

# SCI Psychosocial Process

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## Feature Article

### **Experiences of Atheists with Spinal Cord Injury: Results of an Internet-based Exploratory Survey**

*Karen Hwang, EdD*

#### **Abstract**

Despite the recent focus on religion and spirituality in health and rehabilitation, very little information exists about committed atheists. Semi-structured interviews were conducted with a volunteer sample of 10 atheists with traumatic spinal cord injury (SCI) exploring their personal experiences of nontheistic adjustment to SCI. Findings revealed that a distinct subset of participants considered themselves low- or non-spiritual, but there were no differences between spiritual and non-spiritual individuals, in self-ratings of overall happiness. These results challenge many myths and stereotypes concerning atheism and coping with disability, and suggest that social adjustment may be complicated by isolation and discrimination.

Keywords: atheism, spirituality, spinal cord injury, adjustment

#### **Introduction**

Research in spirituality and religion is receiving greater attention in the medical literature today; specifically regarding the role that spirituality or religion plays in physical and mental health (Miller & Thoresen, 2003; Pargament, Koenig, Tarakeshwar, & Hahn, 2004). Many investigations have found physiological and psychosocial benefits to religion and spirituality with regard to individuals with various medical conditions (George, Ellison & Larson, 2002; Hackney & Sanders 2003; Nairn & Merluzzi, 2003; Laubmeier, Zakowski & Bair, 2004; Brennan, 2004; McNulty, Livneh & Wilson, 2004), as well as disability (Kilpatrick & McCullough 1999; Fitchette, Rybarczyk, DeMarco, & Nicholas, 1999). Based on these reports, it may be easy to assume that people identified as nonreligious or non-spiritual may be predisposed to greater adjustment difficulties or lower happiness relative to religious believers. However, studies of religiosity or spirituality in health and rehabilitation typically neglect the experiences of committed atheists.

#### **Atheism**

The more common understanding of atheism among atheists is “not believing in any gods.” Sometimes this is called “weak” or “default” atheism, defined as a simple lack of theistic belief, as opposed to “strong” atheism, which explicitly denies the existence of any gods. A related position, agnosticism, holds that it is impossible to know for sure if any gods exist or not (Cline, 2006).

Studies investigating the physical and emotional benefits of religious practices in community-dwelling samples often fail to include well-defined nonreligious control groups (Kier & Davenport, 2003).

A systematic literature search combining “atheist” with “spinal cord injury” and other terms such as “adjustment” or “quality of life” yields no results on MEDLINE, CINAHL, or PSYCINFO. Commonly used psychometric instruments such as the Spiritual Well-Being Scale (Ellison & Smith, 1991), which measures spirituality as a construct on a scale of “high” to “low” spirituality, assume that the positive association of religion or spirituality to well-being is unidirectional and therefore tend not to be sensitive enough to differentiate between committed nonbelievers – who may or may not consider themselves to be “spiritual” persons – and believers whose sense of faith is vague, unexamined, or conflicted.

Other researchers rely on stereotypical beliefs about atheism and atheists. One popular stereotype proposes that atheists reject god(s) because of bad parental relationships. In his analysis of 20 prominent atheists such as Freud, Nietzsche and Bertrand Russell, Vitz (1999) posited that atheism results from absent or deficient fathers, while Peteet (2001) found, among a sample of 350 members of an atheist association, over half were described as unhappy in childhood or having lost at least one parent before age 20. Despite the relative popularity of these theories neither one has ever been empirically supported.

It is often believed as well that atheism leads to hopelessness and despair. However, studies by Bugge et al (2000), Riley, Best & Charlton (2005) and O’Connell & Skevington, (2005) have reported that *both* committed atheists and committed believers were significantly less depressed than both wavering agnostics and the half-heartedly religious. Therefore, the data support the idea that it is the consistency and coherence of a person’s theism or atheism—rather than theistic belief itself—that protects against depression.

Also absent in the research is the recognition that atheists as a minority group often encounter social discrimination (Downey, 2004; Edgell, Gerteis & Hartmann 2006; Koproske, 2006), and consequently may suffer stresses associated with an environment of social rejection, hiding and internalized self-hatred. Meyer (2003) described a phenomenon called “minority stress,” defined as the physiological and psychological distress resulting from stigma and social prejudice. Minority stress, most frequently documented in reference to lesbians, gay men, and bisexuals, can predispose members to depression, alcoholism, even suicide. Because of the relative infrequency of nonbelievers in the general population, many atheists may feel “closeted” and socially isolated. Given the evidence from the lesbian/gay/bisexual population, it cannot be discounted that lower subjective well-being is more directly related to minority stress rather than a lack of belief per se.

### **Hypotheses and questions to be investigated**

The objective of this present exploratory study was to investigate the experience of adjustment to SCI from the specific perspective of *committed nonbelievers*, specifically to critically examine some common

assumptions surrounding atheism and atheists in the context of traumatic disability. These hypotheses were adapted from Cline's (2006) list of common myths about atheism:

1. Atheism is due to bad childhood experiences with religion. *Atheists are just rebelling against their families and acting out to get attention.*
2. Atheists are angry at god. *Atheists are angry at God because they think He should have done something for them in their pasts.*
3. Life for atheists must be depressing and meaningless (without god). *Atheism leads to hopelessness and despair.*

In addition, this investigation also aims to describe the specific sources of meaning and strength among nontheistic individuals, and to identify any other common themes to the experiences of nonbelievers coping with SCI, including definitions of spirituality and experiences of social discrimination.

## **Method**

Semi-structured e-mail interviews were conducted with self-identified atheists with SCI. The format of the study was chosen for two reasons: a) the relative scarcity of nonbelievers among the general population would make recruiting enough participants for a large-scale quantitative investigation difficult, and b) because the use of open-ended questions provided an opportunity for people to express themselves in greater depth.

## **Population**

The target population for this exploratory survey consisted of adult atheists with SCI contacted on Internet-based disability communities, *Carecure* and *NewMobility.com*.

Inclusion criteria were fairly liberal, in order to solicit data from adults of any age, and any SCI level.

Because of the topic under investigation and the self-report nature of the data collection, individuals with significant psychiatric or cognitive disabilities were excluded from the survey.

## **Measures**

The primary instrument was a semi-structured e-mail interview consisting of 10 multi-part open-ended questions pertaining to participants' experience of atheism as it related to their psychosocial adjustment to SCI. Questions covered 3 areas: 1) development of nontheistic identity (including age and circumstances in which the participant first self-identified as a nonbeliever); 2) impact of atheism on the participants' adjustment to SCI; and 3) the impact of the person's atheism on relations with others.

## ***Procedure***

Participants were contacted initially through a general recruitment invitation, including description and purpose of the project, e-mailed to personal contacts and posted on two disability message boards, the *Carecure Community* (CC) and *Newmobility.com* (NM). Interested participants were invited to e-mail the investigator. Upon contact, individuals were then e-mailed a more detailed project description along with a consent form. After providing informed consent, participants then received the survey questions, and an additional brief questionnaire providing demographic and SCI-related information. Of the 20 individuals who originally made contact, 15 returned completed data forms.

## ***Data analysis.***

Data analysis involved a combination of constant comparison, phenomenological and narrative approaches (Thorne 2000). Because the number of respondents was not large enough for qualitative or quantitative analysis, the results are presented to illustrate the range of experiences submitted by individuals who identify as atheists. Given the dearth of any available data on atheism and adjustment to disability, these findings remain highly exploratory.

Participant responses were organized into separate, discrete domains in accordance with the format of the original survey: history and development of atheistic identity; the impact of SCI on atheism, including any changes in spiritual beliefs; and social implications of being a nonbeliever with SCI. Common themes were defined as responses reported by at least 3 participants.

## **Results**

### ***Participants***

Twenty people with SCI responded to a general recruitment notice posted on SCI community discussion boards. Of those 20, 15 people (8 men and 7 women) ages 20-62 (M39.58; SD1.066) completed the e-mail questionnaire. All of the respondents were Caucasian except for one Asian-American and one biracial Asian-Caucasian. 3 participants described themselves as students, 3 had paid jobs (2 full-time, 1 part time); 4 were self-employed independent contractors, one was a homemaker, one was a volunteer seeking employment, and the rest were either retired or not currently seeking employment. Educationally, two had associate degrees, one was a high school graduate; the rest had had at least some college. Four were married, two divorced; the rest were single.

### ***Domains of assessment***

***Self-identification of atheism.*** Of the 15 participants in the sample, 7 identified themselves as *strongly atheistic*, 3 participants were *weakly atheistic* and 5 were *agnostic*. The atheistic sample consisted of 7 men and 3 women with a mean age of 40.3 years (range 20-62), 3 of whom had paraplegia and 7 of whom had tetraplegia. All but one were Caucasian, and all but one had had some degree of post-high school

education. Inter-correlations revealed a strong gender difference: of the total participant sample, men were more likely to describe themselves as strongly atheistic ( $n = 6$  out of 8 men), while women were more likely to be weakly atheistic ( $n = 2$ ) or agnostic ( $n = 4$ ). No associations were found between participant atheism or agnosticism and any other demographic variables.

The majority of atheistic participants had begun to self-identify as nonbelievers sometime around adolescence. Not all individuals reported a conscious rejection of theistic belief. The most common themes associated with nontheistic identification were an interest in science, exposure to different traditions of faith, a critical examination of existing belief, and the growing perception of “god” as illogical or internally inconsistent.

... I don't really know exactly at what age this started. I would guess probably around junior high school. Science class was more detailed than grade school and I had an atheist as a teacher for one of those classes. Though the teacher didn't go into any atheist vs. god debates he did offer scientific explanations for different events. Being the son of a minister in the Nazarene church I would take classroom explanations and ask my father about them. Instead of flat out denial of the scientific explanation he would simply state, “Well, that is how god did it”. Though I didn't completely convert to atheism it did start me down that path.

... I was raised Catholic but rarely attended church. My parents were non-practicing Catholics although my siblings went to private Catholic schools, I did not. I grew up in a diverse town with all denominations. I attended temple more than church with my closest friend and through Bar and Bat Mitzvahs. I remember distinctly discussing religion with some friends when I was around 13-14 and one newer friend told us she and her parents did not believe in a "God" and that they were Atheist. This surprised me but intrigued me because I had never met anyone who believed so. From then on I questioned the belief of a "God", was very interested in Mythology, teetered between being an Agnostic and Atheist.

... I was raised in the Christian faith, but after studying religion on my own, I realized I was never a Christian to begin with. I was just following what I was told. I continued going to Christian churches until I was 22 for the wrong reasons--family, boyfriend, the feeling that I was supposed to so I could become a better person.

... When I was between 3rd and 4th grade I was attending Baptist Bible summer camp and I realize that I disagreed with the fundamental reason for believing in God—that I was born sinful and needed to be saved. I did not believe I was sinful at birth nor then. I believed we were all inherently good people. I was a closeted agnostic until college.

Ironically, I helped teach Sunday school classes to preschoolers to avoid having to go to church with my family from the age of about 11-18.

Relationships with significant others, whether positive or negative, also helped influence direction of atheism. Many individuals credited support from parents or teachers with critical development of nonbelief. In addition, a number also perceived a growing disconnect between theistic belief and actual behavior of believers.

... There was an incident in the third grade in catholic school which affected my growth away from religion. I had a stern nun for teacher and I questioned the existence of Jesus one day. I was slapped in the face and locked in the coat closet for the rest of the school day. I remember knowing I was going to be punished as the nun walked towards me and being sure that I didn't deserve punishment... My mother, who'd had a year of college, backed me when I told her what had happened. I had had little respect for the functionaries of the Catholic Church before the incident and almost none after it.

... It happened instantly when I was in the military. I saw a pile of burning bodies on the side of the road in Somalia and I thought, "There is no god, and if there is, I want no part of it." If we were made by some god, then war is the will of god also.

*Influence on adjustment to SCI.* None of the atheistic participants reported any major shifts in spirituality following SCI. Of the 10 individuals surveyed, 5 reported "no change", and 5 reported a strengthening of atheism following injury. In addition, these individuals generally felt their atheism helped them cope with their injury.

... I think [SCI has] strengthened (my atheism). Naturally, I have more time on my hands, thus more time to think about things like religion. And the more I think about it, the more it doesn't make sense.

... After giving a lot of thought to the how and why this happened to me, I came to the conclusion that it was just an accident. God had nothing to do with it. I fell and broke my neck. Accidents happen.

... Post-SCI is when I embraced Atheism. Things I was going through made sense to me. I was no longer frustrated with waiting on this purpose god must have for me. I started getting better; I wasn't stressed out all the time and frustrated with why this happened. Why has there been no revelation from god as to what my purpose should be now that I was SCI.

... I did at one time want to be a believer in a god and heaven because I think some people use their beliefs or hopes as a coping skill when things are not going their way. I also think it would be nice if I had a fairy god mother to call to when times are tough or wish I was a Genie.... My thought process just does not operate that way and or I was not conditioned to think in fantasy terms.

... I don't think I missed out on anything, and have saved me from answering the "why" question. Why did god do this to me?

Meaning, purpose and spirituality. Despite their nontheistic outlook, almost half of the participants ( $n = 4$ ) identified themselves as "spiritual." Subjective definitions of spirituality generally involved an appreciation of nature, a general sense of connectedness to nature and the universe; "the people around the world all connecting together;" "being in touch with their heart and mind;" or "a higher consciousness of ones self and surroundings." These aspects were generally identified as a source of meaning and strength. Another common source of meaning and purpose was significant others, family and children, "I live and do everything for (my kids), they are my purpose."

... I find my source of meaning and purpose in today, one day at a time, the things and people I love such as my animals, family and friends. I am needed and loved. When I'm feeling weak and need mental strength I toughen up by thinking about all I love. When someone does me wrong I hold on to a more of a cosmic belief rather than Buddhist belief in karma. I think every person has an affect in some way on every other person or creature they encounter which gives them meaning and purpose.

... I feel like everyone individually has the responsibility to do their very best to make this world the best it can possibly be. I think when there is a crisis, you just need to bear down and find resources within yourself. I think everyone is far more capable of doing great things than most people imagine. When I am at my lowest of low I look around and see that there are others who struggle with more than I do and that I can make it through this time stronger than I am now.

By contrast, over half of the participants ( $n = 6$ ) did not consider themselves spiritual and rejected the idea of meaning and/or purpose to life. The main objection cited by these individuals was to the term "spiritual," with its basis in the word "spirit," which to them implied belief in a supernatural deity or higher power, "how some people define their personal relationship with their chosen savior" or "a belief in a non-physical universe/dimension, in other words there are spirits, ghost, karma, etc." "I've always connected

spirituality and religion, although I realize most people don't," admitted another respondent. These individuals tended to be extremely self-reliant, in regards to strength and purpose:

...I find my source within my self. I figure a human trying to figure out a meaning and purpose to their life is about as pointless as a duck trying to figure out basic chemistry. I wasn't born so I can cure AIDS as an example, if I do, I did it because I decided to.

... (I)n times of crisis, I look inward to try and figure out how to get out of said crisis (instead of turning it over to "God")

Another theme among the non-spiritual participants was a purely naturalistic interpretation of meaning:

... We are here because we dominated the survival of the species on the evolutionary tree... I believe this is the purpose of all life. Survive and make it so the next generation can achieve that much more then the last.

*Social relations.* The majority of participants ( $N = 9$ ) reported being open about their nonbelief to some degree. However, of this proportion, not all were completely open; almost half ( $n = 4$ ) indicated there were situations in which they could not disclose their lack of belief publicly, and one other reported being completely "closeted." Although all of the individuals reported positive feelings toward religious people generally, and in many cases rather enjoyed discussing or debating spiritual matters, they were not always sure that their views would be equally accepted.

... I'm "out." People (friends & family) around me accept me for who I am and what I believe. They don't question my beliefs because they see me through my spirituality.

...I'm not open about it, but I also don't hide it. For example, if someone says they will pray for me, I simply say "thank you." When the elderly woman across the street from me tries to convince me to join her church, I tell her I'll think about it. If she were to ask me my beliefs, I would tell her the truth, but she doesn't ask. If I'm at a social event and someone says, "Let's pray," I sit there quietly and wait for them to finish—I do not bow my head, I do not put my hands together, I do not say, "Amen." Up until about 10 years ago, though, I did pretend to pray if I were at a social gathering.

... I work at a Christian-based community outreach center. They will not hire anyone that doesn't have a belief in god, regardless of the denomination. For this reason I do not come out as an atheist. I do not participate in discussions regarding religion and the belief in god. I will excuse myself from any situation in which my beliefs could be called into

question. It isn't always easy to keep quiet especially when it comes to miracles. I imagine one day they might know my position on religion but for now I keep it to myself.

Experiences of social discrimination or pressure varied widely across participants. Although only 2 of the atheists could identify instances of overt religion-based discrimination, half of the sample had experienced pressure to accept a faith that they did not believe. One individual, the son of a pastor, reported:

... Because I am disabled I get told a lot I am one of god's miracles. I corrected them and stated I am an Atheist. You would have thought I just told them I was going to kill them. They said, oh you're just upset at god, and go into this sermon on why I should go back to god and might even be healed. I politely say, "That's okay. I'm quite happy where I am now." With three people this similar conversation took place and none have ever called me back to work on their computer.

Three participants reported being "turned off" religion after being approached by aggressively religious people after injury:

... I kept thinking about this purpose everyone said god had for me. I was so sick during those years I would beg god to let me die. I tried many times to end my life to no avail. After an arrogant hospital minister visited my room I started taking a different view of my situation. By removing god completely from all that had been happening and still happening to this day it made clear just why I was going through the hell I was. Put god back into the equation and it got all muddy again. This was the defining moment in which I accepted there is no god in control.

... When I was first injured, people kept preaching to me. Telling me to pray so I could walk again. I tried doing that and nothing happened. Society kept telling me that if I believed in god I would miraculously get up again. I found myself stuck in rehab with people surrounding my bed saying their prayers for me. I just went along with it. I was on too many pain meds to think straight. After giving a lot of thought to the how and why this happened to me, I came to the conclusion that it was a just an accident.

Finally, participants rated themselves in terms of overall happiness on a 6-point scale, with 3 points signifying more unhappiness than happiness, and 3 points signifying more happiness than unhappiness. Among the participant sample, 7 rated themselves "more happy than unhappy", and 3 rated

themselves as “almost always happy”. None of the participants endorsed points at the unhappiness side of the scale.

## Discussion

### *Why do people de-convert?*

Because of the relative unpopularity of committed atheists in the mainstream, one question that arises from these findings goes to why a person would choose to become a nonbeliever in the first place. One popular theory is that *people only become nonbelievers due to bad childhood experiences with religion or religious figures*. However, only a minority of participants reported growing up in an overly religious household or having a negative experience with a religious figure. Two others had described their early experience with religion as positive, and the rest did not mention early experiences. For this sample, the theory of nonbelief being the result of bad emotional experiences with religion does not appear to be widely supported, or may hold true for some people but not for others.

A corollary to this theory is that *nonbelievers are just rebelling against their families and acting out to get attention*. Despite the large proportion of de-conversions occurring during adolescence, there was no evidence to support the idea that these were merely acts of rebellion. Even though adolescence is commonly associated with rebellion, the experiences described did not seem to reflect a typical adolescent rebellion. Rather, participants’ de-conversion processes were generally triggered by an intellectual reappraisal of theistic belief and its ultimate rejection as unscientific, unreliable or self-contradictory. One interpretation is that individuals who reject theism out of rebellion may be less likely to maintain a coherent atheistic or agnostic worldview in later life, as many periods of rebellion tend to be short-lived and transitional. By contrast, de-conversion as a result of careful thought is more likely to result in a worldview that is both intellectually and emotionally coherent. In short, the adolescent de-conversions described by participants occurred not out of rebellion or negative experiences with family or with religion, but as a natural part of identity formation.

### *Are nonbelievers angry?*

Another common perception is that atheism is triggered by anger *at* god. Applied to SCI, this might translate to a rejection of theistic belief over the perceived unfairness of one’s general SCI condition, or as a response to unanswered prayers for recovery. Given this interpretation, one might expect to find a great many de-conversions occurring post SCI. Contrary to expectation, all of the individuals in this participant sample had been nonbelievers prior to injury and for the majority of them SCI had no effect on their position. The changes in spiritual beliefs reported in previous investigations (McColl et al, 2002a; McColl et al, 2002b) were not observed here. Participants who reported any change at all in outlook reported a strengthening of atheism, which was generally seen as a positive experience, rather than one arising out of

anger or spiritual abandonment following injury. By contrast, most participants felt that their nonbelief helped them cope with their injury: rather than questioning the “meaning” or “purpose” to their disability, these respondents were quite comfortable with arbitrary accidents. Thus, for this sample, a nontheistic outlook on life provided a logical and coherent basis for integrating disability within a larger life context.

### ***The question of spirituality***

Four of the atheistic participants described themselves as spiritual and 6 described themselves as non-spiritual. In contrast to the findings previously reported by Ellison & Smith (1991); Riley et al. (1998); and Matheis, Tulskey, & Matheis (2006), the non-spiritual individuals in this sample did not differ significantly from the rest of the sample in any of the demographic characteristics or general happiness self-ratings. It is possible that individuals who consciously reject the need for meaning or purpose in life, who are comfortable with meaninglessness and confident in their own self-reliance, would rate just as highly on subjective and objective quality-of-life indicators as highly spiritual people, although more standardized data is needed to confirm or refute that hypothesis. However, this does indicate the possibility that traditional methods of assessing spirituality may fail to differentiate between *consciously* non-spiritual and traditionally non-spiritual respondents.

### ***Social relations***

Given the statistical and anecdotal evidence of anti-atheism in the general population (Downey, 2004; Koproske, 2006), it was anticipated that most of the individuals surveyed might have suffered some form of social hostility based on their nonbelief. However, the number of people reporting either overt religious discrimination or pressure to conform to a dominant faith was less than expected. It is reasonable to expect that nonbelievers would consciously or unconsciously avoid situations where they might encounter social hostility; nevertheless, a distinct minority of participants did experience discrimination or situations in which they could not discuss their atheism openly among significant others at least some of the time. It is also possible that the individuals surveyed had failed to recognize discrimination that was indeed present, or that anti-atheist prejudice was masked by other forms of prejudice (such as anti-disability, etc.). Without further data any interpretations would be entirely speculative.

### ***Limitations***

The main limitation to this investigation was the small sample size. Given the relative infrequency of nonbelievers in our society, participant recruitment was expected to be difficult, and there is no way to generalize these results onto the general SCI population. That all the participants were either Caucasian or Asian was not surprising, as Hispanic and African-Americans are much less likely to be nonbelievers (Ellison, 1997; Ellison, Hummer, Cormier, & Rogers, 2000; Ellison, Echevarria, & Smith, 2005). In

addition, only current nonbelievers participated in this investigation, so there is no data on the incidence of former atheists, i.e., individuals who converted from atheism to a religious faith following their injury, or individuals who de-converted and re-converted later. Further investigation with standardized quality-of-life assessments and a larger scale participant sample is indicated; however, recruitment issues may also make such research highly difficult. The results of this study, as such, remain highly exploratory.

### ***Clinical implications***

The results of this investigation indicate that nonbelievers constitute a distinct minority with characteristics that standardized assessments of well-being and adjustment may fail to detect. In contrast to the findings of previous studies of spirituality and adjustment, individuals who describe themselves as low- or non-spiritual do not necessarily experience lower than average subjective quality of life, if their atheism is seen as positive, stable and internally consistent.

