

A COMPARISON OF THE ADAPTATION AND QUALITY OF LIFE OF
INDIVIDUALS WITH SPINAL CORD INJURIES FROM KUWAIT
AND THE UNITED STATES: A CROSS CULTURAL PERSPECTIVE

A DISSERTATION

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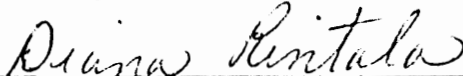
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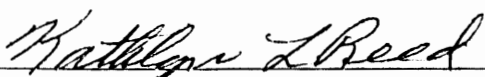
I am submitting herewith a dissertation written by Fahad S. Manee entitled "A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Occupational Therapy.

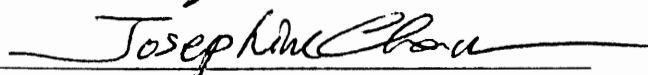


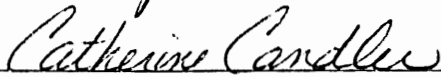
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We have read this dissertation and recommend its acceptance:









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DEDICATION

To my parents, brothers, sisters, wife, and my children who provided support, encouragement, motivation, prayers, and love throughout the process of this interesting dissertation.

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ABSTRACT

FAHAD SAFAH KAYED MANEE

A COMPARISON OF THE ADAPTATION AND QUALITY OF LIFE OF INDIVIDUALS WITH SPINAL CORD INJURIES FROM KUWAIT AND THE UNITED STATES: A CROSS CULTURAL PERSPECTIVE

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According to the National Spinal Cord Injury Statistical Center (NSCISC, 2006), SCI is a nationwide issue and its annual incidence worldwide has been reported to be between 11.5 and 57.8 cases per million population. In the United States, the estimated incidence rate of new SCI cases is quite large at approximately 11,000 per year (NSCISC, 2006). Such a traumatic injury can result in significant and permanent life changes for the injured individual including his/her physical, psychological, and social aspects. Due to the devastating consequences of SCI, QOL becomes the outcome of greatest concern among health care professionals. In turn, quality of life (QOL) is considered one of the major outcomes in occupational therapy and spinal cord injury (SCI) survivors are one of the most common groups that occupational therapists treat. The purpose of this line of research was to investigate the role of adaptation in QOL research among SCI survivors. This line of research also compared the factors that influence the QOL of SCI survivors cross-culturally.

The first study was a quantitative study aimed at comparing the HRQOL of adult Kuwaitis with that of normative data for the American general population as well as with

the HRQOL of Americans with SCI. The second and third studies employed mixed methods designs. This dissertation concluded that recovery from a SCI depends on the dynamic relationship between person, environment, occupation, adaptation, and QOL. These three studies were prepared and submitted to peer reviewed journals.

One outcome of this dissertation was to contribute to the knowledge base of occupational therapy about the recovery experience of SCI survivors. It seems most important for therapists to understand the adaptation process of SCI survivors and the factors that influence their QOL cross-culturally. This dissertation also investigated actors that influence the QOL of SCI survivors' living in Kuwait and the U.S. Results from these three studies could be utilized in occupational therapy education, practice, and research. Recommendations are offered to further explore the findings of this study.

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CHAPTER I

INTRODUCTION

Quality of life (QOL) is considered one of the outcome measures in occupational therapy (AOTA, 2002) and has long been of central focus to occupational therapists (Wilcock, 1993; Yerxa, 1994). The importance of QOL was emphasized by Yerxa et al. (1990), who stated that “medicine is concerned with preserving life; occupational therapy is concerned with the quality of life preserved” (p. 8). Many occupational therapists agree that QOL is multidimensional, dynamic, and intimately related to occupation (Radomski, 1995). Several authors describe the central objective of occupational therapy as promoting health and QOL through enabling occupation (Fisher, 1998; Polatajko, 1994; Yerxa, 1994; Youngstrom et al., 2000). It is because of this connection to health through occupation that many occupational therapists strongly advocate for the use of QOL in both practice and research (Laliberte-Rudman et al., 2000; Liddle and McKenna, 2000; Radomski, 1995).

The term QOL first appeared in research literature in the 1930’s and remains prominent in recent literature of other disciplines. Quality of life has been studied extensively by researchers from different disciplines including rehabilitation, social services, medicine, education, and psychology, however, the body of knowledge in occupational therapy on this topic is still limited.

When working with persons with chronic disabilities such as spinal cord injury (SCI), a person's QOL is considered the ultimate goal for most occupational therapists. Occupational therapy literature on QOL for people with chronic conditions identifies a significant relationship between QOL and that of meaningful occupation and participation (Dooley and Hinojosa, 2004; Duncan-Myers & Huebner, 2000; Huebner et al., 2003; Laliberte-Rudman et al., 2000). Such evidence supports the premise that mastery and occupational performance are associated with improved well-being (Youngstrom et al., 2000). Occupational therapy research also demonstrates a positive relationship between meaningful roles, interests, values, goal-directed action, personal control and life satisfaction and well-being (Duncan-Myers & Huebner, 2000; Hammell, 2007, Smith, Kielhofner, & Watts, 1986). These findings solidify the connection between occupation and health and well-being.

A person's QOL is considered to be complex and multifaceted. In addition to occupation, there are various factors that influence a person's QOL. International studies show that a participant's culture may influence a person's QOL (Dijkers et al., 2002; Kreuter et al., 2005; Ide and Fugl-Meyer, 2001, McColl et al., 2002). These studies have shown that satisfaction with life, and therefore QOL varies among groups and among nations due to various factors such as technology, culture, environment, and the health care system. Researchers in occupational therapy need to further investigate and understand the extent to which occupational performance, environment, and adaptation influence a person's perceptions of his/her QOL. It is important to note that adaptation

can play an essential role in facilitating a person's engagement in functional activities and therefore influencing that person's health, well-being, and QOL.

Occupational therapy as a discipline must consider the significant role of adaptation in QOL. Researchers need to carefully investigate and understand how integration of adaptive responses plays a key role in the dynamic relationship between occupational performance and QOL. One way to do this is by conducting occupational therapy cross-cultural QOL studies comparing occupational challenges, adaptive responses, and QOL among people with SCI. Such studies can assist in explaining the differences in a particular group's QOL and could also be of great benefit in making suggestions for improvement in occupational therapy services nationally and internationally. Currently, there is no study that assesses and compares the QOL of persons with SCI living in an Arabic country to that of persons living in a more developed country. Thus, the scope of this line of research compares the QOL of people with SCI in Kuwait with that of those in the United States.

Statement of the Problem

Quality of life is one of the outcomes of occupational therapy identified in the Occupational Therapy Practice Framework (OTPF) (AOTA, 2002, p. 628). The term QOL continues to emerge as a central construct in outcomes research in the practice of occupational therapy (Fisher, 1998; AOTA, 2002; CAOT, 1994; Polatajko, 1994; Wilcock, 1993; Yerxa, 1994; Youngstrom et., 2000). While it has been studied extensively by researchers from other disciplines, the occupational therapy (OT) body of knowledge on this topic remains limited. Research shows that the domains of

occupational therapy such as adaptation, occupation, and environment are principal constructs in the QOL knowledge base (Dijkers, 1998; Dooley and Hinojosa, 2004; Duncan-Myers & Huebner, 2000; Fuhrer, 1996; Hammell, 2007; Huebner et al., 2003; Laliberte-Rudman et al., 2000). The outcome of QOL also remains consistent with the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). With specific reference to clients with chronic physical conditions such as SCI, the role of the occupational therapist is to promote the QOL for such clients. Although occupational therapists have significantly contributed to QOL research, more studies are necessary to fully expand the concept for other populations.

Statement of the Purpose

While QOL is considered the ultimate goal for most occupational therapists working with persons with disabilities (Graff et al., 2006, Robyn & Linsey, 2007; Todd, 2007), the concept of QOL remains very complex and multifaceted. This proposed dissertation was comprised of two major goals. The first goal was to investigate the role of adaptation in QOL research. To do so, the Occupational Adaptation (OA) model was used as a template for interpretation of the three studies' findings (Schkade & Schultz, 2003; Johnson & Schkade, 2001; Schkade & McClung, 2001; Schkade & Schultz, 1992; Schultz & Schkade, 1992). This research carefully investigated ways in which the integration of adaptive responses plays a key role in the dynamic relationship between occupational performance and QOL. The second goal was to conduct cross-cultural QOL studies to compare occupational challenges, adaptive responses, and QOL among people

with SCI. To date, no study has assessed and compared the QOL of persons with SCI living in an Arabic country to that of persons living in a developed country.

Specific Aims

The dual purpose of this dissertation was accomplished in three separate, but related studies. These studies addressed the adaptation and QOL of individuals with SCI in Kuwait and the United States through a cross-cultural perspective. The first study, “Cross cultural perspectives of quality of life between Kuwaitis and Americans with spinal cord injuries,” was a quantitative study aimed at comparing and investigating the differences of the QOL between adult Kuwaitis and Americans with SCI. The study explored the following research questions:

1. How do Kuwaitis with SCI perceive their health related QOL?
2. What are the similarities and differences of perceived health related QOL of the Physical Component Summary (PCS) and Mental Component Summary (MCS) as identified in the SF-36 between adult Kuwaitis and Americans with SCI?
3. What are the implications for occupational therapy practice based on identified cultural differences?

The second study, “Perspectives of Kuwaitis living with spinal cord injuries: A mixed-method study,” employed a mixed methods design and included both quantitative and qualitative methods. The study examined these research questions:

1. How do Kuwaitis with SCI perceive their roles before and after the injury?
2. How do persons with SCI from Kuwait adapt to their injury?

3. How does the occupational environment in Kuwait impact adaptation following SCI?
4. What are the perceptions of the future for Kuwaitis with SCI?

The third study, ‘Perspectives of Americans living with spinal cord injuries: A mixed-method study,’ used a mixed methods design and asked the following questions:

1. How do Americans with SCI perceive their roles before and after SCI?
2. How do persons with SCI from the United States adapt to their injury?
3. How does the occupational environment in the United States impact adaptation following SCI?
4. What are the perceptions of the future for Americans with SCI?

Significance of the Line of Research

Findings from these studies would increase awareness among occupational therapists about the factors related to successful QOL following SCI. Moreover, the theoretical understanding of a disability through the Occupational Adaptation (OA) framework should allow clinicians and researchers to take account of the important roles that environment, occupational performance, and adaptive response take in influencing a person’s health, well-being, and ultimately QOL. With a clearer picture about the person’s environment, occupational therapists can develop more individualized therapies and thus create successful QOL outcomes for persons with SCI. This broadens or opens-up the actual definition of QOL to include the individual client’s perspective.

These findings might lead to future research regarding the delivery and development of SCI rehabilitation services across other countries and cultures such as in

Kuwait. Finally, these cross-cultural QOL studies should promote greater collaborative effort and support between occupational therapists on a global level. Researchers could make important comparisons across cultures to determine key differences in domains that make up successful QOL. These types of comparisons are of great interest as they promote actual client inclusion within their own plan of treatments and fulfill the goal of occupational therapy. Hence, collaborative findings from these studies would contribute to the improvement of occupational therapy services both nationally and internationally.

CHAPTER II

REVIEW OF THE LITERATURE

Several related topics are discussed in this literature review. First, operational definitions of QOL from occupational therapy and non-occupational literature are described. Quality of life is an outcome that has long been of interest to occupational therapists. Second, QOL as an outcome measure is emphasized by several authors and researchers who describe the central objective of occupational therapy as promoting health and QOL (Fisher, 1998; Polatajko, 1994; Yerxa, 1994; Youngstrom et al., 2000). Because occupational therapy literature on QOL strongly advocates its use in research and practice, QOL research studies in occupational therapy literature are discussed. Major advantages of using QOL as a goal or outcome measure exist, so advantages of QOL measures for occupational therapy are addressed. Because the researcher's interest is particular to SCI, the QOL of SCI survivors is discussed here. Since adaptation is a highly emphasized concept in occupational therapy literature, human adaptation is also investigated. Lastly, an overview of the OA framework is provided, since it was used as a template for understanding a client's adaptive response to an occupational challenge within his/her occupational environment.

Operational Definitions

The Occupational Therapy Practice Framework (OTPF): Domain and Process (AOTA, 2002) defines outcomes as “important dimensions of health that are attributed to interventions, including ability to function, health perceptions, and satisfaction with care” (p.618). The OTPF lists seven categories of occupational therapy outcomes -- one of them being quality of life (QOL) (AOTA, 2002). The OTPF defines QOL as “A person’s dynamic appraisal of his or her life satisfactions (perceptions of progress toward one’s goals), self-concept (the composite of beliefs and feelings about oneself), health and functioning (including health status, self-care capabilities, and role competence), and socioeconomics factors (e.g., vocation, education, income)” (AOTA, 2002, p. 633). Accordingly, QOL consists of an individual’s overall perception of and satisfaction with his/her life. It is this overall perception and satisfaction with life that ties into Zhan’s (1992) operational definition of QOL.

Zhan’s operational definition of QOL includes four dimensions: life satisfaction, self-concept, health and functioning, and socioeconomic factors. This definition of QOL emphasizes “doing” (one of the premises of occupational therapy) as the foundation of self-actualization (Fidler & Fidler, 1978). This definition, describes the influence of purposeful activity (occupation) on QOL as the medium for motivation, satisfaction, sense of mastery, and performance (Wu, Trombly, & Lin, 1994). Zhan’s model suggests that proficiency in activities of daily living (ADL) is but one factor that contributes to perception of a good life (Radomski, 1995). It also suggests that QOL is more than the sum of these parts: life satisfaction, self-concept, health and functioning, and

socioeconomic factors (both actual and perceived) are all interrelated (Radomski, 1995). Because QOL captures the realities experienced by the individual, it tends to be a client-centered approach. A client-centered approach can be defined as “an approach to occupational therapy which embraces a philosophy of, respect for, and partnership with, people receiving services” (Law, Baptiste, & Mills, 1995, p. 253). Since the term QOL first appeared in research literature in the 1930s, it has been extensively researched, reviewed, and discussed in the social sciences, psychology, economic, and medical fields of literature. Ferrans and Powers (1992) defined QOL as “A person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her” (p. 29).

Quality Of Life As an Outcome Measure

QOL is considered one outcome of occupational therapy. Outcome measures are essential in health care because of the move towards greater accountability and evidence based practice. Outcome measures are designed to give an indication of the efficacy of a treatment, by evaluating whether therapeutic goals have been met (Liddle and McKenna, 2000; Rogers & Holm, 1994).

Occupational therapy outcomes of QOL and occupational performance are also consistent with the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). Using the ICF terminology, makes it is easier to attain a more comprehensive picture of a client’s outcome by including measures at all three levels of the disablement model: impairment, activities, and participation (Laliberte-Rudman et al., 2000; Liddle and McKenna, 2000). Similarly, occupational therapy scholars recommend

that occupational therapists classify their goals and outcomes of treatment more specifically to the WHO's model. Many occupational therapists suggest that QOL is an outcome measure at the participation level. 'Participation' (previously handicap) is associated with performance of life roles, such as that of worker, and often involves interaction at a societal level (Liddle and McKenna, 2000; Rogers & Holm, 1994). Health and well-being of the individual are seen as holistic (a core belief of the profession) and can be maintained through active engagement in occupation. In the occupational therapy profession, the construct of QOL has gained prominence because the experience of participation in occupations is considered to be closely associated with QOL (Laliberte-Rudman et al., 2000).

Measurement of Quality of Life

Both qualitative and quantitative methodologies have been used to explore the construct of QOL. Both methods have strengths, and the purpose of the measurement determine the more appropriate choice (Liddle and McKenna, 2000). Qualitative research is important in exploring new areas, or in demonstrating complex realities. This approach involves finding people who have experience in an area, and describing their experience in detail (Liddle and McKenna, 2000). The techniques commonly used to obtain people's insights and perspectives are personal interviews and focus groups using discussions and open ended questioning (Liddle and McKenna, 2000). Qualitative research is particularly useful in explaining the theoretical conceptualization of QOL, a necessary and important forerunner to the development of QOL measures and benchmarks (Lau, Chi, & McKenna, 1998).

In contrast, quantitative methodology typically yields numerical values that may quantify outcomes, in order to determine efficacy of treatment methods and resource allocation (Liddle and McKenna, 2000). Questionnaires and numerical outcomes are typically used. Quantitative research in the area of QOL is based on the underlying assumption that QOL has elements that are common to all people (Liddle and McKenna, 2000). This methodology has provided as a means of establishing a consensual picture of the QOL of large numbers of people (Liddle and McKenna, 2000).

Quality Of Life and Occupational Therapy Literature

There are parallels between the constructs of QOL and the philosophy of occupational therapy (Liddle and McKenna, 2000). Occupational therapy literature from different fields emphasizes the value and importance of QOL to a person. Laliberte-Rudman et al. (2000) conducted a QOL study in the mental health field with clients who had schizophrenia. Their study aimed to explore the perspectives of clients with schizophrenia regarding QOL and develop a QOL assessment that addresses factors experienced as important by consumers. Results revealed seven major factors that had an impact on QOL including activity, social interaction, time, disclosure, “being normal,” finances, and management of illness. These factors relate to three overall themes: managing time, connecting and belonging, and making choices and maintaining control. The findings support beliefs regarding occupation that are central to occupational therapy and the use of occupation as means and ends of therapy.

With specific reference to clients with chronic physical disabilities, Huebner et al. (2003) described the following outcomes of occupational therapy: increase performance

of the activities of life; reintegration into the community and participation in life roles; and QOL. In a study of outcomes after traumatic brain injuries, Huebner et al., (2003) followed 25 adult participants, on average 21 months post-injury. Various areas including community participation and QOL were studied. Results showed that participants were often unemployed, depressed and withdrawn, and experienced limitation in community integration. Half of these participants expressed dissatisfaction in life. They rated their opportunities for learning and control of their life as well as their future below that of the control group. Findings also indicated that less disability (fewer activity limitations) and higher social integration were associated with various aspects of QOL (higher self-esteem, spirituality, and recreation). Further, the study showed that QOL was highly related to all aspects of community integration.

Occupational therapy theory is based on the premise that the provision of choice and achievement of successful adaptation motivates performance and promotes an internal locus of control (Kielhofner, 1992; Nelson & LaMore, 1992). The literature on occupational therapy has demonstrated a positive relationship between measures of interests, values, personal causation, and life satisfaction (Smith, Kielhofner, & Watts, 1986). In a study on the association between perceptions of personal control and QOL among older persons, two self-report instruments were used (Duncan-Myers & Huebner, 2000). Both the Quality of Life Rating (QOLR) and the Duncan Choice Index (DCI) were administered to 21 residents in a long-term care facility. The DCI was developed for this study to measure the amount of choice available in 29 self-care and leisure activities. The results showed a significant positive correlation ($r=.54$; $P = .01$) between the amount

of choice residents perceive they have and QOL. This study suggests that by engaging people in meaningful roles and goal-directed actions, occupational therapy can empower individuals to have control they desire in their everyday lives.

Dooley and Hinojosa (2004) also studied QOL for persons with Alzheimer's disease as well as that of their family caregivers. They examined the extent to which adherence to occupational therapy recommendations would increase the QOL of persons with Alzheimer's disease living in the community and decrease the burden felt by family members caring for them. Using a pre-posttest control group design, the Assessment of Instrumental Function (AIF) was administered to two groups of persons with Alzheimer's disease in their own homes (n=40). Caregivers completed measures of feelings of burden and QOL. Results revealed a significant main effect for caregiver burden and three components of QOL (positive affect, activity frequency and self-care status). The findings suggest that individualized occupational therapy intervention based on the person-environment fit model appears to be effective for both caregivers and clients.

These findings in QOL shows that the construct of QOL can be explored using both qualitative and quantitative methodologies. QOL can be studied by a subjective evaluation of the life circumstances of an individual with respect to his/her values. The literature also shows that QOL can be explained by an objective numerical measure. Depending on the type of QOL assessment tool (objective or subjective measure), various factors of QOL can be identified. Analysis of the QOL concept for adults with either mental health problems or physical disabilities shows various factors (domains) related to QOL. Studies, thereby, prove the importance of health status, physical and psychological

factors (psychiatric symptoms), time, social relations, finances, living situation, leisure, productivity, spiritual well-being, meaningful roles, and the accomplishment of meaningful occupations to the understanding of QOL.

A frequently noted common weakness is the lack of existing QOL assessments to guide the conceptual framework of QOL. The current literature indicates that there is no agreement on how to best conceptualize or measure QOL. Another common limitation is that the definition of QOL and its domains have largely been based on researchers' perspectives, with little input from clients (Laliberte-Rudman et al., 2000). Little is known about clients' values and preferences regarding what domains or factors are important for QOL and how these factors are experienced as affecting QOL. The ways in which researchers and clinicians define QOL and the factors they perceive to be important contributors may be different from clients' perspectives (Clark et al., 1996). Thus, some potential miss-matches between clinicians' and clients' views exist.

First, clinicians and clients may disagree on the importance of specific domains, such as work or education, in terms of their contribution to QOL. Second, clinicians and clients may have different reference systems in judging satisfaction and performance within such domains (Laliberte-Rudman, et al., 2000). Although clients and clinicians may provide similar ratings of satisfaction with respect to symptoms and function, there might be little agreement in terms of social relations and occupational aspects of QOL (Laliberte-Rudman et al., 2000).

Due to the potential discrepancies among the perspectives of researchers, clinicians, and clients, exploring clients' perspectives is increasingly being recognized as

an important research venture, both as a way to further the understanding of issues important to clients and as an initial step in the development of assessments (Clark et al., 1996). There is an emerging consensus that clients' values and preferences need to be addressed in treatment planning and evaluation. This is to ensure that services are not biased to the perspective of service providers and are optimally relevant to clients' lives (Laliberte-Rudman et al., 2000; Radomski, 1995; Youngstrom et al., 2000). Thus, the use of existing QOL assessments that have not incorporated the perspective of clients may mean that treatment and outcome evaluations become focused on factors that clients neither experience nor define as key to their QOL (Laliberte-Rudman et al., 2000). Unfortunately, such an approach contradicts the client-centered philosophy of the profession of occupational therapy.

Advantages of Quality Of Life Measures for Occupational Therapy

In occupational therapy, intervention goals are focused on improving the QOL of the individual. Treatment techniques focus on enhancing the life of a client (Radomski, 1995). Because QOL relates to the actual performance and satisfaction of the client on a participation (e.g., social role) level, it takes into account factors that the client deems to be important (Radomski, 1995). Therefore, it facilitates an intensely person-centered approach (Liddle & McKenna, 2000). Improving QOL as a goal of therapy may also give recognition to areas of practice that are not as easily measured, such as the rapport between the therapist and client (Robnett & Gliner, 1995).

Quality of life can also provide a measure of any potentially detrimental effects of therapy. Intervention at an impairment or activity level may interfere with the performance of life roles due to time in therapy and fatigue. As a result, measures at the impairment or activity level may not show these effects, but a QOL measure at a participation level may (Liddle & McKenna, 2000; Radomski, 1995). Quality of life measures can also assist in determining resource allocation, comparing outcomes, and evaluating the effects of disorders and treatments. These measures also facilitate the discussion of outcomes with other allied health workers, as well as the client and his or her family (Liddle & McKenna, 2000).

In addition, outcomes research and management have influenced the practice of occupational therapy in three main ways: (a) they have fostered the development of and reliance on functional status measures and health related quality of life (HRQOL) evaluations to determine treatment effectiveness; (b) they have forced the participation of

occupational therapy in cultivating outcomes research to remain viable and competitive in the market place; and (c) their impact has dramatically altered the settings in which occupational therapy is delivered (Ellenberg, 1996).

A trend in occupational therapy outcomes research is the use of HRQOL evaluations as a component of rehabilitation outcomes (Ellenberg, 1996). The HRQOL can be used for a specific diagnosis as well as for chronic conditions to report an individual's physical status, emotional wellbeing, social life, overall satisfaction, energy, vitality etc. Various HRQOL instruments exist that are designed specifically for outcomes research, including the Medical Outcome Study 36-item short form health status questionnaire (SF-36) (Hays, Sherbourne, and Mazel, 1993) and Ferrans and Powers Quality of Life Index (QLI) (Ferrans and Powers, 1985).

Correspondingly, Rogers, and Holm (1994) suggested a comprehensive agenda for outcomes research in occupational therapy encompassing: (a) Directions for research of efficacy in programs, (b) Outcomes as therapists relate to variability in practices, (c) Development of practice-based research networks to investigate efficacy in targeted populations, (d) Development of occupational therapy scientists in the research of methods and designs appropriate for studying effectiveness of practice, (e) Increased participation of occupational therapy scientists on federal grant review panels, and (f) Inclusion of essential occupational performance variables in national health databases.

