three key areas of the life care plan including home modifications, attendant care and transportation. These items were also analyzed for pre and post life care plan consumption. Hammel (2004) found the availability of resources (including attendant care, transportation and adequate income) to be at the foundation of quality of life. These three items afford individuals with spinal cord injuries the opportunity for increased independence and improved community participation.

Regarding home modifications, only 5% of respondents reported receiving new, accessible housing prior to life care plan development, while 50% received modifications to their existing homes. The highest level of home modifications received by the majority of respondents prior to life care plan development included ramps, widened doors and accessibility to the bathroom. Pre and post life care plan home modifications consumption patterns were similar.

Figure 3

Pre and post life care plan consumption of disability related goods and services



More noticeable differences in home modification implementation became visible when comparing modifications received by those who did and did not receive life care plan funding. Thirteen respondents in this sample reported obtaining new accessible housing. Of this group, 85% of respondents were in the group with funding. Nineteen respondents received home modifications after their life care plan was developed. Seventy-nine percent of those who received post-life care plan home modification were in the group with funding. Seven individuals reported modifying their home for whole house access. All of those individuals were in the group with funding. None of the respondents in the no funding group reported modifying their home to include whole house access, specialized devices such as ceiling lifts, or storm provisions. For those who did not receive funding, the highest level of home modification received included an accessible bathroom. It becomes clear from this survey that individuals with SCI make the necessary home modifications (e.g. widened doors, ramps to entrance) for the family member to return home. However, for many individuals without funding, they continue to have limited access to much of their primary residence even years after their injury.

In addition to home modifications, respondents described their consumption of disability related van or vehicle modifications. Inclusion of transportation in the life care plan may contribute to the effectiveness of the entire plan (Weed & Berens, 2009) as accessible transportation enables community participation, increases one's ability to attend medical appointments, work and social engagements (Weed, 1999).

In this study, four additional individuals purchased van/ vehicle modifications following life care plan development. Somewhat different consumption patterns emerge when

comparing consumption between the group who did and did not receive funding. Interestingly, all but one respondent in the no funding group reported receiving van or vehicle modifications. While the source of funding for the purchase was not queried, some individuals commented that independent living, Veteran's Affairs, individual or group donations or vocational rehabilitation provided post life care plan items. Responses to question 18 of the survey can be found in the appendix on page 156. It is possible that the above sources paid for transportation, as this is an item commonly purchased through the above agencies.

The final key item investigated was consumption of attendant care services. A 1998 study of adults with SCI reported that attendant care was the most frequently cited need related to quality of life (Boswell, Dawson & Henninger, 1998). This one item can comprise up to 44% of the total recurring cost for in individuals with SCI (Harrell & Krause, 2002; Pomeranz et al., 2006) and unfortunately most people with SCI do not have the resources necessary to pay for this service (Harrell & Krause, 2002). As a result, family members often absorb the burden of caring for someone in the family who sustains this injury which results in disruption in the family system (Harrell & Krause, 2002).

More respondents in this study reported receiving personal assistance following life care plan development (64%) when compared to prior to life care plan development (51%). The majority (66%) of pre life care plan attendant care was provided by family members or unpaid caregivers, with the average number of unpaid daily attendant care received at 13 hours per day. Thirty-three percent of respondents reported receiving paid attendant care, an average of six hours per day. When asked, 63% of respondents reported that they were not at all or only slightly satisfied with the amount of money available to pay for such services.

Following life care plan development, however, unpaid/ family care was consumed by only 20% of respondents. Of the six individuals who did not receive life care plan funding, four relied on unpaid family care for personal assistance, while two received paid care. Of the group with funding, 73% received paid attendant care, while 27% utilized unpaid family care. It is noted that respondents who received paid attendant care, may also receive unpaid attendant care services. Therefore, there is overlap in the responses.

In the group that received life care plan funding, 48% reported that they were not satisfied with their ability to pay for attendant care, while 38% reported being very or extremely satisfied with the amount of money they had available to pay for these services. In the no funding group, 100% of respondents indicated that they were very dissatisfied with the amount of money they had available to pay for attendant care services.

It is clear that in the group with funding, the burden on the family of being solely responsible for the personal attendant care needs of the family member with SCI is relieved by receipt of settlement. When provided open-response questions in describing their day, receipt of personal assistant services was noted by almost all individuals as an essential function in their daily routine. Attendants assisted with bathing, grooming, transportation, housecleaning and other errands that the individual was limited in performing. As attendant care services have been shown to improve quality of life for those with spinal cord injuries, this service may account for the differences seen in quality of life reports for the group with funding.

Life Care Plan Implementation

This research investigated the implementation rates of life care plans developed for adults with spinal cord injuries throughout the United States. Implementation rates were collected via self-report estimation of the percent of items from the life care plans that were implemented by the respondent. The sample consisted of two groups, one group that received funding for the items in the life care plan and one group that did not. The sample was unevenly divided, with 46 individuals receiving funding and eight who did not.

The first analysis answered the question of the percentage of adults with SCI who implemented their life care plan. Of the entire sample of 55, approximately 45% of respondents implemented up to 25% of the items in their plan, while 55% implemented more than 25% of items in their life care plan.