While the characterizations of atheists discussed above may seem like convenient stereotypes within the context of this particular study, larger demographic surveys indicate that atheists as a minority group are misunderstood and often socially isolated (Koproske, 2006). It is hoped that the results of this study will encourage clinicians to examine their own assumptions and possible biases about atheists, and how these assumptions and biases might complicate therapeutic relationships with these individuals. Professional practitioners should take care not to allow negative feelings toward nonbelievers lead to potential abuses of religion such as coercion, stigmatization or proselytizing. Rather, clinicians should recognize that aspects of a consciously nontheistic outlook can be a source of strength in adjustment to trauma and disability. Developing an understanding of the ways in which committed nonbelievers cope can contribute balance to the study of spiritual coping in general and extends its benefits to an otherwise under-recognized population.

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**Feature Article****Spinal Cord Injury, the Body, and Narratives of Recovery in Mental Distress***Brett Smith, PhD***Abstract**

Drawing on data generated from a qualitative project that explores people's experiences of acquiring a spinal cord injury through playing sport, this article explores a group of men's narratives of emotional disruption. The manner in which they are recovering in depression is highlighted and the ways in which this process is influenced by personalized meanings tied to bodily control and other-relatedness are illuminated. It concludes by suggesting that the body as a lived, social, and material entity needs to be taken seriously.

**Keywords:** sport, recovery in mental distress, depression, the body

**Introduction**

Experiencing spinal cord injury (SCI) and becoming disabled is a traumatic and turning-point moment in the life of *any* individual. However, as Cole (2004) notes, even though people can have similar or identical neurological injuries, they can experience and respond differently to their new way of life following SCI. This is especially so when the individual has developed a strong athletic identity and have psychologically and socially invested heavily in developing and maintaining a particular kind of sporting body. For such individuals, the complex issues instigated by SCI as they attempt to reconstruct new body-self relationships over time are likely to be intensified and exemplified.

With this in mind, building on previous work (Smith, 1999; Smith & Sparkes, 2002, 2004, 2005, in-press a, b; Sparkes & Smith, 2002, 2003, 2005), this article draws on life-history data from a qualitative study to explore the stories a small group of men tell about their experiences of SCI through playing the sport of rugby union football and who are now disabled. Its purpose is to illuminate their narratives of mental distress, including depression. In doing so, it hopes to highlight how emotionally disruptive life experiences are embedded within and told through the body. As Stoppard (2000), Emslie, Ridge, Ziebland, and Hunt (2006), and Stepnisky (2007) suggest, despite depression being experienced in and through the body, research has generally neglected the embodied aspect of this distressful emotional experience. As a result, the body as simultaneously a material, lived, and social entity has been separated from depression.

In a similar fashion in relation to disability studies, Hughes and Paterson (1997) and Thomas (2007) note that researchers have largely ignored the corporality of disabled people. Yet, as Hughes and Paterson stress:

Disability is experienced in, on, and through the body, just as impairment is experienced in terms of the personal and cultural narratives that help to constitute its meaning...Most importantly, the (impaired) body is not just experienced: It is also the very basis of experience...Disability is, therefore, experienced from the perspective of impairment. One's body is one's window on the world (334-335).

In relation to disabled bodies, Thomas (2007) further argues that empirical work on disabled bodies is urgently needed since the lived experience of disability involves struggling not only with socio-structural barriers, but also with the psychosocial dimensions of life, the material body, and the effects of impairment. Indeed, for her, any attempt to understand the experiences of disabled people must start from, and engage with, people's bodies as lived, social, and biological entities.

Furthermore, Thomas (2007) highlights that when attempting to understand the experiences of disabled people we need to recognize that anyone who incurs a SCI might not experience disability as a tragedy. Likewise, over time they may not live in mental distress and with depression. This is echoed by Dorset and Fronek (2007) who note that we should be cautious about assuming that depression is an essential stage of successful adjustment and that it is inevitable that persons with SCI will become depressed. In this light, and given that this is a qualitative study with sparse data comparisons, it is important to acknowledge that the findings presented here may not be generalized to other persons. That is, this article makes no claims toward generalizing about the likelihood of incurring depression post-SCI in other persons. These issues need to be kept in mind in relation to what follows.

## **Methods**

This article focuses upon the life stories of fourteen, white, predominantly working-class men, aged between 26 and 51. Their years of age when they sustained a SCI ranged from 16 to 35. Having gained ethical approval from the University of Exeter (UK) Ethics Committee, initial contact was made with the participants via the English Rugby Football Union's support network for injured players. All of the participants were involved in confidential life history interviews conducted in their homes by the primary investigator (Smith & Sparkes, 2005; Sparkes & Smith, 2003). At the start of the first interview the nature of the project was explained and any questions answered. It was made clear that they were free to terminate an interview or withdraw from the project at any time without having to provide any reason for doing so. Further, it was agreed that pseudonyms would be used in all future publications.

During each interview, the primary investigator acted as an "active listener" in an attempt to assist the participant in telling their life story in their own way and in their own words. Each participant was interviewed three times in their own homes over a period of a year, with each interview lasting from two to five hours. All interviews were tape-recorded, transcribed, and subjected to categorical-content narrative

analysis (see Lieblich, Tuval-Mashiach, & Zilber, 1998; Smith & Sparkes, in-press a). This analytic technique seeks central themes, typologies or instances of paradigmatic categories within the narratives told. Here, the researcher looks for similarities in the data and then creates categories to organize the data as a collection of specific instances. This process also seeks to identify relationships among categories. The narrative analysis revealed the participants were *recovering in* depression and that two main body *action* problems—*bodily control* and *body-relatedness*—helped structure and shape the ways in which this group of men storied their experiences of living with depression and mental distress following SCI.

### **Narratives of recovery in mental distress: Body control**

All the men in this study stated that after SCI they experienced depression and were diagnosed by health professionals, including psychologists, as clinically depressed. However, despite the fact that the incident of SCI occurred many years ago, most (12 out of 14) of them had not recovered *from* depression. As Davidson and Roe (2007) note, recovery from serious mental distress “involves the amelioration of systems and the person’s returning to a health state following onset of illness” (p. 5). In contrast, they argue, the concept of recovery *in* depression “refers to the process of living one’s life, pursuing one’s personal hopes and aspirations, with dignity and autonomy, in the face of the on-going presence of an illness and/or vulnerability to relapse” (p. 6). In this sense, recovering is not conceptualized as a linear staged process of adjustment (Dorset & Fronck, 2007; Kennedy & Rogers, 2000). Rather, recovery in depression ebbs and flows, and is influenced by the psych-social world. Thus, it is seen as dynamic and interacting with psychosocial and environmental factors that mediate adjustment.

Accordingly, rather than identifying a point at which “remission” may be said to have occurred when one recovers from depression, all the men suggested they are in recovery. As an exemplar, Rob said.

I feel that I’m dealing with depression now. I’ve got dreams to work again, which I never had because depression consumed me, and stopped me dead. I can have some pretty good days now. But don’t get me wrong, I haven’t beaten depression. I still live with it. In fact, if I’m honest, I still suffer from very bad depression, and that’s eight years after the accident. Some days I’m a complete wreck...So, I certainly haven’t recovered from the injury, or from depression. I suppose I live in it, struggle with it day after day, and can slowly, or at the drop of a hat fall into it, into a big black hole.

For the men in this study, as these comments exemplify, rather than recovering *from* depression, a sense of being *in* recovery was experienced. At the same time, and in line with recovering in mental distress and emotionally disruptive experiences, all revealed they were vulnerable to a relapse into

depression. Notably for these men, relapsing into depression, or not, was partly tied to how they respond to, and the meanings they attach toward, the impaired body's *actions of control*.

According to Frank (1995), the corporeal character of bodies is an obdurate fact. That is, bodies are real, material entities. However, we also experience their existence and our emotions within and through our bodies. Further, he notes, our bodies both socially shape and are shaped by society. Given such issues, the body can never experience itself simply in any way it chooses nor do what it always wants: we are always susceptible to experiencing constraints on what our bodies can feel and do. In other words, having and being a body always involves certain problems, and each problem is a problem of action. Following SCI, one action problem that confronted all the men, and which impacted significantly on their potential to relapse into depression, involved the issue of *control*—assessing how predicable the body's performance will be. As Frank notes, everyone must ask, particularly when disabled or ill, “Can I reliably predict how my body will function; can I control its functioning?” Thus, the question of control suggests the body is lived along a continuum from what he terms *predictability* to *contingency* at the other end. Predictability involves controlling the body whereas contingency is the body's condition of being subject to forces which cannot be controlled. The prominence of control, and how it might impact on recovery in depression, is highlighted in the following comments by Doug:

As an athlete, my body was totally predicable. I had control over it 100%. Now it feels like I have zero control over it. This can be hard for disabled people, and for sports people in particular because we've had control over our bodies and put so much of our lives into making the body controllable so as to play sport and perform in it as best as we can. So when you lose control over the body, its functions, and not being able to pick something up, and such like, or losing control of your bowels, then it hits you hard. It really has hit me hard mentally, and I've come to realize that after nine years of being disabled, control is still one of the biggest things I have to deal with...It's a key thing if you're going to stop yourself falling into depression and help stay on track in recovering. The main point is how you deal with the problem of control that spinal injury throws at you. Do you accept it can't be got back, or do you struggle to live without control? So what control means is key in recovering and living with the possibility of depression.

As these comments suggest, prior to SCI the participant's body defined who they were and their capacity to control it was highly predicable. However, SCI shatters this. This is because SCI is itself a loss of predictability, and it causes further losses: muscle strength, breath adequacy, bladder control, bowel control, temperature regulation, limb movements, and all the other “real corporeal effects” of being and having an impaired body (Thomas, 2007). Thus, SCI results in moving from a body that is predictable in its control toward having and being a body that is contingent. That said, as Doug's comments above also

indicate, there are important differences in how the men responded to this change and the effects of impairments that went with it. That is, there were differing *meanings* (Dorset & Fronek, 2007). For some, over time it was accepted, whilst for the majority of this limited sample, it was not. This difference on what control means, and how acceptance is made sense of, moreover, had implications in terms of one's vulnerability to relapse into depression. With respect to the majority of the participants, when their bodily predictability was shattered, *but* they could not accept the body's contingency, they often relapsed into depression. While it is admittedly unusual for bowel dyscontrol to result in public "accidents" when appropriate care routines are followed, Paul, who has continued problems with this issue, commented:

As a rugby player, playing sport all my life meant that I had my body under control. I could predict what it would do, and was always confident in social settings with it. Now though, that's been shattered because of the spinal injury. The body now feels like a complete mess. Whereas I used to have everything under control, now the body feels totally out of control. I can't seem to predict what it will or won't do. And what you have to remember is that when you've played sport and you're used to controlling the body and putting so much of yourself into this, then when you break your neck, the damage done to yourself and your mental health is huge. So being concerned about controlling my body, controlling my body functions, and especially in public, is something that is really important to me, and, despite living like this for nearly ten years, is something that hits me everyday day. I don't think I'll ever come to terms with not being able to control the body, and it means so much to me to get it back. It really does affect me, and I don't think I'll recover from feeling depressed until I can control my body. I can't accept this is how I'll live for the rest of my life. I can't accept that I can't control my body. I hate it. I have no spontaneity, I have no movement. I can't chat with people eye to eye. Horrible. And it makes me feel very depressed, especially when things go wrong, like losing control of my bowels in public.

As these comments suggest, SCI is a loss of predictability, causes further physical losses, and subjects the body to forces which cannot be controlled. All of which can help facilitate experiences of depression. Importantly, however, these biological matters, this movement toward a highly contingent body and experiences of mental distress, do not take place within a psychosocial vacuum. They also come to mean something, psychologically and socially, to the participants as they strive to accept and live everyday in, through, and as, an impaired body. These meanings tied to acceptance, in turn, help shape one's experiences of recovery in mental distress. That is, for the majority of the participants, they can relapse into depression, or become highly vulnerable to depressive episodes, when control of the body is lost *and* the body's contingency cannot be accepted. The majority of participants further indicated that this situation can be accentuated in certain social contexts. As another example, Colin suggested that a relapse into

depression can occur when one moves from the back or private regions to front or public regions (Goffman, 1963) of the social world.

It's been ten years since I broke neck, and you'd think I would have got used to having no control over my body and accepted that. But no. No. If I could have one wish right now, apart from walking again, it would be to get more control of my body back. I was so used to having it when I was played sport. I was the ultimate machine. Now, I'm a broken machine...I hate it. And I don't say this lightly, and I'm still seeing the doctor, I get very depressed still. And part of that, a large part often, is due to the fact I can't control the body. It's depressing. It often forces me into a situation in which I can't, or won't, leave the house. I can't trust my body, what it will do, or won't. Despite all this political correctness, and stuff, people notice when I crap myself, when I lose control of my bowels, am in a wheelchair and can't walk, and I can feel them looking...I can see how horrified they are, just like I am, and when I'm in public like this, ohhh, the smell, the embarrassment, even when I'm just sitting in my chair. I get very embarrassed, and struggle badly. It's hard work trying to talk to people, or trying not to let it bother me. But it does, and it can depress me, seriously depress me...When I get back home, I feel so low, and start brewing on it, trying to mentally move my legs, or pick something up off the floor, which is stupid really, because it frustrates me more and can send me into a bad depression. I just want more control and then I'd feel happier, or wouldn't be as depressed about life and my situation.

The comments above draw attention not only to the biological aspect of SCI, but also to certain psychosocial aspects of becoming disabled through sport and how these may contribute to recovering in mental distress and relapsing into depression. For example, they highlight the social pressure to control the body and how failure to do this and maintain somatic norms or ideals requires considerable emotional work (Hochschild, 1983) and can restrict positive adjustment outcomes. Further, Wendell (1996) contends that in a society that idealizes the body, people who cannot come close enough to the ideals or norms, and those whose bodies are out of control, become devalued people because of their devalued bodies. They are also “constant reminders to the temporarily ‘normal’ of the rejected body—of what the ‘normal’ are trying to avoid, forget, and ignore” (p. 91). This can result in the marginalization of disabled bodies and their withdrawal from mainstream society which, in turn, suggests Wendell, can limit positive adjustment outcomes to emotionally distressful experiences.

Therefore, it would seem that for the majority of the participants, when control of the body is lost *and* the body's contingency cannot be accepted, relapsing into depression can occur or, at least, they become more vulnerable to this. However, two participants (David and Doug) storied their experiences differently. Indeed, whilst control was important, what it meant to them was often very different. Instead of

a crisis of control and not accepting bodily contingency, they adapt to the body's contingences and accept them as part of the fundamental contingency of life. This acceptance has implications for positive adjustment outcomes and potential for relapsing into depression as part of the process of being in recovery. As David commented:

All bodies have limitations, and we have to accept that some are more controllable than others. That's difficult to say being an old sport man, but that's simply how it is, and you have to accept that. But accepting that can be difficult. I've seen a lot of disabled people not accept it, and they are the ones that really seem to struggle with living a happy life. I've managed to realize that getting control of my body, my legs, my bowels, being pushed sometimes in a wheelchair by someone else, not being able control who I see sometimes because its too cold outside, is part of being disabled. I accept that now, and that's been a huge benefit as I don't get depressed, frustrated, or angry when I can't control my body or when it goes wrong in public. Accepting this, for me at least, has made me feel mentally much stronger, and helps stop me sliding into depression...It helps me live with it and keep it in the background.

In contrast to the other men noted earlier who had a deep rooted need for control and predictability, and who could not accept the body as being subject to forces it could not control, for David and Doug, bodily contingency is accepted. Here, bodily predictability comes to be regarded as exceptional, and contingency comes to be accepted as normative. Notably, for David and Doug, accepting this does not lead to them to relapsing into depression, but instead helps them in making positive adjustment outcomes in terms of recovering in depression and moving toward feeling less vulnerable to relapse. Indeed, their comments suggest that an over-emphasis on bodily predictability can lead to a situation that restricts opportunities to accept bodily contingency and, in turn, becoming 'psychologically healthy.' Accordingly, for David and Doug, bodily contingency was not a problem, but a possibility. It was not something to be overcome by reasserting predictability, but an opportunity to develop both different and differently valued body-self relationships which, in turn, helped them to recover in depression and keeping it in the background of their life narrative.

Of course, this process of development, accepting contingency, and developing positive adjustment outcomes is not easy. Indeed, as if to challenge the ways in which accepting contingency might romanticize SCI, David and Doug made comments that pointed toward a number of embodied dilemmas and problems associated with consumed time and ingested time (see Sparkes & Smith, 2003). Their stories about the body act as a further antidote to any tendency, by others, to oversimplify accepting bodily contingency and recovery in depression. For example, David commented, "I accept that I can't control my body. But sometimes, occasionally when I've had a bad day, I might think a little more control would be

good. That's rare though, because that's not a very healthy way to look at disability and deal with it."

Likewise, Doug said:

My body is a human one, and I accept that I'm not superhuman now. I accept my body can't always be controlled, and it isn't possible to control it no matter how hard I might try or train it...I can say, hand on heart, that accepting that I won't walk again and that I won't be able to control the body has been a very positive experience, and challenge. It's made me realize that I need to enjoy life now, and that it's possible get through an awful injury like I suffered and feel good about yourself...Don't get me wrong though, it can still be tough, and there are occasional moments when I think a controlling my body would be nice. But, that won't happen. And thankfully I don't think like that often, which is good, because it's healthier to accept that the body is disabled and does things you can't control...Accepting that helps me. I certainly don't fall into serious depression like I used to when I was concerned about my lack of control, especially when out with people. Like I say though, it can be difficult because society puts a lot of pressure on you to have this perfect body, and resisting that can be tough. But, I try, and do manage it, which helps keep me mentally stronger and stops me from falling into depression again.

Accordingly, following SCI through playing sport, the participants are recovering in mental distress rather than from it. This process, and the possibility of relapsing into depression, is partly influenced by the action problem of bodily control and what this means for a person. For the majority of the participants, they seemingly cannot accept the body's contingency and wish to regain predictability. This, however, has some costs in terms of emotional distress. Two people, in contrast, accept varying degrees of contingency. For them, a predictable body is now an illusion and striving for control means hindering recovery in mental distress. Thus, control as a bodily action problem and how one interprets it has implications for mental health and recovering in depression.

### **Narratives of recovery in mental distress: Other-relatedness**

Another key body action problem that helped shape the participant's process of recovering in mental distress, intimately connected to control, is concerned with what Frank (1995) terms *other-relatedness*. This refers to the way in which a body relates to other bodies. It is conceptualized in terms of whether the body is *monadic* and closed in on itself or *dyadic* and constituted through either communicative or dominating relations with others. In terms of being monadic in its other-relatedness, and the ways this can contribute to how mental distress is experienced in, through, and out of their bodies, the following comments by Nick are illustrative.

After the injury, I became a loner, and still am, which is the complete opposite to how I was as a sportsman. But, going out in public can take so much planning, and then I worry and get depressed about my body, can I control it or not, and so I don't go out much. I don't have many relationships, or friends. No wife or girlfriend, and I keep people at a distance. So it's a lonely existence being disabled. I can't seem to shake this feeling off, or bring myself to socialize or be with others. I keep people at a distance, and don't let them in my life. Even if I can summon up the energy, or feel better or good in myself, y'know, mentally, in the head, I still struggle. And when I do go out, I'm always on the edge of things. Sitting down here in a wheelchair means I struggle to hear people and can't engage in a conversation with them, or catch the flow of what's being said. So more often than not, even if I'm there, at a party, I'm very isolated and on the edge of it all. In fact, by the end of a night, I'm by myself in the corner. That really gets to me. I go home, and can sink into the most awful depression....I've got worse in pushing people away too. I don't know why, but I push people away, and end up isolating myself even more. I'm my own worst enemy, and end up contributing to my own depression.

For the majority of the participant's, as these comments suggest, their body can in certain situations be fundamentally monadic in its relation to other bodies. Here, their body is closed in upon itself and isolated rather than connected and existing in relation of mutual constitution with others. Furthermore, even when their body is sometimes among others, it is not *with* them. In the short term, this monadic relationship sometimes had little impact on their mental health. This was especially so when time out was needed from the rest of the world to sort one's feeling out and untangle thoughts. As Frank (2005) notes, it's *sometimes* important to be left alone and leave others alone "so that we can be ourselves, unmerged with others' expectations and demands for who we are supposed to be" (p. 299). In the long term, however, a monadic relationship seemed to impact negatively on the process of emotional recovery and making positive adjustment outcomes. Indeed, as their comments suggest, it can help facilitate the experience of depression.

That said, these men did not always adopt a monadic relationship with other bodies. At times, the body was *dyadic*, but notably in differing ways. For twelve of the fourteen men, *dyadic* relations meant *dominating* relations. That is, a relation of being *against* others. For example, Mark commented

My life is a total contrast to my life before the injury, when I played sport. Back then I was a very social person. Now I spend most of my time inside at home. I don't speak with many people now, go out, and have fun with people. I don't want to be with anyone now. And those people that do try and help, or want to be friendly, or carer's or social workers, when they try to become my friend, I don't want that. I don't want their sympathy. I tell them that too. I must admit too that I

sometimes get rather nasty with them. Maybe not nasty, but angry, and vent my frustrations out on people. Which, perhaps, isn't good because I feel bad afterward and it can make me feel terrible which, again, when you're depressed, that just doesn't help. It makes matters worse.

It would seem, therefore, that when bodies like those above perform a dyadic relation *against* others, rather than *for* others, their emotional health suffers. Indeed, as Frank (1995) argues, this dyadic stance can be dangerous since the body can turn on others as well as on themselves. In doing so, it may isolate others and push other bodies away that could be potentially valuable as sources of social support to help maintain the process of being in recovery, limit one's vulnerability to relapsing into depression, and help in making positive adjustment outcomes.

Yet, not all men adopted a dominating dyadic relationship in which their bodies were *against* others. For two (David and Doug), their bodies were most often *for* others. Importantly, this dyadic relationship seemingly helped buffer relapsing into depression. At the same time, it contributed to the process of living in recovery and developing a positive sense of mental health when disabled. For example, David suggested that reaching out to other bodies as a way of being, sharing stories with them, and actively receiving emotional support from others when required, had positive outcomes for his mental health.

Sport can make you feel invincible. Becoming disabled has been tough in that department, but I've come to be in a better place than when I was able-bodied. I'm concerned with other people now whereas before it was all 'me, me, me'. Don't get me wrong, I'm still concerned about myself. But I'm also concerned with other people, helping them, listening to their problems, teaching them that it's okay to be disabled, and not just to the kids at the school where I work. I'll listen to anyone, try to talk with them, and be there. I suppose it's a kind of sharing and teaching. The world might be a better place if we all tried that, communicating more, and being there for each other. I know one thing; it's helped me through a lot of tough times. It's helped me claw my way out of the depression I was in after breaking my neck, and helps me now on those days when I feel as though I might slip back into feeling depressed. So, talking, being there for others, and listening, that can all help, and I would never underestimate the power of it all.

Whilst the majority of the men developed monadic relationships and acted against others, for David and Doug, there is an emergence of a communicative body acting *for* others, and connecting in a dyadic fashion with them (Frank, 1995). Thus, they are not only cared for, but as dyadic storytellers, they also care for others. Their injuries become the source of the potency of their stories. Through their stories, David and Doug create empathetic bonds between themselves and their listeners. These bonds expand as the stories are retold. At the same time, they do not neglect themselves. As such, they engage in what Beck

and Beck-Gernsheim (2002) term *altruistic individualism*. That is, in being dyadic for others and with their own bodies, they pursue their own self-interests while being genuinely concerned with other people. Their decision-making thus remains individualist, but it also shows considerable concern for others. They develop a moral calling centered on telling their stories and communing with other bodies. All of which can help them in recovering in emotional distress and making positive adjustment outcomes.