Despite major advantages, the use of QOL as a goal or outcome measure in occupational therapy has not been widely reported in the occupational therapy literature (Liddle & McKenna, 2000; Mayers, 1995; Radomski, 1995). Lack of consensus of the

literature may have limited its use in occupational therapy; and clinicians may lack the time to access the broad range of literature on QOL (Eakin, 1997; Liddle & McKenna, 2000). Besides, QOL is a more subjective construct and occupational therapists tend to focus more on objective outcomes.

A major reason for limited use of QOL measures in occupational therapy is that the profession lacks a “gold standard” measurement instrument of QOL. Many of the outcome measures traditionally used by occupational therapists have tended to focus on performance components, such as range of motion and muscle strengths, or fragments of a person’s broader life roles, such as certain activities of daily living. There has been less concern with measuring more holistic or global outcomes, such as the return to desired life roles or life satisfaction, which may more potently reflect the success of occupational therapy intervention (Radomski, 1995; Robnett & Gliner, 1995; Liddle & McKenna, 2000). Thus, occupational therapists must advocate for the inclusion and value of occupational therapy in all levels of outcomes research and management (Ellenberg, 1996). Consequently, many occupational therapists strongly advocate for the use of QOL in practice and research (Laliberte-Rudman et al., 2000; Liddle & McKenna, 2000; McKenna, 1993; Radomski, 1995; Robnett & Gliner, 1995). Occupational therapists need to further understand and investigate how occupational performance significantly influences a person’s perceptions of one’s life satisfaction, health, and well-being. To enrich occupational therapy literature on QOL, this line of research focused upon the QOL of people with chronic physical disabilities, specifically SCI.

Quality of Life and Spinal Cord Injury

Spinal Cord Injury is considered a chronic condition. The estimated incidence rate of SCI is approximately 11,000 new cases per year in the USA (National Spinal Cord Injury Statistical Center, 2005). Spinal Cord Injury can affect people of all ages, but statistically, primarily affects young adult males. Since 2000, the average age at injury is 37.6 years and 79.6% of spinal cord injuries reported to the national database have occurred among males (National Spinal Cord Injury Statistical Center, 2005). Impairment severity of SCI is classified based on the American Spinal Injury Association (ASIA) classification system (ASIA, 2002), that combines level and completeness of injury. An ASIA A (Complete) is defined as a person with no motor or sensory function preserved in the sacral segments S4-S5. An ASIA B (Incomplete) is defined as a person with sensory but no motor function is preserved below the neurological level and includes the sacral segments S4-S5. An ASIA C (Incomplete) is defined as a person with preserved motor function below the neurological level, and more than half of key muscles below the neurological level have a muscle grade of 3 or more. An ASIA D (Incomplete) is defined as a person with preserved motor function below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more (ASIA, 2002). SCI is associated with considerable changes in medical health, physical ability, functional status, psychological well being, and social role functioning.

The consequences of a SCI are enormous upon the individual (DeVivo, 1997; Krause & Crewe, 1991). A SCI is associated with considerable changes in medical health, physical ability, functional status, psychological well being, and social role functioning.

Current and existing knowledge shows that the QOL of persons with chronic disabilities (such as SCI) is as essential to understanding their condition as health care outcomes. There is a growing awareness that improvement in long-term QOL should be a primary goal of rehabilitation (DeLateur, 1997; Parmenter, 1994; Rogers & Holm, 1994). The research on SCI shows that QOL has multiple factors. Five broad domains of QOL have been identified:

1. Medical health domain (Fuhrer et al., 1993, a; Johnson et al., 1998; Menter et al., 1997; Turner et al., 2001)
2. Physical health domain (Dahlberg et al., 2005; Tooth et al., 2003; Saikkonen et al., 2004)
3. Psychological domain (Dahlberg et al., 2005; Fuhrer et al., 1993, a; Saikkonen et al., 2004; Tate et al., 1994)
4. Employment domain (Athanasou et al., 1996; Krause & Anson, 1996; Krause & Broderick, 2005; Jang et al., 2005; Saikkonen et al., 2004)
5. Social well being (Dijkers, 1997; Dijkers, 1998; Dijkers et al., 2002; Fuhrer et al., 1993, b)

Few SCI studies have shown that QOL is considered to be an outcome measure at the participation level. Literature has shown that there is very little relationship between the severity of SCI (i.e., level or completeness of injury) and life satisfaction or between the degree of disability (such as a measure of Activities of Daily Livings [ADLs]) and life satisfaction (Dijkers, 1997; Fuhrer, 1996; and Sjosten, et al., 1990). In Dijker's meta-analysis (1997) of the effect of SCI on QOL, no significant correlation between

impairment measures (level of spinal cord) and feelings of well-being and life satisfaction were found. In this same review, the average correlation between impairment level and life satisfaction was .00. Correspondingly, the level or severity of SCI is not a moderating variable between SCI and life satisfaction as one ages, meaning that further studies should be conducted to find out perceptions of QOL among SCI survivors as they age. Similarly, in Fuhrer's meta-analysis (Fuhrer, 1996), the average correlation between disability and QOL across all studies was low (.20). In Dijker's review, it was .17. This means that only 4% of the variation in QOL among people with SCI is due to their degree of disability. At the same time, in a study by Pain et al., (1998), clients undergoing physical rehabilitation and their family members were interviewed to identify their perceptions of QOL. Participants clearly identified their QOL to be associated with their level of perceived societal participation.

Other researchers have reported that psychological and social variables may help explain why levels of impairment or disability do not correlate with measures of QOL (Kemp & Ettelson, 2001). Researchers have proposed that coping strategies and social activities may explain the possible relationship between perceptions of QOL and levels of participation and engagement in life roles among people with SCI. They have found that variables that are most highly correlated with QOL in samples of persons with disability fall into two categories: those that are related to adequate coping with SCI and those that are related to social and community involvement (Kemp & Ettelson, 2001). Examples of coping well with SCI include using social support, perceived self-control, and possessing

a positive personality. Examples of community involvement include: participation in social activities, work, family life, and enjoyable activities (Kemp & Ettelson, 2001). Since satisfaction is considered an important health outcome (Ware, Davis-Avery, and Stewart, 1978) and the goal of most health care systems worldwide is to allow all persons to have a better QOL (Haddad, Fournier, and Potvin, 1998), more research is needed to compare the adaptation and QOL of persons with SCI across a variety of cultures.

Human Adaptation

Adaptation is an essential part of occupational therapy. According to Schultz & Schkade (1997), "Adaptation is a change a person makes in his or her response approach when that person encounters an occupational challenge" (p. 474). In everyday life, it is an ongoing and developmental process involving multiple dimensions (King, 1978; Montgomery, 1984; Schkade and Shultz, 1992; Schultz & Schkade, 1992). In considering its internal and external demands, adaptation is also a lifelong, holistic, and universal concept (Schkade and Schultz, 1992). Adaptation relates to the individual, the environment, and his/her interaction through participation in occupation. Moreover, adaptation can play an essential role in facilitating a person's engagement in functional activities, thereby influencing a person's health, life satisfaction, and QOL (Schultz & Schkade, 1992). To better evaluate the significant relationship between QOL and adaptation, it is necessary to know more about how human beings adapt to a changing environment and how internal changes affect their capacity to act in the environment. Occupational therapy researchers need to consider the significant impact of environment on adaptation and in turn, the person's QOL.

Cultural Differences

Other scholars interested in QOL have conducted international studies to compare life satisfaction among people with chronic conditions across different cultures (Dijkers et al., 2002; Ide & Fugl-Meyer, 2001; Kreuter et al., 2005; McColl et al., 2002). In a cross-sectional study, Kreuter et al. (2005) did a comparative survey study between two groups of persons with SCI, an Australian group consisting of 89 individuals and a Swedish group consisting of 71 individuals. The two groups were matched for sex, age, time since injury and level of injury. The 36-item short-form health survey (SF-36) and the SCI QOL-23-item questionnaire were used to cover essential generic and specific domains of health and QOL. Results revealed that Australian and Swedish groups did not differ concerning pain, general health and mental health. However, the Australian group reported significantly more limitations in physical function and in role performance due to physical problems. The Australian group also had significantly more limitations in social functioning and interaction with others due to emotional problems compared to the Swedish group.

Ide and Fugl-Meyer (2001) investigated cultural differences in life satisfaction between East Asians and Northern European with long-term SCI. These researchers conducted a cross-sectional study in Sweden and Japan using a unified questionnaire. Results showed that Swedish individuals with SCI appeared to be more satisfied than Japanese individuals with SCI in general health, economy, social activity, social service, family life, and sexual life. Several life domains indicated significant differences in life satisfaction between persons with and without a partner in the Japanese sample (i.e.,

general health, leisure, family life, and sexual life). The Japanese respondents who had a partner had higher satisfaction than those who did not have a partner with regard to their general health, leisure, family life, and sexual life. However, no life domains indicated significant differences between those with and without a partner in the Swedish group.

Other international researchers, Lau, Chi, and McKenna (1998), studied self-perceived QOL of Chinese elderly in Hong Kong and found that participants' culturally related philosophical beliefs influenced their QOL. These researchers identified the following domains and components as being important to QOL: physical and functional well-being (good health, leisure), psychological well-being (life satisfaction, happiness), and social well-being (social interaction, social network/support), and economic well-being (money, housing).

Research shows that the domains of occupational therapy such as adaptation, occupation, and environment are central constructs in the QOL knowledge base (Dijkers, 1998; Dooley and Hinojosa, 2004; Duncan-Myers & Huebner, 2000; Fuhrer, 1996; Hammell, 2007; Huebner et al., 2003; Laliberte-Rudman et al., 2000). Although occupational therapists have shown they can significantly contribute to QOL research when working with people with chronic conditions, a need to justify or expand their role still exists. One way to do that is by comparing the living experiences of persons with SCI cross-culturally.

Occupational Adaptation (OA) Model

Occupational Adaptation (OA) is a frame of reference that discusses functional performance in terms of three elements: the person, the environment, and the interaction between them. According to OA, the person is viewed as possessing a combination of physical, psychosocial, and cognitive capacities. The environment is comprised of physical, social, and cultural factors. The interaction between the environment and the person occurs through occupation. The individual's performance of an occupation in response to personal and environmental demands represents the interaction (Schkade & Schultz, 1992; Schultz & Schkade, 1992).

The critical goal of occupational therapy, using the OA frame work, is to facilitate adaptation. According to OA, adaptation is defined as an internal process that requires the individual to generate, evaluate, and integrate responses to occupational challenges presented by the environment (Schkade & Schultz, 1992). The generation, evaluation, and integration of responses are referred to as sub-processes of the adaptation process. The adaptive response generation sub-process requires the individual to assess the type of energy needed, the strategy to use, and the method of employing the plan. Adaptive energy in OA is either primary or secondary. Primary energy is highly structured and focused attention. On the other hand, secondary energy is less structured and more creative. Adaptive responses are termed modes within OA. In essence the individual chooses between the whole groups of existing strategies, combinations of parts from multiple strategies, or totally new approaches to an environmental challenge. The methods for employing the responses are said to be primitive, transitional, or mature.

Primitive behaviors are those with no variation from previous plans. Transitional behaviors are random plans that denote more a trial and error approach. Mature behaviors mix the primitive and transitional approaches. According to Schkade & Schultz (1992), mature behaviors can produce an adaptive response to a challenge. Following the execution of the adaptive response the individual evaluates the result by examining the efficiency, effectiveness, and satisfaction with their actions. Finally, the person incorporates the adaptive response in the integration sub-process. During integration, the person adds the experience to their adaptive repertoire for future occupational challenges. While the individual is evaluating and interpreting the results, the environment is also examining the implication on a broader scale. According to Schkade & Schultz (1992), during the adaptation process the environment represents an occupational challenge, which is couched with a role expectation. Consideration of the environment as an interactive process is taking prominence in occupational therapy (Dunn, Brown, & McGuigan, 1994).

Consequently, the OA framework was chosen as the theoretical support for my line of research for two main reasons. First, the framework combines two important concepts: occupation and adaptation. When one's occupational performance suffers due to a major life crisis such as a SCI, a person's adaptational process can better be understood by applying the OA framework (Schkade & Schultz, 1992; Schultz & Schkade, 1997). Second, the OA framework is concerned with the interaction between the person and environment in which the research has shown that the environment influences an individual's occupational performance following SCI (Sjosten et al., 1990).

Finally, by understanding the occupational adaptation process, the occupational therapist can provide his/her client the desired therapeutic intervention to meet the person's occupational challenge due to an injury, facilitate an adaptive response, and promote functioning.

CHAPTER III

CROSS CULTURAL PERSPECTIVES OF QUALITY OF LIFE BETWEEN KUWAITIS AND AMERICANS WITH SPINAL CORD INJURIES

Introduction

A spinal cord injury (SCI) is an unexpected injury that can happen to almost anyone regardless of social class, gender, or race. The annual incidence of SCI worldwide has been reported to be between 11.5 and 57.8 cases per million population (Ackery et al., 2004). In the United States, it was estimated that the incidence rate of SCI is approximately 11,000 new cases per year (National Spinal Cord Injury Statistical Center -NSCISC, 2006). Some SCI survivors have been fortunate enough to receive rehabilitation services in order to adapt to their injury (Ditunno, et al. 2005). Spinal cord dysfunction can occur due to trauma or disease to the vertebral column or the spinal cord itself (Trombly, 1995). In 2000, the most common cause of SCI was motor vehicle crashes, accounting for 44 % of reported cases (NSCISC, 2006). The second most commonly reported cause of SCI are acts of violence (24%) followed by falls (22%). Although SCI can affect persons of all ages, it statistically affects young adult males the most. In 2006, 79.6% of SCI cases reported to the national database of NSCISC occurred among males with the average age at injury being 37.6 years of age (NSCISC).

After SCI, there are numerous secondary complications that can disrupt a person's life and a great deal of responsibility lies with them to prevent these complications.

Secondary complications may include pressure ulcers, shoulder pain, and bowel dysfunction (Ballinger, Rintala, & Hart, 2000; Garber et al., 1996; Garber & Rintala, 2003; Kannisto & Rintala, 1995). Other complications include respiratory distress or arrest, urinary tract infections, and problems with blood pressure (Zejdlik, 1992). In addition, pain, spasticity, and overuse syndrome are also common among persons with SCI (Rintala, Hart, & Priebe, 2004; Rintala et al., 2005; Paker et al., 2006; Young et al., 1995). The consequences of SCI are complex due to the incidence or development of secondary conditions. Thus, long-term, treatment and rehabilitation of persons with a SCI must be adequate and satisfactory to the individual. It is important to understand that these factors not only affect the physical aspect but also contribute to the individual's Quality of life (QOL). QOL is perhaps the outcome of greatest concern among health care professionals.

Statement of the Problem

The overall goals of many SCI care centers and rehabilitation settings include not only the prevention of death and disability, but also the facilitation of functional recovery and personal independence, the promotion of community reintegration, and good QOL over time (Clayton & Chubon, 1994). Interest in QOL as an outcome following SCI has increased in recent years among the rehabilitation fields. Clinicians, researchers, and policy makers have attempted to identify and understand the source factors determining a person's QOL. This can be very complex. Quality of life for SCI survivors cannot be determined unless health care professionals and researchers understand the complex interaction between inter- and intra-personal factors as well as environmental variables.

Research on SCI has demonstrated that a number of factors cause significant changes in the health experience of persons with SCI. Environmental factors, such as societal, community and cultural issues, have the potential to ease or to complicate the experiences for persons with SCI. Specifically, many researchers have been interested in studying and assessing health-related quality of life (HRQOL) in terms of the differences and disparities among persons from different ethnic, racial, and cultural backgrounds (Fabian, 1990; Fuhrer, Rintala, and Hart, 1993; Fuhrer, et al., 1993; Whiteneck, 1994)

Purpose of the Study

The purpose of this study was to compare the HRQOL of adult Kuwaitis with HRQOL normative data for the American general population and with the HRQOL of Americans with SCI. This study explores the following research questions:

1. How do Kuwaitis with SCI perceive their HRQOL compared with American general population norms?
2. What are the similarities and differences of perceived HRQOL between adult Kuwaitis and Americans with SCI?
3. What are the implications of the findings for occupational therapy practice?

Literature Review

Quality of Life

In the last decade, interest in QOL has increased in importance within the rehabilitation field and has been studied by researchers from various scientific disciplines (Fabian, 1990; Fuhrer, Rintala, and Hart, 1993, a; Fuhrer et al., 1993, b; Whiteneck, 1994). A growing awareness exists that improvement in long-term QOL is a primary goal

of rehabilitation. In addition, there is a need to identify those QOL factors that can impact rehabilitation interventions in order for improvement in recovery to occur (Boswell et al., 1998).

In the SCI research literature, the terms HRQOL and QOL are often used interchangeably. Quality of life represents the widest range of human experience, composed of all the things individuals value (Patrick & Erickson, 1998). The World Health Organization (WHO; Szabo, 1996) defines QOL as “Individuals’ perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (p.355). In short, QOL not only reflects an individual’s overall perception of and satisfaction with how things are in his/her life, but also permits him/her to select those areas of greatest importance (Hornquist, 1982; Sjosteen et al., 1990).

To date, experts still cannot agree on a single definition for QOL, but there seems to be an emerging agreement that HRQOL takes into account an individual’s perception of his/her physical, mental (emotional and cognitive), social and role functioning as well as his/her perception of health and well being (Berzon, Hays, and Shumaker, 1993; Fitzpatrick et al., 1992). Kannisto et al. (1998) defined HRQOL as “The level of well-being and satisfaction associated with an individual’s life and how this is affected by disease, accidents and treatments” (p.193). Patrick and Erickson (1998) defined HRQOL as “the value assigned to the duration of life as modified by impairment, functional status, perception and opportunity influenced by disease, injury, treatment and policy” (p.6). In addition, disease specific HRQOL measures incorporate specific symptoms and

dysfunctions relevant to the disorder. For example, pain and sexual function might be included in measures for use with persons who have SCI (Dahlberg, Alaranta, and Sintonen, 2005). There is emerging research that indicates that QOL for persons with SCI is significantly lower than that of both non-disabled controls and the overall population (Bach & Tilton, 1994; Clayton & Chubon, 1994, Decker & Schulz, 1985; Krause & Crewe, 1991, Rintala et al., 1992; Sjosteen et al., 1990). Current knowledge shows that the QOL of persons with chronic disabilities can affect the progress of the condition as well as health care outcomes. Health care professionals such as occupational therapists can play a major role in improving the QOL of persons with SCI.

Occupational Therapy, SCI, and QOL

QOL is an outcome that has long been a concern to occupational therapists. The link between occupation and QOL is one of the basic beliefs guiding the practice of occupational therapy (Wilcock, 1993; Yerxa, 1994). Many scholars describe the central objective of occupational therapy as promoting health and QOL through enabling occupation (Polatajko, 1994; Yerxa, 1994). Its importance was emphasized by Yerxa et al. (1990), who stated that “medicine is concerned with preserving life; occupational therapy is concerned with the QOL preserved” (p. 8). The role of occupational therapy is to necessitate conditions for improved QOL. Appropriate occupational therapy intervention can help persons with SCI to have happy and productive lives (American Occupational Therapy Association [AOTA], 2001). The philosophy guiding occupational therapy, as characterized by Rogers (1982), is one of independence, that is, to promote

skills and habits that reduce the experience of incapacity, enhance the ability to meet increasing challenges in function, and thus increase the chances for autonomy.

The occupational therapist acts as a resource for his/her clients, educating and encouraging them to be as adaptive and as functionally independent as possible given the constraints of existing environmental factors. Through the utilization of purposeful and meaningful occupational roles, occupational therapy can prevent dysfunction and elicit maximum independence for a person with a SCI. “The unique contribution of occupational therapy is that the practitioner creates the opportunity for individuals to gain the skills and confidence to accomplish activities and tasks that are meaningful and productive, and in doing so, increases their occupational performance, thus their function” (AOTA, 1995, pp. 1019-1020). Hence, occupational therapy intervention for a person with SCI must be purposeful and meaningful to the individual. Again, this is based on the belief that “purposeful activity (occupation), including its personal and environmental components, may be used to prevent and mediate dysfunction and to elicit maximum adaptation” (AOTA, 1979, p. 785).

The role of occupational therapy is to offer people with SCI the necessary means for long-term QOL. Our profession can play a huge role in the life of SCI survivors. Researchers have shown that factors such as age, gender, ethnicity, culture, and religion can significantly influence the QOL of survivors with SCI (Hjelm et al., 2005). Thus, occupational therapists who work with SCI survivors must recognize the influence of various ethnicities, backgrounds and cultures on the individual’s QOL in facilitating their adaptation.

Ethnicity and Cultural Health Differences

Further investigation of QOL cross culturally seems needed. Life domains that may influence QOL include general health, economy, social activity, social service, family life, sexual life, and culture/spiritual life (Hjelm et al., 2005). These domains may differ substantially across different national groups. Consequently, it is necessary to consider and explore the cultural and ethnic differences that tend to play a major role in determining the QOL among SCI survivors.

McColl et al. (2002) identified international differences in outcomes for persons with SCI involving three populations - American, British and Canadian. Results revealed that there are clear international differences among the three samples. American participants had a better psychological profile and fewer health and disability-related problems. British participants reported less joint pain and were less likely to perceive that they were aging more quickly than those without SCI. Canadians had more health and disability complications.

To assess the degree to which environmental barriers impact social participation in two countries, Dijkers et al. (2002) did a comparative analysis between individuals with SCI living in the USA and Turkey. They found significant differences in terms of barriers that interfere with day-to-day life activities. The U.S. subjects described more active lives and reported fewer environmental barriers than the Turkish subjects. In Turkey, individuals with SCI experienced more environmental barriers regarding government and business policies, work and school, and services and assistance outside the home.

Quality of life varies among groups and among nations. It depends on various factors (e.g., technology, culture, environment, and health care system). Since client satisfaction is considered an important health outcome (Ware, Davis-Avery, & Stewart, 1978), more research is necessary to compare the QOL of persons with SCI across a variety of cultures. Currently, there is no study that assesses and compares QOL between an Arabic country and that of a more developed country. Due to growing numbers of SCI survivors in Arabic countries and the need to preserve their long-term QOL, it seems necessary to study and compare the QOL between survivors of SCI in the USA and Kuwait. Such a study could provide useful information specifically for the Kuwaiti population as well as increase our understanding of the role that different physical, cultural, and social environments play in the lifestyle of SCI survivors.

Comparison Between Kuwait and USA

It's important to look at the background and history of Kuwait when determining what factors to use for comparison. Although Kuwait is quickly becoming a westernized country, it is still traditional in many ways by retaining old values and practicing old customs. The Kuwait constitution states that health care is the right of every individual and that the government is responsible for providing health care facilities for prevention and treatment, health promotion, and rehabilitation (Aywaa Group Corporation Kuwait, 2008). Table 1 provides a comparison between Kuwait and USA in term of health care systems, governmental, cultural, and environmental supports and barriers for persons with disabilities. Comparison was adapted from Dijkers et al. (2002).

Kuwait has a total population of approximately three million persons which includes approximately two million non-nationals (Ministry of Information, Kuwait, 2008). Kuwait is a small but rich country. It has a relatively open economy with 10% of the world's proven crude oil reserves. The official language of Kuwait is Arabic, although English is generally understood throughout the country. About 85% of Kuwait's population is Muslim; however, there are much smaller Christian and Hindu populations as well.

Methods

Study Design

This study was quantitative in design. The HRQOL of adult Kuwaitis with SCI living in the community as measured by the SF-36 were compared to American general population norms and the results from American survivors with SCI reported in the Forchheimer et al. study (2004) using the means and standard deviation scores.

Participants

Study participants included 30 Kuwaiti SCI survivors. The participants were recruited from the *Kuwaiti Disabled Club* in Kuwait. In order to allow for comparison with the study by Forchheimer et al. (2004), the researcher recruited only participants living in the community. The sample of participants was intended to be as heterogeneous as possible (i.e., various SCI levels of severity, various ages, both genders, and various lengths of time since injury). Since the study by Forchheimer et al. (2004) included 80% male participants and 20% female, this study attempted to use similar ratios of 80% male participants (n=24) and 20% female (n=6).

The inclusion criteria consisted of (a) participants have had a SCI; (b) participants who are at least 18 years of age; (c) Participants who are 1-20 years post injury; (d) participants with impairment level of grades A, B, or C on the ASIA scale; (e) participants who reside in the community; and (f) participants who have not been hospitalized within the last 4 weeks. The exclusion criteria consisted of (a) clients on ventilators, (b) clients with an impairment level of Grade D on the ASIA scale, (c) clients living in a nursing home, and (e) any significant neurological disorder other than SCI.

Data Collection Procedures

After obtaining approval from both the Texas Woman's University Institutional Review Board (IRB) and the Kuwaiti Disabled Sports Club in Kuwait to interview Kuwaiti individuals with SCI, 30 community living Kuwaiti adult participants with SCI were recruited. The participants signed a consent form indicating their willingness to participate in the study.