However, the contrast between life care plan implementation for the funding and no funding group is more apparent than the group in its entirety. Approximately 40% of the funding group implemented 25% or less of the items in their plan. Approximately 60% (58.33%) of respondents in the funding group reported implementing more than 25% of the items in their life care plan.

In contrast, for those who did not receive funding, almost 60% of individuals in the no funding group implemented less than 25% of the items recommended in their plans, while approximately 40% implemented more than 50% of the items in the plans. It is clear from this analysis that receiving funding for disability related items allows individuals with disabilities to purchase more disability related goods and services than those without funding.

Factors of Implementation

Demographic variables including geographic area of residence, pre-injury education level, ethnicity and severity of injury were examined for differences in the group who implemented and did not implement their plan. Originally, the researcher hypothesized that life care plan implementation rates would be higher for the following groups: 1) those who had higher levels of education, 2) those who were actively involved in life care plan development, 3) those who had the financial resources available to implement the plan, 4) those who received case management services following plan development.

To assess differences in plan implementation among demographic variables, a series of chi-square tests were conducted. The results of the chi-square test indicate whether or not the two variables are independent, with the stronger relationship reflected in larger chi-square statistics (Hatcher, 2003). A statistically significant result suggests that the two variables are likely related in the population (Hatcher, 2003). Alternatively, in some analyses a Fisher's exact test was conducted due to the small sample size. If the data analyzed was from a 2 x 2 table with fewer than five subjects in a cell, this test was used. Effect size results were reported in either a phi coefficient if the test is conducted in a 2 x 2 table or a Cramer's V statistic, if the table is larger than a 2 x 2 (Aron, Aron & Coups, 2005). Both statistics are essentially correlation coefficients but they have slightly different ranges. A phi coefficient ranges from -1.00 to +1.00, while values of Cramer's V may range from zero to+ 1.00. For both statistics, numbers close to zero reflect a weak relationship between predictor and criterion variables.

None of the demographic statistics appeared to affect life care plan implementation. All chi-square and Fisher's exact tests for education, geographic location of residence, ethnicity, level of lesion, gender and age were found to be nonsignificant. Effect sizes ranged from -.20 to .26, all considered to be small to medium effect sizes. The largest effect size .26 was found for geographic area, while the smallest effect size was found for age -.06.

Individuals with disabilities are disproportionately represented in those having lower levels of education (Erickson & Lee, 2008). It was hypothesized that those individuals who had higher levels of education would implement their plan at higher rates. Based upon chi-square test results, this hypothesis was not confirmed. However, it is noted that 70% of the cells in this analysis had fewer than the desired five respondents. A Fisher's exact test cannot be conducted as an alternative as level of education had five levels, rather than two. Therefore, the true relationship between education and life care plan implementation may be different than the .24 statistic obtained from the chi-square test.

In addition to examining demographic variables for their impact on plan implementation, variables specific to life care plan development were analyzed. Originally, it was hypothesized that life care plan implementation would be higher for those who were involved in life care plan development, those who received a settlement, and those who received case management services following plan development. A series of chi-square or Fisher's exact tests were conducted to determine the impact of these factors on life care plan implementation. None of the tests were significant. Effect sizes for each of the analyses were small, ranging from -.09 to .15. Therefore, none of the hypotheses were confirmed based upon statistical analysis.

While previous studies have documented receipt of case management services as a correlate of life care plan implementation, the present study did not confirm these findings. Previous studies also found higher rates of life care plan implementation among those who understood the purpose of the plan and those who were actively involved in plan development, but the present study did not confirm these findings. However, based upon interview with respondents, some with higher levels of education shared stories of how their education levels enabled them to understand the complex legal system and the world of disability management. Stories included being able to cost compare disability related goods, negotiate terms of purchase for goods, understanding annuity concepts to fund lifelong needs and being actively engaged in deciding when to settle a legal case or go to a jury trial. While these effects could not be measured statistically as they relate to life care plan implementation, education was clearly valued to those who sustained injuries. Evidence of this includes many respondents acquiring additional education following their SCI. Thirty-nine of 52 respondents (75%) had at least some college following SCI, compared to 26 (50%) prior to the injury.

Finally, the impact of life care plan implementation on post spinal cord injury employment was examined. Prior to the spinal cord injury, 92% of respondents described themselves as employed or a student. Following the injury, only 36% reported being employed or a student, while 64% of the sample described themselves as unemployed or disabled from employment. Spinal Cord Injury Model Systems data published in 2010, includes 58% who described themselves as employed at the time of injury, compared to approximately 12% one year following SCI. By 20 years post injury, the employment rate of those in the model system was approximately 35% (National SCI Statistical Center, 2010). Therefore, the employment

rate of those in this sample is lower than those in the American SCI population. When compared to the over 90% employment rate prior to the SCI, it is evident that we are losing a significant percentage of individuals who are capable of employment following spinal cord injury onset. Often, vocational rehabilitation plans are included as part of the life care plan, so these individuals have likely undergone a vocational evaluation. However, the employment rate of this sample is no higher than those in the model systems population. This is an area where life care planners can improve their practice to hopefully increase employment outcomes. No statistically significant differences were found in employment rates of those who did and did not implement their plan. However, a number of respondents indicated that they were currently involved in a vocational rehabilitation plan and were participating in educational plans. Hopefully, this employment percentage will increase with those students completing college and returning to successful employment. It is also noted that the settlement or jury award may have been based in part upon lost wages. Therefore, the life care plan funding may be due, in part, to financial reimbursement for the individual's inability to sustain full-time competitive employment which confounds the measurement of return to work in this sample. Finally, employment rates were not measured based upon level of lesion. Previous studies have noted higher employment rates with lower levels of SCI lesion (Marini et al., 2008). As approximately 60% of the respondents in this study had a C2- T1 level lesion, injury severity may confound employment rates in this sample.