### **Conclusion**

In this article, rather than creating a disembodied picture, two embodied ways in which a group of people who have suffered SCI through playing sport narrate their experiences of recovering in emotional distress have been highlighted. It was revealed that these stories of recovery and vulnerability to relapse into depression were shaped partly by what has been termed bodily control and other-relatedness. Despite the men drawing upon these bodily matters to help them understand and impose order on their experiences, important differences were identified in what they meant for, and the influences they had, in the process of recovering in mental distress and reconstructing body-self relationships.

For the majority of men, moving from a predictable body to a contingent body, and the physical and psychosocial problems that were associated with this movement, was difficult to accept. This, it was suggested, helped contribute to their relapses into depression. Contributing further to this process was their monadic relationship along with dyadic relationships that were against other bodies. In contrast, for two men, bodily contingency was accepted and a dyadic relationship with and for other bodies emerged. This acceptance and way of relating for other bodies were regarded as positive contributing factors for recovering in mental distress, for minimizing one's vulnerability to relapsing into depression, and for encouraging a more communicative relationship with bodies (Frank, 1995).

Of course, these bodily action problems are not the only ways that shape how a person deals with recovery and what this means for them. Further, as stressed in the introduction, we should be cautious about generalizing these findings to other persons' and assuming that depression and emotional distress is inevitable for anyone who incurs a SCI. All that said, for the participants, body control and other-relatedness, and what these personally mean for them, do seem to play an important part in this process. As such, they, and the ways in which people make sense and meaning of these bodily matters, need to be taken seriously by health professionals. Therefore, effective clinical interventions need to consider the role of the body in recovery from emotional difficulties and what embodiment means to a person as they cope with SCI over time. This may compliment a focus on coping strengths which, according to Dorset and Fronek (2007), are therapeutic and contribute to enhanced psychosocial and health outcomes (see also Glass, 1999). To further appreciate and develop all this however, further work is needed. For example, whilst statistically there are significantly fewer women that acquire a SCI through playing sport, research exploring their experiences is required. Further, questions remain regarding the processes by which people,

such as the men in this study, move from being in recovery, to recovery from mental distress, and how shifts between these occur. Clearly, it is beyond the scope of this article to address such issues. It remains, however, that the body as a lived, social and material entity matters and needs to be taken seriously when dealing with mental distress and the clinical implications that ensue.

**Acknowledgments**

Thanks to the reviewers for their informed and careful comments. Thank you also to the fourteen men interviewed for allowing me into their lives and for their permission to write about them.

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## Feature Article

### **Caregiver Stress: Taking Care of the Caregiver**

*Anthony Spillie, LCSW, and Jason Mask, LCSW*

#### **Introduction:**

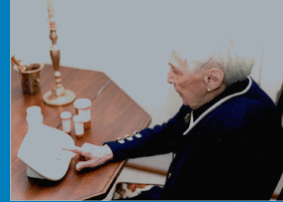
Family care is the most important source of assistance for individuals with a spinal cord injury or impairment. Over 90% of these individuals reside in family dwellings in the community and maintain their independent community living through the assistance of family caregivers. This assistance, however, can come at a tremendous cost to the caregiver in the form of caregiver stress or burnout. Caregivers who experience excessive stress may be at risk of isolation, work strain, emotional and physical health problems, financial strain, and family relationship problems. Caregivers of individuals who are spinal cord injured are especially at risk due to the heavy physical care needs and the duration of providing care over the individual's lifetime.

#### **Telehealth Project:**

In 2006, the Edward Hines, Jr. VA Hospital Spinal Center initiated a Care Coordination Home Telehealth (CCHT) project for veterans with spinal cord injuries and/or impairments. The project maintains veterans' health status using in-home messaging devices which track responses to specific disease dialogues, e.g., HTN, DM, COPD, and CHF. These responses are stratified according to risk levels (low, moderate, high) as well as categorized according to factors impacting the risk level (behavior, symptoms, knowledge). Each factor points toward a specific type of intervention. Behavior problems require the evaluation of non-compliance. Symptoms require the evaluation of the medical condition. Knowledge deficits require re-education. A total of 31 veterans with spinal cord injury participated in the project in 2006. Specific participants were identified based on their high use or high cost of hospital and outpatient care and services. These veterans ranged in age from 45 to 75, were predominately quadriplegic, and had difficulty in managing one of the designated medical conditions.

# Health Buddy® Appliance

- ✧ button self-explanatory action
- ✧ No computer skills required
- ✧ Delivered directly to patient's home
- ✧ Easy to hook-up with telephone
- ✧ Non-intrusive
- ✧ Lifestyle flexible
- ✧ Daily patient partnering
- ✧ Timely patient education
- ✧ Tested with a broad range of patients



## Decision Support Tools: iCare Desktop™

You are viewing sessions for Jul 23, 2003 in the "All Programs" program. Date: ☰  
 26 responses have been received and there are 3 non-responding patients.

Patient	Response Time	Symptoms	Behavior	Knowledge	General
Patel, Krishna	02:58 PM PDT	High	High	High	None
Chamura, Mark	03:38 AM PDT	High	High	Medium	None
Lake, John F.	03:07 PM PDT	High	Medium	Medium	None
McAllister, Troy	01:09 PM PDT	High	Medium	High	None
Rameo, Julie R.	10:43 AM PDT	High	Medium	Medium	None
Zimman, Mary M.	05:14 AM PDT	High	Medium	Medium	None
Schmidt, Anna	02:17 AM PDT	Low	High	Medium	None
Fish, John F.	11:46 PM PDT	Medium	Medium	Low	None
Flock, Kimberly	06:19 PM PDT	Medium	Low	Medium	None
Garden, Herb E.	03:20 AM PDT	Medium	Low	Medium	None
Kawahara, Aolani	12:56 AM PDT	Medium	Low	Medium	None
Smith, Anna N.	07:22 PM PDT	Medium	Low	Medium	None
Soprano, Michael J.	05:29 PM PDT	Medium	Low	Medium	None
Rubenstein, David	01:02 AM PDT	Medium	Low	Medium	None
Kawahara, Aolani	09:31 AM PDT	Medium	Low	Low	None
Chen, Ying	06:36 PM PDT	Medium	Medium	Medium	None
Linton, Lloyd L.	03:00 PM PDT	Medium	Medium	Medium	None
Nguyen, Thanh	02:57 PM PDT	Medium	Medium	Medium	None
Parish, Jason M.	03:00 PM PDT	Medium	Medium	Low	None
Chen, Angela	09:38 AM PDT	Medium	Low	Medium	None
Garcia, Jose	03:07 PM PDT	Low	Medium	Medium	None
Jones, Barbara	01:09 PM PDT	Low	Medium	Medium	None
LeSur, Vincent A.	10:43 AM PDT	Low	Medium	Medium	None
Rodriguez, Francisco L.	05:14 AM PDT	Low	Medium	Medium	None
Smith, Elle	02:17 AM PDT	Low	Medium	Medium	None
Spencer, Sharleen A.	11:46 PM PDT	Low	Medium	Medium	None

[Back to top](#)

Health Hero Network - Microsoft Internet Explorer

Results Date: 06/01/2001 Submit Results: ☰

Results of Day 2 of Month 10 from Health Hero 12 mth CHF Program  
 Taken on Friday, Jun 01, 2001 12:16 AM America/Chicago

Risk	Question	Response	Category	Aspect
	Hi! Well Thank you for coming back! Your Health Buddy is here for your health. Begin when you are ready.	continue	General	None
low	Did you weigh yourself today?	Yes	Behavior	Weight
	What is your weight today? (Use the arrows to indicate your weight)	122	Symptoms	Weight
medium	This is somewhat higher than your usual weight. This could be a sign of fluid retention. Be sure you remember to limit your salt intake and take your medications as prescribed by your doctor.	Okay	Symptoms	Weight
low	Yes or no: I have recently fallen while checking my weight.	No	Symptoms	Weight
	Excellent! Be sure to let your doctor know if you ever have a fall for any reason, especially if you are injured.	continue	Behavior	Weight
high	Do you have any more shortness of breath than usual today?	Yes	Symptoms	Dyspnea
	Increased shortness of breath can	OK	Symptoms	Dyspnea

## Identification of Stress:

An important outcome measure in the project was the perceived stress levels of the family caregivers who provided care to manage the veteran's specific disease conditions. Two instruments have been used to measure these levels: the Zarit Burden Scale and the Caregivers Strain Index. The Zarit Burden Scale consists of twelve questions with four screening questions to determine a caregiver's high risk for stress. The Caregiver Strain Index is a series of thirteen items which are used to evaluate the need for introduction in the areas of financial, personal, emotional and physical strain.

## Measurement Tools

### Zarit Burden Scale

Patient ID:	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) DO YOU FEEL that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
2) DO YOU FEEL stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) DO YOU FEEL angry when you are around your relative?	0	1	2	3	4
4) DO YOU FEEL that your relative currently affects your relationship with family members or friends in a negative way?	0	1	2	3	4
5) DO YOU FEEL strained when you are around your relative?	0	1	2	3	4
6) DO YOU FEEL that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) DO YOU FEEL that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4
8) DO YOU FEEL that your social life has suffered because you are caring for your relative?	0	1	2	3	4

9) DO YOU FEEL that you have lost control of your life since your relative's illness?	0	1	2	3	4
10) DO YOU FEEL uncertain about what to do about your relative?	0	1	2	3	4
11) DO YOU FEEL you should be doing more for your relative?	0	1	2	3	4
12) DO YOU FEEL you could do a better job in caring for your relative?	0	1	2	3	4

**Comments about the survey:**

**Care Coordinatior:**

**Date:**

### *The Caregiver Strain Index*

I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

	Yes=1	No=0
Sleep is disturbed (e.g., because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it s a long drive over to help)		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g., because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of		

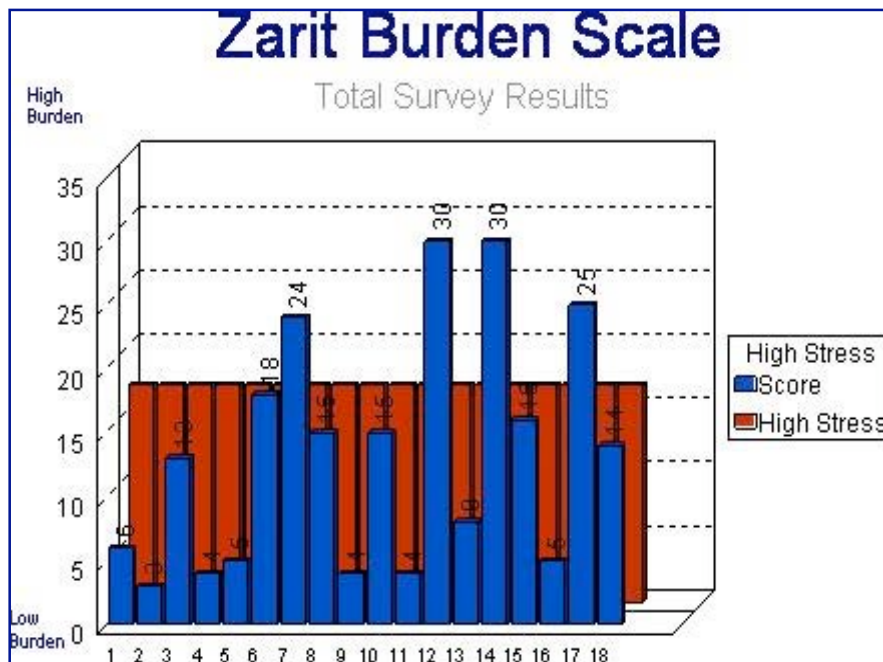
severe arguments)		
Some behavior is upsetting (e.g., because of incontinence; _____ has trouble remembering things; or _____ accuses people of taking things)		
It is upsetting to find _____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be )		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
<b>TOTAL SCORE</b> (Count yes responses. Any positive answer may indicate a need for intervention in that area. <b>A score of 7 or higher</b> indicates a high level of stress.)		

**Outcome Data:**

The families of all 31 CCHT SCI veterans were contacted and asked to complete the two caregiver stress measurement tools. A total of 18 family caregivers completed the questionnaire. The remaining 13 SCI veterans did not have a family member providing care and consequently were not appropriate to participate in this outcome measure. Outcome data for the Zarit Burden Scale is displayed in Graphs 1 and 2 and for the Caregiver Strain Index in Graph 3.

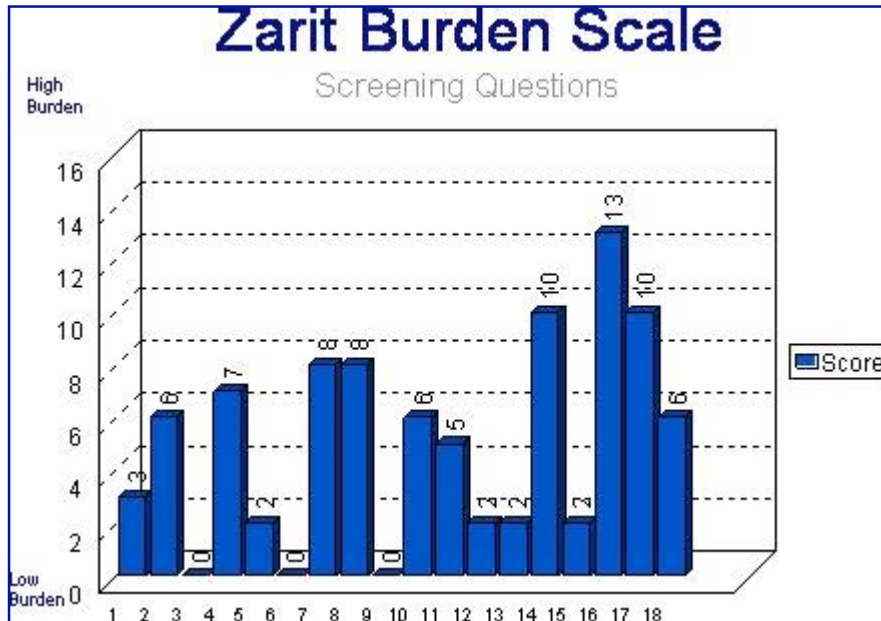
The first graph focuses on the four screen questions of the Zarit Burden Scale with a score of 8 reflecting a high caregiver burden requiring follow-up and possible intervention. Four of the participants had scores reflective of a perceived high burden (8,12,14,10) while 5 other participants had scores close to the tipping point of a score of 8 (7,7,6,6). This means that 50% of family caregivers expressed concerns about the stress generated by their caregiver efforts. Specific areas of stress included: not having enough time for themselves, feeling stressed between caring for the veteran and trying to meet other responsibilities and feeling uncertain about what to do about the veteran’s caregiver needs in the future.

Graph No. 1



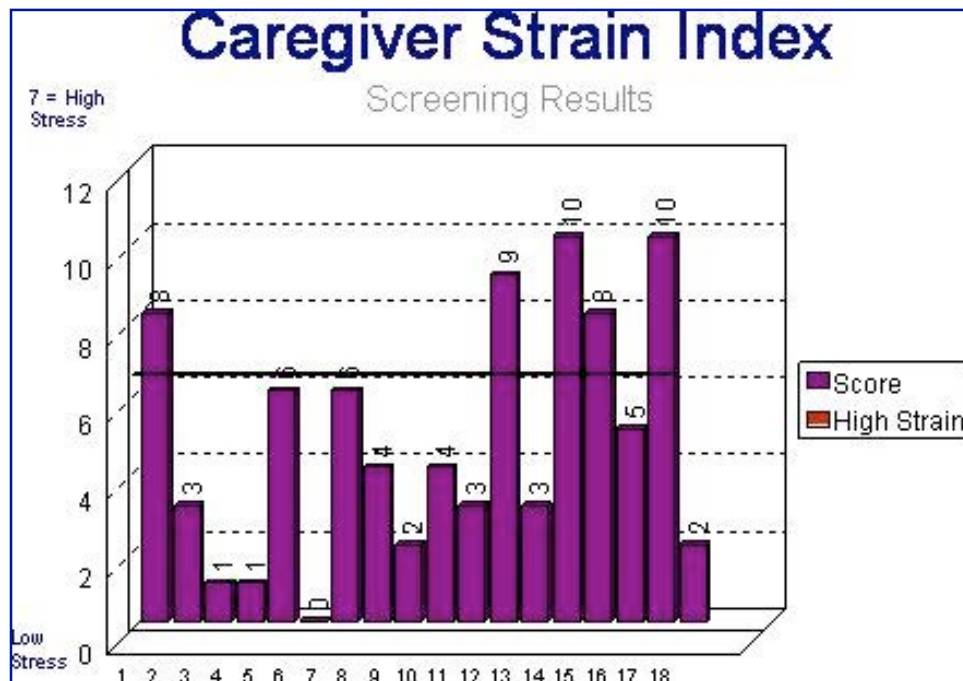
The second graph displays the total score of each participant with a score of 17 indicating perceived high burden on the part of the caregiver. A total of 10 participants demonstrated major concerns about the burden of their caregiver duties with 5 caregivers expressing extremely high scores (18, 24, 30, 25, 30). These concerns focused on: lack of privacy, limited social life, little control over own life, and negative impact on other family relationships.

**Graph No.2**



The third graph illustrates the level of perceived strain regarding caregivers take that caregivers have found to be difficult. A score of 7 or higher indicates a high level of stress. Five participants exhibited high levels of stress (8, 9, 10, 8, 10) with two additional caregivers close to a high level (6, 6). Causes for these high levels ranged from disturbed sleep patterns to the time demands of caregiving to physical and emotional strain to feeling completely overwhelmed.

Graph No. 3



**Interventions:**

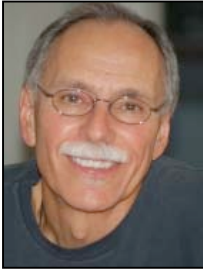
Family caregivers identified specific consequences to providing caregiving services. These consequences were both positive and negative. Benefits to caregiving included satisfaction with helping a family member and developing new skills. Challenges ranged from loneliness and social isolation to strained relationships to financial hardship. Supportive contact was provided to enhance the positive feelings regarding caregiver benefits. Specific interventions were directed at the challenges of caregiving to reduce their negative impact. These interventions included the provision of information and referral services regarding caregiving resources, short-term counseling, caregiver education, skills training regarding stress management, problem solving and effective communication and respite care resources.

*Anthony M. Spillie, LCSW, is a Social Work Executive at Hines VA Hospital in Hines, Illinois. Jason Mask, LCSW, is Editor of SCI Psychosocial Process and is Acting Assistant Chief, Spinal Cord Injury Service at Hines VA Hospital.*

## President's Message

### A Time of Transition

*Lester Butt, PhD*



Wishing all AASCIPSW members a healthy and prosperous New Year.

It goes without saying that these times can be characterized as a most challenging period in our history. However, as we mental health professionals know, challenging times are likewise times of opportunity.

As many of you know, subsequent to our 2007 Annual Conference in Kissimmee, Florida, the Tri-Associations (American Paraplegic Society, American Association of Spinal Cord Injury Nurses, and the American Association of Spinal Cord Injury Psychologists and Social Workers) held a Strategic Planning Meeting. This meeting was comprised of three representatives from each of the Tri-Associations, in addition to Paul Tobin and Vivian Beyda from United Spinal Association and Tom Stripling from Paralyzed Veterans of America (PVA). An external organizational consultant from Washington, D.C., who had been part of this process virtually from its inception, moderated this session. AASCIPSW's representatives included Jason Mask, President Elect; Terrie Price, Immediate Past President; Helen Bosshart, former Past President; and myself. During these sessions, a multitude of topics were considered, including but not limited to, necessary and essential fiscal changes, organizational restructuring, planning for the upcoming 2008 and 2009 Annual Conferences, and relationships with our fiscal partners, i.e., United Spinal and Paralyzed Veterans of America.

During our time together, there were tangible decisions upon which there was consensual agreement. For example, in order to provide a more integrated 2008 Annual Conference, the Strategic Planning Council established the Joint Program Committee (JPC) which likewise was composed of three representatives from each of the Tri-Associations. AASCIPSW's representatives include Nancy Benjamin, Alan Goldberg, and Stan Ducharme. In addition to representatives from the Tri-Associations, the JPC will also include individuals from the Therapy Leadership Council, (TLC) which represents the disciplines of occupational and physical therapy. It is the belief that our conference is best served if there exists a more accurate reflection of a true multi-disciplinary rehabilitation team. This more representative JPC convened in mid-January to construct our 2008 Annual Conference. The conference will consist of four concurrent tracks occurring within the same time frames to allow participants to seamlessly move from one lecture to another. The four tracks will reflect a presentation from each of the Tri-Associations and TLC. In addition, there will be keynote speakers presenting to all conference participants as a total group. We believe this will offer an exciting and educationally rewarding program.

The Strategic Planning Council (SPC) is planning subsequent meetings to continue our dialogue surrounding organizational issues. “Economy of scale” dictates that we consider various organizational possibilities. Within our present schema, there is significant duplication of Tri-Association activities. This redundancy leads to unnecessary expenditures that must be constructively addressed. It is the pledge of the SPC that we will consider alternatives in structure that preserve professional identity, maintain conference excellence, reduce duplicative costs, and continue the tangible opportunities for networking. As more specifics are established, we will assuredly inform the membership of these developments.

One of the important issues for the future revolves around our heightened financial independence as an Association. For decades, AASCIPSW and the other Associations have been the recipients of incomparable generosity, formerly by Eastern PVA and presently via United Spinal Association. While support, both personnel-wise and financially, will continue to exist from United Spinal, it is imperative that we begin to exhibit more fiscal self-determination for our operation. As a result, we have established the Financial Committee to investigate and explore additional funding sources. Involved with this committee are Scott Richards (Chair), Berne Brucker, Dan Rohe, Steve Wegener, Barry Nierenberg, and Lester Butt. If any of the members have ideas in this regard, please contact Scott Richards at [Richards@uab.edu](mailto:Richards@uab.edu).

There are invaluable gifts that can be offered by AASCIPSW membership. I urge all interested parties to consider applying for the Board of Directors or an Association committee. This is an excellent way to repay, in part, United Spinal’s generosity.

Other manners of giving exist as well. I would strongly encourage members to solicit at least one additional professional to consider applying for AASCIPSW membership. Not only does this add richness to our membership but also assists with our bottom line. Our renewal application for membership will be presently mailed. I hope that all members will consider giving additional money to our unrestricted fund. This helps our Association in innumerable ways to subsidize necessary activities and functions.

In addition to the support from United Spinal and Paralyzed Veterans of American, we continue to look for additional organizations that share our vision, e.g. assisting those with spinal cord injury and compromise. Again, if you have ideas in this regard, please feel free to contact any member of our Board of Directors or me directly at [lbutt@craighospital.org](mailto:lbutt@craighospital.org).

It is a pleasure to again serve AASCIPSW during this time of transition. I trust those who remain in our ranks are similarly committed to maintaining the highest caliber of care for those with spinal cord injury. Presently, we need your energy, expertise, and willingness to devote to our Association’s longevity. Many of us have received extraordinary blessings by virtue of our involvement with AASCIPSW. This might have taken the form of professional opportunities, networking, and/or conference attendance and associated grants. It is now our turn to reciprocate. Let us collectively render this time of transition one that will be remembered for our involvement and opportunistic ingenuity.