The primary researcher received permission to interview community living individuals from this club. A gatekeeper at the Club (a physician) assisted with the recruitment process. He identified Kuwaiti community living participants with SCI who met the inclusion and exclusion criteria. The primary researcher then informed these identified Kuwaiti participants of the study (about 35 individuals) by giving them a brief presentation at the club. Persons interested in participating in this study provided his/her name and phone number to the primary researcher. Then, the potential participant was contacted by the primary researcher to set a date and time to conduct the interview at a location selected by the participant.

Research Instrument

To measure HRQOL, the standardized generic Arabic version of the Short-Form 36-item health status questionnaire was used (SF-36) (Hays, Sherbourne, and Mazel, 1993). The SF-36 has been shown to have good psychometric properties (Freeman et al., 2000; Jacoby, Baker, & Steen, 1999) and has been translated into many languages including Arabic. It has been validated in Saudi Arabia and has been available for research in the Arab language since 1997 (Coons et al., 1998; Mrabet et al., 2004).

The SF-36 includes eight health domains representing multiple operational definitions of health, including function and dysfunction, distress and well being, and favorable and unfavorable self-ratings of one's general health status (Ware & Sherbourne, 1992). The physical functioning scale (PF; 10 items) measures the ability to perform basic activities of daily living and also more demanding activities such as pushing a vacuum cleaner and participating in sports. Role physical (RP; four items) reflects the extent that physical health has a limiting effect on work or other activities. Bodily pain (BP; two items) concerns the amount of pain felt and whether it interferes with normal activities. General health (GH; five items) measures perceived general health status. Vitality (VT; four items) includes items on energy, tiredness, etc. Social functioning (SF; two items) concerns how social activities are affected by physical health or emotional problems. Role emotional (RE; three items) reflects the extent that work or other activities are limited by emotional problems. Mental health (MH; five items) measures emotional well being. All scale scores range from 0 to 100 after weighting and linear transformation according to an algorithm, where high scores represent optimal

physical functioning and psychological well being. The eight domains are collapsed to create two global components, a physical component (PCS) and a mental component score (MCS). Four of the subscales (PF, RP, BP, and GH) combine to yield a physical component summary (PCS) and the other four subscales (MH, RE, SF, and VT) combine to yield a mental component summary (MCS). The eight subscales and the two component scales are standardized to a mean score of 50 and standard deviation (SD) of 10 (Ware & Sherbourne, 1992).

Normative data of the general U.S. population was taken from Ware et al. (2000). The total sample size was 2,474 (males - 1,052, females - 1,422). The U.S. general population sample included adult individuals from various age groups (18-75 and over). Linear transformations were performed to transform scores to a mean of 50 and standard deviations of 10, in the general U.S. population. It makes it possible to meaningfully compare scores for the eight-scale profile and the physical and mental summary measures (Kosinski et al., 2000).

Forchheimer et al. (2004) conducted a study to explore the applicability of the SF-36 for assessing HRQOL among persons with SCI. A sample of community living individuals (n = 215) who had experienced new traumatic SCI were included in the study. Correlations between the SF-36's physical and mental component scores were appraised. Their results revealed that the two components measured separate and distinct constructs.

Data Analysis

The descriptive statistics including means and SDs of the demographic data as well as the SF-36's eight subscales and two component summaries (PCS & MCS) were

calculated using SPSS 15.0. In order to allow for ready comparisons across scales, data were transformed such that means equal 50 and standard deviations equal 10. Statistical significance was based on an alpha level of 0.005 (0.05/10) due to the analysis of 10 dependent variables. Using t-tests, the Kuwaiti participants' scores on the eight subscales and the two summary scores of the SF-36 were compared to the data reported by Ware et al. (1992) for the American normative sample and to the data for Americans with SCI as reported by Forchheimer et al. (2004). Additionally, the demographic data of the Kuwaiti participants with SCI were compared to those of the American sample with SCI.

Results

Characteristics of the Sample

The demographic variables for the 30 Kuwaiti participants with SCI consisted of gender, age at injury, age at interview, ASIA scale, marital status, educational level, employment status at the time of the injury, employment status at the time of the interview, and living situation. The age of the Kuwaiti subjects at the time of the interview ranged from 21 to 52 years. Their ages at the time of the injury ranged from 18 to 50 years. As planned, there were more male subjects ($n = 24$, 80%) than female subjects ($n = 6$, 20%). A comparison was done between the demographics of the American and Kuwaiti samples. Results revealed that there were significant differences between the two SCI samples in term of age at interview, age at injury, ASIA neurological classification, and pre-injury employment (See Table 2)

Comparison with the American Normative Data

The Kuwaitis with SCI scored significantly lower than the American normative group on all subscales. The scores of the eight SF-36 scales and the PCS and the MCS measures were significantly lower ($p < 0.001$) with regard to the normative value of a mean of 50 and a standard deviation of 10 (See Table 3)

Comparison with the Adult Americans with SCI

When comparing the scores of the Kuwaiti participants with the adult Americans with SCI as cited in Forchheimer et al. study (2004), the scores of the Kuwaitis were significantly lower on three of the subscales (i.e., social functioning, role emotional, and mental health) and the MCS of the SF-36 (See Table 4)

Discussion

This study shows that adult Kuwaitis with SCI had a significantly lower HRQOL compared with that of American general population norms on all eight subscales and the two composite summaries of the SF-36. Furthermore, the Kuwaiti sample had lower HRQOL than a sample of American's with SCI on three mental and emotional subscales and the MCS.

The first research question in this study addressed how Kuwaitis with SCI perceived their HRQOL. This study showed that the Kuwaiti participants with SCI had poor QOL in their functional activities as well as in their psychological well-being compared with the American normative sample.

The second research question investigated the similarities and differences of perceived HRQOL between adult Kuwaitis with SCI and Americans with SCI. This study

showed that the Kuwaiti participants scored significantly lower than the American participants in regard to mental health and psychological well-being.

A demographic comparison showed significant differences between the two SCI samples in term of age at interview, age at injury, and ASIA neurological classification. Kuwaiti participants were younger at injury as well as time of interview. The mean age of the Kuwaitis at injury was 24 years and the mean of their ages at time of the interview was 33 years. In contrast, the mean age of the Americans at injury was 34 years and the mean of their ages at time of interview was 38 years.

According to the ASIA scale, comparison analysis showed that Kuwaitis were less impaired. The Kuwaiti sample had more participants with paraplegia (63.3%). Kuwaiti participants with low tetraplegia were 23.3% and participants with high tetraplegia were 13.3%. On the other hand, the American sample had equal distribution of ASIA scales. For instance, participants with ASIA D were 24.8%, with paraplegia were 35.9%, with low tetraplegia were 26.7%, and with high tetra were 12.6%. Yet, the Kuwaiti sample as well as the American sample with SCI had a low mean subscale score in physical functioning (PF). Most of the 10 items found in the PF scale of the SF-36 essentially dealt with the capacity for walking and climbing stairs. Even though the majority of the SCI survivors compensate adequately for this “physical functioning” by the use of an adapted wheelchair, both groups scored the lowest on the PF scale. Although there was no significant difference between the two samples on the PF scale, the direction of the differences between the two groups was always the same such that that Kuwaitis with SCI had lower scores than Americans with SCI.

In addition, both Kuwaiti and American individuals with SCI reported low QOL in the bodily pain (BP) and general health (GH) subscales of the SF-36. Medical complications such as pain and other physical symptoms following SCI may account for poor QOL scores in these subscales. Research shows that individuals with SCI experience various medical complications post- injury such as urinary tract infections, decubitus ulcers and pain (Johnson et al., 1998; Menter et al., 1997; Saikkonen et al., 2004; Turner et al., 2001). Possibly due to these neurological issues, medical complications, and limited functional activities in their everyday lives, Kuwaiti participants rated the QOL of their general health (GH) as only fair.

With regard to mental health, scores of the Kuwaiti sample on the four scales that mainly contribute to the mental health summary measure (VT, SF, RE, MH) were significantly lower than that of the normative data. Additionally, three of those subscales (MH, SF, and RE) were significantly lower than Americans with SCI as cited in Forchheimer et al. study (2004). Studies have shown that fatigue is common among people with SCI (Dahlberg et al., 2005; Saikkonen et al., 2004). Therefore, it is not surprising that both Americans and Kuwaitis with SCI rated their QOL in the vitality scale (VT) as poorer than the American normative sample. Kuwaitis also rated their QOL in social functioning (SF) as poorer than those of both the normative sample and the Americans with SCI.

There are many possible reasons for the poor rating scores but given the scope of this study, we can only speculate on the causative factors. Foremost, the American sample was older than the Kuwaiti sample at the time of injury. Perhaps, as a result, the

Americans had more maturity which helped them to adapt to their SCI; in turn, the Kuwaitis were did not possess sufficient maturity to deal with their injuries and adapt to their SCI. Environmental accessibility could also be another factor for low scores. Restricted physical environments in Kuwait might lead participants to be isolated and unable to participate in activities outside the home. Diverse environments can either facilitate or hinder opportunities toward a successful and productive life (Dunn et al., 1994; McCuaig & Frank, 1991). The World Health Organization (WHO; 2001) emphasizes the impact of the external environment on the individual. Another causative factor could be the stigma from the Kuwaiti society toward people with disabilities. This could lead to a lack of community integration and cause frequent interference with the participants' social activities.

This study also showed that Kuwaitis with SCI had greater emotional and psychological problems (MH) than both the American normative and SCI samples. SCI studies have shown that depression following SCI is common (Dahlberg et al., 2005; Fuhrer et al., 1993; Saikkonen et al., 2004). Distress and anxiety are also common among people following SCI (Hancock et al., 1993; Tate, Forchheimer, Maynard, & Dijkers, 1994). There are various possible reasons for Kuwaitis to have poorer mental health than Americans with SCI. Again, social stigma from society can lead to isolation. SCI survivors are more likely to lose their previous roles both at the personal and social level. In terms of their role emotional (RE) state, the Kuwaitis also had a lower QOL score. One possible reason for Kuwaitis with SCI to score lower on the role emotional scale than Americans with SCI might be that they are not as active as they used to be before their

injuries. They might feel that they are not being productive in regards to personal activities, school, and/or work and have lost many of their social activities and contacts with friends. These changes can have a huge effect upon the emotional state of the individual.

The functional and emotional state of a person with a SCI depends on many factors such as the quality of rehabilitation services and health care management, environmental accessibility, social support, and options available in the environment in which the individual functions. It is no surprise that the Kuwaiti individuals with SCI were found to have relatively poor QOL in terms of their physical and emotional states.

Implications for Occupational Therapy Practice and Research

Quality Of Life is considered one of the main outcomes of occupational therapy (AOTA, 2002, p. 628). Results of this study have implications for both occupational therapy practitioners and researchers. Findings indicate that occupational therapy practitioners in undeveloped countries like Kuwait need to broaden their views when working with people with chronic disabilities. They must begin to recognize that every human being has the potential for a high QOL, regardless of disability. Practitioners should consider the complexity and multifaceted factors determining QOL. Instead of focusing only at the impairment level, they need to take a more holistic approach with their clients. Occupational therapy assessments and therapeutic interventions should clearly emphasize the person's well-being, life satisfaction, and QOL. Lastly, occupational therapists working in undeveloped countries must further recognize the essence of comprehensive occupational therapy services that impact the lives of people

with SCI. Using a client-centered approach, occupational therapy practitioners can closely work with their clients to attend to multidimensional domains of QOL such as emotional health, social functioning, community integration, and psychological well-being in addition to general health, physical ability, functional status.

Studies in SCI show that the element of participation correlates significantly with an individual's QOL (Dijkers, 1997; Fuhrer, 1996). This study also showed that adult Kuwaiti participants with SCI were less functionally active than the American general population and less socially engaged than both the normative sample and Americans with SCI. These results imply that the Kuwaitis with SCI have relatively poor QOL. This means that participation of an individual in an occupation may have a major effect on a person's overall satisfaction and well-being in life. This evidence is also in accordance with the belief of occupational therapy that health and well-being are maintained through active engagement in meaningful occupation (AOTA, 2002). This evidence should also encourage occupational therapy researchers to continue to investigate and understand the value of occupational performance and occupational roles on a person's QOL in both developed and undeveloped countries. Such research can demonstrate the importance of occupational roles and active occupational engagement for a successful and productive life.

This reinforces the vital role that occupational therapy holds as a profession that enables clients with disabilities to stay healthy, accomplish life necessities, and gain life satisfaction.

Limitations of the Study

Despite the obvious usefulness of the SF-36 as a self-report questionnaire addressing HRQOL, it cannot provide a complete global understanding of an individual's QOL and the factors that influence it. Hence, it is likely to be helpful to expand our understanding of QOL using qualitative methodology. Second, the sample of this study was not randomly selected. A selection bias could be argued since all participants belonged to the Kuwaiti Disabled Sports Club and may not be representative of all adult Kuwaitis with SCI. Third, since the SF-36 normative values for the Kuwaiti general population were not available, the normative values for the general American population were used. There might be some differences in the QOL between the normative general populations of Kuwait and America. Fourth, the results of this study were compared to the results of a study that was 4 years old. Due to the advancement of SCI management in the U.S., Americans with SCI could have different views and better scores in their QOL when administering the SF-36 compared to that of four years ago. Fifth, exclusion criteria in this study did not match exclusion criteria in Forchheimer et al. study (2004). Forchheimer et al. included persons with ASIA D, which would raise their scores at least on the physical scales compared to current study in which persons with ASIA D were excluded.

Conclusion

Quality of life is an important outcome and improving it is often stated as the major goal of therapy. Cross cultural QOL studies can help our understanding of QOL for persons with chronic disabilities. To the author's knowledge, this study was the first of its

kind to compare the QOL between survivors of SCI in the USA and Kuwait. This present study may encourage policy makers in Kuwait to develop new health policies to improve services and rehabilitation outcomes in Kuwait. Also this methodology introduces a new area of research for occupational therapists cross-culturally. Such cross-cultural studies can help in generating many new hypotheses regarding occupational therapy health care issues.

This area of research also contributes to the body of knowledge on occupational adaptation by expanding greater opportunities for its inclusion in international research. In dealing with people of chronic conditions (such as SCI), occupational therapy researchers and practitioners must take into consideration the complexity of QOL. When working with people with chronic conditions, occupational therapy practitioners and researchers must analyze and understand the complex interaction between areas of occupation, environment, and adaptation. Further investigation on the impact of those constructs on the QOL of persons with SCI both nationally and internationally could lead to better, healthier and more productive lives.

Table 1

*Summary of Barriers and Supports for Persons with a Disability Between Kuwait and the USA**

Domain	USA	Kuwait
Health System	Health care system is well-planned and developed (emergency, medical care services, rehabilitation, and social services).	Health care system is not well-planned and developed. Limited emergency and health care services. Limited specialized orthopedic and rehabilitation hospitals
Health care coverage	Low income individuals receive Medicaid and Medicare health care coverage. It covers limited health and rehabilitative services.	Government provides universal health-care coverage to all its citizens including rehabilitative services.
Provision of lifelong pension/support	People with disabilities are entitled to lifelong pensions from Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) programs.	A Kuwaiti person with a disability is entitled to a governmental life long pension.
Cultural view of disability	Movement toward independence. Movement toward accepting disability (cognitive/physical) as just another human characteristic.	Emphasis is on interdependence. More family/care giver involvement with the person with a disability. Disability is considered to be sent by God and is commonly accepted and respected.

Table 1 (Continued)

*Summary of Barriers and Supports for Persons with a Disability Between Kuwait and the USA**

Domain	USA	Kuwait
Accessibility	Americans with Disabilities Act (ADA) allows laws and civil rights guarantees (accessibility, schooling, employment, and health care)	Laws are written down, but civil organizations lack the power to impose enforcement. Majority of public and governmental buildings are not accessible. Schooling and employment options are very limited.
Coverage of medical supplies	Depends on health care coverage. Basic medical supplies are covered.	Government provides all basic medical supplies including wheelchairs, hearings aids, orthoses and walking aids.
Governmental programs	Support for vocational rehabilitation and independent living programs and recreation programs	The government provides support for one vocational rehabilitation program in the country.

Note. * Adapted from Dijkers et al. (2002).

Table 2

Comparison of Demographic Data Between Kuwaiti Sample with SCI and American Sample with SCI as Cited in Forchheimer et al. Study (2004)

Demographic Background	Kuwaitis With SCI (n=30)	Americans With SCI (n=215)	p	
Age at injury, yrs, mean, (SD)	24 (9.31)	34.7 (15.2)	t = 3.75	<0.001
Age at time of interview, yrs, mean, (SD)	33.1 (8.96)	38.8 (14.5)	t = 2.10	0.037
	%	%		
Gender			Fisher	1.000
Male	80.0	78.5	exact	
Female	20.0	21.5		
Neurological Classification (ASIA Scale)			Chi sq. =	0.006
ASIA D	0.0	24.8	12.63	
Paraplegia, ASIA, A,B,C	63.3	35.9		
Low Tetraplegia ASIA A,B,C	23.3	26.7		
High Tetraplegia ASIA A,B,C	13.3	12.6		

Table 2 (Continued)

Comparison of Demographic Data Between Kuwaiti Sample with SCI and American Sample with SCI as Cited in Forchheimer et al. Study (2004)

Demographic Background	Kuwaitis With SCI (n=30)	Americans With SCI (n=215)		p
Marital Status			Chi sq. =	0.855
Single	53.3	47.8	0.314	
Married	30.0	33.0		
Divorced	16.7	12.9		
Education Status			Chi sq. =	0.086
Less than high school	36.7	26.4	4.896	
high school	36.7	57.7		
More than high school	26.7	15.9		
Employment status at time of injury			Chi sq. =	<0.001
Employed	46.7	66.3	20.16	
Homemaker	10.0	4.3		
Student	43.3	14.4		
Retired	0.00	6.7		
Unemployed/Other	0.00	6.3		

Table 2 (Continued, 2)

Comparison of Demographic Data Between Kuwaiti Sample with SCI and American Sample with SCI as Cited in Forchheimer et al. Study (2004)

Demographic Background	Kuwaitis With SCI (n=30)	Americans With SCI (n=215)	p	
Employment status at time of interview			Chi sq. =	0.180
	20.0	21.6	6.275	
Employed	10.0	4.3		
Homemaker	10.0	11.5		
Student	30.0	16.3		
Retired	30.0	36.5		
Unemployed/Other				

Table 3

Comparison of the Kuwaitis SF-36 Scales, PCS, Mean Scores with the Normative Scores.

P-value of The Two-Sided Comparison (alpha =.005)

Scale	Kuwaiti Sample Mean (SD) (n = 30)	American Normative Sample Mean (SD) (n = 2474)	t-test	p-value*
Physical functioning (PF)	22.74 (4.62)	50 (10)	14.90	0.000*
Role function, physical (RF)	37.14 (10.69)	50 (10)	6.99	0.000*
Bodily pain (BP)	38.95 (10.87)	50 (10)	6.00	0.000*
General Health (GH)	39.24 (8.58)	50 (10)	5.86	0.000*
Vitality (VT)	44.79 (7.15)	50 (10)	2.84	0.009*
Social functioning (SF)	34.15 (9.84)	50 (10)	8.62	0.000*

Table 3 (Continued)

Comparison of the Kuwaitis SF-36 Scales, PCS, Mean Scores with the Normative Scores.

P-value of The Two-Sided Comparison (alpha =.005)

Scale	Kuwaiti Sample Mean (SD) (n = 30)	American Normative Sample Mean (SD) (n = 2474)	t-test	p-value*
Role function, emotional (RE)	37.08 (14.08)	50 (10)	6.99	0.000*
Mental Health (MH)	38.78 (8.53)	50 (10)	6.11	0.000*
Physical Component Summary (PCS)	32.66 (6.28)	50 (10)	9.47	0.000*
Mental component summary (MCS)	42.55 (11.01)	50 (10)	4.04	0.000*

Note. df for all tests = 2502.

Table 4

Comparison of the SF-36 Scales, PCS, and MCS Scores with Adult Americans with SCI.

P-value of the Two-Sided Comparison (alpha = .005)

Scale	Kuwaitis' Mean & (SD) (n = 30)	Americans' Mean & (SD) (n = 215)	t-test	p-value
Physical Component Summary (PCS)	32.6 (6.2)	33.5 (10.1)	0.44	0.660
Physical functioning (PF)	22.7 (4.6)	26.6 (11.5)	1.81	0.071
Role function, physical (RF)	37.1 (10.6)	40.7 (10.9)	1.67	0.095
Bodily pain (BP)	38.9 (10.8)	42.2 (12.4)	1.36	0.174
General Health (GH)	39.2 (8.5)	44.4 (11.8)	2.30	0.021*
Mental component summary (MCS)	42.5 (11.0)	53.5 (11.6)	4.86	0.000**
Vitality (VT)	44.7 (7.1)	46.8 (9.6)	1.10	0.271
Social functioning (SF)	34.1 (9.8)	43.0 (13.3)	3.50	0.000**
Role function, emotional (RE)	37.0 (14.0)	49.0 (10.6)	5.52	0.000**
Mental Health (MH)	38.7 (8.5)	48.3 (11.0)	4.54	0.000**

Note. df for all tests = 243.

CHAPTER IV

PERSPECTIVES OF KUWAITIS LIVING WITH SPINAL CORD INJURIES:

A MIXED-METHOD STUDY

Introduction

A spinal cord injury (SCI) is a devastating event that results in significant and permanent life changes for the injured individuals. In the United States, the estimated incidence rate of new SCI cases is approximately 11,000 per year (NSCISC, 2006). Although SCI can occur among people of all ages, it most commonly affects young adult males with an average age of 37 years old at injury. The consequences of a SCI are significant from the physical, psychological, and social aspects. This brings about the emergence of quality of life (QOL) as a major concern in the healthcare field.

Quality of life is generally considered to be a multidimensional construct, primarily based on an individual's subjective appraisal of his or her physical, functional, emotional, and social well-being (Berzon et al., 1993; Fitzpatrick et al., 1992). A catastrophic injury such as a SCI imposes multiple challenges to those constructs that encompass QOL. Healthcare practitioners have begun to recognize the importance of measuring QOL as a major contributor to successful treatment and rehabilitation outcomes. The recognition of the importance of QOL is an essential part of the adaptation process for both survivors and their family members.

Statement of the Problem

Spinal cord injury is a nationwide issue (Ackery et al., 2004). Changes in life roles due to SCI can influence the ability to satisfactorily perform various roles such as spouse, caregiver, and/or worker. These changes especially represent as challenge for people with SCI and their QOL. Because reactions to disabilities vary by individual, each individual with SCI will experience a unique adaptive process. Since adaptation to an injury is a very complex process (Schkade and Schultz, 1992), it cannot be assessed unless researchers understand the complicated interaction between inter- and intra-personal factors as well as environmental influences. Without a clear understanding of the person's perception, personal values, and goals, it is difficult to help an individual develop adaptive strategies. Due to the complex nature of the concept of QOL and the lack of adaptation studies among SCI survivors in developing countries, health care professionals have limited information about the impact of SCI injury on QOL, possible challenges to QOL, and over all satisfaction with QOL of the injured person. It seems essential to explore the values, experiences, adaptive responses, and QOL of people with SCI from their perspectives. Such research can help in understanding and investigating dimensions that facilitate a satisfying and a productive QOL for SCI survivors.

Statement of Purpose

The purpose of this study was to gain a deeper understanding from the perspectives of Kuwaiti individuals about their occupational challenges, adaptive responses, and life satisfaction following a SCI. This study explored the following research questions:

1. How do Kuwaitis with SCI perceive their roles before and after the injury?
2. How do persons with SCI from Kuwait adapt to their injury?
3. How does the occupational environment in Kuwait impact adaptation following SCI?
4. What are the perceptions of the future for Kuwaitis with SCI?

Literature Review

Measurement of Quality Of Life

An increase in the use of QOL measures among health care practitioners and for researchers in particular as evident in the field of rehabilitation, where clients with SCI are often the major focus of therapy (Dahlberg et al., 2005). In spite of general agreement concerning the importance of QOL as an outcome, the way this concept is defined and measured remains unclear. Wide ranges of both definitions and measures of QOL are used among different practitioners and researchers. Though numerous quantitative studies have been conducted, a common limitation within the area of QOL research is the use of descriptive methods such as qualitative (interview, participant observation, and documents) or mixed methods design (objective and subjective measures). A possible reason for the imbalance may be that researchers and practitioners are simply at a loss as

to how to best capture the various constructs of QOL. Creating common ground would help set a precedent for understanding the extent to which QOL affects individual outcomes following chronic injury.

Quantitative Measurement

Quantitative methodology typically yields numerical values that quantify outcomes in order to determine efficacy of treatment methods and resource allocation (Liddle and McKenna, 2000). Quantitative methodology typically uses questionnaires and numerical outcomes based on the underlying assumption that QOL has elements that are common to all people (Liddle & McKenna, 2000). While this assumption may not necessarily be valid (McKenna, 1993), this methodology has provided a means of establishing a consensual picture of the constructs of QOL for large numbers of people (Liddle & McKenna, 2000).