Quality of Life Analysis

Following an examination of life care plan implementation rates, differences in quality of life reports were examined for the group of respondents who implemented their plan compared to those who did not. Plan implementation was measured at two levels, less than 50% implementation and 50% or greater plan implementation. This 50% percentage was chosen because it represented a majority of the plan being implemented. Quality of life was measured among four domains including physical, psychological, social and environmental domains. MANOVA results were nonsignificant with only three percent of the variance in quality of life accounted for by life care plan implementation. This result was surprising, as it was hypothesized that higher rates of plan implementation would result in higher quality of life reports. It is noted that in a 2007 life care plan implementation study, Marini and Miller also found, despite the fact that 80% of respondents reported that their financial needs were taken care of, 60% of respondents reported a lower quality of life than prior to their injury.

It was also hypothesized that higher life care plan implementation rates would correlate with higher levels of social, psychological and environmental quality of life domain scores. While not statistically different, examination of the quality of life means, three of the four domains were higher for those who implemented 50% or more of their life care plan, compared to those who did not. Psychological, social and environmental quality of life domain means were higher for the group who implemented their plan, compared to those who did not. While not reaching a statistically significant level, comparison of the means reflects a trend toward higher quality of life for those with higher life care plan implementation rates and lower quality of life scores for those who implemented less of their plan.

It was hypothesized that the psychological quality of life domain would be higher for those who implement their plan when compared to those who do not. This domain consists

of feelings of enjoyment, meaning in life, ability to concentrate, satisfaction with bodily appearance, satisfaction with life and feelings of depression. Based upon MANOVA results, there were no significant differences between the mean scores on quality of life domains. However, a review of means for psychological quality of life reveals a slightly higher mean score for those who implemented their plan (22.71) compared to those who did not (22.27). Based upon this analysis, it appears that psychological functioning may be resilient to the effect of not having the necessary resources to purchase disability related goods and services. None of the respondents in the no funding group received counseling services following life care plan development so it is unlikely that this is a result of pure psychosocial adaptation to disability. The nonsignficant difference in psychological quality of life may reflect error in measuring life care plan implementation.

A second analysis was conducted to determine the quality of life differences for those who did and did not receive a settlement or monetary award to fund their plan. A MANOV A for this analysis was significant, indicating that the group quality of life means were different for the group who received funding. Follow-up tests indicating that the difference was primarily due to the differences in the physical quality of life domain mean, with a significant ANOVA for this domain score. In 2002, Kendall et al., hypothesized that implementation of the life care plan will accomplish the mission of decreasing the frequency and severity of SCI related complications and improving the individual's quality of life. In this sample, therefore, it can be concluded that the life care plan accomplished its mission.

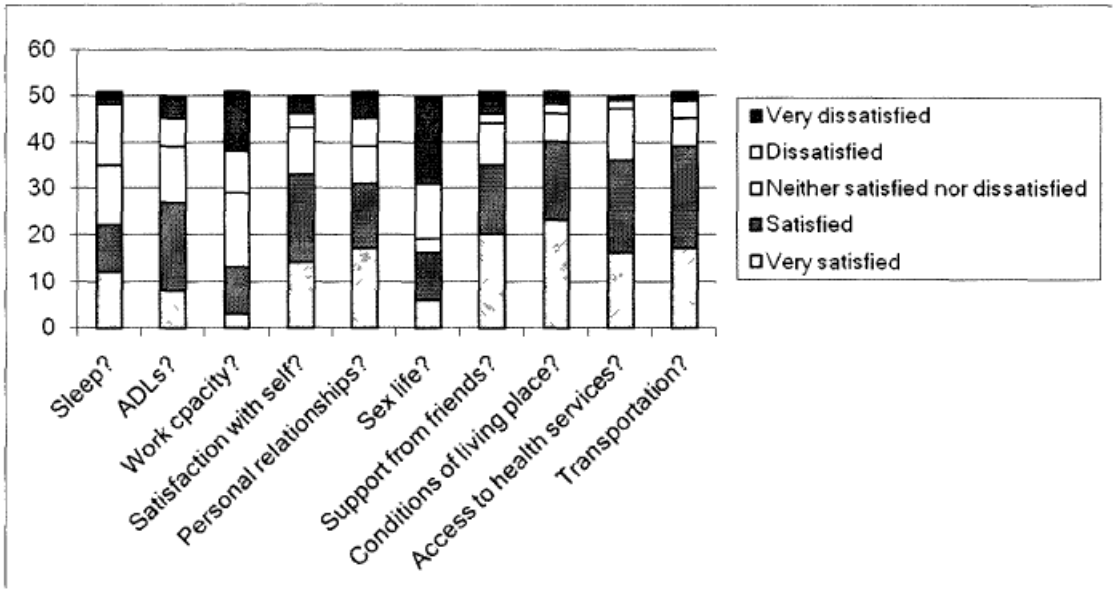
Noting that there were significant differences in quality of life is important. However, examining the particular domains that were different is equally important. Historically, rehabilitation practice and service delivery has focused on improving the health related quality of life for individuals with spinal cord injuries. The life care plan, in addition to addressing medically related goods and services, addresses quality of life issues, long term needs of the individual and their family as well as non-medical disability-related needs including transportation and architectural renovations (Weed & Field, 1994). With the *Daubert* ruling in 1995, however, the courts have often determined that a medical professional must make recommendations for the items in the life care plan for the plan to admissible in court. Therefore, the life care planner's recommendations alone may not be substantiated as admissible within the court system. This study has demonstrated that the majority of those for whom life care plans are prepared (60-75% in this study) receive treatment from general practitioners, compared to 13-25% who receives treatment from physiatrists. As general practitioners often lack specialty training in spinal cord medicine, the medical professionals making recommendations for items and services in the life care plan may simply be uneducated about the needs of individuals with spinal cord injuries. Therefore, the life care plan may only be admissible in a court if it includes items and services recommended by someone untrained in treating individuals with spinal cord injuries. Further, life care planners who must rely on medical professionals trained in the medical model of disability, rather than the biopsychosocial model of disability, may also develop plans with more focus on medically related than non-medically related areas. This may explain, in part, the significant difference found in the physical domain of quality of life and the nonsignficant differences found in the psychological, social and environmental quality of life domains. It is noted that in addition to the significant difference noted in the physical quality of life domain, the psychological and environmental quality of life means were also higher in the funding group than the no funding