**Lester Butt, PhD**

**Craig Hospital**

## News Briefs

Irmo Marini, PhD



### Senate Urged to Restore ADA's Purpose

Advocates both in support and opposition of the Americans with Disabilities Restoration Act of 2007 gave testimony in mid-November to members of the U.S. Senate Committee on Health, Education, Labor and Pensions. Senator Tom Harkin of Iowa and former US Attorney General Dick Thornburgh both advocated for Senate Bill 1881, which would essentially bring the language of the ADA in line with existing laws such as civil rights. If the bill becomes law, the legislation would remove a number of barriers, which until now have prevented countless persons from winning, or even filing, ADA suits. Until recently, courts have focused on requiring that plaintiffs prove their level of disability rather than whether discrimination has occurred. Steven Orr from Rapid City, South Dakota alleged that he was fired by his employer for having Type-1 diabetes but the court ruled he did not have a disability and was not protected under the ADA. Senate Bill 1881 changes the language in civil rights law so that it would prohibit discrimination “on the basis of a disability” instead of “against an individual with a disability” as it currently reads. For the opposition, Chicago attorney Camille Olson argued that if the Bill becomes law, it would so broaden the scope of the ADA that nearly anyone could be protected.

### California Courthouses Sued for Inaccessibility

In San Bernardino, California, five wheelchair users are suing the San Bernardino County and its Superior Court for noncompliance with the ADA. The group cited numerous accessibility problems at 11 courthouses, including parking, courtrooms, witness stands, clerk filing windows, restrooms, cafeterias, and elevators. Plaintiffs allege that the courtrooms have not kept up with the 17-year-old ADA and are also in violation of California's Constitution, and both the First and Fifth Amendment.

### World News

**Pyongyang, North Korea**—An unnamed United Nations human rights official alleges that people with disabilities are routinely gathered up by the government and sorted by disability to be sent off to segregated camps called “Ward 49” where they are subjected to inhumane conditions including torture, starvation, and preventing certain groups from marrying. Persons with disabilities who attempt to leave the country are apparently subjected to undisclosed harsh punishments.

**Toronto, Ontario**—The father of an 11-year-old boy was released from a minimum security prison after drugging and strangling his son, supposedly to save him from what the father described as a “living hell,”

after his son was diagnosed with epilepsy. Forty-eight year-old David Carmichael was released to the custody of his mother, despite several psychiatrists' warnings that Carmichael was a significant risk to the public. The boy, Ian Carmichael, had been taking the medications which had kept him seizure-free for several months until his death.

**London, England**—In a related story, a London court released a man after tying a plastic bag around his wife's neck and waiting 30 minutes for her to die. The judge sentenced David March to only nine months in prison for allegedly assisting in his wife's suicide after she was diagnosed with multiple sclerosis. March had been facing a 14-year sentence. Details of the judge's decision were not released.

*Irmo Marini, PhD, is an assistant professor with the Rehabilitation Counseling Department at the University of Texas–Pan American in Edinburg, Texas.*

## Practice Resources

### Resources for Children and Adults with Diseases of the Spine

*Allyson L. Morch, BA*

Children affected with spinal muscular atrophy and other muscle-related diseases of the spine may be eligible for services through the Muscular Dystrophy Association (MDA). Diseases covered by the MDA include motor neuron diseases, myopathies, neuromuscular disorders such as complications related to muscular dystrophies, diseases of the peripheral nerves, and immune system related disorders. Visit [www.mda.org/disease/](http://www.mda.org/disease/) for a complete list of diseases covered by the MDA.

One of the unique services offered by MDA is summer camp. Hosted annually at various locations throughout the United States, these overnight camps are scheduled for a one-week stay and are of no cost to the family. Eligible children are between the ages of 6 and 21 years and are affected by one of the 43 diseases covered by the MDA. This fantastic opportunity allows for these children to participate in activities that may not ordinarily be available to them, including fishing, swimming, horseback riding, canoeing, crafts, sports, and other outdoor activities. It is also a chance for these children to interact with compassionate personal volunteers and relate to peers with similar challenges. To obtain more information about these camps visit [www.mda.org](http://www.mda.org) or call 1-800-572-1717.

MDA also hosts over 200 specialty clinics at hospitals across the country for all ages and diseases covered under this non-profit organization's umbrella of neurological disorders. The clinics are staffed by multidisciplinary teams consisting of services such as neurological consultation, physical therapy,

nutritional counseling, respiratory therapy, occupational therapy, genetic counseling, social work services, wheelchair specialists, and other disciplines depending on the affiliated hospital. These clinics are especially useful for those who are uninsured or have financial struggles. In order to be eligible for services, an individual needs a diagnostic statement or referral from a physician.

Other services provided by the MDA include research, clinical trials, events, support groups, public health education publications, on-line chat groups, equipment loans, and funding for some medical equipment. The monetary support for medical equipment includes funding for wheelchairs and leg braces, repairs and modifications, and communication devices. The loan program provides medical equipment such as Hoyer lifts and wheelchairs regardless of age or employment status. For more information regarding these services visit [www.mda.org](http://www.mda.org).

### **Other resources for children**

The National Dissemination Center for Children with Disabilities (NICHCY) serves as the nation's source of information for children with disabilities. This site provides a listing of service organizations and resources on disabilities and research in each state. It also provides information on laws and accommodations such as the No Child Left Behind Act as it relates to children and disabilities. For more information on NICHCY visit [www.nichcy.org](http://www.nichcy.org)/ or call 800-695-0285.

Families of Spinal Muscular Atrophy (FSMA), is a service organization dedicated specifically to this disorder. Located on the web at [www.fsma.org](http://www.fsma.org), this site offers a wide range of resources for children and adults. It provides links for home renovations, accessible design, adaptations, and equipment that can be useful for people with disabilities. Diagnosis, genetic testing, public forums, and clinical trials are other areas of involvement for FSMA and this organization may be reached at 800-886-1762.

Parent Project Muscular Dystrophy is a non-profit organization that focuses specifically on Duchenne and Becker Muscular Dystrophy. Parent Project addresses educational, emotional, and advocacy issues at great length. There is also information on the physical aspects of the disease such as surgery, scoliosis, splinting, and bracing. Extensive information is made available on treatment options, clinical trials, and current research news. This organization can be contacted at 800-714-KIDS or on the Internet at [www.parentprojectmd.org](http://www.parentprojectmd.org).

Kids On Wheels serves as an educational site for children and parents on the web at [www.kidsonwheels.us](http://www.kidsonwheels.us). This site hosts parent forums for children affected with cerebral palsy, spinal bifida, muscular dystrophy, spinal cord injury, and osteogenesis imperfecta. For children, there are question and answer columns, message boards, and a quarterly magazine. It also serves as a great source for parents and teachers for advice from rehabilitation and other medical professionals.

## **ALS organizations**

The ALS Association, or ALSA, is a non-profit organization dedicated specifically to Amyotrophic Lateral Sclerosis. ALSA provides support groups, ALS centers, clinics, and events. There are clinic centers located throughout the United States that provide specialized care for patients with ALS. For more information on ALSA visit <http://www.alsa.org/>.

The Les Turner ALS Foundation is an independent non-profit organization at the Northwestern University Feinberg School of Medicine in Chicago. Areas of specialty include support groups, professional in-home consultation, communication and durable medical equipment programs, respite grants, and education initiatives. The clinic team at Northwestern University provides state of the art care for those affected with ALS, and can be visited on the internet at [www.lesturnerals.org/als.htm](http://www.lesturnerals.org/als.htm).

The Muscular Dystrophy Association also provides research, clinical trials, and funding for ALS. Bi-monthly magazines are published and made available to registered participants along with several other educational guides for ALS. Equipment funding for wheelchairs and communication devices are made available for those diagnosed with ALS. The MDA also has an equipment loan and donation program for wheelchairs, communication devices, and other adaptive equipment for the home. For more information, visit, [www.als-mds.org/](http://www.als-mds.org/).

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## **Commentary**

### **An Overview of Coping Among Individuals with Spinal Cord Injury**

*Adam A. Milz, BA and Samuel T. Gontkovsky, PsyD*

Spinal cord injuries (SCI) have an incidence rate of 4.5 out of 1,000 (Hirtz et al., 2007) and, like other serious neurophysiological and neuropsychological injuries, are life-changing events for the individual. Anxiety and depression are common sequelae of SCI, both in the acute and long-term recovery stages, necessitating an awareness of post-injury psychological functioning on the part of clinicians (Kennedy & Rogers, 2000). Often, drastic post-injury adjustments must be made by the individual and his or her family in order to manage the emotional and physical toll that is effected by such injuries. The importance of coping strategies among individuals with SCI has become increasingly recognized through the years (Buckelew, Baumstark, Frank, & Hewett, 1990).

Adjusting to SCI has historically been viewed as a sequential process that occurs in stages. This view has been criticized, however, because it assumes that depression and other forms of psychological distress are common and expected responses (Buckelew et al., 1990). In comparison, Galvin and Godfrey (2001) reviewed the application of the Stress Appraisal and Coping (SAC) model to spinal cord injury rehabilitation populations. The SAC is a “process formulation for explaining an individual’s ability to cope with, and adjust to, life stress” (p. 616), which the authors argued is particularly suited for the SCI population. They also postulated that the SAC model could possibly be a unifying model of adjustment for individuals with SCI that can guide research and treatment in this area.

Coping strategies play a critical role as mediators in the SAC model. Broadly speaking, coping can be dichotomized into two main types: emotion-focused and problem-focused (Lazarus & Folkman, 1984). Emotion-focused coping occurs when individuals feel unable to change the situation and thus attempt to regulate their emotional responses. Problem-focused coping occurs when the person feels that the situation can be controlled and responds with attempts to manage the stressor.

Hanson, Buckelew, Hewett, and O’Neal (1993) explored the relationship between coping and adjustment in a sample of persons with SCI five to six years post-injury. They found that in general the participants had higher levels of psychological distress at that five-year follow-up period than what is found in the general population, suggesting that adjustment to a spinal injury is a long-term process. Their results also suggested that coping with SCI is a dynamic rather than static process, as the importance and effectiveness of specific coping strategies change over time. For example, individuals reporting high levels of self-blame on the Ways of Coping-Revised questionnaire (Felton & Revenson, 1984) during the acute recovery stage reported higher levels of psychological dysfunction at that time. However, despite stable levels of self-blame between the acute and five-year follow-up periods, this strategy ceased to be correlated with psychological distress at follow-up.

Hanson et al. (1993) also found an increase in the use of cognitive restructuring techniques over a five-year span. At follow-up, the use of cognitive restructuring strategies was positively correlated with the participants’ acceptance of their disability, suggesting that the use of active coping strategies like cognitive restructuring is more adaptive than passive ones, such as wish-fulfillment fantasy. Incorporating active strategies in general, and cognitive restructuring techniques specifically, can thus be effective in helping individuals with SCI reduce psychological distress during the short- and long-term recovery phases.

In more recent research, Elfström, Rydén, Kreuter, Taft, and Sullivan (2005) examined the relationship between coping strategies and health-related quality of life (HRQL) among persons sustaining traumatic spinal cord lesions. In general, the authors found that coping was a correlate of HRQL, again suggesting that adaptive coping should be an emphasis in SCI rehabilitation programs. Specifically, greater acceptance, in which the individual reevaluates life values, and less social reliance, where the person exhibits independent behaviors, led to better HRQL. Buunk, Zurriaga, and González (2006) examined how

social comparison related to coping among an SCI sample. Downward contrast, where people contrasted their situation with someone who was worse-off, was positively correlated with constructive coping wherein people thought positively about their situation and tried to deal with it directly. Less adaptive social comparisons included downward identification, or the perception of worse-off others as a potential future, and upward contrast, feeling bad after seeing others that are well-off; both positively correlated with wishful thinking and blaming others. Upward contrast, specifically, was related to the increased levels of depression.

Buckelew et al. (1990) attempted to identify specific coping strategies used in a sample of 57 persons with SCI with differing levels of psychological distress participating in a rehabilitation program. Among those with more psychological distress, wish-fulfilling fantasy, emotional expression, self-blame, and threat minimization were used more commonly than among those with lower levels of distress. Among the individuals with lower levels of distress, cognitive restructuring strategies were the most commonly employed, suggesting that techniques such as reframing strengths and weaknesses and the establishment of rehabilitation goals were more effective than self-blame and emotional expression. Further, the authors found that among their participants, self-blame was most associated with psychological distress, which is somewhat at odds with past findings (e.g., Bulman & Wortman, 1977; Taylor, 1983).

In another example of paradoxical findings, Frank et al. (1987) performed a cluster analysis in a sample of persons with SCI and found rather contradictory results. Individuals with external health attributions who relied on the seven specific strategies that encompass the Ways of Coping Questionnaire—Problem Focused, Wishful Thinking, Mixed, Growth, Minimization of Threat, Seek Social Support, and Self-Blame (Folkman & Lazarus, 1980)—reported higher levels of depression and psychological distress than those who endorsed internal health attributions and relied less on the specific coping techniques. These results suggest that increased use of coping strategies paradoxically leads to higher levels of distress, possibly as a result of the individual not believing in, and relying on, internal resources.

Despite these contradictory findings, it appears that a SAC model can be successfully applied to SCI populations in treating post-injury psychological distress. King and Kennedy (1999) developed a group-based Coping Effectiveness Training (CET) program that was based on the Lazarus and Folkman (1984) cognitive theory of stress and coping. The program consisted of four primary components: appraisal training, cognitive-behavioral coping skills training, strategies for choosing the correct match between appraisal and coping techniques, and obtaining/maintaining social support. Individuals with SCI enrolled into the group showed significantly greater reductions in both depression and anxiety than the matched controls both immediately following the intervention and at a six-week follow-up, despite the fact that the group members generally did not use different coping strategies than the controls. Additionally, the group members did not show significant changes in the coping strategies used over time. Qualitative

data suggested that interactions with other persons with SCI were particularly meaningful for the group members.

Using the CET group program with a different SCI sample, Kennedy, Duff, Evans, and Beedie (2003) also found the intervention to be effective in significantly reducing levels of depression and anxiety. Additionally, they replicated the earlier findings that there was no significant change in coping strategies used by the group members. The authors did find, however, that the group members changed their negative appraisals of the implications of suffering from a spinal cord injury. The intervention was successful in decreasing the discrepancy between the ideal self and true self, and the ideal self without injury and the true self. The authors argued that these improved appraisals of their situations helped the group members perceive the implications of their injuries as manageable.

## Conclusion

As the research suggests, coping is a critical component of post-injury rehabilitation in cases of SCI. Logically, this makes sense as Buunk et al. (2006) noted, “[s]ustaining a traumatic spinal cord injury... involves a major change in all aspects of one’s life. An individual’s life is permanently altered resulting in a broad range of physical and emotional challenges” (p. 791). Accordingly, more research is needed to further elucidate the relationship between coping and psychological adjustment to spinal cord injury, especially in light of certain discrepancies in the existing literature concerning specific coping techniques used by this group. Additionally, research is necessary to explore the relationship between hope and coping among individuals with SCI in light of research by Chang and DeSimone (2001) indicating significant associations between coping strategy and both hope and appraisals. Continued establishment and implementation of coping-based interventions such as King and Kennedy’s (1999) CET program into post-injury rehabilitation will also be a critical component of treating individuals suffering from this traumatic event.

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## Selected Abstracts from the 2007 AASCIPSW Conference

### **208 Amyotrophic Lateral Sclerosis: The Needs & Quality of Life of the Family Caregiver**

*Mary Tederous Williams, PhD, RN; James P. Donnelly, PhD; Tomas Holmlund, MD; and Michael J. Battaglia, DO*

**Aims:** The goals of this study were to develop a model of the needs of the amyotrophic lateral sclerosis family caregivers, to assess the quality of life (QoL) of family caregivers, to examine the relationship of identified needs, and QoL to patient & family characteristics.

**Methods:** This study was conducted in three phases: 1) ALS family caregivers ( $N = 19$ ) seen in a multidisciplinary ALS clinic were asked to identify their needs since the time of ALS diagnosis of their family member; 2) The resulting 109 unique needs were printed on individual cards and sorted by 12 of the caregivers; 3) The needs were rated on importance by the same 12 caregivers who completed the sorting. The caregivers also completed a brief standardized measure of health-related quality of life (SF-8). The sort data were analyzed in two steps: 1) Nonmetric multidimensional scaling (MDS); 2) Cluster analysis of the MDS values for each need. The SF-8 data was analyzed in relation to the needs ratings, patient and caregiver characteristics.

**Results:** The MDS produced an interpretable solution with a stress value of .36. The cluster analysis resulted in a four map of ALS caregivers needs: Stage 1: Early Coping & Adjustment; Stage 2: Maintenance; Stage 3: Transition to End Stage; and Stage 4: Coping with Change & Loss. Results further indicated that the symptom presentation of ALS in the caregiver's family member was associated with lower levels of mental and physical health relative to national means, particularly for patients with initial bulbar symptoms ( $p = .03$ ). Additionally, caregivers who resided with their family member with ALS and responsible for 24-hour care had poorer mental ( $p = .04$ ) and physical health ( $p = .02$ ) than ALS family caregivers that did not live with the ALS family member.

**Conclusions:** The data from this study of caregiver needs suggest there is a predictable pattern of specific needs, and that QoL for caregivers is related to characteristics of the patient's disease, living arrangements and other differences. Future studies should examine the relationship of need satisfaction to QoL as well as the potential of caregiver support programs to meet identified needs and improve QoL.

#### **Objectives**

- To learn about ALS (amyotrophic lateral sclerosis) as it relates to the uncertainty of families dealing with a chronic illness that is terminal
- To learn about the needs of ALS family caregivers
- To understand from the ALS families, their quality of life from their perspective

## **211 State-of-the-Art Psychological First Aid**

*Annette M. Bailey, PhD, MSW, ACSW, LCSW*

During times of natural and man-made disaster, individuals with SCI/D are among the most vulnerable members of our communities. This presentation provides an overview of some of the unique issues faced by individuals with disabling condition(s) and/or disease(s) and their families during disaster. Emphasis will be placed on understanding some of the unique social-emotional and developmental issues for individuals with SCI/D (and their support system) such as caregiving, preparation and planning, and the possibility of emotional vulnerability during disaster.

Clinical in nature, this presentation will also present techniques and strategies for

“psychological first aid” which is an intervention protocol from the field of disaster mental health.

Psychological First Aid is a state-of-the-art intervention that can be used to address the need of individuals with SCI/D during times of violence, disaster, and terrorism. Case examples will be shared to apply theoretical information to work with individuals with SCI/D.

Psychological First Aid is an evidence-informed approach used to assist people after violence, disaster, and terrorism. It is being used to reduce initial distress, and to foster short and long-term adaptive functioning.

It can be used not only with survivors and individuals affected by disaster but also with first responders, primary and emergency health care providers, disaster relief organizations, and community organizations in diverse settings.

The World Health Organization, American Red Cross, National Center for Post-Traumatic Stress, the National Center for Child Traumatic Stress, SAMSA, and U.S. Department of Health and Human Services have replaced Critical Incident Stress Debriefing (CISD) with Psychological First Aid due to the potential for iatrogenic harm to CISD participants. “Factors such as listening to others describe the incident, being forced to think about the incident, and being forced to discuss the incident can actually increase stress levels possibly leading to vicarious traumatization and worsening of stress symptoms.”

### **Objectives**

- Identify the unique issues that are likely to affect individuals with SCI/D (and their support system) at times of violence, disaster, or terrorism.
- Identify psychological first aid as an intervention.
- Outline practical strategies for using psychological first aid to address the needs of individuals with SCI/D—including ways to consider modifying current practices to address their unique needs during disasters.

## 304 Outcomes and Properties of the Patient Health Questionnaire Measure of Depression (Part 1)

James S. Krause, PhD; Chuck Bombardier, PhD; and Susan Newman, BSN

**Background:** The purpose of this study was to identify the underlying factor structure of the Patient Health Questionnaire-9 (PHQ-9), endorsement rates of specific depressive symptoms, and prevalence of major depressive disorder (MDD) during inpatient rehabilitation after spinal cord injury.

**Research Design:** Survey. The setting was a large specialty hospital in the Southeastern United States. The PHQ-9, a 9-item screening measure of major depressive disorders based on DSM-IV criteria, was administered a median of 43 days after SCI onset.

**Methods:** There were 568 participants who met three inclusion criteria: (a) traumatic spinal cord injury, (b) 16 years of age or older, and (c) assessed during inpatient rehabilitation.

**Results:** The results indicated that 21.7% screened positive for probable MDD, and 11% reported symptoms that would meet DSM-IV MDD criteria. Factor analysis revealed two factors, one of which reflected three somatic symptoms. These three items were the most highly endorsed items, including sleep disturbance (33.6%), poor energy (33.0%), and appetite disturbance (30.6%). Few scores were observed at either extreme of the symptomatology spectrum, as only 9.5% reported no depressive symptoms and 2.5% reported extreme symptomatology scores (20-27; scale range is 0-27). Item endorsement was unrelated to time between injury and assessment.

**Conclusions:** Validity of diagnosis of MDD during inpatient rehabilitation with the PHQ-9 may be compromised by exaggerated endorsement of somatic symptoms which could lead to misdiagnosis and overestimates of depressive disorders. The limited number of scores at the extreme ends of the scale and the absence of a relationship between symptom endorsement and days between SCI onset and assessment suggests that depressive symptoms may not begin to crystallize until after the initial hospitalization.

### Objectives

- Identify the most frequently cited symptoms of depression during inpatient SCI rehabilitation.
- Identify the primary threat to validity when using the PHQ-9 during inpatient SCI rehabilitation.
- Have an understanding of whether the PHQ-9 likely overestimates or underestimates depressive symptomatology during SCI inpatient rehabilitation.

Funding Source: NIDRR Grant #H133N060009

## 304 Factor Structure of the PHQ-9 Screen for Depression Varies with Time Since Injury among Persons with Spinal Cord Injury

### (Part 2)

Elizabeth J. Richardson, MA and J. Scott Richards, PhD, ABPP

**Objective:** The overlap of somatic-depressive symptoms and physical sequelae of SCI has raised concerns regarding validity of depression screens used within this population. The Patient Health Questionnaire-9 (PHQ-9) is a measure that parallels DSM-IV criteria of major depression. We investigated the PHQ-9

factor structure among persons with SCI at various times post-injury, hypothesizing two factors would emerge early post-injury.

**Design:** Principal axis factoring with Varimax rotation, alpha coefficients for internal consistency.

**Setting:** University of Alabama at Birmingham Model SCI System and the National SCI Data Center.

**Participants:** 2,570 participants at one year ( $n = 682$ ), five years ( $n = 517$ ), 15 years ( $n = 653$ ), and 25 years ( $n = 718$ ) post-injury.

**Outcome Measure:** PHQ-9.

**Results:** A two-factor solution emerged one year post-injury, with primary and secondary factors reflecting cognitive and somatic items respectively. One-factor solutions emerged at five and 15 years. At 25 years post-injury, a two-factor solution again emerged with somatic and cognitive items loading on primary and secondary factors respectively. All factor scores negatively correlated with satisfaction with life.

**Conclusions:** The PHQ-9 factor structure varies with time post-injury in the SCI population. Somatic item endorsement appears ambiguous early and late, but still reflects depressive symptoms.

### **Objectives**

- Share research results regarding self reported depressive symptoms via Patient Health Questionnaire-9 (PHQ-9) among persons with spinal cord injury with various lengths of injury duration.
- Aid in elucidating the validity of the PHQ-9 depression screen in the context of possible confounding physical sequelae of spinal cord injury.
- Promote awareness and interest in further examination of somatic-depressive symptoms and physical sequelae of spinal cord injury.

Funding Source: Supported by grant #H133A 011201 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitation Services.