Qualitative Measurement

Qualitative research is essential to explore individual response and to describe complex realities. The approach involves identifying people who have experience in a particular area and who can describe their experience in detail (Liddle & McKenna, 2000). Listening to an individual's experience of an injury is of great importance because it reflects the person's feelings, thoughts, emotions, and satisfaction level. The techniques commonly used to obtain these perspectives are personal interviews and focus groups using discussions and open ended questioning (Liddle & McKenna, 2000).

Mixed Methods Design

A number of studies have used a combination of subjective and objective measures to develop a greater understanding of the nature of QOL after SCI. This mixed methods study design is becoming popular in QOL research due to its multifaceted and multidimensional aspects (Patton, 2002). Such an approach is helpful in order to elaborate on the perception of a complex topic such as QOL following a chronic injury such as a SCI (Boschen et al., 2003; Chappell & Wirz, 2003). The exploration of individuals' perspectives objectively and subjectively is increasingly recognized as an important approach to further understanding the importance of QOL to the individual (Hammell, 2007). Mixed-method analyses of QOL studies suggest that QOL should be viewed in a holistic way. The holistic approach means taking into account an individual's perception from various dimensions including the person's physical, emotional, cognitive, social, and role functioning as well as his/her perception of health and well-being (Boschen et al., 2003; Chappell & Wirz, 2003).

Adaptation

The onset of a sudden, severe disabling condition such as a SCI results in profound disruption of a person's life and social situation. A SCI imposes multiple challenges to adaptation for persons with SCI and their family members. The challenge to adaptation of life changes creates further stress by altering or potentially threatening to change many aspects of social roles and functional abilities (Montgomery, 1984). Thus, adaptation is a critical factor in the relationship between stressful life events created by a SCI and successful adjustment to it.

Following a SCI, the transition from living in a state of independent function to dependency often necessitates redefining and reevaluating personal, social, and vocational goals (Gill, 1999; North, 1999). One of the main reasons for studying coping and adaptation strategies is to understand why people's responses to the same significant life events differ so much and how these responses affect their overall QOL outcomes.

Occupational Therapy and Adaptation

The field of occupational therapy has focused on helping individuals adapt in meaningful ways (Meyer, 1922; White, 1971; Yerxa, 1967). Adaptation in occupational therapy refers to an internal and external process of change. From an individual perspective, adaptation is an internal shift in one's thoughts, beliefs of self, and actions that lead to improved functional performance (King, 1978), and hence improved QOL. From an external view, occupational therapy often refers to adaptation as environmental modification, assistive technology, or physical changes made to enhance compensation (Wood, 1995). Montgomery (1984) described adaptation as individual, flexible behavior to face the shifting needs of the changing environment. In order to have a successful adaptation process, the individual must interact with the environment. Ultimately, adaptation can be facilitated when the occupational therapist develops a more supportive context enabling the person to perform better within that context (Dunn et al., 1994).

All human beings have adaptive potential, but impairment and disability increase the degree of challenge. While challenges themselves add to a person's QOL, the difference exists in the debilitating conditions and types of challenges that can occur as a result of an injury like SCI thus, adversely affecting a person's QOL. Schkade and Schultz (1992)

advocate successful adaptation occurs when the individual engages in meaningful activity, with the occupational therapist as the agent of change within the environment.

Occupational Adaptation (OA) Model

Occupational Adaptation (OA) is a frame of reference that discusses functional performance in terms of three elements: the person, the environment, and the interaction between them. According to the OA, the person is viewed in a combination of physical, psychosocial, and cognitive capacities. The environment is comprised of physical, social, and cultural factors. Occupation is the interaction between the environment and the person. The individual's performance of an occupation in response to individual and environmental demands represents the interaction (Schkade & Schultz, 1992; Schultz & Schkade, 1992). The critical goal of occupational therapy, using the OA frame work, is, of course, to facilitate adaptation. According to OA, adaptation is defined as an internal process that requires the individual to generate, evaluate, and integrate responses to occupational challenges presented by the environment (Schkade & Schultz, 1992). The generation, evaluation, and integration of responses are referred to as sub-processes of the adaptation process. The adaptive response generation sub-process requires the individual to assess the type of energy needed, the strategy to use, and the method of employing the plan.

The person incorporates the adaptive response in the integration sub-process. During integration, the person adds experience to adaptive repertoire for use in dealing with future occupational challenges. During the adaptation process the environment may represent an occupational challenge (Schkade & Schultz, 1992), which is couched with

role expectations. Often times role expectations are essential parts in a person's QOL due to social norms and other factors that influence his/her experiences.

Culture and Adaptation

A person's cultural environment may also influence his/her QOL following a SCI. Factors that weigh heavily on QOL may differ among people due to their cultures, ethics, and religious values (Radomski, 1995). Occupational therapy literature on QOL strongly advocates exploring cultural issue in research and practice, but the profession lacks research studies that focus upon adaptation of people following SCI. While research in such areas remains very limited, the topic of QOL has been studied by some international occupational therapists (Lau et al., 1998). The authors reported that participants' culturally related philosophical beliefs were found to influence their QOL. Further investigation of adaptation following SCI in different cultures seems warranted.

Methods

Study Design

This study used a mixed methods design to describe the participants' perspectives of SCI, their adaptive responses, and life satisfaction. The researcher used the phenomenological approach for the qualitative aspects of the study. For the quantitative measurement of QOL, the researcher used the Arabic Version (Halabi, 2006) of the Ferrans and Powers Quality of Life Index (QLI) – Generic Version – III (Ferrans & Powers, 1985).

Sample

Eight Kuwaiti participants with SCI who participated in an earlier study were asked to participate in the current study. These participants were heterogeneous (in term of different SCI diagnoses, ages, gender, and varied lengths of time since injury). The inclusion criteria consisted of (a) participants have a SCI; (b) participants are at least 18 years of age; (c) participants are 1-20 years post injury; (d) participants have an impairment level of grade A, B, or C on the ASIA scale; (e) participants reside in the community; and (f) participants have not been hospitalized within the last 4 weeks. The exclusion criteria were (a) persons on ventilators, (b) persons with impairment level on Grade D on the ASIA scale, (c) persons living in a nursing home, and (d) persons with any significant neurological disorder other than SCI (e.g., stroke, traumatic brain injury).

Data Collection Procedures

After obtaining approval from both the Texas Woman's University Institutional Review Board as well as the Kuwaiti Disabled Sports Club in Kuwait to interview Kuwaiti individuals with SCI, eight community living participants were recruited. The participants signed a consent form indicating their willingness to participate in this study.

This study included both qualitative and quantitative data collection methods. First, the participants were interviewed by the investigator using an Arabic interview guide form which had been translated by a certified translator and approved by two bilingual speakers. Arabic translated interview questions were used along with prompts if necessary to elicit greater details. All the interviews were conducted in Arabic by the primary researcher who is a bilingual speaker. Then, the Arabic interviews were

translated into English by a certified translator. Two coders coded the English translated transcripts. Interviews took approximately one hour and were audio taped upon the participant's approval. Each interview was conducted at a time and private location preferred by the participant.

To quantitatively measure the QOL of individuals with SCI, the investigator asked the participants to complete the Arabic questionnaire. Halabi (2006) found the Arabic QLI to be reliable and valid tool (Halabi, 2006). The QLI is a self-administered questionnaire but can also be administered in an interview format. It takes approximately 10–20 minutes for respondents to complete. The QLI consists of two parts. The first addresses satisfaction with daily life and the second covers the importance of activities of daily living. Each of the parts consists of 33 items, for a total of 66 items. All of the items are used to calculate a total score, which reflects overall QOL. Besides the total QOL score, there are four subscale scores reflecting (a) health and functioning, (b) social and economic, (c) psychological/spiritual, and (d) family. Responses are ranked from 1 to 6, with 1 representing very dissatisfied or unimportant and 6 representing very satisfied or important. Scores can range from 0-30, with higher scores viewed as indicative of higher QOL.

Data Analysis

Audiotaped data were transcribed verbatim using a private transcriber hired by the researcher. Participants' names were omitted. Transcripts were subjected to open coding analysis by the researcher and two other coders familiar with qualitative methodology. The readings were completed until redundancy was reached. Then, the codes were

identified and described by the author and the coders and placed into emerging clusters of themes (Patton, 2002). To ensure credibility and quality of the findings, member checking and data triangulation techniques were utilized (Krefting, 1991; Patton, 2002). The researcher reviewed the data with the Kuwaiti informants to ensure that these data reflected their own experience via a member check. Additionally, two peer reviewers were asked to confirm the data. They communicated with the researcher regarding agreement with identified themes.

To determine the mean and standard deviation of the overall QOL score and the four subscale scores for the Kuwaiti sample, the researcher used SPSS software, version 15. The researcher followed the scoring calculations of the generic version of the QLI available on the web (Ferrans & Powers, 1998).

Results

Characteristics of the Sample

Demographic data of the key informants are summarized (See Table 5). The demographic variables for the eight Kuwaiti participants with SCI included gender, age at injury, age at interview, ASIA scale, marital status, educational level, employment status at the time of the injury, employment status at the time of the interview, and living situation. The age of the Kuwaiti subjects at the time of the interview ranged from 26 to 49 years (mean= 33, SD= 7.96). There were six male subjects (75%) and 2 female subjects (25%) interviewed.

Results from Quantitative Data

Means, standard deviations, and ranges for the total QLI and the four subscales were calculated and depicted in Table 6. Results of the study revealed that Kuwaiti survivors with SCI had relatively low scores in all areas of QOL measurement. The overall QLI score for the Kuwaiti survivors with SCI was 12.69 out of 30. The four QOL subscales for the Kuwaiti survivors also resulted in low scores, ranging from 10.46 to 15.56 out of 30.

Themes from Qualitative Data

During face-to-face semi-structured interviews, each of the eight informants was interviewed in a private room at the Kuwaiti Disabled Sports Club in Kuwait. Each informant was encouraged by the researcher to elaborate extensively and freely about his/her experiences, thoughts, concerns, and feelings regarding his/her life before and after SCI, challenges encountered, adaptation to the injury, QOL, hope and the future following the injury. As a result, rich data were gained leading to the emergence of seven themes and sub-themes (Table 7). The themes were (a) Role change, (b) Participation restrictions, (c) Social unacceptance, (d) Psychosocial issues, (e) Ways of overcoming injury, (f) Dissatisfaction with support systems, and (g) Faith, support, and hope.

Role Change

Before injury. Most of the Kuwaiti participants were satisfied with their lives before the SCI. When asked about their lives before injury, most of them reported that they considered themselves to be normal. They perceived that they had good QOL before

the injury because they were able to do things they liked and they were independent, socially active and integrated into the community.

According to informant #1, “I was having a normal life like anyone...I was employed in the ministry of defense and I enjoyed my social life.” Likewise, informant #5 added “before injury, I was a normal person and I enjoyed my life....I enjoyed swimming, getting outdoors, going out with friends to the sea.” Most participants reported having a normal life cycle prior to the injury. The majority of them reported that they were very satisfied with their lives before the injury.

After injury. After injury, most of the Kuwaiti survivors with SCI experienced a considerable amount of role change. Most reported that SCI had a negative impact on the quality of their lives due to lost social and occupational roles, inability to do things that they used to do before the injury, dependency on others, and inability to engage in leisure activities.

SCI caused a disruption in the routine of the informant #1. He reported that his daily life activities were affected. He felt that there was a change in his daily routine, reporting that he currently needed help in most of his daily activities. He also revealed that he had a personal assistant to help him in some of his everyday functional activities such as pushing the wheelchair, placing the wheelchair inside the trunk of the car, and organizing his personal items.

Informant #2 said about his life after injury” Now, I don’t need my wife to help me physically, but I need her help in washing my clothes, cleaning the house, and cooking my favorite meals.” Likewise, when describing her life after injury, informant #8

said, “Faithfully, now I am dependent on my self at a rate of about 60% and the rest I depend on my maid.” She added “the maid helps me in cleaning and organizing my bedroom, washing my clothes, and preparing the bathroom for me.”

Participation Restrictions

Following SCI, most of the Kuwaiti survivors expressed feelings about the challenges they faced. There were various occupational challenges which prevented them from practicing their leisure activities and integrating into the community.

Informant #2 complained of restrictions from Kuwait Airways. He said, “I don’t enjoy traveling as before because Kuwait Airways don’t provide us comfortable seats while we are on board.” Dependency on others is another reason that prevented Informant #5 from participating in leisure and social activities. He said “when I need to go outside the home, I need somebody to be with me..... because I always encounter those barriers in Kuwait.” He added “I like swimming and going to the beach but I face problems practicing such activities in Kuwait.”

When describing her restrictions going to the beach, informant #6 said that she could not enjoy the beach as before due to the heavy sand and inaccessible roads. As a result, she rarely went to the beach. Informant #8 was restricted from shopping and outing activities again due to the inaccessible community. Environmental barriers and restrictions have greatly affected some of the participants’ leisure and social activities. This has resulted in the participants’ reduced integration into the community.

Social Unacceptance

Societal stigmatizing beliefs about disability and its influences on the participants were commonly reported. Since Kuwaiti society does not actively encourage wheelchair users through its inaccessibility, they are essentially excluded as part of the community. A great deal of this reasoning exists in the culture of Kuwaiti society and it underestimates the capabilities of people with disabilities and thus diminishes the QOL. According to informant #1, he stated “Unfortunately, our society doesn’t help us to be part of the society....people in Kuwait tend to under-estimate wheelchair users and look at them as weak persons. Similarly, informant #2 said, “Some people neglect disabled person especially those who are wheelchair users.” At the cultural level, Kuwaiti society has not bridged the gap in making the connection with integration into community and how it affects QOL for persons with disabilities.

Astonishment and staring are typical behaviors expressed by Kuwaiti people when they encounter wheelchair users. Informant #3 said, “When I go to malls or other places on my wheelchair, people look at me with astonishment, amazement, and gaze.” He added, “Sometimes, I prefer not to go outside my home due to their strange look.”

Curiosity from the public and ignorance are also constant behaviors among Kuwaitis when dealing with people with disabilities. For example, informant #7 said, “Some people don’t care about us and they take our parking spots.” At the same time, informant #8 added, “Whenever I go outside with my wheelchair, people keep looking at me as they think it is an odd thing for a girl in a wheelchair to be out shopping.”

The majority of the Kuwaiti SCI survivors agreed that Kuwaiti society has diminished understanding about the skills of the disabled individual. Society lacks awareness regarding concerns, needs, and priorities of persons with disabilities. Such a society does not accept those individuals to be a part of the community. It considers them as weak and unproductive. Additionally, some informants expressed their concerns that the general public in Kuwait think that disabled persons should not marry or enjoy a normal life.

Psychosocial Issues

Besides role changes, participation restrictions, and social unacceptance following SCI, other psychosocial issues were common among the participants. The most commonly reported psychosocial manifestations were feelings of shock, depression, sadness, isolation, anxiety, nervousness, agitation, helplessness, and loss of hope.

During their first months following injury, most of the participants were in states of shock, depression, and sadness when they first realized their medical condition. Informant #4 said "frankly, I cried the whole day when I learned that I am going to be a quadriplegic all of my life." Informant #5 and #8 were also very sad and depressed when they learned of their paralyses.

Isolation from others was a common behavior among survivors with SCI. After knowing their level of injuries, most of the participants tended to isolate themselves from others. For example, Informant #4, "at the beginning of my injury, I didn't like to go out, visited friend....I preferred to be alone and isolated." Similarly, Informant #8 said "I

didn't like to go to parties, weddings, celebrations, and not even to visit my friends and relatives."

Some participants were also very anxious, nervous, and agitated. For example, informant #6 said, "I was very anxious and worried about my general condition....I wanted to know whether or not I would be able to return to my normal life and duties as a wife and as a mom." Other clients also expressed their anxiety about their future, wondering about their chances for getting married and having children.

Ways of Overcoming Injury

Kuwaiti survivors with SCI were challenged with role changes, occupational challenges, participation restrictions, societal unacceptance, and psychosocial manifestations. To eliminate and/or reduce their hardships and difficulties in performing their life roles, participants generated their own adaptive responses to overcome the encountered occupational challenges. These adaptive actions helped them to maximize their own function at home, work, community, and society.

Exploring new leisure activities that were enjoyable and satisfying to the individual was one way to elicit an adaptive response. For example, Informant #1 utilized his laptop computer and the internet as a means to fill his time. Similarly, informant #2 used a laptop computer to help him with his job assignments and to communicate with his friends.

Another means of adaptation occurred through the utilization of peer support. The majority of the participants utilized their peers at the Kuwaiti club as a way to receive supports and advice from others to overcome the challenges in their lives. For example,

Informant #1 said, "I looked for a place that could suit my disability which is the Kuwaiti Disabled Club.....I like this club because there are supportive peers that could answer my questions." Informant #2 pointed out that at the club, he could meet friends with the same injury and shared with them ideas, suggestions, and solutions to the problems that he faced.

For some of the Kuwaiti SCI survivors, self-determination and internal motivation were key factors that led them to their desired adaptive responses. For example, informant #4 said, "When I understood that my injury was permanent, I had to adapt myself to the injury and get accustomed." He added, "One way to be totally self-dependent was through trial and error Informant #7 added, "I challenged difficulties and adapted myself."

Dissatisfaction with Support Systems

Most of the participants in this study expressed their dissatisfaction with the health care services in Kuwait. They were unhappy with the SCI rehabilitation services in Kuwait. The majority of them reported that they did not benefit from the rehabilitation. Some of them even reported they went abroad to Europe and U.S for further rehabilitation.

Caregiver restrictions and misunderstanding of disability was another factor that caused dissatisfaction among participants. They pointed out that some of their caregivers lacked awareness about SCI. Therefore, they did not understand the possible capabilities of a person with a SCI. For instance, during the early months of injury, most of the

survivors' caregivers asked participants to remain at home instead of participating in outing activities.

The majority of the participants complained of the shortcomings of the Kuwaiti government. They expressed their dissatisfaction with the present disability law system in Kuwait. For example, those relying primarily on the monthly government's support (about \$1400) felt that amount was not sufficient. Others expressed their dissatisfaction with the employment system for people with disabilities. Some of the participants were not allowed to return to work. Finally, some of the participants pointed out that the Kuwaiti government neglected them. Participants expressed their sorrow that civil rights laws are only written on paper but unfortunately they are not enforced. Participants believed that reasoning behind being treated as a minority group in Kuwait is due to the weak actions of the Kuwaiti government. Again, this is one example of how cultural views of persons with disabilities can influence government and thus shape a person's QOL.

Faith, Support, Hope, and QOL

Faith in God, prayers, and spiritual support were reported by some of the participants as helpful. They utilized such strategies to overcome their occupational challenges and to attain a satisfactory QOL. Informant #3 showed the impact of prayers in improving his QOL following his injury. He said, "Religious lectures, prayers and reciting Quran had great effect on my happy life." Increased faith in God and a strong belief in Allah helped informant #4 to accept his quadriplegic injury and strive to be a productive and a successful person.

Furthermore, several participants indicated that the spiritual support they received from family members, relatives, friends, and others contributed significantly to their self-esteem, enhanced their psychological status, prompted their adaptive responses, and promoted their health and QOL. Hope was a strong facilitator of the client's adaptive responses because it substantially motivated the clients to believe that a satisfied life was awaiting them. Hope led some Kuwait survivors with SCI to overcome their challenges, reduce their restrictions and therefore to continue their lives in Kuwait.

Informant #1 and informant #5 hoped to get married and have children. Informant #2 hoped to live a better life without barriers and restrictions. Likewise, informant #5 hoped to graduate from the university and become a teacher.

Additionally, the two women with SCI (informants #6 and #8) reported they still hoped to walk again. Informant #8 said, "I am still hopeful that one day I will have a successful operation to help me walk again." Informant #6 said, "I hope that I can have a surgery that will make me walk again."

Narrative descriptions of SCI survivors are beneficial in identifying issues of QOL from the individual's perspective. People with chronic conditions should be encouraged to express their feelings, concerns, and needs regarding QOL following their injuries, especially if they are to achieve successful rehabilitation outcomes. Rehabilitation professionals should consider utilizing qualitative sections in their assessments as well as in their intervention programs in order to find ways to improve the QOL of their clients and family/caregivers,

Discussion

The purpose of the mixed design was to investigate the QOL of Kuwaiti survivors with SCI. Quantitatively; the study utilized the Arabic version of the Ferrans and Powers QLI to understand the overall QOL of the survivors as well as their specific domains of life including health and function, social and economical, psychological/spiritual, and family. Qualitatively, this study aimed to identify factors that influenced the survivors' QOL. From their perspectives, the effects of the injury, challenges encountered and subsequent impact on their occupational performance, adaptation, and QOL were examined.

The first research question in this study addressed how Kuwaitis with SCI perceived their roles before and after the injury. The face-to-face interviews in this study showed that the Kuwaiti participants were satisfied with their lives before the SCI. However, after injury, the interviews and the QLI showed that the majority of Kuwaitis in this study had poor QOL.

Quantitative results from Ferrans and Powers QLI – III questionnaire supported literature that maintains that SCI can influence the QOL of SCI survivors (May and Warren, 2002). Kuwaiti SCI survivors rated their overall QOL as poor as well as each of the four subscales of health and function, social and economical, psychological/spiritual, and family.

To clearly understand the QOL of Kuwaiti survivors compared with persons from other countries with the same injury, the Kuwaiti data were compared to American survivors with SCI. The American data were used from a previously published study by

May and Warren (2002) who used the English version of the Ferrans and Powers questionnaire. Comparison of the two groups showed that Kuwaitis with SCI had significantly lower scores than Americans with SCI in all areas of QOL measurement (See Table 8).

The second research question in this study investigated how Kuwaitis with SCI adapted to their injuries. Through qualitative data, this study showed that adaptative strategies varied among participants. Of the 8 Kuwaiti participants, 5 were unable to adapt to their role functioning successfully following injury. On the other hand, three were able to adapt successfully to their SCI. They were able to carry out their roles and they appeared to be satisfied with their lives.

The perceived low QOL of the Kuwaitis was further interpreted using the Occupational Adaptation (OA) model as a guide for interpretation of study findings. According to Schkade and Schultz (1992), humans experience a normative internal process in periods of transition. This process is called occupational adaptation. The OA model views the process of occupational adaptation as one that emerges from complex interaction of person, context, and occupation. Transition in life, such as what occurs in SCI, represented difficulties for the Kuwaitis due to various challenges that they experienced from their context (e.g., caregivers, society, and the physical environment), their occupational performance (role changes in basic and instrumental activities of daily living, leisure activities, work and school), as well as the personal level (psychosocial, cognitive, and sensorimotor). Such complex interactions influenced the adaptation process of the Kuwaiti SCI survivors.

After a SCI, a person can be negatively affected due to the improper balance between the psychosocial, cognitive, and sensorimotor subsystems. In this study, many Kuwaitis encountered many psychosocial problems following their injury. Consequently, the psychosocial subsystem can override and dominate the person's other subsystems (cognition and sensorimotor involvement) causing an imbalance. Such an improper balance affected the Kuwaitis' desired role performance, thus limiting their ability to successfully adapt to their injury. Consequently, the majority of the participants in this study had poor QOL due to experiences of occupational limitations in self-care tasks, leisure, and work.

Informants #1, 2, 3, 6, and 8 had poor QOL. During their interviews, those participants seemed not to have a desire for mastery, internal motivation, and participation in meaningful occupations. They were dependent on their aids and their caregiver/family members for their basic self-care tasks. Additionally, various restrictions and barriers from the occupational environment (physical environment, societal stigma, and restrictions from family members /caregivers) made life more difficult for them. The occupational challenges diminished the participants' hope, led to weakening of their relative mastery, and decreased satisfying outcomes. Such obstacles affected the balance in the Kuwaiti survivors' person subsystems and did not assist them in overcoming their encountered challenges. Ultimately, the majority of the Kuwaiti SCI survivors produced maladaptive responses. Most of them accepted the injury by relying on others and isolating themselves from work or leisure opportunities. As a result, they were unable to carry out their roles and rated their QOL as poor.

On the other hand, three persons (Informants #4, 5, and 7) appeared to have the desire for mastery, internal motivation, and participation in meaningful occupations. That desire promoted more balance in these persons' subsystems and assisted them in overcoming the encountered challenges and producing more adaptive responses. In addition to the availability of support from caregivers and peers, increased faith and hope led to improved relative mastery and thereby promoted their outcomes. Thus, those SCI survivors were able to carry out their roles. They appeared satisfied with their lives and scored a fair QOL.

Some literature shows that the level of SCI affects the extent of the survivor's physical abilities (Dahlberg et al., 2005; Saikkonen et al., 2004; Tooth et al., 2003). Persons with higher levels of injury tend to have more physical impairments and therefore a poorer QOL (Dahlberg et al., 2005; Tooth et al., 2003). However, findings from this study contradict this point. This study confirmed with other studies that showed impairment (e.g., level of injury, completeness of the injury) and disability did not correlate with QOL (Dijkers, 1997; Fuhrer, 1996; Sjosteen, et al., 1990). In this study, some individuals with a high level of lesion (Informant # 4 and #6) had fair QOL compared to others with a lower level of injury.