group.

Interestingly, the social quality of life domain mean score was higher for the no funding group than the funding group. This domain consists of only three items. One item queries satisfaction with personal relationships, one item inquires about satisfaction with support from friends and one item inquires about satisfaction with sex life. Responses to the sex life question were consistently low, with 30 of 47 respondents rating their satisfaction with their sex life as 1 (very dissatisfied) or 2 (dissatisfied) while only five respondents reported being very satisfied with their sex life. For individuals without disabilities, satisfaction with sex may be confounded by injury-related physical problems that interfere with sexual function. The sex life question, for this population, may be affected by forces subsumed both under the social and physical domains of quality of life. Therefore, it is possible that this item, in this sample, would equally load with the physical as well as the social domain. It is noted that in previous confirmatory factor analyses, the social domain demonstrated the lowest factor loading (.66-.68) of the four scales, with the highest factor loading found in the physical domain (.82-.84), which was concluded to affect quality of life the most (Miller et al., 2008). These statistics should be considered when interpreting the findings of this study. Response rates to satisfaction with various aspects of life can be found in Figure 4.

Figure 4

WHOQOL-Brefresponses to satisfaction questions



Based upon responses to this item, most individuals in this study report dissatisfaction with their sex life. This is clearly an area that requires additional attention and resources by life care planners when planning for future needs of individuals with spinal cord injuries. Resources should be allocated in the form of education, resources and intervention when necessary to improve post-SCI sexual health. Again, treatment with a physiatrist may also improve this area of function. Based upon current results, it is suggested that with or without funding for disability related purchases, one's satisfaction with social support may be

the same. This may be explained using Bishop's disability centrality model that argues that quality of life reports depend upon the importance of the domain to the individual. Within this area, personal relationships may simply be more important than financial resources or access to goods and services for the individuals in the no funding group.

The researcher also hypothesized that the environmental quality of life domain score would be higher for individuals who reside in metropolitan areas, when compared to those who reside in rural areas. Individuals with disabilities are disproportionately represented in those residing in more sparsely populated areas (Waldrop & Stern, 2003). It is estimated that approximately 57,500 individuals reside in rural America with spinal cord injuries (Hagglund et al., 1998). Individuals with disabilities residing in rural areas may disproportionately experience limited access to healthcare and other services as well as limitations in accessible transportation. It is estimated that only 35% of rural, fixed route vehicles are accessible to people with disabilities, compared to 60% of urban buses (Hagglund et al, 1998). Individuals with SCI report limited access to healthcare practitioners skilled in treating spinal cord injuries with one study noting that over 90% of respondents had to travel at least 26 to 51 miles to obtain rehabilitation services (Hagglund et al., 1998). In this study, there were no statistically significant differences between quality of life domain means for those residing in rural or urban areas.

A review of environmental quality of life domain means in this sample revealed that those in urbanized areas (populations greater than 50,000) and rural areas (those with fewer than 2,500 people) reported higher levels of environmental quality of life than those in urban clusters (areas with more than 2,500 but fewer than 50,000 people), which was surprising. However, on social, psychological and physical domain scores, those in rural areas reported lower quality of life scores than individuals in the other groups. As issues pertaining to individuals with disabilities in rural areas are further studied by agencies like The Office of Rural Health Policy (ORHP), quality oflife differences between those who reside in rural areas and those who reside in urbanized areas should provide insight to areas that require governmental intervention.