### **307 Reflection and Conversation On Psychotherapy**

*Stephen Wegener, PhD, ABPP and Lester Butt, PhD, ABPP*

While much attention has been given to the study of adaptation, psychopathology, and psychological responses to spinal cord injury, relatively modest efforts are devoted to improving psychotherapy skills. The question naturally arises as to whether contemporary clinical training, which emphasizes techniques, strategies, and quantitative assessments and is, in the process, losing sight of the nonspecific factors that result in a successful psychotherapeutic encounter. While there is a need to pursue evidence-based therapies, it is held that enhancing nonspecific aspects of psychological contacts build a therapeutic alliance that provides the essential fulcrum for behavior change. This workshop will reflect upon and discuss key questions in psychotherapy when working with persons with SCI.

These include, but are not limited to the following: What barriers do we as professionals inadvertently construct that prevent us from genuinely connecting with others? How does the skilled therapist move past their own preconceptions of disability? How do we meet the needs of the patient rather than meeting our

needs as professionals? How do shortened lengths of stay and current business models impact our psychotherapeutic interactions? How do we garner knowledge about the lives, personal narratives and stories of patients through the process of psychological consultation? How do we more fully appreciate the individualized and connotative meaning of the SCI to the person? Workshop participants will engage in a reflective and interactive conversation on the following topics:

- (1) Reflection upon their approach and style to psychotherapy.
- (2) Reflection upon how the initial psychological contact is conducted?
- (3) Discussion of the important factors that create a constructive therapeutic alliance.
- (4) Appreciation how language facilitates receptivity, intimacy, trust, mutuality and relationship building with patients in rehabilitation settings.
- (5) Appreciation of the necessity for rehabilitation professionals to embrace both biological as well as biographical information, moving from seeing the person as a patient to seeing the patient as a person.
- (6) Understanding constructive and ill-advised roles rehabilitation professionals employ in their practices.
- (7) How various organizational structures utilize mental health services in their treatment milieu and how these models can differentially impact the success and value of the psychotherapeutic process.

## **Objectives**

- Reflect upon their approach and style to psychotherapy.
- Appreciate how language facilitates receptivity, intimacy, trust, mutuality and relationship building with patients in rehabilitation settings.
- Understand constructive and ill-advised roles rehabilitation professionals employ in their practices.

## **P1 The Measurement of Spirituality in SCI: Differences Across Age Groups**

*Martin Forchheimer, MPP*

Increasingly, spiritual well-being has been accepted as an important component of quality of life. Several studies have explored the use of pastoral approaches to enhance physical and emotional well-being. Key to these activities is successful measurement of spiritual well-being.

One instrument that has been used among people with SCI is the Functional Assessment of Chronic Illness Therapies—Spiritual (FACIT-SP). It contains two scales: Meaning and Faith. Using factor analysis, Forchheimer and Tate found that the dynamics of the FACIT-SP were similar in a large sample of people with SCI to the established norms. While this suggests that the FACIT-SP measures Faith and Meaning similarly among people with SCI on average, it does not indicate that these scales measure spirituality consistently and appropriately among people at different maturational stages. If it does not, use of the FACIT-SP may lead to systematic mis-inference.

This study addressed this issue using data from subjects who participated in a large study of aging with SCI ( $N = 358$ ). Subjects were divided into three groups, based on current age: under age 40; between 40 and 50; and over 50. Factor analysis with Varimax rotation was conducted in each group. In the youngest group, a three factor solution resulted: the established Faith scale; a factor comprised of the FACIT-SP Meaning

items with a cognitive orientation, e.g., “I find meaning in life”; and an emotion-oriented factor, e.g. “I feel at peace with myself.” For the middle aged group, a two-factor solution emerged, Faith and Meaning, which was identical to that previously reported in SCI and the population as a whole. For the oldest cohort, spirituality appears to have been interpreted as a largely unidimensional construct. Ten of the 12 items including all of the faith items clustered onto a single factor and no common theme linked the remaining two items, one having a cognitive and one an emotive orientation. This study suggests that assumptions of constant dimensionality of the FACIT-SP over time are inappropriate. More significantly, it suggests that the very way people think about spirituality may change with maturation, with implications reaching far beyond interpretation of the FACIT-SP.

**Objectives**

- To learn about the FACIT-SP, a measure of spirituality developed for people with health limitations
- To understand the results of the study’s factor analyses
- To understand the range of implications of these study results

Funding Source: National Institute on Disability and Rehabilitation Research

**P04 Gender-related differences in Persons with Spinal Cord Injuries and Disorders**

*Sherri L. LaVela, MPH, MBA; Frances M. Weaver, PhD; and Mara Stankiewicz, BS*

**Background:** Due to the small number of females with SCI/D, women have typically been underrepresented in research. This study describes gender differences for a range of disease prevalence and quality of life issues among veterans with SCI/D.

**Research Design:** National cross-sectional survey.

**Methods:** The survey was distributed to veterans with SCI&D who use and do not use VA health care services. Chi-square and *t*-tests were used to assess differences in individual characteristics, disease prevalence, and health status/quality of life measures by gender. Findings were stratified by age.

**Results:** Analysis included 4,199 individuals with SCI/D (female = 129; male = 4,070). Asthma was higher in females in both age groups (age < 55: 19% vs. 11%,  $p = 0.0211$ ; age > 55: 24% vs. 9%;  $p = 0.0005$ ). Females under 55 less commonly reported high blood pressure (HBP) than did males (20% vs. 32%,  $p = 0.0247$ ); however this difference did not exist for individuals aged 55 and older. Among those aged 55 and older, coronary heart disease (CHD) was significantly higher in women (30%) compared with men (16%),  $p = 0.0100$ ; but not for the younger group. Hepatitis C was more prevalent in males (10%) than females (1%) in those under age 55, ( $p = 0.0176$ ). There were no statistically significant gender differences in the prevalence of diabetes, high cholesterol, heart attack, stroke, or gum disease. Females aged 55 and older reported more days when their physical health was not good (16 vs. 12 days,  $p = 0.0087$ ). Days with pain was significantly higher in older women than men (17 vs. 12 days,  $p = 0.0049$ ), as were days without enough sleep (14 vs. 9,  $p = 0.0049$ ); but neither pain nor sleep difficulties differed by gender for those younger than 55.

**Conclusions:** Pain, lack of sleep, and poor physical health were perceived to be worse among older females. Highly prevalent asthma in women of all ages and CHD in those 55 years and older, in addition to hepatitis C and HBP among males under 55, deserve attention. Tailoring of services may be required to meet the specific needs of individuals with SCI&D based on gender and age.

### **Objectives**

- Participants will be able to identify diseases/conditions prevalent in persons with SCI/D.
- Participants will understand differences in disease prevalence, health status, and quality of life among persons with SCI/D.
- Participants will be better equipped to develop health care and prevention strategies that address complexities that differ by gender and age in persons with SCI/D.

Funding Source: This material is based upon work supported by the Office of Research and Development, Health Services Research and Development Service of the Department of Veterans Affairs, Quality Enhancement Research.

## **P5 The Effect of Alcohol Use on Unintentional Injuries Post-Spinal Cord Injury**

*Sherri L. LaVela, MPH, MBA and Bridget Smith, PhD*

**Background:** Alcohol use after a SCI has been associated with increased risk for medical complications and adverse rehabilitation outcomes. The objective was to assess the effects of alcohol use on unintentional injury (UI) occurrence post-SCI.

**Research Design:** National, cross-sectional questionnaire.

**Methods:** The mean number of UIs in the past year, since SCI, and the number of hospitalizations resulting from UIs were calculated for levels of drinking. A zero-inflated negative binomial model (ZIB) was used to examine the association between individual characteristics and drinking behavior with UI (discrete counts). The percentage change in expected counts for each variable was computed in those who had at least one UI. 87

**Results:** Respondents included 3,417 veterans with SCI; the fitted model included 2,874 with complete data. Nearly 20% had at least one UI in the prior year, 44% of which indicated multiple UIs. Since SCI, 61% had at least one IU, among which 64% had at least one IU-related hospitalization. Nearly 40% consumed at least one drink in the past 30 days; the average number of drinks per day was 2.2. Overall, 4% were chronic and 10% binge drinkers. The ZIB showed that the expected number of UIs increased by 39% for veterans with at least one chronic disease (IRR = 1.39; 95% CI: 1.03-1.87;  $p = 0.031$ ). Persons with paraplegia were at greater risk for UI within the prior year and had an expected UI count 48% higher (IRR = 1.48; 95% CI: 1.15-1.89;  $p = 0.002$ ) than those with tetraplegia. Days of poor physical (IRR = 1.024; 95% CI: 1.010–1.039;  $p = 0.001$ ) and mental (IRR = 1.041, 95% CI: 1.029–1.054,  $p = 0.000$ ) health within the past month was associated with higher numbers of UIs during the prior year. As the mean number of drinks per day increased, the expected number of UIs increased by 19% (IRR = 1.19; 95% CI: 1.10-1.28;  $p = 0.010$ ).

**Conclusion:** Many have experienced one or more post-SCI UIs and UI-related hospitalizations. UIs can strain the individual (decrease functioning) and the health system (avoidable costly visits). The findings showed that risk for IUs increased as the number of monthly drinks consumed increased. Alcohol use, and the effects on UI, warrants further study.

### **Objectives**

- Participants will be able to describe alcohol consumption patterns in persons with SCI.
- Participants will be able to describe occurrence of unintentional injuries after SCI and UI-related hospitalizations.
- Participants will understand the effects of alcohol use on unintentional injury occurrence post-SCI.

**Funding Source:** This material is based upon work supported by the Office of Research and Development, Health Services Research and Development Service of the Department of Veterans Affairs.

### **P6 Does Substance Use History Correlate with Pressure Sore Occurrence During Inpatient Rehabilitation?**

*Ann Marie Warren, PhD; R. Lance Bruce, MD; and Timothy Elliott, PhD, ABPP*

**Objectives:** To examine the relation of substance use history with pressure sores occurrence among persons with spinal cord injuries during their inpatient rehabilitation program.

**Design:** Cross-sectional analyses of archived data collected from patients admitted to an inpatient rehabilitation program for recent-onset, traumatically-acquired SCI.

**Setting:** Rehabilitation hospital in a metropolitan setting.

**Participants:** 112 men and 48 women with SCI (average age = 40, range 14–88 years old). Most participants had either a paraplegic injury ( $N = 64$ ) or tetraplegia ( $N = 71$ ); 46% of the sample had an ASIA grade of D, C or B and 44% had an ASIA grade of A. The ethnic composition of the sample was predominately Caucasian (65%); blacks (13.8%), Latinos (10%) and Asian/Pacific Islanders (5%) were also represented. The majority of participants did not have a pressure sore during the inpatient stay (64%), but 36% of the sample were diagnosed with at least one pressure sore.

**Main Outcome Measure:** Presence of pressure sore was coded as none (0) or as at least one pressure sore (1).

**Results:** Younger patients (35 vs. 43.11 years) were more likely to have a sore; women were less likely ( $p$ 's < .05). Greater tobacco use was significantly associated with greater alcohol use (.37) and with lower cognitive FIMS at admission (-.19). Pressure sore occurrence was more likely among persons with tetraplegia. Persons with a pressure sore had lower motor FIMs (15.41 vs. 28.59) and lower cognitive FIMs (28.20 vs. 30.1) at admission, and they had longer lengths of stay (54.33 days vs. 33.33 days;  $p$ 's < .05). A logistic regression model (using forward entry procedure) revealed motor FIM scores at admission and being male predicted pressure sore occurrence, correctly classifying 72.1% of the sample with and without a pressure sore.

**Conclusions:** Men and persons with lower FIM motor scores may be particularly at risk for pressure sore occurrence during initial rehabilitation for SCI. However, this study indicates that tobacco use and alcohol use history may have no association with pressure sore occurrence during initial rehabilitation.

### **Objectives**

- Examine the relationship of substance use and pressure sores of those with traumatic spinal cord injury.
- Examine the relationship between FIM scores and pressure sores during inpatient rehabilitation.
- Examine the variables correlated with pressure sores during inpatient rehabilitation

### **P23 Coping Effectiveness Training Group (CET) for Acute SCI in a Veteran/Military Population**

*Jennifer J. Duchnick, PhD, and Elizabeth Letsch, PhD*

**Introduction:** The challenges posed by living with spinal cord injury are numerous, yet acutely injured patients may lack the skills for successfully coping with stress associated with the demands of management of injury. Chronic stress can have a negative impact on both emotional and physical health. Additionally, the use of maladaptive coping strategies, such as stress-related alcohol use, can contribute to problems with health, relationships, and overall quality of life. Psychoeducational and cognitive-behavioral stress management interventions may be useful in minimizing negative health effects of stress following SCI.

**Objective:** To develop a group intervention for use in a rehabilitation setting that builds skills for coping with stress associated with acute SCI.

**Method:** The literature was reviewed for empirically supported group interventions for stress management. Coping Effectiveness Training (CET; Folkman et al., 1991) was researched and selected as the intervention of choice. The CET treatment protocol for SCI was identified and obtained from Stoke Mandeville Hospital, UK (Coping Effectively with Spinal Cord Injury; Kennedy & Duff, 2001). The protocol was further refined and adapted for use with an American veteran/military population.

**Results:** The CET program consists of six, 60-minute group intervention sessions based on Lazarus and Folkman's theory of stress and coping. The program follows a primarily psychoeducational format and incorporates elements of stress management techniques. It provides a framework for choosing among problem-focused and emotion-focused coping strategies to maximize the fit between strategy and the extent to which a situation may be changed. Session topics include: Stress and Appraisal; Problem Solving; Communication Skills; Behavioral Skills; Cognitive Skills; and Social Support/Assertiveness. The group is open to new rehabilitation participants and topics rotate each week. The sessions are structured to provide education and skill-building in areas of: identification of personal stress reactions; situation appraisal; awareness of interaction between thoughts, emotions, and behaviors; assertive communication; relaxation; problem-solving; challenging of negative assumptions; choice of coping strategies; and maintenance of social support. Group sessions incorporate education, group discussion, and modeling of adaptive coping behaviors. Components of the intervention are further described.

## Objectives

- Increase familiarity with a model of stress and coping.
- Increase knowledge of a group coping intervention.
- Increase knowledge of various types of coping skills taught.

## Clinical Issues

### **Mental Health Disorders and Spinal Cord Injury**

*Eva Miller, PhD*

Psychological disorders such as depression, generalized anxiety, posttraumatic stress disorder (PTSD), and substance abuse have been viewed by many clinicians and medical practitioners as an inevitable consequence of spinal cord injury (Charlifue & Gerhart, 2004; North, 1999; Skinner, Armstrong, & Rich, 2003). However, although recent controlled studies purport that the contemporary view of psychological reactions to SCI varies inter-individually and that mental health disorders are not a pre-requisite to adjustment to SCI, they do acknowledge that a significantly high proportion of people with SCI are prone to depression and anxiety (Osteraker & Levi, 2005), substance abuse (Kolakowsky-Hayner et al., 2002); and PTSD (Kennedy & Duff, 2001).

The purpose of this article is to (a) provide an overview of the some of the most common mental health disorders found among persons with SCI, (b) identify risk factors associated with these disorders, (c) examine diagnostic techniques commonly used to detect mental health disorders among persons with SCI, and (d) provide clinical guidelines to enhance successful rehabilitation outcomes among individuals with SCI.

### **Mental Health Disorders**

Depression is known to be a common psychological reaction to acute SCI and is possibly one of the most frequently studied variables in the SCI population. Some researchers (e.g., Kennedy, Duff, & Beedie, 2003; North, 1999) suggest that between 23% and 38% of persons with SCI are clinically depressed during their initial rehabilitation. Elevated levels of anxiety of approximately 27% have also been found in this population (Kennedy & Rogers, 2000). However, North suggested that the detection of depression may yield extremely low rates (estimated at a figure of less than 10%) in clinical settings because many health care professionals tend to “normalize” mood disorders among persons with SCI and, as such, may believe psychological intervention for this population is unnecessary. Since depression and anxiety often co-exist in persons with SCI (as well as the general population), it is likely that anxiety disorders are also overlooked during clinical assessment.

Spinal cord injuries are viewed as traumatic events that involve physical problems such as pain and paralysis, and bladder bowel, and sexual dysfunction; vocational and economic issues such as re-

training and re-entry into the work force; and psychosocial factors, including fear of vulnerability problems with adjustment, and even death. Although classified as an anxiety disorder in the *Diagnostic and Statistical Manual of Mental Disorders-Text Revised* (DSM-IV-TR; APA, 2000), PTSD involves a host of symptoms such as intense fear, helplessness, horror, dissociation, avoidance of stimuli associated with the trauma, and re-experiencing the trauma, that are typically not seen in anxiety disorders other than Acute Stress Disorder, which often leads to the development of PTSD. In a review conducted by Kennedy and Duff (2001), the prevalence of PTSD following SCI was estimated to be 10-40%. Although recency of the trauma was not a significant predictor of PTSD, Kennedy and Duff noted that individuals with paraplegia showed greater symptomatology than those with tetraplegia, persons with chronic PTSD were at increased risk for developing other disorders such as depression, and that childhood abuse was correlated with PTSD. Nielson (2003) also evaluated the prevalence of PTSD and emotional distress among persons with acute SCI and found that 20% of the individuals surveyed met the criteria for PTSD. Additionally, persons with PTSD had co-existing mental health problems such as dysphoria, irritability, social withdrawal, rumination over past events, and fewer expectations for the future. In this study, however, there was not a significant relationship found between prevalence of PTSD and onset of SCI.

While the prevalence of substance abuse varies among persons with SCI, researchers have found that both alcohol and drug abuse present an obstacle to their rehabilitation. For example, Kolakowsky-Hayner et al. (2002) found that of the 30 individuals with SCI they surveyed, 16.7% of the individuals fell into the *heavy* drinking range and 33% were within the *moderate* range. Persons with SCI were also more likely than individuals with traumatic brain injuries to drink on a daily basis. Although not statistically significant, pre-drinking rates correlated with drinking behavior following the onset of SCI. With regard to illicit drug use, the researchers found that 21% of those with SCI reported using illicit drugs six to 12 months post-injury. The most commonly used drugs were marijuana, poly-drug use, cocaine, and heroin/opiates, respectively. Osteraker and Levi (2005) also examined the rate of alcohol abuse among 36 persons with SCI and found that 25% of their sample reported high alcohol consumption.

## **Risk Factors**

To determine who is actually at risk for developing psychological disorders is an important task for clinicians and researchers working with individuals with SCI. Because many of these disorders may be overlooked in clinical settings, it behooves clinicians and medical health professionals to be aware of some of the most salient psychological risk factors associated with SCI. These include a reduced sense of control, lack of predictability, and perceived inadequacy of coping skills to deal with future implications of the injury. Additional psychosocial factors that have been positively correlated with mental health disorders and SCI include self-neglect, separation and divorce, poor body image, and adjustment issues. Other risks include chronic pain; medication side effects such as sedation, confusion, and fatigue; medical complications such as pressure sores, urinary tract infections, and respiratory problems; and cognitive problems (North, 1999). Middleton, Lim, Taylor, Soden, and Rutkowski (2004) examined the patterns of

re-hospitalization over a 10-year period among 432 individuals with SCI and found that in addition to gastrointestinal, musculoskeletal, and skin-related problems, 6.8% were hospitalized for psychiatric disorders. Substance abuse was the most common reason for hospitalization, followed by psychoses, overdose, and mood and adjustment disorders, respectively.

## **Assessment**

Despite continued improvements in the detection of mental health disorders among individuals with SCI, the immediate psychological consequences of the injury are often poorly understood, due in part to complications of the early stages of SCI, the effects of medications and various medical complications, and potential delays in the full realization of the significance of the injury on the individual and his or her life. The fact that many people view psychopathology as a normal phase of the adjustment process for individuals with SCI further complicates accurate clinical assessment. Although a number of algorithms of assessment processes and psychological instruments have been suggested for detecting mental health problems among persons with SCI, it is important to conduct a comprehensive intake that includes cause of injury, pre- and post-injury psychological pathology or deficits, personality traits, coping mechanisms, self-image, family supports, and work satisfaction, to mention a few. Neurological status and medical complications are also critical in the assessment process. Using psychological instruments that are known to be reliable and valid in the assessment of persons with SCI or closely related disabilities is also necessary. Osteraker and Levi (2005) conducted a comprehensive assessment of indicators of psychological distress in persons with post-acute SCI, using ASIA classifications, a mental status examination, a depression inventory, a brief personality inventory, global assessment of functioning, a screen for substance abuse, and a description of current psychotropic medications. Although this battery may not be appropriate for assessing all types of psychological disorders—PTSD, for instance—it can be used as a guideline for examining some of the most common psychological disorders associated with SCI.

## **Clinical Guidelines**

Most clinicians and researchers would agree that a combination of factors that include consultation with the rehabilitation team, application of learning principles related to the rehabilitation process, specific application based on individual cases, and psychological evaluation of a person's assets and limitations are essential components for enhancing the quality of life for an individual with a SCI and their family.

According to North (1999), some of the most effective techniques for working with individuals with SCI include enhancing self-responsibility and self-control, understanding of the physiological and psychosocial implications of SCI, and education regarding self-managed care. Identification of mental health disorders early in the rehabilitation process may allow rehabilitation and medical professionals to reduce or circumvent problems at a critical time in the recovery process. Others (e.g., Kennedy et al., 2003) have found that coping effectiveness training is highly efficacious for treating depression and anxiety among persons with SCI. Cognitive behavior therapy has also been found to reduce maladaptive and faulty ways

of thinking that often accompany SCI (North). For some, psychotropic medication is indicated, especially for severe cases of psychopathology.

Although there are many therapeutic approaches that can be used to treat mental health disorders among persons with SCI, it is essential that clinicians and other rehabilitation professionals acknowledge that not everyone with SCI has a mental disorder. Conversely, the possibility that a disorder has been attributed as a “normal” reaction to an abnormal situation must also be considered. Perhaps the best method for providing sound mental health services for people with SCI entails an eclectic approach that addresses the unique aspects of each individual situation.

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## News Clips From Mather Lifeways

Mather LifeWays, based in Evanston, Illinois, was founded in 1941 by humanitarian Alonzo Mather and seeks to provide a continuum of living and care, making neighborhoods better places for older adults to live, work, learn, contribute, and play; and to identify, implement, and share best practices for wellness, workforce issues, memory care support, and empowering caregivers. For more information, please visit **[www.matherlifeways.com](http://www.matherlifeways.com)**.

### *New Guide for Family Caregivers*

*The American Red Cross* (July 2007) The American Red Cross released a new family caregiving reference guide that promotes considerate, skillful, and confident caregiving. It also provides instructions for creating a safe home environment, providing healthy nutrition, and tips on dealing with legal and financial issues. The guide comes with a DVD and can be obtained through local Red Cross chapters and its online store at **<http://www.redcross.org>**.

### *Costs of Adult Day Services and Home Care*

*The MetLife Mature Market Institute* (September 2007)

Metlife and LifePlans, Inc. conducted a telephone survey in order to estimate home care and adult day services costs nationwide. The national average for a home health aide is \$19 per hour and \$61 per day for adult day services. For home health aides, the hourly rate ranged from \$12 in Shreveport, Louisiana, to \$25 in Rochester, Minnesota. For adult day services, the daily rate ranged from \$21 per day in Montgomery, Alabama, to \$130 in Vermont. For more information, visit **<http://www.metlife.com>**.