The third research question in this study addressed how the occupational environment in Kuwait impacted adaptation following SCI. This study showed that the Kuwaiti environment is often inaccessible and causes multiple restrictions and barriers to people with disabilities. Therefore, such unsupportive occupational environments influenced the SCI survivors' successful adaptation.

Participants identified several factors that they believed affected their QOL, including an inaccessible community, societal stigma, restrictions imposed by caregivers, and ineffective SCI rehabilitation. Such restricted occupational environmental factors presented challenges to the participants because they disrupted the adaptation process as well as QOL. These factors require closer attention from occupational therapists and caregivers in order to make the connection of just how outcomes can be affected. Policy makers also need to acknowledge these issues as they make recommendations for benefits to help improve QOL outcomes for SCI survivors. Acknowledgment and understanding will provide the initial step towards a better community life for people with disabilities.

The fourth research question in this study investigated the perceptions of the future for Kuwaitis with SCI. Findings from this study showed the different perceptions about the future and satisfaction in life among participants. Specifically, this study showed that some Kuwaiti male participants were hopeful and optimistic about their future unlike Kuwaiti female participants.

Females in this study did not accept the reality of their injury and conditions. Both females still hoped to recover from their injuries and dreamed of walking again. Both reported that they could not successfully perform their different occupational roles in life since they were considered wheelchair users. Although each of these women had a good social support system, they seemed to have psychosocial issues such as low self-esteem, depression and hopelessness. Such negative feelings did not facilitate their adaptive

responses to meet the encountered challenges. Therefore, those feelings seem to increase their suffering and decrease their hope, future, and QOL.

Significance of the Study

This study reflected the QOL of people living with chronic disabilities across two different cultures. The present study demonstrated the utility of the OA framework as a template for the interpretation of clinical research findings. Such a study could also explain the relationship between occupational challenges, adaptive responses and a person's QOL. It also identified possible unique components of QOL including community accessibility, government support, and cultural influences. The current study shows that further attention should be given to the SCI survivors' QOL.

Limitations of the Study

This study had some limitations. First, data gathering was taken from just one site in Kuwait. Second, due to the design of this study, the findings can not be generalized to a larger population. Third, further research studies are needed to support the utility of the OA framework with other chronic physical conditions such as traumatic brain injuries, stroke, and multiple sclerosis. Fourth, replication studies are recommended to examine the cultural applicability of the OA framework and support its inclusion at the international level.

Conclusion

According to this study, Kuwaitis with SCI had poor QOL. This study presented insights from SCI survivors about their QOL as influenced by their injury. Utilizing OA as a framework, the adaptation and QOL of Kuwaiti SCI survivors were explored.

Possible components of QOL identified in this study included social support, environmental accessibility, government support, and cultural values. To allow Kuwaiti individuals with chronic conditions to experience good QOL, long term-rehabilitation and psychosocial follow- up services are recommended. Further studies as to the extent that culture influences social and environmental constructs of QOL would also prove beneficial on the international front.

Table 5

Background Information on Participants in Study II

Informant s	Age/ gender	ASIA Scale	Years Post Injury	Marital Status	Education al Status	Employment Status
# 1	30/male	High Tetraplegia ASIA A,B,C	8	Divorce d	Less than High School	Retired
# 2	40/male	Paraplegia ASIA A,B,C	20	Married	High School	Retired
# 3	35/male	Paraplegia ASIA A,B,C	3	Single	Less than High School	Unemploy ed
# 4	28/male	Low tetraplegia ASIA A,B,C	8	Single	More than High School	Employed
# 5	26/male	Paraplegia ASIA A,B,C	9	Single	More than High School	Student
# 6	49/femal e	Paraplegia ASIA A,B,C	1	Married	High School	Retired

Table 5 (Continued)

Background Information on Participants in Study II

Informant s	Age/ Gender	ASIA Scale	Years Post Injury	Marital Status	Education al Status	Employment Status
# 7	27/male	Low tetraplegia ASIA A,B,C	6	Single	More than High School	Retired
# 8	29/female	Paraplegia ASIA A,B,C	6	Divorced	Less than High School	Homemaker

Table 6

Sample Means and Standard Deviations

QOL Scores	Mean	Standard Deviation	Range
QLI	12.69	4.57	7.75-22.20
HFSUBa	10.46	5.34	4.46-22.50
SOCSUBb	14.50	5.36	7.71-21.71
PSPSUBc	12.97	6.55	4.14-25.71
FAMSUBd	15.56	5.26	7.50-24.20

Note. * n=8, HFSUBa (Health and Function), SOCSUBb (Social and Economic), PSPSUBc (Psychological/Spiritual), and FAMSUBd (Family).

Table 7

Factors Associated with Quality of Life of SCI Survivors: Main Themes

Main Themes
Role Change
Before injury
After injury
Participation Restrictions
Social Unacceptance
Psychosocial Issues (For example feelings of shock, depression, sadness, isolation, anxiety, nervousness, agitation, helplessness, and loss of hope).
Ways of Overcoming Injury
Dissatisfaction With Support Systems
Faith, Support, and Hope

Table 8

T-Test Comparisons of Sample Means and Standard Deviations with American Survivors' Means and Standard Deviations as Scores Were Obtained from Marry and Warren (2002)

QOL Scores	Kuwaitis' Mean & (SD)	Americans Mean & (SD)	t-test	p-value*
QLI	12.69 (4.57)	21.01 (4.27)	5.26	0.000
HFSUBa	10.46 (5.34)	19.92 (4.83)	5.28	0.000
SOCSUBb	14.50 (5.36)	21.56 (4.26)	4.41	0.000
PSPSUBc	12.97 (6.55)	21.74 (5.49)	4.28	0.000
FAMSUBd	15.56 (5.26)	22.94 (5.58)	3.60	0.000

Note. * df for all tests = 104, HFSUBa (Health and Function), SOCSUBb (Social and Economic), PSPSUBc (Psychological/Spiritual), and FAMSUBd (Family).

CHAPTER V

PERSPECTIVES OF AMERICANS LIVING WITH SPINAL CORD INJURIES: A
MIXED-METHOD STUDY

Introduction

A spinal cord injury (SCI) is an unexpected injury that typically occurs among young adult males (NSCISC, 2006). In the United States, the estimated incidence rate of new SCI cases is approximately 11,000 per year (National Spinal Cord Injury Statistical Center -NSCISC, 2006). Such injury can result in significant and permanent life changes for the injured individuals. Due to the devastating consequences of SCI, quality of life (QOL) becomes the outcome of greatest concern among health care professionals.

The concept of QOL is very complex and multifaceted (Berzon et al., 1993; Fitzpatrick et al., 1992). A catastrophic injury such as a SCI imposes multiple challenges to those constructs that encompass QOL. Adaptation to life changes following an injury is a critical factor contributing to QOL. Adaptation can play a key role in explaining the relationship between stressful life events and satisfaction in life, health and well-being. Healthcare practitioners have begun to recognize the great importance of adaptation as a major contributor to successful and satisfying outcomes. Adaptation plays an essential role in facilitating a person's engagement in functional activities, thus influencing the person's health, well-being, and QOL.

Statement of Problem

Quality of life is one of the outcomes of occupational therapy identified in the Occupational Therapy Practice Framework (OTPF) (AOTA, 2002, p. 628). QOL is central to the practice of occupational therapy (AOTA, 2002; CAOT, 1994; Fisher, 1998; Polatajko, 1994; Wilcock, 1993; Yerxa, 1994). The term QOL continues to emerge as a central construct in outcomes research. It has been studied extensively by researchers from different disciplines. However, the occupational therapy (OT) body of knowledge on this topic remains limited. Research shows that the domains of occupational therapy such as adaptation, occupation, and environment are central constructs in the QOL knowledge base (Dijkers, 1998; Dooley and Hinojosa, Duncan-Myers & Huebner, 2000; 2004; Fuhrer, 1996; Hammell, 2007; Huebner et al., 2003; Laliberte-Rudman et al., 2000). The outcome of QOL also is a concept used in the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

With specific reference to clients with chronic physical conditions such as SCI, the role of the occupational therapist is assumed to be the promotion of QOL of such clients. Although occupational therapists have shown they can significantly contribute to QOL research, a need to justify and expand their role exists. One way to contribute to this body of research is by studying the relationship between adaptation to stressful life events created by a SCI and QOL.

Purpose of Study

The purpose of this study was to gain a greater understanding from the perspectives of the American survivors with SCI about their occupational challenges,

adaptive responses, and life satisfaction following a SCI. This study explored the following research questions:

1. How do Americans with SCI perceive their roles before and after SCI?
2. How do persons with SCI from the United States adapt to their injury?
3. How does the occupational environment in the United States impact adaptation following SCI?
4. What are the perceptions of the future for Americans with SCI?

Review of the Literature

Spinal Cord Injury and Quality of Life

Spinal cord injury is a nationwide injury (NSCISC, 2006). According to the American Spinal Injury Association (ASIA), impairment severity of SCI is classified based on the ASIA classification system (ASIA, 2002) which combines the level and completeness of injury. This injury is associated with considerable changes in medical health, physical ability, functional status, psychological well being, and social role status. Current knowledge shows that facilitating QOL for persons with chronic disabilities (such as SCI) is essential to the person's progress as well as health care outcomes (Dahlberg, Alaranta, and Sintonen, 2005; Dijkers, 2005; Jang, Wang, and Wang, 2005; Krause & Broderick; 2005).

Occupational Therapy and QOL of Individuals with SCI

When working with persons with chronic disabilities such as SCI, a person's QOL is considered to be complex and multifaceted. Occupational therapy research on QOL suggests that occupational therapy can contribute significantly to the QOL of

individuals with SCI (Dooley & Hinojosa, 2004; Duncan-Myers & Huebner, 2000; Huebner et al., 2003; Laliberte-Rudman et al., 2000). Occupational therapy researchers need to further investigate and understand how occupational performance, environment, and adaptation can significantly influence a person's perceptions of one's life satisfaction, health, and well-being (Dooley & Hinojosa, 2004; Duncan-Myers & Huebner, 2000; Huebner et al., 2003; Laliberte-Rudman et al., 2000). Occupational therapy research shows that the provision of choice and achievement of successful adaptation motivates performance and promotes an internal locus of control (Kielhofner, 1992; Nelson & LaMore, 1992). The literature also demonstrates a positive relationship between meaningful roles, interests, values, goal directed action, personal control and life satisfaction and well-being (Duncan-Myers & Huebner, 2000; Hammell, 2007; Smith, Kielhofner, & Watts, 1986).

Human Adaptation

Adaptation is a frequently described phenomenon in occupational therapy literature. According to Schultz & Schkade (1997), "Adaptation is a change a person makes in his or her response approach when that person encounters an occupational challenge" (p. 474). In everyday life it is an ongoing and developmental process involving multiple dimensions (King, 1978; Montgomery, 1984; Schkade & Shultz, 1992S; Schultz & Schkade, 1992). In considering its internal and external demands, adaptation is also a lifelong, holistic, and universal concept (Schkade & Schultz, 1992). Adaptation relates to the individual, the environment, and their interaction through participation in occupation. Moreover, it can play an essential role in facilitating a

person's engagement in functional activities, thereby influencing a person's health, life satisfaction, and QOL (Schultz & Schkade, 1992). To better evaluate the significant relationship between QOL and adaptation, it is necessary to know more about how human beings adapt to a changing environment and how internal changes affect their capacity to act in the environment. Occupational therapy researchers need to consider the significant impact of adaptation on the person's QOL.

Occupation Adaptation Model

The Occupational Adaptation (OA) framework was chosen as the theoretical support for the current line of research for two main reasons. First, the framework combines two important concepts: occupation and adaptation. When one's occupational performance suffers due to a major life crisis such as a SCI, a person's adaptational process can better be understood by applying the OA framework (Schkade & Schultz, 1992; Schultz & Schkade, 1997). Secondly, the OA framework is concerned with the interaction between the person and environment. Research has shown that the environment influences an individual's occupational performance following SCI (Sjosten et al., 1990).

Methods

Study Design

This study used a mixed methods design to describe the participants' perspectives of SCI, their adaptive responses and QOL. The researcher used the phenomenological approach for the qualitative aspects of the study and a quantitative measure of QOL, the

Ferrans and Powers Quality of Life Index (QLI) – Generic Version – III (Ferrans & Powers, 1985).

Participants

Eight American community living adult participants with SCI were recruited from the Texas Paralyzed Veterans Affairs (TPVA) organization in the Houston area. This study included participants from various ethnicities and backgrounds. *The inclusion criteria consisted of* (a) participants have a SCI; (b) participants are at least 18 years of age; (c) participants are 1-20 years post injury; (d) participants have an impairment level of grade A, B, or C on the ASIA scale; (e) participants reside in the community; and (f) participants have not been hospitalized within the last four weeks. *The exclusion criteria were* (a) persons on ventilators, (b) persons with impairment level on Grade D of the ASIA scale, (c) persons living in a nursing home, and (d) persons with any significant neurological disorder other than SCI (e.g. stroke, traumatic brain injury).

Data Collection Procedures

After obtaining approval from both the Texas Woman's University Institutional Review Board as well as the PVA organization, eight community living participants were recruited. The participants signed a consent form indicating their willingness to participate in this study.

Each participant was interviewed individually in person by the investigator for 60 minutes. Interview questions were used along with prompts, if necessary, to elicit greater details. Interviews were audiotaped upon the participant's approval.

To quantitatively measure the QOL of individuals with SCI, the researcher used the standardized generic version of the QLI (Ferrans & Powers, 1985). The QLI is a self-administered questionnaire but can also be administered in an interview format. The QLI consists of two parts. The first addresses satisfaction with daily life and the second covers the importance of activities of daily living (ADL). Each of the parts consists of 33 items. All of the items are used to calculate a total score, which reflects overall QOL. In addition to the total QOL score, four subscale scores are obtained: (a) Health and functioning, (b) Social and economic, (c) Psychological/spiritual, and (d) Family. Responses are ranked from 1 to 6, with 1 representing very dissatisfied or unimportant and 6 representing very satisfied or important. Scores ranged from 0-30, with higher scores viewed as indicative of higher QOL. The QLI can be completed in 10-20 minutes.

Data Analysis

Audiotaped data were transcribed verbatim using a private transcriber hired by the researcher. Participants' names were omitted. Transcripts were subjected to open coding analysis by the researcher and three coders familiar with qualitative methodology. The readings were completed until redundancy was reached. Then, the codes were identified and described by the author and the coders and placed into emerging clusters of themes (Patton, 2002). To ensure credibility and quality of the findings, member checking and data triangulation techniques were utilized (Krefting, 1991; Patton, 2002). The researcher reviewed the data with the informants to ensure that these data reflected their own experience via a member check. To determine the mean and standard deviation of the overall QOL score and the four subscale scores for the sample, the researcher used SPSS

software, version 15. The researcher followed scoring instructions of the generic version of the QLI available online (Ferrans & Powers, 1998).

Results

Characteristics of the Sample

Demographic data of the key informants are summarized in Table 9. The demographic variables for the eight American participants with SCI included gender, age at injury, age at interview, ASIA scale scores, marital status, educational level, employment status at the time of the injury, employment status at the time of the interview, and the living situation. The age of the subjects at the time of the interview ranged from 20 to 36 years (mean= 27, SD= 7.03). There were seven male subjects (87.5%) and 1 female subject (12.5%) interviewed.

Results from Quantitative Data

Results from the QLI index revealed that American survivors with SCI had relatively high scores in all areas of QOL measurement. The overall QLI score was 24.04 out of 30. The four subscales scores ranged from 22.63 to 24.81 (See Table 10).

The results from the QLI in this study were compared to the findings for the general population of healthy individuals. General population data were received from Dr. Ferrans through personal communication. According to Dr. Ferrans, subjects were drawn randomly from a telephone directory representing urban, suburban, and rural areas in the Midwestern United States. Data were collected by mailed questionnaire. Sample size of the general population was 339. Their mean age was 48.42 years (SD = 16.83). Of the general population, 65.2% were male and 34.8 were female.

Comparison of the two groups showed that survivors with SCI in this study did not differ significantly from the general population in any area measured by the QLI. The overall QLI for the general population was 23 out of 30; whereas the overall QLI score for the SCI survivors was 24.04 (See Table 11).

Themes from Qualitative Data

During face-to-face semi-structured interviews, each of the eight informants was interviewed in a private room for duration of one hour. Each informant was encouraged by the researcher to elaborate extensively and freely about his/her experiences, thoughts, concerns, and feelings regarding his/her life before and after SCI, challenges encountered, adaptation to the injury, QOL, and hope and future following the injury. As a result, rich data were gained leading to the emergence of seven themes and sub-themes (See Table 12). The themes were (a) attitude; (b) activity level; (c) coping strategies; (d) support systems; (e) social labels/social ignorance; (f) hope; and (g) the future, and QOL.

Attitude

A variety of attitudes were noted among the participants, including self-confidence, high self-esteem, optimism, determination, strong will, positive thinking, and risk taking. Participants were asked about how they accepted their injuries. Informant #1 said, "Once I broke my neck and realized that I'm paralyzed....After that I said, "All right. You've got to live on and make the best of it." Likewise, informant #2 said, "I'm still the same person I was... I'm just in a chair." He added, "Each person is basically judged on how he looks at life and how he perceives it."

Additionally, perseverance and determination were essential characteristics of success following an injury. Informant #8 reported that having those two traits were important because nothing could stop an individual from doing anything that he/she liked to do. At the same time, free spirit and strong will were also distinctive features which allowed the person to successfully handle a devastating condition such as SCI. Informant #3 believed that after his injury, he was a very strong person and he was levelheaded and free spirited. Similarly, informant #4 reported that he tried positive thinking. At the same time, he was explorative and very optimistic. He said, "I am willing to explore and do anything...I am not going to have anything holding me back."

Activity Level

Most of the participants were very active before the injury and continued to be productive after the injury. They either worked or went back to school. Informants #1, 2, 6, and 7 were working full time, and informants #3, 4, 5, and 8 were students. Informant #2 had his own medical business company. Additionally, a majority of the participants enjoyed outdoors activities as well as sports activities. For instance, informants #1 and #2 loved hand cycling. Informant #2 also enjoyed traveling. While, informants #1, 2, 3, 4, and 5 played wheelchair quad-rugby, informants #6, 7, and 8 played wheelchair basketball. Informant #4 enjoyed boating and fishing while #7 liked water skiing and upper body strengthening exercises.

Most of the participants agreed that the kinds of sports they practiced helped them in many ways. Regularly playing sports helped them to stay in shape, be happy, and have fun. Playing sports also kept them healthy and satisfied with their lives. Informant #1

described advantages of sports by saying “I haven’t allowed my injury to change me too much.” Informant #2 believed that when he started playing rugby, it opened a many doors for him personally, socially, and professionally.

Coping Strategies

As a result of the occupational challenges encountered while performing their different roles, the participants generated various coping strategies. Such strategies helped them to overcome the encountered challenges, maximized their own functioning and allowed them to actively participate in meaningful occupations at school, work and home. As a means of adaptation, informant’s #1 coping strategy consisted of his ability to relearn doing things in new ways. For instance, informant #1 reported that he held onto to his small son’s belt so that he could not run off.

Exploring new adaptive strategies that were satisfying to the individual was one way to elicit an adaptive response. For their school assignments and projects, informants #3 and 5 utilized their laptops and other special note taking devices such as speech recognition software (e.g., Dragon Naturally Speaking). Another means of adaptation occurred through the utilization of peer support. The majority of the participants utilized their peers as a way to receive support and advice from others to overcome the challenges in their lives. For example, informant #6 believed that peer support from the wheelchair basketball team helped her to overcome some of her occupational challenges. Informant #4 said about his peer support, “Getting to know how they lived their lives and seeing them out doing stuff. They have families and kids and they do everything. So I mean it

really changed my outlook and it helped.” Similarly, informant #5 liked the support that he received from his rugby team peers. He believed they were very supportive.

For some of the SCI survivors, being innovative, asking for help when needed, and having faith in God were key factors in their desired adaptive responses. For example, informant #2 believed that he adapted to his injury through trial and error. Likewise, informant #6 believed that the major factor to her success was the ability to try to figure things out in different ways.

Asking people for help was another way that survivors coped with their injuries. For example, informant #8 said, “When I’m feeling tired, I’ll ask people for help.” Informant #4 relied on his friends for different kinds of transfers when they went fishing or boating. Furthermore, faith in God was an important factor in the adaptation process following SCI. For example, informants #7 and 8 believed that God had a reason for their SCI. For example, informant #1 said, “You just have to go with what God gave you.”

Support Systems

Most of the participants in this study expressed their satisfaction with the therapy services received during their rehabilitation. The majority of them reported that they benefited from their rehabilitation and health care providers. Occupational therapy (OT) and physical therapy (PT) played a huge role in their success following injury. Most participants with SCI reported that rehabilitation team members were very skillful, knowledgeable, and hard working. They encouraged them to be active and productive. Informant #5 said, “My OT helped me the biggest, he was teaching me how to get

dressed and get out of bed...That was my biggest thing; I couldn't do that for a long time."

Caregivers, family members, and extended relatives were instrumental to participants through their help and support during recovery. For instance, informants #1 and 2 reported that their parents and wives played a key role in their successful adaptation. Informant #6 reported that she had good support from her husband and her parents. Like wise, informants #3, 4, 5, and 8 had good support from parents and peers

Governmental support was another factor that contributed to the SCI survivors' success following their injuries. The majority of the participants agreed that the Americans with Disabilities Act (ADA) played a huge role in recovery. They reported that they could now go anywhere easily without facing restrictions or problems. For instance, those who were still in school (informants# 5 and 8) believed the physical environments of their schools were very accessible.

Social Labels/Social Ignorance

The participants reported that American society seemed to stigmatize people with disabilities. The majority of the participants agreed that there was a social label attached to people in wheelchairs. Informant #1 said, "They automatically assume that you need help with everything when you generally don't....They will come up to you and want to push you or help you put your chair together." Likewise, informant #6 added, " We're all normal...and that stigma that we sit at home and look out the window and twiddle our thumbs is a very big stereotype." Ignorance was also perceived as a cause of stigmatizing behavior in American society. Social ignorance was commonly reported by the

participants. For example, informant #2 believed that people are not comfortable with people with disabilities because people might be scared of being around them.

Astonishment, gazing, and fear were typical behaviors demonstrated by the public when they encountered wheelchair users. Informant #3 said, "I get used to the people's glance and that goes out the window." Informants #7 and 8 agreed that when some people look at an individual using a wheelchair, they want to say or ask something but they do not do so because they are afraid. Additionally, some people tended to avoid directly looking at the individual. For instance #5 said, "You can still see that pity look, they always look at your legs before they do your face."

The majority of the participants in this study believed that social stigma would always be there. Most of them agreed that they have learned to ignore such behavior and not let it bother them. The informants seemed to feel that some people in American society have diminished understanding about the skills of individuals with disabilities because people do not make an attempt to learn about the world of people with disabilities.

Hope, the Future, and QOL

Several participants indicated that the support they received from family members, relatives, friends, and others contributed significantly to their self-esteem, enhanced their psychological status, prompted their adaptive responses, and promoted their health and QOL. Hope was a strong facilitator of the client's adaptive responses because hope substantially motivated the clients to believe that a satisfying life awaited

them. Hope led a majority of SCI survivors to overcome their challenges and to live their lives successfully.

Most of the participants in this study were very hopeful. Informant #1 hoped to maintain his health, be involved more with his family and earn his doctorate degree. Informant #2 planned to have his business grow and to have a baby. Informants #3, 4, 5, and 8 hoped to get a job, get married and have children. Informant #6 hoped to be more in shape and have children. Informant #4 hoped to graduate and get a job. Likewise, informant #8 hoped to play for the USA wheelchair basketball team.

Some participants had worries about the future. Some were unsatisfied with the employment system for people with disabilities. They believed that ADA did not help people with disabilities at the employment level. Some of the participants reported that, at present, there was a great deal of discriminations in terms of job selection and approval of people with disabilities. Informants #4, 5 and 8 expressed their worries about their future work after graduating from school. They thought that some people do not like to hire people in wheelchairs. Some participants reported that there are others who think that people with disabilities cannot do the work or they are not fully capable. Because of his disability, informant #4 worried about gaining employment and having a steady job. Similarly informant #5 expressed his worries about his future job. He said, "I am going to try hard to get employed."

Discussion

The purpose of this mixed design study was to investigate the QOL of a sample of Americans who were SCI survivors. Quantitatively, the study utilized Ferrans and

Powers QLI to understand the overall QOL of the survivors as well as specific domains of life of their lives including health and function, social and economical, psychological/spiritual, and family. Qualitatively, this study aimed at identifying factors that influenced the SCI survivors' QOL. From their perspectives, the effects of the injury, challenges encountered and subsequent impact on their occupational performance, adaptation, and QOL were examined.