Limitations of the Study

One limitation in the current research is the limited number of life care planners who participated. Bellini and Rumrill (2009) note that rehabilitation service delivery must demonstrate successful outcomes through research. As evidenced based research is now the foundation for rehabilitation practice, so too will the field of life care planning need to continue to demonstrate its efficacy through research and practice. The International Association of Life Care Planners included in their standards of practice the need to develop measurement tools to analyze life care plan outcomes (IALCP, 2002). As early as 2001, McCollom and Crane called for intensive retrospective study to determine the accuracy of assessment and planning in the field of life care planning. Despite this call to research to demonstrate the efficacy of life care planning practice, 98% of life care planners chose not to participate in this study, some vocalizing disapproval of the study for fear of outcomes. Despite study announcements through three professional list serves, offers of continuing education credits, and announcement of the study by the credentialing body for the certified life care planner certification, only two percent of life care planners chose to participate. While some life care planners encouraged the study, there was expressed concern about the need of life care plan-

ners to defend the outcome of the study in a litigated environment. Despite the concern by some in the field, outcome based research remains an area that life care planners must explore in order to demonstrate the best service delivery to those whom we serve. The result of limited life care planner participation was reliance on a small convenience sample of adults with spinal cord injuries. This limits the generalizability of the current research findings.

One commonly cited concern about the study was how to encourage participants in the study without disclosing their contact information (i.e. name, telephone number etc.). Additionally, some life care planners referred the researcher to the person's attorney some of whom indicated that they were unable to provide the researcher with contact information for their former clients. In this situation, the study link was provided to the attorney and/ or the life care planner for them to contact the possible participant. However, this was rarely, if ever, done. With only two percent of life care planners participating, generalizability of the study's findings should be done with caution. It is noted that the sample in this study reflects similar characteristics to the population of adults with SCI followed by the SCI Model Systems and therefore appears to be a representative sample of adults with SCI. However, with the participation of a greater number of life care planners, generalizability of findings would be improved.

There were also limitations in the instruments used in this study. Although the WHOQOL-Bref has been tested with individuals with spinal cord injuries, the social domain remained particularly problematic for this sample. The WHO ICF model on which the WHOQOL-Bref was developed is designed to measure health and function both for those with and without disabilities. Therefore, there is at least one area identified by this study, the sex life question within the social domain, which is questionable with a population of adults with spinal cord injuries. Were this instrument normed primarily on individuals with spinal cord injuries, the sex life question may be more appropriately contained on the physical domain of quality of life. This may be explored in future studies.

Another instrument limitation is that the life care plan survey was not field tested. The instrument was designed by combining common elements of previously developed life care plan follow-up surveys and having the content reviewed by a panel of life care planning experts. However, having the survey completed by respondents revealed several potential problems with the instrument. First, the life care plan survey inquired about goods and items purchased prior to and after the life care plan was completed, with pre-life care plan services asked first. Several respondents included services that they were currently receiving in the pre-life care plan section. Therefore, pre and post life care plan differences were confounded, even though they may truly exist. Additionally, the survey relied on self-report estimations of what was purchased before and after the life care plan. For some, the life care plan was developed up to 20 years ago and they had difficulty recalling what was in the plan. In fact, 52% of respondents indicated that they did not recall items in the plan very well. The majority of respondents (73%) did not have access to the plan at time of survey completion. However, the survey incorporated items that are specific to spinal cord injuries and likely included in every life care plan for individuals with this type of disability and questioned the purchase of each of those items to cross-check the items that have been purchased. Additionally, the respondent did not need to recall items that were purchased, but respond affirmatively or negatively to a list of items provided by the researcher. As this method was used for items commonly purchased by individuals with SCI, this research should not be gen-

eralized to other disabilities as the items and services received would likely be very different.

The effect of estimating the percentage of life care plan implementation without the respondent's knowledge of the items in the plan likely lead to underreporting of the percentage of items estimated for implementation. For example, some respondents reported receiving the majority of items provided in the survey. However, when asked what percentage of items they implemented, they indicated 25%. As the items and services on the checklist were all likely included in their plan based upon their disability, and they purchased the majority of items on the checklist, it is likely that 25% is an underestimation of their level of life care plan implementation. This underestimation may account for the lack of statistical differences between the groups who implemented and did not implement their plan.

Conclusions

The purpose of this study was to assess the implementation rates of life care plans developed for individuals with spinal cord injuries, to see what specific aspects of their life care plans persons with SCI purchased, to determine what variables contributed to implementation rates, and to determine how plan implementation impacted the

individual's quality of life. The goal of the study was to answer these questions in an attempt to establish an outcome measurement for life care planning that has previously been unavailable to all but a handful of life care planners. Prior to this study, only four previous life care plan follow-up studies have been published. The samples of previous life care plan implementation studies were relatively small, the largest of which involved 23 individuals, and only involved clients of the individual author's caseload. This study attempted to broaden the scope of the research question by surveying clients throughout the United States from the caseloads of multiple life care planners. Unfortunately, only 2% of life care planners chose to participate and the sample size of this study was 55 adults. Nevertheless, information about how adults with SCI implemented their plans was obtained. There were noticeable differences in receipt of items and services for those who had funding to purchase disability-related items and those who did not. It was noted that although life care plan implementation, per se, did not have a statistically significant impact on quality of life, there were differences in quality of life reports for those who did and did not receive monetary settlement or award to purchase the items recommended in their life care plan. Those who received monetary awards demonstrated significantly higher physical quality of life than those without awards. The physical quality of life domain included items pertaining to pain, energy, sleep, activities of daily living, getting around, medical treatment and employment. As the goal of the life care plan is to prevent complications and enhance quality of life, this study demonstrated that without funding for the items in the plan, individuals with disabilities are unable to accomplish these goals. For those who are able to obtain the items and services in the life care plan via monetary settlement, their quality of life is significantly higher than those who cannot.