### *Aging in Industrialized Nations*

*AARP* (September 2007)

This paper reports on a survey of employers, workers, and policymakers of the major industrialized nations that comprise the G7: Japan, Germany, France, Britain, Italy, Canada, and the United States. It combines workforce and population demographics, public policy responses, and research to paint an international picture of the aging workplace. The research indicates that G7 countries vary widely in their preparedness for demographic change. For more information, visit **<http://assets.aarp.org>**.

### *Consumer Protection Advice for Older Adults*

*The New York Times* (October 2007)

The *Times* published a series of business articles meant to inform the consumer choices of older adults. The “Golden Opportunities” series included articles outlining government oversight of long-term care insurance, the impact of private investment firms on the quality of nursing homes, advice for older adult

investors, tips on privacy protection, and implications of the life insurance boom. Most recently, an article reporting on the federal audits of Medicare demonstrates the influence the new private plans have had on the health coverage of older adults. For more information, visit <http://topics.nytimes.com>, and read the related article at <http://www.nytimes.com>.

### ***Workplace Policies Concerning Unpaid Caregivers***

*The Equal Employment Opportunity Commission* (October 2007)

Current federal Equal Employment Opportunity Commission (EEOC) law does not prohibit discrimination against caregivers; however, the EEOC has outlined the circumstances under which discriminating against caregivers can constitute violations of existing laws, which include ethnicity and sex-based discrimination, where females and persons of color are singled out in their role, or presumed role, as caregivers for disparate treatment at any point in the work cycle. For more information, read the guidelines and recommendations at <http://www.eeoc.gov>.

### ***An Updated Guide to Medicare & Medicaid***

*The MetLife Foundation* (August 2007)

The MetLife Mature Market Institute offers an updated version of its guide to Medicare and Medicaid. Part of the *Since You Care* series, the publication provides information about recent changes to Medicare; basic enrollment and coverage; the structure of Medicare and Medicaid and costs associated with each coverage option; Medigap; Medicare Advantage; Medicare's prescription drug program; Medicaid services and eligibility; and a reference guide. For more information, visit <http://www.metlife.com>.

### ***Recent Studies on Informal & Formal Caregiving***

*American Journal of Alzheimer's Disease and Other Dementias* (September 2007)

The *American Journal of Alzheimer's Disease and Other Dementias* published research reports touching on the job satisfaction of formal caregivers, caregiver sadness, and the impact of interventions on the caregiver. Notable findings included job satisfaction rates are higher among formal caregivers who have entered the profession after previously caring for a loved one informally; psycho-educational programs may boost caregivers' coping capacities and provide memory support for sufferers of dementia; and higher levels of a depressed mood were found in informal caregivers experiencing higher levels of disruption in their social relationships as a consequence of their caregiving. For more information, click on the links at <http://aja.sagepub.com>.

## ***The Economic Impact of Chronic Disease***

*The Milken Institute* (October, 2007)

The Milken Institute released a comprehensive report detailing the costs of treatment and productivity losses associated with the seven most common chronic diseases: cancer, diabetes, hypertension, stroke, heart disease, pulmonary conditions, and mental disorders. This report also provides historical data, direct-cost estimates broken down by state and disease type, and it projects future economic consequences of current disease trends while comparing them to projected savings created by behavior changes known to mitigate risk for chronic diseases. For more information, read the report at

**<http://www.milkeninstitute.org>**.

## ***Hospital Quality in America***

*Health Grades* (October 2007)

Health Grades released its 10th annual hospital quality study report, which provides quality ratings of 5,000 hospitals nationwide and gives state- and hospital-specific mortality rates associated with common diseases and procedures. This research suggests that significant variation in the quality of care has been consistent with previous reports over the past eight years. For instance, the overall mortality rate at “five-star” hospitals is 71% lower. For more information, read the report at **<http://www.healthgrades.com>**.

## ***A Caregiver’s Impulse to Commit Elder Abuse***

*Research on Social Work Practice* (November 2007)

This study examined the validity and reliability of an assessment tool designed to assess a caregiver’s impulse to commit elder abuse. The tool proved to be highly reliable, and analysis demonstrated two important factors: emotional and physical abuse. This research was meant to justify the use of this assessment tool by professionals who work to support caregivers and the older adults for whom they care. For more information, read the abstract at **<http://rsw.sagepub.com>**.

## ***A Caregiver That’s a Robot?***

*Reuters* (November 2007)

Engineers have been developing a robot designed to assist with activities of daily living. This robot has a grip soft and strong enough to assist older adults getting in and out of chairs or beds and has the ability to serve food. Technical difficulties (e.g., battery and overheating problems), however, suggest that this form of caregiving is still years away. For more information, read the article at **<http://today.reuters.com>**.

## ***Proposal to Improve Caregiver Resources***

*The MIT Workplace Center* (November 2007)

MIT seeks to increase public awareness of problems associated with caregiving and to promote the improvement of caregiver resources. In its report, researchers make recommendations for improving caregiver resources (e.g., encouraging expansion of employer-sponsored programs), share information about its associated research project, and provide a transcript of an expert panel discussing the challenges and opportunities facing caregivers. For more information, read the report at <http://web.mit.edu>.

## ***A State-by-State Look at Medicaid Long-Term Care***

*National Association of State Medicaid Directors* (October 2007)

This report tracks the decade-long shift in distributing Medicaid long-term care funding toward community- and home-based care and outlines the impact that this shift has had on long-term care practices state by state. Specifically, this report outlines how states use their money for long-term care, how many states have special needs plans in place, and the implementation of the Family Opportunity Act. For more information, read the report at <http://www.nasmd.org>.

## ***Beer & Alzheimer's***

*Food and Chemical Toxicology* (January 2008)

Researchers in Europe determined that moderate beer consumption reduces the risk of Alzheimer's by slowing the accumulation of aluminum in the body. Beer is a common dietary source of silicone, which works to slow the uptake of aluminum in the digestive tract. For more information, read the abstract at <http://www.sciencedirect.com>.

## **Assistive Technology**

### **It's Not About the Medical vs. Social Models—It's About Empowerment**

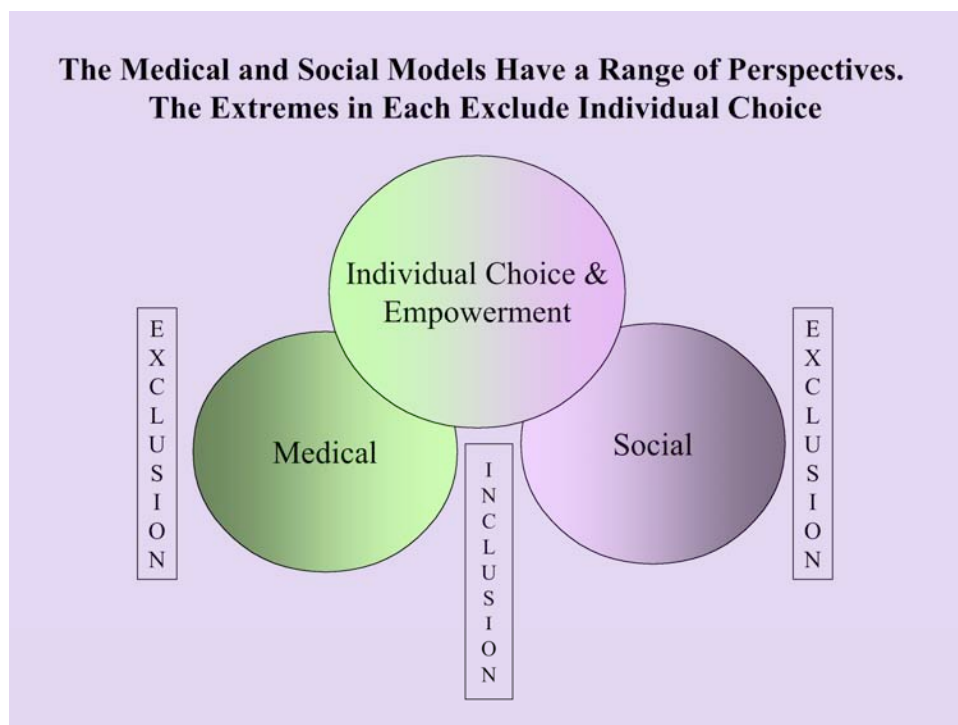
Marcia J. Scherer, PhD, CRC, NCC

In the last two AT columns, Kimberly Walters shared her *disability experience* as well as her use and views of assistive technology devices. Kimberly has a spinal cord injury and works for an independent living center in New York State. Thus, she shared a consumer empowerment perspective with you.

Thanks in part to assistive technology devices (ATDs), individuals with spinal cord injuries like Kimberly can now lead more independent lives, live in their communities, attend regular schools, and seek

professional careers. Concomitantly, we are hearing the plea to move away from the *medical model* of rehabilitation, to a *social model*. The medical model places emphasis on individual limitations, while the more recently evolved social model emphasizes inclusion and participation, and support for this through universal design, legislation, and societal attitudes of acceptance. Each of these models, however, has something to offer the consumer selecting ATDs. While there is not a pure medical or social model, with the exception of those espousing radical views, each comprise a range of adherents who are more or less inclined towards consumer inclusion. The *individual choice and empowerment* perspective recognizes the value of, and need for, the inclusionary supporters in each. This blended approach is depicted in Figure 1.

**Figure 1.**

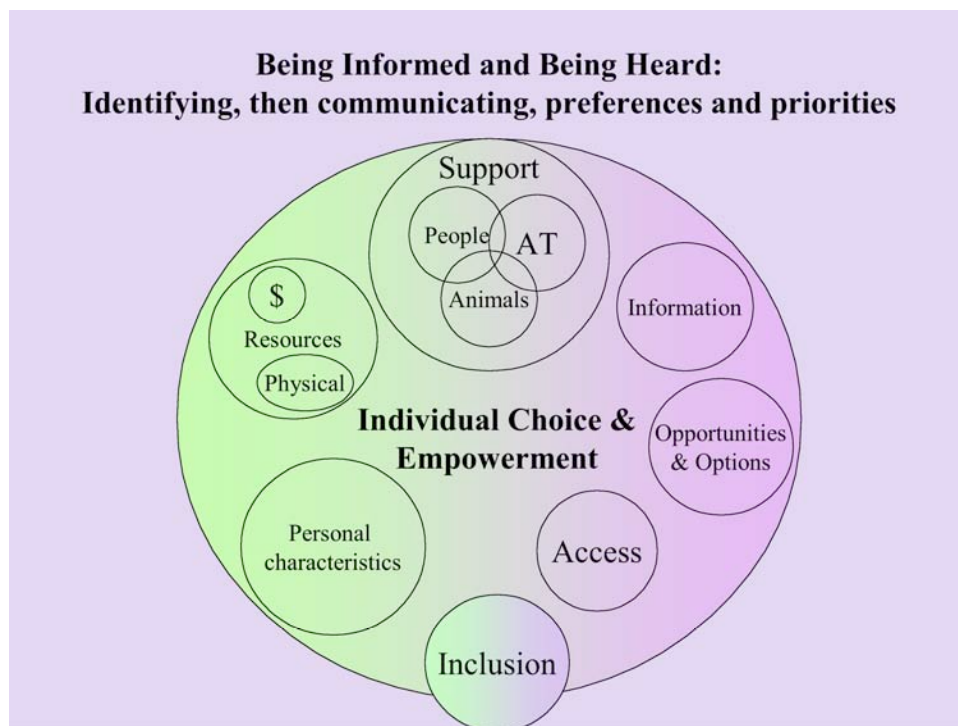


For the *individual choice and empowerment* perspective to succeed, a complex mix of characteristics needs to be considered that includes the person’s personal characteristics, expectations, prior experiences and opportunities, and psychosocial environment. It also depends on aspects of the disability and the type and amount of rehabilitation and “empowering resources”—the opportunities and choices available to the person.

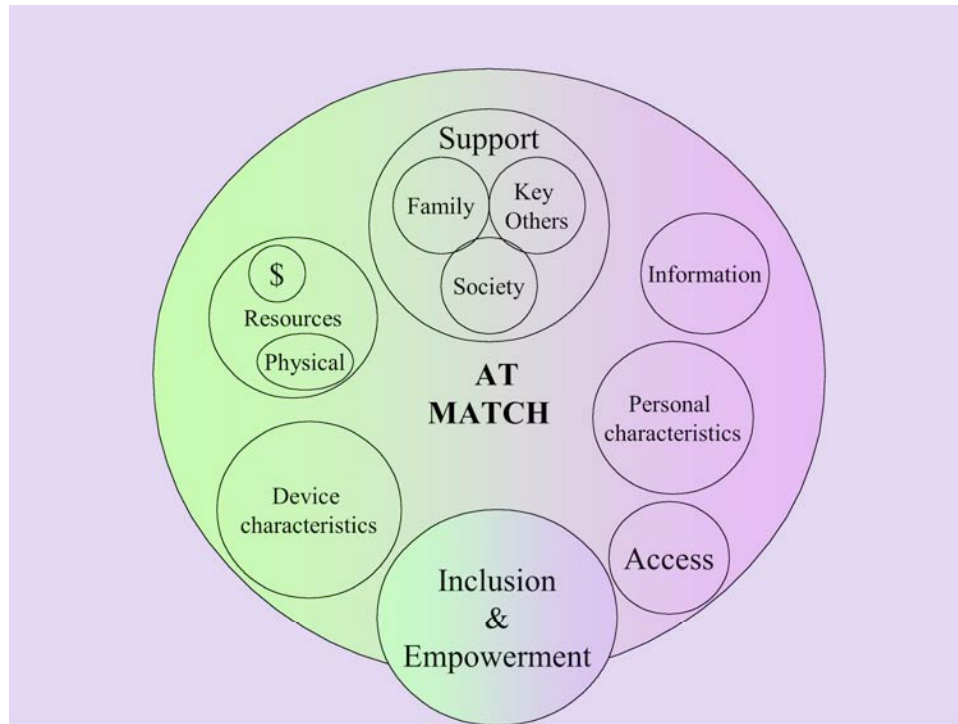
The individual empowerment model believes that *both* environmental modification and “equipping the individual” are necessary. This more comprehensive perspective sees the environment as presenting barriers and challenges, but also as stimulating and offeriopportunities for accomplishment.

ATDs must, therefore, pass the acid test of fostering autonomy and participation and contributing to a positive identity, enhanced self-esteem, and improved quality of life *as defined by that particular person*. Empowering individuals means looking beyond environmental accommodations and individual functional capabilities to the achievement of a higher quality of life and participation in all desired roles and activities. Assistive technology devices can be important enablers, and a poor match of person and technology, or no technology provision at all, can be considered a barrier, yet other supports and services are just as important. Figures 2 and 3 depict the need for the consideration of comprehensive, interacting, elements impacting the consumer and, focusing on the match with ATD in particular, the need to work from an empowering model.

**Figure 2.**



**Figure 3.** A Good Match of Person and Technology Requires Comprehensive Considerations



Psychosocial services need to be an integral part of rehabilitation programs. Unlike most other professionals, psychologists, counselors, and social workers are very adept at working with subjective, multi-dimensional, interactive, and individualized factors. Individuals want and need opportunities to discuss feelings, attitudes, preferences, goals, and priorities, and these professionals are highly skilled listeners. The identification of goals needs to be a first step, and then the provision of the ATDs and other supports and resources to achieve them. In this way, rehabilitation interventions are best accepted and adopted by the consumer. Psychosocial services need to be given a further priority because they will ultimately save many dollars and pay for themselves in helping persons who are depressed, who abuse substances, who need to develop new coping strategies and new relationships. Many also need help to come to terms with barriers to their own functioning, developing a sense of connection and belonging, and augment motivation. Psychologists, counselors, and social workers, trained to have an interactive, comprehensive, and interdisciplinary approach to problem intervention, are pivotal guides for the consumer seeking the best possible match with an ATD.

## ATD Selection

How does one help the consumer to decide when to use AT and when to seek assistance from another person? While AT helps to break down physical barriers to social participation and relationships, some

ATs can be barriers to interpersonal contact. An emphasis needs to be placed on empowerment by working with the consumer to:

- discover that person's best blend of independence, interdependence, and often unavoidable dependence;
- know what to share, just how much, when and with whom;
- learn ways to convey needs and preferences in a manner that preserves self-esteem and respects the needs, preferences, and feelings of others;
- manage social interactions in the context of pain, fatigue, and the need to do things in different ways and at particular times;
- anticipate what might occur in social encounters and prepare strategies for handling the unexpected; and
- tempering reactions and knowing when to use humor, and when to enlist specific communication skills, such as assertiveness.

As psychosocial experts, we know that the most important influence on an individual's use of an ATD is how well it actually performs for that person. That is, it helps them accomplish desired goals and activities, fits with their lifestyle and routines, and can be used without undue fatigue or stress. When presented with a choice, consumers will select assistive devices, as they do with any product, according to characteristics that satisfy their preferences. Therefore, as the diversity of both products and the users of those products expands, it is increasingly important to be able to understand the different needs and preferences among users and to provide consumers with the products that each of them need. That preferences vary is crucial for providers to understand when matching a person and a device. In the case of many ATs, users may not have a choice over whether or not to use it, but they can at least exercise choice over style, size, and other device features.

When recommending a specific device for a person's use, it is important to keep in mind the Matching Person & Technology (MPT) factors (Scherer, 2005):

- a) the characteristics of the environments, or **Milieu**, in which the device will be used;
- b) the individual's **Personal** characteristics and preferences;
- c) the features and characteristics of the **Technology** under consideration.

It is also crucial to:

- Assess and understand a person's functional *capabilities* as well as limitations.
- Evaluate the impact of related limitations; such as low vision for the user of an augmentative communication system.
- Select the most cost-efficient device that is the best match in terms of usability and aesthetics.

- Provide training and support in use and maintenance of the device.
- Follow up to determine the extent to which the device is meeting the consumer's needs and determine any secondary effects it may have created or exacerbated.

The recommendations which then emerge will be driven by, and reflect, that person's unique needs and preferences.

In conclusion, services for persons with disabilities are very responsive to the physical needs of individuals with disabilities. Yet there is still less attention given to the individual's emotional and social needs and preferences. This is precisely what makes psychologists, counselors and social workers so vital to the well-being of individuals with disabilities because they can guide the consumer in finding his or her own balance of independence, interdependence, and dependence. As paradoxical as it may sound, assistance from others and ATDs can enhance a person's independence. All too often, however, the emphasis is on the physical aspects to the near exclusion of the user's psychosocial needs.

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Note: This book was reviewed in United Spinal Association's member magazine, *Action*, and can be accessed online at: <http://www.unitedspinal.org/publications/action/2005/08/02/living-in-the-state-of-stuck/>.

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## Person Profile: Lauri Yablick, PhD

*Jeanine Penzo, MSW, LISCW*

Who is Lauri Yablick? Most readers would recognize her as the previous editor of the Person Profile column. Those of you who were lucky (?) enough to have been featured, might share tales of her clever approaches to interviewing. But, who is Lauri, apart from her professional work? As the new section editor for Person Profile, I thought it fitting to spotlight this column's retiring editor, and give readers a

more personal look at Lauri. She agreed and even dared to share the names of friends and colleagues in the organization who might want to add their own colorful anecdotes. Interesting that there were few incriminating details to share, given the number of years they have worked together.

Lauri resides in Tucson, AZ, and has worked in the field of psychology for the past 20 years. After earning a BA with Distinction in psychology from George Washington University in Washington, DC, she completed her graduate work in Clinical Psychology at Washington University in St. Louis, MO. Her employment experience includes work as a Rehabilitation Neuropsychologist in acute rehabilitation settings and 10 years in long-term care settings. Lauri currently works for Southwest Neuropsychology Associates with geriatric, cognitively impaired, and medically ill adults. She has been a member of AASCIPSW since 1991 and served as Person Profile Editor for the past six years. As she steps down from her editorial position, Lauri begins her new role as a member of the Program Committee, channeling her talents in a new direction. According to Alan Goldberg, a fellow member of the Program Committee, he and Lauri are “like brother and sister, fight like cats and dogs and the committee is now catching the action firsthand!” Alan did add that, occasionally, they do agree on something, which should be a relief to their fellow committee members.

When Lance Harris, Associate Editor of *SCI Psychosocial Process*, approached Lauri about writing Person Profile, she agreed and added, “You don’t know how good the fit is for me—I’m really looking forward to it”. He said that he thought, “That’s what they all say” but soon learned that “she meant it!” Lauri shared that she really enjoyed writing the column, more than she expected. She describes herself as a “nosey” person who enjoys talking with people and getting to know them. Lauri added that she took “a light approach” to creating her columns, saying, “we can all take ourselves too seriously.” It appears that most readers appreciated her approach despite the fact that she admits to having stepped on a few toes along the way. Lance appreciated Lauri’s approach to the column, describing her work as “fun, unpredictable and, God forbid, edgy.”

In my conversation with Lauri, I asked if she would share any positive or not-so-positive experiences as editor. She needed little time to reflect, immediately saying that her “single best experience” was her interview with the late Barry Corbet, a respected member of the association who passed away in 2004. He was an inspiring person to interview and Lauri learned much from him. Lauri also admitted that submitting her articles in a timely fashion was always a challenge and a source of constant angst for the journal’s editors. This actually was a factor in her decision to move on to a new role in AASCIPSW as she regretted always keeping the editors waiting for her submissions. Lance Harris described her submissions as “the last damn article to clog my e-mail” and added that despite his best efforts, she could never make the deadline. But Lance was quick to add that her columns were always worth the wait and that it will be a long time before he forgives “Lauri the Turncoat Yablick” for ending her tenure on the editorial board.

I have learned that Lauri had creative interviewing methods and one friend went so far as to describe them as “devious”. Lauri found him with his usual glass of wine at the end of a busy day at the

Annual Conference. As she bought him more wine, he became more willing to participate in the interview, admitting, “I told her everything I knew” by the time they finished! “She was just a pro at manipulating the naïve.”

Lauri loves animals, especially her dog and her horse, enjoys being outdoors and takes environmental issues very seriously. Her friend and colleague, Stan Ducharme, noted that he is always on his best environmental behavior when Lauri is around because [she] “can put me to shame.” She especially enjoys the beauty of Tucson while riding and loves sharing her passion for the sport. Stan often traveled to Tucson when serving as the AASCIPSW liaison to CARF and enjoyed his outdoor adventures with Lauri and Vivian Beyda, who was often in attendance as well. One of their more memorable afternoons was spent at Kartchner Caverns, just outside of Tucson, where the trio hiked, explored, avoided the resident bats with as little impact (of course) as possible on the environment. Stan did add that Lauri would be the perfect friend and colleague, “if she only played golf on those beautiful Tucson courses.”

There is an artistic side to Lauri as well. She enjoys lampworking: the craft of making glass, beads, jewelry, and small sculptures. In fact, on the afternoon of my phone interview, Lauri was headed to her studio to pursue her creative talents. She also enjoyed making pottery for 10 years before deciding it was time to move on to something else.

Lauri is a respected member of AASCIPSW and her colleagues only affirmed this fact. However, they also enthusiastically described the value they place on their friendships with this woman. Stan Ducharme summed it up: "Always eager to help others, Lauri is always there to share her knowledge of neuropsychology and to offer opinions on clinical matters. She is genuine, sincere, and a loyal friend. Beyond that she is an outgoing, engaging and fun person to be with."

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## Literature Review and Commentary

### Depression in Men with Spinal Cord Injury: Rethinking the “Strong Silent Type”

*Claire Z. Kalpakjian, PhD, MS*

#### Introduction

In 2006, a colleague and I conducted a retrospective analysis of depression symptoms in a large case-matched sample of women and men with SCI from the National SCI Model Systems database. We both presumed that women would outnumber men in symptom severity and probable depression based on the

large body of literature indicating greater depression vulnerability among women. Instead, men slightly, although not significantly, outnumbered women. This unexpected result got me thinking—were men the ones who were actually at higher risk for depression compared to the women? Was there something about this injury that “leveled the playing field” and wiped away the expected differences in depression rates? What was underneath the surface that I had not considered before?