The first research question in this study addressed how Americans with SCI perceived their roles before and after the injury. The face-to-face interviews in this study showed that participants were satisfied with their lives before the SCI. Similarly, after their injuries; most of them were very active and productive. The majority of the participants were either working or attending school. Additionally, most of them enjoyed playing sports and other outdoor activities. As a result, most of the survivors with SCI were able to carry out their roles at different levels (personal, school, work, and society) and they appeared to be satisfied with their lives.

Quantitative results from Ferrans and Powers QLI – III questionnaire in this study supported literature that individuals following SCI can still have good QOL (May & Warren, 2002; McColl et al., 2002). American SCI survivors rated their QOL high in all areas of the questionnaire (mean score = 24.04). They also showed that they were satisfied with other domains of life including health and function, social and economic, psychological/spiritual, and family. Their QOL scores in the Ferrans and Powers QLI-III were similar to the general population. The results of this study contradict other studies which have indicated that QOL for persons with SCI is lower than non-disabled controls

and the overall population (Bach & Tilton, 1994; Clayton & Chubon, 1994, Decker & Schulz, 1985; Krause & Crewe, 1991, Rintala, Young, Hart, Clearman, & Fuhrer, 1992; Siosteen et al., 1990). There are possible reasons for the perceived high QOL among survivors with SCI. Due to the duration of their injuries, most of the American survivors seemed to have successfully adapted to them over time. As a result, they appeared able to adjust to most psychosocial problems following their SCI. Such adjustment to their psychosocial issues might have facilitated the participants' desired role performance and his/her ability to overcome any encountered challenges. Additionally, participants in this study had excellent support systems which helped them not only to promote their healthy outcomes but also to improve their QOL.

The second research question in this study investigated how Americans with SCI adapted to their injuries. Through qualitative data, this study showed that participants utilized various adaptative strategies to overcome their occupational challenges. This study showed that Eight American participants adapted successfully to their role functioning following injury.

The perceived high QOL of the American participants with SCI was further explored using the Occupational Adaptation (OA) model as a guide for interpretation of study findings. According to Schkade & Schultz (1992), humans experience a normative internal process in periods of transition. This process is called occupational adaptation. The OA model views the process of occupational adaptation as one that emerges from the complex interaction of person, context, and occupation. Transition in life, such as what occurs in SCI, did not represent difficulties for the Americans due to various possible

reasons. At the personal level, the majority of the participants were motivated to adapt to their injuries and to continue living as satisfied and happy as possible. Additionally, participants in this study had excellent support systems (context) from their caregivers, family members, Americans with Disabilities Act (ADA), and the physical environment. In terms of occupational performance, most of the participants with SCI were independent in their basic ADLs and Instrumental ADLs such as shopping, doing laundry, taking part in social and leisure activities, and driving or arranging transportation. Additionally, the participants were very active and productive in various other occupations including leisure activities, school, and work. Such complex interactions facilitated the adaptation process of the American SCI survivors. At the same time, it can be argued that participants' abilities to adapt facilitated their participation in the above mentioned occupations. The majority of the participants in this study appeared to have a desire for mastery, internal motivation, and participation in those meaningful activities and occupations. That desire promoted more balance in the participants' subsystems (psychosocial, cognitive, and sensorimotor) and assisted them in overcoming the encountered challenges and producing successful adaptive responses.

The third research question in this study addressed how the occupational environment in America impacted adaptation following a SCI. This study showed that the American environment is often accessible for people with disabilities. The American environment facilitated greater community participation among SCI survivors without restrictions. Therefore, such supportive occupational environments enabled the SCI survivors' successful adaptation.

Participants identified several environmental factors that they perceived to have facilitated their QOL, including supports from their caregivers, family members, and peers. Additionally, effective rehabilitation services were vital for their successful recovery following injury. Most of the participants praised the SCI rehabilitation services in the U.S. They appreciated rehabilitation's effectiveness and usefulness in terms of facilitating them to be physically strong, independent in their self-care, and preparing them for a new and challenging world. On the other hand, this study showed that there were some obstacles that prevented successful adaptation of people with disabilities. Most SCI survivors complained of societal stigma and social ignorance. Such negative attitudes could present challenges to some of the participants because such negative attitudes could disrupt their adaptation process as well as their QOL. As a result, such significant environmental factor requires closer attention from occupational therapists, other health care providers, and caregivers in order to understand how the environment has an effect upon health outcomes. Additionally, policy makers and health care managers need to acknowledge the issue of societal stigma and societal ignorance. They should understand its consequences and find solutions for these concerns when they are formulating health care policies. Such planning is essential because of the effect such plans could have in integrating SCI survivors into the community. Acknowledgment and understanding of the world of the person with disability could provide first steps to an improved community life for people with disabilities.

The fourth research question in this study investigated the perceptions of the future for Americans with SCI. Findings from this study showed different perceptions

about the future and life satisfaction. Specifically, this study showed that some SCI survivors, who were still students, expressed their worries about future employment. Unfortunately, some of them believed that job discrimination was still present in the society. Consequently, most of the students with disabilities in this study had some doubts and concerns about their future.

Implications for Occupational Therapy

All eight participants in this study were occupationally engaged at various levels (person, leisure, school, work). Research in SCI demonstrates that occupation promotes a person's health and QOL (Dijkers, 1997; Fuhrer, 1996). Additionally, occupational therapy literature (Dooley & Hinojosa, 2004; Duncan-Myers & Huebner, 2000; Huebner et al., 2003; Laliberte-Rudman et al., 2000) has documented the value and effect of occupation upon the individual's health, well-being, and QOL. This evidence is also in accordance with the belief of occupational therapy that health and well-being are maintained through active engagement in meaningful occupation (AOTA, 2002). Similarly, the World Health Organization (WHO) believes in the association between positive health and what people do (WHO, 2001). When asking participants in this study about the value of occupational engagement, informant #1 said, "It makes me feel good that I am doing something... also that help other people...I like to work.... It makes me feel whole, it makes me feel good." Likewise informant #5 said, "It gets me out and that was great when I went back to school, working for the recreation center just because I could talk to everybody, worked on my social skills." These perceptions demonstrate the

value of occupational performance and its relationship to the high scores of QOL reported by the American participants.

Such evidence should encourage occupational therapy researchers to continue exploring the value and benefits of occupation to the individual. Occupational therapy researchers are needed to further investigate and understand the value of occupational performance and occupational roles on a person's health and QOL. Their work can demonstrate that occupational roles and active occupational engagement are necessary for a successful and productive life. Accordingly, occupational therapy researchers can advocate the value of their unique profession among other health care disciplines. Occupational therapy is a vital profession that enables clients with disabilities to stay healthy, accomplish life necessities, and improve life satisfaction through participation in purposeful and meaningful occupations.

Significance of the Study

This study explored the QOL of adult American SCI survivors. It demonstrated the utility of the OA framework as a template for the interpretation of clinical research findings by explaining the relationship between occupational challenges, adaptive responses and a person's QOL. The study also identified a plausible relationship between occupational performance and a person's health, well-being, and QOL. The current research showed that further attention should be given to the study of QOL with SCI survivors.

Limitations of the Study

This study had some limitations. First, current study consisted of a small sample size. Second, the participants in this study were from a convenient sample and not randomly selected. Third, they were self-selected and came from a particular social activity group of SCI survivors. Therefore, participants in this study could not represent the attitudes of the majority of Americans with SCI. Fourth, further research studies are needed to support the utility of the OA framework with other chronic physical conditions such as traumatic brain injuries, stroke, or multiple sclerosis.

Conclusion

According to this study, Americans with SCI have a good QOL. This study presented insights from SCI survivors about their QOL as influenced by their injury. Utilizing OA as a framework, the adaptation and QOL of American SCI survivors were explored. This study emphasized the complex interaction between person, occupation, adaptation, and environment by identifying possible components of QOL including self-confidence, self-esteem, internal motivation, occupational performance, successful adaptive responses, rehabilitation services supports, social supports, environmental accessibility, and government support. To allow American individuals with chronic conditions to continue experiencing a good QOL, psychosocial follow-up services and studies are recommended to overcome present social stigma/social ignorance.

Table 9

Background Information on Participants in Study III

<u>Subjects</u>	<u>Age/</u> <u>gender</u>	<u>ASIA Scale</u>	<u>Years</u> <u>Post</u> <u>Injury</u>	<u>Marital</u> <u>Status</u>	<u>Educational</u> <u>Status</u>	<u>Employment</u> <u>Status</u>	<u>Ethnicity</u>
# 1	36/male	Low Tetraplegia ASIA A,B,C	16	Married	More than High School	Employed	Caucasian/ White
# 2	36/male	Low Tetraplegia ASIA A,B,C	19	Married	More than High School	Employed	Caucasian/ White
# 3	20/male	High tetraplegia ASIA A,B,C	3	Single	High School	Student	Caucasian/ White
# 4	24/male	High tetraplegia ASIA A,B,C	5	Single	High School	Student	Caucasian/ White
# 5	23/male	Paraplegia ASIA A,B,C	6	Single	High School	Student	Caucasian/ White
# 6	27/female	Paraplegia ASIA A,B,C	10	Married	More than High School	Employed	Caucasian/ White
# 7	36/male	Paraplegia ASIA A,B,C	13	Single	High School	Employed	Hispanic
# 8	21/male	Paraplegia ASIA A,B,C	10	Married	High School	Student	African American

Table 10

Sample Means and Standard Deviations

<u>QOL Scores</u>	<u>Mean</u>	<u>Standard</u> <u>Deviation</u>	<u>Range</u>
QLI	24.04	4.07	16.26-29.25
HFSUBa	24.33	4.89	13.92-30.00
SOCSUBb	22.63	3.32	18.86-28.29
PSPSUBc	24.81	4.38	17.86-30.00
FAMSUBd	24.47	5.16	16.50-30.00

Note. * n=8, HFSUBa (Health and Function), SOCSUBb (Social and Economic), PSPSUBc (Psychological/Spiritual), and FAMSUBd (Family).

Table 11

T-Test Comparisons of Sample Means with General Population Means

<u>QOL Scores</u>	<u>American</u> <u>survivors' Mean</u> <u>& (SD)</u>	<u>General</u> <u>Population's</u> <u>Mean & (SD)</u>	<u>t-test</u>	<u>p-value*</u>
QLI	24.04 (4.07)	23.00 (4.04)	.72	.472
HFSUBa	24.33 (4.89)	23.19 (4.47)	.71	.478
SOCSUBb	22.63 (3.32)	21.83 (4.11)	.54	.589
PSPSUBc	24.81 (4.38)	22.95 (5.21)	1.00	.318
FAMSUBd	24.47 (5.16)	25.60 (4.49)	.69	.490

Note. * df for all tests = 345, HFSUBa (Health and Function), SOCSUBb (Social and Economic), PSPSUBc (Psychological/Spiritual), and FAMSUBd (Family).

Table 12

Factors Associated with Quality of Life of SCI Survivors: Main Themes

Main Themes
1. Attitude
2. Sports Driven
3. Coping Strategies
4. Support Systems
5. Social Labels/Social Ignorance
6. Hope, the Future and QOL

CHAPTER VI

CONCLUSIONS AND IMPLICATIONS

Introduction

This chapter synthesizes the findings of the three studies. Conclusions and implications are discussed concerning the following topics: QOL findings from the three studies; value of cross cultural QOL studies to occupational therapy education, practice, and research; the importance of mixed methods design; significance of the OA model to clinicians and researchers; implications for health care professionals and policy makers in Kuwait, and a conceptual model.

Quality Of Life Findings from the Three Studies

This dissertation was accomplished in three separate, yet related studies. These studies addressed the adaptation and QOL of individuals with SCI in Kuwait and the United States through a cross-cultural perspective. This line of research was comprised of two major goals, the first being to investigate the role of adaptation in QOL research. The second goal involved conducting cross-cultural QOL studies among Kuwaitis and Americans with SCI. Results from these three studies showed significant differences between the QOL of Kuwaiti and American survivors with SCI. Findings from these three studies could have major implications in occupational therapy both nationally and internationally.

The first study compared the Health Related Quality Of Life (HRQOL) of adult Kuwaitis SCI survivors with American SCI survivors and normative data for the American general population. Three research questions were proposed, beginning with how Kuwaitis with SCI perceived their HRQOL compared to that of American general population norms. Results showed that adult Kuwaitis with SCI had a significantly lower HRQOL compared to that of American general population norms on all eight subscales and the two composite summaries of the SF-36 (PCS and MCS measures). When compared to the American normative sample, the Kuwaiti participants with SCI had poor QOL in their functional activities and in their psychological well-being.

The second research question in this first study investigated similarities and differences of perceived HRQOL between adult Kuwaitis and American SCI survivors. As cited in the Forchheimer et al. study (2004), the scores of Kuwaitis proved significantly lower on three of the subscales (i.e., social functioning, role emotional, and mental health) and the MCS of the SF-36. This meant that Kuwaiti participants scored considerably lower than the Americans in regard to mental health and psychological well-being. The last question in this first study addressed the implications of the findings for occupational therapy practice. Findings from the first study indicated that occupational therapy practitioners in undeveloped countries need to broaden their views when working with people with chronic disabilities. They must recognize that, regardless of disability, every human being has the potential for a high QOL. Occupational therapy assessments and therapeutic interventions should clearly incorporate the person's well-being, life satisfaction, and QOL. Furthermore, occupational therapists working in undeveloped

countries must recognize the essence of holistic occupational therapy services that can impact the lives of people with SCI. Using a client-centered approach, occupational therapy practitioners can closely work with their clients to attend to the multidimensional domains of QOL such as emotional health, social functioning, community integration, and psychological well-being in addition to general health, physical ability, and functional status.

The second study aimed to gain a deeper understanding of the perspectives of Kuwaiti individuals about their occupational challenges, adaptive responses, and life satisfaction following a SCI. Four research questions were posed. The first addressed how Kuwaitis survivors perceived their roles before and after the injury. Face-to-face semi-structured interviews in this study revealed that Kuwaiti participants were satisfied with their lives before the SCI. After the injury, qualitative data showed that the majority of them were dissatisfied with their lives. The majority of the participants were unemployed and relied on a government pension. Most of them had lost their functional roles of work and leisure and they had become passive and unproductive. Consequently, when assessing their QOL, the Kuwaitis rated it as poor.

The second research question in this study investigated how Kuwaitis with SCI adapted to their injuries. Qualitative data showed that adaptative strategies varied among participants. Of the eight Kuwaiti participants, five were unable to adapt successfully to their previous role functions following injury. Only three Kuwaitis apparently were able to adapt successfully to their injury. These three were able to carry out their roles of work, leisure, and outgoing activities. As a result, they appeared to be satisfied with their

lives. The third research question in this study pertained to how the occupational environment in Kuwait impacted adaptation following SCI. This study showed that the Kuwaiti environment is often inaccessible, containing multiple restrictions and barriers for people with disabilities such as SCI. There were various obstacles in the occupational environment including an inaccessible community, societal stigma, restrictions imposed by caregivers, and ineffective SCI rehabilitation. It appeared that these unsupportive occupational environments contributed to the Kuwaiti SCI survivors' unsuccessful adaptation. The fourth question in this study explored perceptions of the future for Kuwaitis with SCI. Unlike the female participants, the findings showed that some Kuwaiti male participants were hopeful and optimistic about their future. Two female participants reported that they could not successfully perform different occupational roles in life because they used a wheelchair.

The third study helped to gain a deeper understanding from the American SCI survivors about their occupational challenges, adaptive responses, and life satisfaction following injury. This study explored four research questions. First, it addressed how Americans with SCI perceived their roles before and after the injury. Face-to-face interviews in this study showed that participants were satisfied with their lives before the SCI. Similarly, after their injuries most of the participants were very active and productive. The majority of them were either working or studying. Many of the participants enjoyed playing sports and other outdoor activities. Results from the Ferrans and Powers QLI showed American SCI participants rated their QOL as high. The second question focused on how Americans with SCI adapted to their injuries. The qualitative

data here revealed various unique adaptative strategies used by participants to overcome their occupational challenges. Eight American participants seemed to have adapted successfully to their role functions following injury. Most of these participants indicated they were able to carry on their functional roles at different levels (personal, school, work, and society). As a result, they appeared to be satisfied with their lives.

The third question in this study addressed how the occupational environment in America impacted adaptation following SCI. This study confirmed that the American environment is often more accessible for people with disabilities in contrast to the Kuwait environment. The American environment facilitated greater community participation among SCI survivors. Such supportive occupational environments enabled the American survivors' successful adaptation. The last question in this study dealt with the perceptions of the future for Americans with SCI. Some participants, who were still students, expressed their worries about future employment.

Unfortunately, some also felt that job discrimination still occurs in American society. Most of the students in this study held some doubts about their future. Despite confirmation that an American environment fosters better community participation and options for survivors, their concerns remain similar to that of Kuwaiti survivors. These similarities and differences reinforce a need to conduct cross cultural studies.

The participants in the third study were from a convenient sample and not randomly selected. In addition, they were self-selected and came from a particular social activity group of SCI survivors. Therefore, participants in this study could not represent

the attitudes of the majority of Americans with SCI. Thus, findings of current study could not be generalized to all Americans with SCI.

Value of Cross Cultural Quality Of Life Studies to Occupational Therapy Education, Practice, and Research

The three studies in this dissertation have shown the value of cross-cultural studies. Cross cultural studies are of great value to health care professionals including occupational therapists because they serve as a means of comparing and contrasting occupational challenges, rehabilitation environments and QOL. The findings from these three studies emphasize the importance of cross cultural studies in that education and increased awareness among occupational therapists is important and could have an influence on improving practice, thereby improving clients' QOL.

These studies could inform occupational therapy educators of the value of conveying to students how culture influences QOL not only for SCI survivors but also for persons with other types of disabilities. By having educators convey the value of assessing QOL nationally and internationally among individuals with chronic conditions, stigmas or negative perceptions of disability among cultures could be lessened. By working with people from different backgrounds, cultures, and ethnicities, occupational therapy students stand to broaden their views. As their perspectives expand, this can in turn affect individual outcomes by changing the client's view or perspective on his/her disability and QOL.

Each person with a disability values and recognizes his/her QOL differently. As an example, the World Health Organization (WHO) now emphasizes the need for further

understanding of the individual's overall perception of and satisfaction with how things are in his/her life. The WHO believes in the relationship between positive health and what people do. In terms of occupational therapy, this concept reinforces the importance of facilitating clients from different cultures and backgrounds to adapt. Occupational therapy students must understand that it is essential to look at the individual holistically. More specifically, they must consider the individual's perception of his/her physical, mental, emotional, cognitive, social, role functioning as well as his/her perception of health and well being. Quality of life is an important index of outcome after injury and is likely to be more relevant to the individual than the impairment or disability (Dijkers, 1997; Fitzpatrick, et al., 1992).

Going one step further, occupational therapy educators need to consider the relationship between occupation and QOL. Functional engagement of an individual in his/her desired occupational roles (i.e., home, school, workplace, and community) is extremely relevant to his/her QOL. The three studies in this dissertation as well as others (Dijkers, 1997; Fuhrer, 1996) demonstrate how engagement in occupational roles correlates significantly with an individual's QOL. This evidence is common across cultures. It is also in accordance with the belief of occupational therapy that health and well-being are maintained through active engagement in meaningful occupation (AOTA, 2002). Both nationally and internationally, occupational therapy educators must work to teach students about the major role occupational performance has in shaping a person's health, well-being, and QOL.

From a practical perspective, QOL is important in measuring the effectiveness of occupational therapy interventions. For instance, the second study reported that ineffective SCI rehabilitation services might have contributed to poor QOL for most of the Kuwaiti participants. On the other hand, American survivors had higher QOL than the Kuwaitis and reported feeling very satisfied with their rehabilitation services. In future practice, it may be useful to review a client's QOL and how it relates to the level of satisfaction with the effectiveness of occupational therapy.

Occupational therapists should recognize the essence of comprehensive services that contribute to the lives of people with chronic conditions. Evaluations and therapeutic interventions should go beyond traditional measures of clinical status e.g., range of motion, endurance, muscle strength. Rather, practitioners need to attend to the multidimensional domains of QOL such as general health, physical ability, psychological well-being, functional status, occupational performance, self-fulfillment, and self-worth. Since one of the ultimate goals of occupational therapy services is satisfactory QOL, occupational therapy practitioners need to broaden their views when working with people with chronic disabilities. Instead of focusing only on the impairment level, they should view their clients holistically. Occupational therapy assessments and therapeutic interventions should clearly emphasize the person's well-being, life satisfaction, and QOL.

Literature from the three studies in this dissertation have shown how researchers have long been interested in studying and assessing QOL in terms of the differences and disparities among various ethnic and cultural groups (Fabian, 1990; Fuhrer, Fuhrer,

Garber, Rintala, Clearman, and Hart, 1993; Rintala, and Hart, 1993). Ethnic and cultural differences in the patterns of rehabilitation outcomes and disability are important because they may provide data on how QOL for certain groups changes over age and time.

For example, the cross cultural findings from the first study showed that Americans and Kuwaiti have different emotional and social conditions following SCI. Due to apparent differences of the availability of resources in these two countries, the survivors with SCI had significant differences in terms of their emotional and psychological well-being as measured by the SF-36. Qualitative data supported the quantitative findings in that the Kuwaitis did not have adequate psychosocial support, governmental support, effective rehabilitation and accessible physical environment. Therefore, limited resources in Kuwait could affect the HRQOL of the Kuwaiti survivors with SCI in terms of mental, emotional and social conditions.

On the other hand, due to the availability of various resources in the U.S., the American survivors with SCI reported better emotional and psychological well-being than Kuwaitis as measured by the SF-36. Qualitative data revealed that the Americans had adequate psychosocial support, governmental support, effective rehabilitation and accessible physical environment. Such resources seem to facilitate the adaptive responses of the Americans following their SCI. They rated their HRQOL as good in terms of their mental, emotional, social well-being.

Findings of QOL from cross cultural studies may lead to indicators of future disability trends that could aid in the development of health policy.

Research in the area of QOL can contribute significantly to the field of occupational therapy in two important dimensions. First, occupational therapy researchers can consider the complexity and multifaceted concept of QOL. Second, occupational therapy scholars should investigate the significant impact of occupational performance and functional engagement on a person's QOL. Evidence from the three studies showed that occupational performance played a major role in promoting a person's health, well-being, and QOL. Increased research could demonstrate how occupational roles and active occupational engagement contribute to successful and productive life. Accordingly, occupational therapy could be viewed as a vital service enabling clients with disabilities to stay healthy and gain life satisfaction through engagement and participation in purposeful and meaningful occupations. Moreover, occupational therapy could help persons with disabilities regain or retain important connections to their communities and peers through their participation. These types of connections are essential for reinforcing life satisfaction and reducing social stigmas about disabilities. Additional investigation is needed to fully understand the value of occupational performance and the impact of occupational roles on a person's QOL.

Importance of Mixed Methods Design

This dissertation employed different types of research designs. The first study was quantitative in design. It utilized a quantitative measure, the SF-36, to compare HRQOL among Kuwaiti and American survivors with SCI. This research was helpful in yielding numerical values for the HRQOL comparison between the two groups. The objective measures of SF-36 had many limitations with respect to its use among individuals with

SCI. The SF-36 was not developed specifically for individuals with SCI. Therefore, the relevance of the measure's content is questionable, lacking enough consistency and sensitivity to be able to capture changes in beliefs and personal values among individuals with SCI (Tate et al., 2002).

When utilizing the SF-36 in the first study, it was assumed that QOL included only eight elements of life (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health). The study was based on the underlying assumption that QOL has elements that are common to all people. In fact, this assumption may not necessarily be valid because each individual may value life differently. In fact, in the first study, little was known about SCI survivors' values and preferences regarding what domains or factors were important for their QOL. As an example, other domains such as occupation, adaptation, employment, sexual life, having and raising children, financial life, and leisure activities could also be addressed as important dimensions to a person's QOL. The first study lacked enough information from the SCI survivors to understand how the eight experienced SF-36 factors affecting their QOL following SCI.

In contrast, the second and third studies utilized a mixed methods design. In addition to the utilization of a quantitative measurement (Ferrans and Powers QLI), the researcher utilized qualitative methodology. Qualitative methods are ideal when exploring SCI's responses to occupational challenges, adaptive response, and life satisfaction. Because of the complexity of the nature of QOL, adding a qualitative measurement to the quantitative approach provided an insider's view to the picture.