Implications of the Study

This study differed from previous life care plan follow-up studies as it included respondents from the caseloads of multiple life care planners. Prior life care plan follow-up studies consisted of life care planners conducting follow-up with their previous clients. This

study included participants from approximately 16 life care planners throughout the country. By understanding trends among adults throughout the United States for whom a life care plan was developed, life care planners can learn more about best practices to improve the lives of individuals with disabilities whom we serve. As life care planning is a relatively new field to rehabilitation, existing only for approximately 30 years, there remains a need to demonstrate the efficacy of the plans that we develop.

Life care planners function often within litigated environments, making their life care plans subject to judicial scrutiny. The U.S. Supreme Court in 1995 decided that expert testimony that had previously been admitted due to the expert's education and experience must now be subjected to judicial scrutiny for admissibility. The criteria are truly more applicable to "hard" sciences like chemistry or engineering than "soft" sciences like psychology or rehabilitation. Nevertheless, the field of life care planning has been subject to *Daubert* scrutiny to determine admissibility of the plans that are developed. The judicial system, with its history of applying the medical model of disability, has been slow to adopt a biopsychosical model of disability. Therefore, judges reviewing life care plans often require a medical physician to make recommendations for items in the life care plan to be admitted. Additionally, the jurors who hear these cases, based upon their cultural conditioning, may believe that the testimony about future needs of an individual with a disability may be better determined by a medical doctor than a rehabilitation professional or life care planner.

In reality, however, many general practitioners consulted for recommendations in the life care plan, at least anecdotally, indicate that they are limited in their knowledge of independent living for individuals with disabilities. In fact, this is rarely covered in the curricula of medical schools. The result of these factors in the life care plan process may be a substantial gap in the expertise of the individuals whom the courts have deemed qualified to make recommendations in the life care plan and those who have the necessary expertise to make a difference in the quality of life for individuals with disabilities.

The goal of all of the parties involved in the life care plan process is the same, to facilitate maximal independence and quality of life for the individual with the spinal cord injury and reduce future injury-related complications. However, it is clear that those involved are approaching this goal with very different models. The attorneys involved may seek higher levels of damages, the courts may rely on the opinions of individuals simply not trained in rehabilitation issues and the medical system may be more attuned to providing acute medical care than planning for lifelong independence. What this studied highlighted was that while life care plan funding improved the physical domain of quality of life, it did not improve social, psychological or environmental areas of quality of life. Perhaps with an examination of the models used to determine future needs and through education by individuals with disabilities, the justice system and those who interface with the system including attorneys and life care planners will be better able to address with greater breadth and efficacy, the issues that truly impact quality of life for people with disabilities.

If challenging how disability is conceived of within the judiciary, attention should be given to the possible ramifications of such a pursuit. First, judges may be challenged with deferring to the wishes of individuals with disabilities, rather than relying on precedents decided within the medical model of disability. Second, attorneys who both represent the injured party as well as those who defend such claims may require consultation and education by those outside of the medical field, a departure from the current process. Third, physicians

treating those with disabilities may admit limitations in their expertise, which may threaten one's professional practice. Fourth, many life care planners come from the medical field, including approximately 48% of life care planners who are registered as a nurse and a small number of physicians (Neulicht, Riddick Grisham & Goodrich, 2010). Examining the model used in disability conceptualization may be required for those life care planners trained in the medical model. Finally, life care planners, if relied on more heavily by the courts as true experts in disability related matters, may be called to demonstrate the efficacy of the plans that they develop, which is an area that life care planners have, as a whole, resisted.

In this study, it was hypothesized that higher rates of life care plan implementation would correlate with higher quality of life reports. However, this study did not find this expected result. While there were study limitations that may have eclipsed this finding, including a small sample size and lack of field testing of the life care plan survey, the results of this study call into question assumptions about how the lives of individuals with disabilities are improved. The finding that funding did not improve three of four quality of life domains necessitates the examination of the expected correlates of quality of life. While positive correlates of quality of life for individuals with spinal cord injuries have included work opportunities and level of resources (Boswell et al., 1998); self-assessed health, social support, mobility, adequate income, satisfaction with relationships, and employment (Hammell, 2004); and negatively correlated with rehospitalizations, pain, inadequate income, and unemployment, (Hammell, 2004), in this sample greater levels of resources improved only the physical domain of quality of life. Such a finding deserves worthwhile consideration of the determinants of quality of life for adults with spinal cord injuries. The results of this study suggest that despite limited resources and dissatisfaction with one's sex life, there were no significant differences in three of four domains of quality of life. Perhaps with these findings there is a challenge to existing models of quality of life. By closer examination, we may uncover factors that may improve the services that are funded for individuals with disabilities.

Individuals with spinal cord injuries continue to live longer and report higher levels of quality of life. As a result, life care planners will benefit from the results of this study that demonstrate differences in quality of life reports. Comments of the respondents in this study are critical to improving rehabilitation practice for life care planners and perhaps for those involved in disability policy formation. Additionally, several areas of future research pertaining to life care planning have been identified by this study. These are discussed in greater detail in chapter six.