Until then, I did not really question the “fact” that women were at a higher risk for depression and met criteria for being depressed at nearly twice the rate as men. Women are assumed to have a certain vulnerability to depression while men are often considered to be comparatively healthier or silent in their experience of depression (Brownhill, Wilhelm, Barclay, & Schmied, 2005). I accepted the presence of this gender disparity, because after all, there was an abundance of statistical evidence to support the reality of this discordance in the prevalence of depression. Indeed, I was fairly comfortable with an uncritical acceptance of the “evidence;” that is, until I started reading the literature on this topic in greater depth.

In recent years there has been a growing interest in understanding the unique aspects of depression in men; in fact, the February 28, 2007, Newsweek cover story was “Men and Depression.” Although men are diagnosed with depression at lower rates than women, they commit suicide four to fifteen times more often (see J. R. Mahalik & Rochlen, 2006). In general, compared to women’s psychological functioning, men’s mental health has been largely unexamined (Emslie, Ridge, Ziebland, & Hunt, 2007). Advocates for a male syndrome of depression argue that behaviors such as aggression and violence, substance abuse and high risk behaviors, far more prevalent among men, represent male depression. In addition, these advocates allege, because depression measures and diagnostic criteria represent a more “female” experience of depression such as crying, emotionality, helplessness and passivity, depression in men will be under-recognized. In support of this, in studies examining depression and other mental disorders in communities where these kind of risk behaviors are prohibited, gender disparities narrow (see Brownhill et al., 2005).

What has struck in me in particular is this contention that behaviors such as high risk taking, aggression and violence, and substance abuse represent depression in men. It is an undisputed fact that men significantly outnumber women in SCI incidence (4:1) and that a large proportion of these injuries result from those very factors: high risk taking, aggression and substance abuse. While the literature has reported on these factors themselves, and, of course, depression has been extensively studied, research has not pointedly examined whether these behaviors indeed represent depression in men with SCI and if current measurement tools adequately capture the range of possible symptoms that men may experience.

After considering the unexpected results of our study and delving into the gender disparities literature, a fundamental question emerged for me—one that has yet to be explored fully in the SCI literature in my view: *How does the experience of a SCI interact with the male experience and expression of depression?* If the men who are injured are more likely to be depressed in the first place, how does the SCI impact their experience and expression of depression after injury?

This question touches upon several key perspectives that are proposed in the psychology literature on depression in men: 1) behaviors such as high risk taking, substance abuse and aggression are a

manifestation of depression; 2) masculine gender role socialization reinforces these behaviors and restricts help-seeking behaviors and the expression of symptoms readily identified as depressive, such as crying or helplessness; and 3) current measurement tools tend to represent more typically female expressions of depression and therefore are likely to underestimate depression in men.

For this Review and Commentary column, I have selected several publications from the SCI and psychology literature. I submit this not as a comprehensive review of a complex body of literature, but rather in the hopes of stimulating thought and discussion among researchers and clinicians, and to encourage further research to more deeply understand the unique aspects of depression in men with SCI.

### **Review and Commentary**

#### ***Encountering the Unexpected***

There have been very few papers addressing gender differences in depression incidence, prevalence and symptom profiles in the context of SCI despite the volume of literature on depression in SCI. Also, most depression studies understandably have a majority of male subjects which limit the ability to explore gender differences. In our study (Kalpakjian & Albright, 2006), we used a large case-matched sample of men and women with SCI (584 pairs of men and women matched on injury level/completeness, time since injury and age). We expected that while symptoms, measured by the PHQ-9, were likely to be elevated for both women and men, the usual gender disparity of 2:1 women to men having probable depression would likely hold. Instead, we found no such gender differences.

We pondered these unexpected results – did SCI somehow equalize gender-related differences in the experience of depression and its symptoms in this sample? If men and women with SCI were equal in the prevalence of probable depression and symptom severity, this suggested that *men*, not women, were at a higher risk for depression after injury if gender disparities in the general population reflected a real difference in depression risk (as I discuss, this is debatable). What factors eliminated the expected disparity? Did the experience of a SCI increase emotional expressivity through contact with mental health professionals as part of rehabilitation? Did the intense experience of having an injury “unlock” emotional expressivity for some men? Did it fundamentally alter their masculine role self-concept that then changed their experience and expression of depression?

#### ***Looking Beyond Prevalence***

Clearly, it is not enough to simply accept prevalence alone as evidence for a gender difference—or, as in our case, the lack thereof—for such a complex phenomenon as depression. Furthermore, if, as many contend, customary measurement tools and diagnostic criteria reflect more female expression and experience of depression, then simply accepting prevalence rate differences or similarities without questioning what lies beneath the numbers does a great disservice to the men and women with SCI that we serve. Unfortunately, in our study we were unable to delve more deeply into the possible influences on this lack of difference given the limitations of using archival data. But the data certainly raised the important

question of whether men with SCI were more vulnerable than women, and for me, forever put to rest the idea that I could simply and uncritically extrapolate findings from the general population to men and women with SCI.

### ***Masculine Gender Roles and Depression***

One of the most frequently cited factors influencing gender disparities in depression rates is the influence of the masculine gender role on the experience and expression of depression. The masculine gender role is characterized by emotional control, self-sufficiency, power, dominance, and a drive for success (Addis & Mahalik, 2003). Masculine gender role socialization—that is, the process by which societal beliefs, norms and values about masculinity are conveyed—can result in difficulty for men in expressing emotion and identifying and describing their feelings. Endorsement of masculine ideologies has been consistently associated with a range of presenting problems (Mahalik, Good, & Englar-Carlson, 2003).

Addis and Mahalik's (2003) thoughtful review of masculine gender role socialization and its relationship to help-seeking addresses the question of how to approach understanding potential differences between men and women. In contrast to the sex-differences approach of "men versus women," they contend it is more meaningful to attempt to discern the individual differences in the extent to which men embrace the masculine gender role and the conflicts that can arise from that. So I wondered – what do we know about masculine gender roles and the impact of SCI?

Recently, Schopp and colleagues examined the influence of masculine gender roles and their influence on outcomes in a small but interesting study conducted with 20 men with SCI (Schopp, Good, Mazurek, Barker, & Stucky, 2007). This study examined gender role conflict and traditional masculine role adherence and its association with function and psychological outcomes; a largely unexplored area in the SCI literature. Results indicated that traditional masculine roles both supported adjustment and attenuated rehabilitation progress. Contrary to the notion that suppression of emotion leads to increased distress in men, this study found that emotional control was actually related to both positive functional outcomes, as demonstrated by greater improvement in FIM scores after discharge, and marital relationships, in terms of lower rates of change in marital status. The ability to regulate emotion during early adjustment to SCI was postulated to be protective by allowing men to face numerous role transitions, stressors and rehabilitation demands. Another interesting finding was that men who placed a higher value on violence reported greater life satisfaction. One possible explanation offered by the authors is that men who value violence also place a high value on toughness and overcoming physical adversity. This in turn may influence a focus on the active pursuit of goals—the ability to focus on personal goals and make independent decisions that reflect perceived control and shown to be strongly associated with life satisfaction.

This supports Addis and Mahalik's (2003) contention that testable models of help-seeking behavior in men should assist in explaining why some men seek help for some problems under some conditions and not others. They assert that these models should allow for the possibility that masculinity

and help-seeking are not stable properties of an individual, but are rather patterns that become more or less likely depending on the person-environment interaction. This is an important consideration for understanding help-seeking for depression in men with SCI. Schopp's results also support Addis and Mahalik's caution that holding to rigid sex stereotypes (men "always", women "always") is not helpful for understanding such a complex phenomena—instead we are wiser to examine which facets of the masculine gender role facilitate and which hinder adjustment after SCI and that help to form the experience and expression of depression in men with SCI.

### **“Masked Depression”**

Depression in men is often referred to as “masked” or “hidden” or “silent.” At the heart of the research on men and depression is the contention that high risk behaviors, substance abuse and aggression—over-represented in men—are in truth manifestations of depression. A “male depressive syndrome” has been put forth to highlight those symptoms that describe a sub-set of depressed men (Rutz, Vonknorring, Pihlgren, Rihmer, & Walinder, 1995; Walinder & Rutz, 2001). This is characterized by low stress tolerance, acting out, low impulse control, irritability, substance abuse, antisocial behavior, and depressive thought content. Depression is masked by these atypical symptoms which may be misleading when trying to diagnose depression in some men. Depressed men also have been shown to have a greater tendency to have “anger attacks,” lower impulse control, substance abuse and hyperactivity during depressive episodes than depressed women (Winkler et al., 2004). Men more often experience a “build up” of emotions, with the release likely to be triggered by some external event and often resulting in injury to themselves or others, when compared to women (Brownhill et al., 2005).

Mawson and colleagues conducted a case-control study examining sensation seeking and criminality among 140 men with SCI matched to non-SCI controls by age, sex, race, zip code, and education (Mawson et al., 1996). Criminality, defined by having been arrested, committing a crime or placed in a correctional facility (<16 years and > 17 years of age); and vulnerability to injury were hypothesized to share a common factor of increased sensation-seeking behavior. Sensation-seeking behavior was characterized by disinhibition and susceptibility to boredom. Men with SCI had significantly greater sensation-seeking than controls and were 31 times more likely to have been incarcerated after age 17. Krause also examined risk for subsequent injuries after SCI in men and women. Although he did not compare risk by gender, high sensation-seeking, heavy drinking, and over use of prescription pain medication were among the risk factors for subsequent injuries (Krause, 2004).

### ***Help-Seeking Behavior***

Help-seeking behavior is also cited as one of the primary contributors to gender disparities in depression: fewer men seek help, thus fewer are accounted for in prevalence rates. Seeking assistance requires relying on others, admitting the need for help, and recognizing and labeling an emotional problem, all of which are at odds with a masculine gender role (J. Mahalik et al., 2003). Unwillingness to seek help has serious

consequences for men in general and men with SCI in particular, yet there has been little work in the area of help-seeking for emotional problems among men with SCI.

In Schopp and colleagues' (2007) study of masculinity and SCI, dominance was associated with poorer rehabilitation outcomes. Men who place a high value on control and interpersonal authority may be less likely to seek help or to accept it when it is offered and needed. Rehabilitation, as the authors rightly point out, requires collaboration and cooperation that may be hard to come by for men strongly aligned with dominance, independence and control. Therefore, one of the key questions is how the experience of injury interacts with help-seeking behavior in men with SCI, particularly for depression. On inpatient units—particularly those seen at SCI Model Systems centers (from which the data for our study were drawn)—these men would have likely met with psychologists, at least once. For many men, it may have been their first encounter with psychology. What kind of effect might this have on a man's willingness to talk? Would the intensity of experiencing a SCI make an otherwise reluctant talker, talk? Would the fact that help was "delivered" rather than sought change a particular man's responsiveness?

Considering Addis and Mahalik's (2003) caution that situations are likely to interact with help-seeking behavior, I wonder about how the experience of rehabilitation ultimately affects help-seeking behavior in men with SCI. Consider that a man with an SCI directly after injury has help thrust upon him—he need not seek it, rather it is clearly necessary for survival. Does this somehow, for some men, fundamentally alter help-seeking behavior in the future? If so, is there an interaction between help-seeking and the problem for which help is sought? Of course, we must always keep in mind that an absence of help-seeking is not necessarily an absence of a problem.

### **Measuring Depression in Men**

One of the most important and relevant questions that this literature raises is whether widely used depression measures and diagnostic criteria adequately define the range of symptoms that men may experience when depressed. Tools that are developed using more "feminine" expressions of depression such as crying, and which do not capture more "masculine" depressive behaviors such as aggression or high risk taking, will be less valid for capturing a subset of men who actually may be suffering from depression.

Unfortunately, despite the body of literature on depression after SCI, there are few studies of gender differences in symptomatology, and measures have not deviated widely from accepted scales. These measures do not typically include behaviors such as high risk-taking, aggression and substance abuse as depressive features. That being said, our study found no significant gender difference on the PHQ-9, modeled after DSM-IV diagnostic criteria. This raises the question of whether the advent of a serious injury changes (or perhaps broadens?) the expression of depression in men with SCI. That is, in those men who may be more likely to avoid expression of typically female depressive symptoms, but who may actually be depressed; does their experience of a SCI lead them to be more responsive to scales such as the PHQ-9? If we were to use scales that included both typically female symptoms and the proposed profile of male

symptoms that Walinder and Rutz (2001) offer, would men with SCI *exceed* women in prevalence of depression?

Brownhill and colleagues (2005) conducted an interesting qualitative study examining the experience and expression of depression among Australian men. In this study, women were ready to express emotions by crying or seeking out support in others and to admit to depressive symptoms. In these women, depression was more readily “available” to the observer or assessor than was the case for the men. These authors wisely note that while the men in their study were more likely to avoid showing signs of “weakness,” their *internal* experience of depression appeared to be similar to that of the women. Others have similarly found that while the internal experience of symptoms does not appear to significantly differ between men and women (Brownhill et al., 2005), the expression of them does. And that can make all the difference.

There is a related issue in the measurement of depression in the context of SCI, namely, the influence of somatic symptoms. There is a large body of literature in primary care on the *under-recognition* of somatic symptoms as indicative of depression, with somatic symptoms often the first signs of depression (Greden, 2003; Kroenke, 2003). For both SCI researchers and clinicians, accounting for somatic symptoms related to depression is one of the many complexities we face. If we, ourselves, are unclear, would not persons with SCI be as well? If primary presenting problems of depression tend to be somatic; and we have no evidence that, for people with SCI, somatic symptoms are *not* a part of depression symptomatology; to what extent might depression be overlooked due to a focus on somatic complaints as implying only physical difficulties in rehabilitation settings? Further, if men are more likely in general to avoid talking about emotional distress and focus instead on somatic issues with their psychiatrists, would that not further compound the issue of the under-recognition of depression?

Unfortunately we lack the ability to look inside people, and outward expressions of internal emotional states are all we have to go on. Given this inherent limitation in our powers of observation, it is wise to explore the utility of including high risk behaviors such as substance abuse, aggression and anger as possible signs of depression in men with SCI, in both formal measurement tools as well as in clinical settings.

## Conclusions

This brief review and commentary raises many questions about the role of masculine gender roles, help-seeking and the measurement of depression in men with SCI. Despite the attention we have paid to depression, there remain many unanswered questions that, I suggest, are fundamental to our understanding of it in men with SCI. Despite the temptation to say that “all men” are not silent and “all women” readily talk about their feelings, there are, of course, no easy answers. Rigid stereotypes always serve to blunt our understanding. At the same time we cannot ignore the social, cultural and biological forces that shape our gender. Striking a meaningful balance between the two is our challenge—are we up to it?

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**Pediatric SCI****The Promise of Positive Psychology Interventions for Pediatric-Onset SCI***Jonathan I. Kirschner, BA, and Bret A. Boyer, PhD*

Traditional psychotherapeutic interventions for chronic illness, including SCI, originally emerged from a medical model in which the chief goal is to rebuild and to repair (Seligman & Csikszentmihalyi, 2000). Under this traditional lens, it is the role of psychotherapist to treat symptoms, such as maladaptive cognitions and behaviors, a damaged self-esteem, or a troubled childhood. Though this model continues to dominate the psychotherapeutic arena, its imbalanced focus on pathology risks skipping over another critical area: all that is going well for the individual. The recent positive psychology movement has sought to restore balance in both our conceptualization and treatment of patients so that treatment is “not just fixing what is broken; it is nurturing what is best” (Seligman & Csikszentmihalyi, 2000, p. 7).

The growing positive psychology literature over the past 10 years provides compelling evidence that a little dose of optimism can go a long way. In their research of men infected with HIV, for instance, Taylor, Kemeny, Reed, Bower, and Gruenwald (2000) found that participants who were able to stay optimistic showed fewer symptoms at a later date, and had significantly higher survival rates than participants who were more “objective” about their situation. Furthermore, the researchers found that optimistic patients were more likely to engage in habits that promote health and pursue social support. Thus, not only did optimism preserve mental health in the face of a severe chronic illness, it served as a protective factor for an individual’s physical health as well.

Paralleling the evolution of positive psychology, rehabilitation psychology has also undergone a shift from a strictly pathology-based model to one which considers an individual’s strengths (Dunn & Dougherty, 2005). In consideration of these trends and the research that supports them, it is likely that the tools of positive psychology can prove effective not only for the general population, or clinical psychology settings, but also have significant application for the pediatric-onset SCI population.

**History**

The field of positive psychology was formally founded in 1998 by Martin Seligman and Mihaly Csikszentmihalyi in an effort to pursue the scientific study of human strengths, virtues, and happiness--the positive aspects of human experience. Seligman and Csikszentmihalyi describe positive psychology as a science devoted to understanding positive subjective experience, positive individual traits, and positive institutions (Seligman & Csikszentmihalyi, 2000). Under this broad definition and with these ambitious goals, positive psychology has found itself impacting a diversity of fields ranging from organizational and occupational settings, to prevention programs for children, to the clinical and rehabilitative realm. Despite this rapid growth, however, less attention has been given to chronic illness populations, and the pediatric-onset SCI population in particular. In reviewing the literature on both intervention and assessment, we feel

it is plausible to extrapolate from the current literature to explore potential application of positive psychology in working with children who have a SCI.

## **Intervention Studies:**

Despite its youth, the positive psychology movement has generated prolific research addressing theory, assessment, and practice. In particular, a growing literature for clinical applications shows promising evidence that positive psychology interventions are capable of supplementing traditional psychotherapy for clinical populations or serving as a stand-alone interventions for non-clinical settings.

The majority of the studies have been conducted with either college students or adult populations. Perhaps the largest study to date was conducted by Seligman, Steen, Park, and Peterson (2005). In this placebo controlled Internet study, participants were randomly assigned into one of six groups. Five groups were assigned different happiness interventions while a sixth group was assigned a control exercise. In measuring post-test data, three of the five interventions increased happiness and reduced depressive symptoms. The three successful interventions will be briefly described, and we will speculate as to how such interventions may be utilized with the pediatric-onset SCI population.

For the *Three Good Things* intervention, participants were instructed to record three things that went well in their day along with a causal explanation for each of those things. Participants practiced this exercise daily for one week. In the *Using Signature Strengths* intervention, participants took an inventory of personal character strengths over the Internet and received individualized feedback regarding their top five strengths, or what the authors call *signature strengths*. They were then instructed to use one of these top strengths in a new and different way every day for one week. These two interventions were found to increase happiness and decrease depressive symptoms over six months.

A third intervention, the *Gratitude Visit*, was found to cause large positive changes over a one-month period but not at the six month follow up. For this activity, participants were given one week to write and then personally deliver a letter of gratitude to someone who had been especially kind to them but had never been properly thanked. The investigators isolated each intervention to test their efficacy. However, since the *Gratitude Visit* intervention showed large improvements, but did not maintain as well as the *Three Good Things* and the *Using Signature Strengths* interventions, one may ponder the increased additive effect of utilizing these interventions in a combined intervention package.

In a separate study, Seligman, Rashid, and Parks (2006) found that Positive Psychology Therapy (PPT) significantly reduced depressive symptoms for depressed college students compared to a treatment as usual group and a treatment as usual with medication group. Similar results were found when using PPT in a group therapy format. In this study, individual PPT was composed of traditional psychotherapy conducted at a college counseling center, but with substantial focus on strengths and optimism. Activity assignments,

such as the ones just mentioned, were used as homework assignments. Group therapy treatment was composed of six sessions, and each session used half the time to process the previous week's exercise and in the remaining hour a new exercise was introduced.

### **Children**

While composing a much smaller literature, positive psychology research with children points to the same promising findings achieved with adult populations. In one study, a program called *Penn Prevention* investigated the consequences of negative thinking in children. In the experimental group, children were taught how to identify negative beliefs, consider the evidence for these beliefs, and create realistic alternatives if necessary. They were similarly taught the same process for evaluating pessimistic explanations for events and creating alternative explanations that were more positive. While these interventions appear to parallel standard cognitive behavioral therapy interventions, they were applied preventively. In comparing these children to a group of controls, researchers found that children in the prevention condition had half the rate of depression as the control group. Furthermore, children who finished *Penn Prevention* while in their preadolescence were able to confront challenges they faced later in adolescence more effectively and had less depression than children in the control group (Roberts, Brown, Johnson, & Reinke, 2002). While some may attribute these positive outcomes to the preventive application of standard CBT interventions, the implication supports the idea that fostering positive psychological skills or strength-nurturing interventions may create ongoing resiliency, and prevent the development of psychopathology.

### **Assessment**

Perhaps one of the greatest accomplishments of the positive psychology field was the development of a manual called the Characters Strengths and Virtues, or CSV. The CSV was developed by Peterson and Seligman (2004) in the effort to create for wellbeing, what the DSM IV (Diagnostic and Statistical Manual for Mental Disorders) accomplishes for psychological disorders. The CSV is a manual that codifies and describes character strengths and virtues that facilitate thriving. The CSV identifies six virtues: wisdom, courage, humanity, justice, temperance, and transcendence, which are universally found throughout most cultures. Each virtue has its own strengths, such that 24 identified strengths were classified under one of the six virtues (see table 1). The classification was extremely important for the field, not only because it created a common language that positive psychologists could use to communicate, but also for its value in assessment.

With a standardized classification of strengths in place, the Values in Action Inventory (VIA) and Values in Action Inventory for Young People (VIA-YP) were created to measure an individual's strengths and virtues. This assessment was used in the aforementioned Internet-based study and is currently available

to take on the Internet at <http://www.authentic happiness.sas.upenn.edu/Default.aspx>. The VIA and VIA-YP assessments provide a valuable way to identify an individual's strengths, and can serve as a major tool for developing a Positive Psychology Treatment strategy (Duckworth, Steen & Seligman, 2005, p. 638).

**Table 1.** Classification of Six Virtues and 24 Associated Character Strengths

## 1. **Wisdom and Knowledge**

Associated Character Strengths:

- Creativity
- Curiosity
- Open-Mindedness
- Love of Learning
- Perspective

## 2. **Courage**

Associated Character Strengths:

- Authenticity
- Bravery
- Persistence
- Zest

## 3. **Humanity**

Associated Character Strengths:

- Kindness
- Love
- Social Intelligence

## 4. **Justice**

Associated Character Strengths:

- Fairness
- Leadership
- Teamwork

## 5. **Temperance**

Associated Character Strengths:

- Forgiveness

- Modesty
- Prudence
- Self-Regulation

## 6. Transcendence

Associated Character Strengths:

- Appreciation of beauty and excellence
- Gratitude
- Hope
- Humor
- Religiousness

*Adapted from Peterson & Seligman, 2004*

## Positive Psychology Treatment for Pediatric SCI Population

Utilizing current knowledge of positive psychology interventions and assessment, we can extrapolate from this literature to design a positive psychology treatment for the pediatric-onset SCI population. As in any well-designed treatment plan, consideration must be given at the outset regarding the completeness and level of SCI injury, the characteristics of the child's physical and social environment, and available resources in determining the appropriateness of the treatment plan.

An assessment-intervention combination may be the most desirable, since a valid and reliable assessment tool can provide useful information about an individual's salient features and focus issues for treatment. Using the VIA-YP, for example, the presence of a child's strengths can be evaluated. Thus, for a child whose signature strengths might be hope, leadership, and persistence, a treatment team can tailor a treatment plan that affirms and builds upon these signature strengths, and extends these strengths to newly encountered issues regarding the injury and adjustment to the injury.