Qualitative interviews provided the survivors opportunities to talk about their lives and experiences in detail. Listening to an individual's experience of SCI was of great importance because it reflected the person's thoughts and emotions. Through the use of qualitative methods such as interviews, numerous quotations demonstrated the richness of data collected when hearing the survivors' own words (Pentland et al., 2002). Additionally, Hammell (2007) also believed that individual issues are best served by using subjective means to measure QOL. Thus, qualitative research in this dissertation helped in understanding what underlies unexplained phenomena such as a QOL following a SCI. The use of a combination of subjective and objective measures in the second and third studies allowed the researcher to develop a greater understanding of the nature of QOL after a SCI. Using mixed method designs was very important due to the multifaceted and multidimensional aspects of QOL. This technique allowed participants to elaborate on the perception of a complex topic such as QOL following a chronic injury. The mixed methods design in the second and third studies provided a look into the individual's perspective of various life domains including the physical, emotional, cognitive, social, occupational role, spiritual, cultural, as well as his/her perception of health and well-being. The exploration of individuals' perspectives objectively and subjectively is increasingly recognized as an important approach to further understanding the magnitude of QOL to the individual (Hammell, 2007). The third and second studies in this dissertation also provided suggestions to clinicians that clients' values and preferences need to be addressed in treatment planning and evaluation. This suggests the client centered approach by pointing out that the person himself must be involved in their

own rehabilitation. Clinicians must actually involve their clients in the process because ultimately they affect their outcomes and in turn, QOL.

Significance of the OA Model to Clinicians and Researchers

According to Schkade and Schultz (1992), adaptation is the process by which humans achieve satisfaction that is triggered by internal and external needs, desires, and requirements. Occupational adaptation is a normative and cumulative process that leads to competence in occupational functioning. This results from the interaction between the person and his/her occupational environment through participation in occupation (Schkade & Schultz, 1992). The theoretical understanding of a disability through the Occupational Adaptation (OA) framework allows clinicians as well as researchers to take account of the important role of the environment, occupational performance, and the adaptive response in influencing a person's health, well-being, and QOL.

In the second and third studies, the OA framework helped in understanding the adaptation process following a chronic condition such as SCI. The OA helped to identify factors that may explain the relationship between adaptation and QOL. Research from these findings showed that duration post injury could play a major factor in explaining why people have different QOL following an injury (Krause & Broderick, 2005). For example, participant # 2 in the second study reported high QOL scores in the overall QLI score as well as in the other four subscale scores of the QLI. This participant had a long time duration post injury of 20 years. Qualitative data revealed that this individual was successfully adjusted to his injury in terms of physical independence, mobility, emotional relationships, financial status, and social integration. His adaptive responses helped him

to meet his occupational challenges and improved his relative mastery which led him to be highly satisfied in life.

In contrast, short time duration post injury could have a negative effect on the QOL of the individual. This was evident in the third study when seven of the eight participants reported high scores in the QOL measurements. However, participant # 3 reported poor QOL scores in the overall QLI score as well as in the other four subscale scores of the QLI. Qualitative data revealed that participant # 3 was not yet successfully adjusted to his injury. Apparently, due to his shorter time post injury, he reported that he was still dependent on transfers and mobility. He had very limited personal relationships and leisure activities, was not fully integrated into the community, and was unstable financially. In turn, this individual reported experiencing some occupational challenges following his injury and had not seemingly fully adapted to his injury as reported by poor QOL measure.

The key elements of the occupational adaptation (OA) model are geared toward understanding the actual process of human adaptation, focusing on the client's adaptive response, and emphasizing the role of occupational environment (Schultz & Schkade, 1997). The onset of a sudden severe disabling condition such as a SCI results in profound disruption in a person's life and social situation. Changes in life roles of persons due to chronic conditions such as SCI influenced their ability to satisfactorily perform their various life roles. In fact, such changes represented huge challenges to some people with SCI, especially the Kuwaiti survivors.

Because reactions to disabilities vary, each individual with SCI presented a unique adaptive process to his/her injury. The second and the third studies in this dissertation revealed that people coped differently to a stressful situation following an injury. The second study showed that few Kuwaitis with SCI utilized adaptive strategies to overcome their occupational challenges. What adaptive strategies they used consisted of exploring new leisure activities that were enjoyable and satisfying to the individual, increased faith and hope, self-determination, and participation in meaningful occupations. Such strategies helped those Kuwaitis (informant # 4, 5, and 7) in overcoming their encountered challenges and producing more adaptive responses. As a result, those survivors were able to carry out their roles and appeared to be satisfied with their lives.

Correspondingly, the third study showed that Americans with SCI adapted to their injuries more successfully. The eight American survivors in the third study utilized various unique adaptive strategies and even explored new ones to overcome their occupational challenges. These included: playing sports, being innovative, asking for help when needed, having faith in God, self-determination, and participating in meaningful occupations. They were the key factors in coping with their injuries. Most of the American SCI survivors were able to carry out their roles at different levels (personal, school, work, and society) and appeared to be satisfied with their lives.

According to the OA model, adaptation to an injury is a very complex process. It cannot be determined unless researchers understand the complex interaction between inter- and intra-personal factors as well as environmental variables. Schultz & Schkade

(1992) believe that the occupational adaptation framework is “a perspective that promotes a holistic practice” (p. 829). A variety of resources were identified in the second and third studies as contributing factors to survivors’ successful adjustment following SCI. Some of these resources included effective rehabilitation services, caregivers/family members’ support, extended families, peer supports, and government support. Such a holistic view of the client could aid occupational therapy clinicians and researchers in identifying, analyzing, and understanding the complex interaction between person, environment, and adaptation.

According to the OA model, when the client is engaged in meaningful occupation, the process of “doing” facilitates greater functional adaptation (Schkade & Schultz, 1992; Schultz & Schkade, 1992). A person’s self-evaluation of relative mastery is aimed to extend to situations and experiences outside the clinic whenever the client is faced with future occupational challenges (Jackson & Schkade, 2001). Accordingly, in this dissertation, specifically in the third study, eight American participants with SCI rated their QOL as high. Those individuals appeared to have good health, well-being, and QOL were occupationally engaged at various levels (person, leisure, school, work). Hence, occupational performance could be the major factor in explaining the high scores of QOL reported by Americans with SCI.

Adaptation can play an essential role in facilitating a person’s engagement in functional activities. Adaptive strategies are closely connected to the achievement of life goals and life satisfaction. Clinicians and researchers need to carefully investigate how the integration of adaptive responses plays a key role in the dynamic relationship between

occupational performance and a person's QOL. To do this, it is necessary to know more about how human beings adapt to a changing environment and how internal changes affect their capacity to act on the environment. In summary, occupational therapy clinicians and researchers must consider the key role of adaptation in a person's QOL.

Implications for Health Care Professionals and Policy Makers in Kuwait

This dissertation could benefit Kuwaiti health care professionals working with people who have acute and/or chronic conditions. This line of research could also be of great value to Kuwaiti policy makers, managers, and program developers. Perhaps, these findings will give insight as to how persons can live more independently within their communities. Policy makers can introduce improved rehabilitation programs to help citizens become motivated, regain strength, be more productive, engage in their communities, and gain employment, thus making them productive citizens and reducing the social stigma about disability.

There is a growing awareness that improvement in long term QOL is a primary goal of rehabilitation (Boswell et al., 1998). The results of this dissertation pointed out that some Kuwaiti survivors with SCI had poor QOL. On a larger scale, these findings could be generalized to many other clients with different chronic conditions or disabilities living in Kuwait who may also be at risk of having poor QOL. Therefore, the objectives of SCI rehabilitation services in Kuwait should not only focus on the prevention of disability, but also on the facilitation of functional recovery, personal independence, and the promotion of community reintegration. Findings of this dissertation require careful

review from Kuwaiti health care professionals as well as policy makers, managers, and program developers.

Results of this dissertation should encourage health care professionals working in Kuwait to move away from equating QOL with functional status. Kuwaiti health care professionals should consider the complexity and multifaceted of QOL. When working with persons with chronic disabilities, it is very important for them to put emphasis on other domains such as occupational performance, emotional health, social functioning, and community integration. The rehabilitation team in Kuwait needs to move beyond treatment for symptoms and improvement of physical function and to deal with occupational engagement at various levels including personal, leisure, school, and work. Health care professionals should also look at a person's emotional issues such as hope, self-esteem, and stress management. A person with a chronic condition should be encouraged to be more socially involved and fully integrated into the community with the least restricted environment. The findings from this dissertation might encourage health care professionals in Kuwait, including occupational therapists, to be visible in community development and advocacy activities that promote high QOL and well-being.

Every human being has the potential for a high QOL, regardless of disability. Kuwaiti managers and policy makers should frequently examine the outcomes of their rehabilitation programs. This dissertation should encourage policy makers, managers, and program planners to attend to the client's subjective experience of occupational challenges, sense of community belonging, and community participation to influence QOL. Quality Of Life perceived by the clients with a chronic condition (such as SCI) is

an important guideline for treatment planning. Kuwaiti managers, policy makers, and managers should view a client's QOL as a multi-factorial concept that deals with issues of perceived disability. If a program in Kuwait is to state that it serves to improve the QOL of clients, the program needs to evaluate QOL as defined by the clients themselves. This dissertation can help health care professionals as well as policy makers to explore the nature of relationships between a person's injury, occupational performance, adaptation, values, QOL, health and well-being. This dissertation can also help them to identify specific factors that enable or constrain the adaptive processes of individuals with SCIs. For instance, this dissertation highlighted on the value of purposeful activity (occupation) as a powerful therapeutic medium that can be used to prevent and remediate dysfunction. Findings of this dissertation also emphasized that over reliance on techniques departs us from our real identity as occupational therapists and weakens our body of knowledge as a unique profession. The application of the concepts, principles, and methods of the OA framework in the clinical context are geared towards improving the client's overall occupational functioning and promoting health and wellness. It is highly recommended that these concepts, principles, and methods be examined at the national and international level where it can offer a conceptual base for intervention in the health care environment. The benefits of SCI rehabilitation could be enhanced if the coping responses and psychosocial needs of each individual were assessed early in the process using the OA Framework.

life roles (home, school, work; Figure 1). As a matter of fact, due to restrictions in participation in meaningful occupations and due to maladaptive responses, study two showed that Kuwaiti survivors with SCI appeared to experience decreased health status (physically, cognitively, and psychologically). In turn, they seemed unsatisfied with life and rated their QOL as poor.

Recovery from a SCI depends on several factors that influence adaptation and QOL including resources available to the SCI survivor to help him/her deal with the situation. From this dissertation, the factors that influenced the adaptation and QOL of Kuwaiti survivors with SCI were: not being able to do things that they did before the SCI, difficulty/inability to perform the activities of daily living (i.e., dressing), difficulty performing household activities (i.e., cooking and cleaning house), dependency on others, limitation of participation in leisure activities (i.e., ping pong, fishing), limitation in social participation, role changes (i.e., losing a job and retirement), and loss of control over one's life.

The availability of resources is important to SCI survivors in order for them to adapt to the injury. From study three, the resources that influenced adaptation and QOL of American survivors with SCI were personal attitudes, effective coping strategies, family support, rehabilitation services, social support, government support, environmental accessibility, hope, and spirituality. These resources can be summarized under four main categories: personal attributes, psychosocial support, accessibility, and rehabilitation services (Figure 1). Thus, study two showed that the availability of these

resources to American survivors with SCI helped them in being able to recover from their SCI. They appeared to be satisfied in life and rated their QOL as high.

Conclusion

Several limitations were identified among all three studies. First, the SF-36 did not provide a complete global understanding of an individual's QOL and the factors that influence it. Second, the Kuwaiti sample in this study was not randomly selected. Third, the researcher used the normative values for the general American population because the SF-36 normative values for the Kuwaiti general population were not available. Fourth, the results of this study were compared to the results of a study that was 4 years old. Fifth, the exclusion criteria in this study did not match the exclusion criteria in Forchheimer et al. study (2004).

Studies two and three shared these same limitations. Both studies consisted of a small sample size. The participants in both studies were from a convenient sample and not randomly selected. In addition, they were self-selected and came from a particular social activity group of SCI survivors. Therefore, participants in both studies could not represent the attitudes of the majority of Kuwaitis or Americans with SCI. Thus, the findings from both of these studies cannot be generalized to a larger population. Further national and international research studies are needed to support the utility of the OA framework with other chronic physical conditions such as traumatic brain injuries, stroke, or multiple sclerosis.

The findings from the three studies hold major implications for occupational therapy practice and research. Not only did the studies demonstrate the usefulness of

utilizing the OA framework, they also helped explain the relationship between stressful life events and QOL, health and individual well-being. Also, these findings could increase awareness among occupational therapists about the factors related to successful QOL following chronic conditions such as SCI. Cross-cultural QOL studies could promote greater collaborative effort and support between occupational therapists globally.

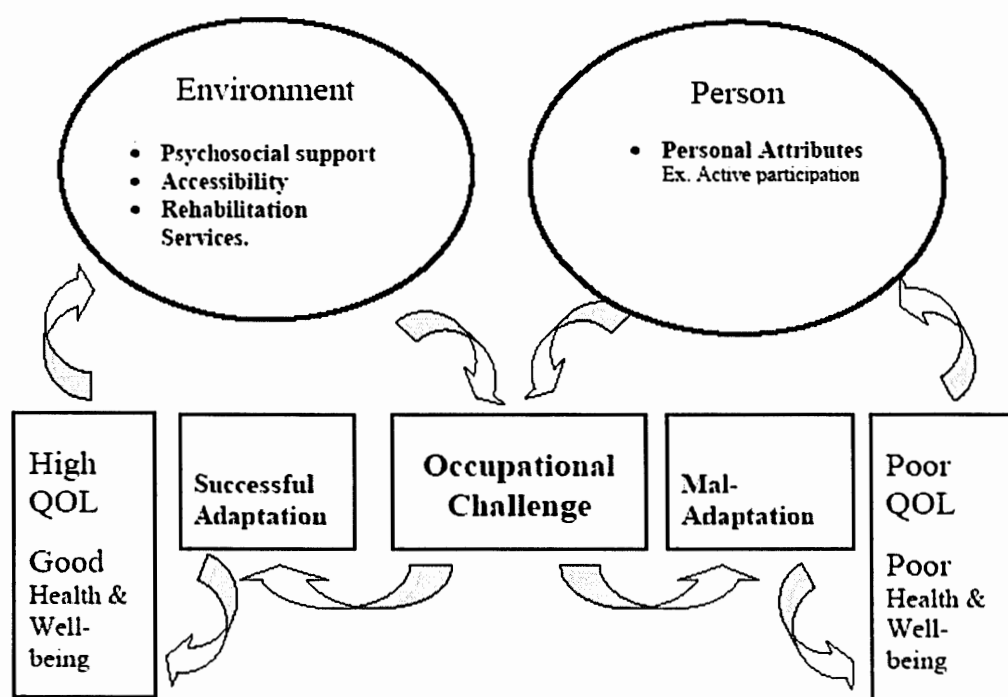


Figure 1. A conceptual model of the relationship between person, environment, occupation, adaptation, and quality of life.

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APPENDIX A

IRB Approval

INSTITUTIONAL REVIEW BOARD
Texas Woman's University
Denton Dallas Houston

INSTITUTIONAL REVIEW BOARD - HOUSTON CENTER

IRB APPROVAL FORM

Name of Investigator(s) Fahad S. Mance
TWU ID# (s) 0837474
Name of Research Advisor(s) Gayle Hersch, PhD
Address: 7550 Kirby Drive # 835
Houston, TX 77030
Type of Review: Full ☐ Expedited ☒

Dear: Fahad Mance

Your study entitled: A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective
(The applicant must complete the top portion of this form)

has been reviewed by the Institutional Review Board - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Institutional Review Board Chairman. Any exception to this requirement is noted below. Furthermore, according to IRIS regulations, another review by the IRB is required if your project changes or if it extends beyond one year from this date of approval.

Any special provisions pertaining to your study are noted below:

_____ The filing of signatures of subjects with the Institutional Review Board is not required.

_____ Other: see attached sheet.

_____ No special provisions apply.

Sincerely,

John D. Radcliffe
John Radcliffe, PhD
Chair, IRB - Houston Center

May 5, 2001
Date



Office of Research
6700 Fannin Street
Houston, TX 77030-2343
713-794-2480 Fax 713-794-2488

May 5, 2008

Mr. Fahad Manec
School of OT - Gayle Hersch Faculty Advisor
6700 Fannin Street
Houston, TX 77030

Dear Mr. Manec:

Re: *"A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective"*

Your application to the IRB has been reviewed and approved.

This approval lasts for one (1) year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

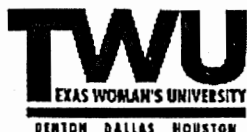
Remember to provide copies of the signed informed consent to the Office of Research, IHS 10110 when the study has been completed. Include a letter providing the name(s) of the researcher(s), the faculty advisor, and the title of the study. Graduation may be blocked unless consents are returned.

Sincerely,

Dr. John Redcliffe, Chair
Institutional Review Board - Houston

APPENDIX B

Consent Forms



School of Occupational Therapy
6700 Fannin Street, Houston, TX 77030-2243
713-794-2128 Fax 713-794-2122

TEXAS WOMAN'S UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

Title of the Study: A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective

Investigator: Fahad S. Manec, B.Sc., M.Sc.965-692-9213
Advisor: Gayle Hersch, PhD, OTR713-794-2153

Explanation and Purpose of the Research

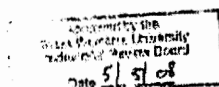
You are being asked to participate in a research study for Mr. Manec's dissertation at Texas Woman's University. The purpose of this research is to conduct cross-cultural quality of life studies to compare the challenges, coping strategies, and life satisfaction of individuals living with spinal cord injury. This research will compare those three factors among Kuwaiti and American people with spinal cord injury (SCI).

Research Procedures

For this study, the investigator will ask Kuwaiti individuals with spinal cord injuries to complete the Arabic version of Short-Form 36-item Health Status Questionnaire (SF-36). The questionnaire should take no more than 30 minutes of your time. The SF-36 includes eight areas of health representing how you function in your daily life, your stress, and life satisfaction. With your voluntary agreement, there will be an opportunity to participate in two other interviews. May I contact you, if you are selected to participate in those two interviews.

Potential Risks

Potential risks related to your participation in the study include loss of confidentiality, fatigue, possible interruption of daily routine and heightened sensitivity or discomfort to certain personal questions. If you feel uncomfortable or fatigued, you may take a break (or breaks) during the interview as needed. If you experience increased sensitivity at any time in the process, you may stop the interview without penalty.



p. 1/3

Participant's initials

Think SUCCESS ★ Think TWU

Confidentiality will be protected by to the extent by law. The interview will take place in a private location agreed upon by you and the investigator. A code number rather than your name will be used on the questionnaires. The data will be stored in a secured file cabinet at the PI's home. Only, the PI will have direct access to the locked file cabinet. Hard copies of the consent forms will be shredded within five years. It is anticipated that the results of this study will be published in the investigator's dissertation as well as in other research publications. However, no names or other identifying information will be included in any publication.

Efforts will be made to prevent any complications that could result from this research. You should let the researcher know immediately if there is a problem and the Investigator will help as much as possible. However, it is understood that Texas Woman's University does not provide medical services or financial assistance for injuries that might happen as a result of your participation in the study.

Participation and Benefits

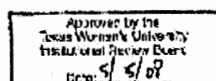
It is understood that your participation in this research study is completely voluntary, and you may discontinue your participation in the study at any time without penalty. There are no alternative procedures in this study. This research project may not have any benefits to you except that upon your request a summary of the results will be mailed to you at its completion. After participating in this research study, you will be offered shower baskets as gifts of appreciation for taking the time to be interviewed.

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the study, you may ask the investigator or his advisor; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at (713)794-2840 or via e-mail at IRB@twu.edu.

Are you willing to participate in two further interviews relevant to the study:

- ☐ Yes
- ☐ No



p. 2/3

Participant's initials

Title: A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective

Signature of Participant

Date

Signature of Guardian

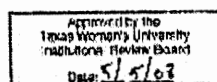
Date

The above consent form was voluntarily read, discussed, and signed by the participant in my presence. In my opinion, the person signing this consent form did so freely and with full knowledge of its contents.

Signature of Investigator

Date

If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent:



p. 3/3

Participant's initials



School of Occupational Therapy
6700 Fannin Street, Houston, TX 77030-2343
713-794-2128 Fax 713-794-2122

TEXAS WOMAN'S UNIVERSITY

CONSENT TO PARTICIPATE IN RESEARCH

Title of the Study: A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective

Investigator: Fahad S. Manee, D.Sc., M.Sc.965-692-9213
Advisor: Gayle Hersch, PhD, OTR713-794-2153

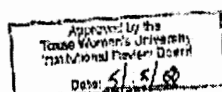
Explanation and Purpose of the Research

You are being asked to participate in a research study for Mr. Manee's dissertation at Texas Woman's University. The purpose of this research is to conduct cross-cultural quality of life studies to compare the challenges, coping strategies, and life satisfaction of individuals living with spinal cord injury. This research will compare those three factors among Kuwaiti and American people with spinal cord injury (SCI).

Research Procedures

During the first interview, the primary investigator will conduct face-to-face interview. The interview questions will focus on the challenges due to injury, coping strategies, and satisfaction in life. The primary investigator will audiotape you during the face-to-face interview to provide transcription of the information discussed in the interview and to assure the accuracy of the reporting of that information. Upon your approval, only the primary investigator and you will be present during the interviews. The audiotaped interview will take about one hour.

During the second interview you will be asked to complete a Quality of Life Index (QLI) - III questionnaire. You will be able to complete the QLI yourself. This questionnaire consists of two parts. The first addresses satisfaction with daily life and the second covers the importance of activities of daily living. It is expected to take about 15 minutes of your



p. 1/4

Participant's initials

Think SUCCESS  Think TWU

Title: A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective

time to complete the questionnaire. If you agree to be interviewed in these two interviews, your total time for participation will be about one hour and 15 minutes. Information from the interview and the Quality of Life Index (QLI) -- III questionnaire will be coded to minimize your identification when being examined or discussed. The interviews will be done at a private location agreed upon by you and the investigator and will be conducted at a time which is most convenient to you.

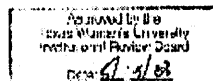
Potential Risks

Potential risks related to your participation in the study include loss of confidentiality, fatigue, possible interruption of daily routine and heightened sensitivity or discomfort to certain personal questions. If you feel uncomfortable or fatigued, you may take a break (or breaks) during the interview as needed. If you experience increased sensitivity at any time in the process, you may stop the interview without penalty.

Confidentiality will be protected to the extent allowed by law. The interview will take place in a private location agreed upon by you and the investigator. A code number rather than your name will be used on the audiotape and transcripts.

Transcriptions mean that for the data analysis of the taped interviews, audiotaped data will be transcribed verbatim by a transcriber (Elizabeth Reynolds). Transcriptions will be subjected to open coding analysis by the researcher and other committee team members. Transcriptions will be coded initially sentence by sentence. After several readings of each interview, redundancy will be examined and codes will be developed. Only the investigator and the transcriber will have access to the audio tapes which will have pseudonyms or codes to protect confidentiality. The peer reviewers will consist of the research committee team members (Dr. Hersch, Dr. Reed, Dr. Chan, and Dr. Rintala). They will have access to the transcriptions. The tapes, hard copies of the transcriptions, and the computer diskettes containing the transcriptions text files will be stored in a locked filing cabinet at the PI's home. The tapes and transcriptions diskettes will be erased and hard copies of the transcriptions, interview results and consent forms will be shredded within five years. It is anticipated that the results of this study will be published in the investigator's dissertation as well as in other research publications. However, no names or other identifying information will be included in any publication.

Efforts will be made to prevent any complications that could result from this research.



p. 2/4

Participant's initials

Title: A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective

You should let the researcher know immediately if there is a problem and the investigator will help as much as possible. However, it is understood that Texas Woman's University does not provide medical services or financial assistance for injuries that might happen as a result of your participation in the study.

Participation and Benefits

It is understood that your participation in this research study is completely voluntary, and you may discontinue your participation in the study at any time without penalty. There are no alternative procedures to this study. This research project may not have any benefits to you except that upon your request a summary of the results will be mailed to you at its completion. After participating in this research study, you will be offered shower baskets as gifts of appreciation for taking the time to be interviewed.

Questions Regarding the Study

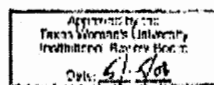
You will be given a copy of this signed and dated consent form to keep. If you have any questions about the study, you may ask the investigator or his advisor; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at (713)794-2840 or via e-mail at IRB@twu.edu.

Signature of Participant

Date

Signature of Guardian

Date



p. 3/4

Participant's initials

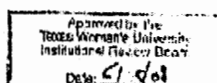
Title: A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective

The above consent form was voluntarily read, discussed, and signed by the participant in my presence. In my opinion, the person signing this consent form did so freely and with full knowledge of its contents.

Signature of Investigator

Date

If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent:



p. 4/4

Participant's Initials



School of Occupational Therapy
6700 Fannin Street, Houston, TX 77030-2343
713-794-2128 Fax 713-794-2122

CONSENT TO RECORD

TEXAS WOMAN'S UNIVERSITY

A COMPARISON OF THE ADAPTATION AND QUALITY OF LIFE OF
INDIVIDUALS WITH SPINAL CORD INJURIES FROM KUWAIT AND THE
UNITED STATES: A CROSS CULTURAL PERSPECTIVE

The undersigned consents to the recording of his/her voice by the investigator: Fahad Manec, acting under the authority of the Texas Woman's University for the purposes of the research project entitled "A Comparison of the Adaptation and Quality of Life of Individuals with Spinal Cord Injuries from Kuwait and the United States: A Cross Cultural Perspective." The undersigned understands that the material recorded for this research may be made available for educational, informational, and/or research purposes and consents to such use.