Summary

Several keys areas were identified as salient by this study. These included differences in quality of life reports by individuals with similar diagnoses who were and were not provided the necessary resources to purchase disability related goods and services. Additionally, this study demonstrated differences in purchases for those who did and did not have available funding to purchase items necessary due to their disability. While statistically significant differences in quality of life reports were not identified based upon life care plan implementation, they were identified based upon receipt of settlement or jury award. Finally, multiple barriers were identified by respondents that provide evidence of the need for continued research in the field of life care planning and spinal cord injury.

Chapter VI - Future Research

This study attempted to provide information about implementation of life care plans for adults with spinal cord injuries throughout the United States. The goal was to provide an outcome based measure that informs life care planners about how their plans are used by individuals with disabilities once they are developed. Several important practice points were identified as a result of the research.

First, it was revealed that over 40% of individuals in this sample did not receive a copy of their life care plan. As it is common practice for life care planners to submit the life care plan to the referring party (i.e. attorney or insurance company), it may be that those parties are not providing copies of the life care plan to the individual or family of the individual with the disability. It is important that if the plan is developed for the individual with the disability, that they receive a copy of the plan. Those who did not receive a copy indicated a desire to have a copy currently and wished that they had a copy of the plan in the years following SCI onset.

Most individuals surveyed by telephone expressed confusion and feeling overwhelmed after the onset of the SCI when attempting to navigate the world of disability management. Most expressed a desire to have someone educated in these areas to assist them in navigating medical, insurance and vendor systems that they did not understand. Additionally, several respondents who had received case management services complimented the services received indicating that they were essential in the years soon after their SCI.

Although development of each life care plan includes an interview with the person with the disability and/or the family of the individual, approximately 30% of individuals reported that they were not actively involved in the process. Several respondents commented that although they recalled the interview, they did not know the outcome of the interview. Some did not understand the purpose of the plan or the process by which it was developed. This may be due in part to the time that lapsed for some individuals since the life care plan was developed. Those who more recently participated in the process seemed to recall their role in plan development better. As life care planners, we must ensure that the person with the disability understands their role not only in plan development, but in how to use the plan once litigation is complete. This very important resource may be untapped for some who do not understand how to use the plan for future care coordination. Finally, some respondents reported that they would have liked to have information about local vendors to contact to procure items or services recommended by the life care planner. Incorporation of vendor information should be considered by life care planners who do not currently provide this information to their clients.

If life care planners continue to provide a valuable service, not only to attorneys and insurance or trust companies, but to individuals who sustain disabilities, we must ensure that those with disabilities are educated on the purposes and uses of the plan and are provided copies of the plan for current and future use. One practice suggestion is to incorporate life care plan follow-up as part of the process of plan delivery. This would ensure that the individual has a copy of the plan following litigation, understands how to utilize the plan and has vendor and cost information about the cost of recommended services. If the life care plan is a tool only of the legal system, it is not serving its original purpose and may not be adequately serving the population that it was intended to help.

Similarly, if life care planners are unable to establish the importance of the plans in the lives of the clients whom we serve, the field will lack the evidence based practice standard that has become critical to the survival of the field of rehabilitation. While establishing the reliability and validity of the plans that are developed was critical to surviving the standard set by the United States legal system in most notably in *Daubert v. Merrell Dow Pharmaceuticals, Inc.*, 43 F.3d 1311 (1995) the survival of life care planning as a field, may now turn on the field demonstrating that the plans that we develop are important in the lives of individuals who sustain disabilities.

Finally, this study has empirically demonstrated the importance of having resources available to purchase disability related items in the lives of individuals with disabilities. While previous spinal cord injury studies linked availability of resources to post-SCI life expectancy (Krause, 2002) and quality of life reports (Miller et al., 2008) the only study previously published in the life care planning literature that examined the effect of financial settlement on quality of life found no statistically significant impact (Salmons, 2008). This study, however, found statistically significant differences in quality of life for those who did and did not receive funding for life care plan items and services. There were clear quality of life differences in the group of individuals with spinal cord injuries who received funding for disability related purchases and those who did not. As life care planners are often the only voice to explain the costs of medically related goods and services, it is incumbent upon the field to demonstrate that the decisions that jurors make have significant impact on the lives of those who sustain serious injury or illness. As individuals with disabilities are disproportionately represented in those living under the poverty line in the United States (Erickson & Lee, 2008), access to resources to pay for disability related goods and services is critical to those with disabilities. This studied demonstrated that a group of adults with similar levels of SCI have improved quality of life when they are provided funds necessary to purchase disability related goods and services.

In addition to quantitative information, open response questions were provided for respondents to comment on barriers that they experienced as a result of their SCI. Commonly cited barriers identified by respondents included lack of accessible parking, buildings that were not accessible, lack of curb cut outs, stores that place merchandise in the aisles preventing wheelchair navigation, lack of accessible timely transportation, lack of dental and physician offices that accommodate those with disabilities and difficulties in accessing employment. Twenty years after passage of the Americans with Disabilities Act, respondents in this study consistently pointed to examples in the community where there remain substantial barriers. These problems continue to require attention of rehabilitation professionals as well as government officials to ensure that the ADA is being implemented as intended.

Future Research Suggestions

As a result of the current research, a number of future research projects were identified. First, there continues to be need for a large scale nationwide survey of life care plan implementation for individuals for whom a life care plan is developed. Originally, this study was designed with the targeted sample size of 260 adults. However, based upon limited response from the life care planning community, the sample consisted of only 55 adults.

By surveying a larger number of individuals, particularly more individuals who did not receive a settlement or jury award, differences between groups may become more appar-

ent and perhaps statistically significant. This will only be accomplished by greater life care planner participation. As 98% of life care planners declined to participate and several expressed concern about the need to defend in court the outcome of this study, there needs to be further discussion among life care planners about the need for evidenced based outcome. Life care planners, as recently as the 2010 summit attended by the researcher, demonstrated ambivalence toward research in the field of life care planning. In contrast to participation in this life care plan implementation study, the 2009 Life Care Plan Survey: Process, Methods and Protocols survey received a 23% response rate from life care planners nationwide. Clearly, some life care planners continue to be reluctant to empirically measure the outcomes of the life care plans that they develop. This is an area that needs continuing conversation in the life care planning community. Failure to provide interested parties in outcome research may lead many to continue to question whether or not the plans that are developed accomplish the goals outlined in the life care planning literature.

Next, there is an identified need for an agreed upon follow-up instrument that is utilized by life care planners following life care plan development. If life care planners are interested in the outcomes of the life care plans that are developed, creating an instrument that is designed to follow-up on life care plan implementation would be a worthwhile endeavor. With an agreed upon instrument, multiple life care planners could track implementation of the plans that they develop and have an outcome measure for their practice.

In the 1980s, Dr. Paul Deutsch published a standardized format for life care plan development that continues in existence today. Additionally, the field of life care planning has conducted several role and function studies and has held six life care planning summits to establish best practices data. Even with these efforts, there has been a dearth of published research pertaining to what happens to life care plans when litigation is concluded. By developing and field testing a follow-up outcome instrument, life care planners can incorporate its use into their practice, perhaps establishing a national database for life care plan follow-up. Such longitudinal data will explain the role of the life care plan in the lives of individuals with disabilities over time and may be important to those who interface with life care plans or life care planners in the various systems in which we engage.

A third suggestion for future research is to codify the definition of life care plan implementation. Having an agreed upon definition of life care plan implementation would help to stratify implementation across practitioners and disabilities. In this study, implementation at the 50% mark was used to define life care plan implementation. However, by surveying life care planners or examining trends identified in this study, we may be better able to identify the critical mark at which life care plan implementation begins to significantly impact the lives of those for whom they were developed. In this study, there appeared to be differences in how individuals who did and did not receive funding purchased items and services at the 25% mark. A method other than self-reported estimations may be identified through these efforts to collect data regarding plan implementation.

In this sample of respondents, the majority of individuals reported dissatisfaction with their sex life. Additionally, the group without funding reported a slightly higher social quality of life, where the question about sex is contained. Therefore, future research should examine the social domain of quality of life specifically for individuals with spinal cord injuries. An exploratory factor analysis with a similar sample may show factor loading of this item on one of the other three scales.

Fifth, the employment rate of respondents in this sample was less than 36%, compared to 58% in the model systems population. This is significantly lower than the over 90% employment rate prior to SCI onset, highlighting the need for follow-up on employment outcomes by individuals who have had life care plans developed. If life care planners are incorporating vocational assessments or evaluations as part of their plan development process, there outcomes should be at least as high as the model systems population. Providing follow-up of life care plan vocational interventions and employment outcomes is another line of worthwhile research identified by this study.

There are several implications for life care planning practice. In this study, 4% of respondents did not receive a copy of their life care plan. Life care planners must ensure that the individuals for whom the plans were developed receive a copy of the plan along with information on the purpose of and use of the plan. Additionally, 30% reported that they were not involved in life care plan development. It is likely that many of these individuals were involved in the process, but did not understand the purpose of the interview. It is incumbent upon life care planners to provide education about the life care planning process, and to maintain open communication with the person with the disability. Finally, several respondents commented on the scarcity of information about vendors available to provide disability-related services. Information about local and national vendors available to provide services to individuals with disabilities should also be incorporated by life care planners to ensure that following litigation those with disabilities can access such information.

Finally, one concept not anticipated by the researcher, but raised by multiple respondents of the study was the limitations in funding for their purchases following payment of attorney's fees. As the life care planner outlines future costs of goods and services, a total estimated cost is requested for future medical costs. However, once an award or settlement is made, the individual with the disability must pay attorneys fees and costs of litigation, including the fees to the life care planner. Multiple respondents commented that out of the millions that were awarded, they received only a fraction after payment of attorney's fees and litigation costs. The result is that the person with the disability receives a fraction of the monies outlined as necessary to fund future goods and services outlined in the plan. While this was an unanticipated issue by the researcher, it is one that warrants discussion in the life care planning community.

Summary

This study accomplished its goal of measuring life care plan implementation in a nationwide sample of respondents from various life care planners. There were differences found in the ways that respondents implemented their plans if they did or did not receive necessary funding to purchase recommended items and services. There were accompanying differences in quality of life reports for these two groups. As a result of this research, there were a number of future research projects identified. While this study was the largest of its kind completed in the life care plan community, recruiting a larger number of respondents for future similar research is recommended.