Signature of Participant

Date

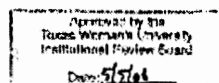
Signature of Guardian

Date

The above form was read, discussed, and signed. The person signing this consent form did so freely and with full knowledge and understanding of its content.

Representative of the
Texas Woman's University

Date



Think SUCCESS ★ Think TWU

APPENDIX C

Quality of Life Assessment Forms

استبيان صحي

الجنس ☐ ذكر

☐ أنثى

العمر _____ سنة

المزهل العلمي: ☐ ابتدائي

☐ اعدادي

☐ ثانوي

☐ بكالوريوس

☐ ماجستير

☐ دكتوراه

من فضلك، أجب على كل الأسئلة الموجودة في هذا الاستبيان. في حالة عدم وضوح أي سؤال، أرجو اختيار أقرب اجابة لمفهوك للسؤال.

١- بصورة عامة، كيف ترى حالتك الصحية؟

(اختر اجابة واحدة وضع علامة ✓ أمام الاجابة المناسبة)

☐ مقاربة

☐ جيد جدا

☐ جيدة

☐ لا بأس بها

☐ سيئة

٢- مقارنة بعام مضى، كيف تقيم حالتك الصحية الآن بصورة عامة؟

(اختر اجابة واحدة وضع علامة ✓ أمام الاجابة المناسبة)

☐ أفضل بكثير مما كانت عليه قبل عام

☐ أفضل نوعا ما من العام الماضي

☐ تقريبا على ما هي عليه

☐ أسوأ نوعا ما من العام الماضي

☐ أسوأ بكثير مما كانت عليه قبل عام

٣- تتعلق البنود التالية بأنشطة يمكن أن تقوم بها خلال يومك العادي.
في الوقت الحالي، إلى أي مدى تقيدك حالتك الصحية:

(اختر إجابة واحدة وضع علامة ✓ تحت الإجابة المناسبة)

لا تقيدني إطلاقاً	نعم تقيدني قليلاً	نعم تقيدني كثيراً	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(أ) من ممارسة الأنشطة الشاقة مثل: الجري، حمل الأشياء الثقيلة أو مزاولة الأنشطة الرياضية المجهدة جداً؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(ب) من ممارسة الأنشطة متوسطة الجهد، كتحريك الطاولة أو التنظيف باستخدام المكينة الكهربائية أو تنظيف حديقة المنزل والعناية بها ؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(ج) من حمل المشتريات من البقالة أو السوق المركزي (السوبرماركت)؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(د) من صعود الدرج لعدة أدوار؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(هـ) من صعود الدرج لدور واحد فقط؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(و) من الانحناء أو الركوع أو السجود ؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(ز) من المشي لأكثر من كيلومتر ونصف؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(ح) من المشي لمسافة نصف كيلومتر؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(ط) من المشي لمسافة مئة متر؟
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	(ي) من الاستحمام أو ارتداء الملابس بنفسك؟

الصحة الجسمية

٤- تتعلق البنود التالية (أ ، ب ، ج ، د) بالمشاكل التي يمكن أن تواجهك خلال تأديتك لعملك أو للأنشطة اليومية المعتادة نتيجة لحالتك الصحية الجسمية. خلال الأسابيع الأربعة الماضية، هل تسببت حالتك الصحية الجسمية في:

(اختر إجابة واحدة وضع علامة ✓ تحت الإجابة المناسبة)

لا	نعم	
<input type="checkbox"/>	<input type="checkbox"/>	(أ) التقليل من الوقت الذي تقضيه في العمل أو أي أنشطة أخرى؟
<input type="checkbox"/>	<input type="checkbox"/>	(ب) التقليل مما تود إنجازه من العمل أو أي أنشطة أخرى؟
<input type="checkbox"/>	<input type="checkbox"/>	(ج) تقيدك في أداء نوع معين من الأعمال أو أي أنشطة أخرى؟
<input type="checkbox"/>	<input type="checkbox"/>	(د) أن تجد صعوبة في تادية العمل أو أي أنشطة أخرى (على سبيل المثال، احتجت إلى جهد إضافي لتأديتها)

الصحة النفسية

٥- تتعلق البنود التالية (أ ، ب ، ج ، د) بالمشاكل التي يمكن أن تواجهك خلال تأديتك لعملك أو الأنشطة اليومية المعتادة كنتيجة لحالتك الصحية النفسية (مثلا الشعور بالاكئاب أو القلق). خلال الأسابيع الأربعة الماضية، هل تسببت حالتك الصحية النفسية في:

(اختر إجابة واحدة وضع علامة ✓ تحت الإجابة المناسبة)

لا	نعم	
<input type="checkbox"/>	<input type="checkbox"/>	(أ) التقليل من الوقت الذي تقضيه في العمل أو أي أنشطة أخرى؟
<input type="checkbox"/>	<input type="checkbox"/>	(ب) التقليل مما تود إنجازه من العمل أو أي أنشطة أخرى؟
<input type="checkbox"/>	<input type="checkbox"/>	(ج) عدم إنجاز العمل أو أي أنشطة أخرى بالحرص المعتاد؟

الصحة الجسمية أو النفسية

٦- خلال الاسبوع الاربعة الماضية، الى اي مدى تعارضت مهجتك الجسمية او النفسية مع تاديبك لنشاطاتك الاجتماعية المعتادة مع عائلتك او اصدقاءك او جيرانك او اي من المناسبات الاجتماعية الأخرى؟

(اختر اجابة واحدة وضع علامة ✓ أمام الاجابة المناسبة)

- ☐ لم يكن هناك أي تعارض إطلاقاً
- ☐ كان هناك تعارض قليل
- ☐ كان هناك تعارض متوسط
- ☐ كان هناك تعارض كبير
- ☐ كان هناك تعارض كبير جداً

شدة الألم

٧- ما شدة الألم الجسدي الذي عانيت منه خلال الاسبوع الاربعة الماضية؟

(اختر اجابة واحدة وضع علامة ✓ أمام الاجابة المناسبة)

- ☐ لم يكن هناك أي ألم
- ☐ كان هناك ألم خفيف جداً
- ☐ كان هناك ألم خفيف
- ☐ كان هناك ألم متوسط
- ☐ كان هناك ألم شديد
- ☐ كان هناك ألم شديد جداً

٨- خلال الاسبوع الاربعة الماضية، الى اي مدى ادى الالم الجسمي الى التعارض مع تأديتك لأعمالك المعتادة (سواء داخل المنزل او خارجه)؟

(اختر اجابة واحدة وضع علامة ✓ أمام الاجابة المناسبة)

- ☐ لم يكن هناك أي تعارض
- ☐ كان هناك تعارض قليل جدا
- ☐ كان هناك تعارض متوسط
- ☐ كان هناك تعارض كبير
- ☐ كان هناك تعارض كبير جدا

٩- الأسئلة التالية تتعلق بكيفية شعورك وطبيعة سير الأمور معك خلال الأسابيع الأربعة الماضية. الرجاء إعطاء إجابة واحدة لكل سؤال بحيث تكون هذه الإجابة هي الأقرب إلى الحالة التي كنت تشعر بها. خلال الأسابيع الأربعة الماضية، كم من الوقت:

(اختر إجابة واحدة وضع علامة ✓ لعمد الإجابة المناسبة)

لم أشعر في أي وقت من الأوقات	في قليل من الأوقات	في بعض الأوقات	في كثير من الأوقات	في معظم الأوقات	في كل الأوقات
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
أ) شعرت بأنك ملئ بالحيوية والنشاط؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ب) كنت شخصا عصبيا جدا؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ج) شعرت بأنك في حالة اكتئاب إلى درجة لم يمكن معها استئصال السرور اليك؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
د) شعرت بالهدوء والطمأنينة؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
هـ) كانت لديك طاقة كبيرة؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
و) شعرت بالاحباط واليأس؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ز) شعرت بأنك منهك (استنفذت قواك)؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ح) شعرت بأنك شخص سعيد؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
ط) شعرت بأنك تعباً؟					
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

١٠- خلال الاسبوع الاربعة الماضية، ما مقدار الوقت الذي تعارضت فيه صحتك الجسمية أو مشاكلك النفسية مع نشاطاتك الاجتماعية (مثل زيارة الأصدقاء والاقارب وغير ذلك) ؟

(اختر اجابة واحدة وضع علامة ✓ أمام الاجابة المناسبة)

- ☐ كان التعارض في كل الأوقات
- ☐ كان التعارض في معظم الأوقات
- ☐ كان التعارض في بعض الأوقات
- ☐ كان التعارض في قليل من الأوقات
- ☐ لم يكن هناك تعارض في أي وقت من الأوقات

١١- ما مدى صحة أو خطأ كل من العبارات التالية (أ ، ب ، ج ، د) بالنسبة الى حالتك الصحية؟				
خطأ بلا شك	خطأ غالباً	لا اعلم	صحيحة غالباً	صحيحة بلا شك
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(أ) يبدو أنني أصاب بالمرض أسهل من الآخرين.				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(ب) حالتي الصحية مساوية لأي شخص أعرفه.				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(ج) أتوقع أن تسوء حالتي الصحية.				
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(د) حالتي الصحية ممتازة.				

دليل المقابلة (معد من Hammell , 2004)

1. هل يمكنك أن تحدثني عن حياتك قبل إصابة الحبل الشوكي التي تعرضت لها؟
على سبيل المثال :

- هل تستطيع ان تخبرني ماذا كنت تعمل (الوظيفة أو غيرها من المسؤوليات)
- اخبرني عن كيفية استقلالك في النشاطات الخاصة بالعناية الذاتية؟
- ما هي انشطتك الممتعة ومع من؟

- قبل وقوع الضرر ، كيف كنت راضياً عن حياتك؟
- قبل وقوع الضرر ، وكيف تصف حياتك الاجتماعية؟
- 2. بعد الإصابة، ما هي الصعوبات التي تواجهها؟

على سبيل المثال :

- كيف تأثرت رعايتك لنفسك ؟
- كيف تأثرت انشطتك الترفيهية ؟
- كيف أثرت الإصابة على الرضا في الحياة؟
- كيف تؤثر الإصابة على علاقاتك الاجتماعية؟
- 3. كيف تتعامل أو تتكيف مع إصابة الحبل الشوكي؟

على سبيل المثال :

- اخبرني عن كيفية التعامل في حياتك العائلية؟
- اخبرني عن كيفية التعامل مع القضايا المتصلة بأعمالك؟
- (إذا كنت قادراً على الاستمرار بنجاح في الحياة) كيف تقوم الشبكة الاجتماعية الخاص بك (الاسرة أو الأصدقاء أو مجموعة الدعم في التغلب على أوجه القصور في الحياة؟
- (إذا كنت قادراً على الاستمرار بنجاح في حياتك (كيف ساعدتك الكنيسة على تجاوز القصور في حياتك؟
- (ان لم تكن قادر الاستمرار بنجاح في الحياة) من فضلك، هل يمكن ان تخبرني عن الاشياء التي تمنعك من التغلب على الحواجز في الحياة (الاسرة ، العمل ، والتمويل ، وامكانيه الوصول, الى أخرى)
- 4. كيف تنظر الى حياتك بعد 2-5 سنوات من الان؟

على سبيل المثال

- على المستوى الشخصي (الصحة ، والعاطفه ، والانشطه الترفيهية ، والعمل ، والتعليم).
- على الصعيد الاجتماعي (الزوج ، والاسرة ، الكنيسة ، وزملاء العمل ، الاصدقاء).

مقياس نوعية الحياة Quality of Life Index

(النموذج العام - III Generic Version)

الجزء الأول: يرجى وضع دائرة حول الإجابة الملائمة لكل مما يلي وفقا لما تراه مناسباً لوصف مدى رضاك عن نواحي مختلفة من حياتك. الرجاء وضع دائرة حول الرقم الذي يمثل رأيك علماً بأنه لا توجد إجابة صحيحة أو خاطئة

كم أنت راضٍ عن	غير راضٍ جداً	غير راضٍ بشكل متوسط	راضٍ قليلاً	راضٍ بشكل متوسط	راضٍ جداً
١. صحتك؟	١	٢	٣	٤	٥
٢. العناية الصحية التي تتلقاها؟	١	٢	٣	٤	٥
٣. مقدار الألم في حياتك؟	١	٢	٣	٤	٥
٤. مدى طاقتك على القيام بالنشاطات اليومية؟	١	٢	٣	٤	٥
٥. قدرتك على رعاية نفسك بنفسك؟	١	٢	٣	٤	٥
٦. مدى سيطرتك على حياتك؟	١	٢	٣	٤	٥
٧. فرصك لعيش الفترة الزمنية التي تتمناها؟	١	٢	٣	٤	٥
٨. صحة عائلتك؟	١	٢	٣	٤	٥
٩. أطفالك؟	١	٢	٣	٤	٥
١٠. سعادة عائلتك؟	١	٢	٣	٤	٥
١١. حياتك الجنسية؟	١	٢	٣	٤	٥
١٢. علاقتك مع شريك حياتك؟	١	٢	٣	٤	٥
١٣. أصدقائك؟	١	٢	٣	٤	٥
١٤. الدعم المعنوي الذي تتلقاه من عائلتك؟	١	٢	٣	٤	٥
١٥. الدعم المعنوي الذي تتلقاه من الآخرين؟	١	٢	٣	٤	٥

كم أنت راضٍ عن					
غير راضٍ جداً	غير راضٍ بشكل متوسط	غير راضٍ قليلاً	راضٍ قليلاً	راضٍ بشكل متوسط	راضٍ جداً
١	٢	٣	٤	٥	٦
١٦. قدرتك على القيام بالواجبات العائلية؟					
١٧. فائدتك للآخرين؟					
١٨. مقدار الضغط النفسي أو القلق الذي تعانيه في حياتك؟					
١٩. جيرانك؟					
٢٠. بيتك أو منزلك أو مسكنك؟					
٢١. عملك (إذا كنت تعمل)؟					
٢٢. عدم حصولك على عمل (إذا كنت لا تعمل، أو متقاعد، أو غير قادر على العمل)؟					
٢٣. تحصيلك العلمي؟					
٢٤. قدرتك على تدبير أمورك المالية؟					
٢٥. الأنشطة التي تسلي بها نفسك؟					
٢٦. فرصك لتحقيق مستقبل سعيد؟					
٢٧. راحة بالك أو استقرارك النفسي؟					
٢٨. إيمانك بالله عز وجل؟					
٢٩. تحقيقك للأهداف الشخصية؟					
٣٠. سعادتك بشكل عام؟					
٣١. حياتك بشكل عام؟					
٣٢. مظهرك الشخصي؟					
٣٣. نفسك بشكل عام؟					

الجزء الثاني يرجى وضع دائرة حول الإجابة الملائمة لكل مما يلي وفقا لما تراه مناسباً لوصف مدى أهمية كل من النواحي التالية من حياتك الرجاء وضع دائرة حول الرقم الذي يمثل رأيك علماً بأنه لا توجد إجابة صحيحة أو خاطئة

كم هو مهم بالنسبة لك	غير مهم	غير مهم	مهم قليلاً	مهم بشكل متوسط	مهم جداً
	مهم جداً	مهم بشكل	مهم قليلاً	مهم بشكل	مهم جداً
	١	٢	٣	٤	٥
١ صحيتك؟	١	٢	٣	٤	٥
٢ للرعاية الصحية؟	١	٢	٣	٤	٥
٣ خلو حياتك من الألم؟	١	٢	٣	٤	٥
٤ توفر طاقة كافية لديك للقيام بالنشاطات اليومية؟	١	٢	٣	٤	٥
٥ رعاية نفسك بنفسك؟	١	٢	٣	٤	٥
٦ للفترة على ضبط أمور حياتك؟	١	٢	٣	٤	٥
٧ العيش للفترة التي تراها مناسبة؟	١	٢	٣	٤	٥
٨ صحة عائلتك؟	١	٢	٣	٤	٥
٩ أطفالك؟	١	٢	٣	٤	٥
١٠ سعادة عائلتك؟	١	٢	٣	٤	٥
١١ حياتك الجنسية؟	١	٢	٣	٤	٥
١٢ علاقتك مع شريك حياتك؟	١	٢	٣	٤	٥
١٣ أصدقائك؟	١	٢	٣	٤	٥
١٤ الدعم المعنوي الذي تتلقاه من العائلة؟	١	٢	٣	٤	٥
١٥ الدعم المعنوي الذي تتلقاه من الآخرين؟	١	٢	٣	٤	٥

كم هو مهم بالنسبة لك :	غير مهم جدا	غير مهم	غير مهم قليلا	غير مهم بشكل متوسط	مهم جدا
	١	٢	٣	٤	٥
١٦. القيام بالواجبات العائلية؟	١	٢	٣	٤	٥
١٧. مدى استفادة الآخرين منك؟	١	٢	٣	٤	٥
١٨. خلو حياتك من الضغوطات النفسية؟	١	٢	٣	٤	٥
١٩. جيرانك؟	١	٢	٣	٤	٥
٢٠. بيتك أو منزلك أو مسكنك؟	١	٢	٣	٤	٥
٢١. عملك (إذا كنت تعمل)؟	١	٢	٣	٤	٥
٢٢. حصولك على عمل (إذا كنت لا تعمل، أو متقاعد، أو غير قادر على العمل)؟	١	٢	٣	٤	٥
٢٣. تحصيلك العلمي؟	١	٢	٣	٤	٥
٢٤. قدرتك على تدبير امورك المادية؟	١	٢	٣	٤	٥
٢٥. القيام بأنشطة ترفيهية؟	١	٢	٣	٤	٥
٢٦. حصولك على مستقبل سعيد؟	١	٢	٣	٤	٥
٢٧. راحة بالك أو استقرارك النفسي؟	١	٢	٣	٤	٥
٢٨. إيمانك بالله عز وجل؟	١	٢	٣	٤	٥
٢٩. تحقيق أهدافك الشخصية؟	١	٢	٣	٤	٥
٣٠. سعادتك بشكل عام؟	١	٢	٣	٤	٥
٣١. أن تكون راضيا عن حياتك؟	١	٢	٣	٤	٥
٣٢. مظهرك الشخصي؟	١	٢	٣	٤	٥
٣٣. نفسك بالنسبة لك؟	١	٢	٣	٤	٥

Open-ended and semi-structured interview questions along with prompts

Interview Guide (Adapted from Hammell, 2004)

1. Could you tell me about your life before the SCI injury?

Prompts:

- Can you tell, what you used to do (job, or other responsibilities)
- Tell me about how independent you were in self-care activities?
- What were your fun activities and with whom?
- Prior to the injury, how satisfied in life were you?
- Prior to the injury, how would you describe your social life?

2. After the SCI, what difficulties have you faced?

Prompts:

- How were your self-care tasks affected?
- How were your leisure activities affected?
- How did the injury affect your satisfaction in life?
- How did the injury affect your social relations?

3. How did you handle or cope with the SCI injury?

Prompts:

- Tell me about how you handle your family life?
- Tell me about how you handle your work-related issues?
- (If able to cope successfully in life) how has your social network (family, friends or support group) helped you to overcome limitations in life?
- (If able to cope successfully in life) how has your church helped you to overcome limitations in life?
- (If not able to cope successfully in life) Please, can you tell me about the things that prevent you from overcoming barriers in life (family, work, funding, accessibility etc)

4. How do you see your life 2-5 five years from now?

Prompts:

- At the personal level (health, emotion, leisure activities, work, and education).
- At the social level (spouse, family, church, co-workers, friends)

Ferrans and Powers
QUALITY OF LIFE INDEX[®]
GENERIC VERSION - III

PART I. For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
HOW SATISFIED ARE YOU WITH:						
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of pain that you have?	1	2	3	4	5	6
4. The amount of energy you have for everyday activities?	1	2	3	4	5	6
5. Your ability to take care of yourself without help?	1	2	3	4	5	6
6. The amount of control you have over your life?	1	2	3	4	5	6
7. Your chances of living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

HOW SATISFIED ARE YOU WITH:

	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
16. Your ability to take care of family responsibilities?	1	2	3	4	5	6
17. How useful you are to others?	1	2	3	4	5	6
18. The amount of worries in your life?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. How well you can take care of your financial needs?	1	2	3	4	5	6
25. The things you do for fun?	1	2	3	4	5	6
26. Your chances for a happy future?	1	2	3	4	5	6
27. Your peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Your achievement of personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Your life in general?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Yourself in general?	1	2	3	4	5	6

PART 2. For each of the following, please choose the answer that best describes how *important* that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having no pain?	1	2	3	4	5	6
4. Having enough energy for everyday activities?	1	2	3	4	5	6
5. Taking care of yourself without help?	1	2	3	4	5	6
6. Having control over your life?	1	2	3	4	5	6
7. Living as long as you would like?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your sex life?	1	2	3	4	5	6
12. Your spouse, lover, or partner?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from your family?	1	2	3	4	5	6
15. The emotional support you get from people other than your family?	1	2	3	4	5	6

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
16. Taking care of family responsibilities?	1	2	3	4	5	6
17. Being useful to others?	1	2	3	4	5	6
18. Having no worries?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your home, apartment, or place where you live?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Being able to take care of your financial needs?	1	2	3	4	5	6
25. Doing things for fun?	1	2	3	4	5	6
26. Having a happy future?	1	2	3	4	5	6
27. Peace of mind?	1	2	3	4	5	6
28. Your faith in God?	1	2	3	4	5	6
29. Achieving your personal goals?	1	2	3	4	5	6
30. Your happiness in general?	1	2	3	4	5	6
31. Being satisfied with life?	1	2	3	4	5	6
32. Your personal appearance?	1	2	3	4	5	6
33. Are you to yourself?	1	2	3	4	5	6

APPENDIX D
Publication Correspondence

OCCUPATIONAL THERAPY INTERNATIONAL

Acknowledgement of Authors' Responsibility and Confirmation of Originality

The author(s) named below affirm that the manuscript:

CROSS CULTURAL PERSPECTIVES OF QUALITY OF LIFE BETWEEN
KUWAITIS AND AMERICANS WITH SPINAL CORD INJURIES

and submitted for publication in Occupational Therapy International meets the following requirements:

1. The manuscript is original, is a product of the authors' own work, has not been published previously in whole or in part and is not being considered at this time for publication by any other journal or as a chapter in a book.
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Subject: Occupational Therapy International #210
Date: Tue, 26 Aug 2008 13:59:34 -0500
From: Franklin.Stein@usd.edu
To: fmanee@hotmail.com

August 26, 2008

FAHAD S. MANEE,
School of Occupational Therapy,
Texas Woman's University, Houston, Texas;
fmanee@hotmail.com

Dear Dr. Manee:

This letter is to acknowledge receipt of a electronic copy and two hard copies of your Manuscript CROSS CULTURAL PERSPECTIVES OF QUALITY OF LIFE BETWEEN KUWAITIS AND AMERICANS WITH SPINAL CORD INJURIES, for possible publication in Occupational Therapy International.

Two referees will evaluate your manuscript and the reviews should be sent to you in about three to four months. I have attached the author's acknowledgement form. Please have all authors sign the form and return it to me at: Dr. Franklin Stein, Editor, Occupational Therapy International, 7334 New Washburn Way, Madison, WI, 53719-3010 USA.

Best wishes,

Franklin Stein, PhD, OTR, FAOTA
Editor, Occupational Therapy International
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Acknowledgement of Authors' Responsibility and Confirmation of Originality

The author(s) named below affirm that the manuscript:

PERSPECTIVES OF KUWAITIS LIVING WITH SPINAL CORD INJURIES: A MIXED-METHOD STUDY

and submitted for publication in Occupational Therapy International meets the following requirements:

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Subject: Occupational Therapy International #212
Date: Tue, 26 Aug 2008 14:06:46 -0500
From: Franklin.Stein@usd.edu
To: fmanee@hotmail.com

August 26, 2008

FAHAD S. MANEE,
School of Occupational Therapy,
Texas Woman's University,
Houston, Texas;
fmanee@hotmail.com

Dear Dr. Manee:

This letter is to acknowledge receipt of a electronic copy and two hard copies of your Manuscript: PERSPECTIVES OF KUWAITIS LIVING WITH SPINAL CORD INJURIES: A MIXED-METHOD STUDY, for possible publication in Occupational Therapy International.

Two referees will evaluate your manuscript and the reviews should be sent to you in about three to four months. I have attached the author's acknowledgement form. Please have all authors sign the form and return it to me at: Dr. Franklin Stein, Editor, Occupational Therapy International, 7334 New Washburn Way, Madison, WI, 53719-3010 USA.

Best wishes,

Franklin Stein, PhD, OTR, FAOTA
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From: Carolien.vandergaag@springer.com
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