How this treatment plan becomes actualized through therapy is dependent on the individual and on the therapist's orientation. For example, a child who has an SCI and lives at home may benefit from a PPT that includes weekly outpatient therapy that combines CBT technique with positive therapy activities for homework. Alternatively, there may be situations where assigning just the activities may be useful. For example, in a hospital setting where weekly group psychotherapy may be feasible, the group applications of PPT may be helpful for all individuals with pediatric-onset SCI. When weekly psychotherapy is not available, a child can be given positive psychology assignments such as the *gratitude visit*, or *three good things*, or perhaps both, with sufficient positive benefit. The prescribed activities do not necessarily need to

be pre-existing versions of the PPT exercises. Activity assignments can be designed by the therapist to fit a given child's matrix of strengths.

Regardless of the intervention's makeup, it is important to emphasize that by no means should a positive psychology intervention become a treatment that focuses exclusively on the positive. It would be fallacious to deny the necessity of confronting painful emotions, cognitions, or maladaptive behaviors that need to be worked through and ameliorated. A positive psychology intervention, instead, serves to counterbalance the focus on what was lost or damaged with the strengths and virtues an individual still has.

### **Discussion**

Reviewing the positive psychology literature, one quickly becomes inspired by its hopeful message of "building what's strong" rather than only "fixing what's wrong" (Duckworth et al., 2005, p. 631). Funneling that inspiration into practical technique is a much more difficult task and is one which the young literature is still in its early stages in trying to accomplish. The current article makes an attempt to introduce pre-existing positive psychology ideas and treatments into the services for the pediatric-onset SCI population. The SCI treatment community would be wise to utilize these intervention and prevention strategies and to test their efficacy on the psychosocial outcomes for those with pediatric-onset SCI, thereby contributing to both the services for pediatric-onset SCI and the developing literature on the utility of positive psychology intervention strategies.

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## **Spinal Cord Disorders**

### **A Telehealth Intervention for Caregivers of Persons with Multiple Sclerosis**

*Erin O. Zerth, MA; Kathleen Chwalisz, PhD; and Stephanie Clancy-Dollinger, PhD*

Informal family caregivers provide services that help narrow the often large gap between care recipient needs and available medical care for individuals with multiple sclerosis (MS). Expenditures for institutional or in-home care for older adults with a disability, for example, currently reach more than \$100 billion each year, yet eighty percent of individuals actually needing care receive most or all assistance from informal caregivers. Thus, caregivers have provided the “free care” needed to support current long-term care policies and to help support the economy and control medical costs, often at the expense of their own physical and mental well-being. Clearly, keeping the caregiver physically and emotionally well is vital to the health of both the individual with MS and the nation’s economy—when caregivers are ill, treatment costs increase for both the caregiver and the care recipient, creating a dual drain on the health care system. Therefore, it is essential for individuals with MS, their caregivers, and their health care providers to be knowledgeable about the risks of caregiving and to learn ways of reducing the negative fallout from that caregiving.

**Multiple Sclerosis and Caregiver Burden.**

Why are caregivers of individuals with MS at-risk for negative outcomes of caring? The term “Caregiver burden” encompasses reported accounts of distress by informal caregivers and represents the entire range of social, emotional, financial, psychological, and physiological stressors experienced by the caregiver (Thompson & Gallagher-Thompson, 1996). For some individuals, caregiving can be a very rewarding and reciprocating activity that contributes to self-worth, self-esteem, and companionship (Altholz, 1991). Yet caregiving adversely affects caregivers’ well-being, even after controlling for care recipient condition (Gallagher-Thompson, Coon, Rivera, Powers & Zeiss, 1998). For example, caregivers have been found to repeatedly put their care recipient’s needs before their own (Lezak, 1978). Neglect of self-care and the burden of caring is associated with a plethora of negative outcomes for caregivers including depression, anxiety, distress, isolation, physical disability, and lowered immune system functioning (Burton, Newson, Schulz, Hirsch, & German, 1997; Caplan & Moelter, 2000; Schofield, Murphy, Herman, Bloch & Singh, 1997; Vitaliano, Russo, Young, Teri, & Maurio, 1991; Weitzenkamp, Gerhart, Charlifue, Whiteneck, & Savic, 1997).

Studies of caregivers of individuals with MS are limited, particularly in comparison to other major disabling, long term illnesses. Furthermore, very few researchers have examined predictors or buffers of distress for caregivers of individuals with MS (Suh et al., 2005) as most available literature focuses on the patient. However, literature on caring for individuals with spinal cord injury and disorder (SCI/D) provides clues in conceptualizing the experience of caring for an individual with MS. Caring for individuals with SCI/D is a unique type of caregiving career: the caregiving role is often unexpected, meaning that caregivers have little preparation to assume their new role and must rapidly acquire new skills, and caregivers must simultaneously grieve for the loss of the independence and perhaps a change in family financial status (Roth, Owen, Clay, Olivio & Goode, 2001). Caring for individuals with MS also has its unique challenges and the caregiving role is often as unpredictable as the course of the disease, requiring a great degree of long-term care planning. Also, caregivers must simultaneously grieve for the loss of the physical and possibly cognitive abilities of the individual with the disability.

Caregiving for individuals with SCI/D is associated with a wide range of negative consequences for the caregivers. Caregiving spouses of SCI patients reported significantly higher amounts of depression and stress compared to non-caregivers and their SCI care recipients (Weitzenkamp et al., 1997). Manigandan et al., (2000) found that 78.9 percent of caregivers of individuals with SCI/D were psychologically distressed. In addition, researchers conducting a study of 50 primary caregivers of individuals with SCI/D found that the caregiver role was associated with a significantly lower quality of life compared to a matched sample of non-caregivers (Unalan et al., 2001). Parameters of the disability such as level of injury, duration, course, and complications did not help explain this association.

Available research also documents the negative effect caregiver distress can have on the care recipient with SCI/D (e.g., Elliot, Shewchuk, & Richards, 1999; Unalan et al., 2001; Weitzenkamp et al., 1997), emphasizing the need for effective intervention. Social support appears to be one important intervention component to help caregivers be better providers to their care recipients. Caregiver ratings of perceived support have shown that this nurturance is directly related to care recipient psychosocial functioning, and also helps to buffer the consequences of other stressors for the caregiver (Friedland & McColl, 1987; Morris, Robinson, Raphael, & Bishop, 1991). Problem solving presents a second area of intervention focus. Caregiver tendencies to solve problems impulsively and carelessly were significant negative predictors for SCI acceptance by the care recipient at discharge from medical rehabilitation. Furthermore, caregiver problem-solving difficulties actually predicted the presence of pressure sores, a significant and very painful complication of SCI, in the care recipient at one-year post-injury (Elliot et al., 1999).

McKeown, Porter-Armstrong and Baxter's (2003) review of the MS caregiving literature indicated that providing care for an individual with MS has a potentially harmful impact on multiple facets of the caregiver's life. For example, Parkenham (2001) found that almost 33% of MS caregivers reported clinically significant levels of psychological distress, and found that social support and level of disability was related to caregiver outcomes. Furthermore, Rivera-Navarro, Morales-Gonzalez, and Benito-Leon (2003) noted that work-related consequences of caregiver burden may exert a negative influence on the occupational or professional life of the caregiver. Caregivers for individuals experiencing memory difficulties associated with MS were particularly at risk as such difficulties were linked to higher amounts of strain including the amount of time a caregiver could spend in self-care activities, the caregiver's mood, and that individual's feelings toward the person with MS (Chipchase & Lincoln, 2001). The perceived presence of social support, emotional support, and instrumental support, and possessing good communication skills, were all shown to have a beneficial impact on the caregiver (Kleiboer, Kuijer, Hox, Schreurs & Bensign, 2006; McKeown, 2003; Parkenham, 2001).

### **Telehealth Interventions for Caregivers**

Telehealth, the use of communication technologies to provide psychological interventions when distance or other factors make face-to-face contact infeasible or impossible, has the potential to bridge the gap between health care services needed and those actually available to caregivers (Nickelson, 1996). Telemedicine has recently gained increased interest in response to the demand for quality, accessible, compact, private, and affordable care (Nickelson, 1996; Siden, Young, Starr, & Tredwell, 2001; Wright, Bennet, & Gramling, 1998). Furthermore, Stamm (1998) suggested that "telehealth can transcend troublesome boundaries like

economic status, culture, climate, geography, and even warfare” (p. 536). A telehealth intervention for caregivers of adults with MS has the additional benefit of allowing for a flexible intervention provision schedule to accommodate a busy caregiver with an unpredictable schedule. A telehealth phone hotline would also serve as a resource for urgent questions arising during caregiving situations such as the immediate need for information about a care recipient’s condition, resources in the area, problem-solving difficulties, or managing the emotions and stress often associated with the caregiving role. Such a procedure might also increase the frequency of available intervention, since it allows for home-based interactions, reducing the costs of driving and the significant inconveniences often associated with the caregiver’s absence, such as the need to find an alternative care provider or cope with the problems of transferring the care recipient in and out a vehicle. Finally, telehealth interventions have been demonstrated to positively influence outcome measures of physical health and psychological well being (Steffen, 2000; Steffen & Mangum, 2003).

As a result of the current economy and health care system, informal caregivers of individuals with MS are assuming a large percentage of the caregiving duties following hospital discharge. Unfortunately, such caregivers are at risk for a number of negative physical and psychological effects associated with providing care. Keeping caregivers healthy is an essential component in preventing skyrocketing health care costs by preventing the institutionalization or excessive use of services by care recipients, and by preventing future illness in their caregivers. Current caregiver intervention research often lacks a longitudinal design, a multi-component and theoretical approach, an individualized program, and convenience for the care recipient. Interventions for caregivers of individuals with MS are needed to help overcome potential barriers to treatment, particularly rigid scheduling and the hassle of having to leave the home. A telehealth caregiver intervention is suggested as a promising approach to treating caregivers of individuals with MS, particularly those in rural areas with limited access to traditional treatment options.

### **The Tele-Help Line for Caregivers**

The Southern Illinois Rural Caregiver Telehealth Project is an ongoing multi-component telehealth intervention developed in 2003 for informal caregivers of older adults in rural areas (Chwalisz & Clancy-Dollinger, 2003). The project is funded by the National Institute of Nursing Research and the National Institute on Aging, and delivered free of charge to participants. The intervention: the Tele-Help Line for Caregivers (TLC), is designed to specifically meet the needs of informal caregivers in a rural area by allowing the provision of care where access is limited, and caregivers can receive support services at the times of their choosing from their own home. Participants are randomly assigned to one of three conditions: (a) An eight-week structured telephone-counseling intervention, (b) a helpline condition in which caregivers call as needed with the intervention components matched to the caregiver's presenting concerns,

and (c) a services-as-usual control group. Sensitive outcome measures were collected pre- and post-intervention, as well as at a six-month follow-up period for both intervention groups and the control group.

The TLC intervention is based on the Perceived Stress Model of Caregiver Burden (Chwalisz, 1996) and delivered according to a flexible treatment manual. The treatment components are both theoretically and empirically derived (Chwalisz & Clancy-Dollinger, 2002; Chwalisz & Morse, 2003) and include: knowledge, problem solving, social support, and managing feelings. The objectives of the first session, *knowledge*, are to deliver information and, if appropriate, to train caregivers on how to seek information about the stages of caregiving, the care-recipient's condition, and available services and resources. In sessions two through four, *social problem solving*, the caregiving specialists lead caregivers through the five stages of the FOCUS problem solving model: facts, optimism, creativity, understanding, and solution (Kurylo, Elliot, & Shewchuk, 2001). The first problem-solving session is designed to improve the caregiver's self-efficacy for problem-solving and to help the caregiver identify a significant caregiving problem they currently experience. The objectives for the second session are to increase the understanding the caregiver has for the identified problem, and to help increase their creative problem-solving abilities by leading the caregiver through the compilation of a list of possible solutions, analyzing the quality of each of them. At least one solution is chosen to implement between the second and third problem-solving sessions. The third and final problem-solving session assesses the success of the implementation of the chosen solution, reevaluates the range of available solutions, or explores barriers to carrying out a given solution.

The third component, *social support*, is typically carried out over two sessions. The first session is used to assesses the caregiver's current level of social support and identify strengths and deficits in the amount and type of support networks available. The goal is to increase both actual and perceived social support. A social support goal is then chosen for the caregiver to try out between sessions. The objectives of the second social support session are to assess the social support-related goals and make plans for continued strengthening or maintenance of one's support network.

The fourth and final component, *managing feelings*, is also a two-session one, and aims to address negative emotions and mental health concerns. The initial objectives are to normalize the caregiver's situation and emotions and increase that person's ability to cope with negative emotions. The second session of the managing feelings component aims to talk about stress-producing beliefs and caregiver self-care.

Preliminary outcome data is based on 91 informal caregivers of rural older adults who participated in the Tele-Help Line for Caregivers and completed the intervention and six-month follow-up (e.g., see Clancy-Dollinger, Chwalisz, & Zerth, 2006; Clancy-Dollinger, Chwalisz, Zerth & Hand, 2007). Results indicated that the delivery of a multi-component intervention by means of the telephone can be a successful

form of health communication, and is ideally suited for a rural caregiver population for whom access to services may be limited. For example, caregivers participating in the full eight-week treatment reported improved emotional well-being including decreased reports of nervousness and depression compared with caregivers in the control group. Furthermore, caregivers in the eight-week and helpline treatment groups reported improvements in social role/interpersonal functioning relative to the control group.

A more focused study of the effectiveness of the Tele-Help Line for Caregivers intervention examined informal caregivers of patients on acute rehabilitation inpatient units for SCI/D, stroke, and traumatic brain injury. Forty-three rural caregivers participated in this study and preliminary data suggested that caregivers of rehabilitation patients generally reported decreased emotional and physical health eight weeks after assuming the caregiver role. Compared to general caregivers of older adults, they also provided more care hours per week, and provided a higher level of skilled services. Whereas it is important to recognize that caregivers of rehabilitation patients may be especially at risk for negative consequences for caregiving several weeks following their loved one's hospital discharge, the Tele-Help Line for Caregivers appeared to buffer the effects of caregiver burden for those individuals participating in either of the two treatment groups. For example, caregivers in the eight-week and helpline treatment groups reported experiencing less physical pain and increased interpersonal functioning relative to participants in the services as usual control group (Zerth, Chwalisz & Clancy-Dollinger, 2007).

Macnamara and colleagues (1990) encourage health care institutions to go beyond the simple provision of caregiving information, and to link caregivers to effective interventions. Furthermore, they strongly recommend that caregivers be helped to recognize the importance of self-care, and to manage the many difficult emotions that are expected when caring for an individual with a disability. Programs such as the Tele-Help Line for Caregivers provide an accessible means of delivering effective interventions to rural caregivers and can be used to help protect the caregivers of individuals with MS from many of the negative consequences associated with providing such care.

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## Clinically Focused Research

### The Steel Conference on Pediatric Spinal Cord Injury, 2006

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#### Introduction

Spinal cord injuries are devastating events. They can drastically alter an individual's life as well as the lives of those around that person. Such a traumatic life event seems particularly devastating when it occurs in childhood. There are many unique features of SCI in children and adolescence as they experience their SCI in the realm of ongoing growth and development. The Howard H. Steel Conference on Pediatric Spinal Cord Injury in December of 2006 offered an opportunity for professionals to learn more about this uniqueness. The following reviews are based on four abstracts that were presented at this conference and the subsequent articles written for a special edition of the *Journal of Spinal Cord Medicine*.

**Johnson, K. A. & Klaas, S. J. (2007). The changing nature of play: Implications for pediatric spinal cord injury. *Journal of Spinal Cord Medicine, 30*(1). S71-S75.**

This article discusses the current state of societal changes in the nature of play and the effects of these changes on children's physical health, emotional well-being, and cognitive functioning. The therapeutic and developmental benefits of play are crucial for children with spinal cord injuries and yet are often difficult to achieve. In light of this concern, the article discusses implications for practice with pediatric SCI patients. A study examining leisure activities for 66 children and adolescents with SCI found that the top five recreation activities were listening to music, reading, using computers, playing video games, and watching television. These are all indoor sedentary activities involving little social interaction. Data collected in 2005 found that 203 of 326 patients surveyed reported no participation in adult-organized activities at a time when these activities are highly prevalent among their able-bodied peers. The article discusses potential interventions for preschool, school-aged, and adolescent patients that focus on creative expression, outdoor play and personal interaction with peers. The article makes the point that it is necessary for health care professionals to understand societal changes in the nature of play in order to brainstorm creative interventions.

**Anderson, C. J., Vogel, L. C., Chlan, K. M., Betz, R. R., & McDonald, C. M. (2007). Depression in adults who sustained spinal cord injuries as children or adolescents. *Journal of Spinal Cord Medicine*, 30(1). S76–S82.**

This article presents the results of a study which assessed the occurrence of depression and the outcomes associated with depression for adults with pediatric-onset spinal cord injuries. Of the 232 adults assessed, 27% reported mild to severe depressive symptoms, 7% reported recent suicidal ideation, and 3% reported symptoms consistent with major depressive disorder. Depression was found to be associated with low rates of employment, low income, medical complications, and low life satisfaction. Depression was also associated with incomplete injury. The article concludes that depression is a significant concern for patients with spinal cord injuries, and that these issues should be addressed as clinicians work with children and adolescents on their transition to adulthood.

**Augustis, M. A., Levi, R., Asplund, K., & Berg-Kelly, K. (2007). Psychosocial aspects of traumatic spinal cord injury with onset during adolescence: A qualitative study. *Journal of Spinal Cord Medicine*, 30(1). S55–S64.**

This study aimed to better understand the psychosocial aspects of the rehabilitation process from the point of view of Swedish adults who had sustained SCI during early to mid-adolescence. Qualitative research methodology was used. Twenty-four semi-structured interviews were conducted with young adults ranging from 17 to 30 years of age, 58% male, 63% with paraplegia. Time since injury ranged from 4-15 years. Through the use of content analysis, the authors identified seven primary psychosocial categories from the semi-structured interviews with the participants: the individual, family, peers, romantic partner, other significant adults, school, and healthcare professionals. Findings indicate that support from parents and

peers is pivotal. Participants indicated that their parents served not only as their advocates, but as their primary source of support as well. Additionally, connectedness with peers seems to promote activity level and identity development in youth with SCI. These preliminary findings indicate that healthcare professionals may underestimate these sources of support for the patient and recommends that parents and peers be included in the rehabilitation effort. Rehabilitation professionals are encouraged to learn more about typical adolescent development to better meet the specific needs and demands of individuals in this age group in order to improve outcomes and satisfaction with the rehabilitation process.

**Alexander, M. S., & Alexander, C. J. (2007). Recommendations for discussing sexuality after spinal cord injury/dysfunction in children, adolescents, and adults, *Journal of Spinal Cord Medicine*, 30(1), S65–S70.**

This article reviewed the literature and provided a framework for sex education for individuals with spinal cord injury/dysfunction across the lifespan. Overall, the literature on sexuality in children and adolescents with SCI/D was lacking, but appropriate links were made from what was found in the literature about sexuality in adults with SCI/D to their younger counterparts. Recommendations for teaching children and adolescents with SCI/D and their caregivers about sexuality were made for the following age groups: infancy to age 3, preschool years, ages 5-8, ages 8-11, and adolescents. Additionally, general information from the adult literature regarding expected sexual response, sexual dysfunction, and the treatment of sexual dysfunction was provided. Healthcare professionals were strongly encouraged to provide disability-specific information and to create an open dialogue about sexuality for the individual with SCI/D, their parents, and their partners. It was asserted by the authors that increased knowledge about, and comfort with, sexuality will promote healthy, satisfying, and safe sexual practices throughout the lifespan.

*Sara J. Klaas, MSW, C-ASWCM, is Director of Care Coordination, Spinal Cord Injury Care Coordinator, Shriners Hospitals for Children, Chicago, Illinois.*

*Heather Russell, PhD, is a Licensed Psychologist/Medical Staff at Shriners Hospitals for Children, Philadelphia, Pennsylvania*

*Julie Gorzkowski, BS, is an MSW intern at Shriners, Chicago*

*Cindy Buchanan, MS, is a doctoral intern at Shriners, Philadelphia*

## Events Calendar

### ***Events, Continuing Education, Conferences and Links***

Many organizations also offer further information on conferences, symposium, annual meetings, forums, workshops, seminars, organizational events and professional development opportunities including continuing education courses such as online courses and teleconferences. You can also find information about advocacy efforts; updates about their chapters, divisions, regions or branches; codes of ethics; scope of practice; research; publications and newsletters; resources and resource centers, career opportunities; affiliates, and links. Please go to their web sites for more up-to-date information.

If you learn of any additional conferences, or know of additional organizations of interest to the membership please contact me at [jjk1009@hotmail.com](mailto:jjk1009@hotmail.com), or call 203-631-4800.

Thank you. Jayne Kleinman

### **2008**

**WHAT:** American Counseling Assn. and American Rehabilitation Counseling Assn.  
**WHEN:** March 26–30, 2008  
**WHERE:** Honolulu, HI  
**MORE INFO:** [www.counseling.org/](http://www.counseling.org/)

**WHAT:** RESNA (Rehabilitation Engineering & Assistive Society of North America)  
(Pre-conference Abilities Expo)  
**WHEN:** March 27, 2008  
**WHERE:** New Jersey Convention Center, Edison, NJ  
**MORE INFO:** [www.resna.org/](http://www.resna.org/)

**WHAT:** Abilities Expo/New York Metro  
**WHEN:** March 28–30, 2008  
**WHERE:** New Jersey Convention Center, Edison, NJ  
**MORE INFO:** [www.abilitiesexpo.com](http://www.abilitiesexpo.com), 1-800-385-3085

**WHAT:** Social Work Health Leadership Foundation 43rd Annual Meeting & Conference  
“CrossingBorders, Building Bridges...Expanding Horizons”  
**WHEN:** April 2–5, 2008  
**WHERE:** Hyatt Regency, Montreal, Quebec, Canada  
**MORE INFO:** [www.sswlhlc.org](http://www.sswlhlc.org)

- WHAT:** Neurobehavioral Consequences of Acquired Brain Injury  
Contemporary Forums
- WHEN:** April 2, 2008
- WHERE:** Orlando, FL
- MORE INFO:** [www.contemporaryforums.com/](http://www.contemporaryforums.com/)
- 
- WHAT:** Brain Injuries Contemporary Forums
- WHEN:** April 3–5, 2008
- WHERE:** Orlando, FL
- MORE INFO:** [www.contemporaryforums.com/](http://www.contemporaryforums.com/)
- 
- WHAT:** ADAPT’s 25th Anniversary Week,  
“The ADAPT Community: 25 years of Activism and Counting”
- WHEN:** April 26–May 2, 2008
- WHERE:** Washington, DC
- MORE INFO:** [www.adapt25.org](http://www.adapt25.org) or 512-442-0252, 303-733-9324
- 
- WHAT:** 15th Annual NICM Clinical Case Management Conference &  
9th Annual American Case Management Assn. Meeting
- WHEN:** April 28–May 1, 2008
- WHERE:** Red Rock Casino, Las Vegas, NV
- MORE INFO:** [www.acmaweb.org/](http://www.acmaweb.org/)
- 
- WHAT:** World of Possibilities Expo 2008 and Hire Disabilities Solutions Career Fair
- WHEN:** May 2–3, 2008
- WHERE:** Montgomery County Fairgrounds, Gaithersburg, MD
- MORE INFO:** [www.caringcommunities.org/](http://www.caringcommunities.org/)
- 
- WHAT:** Neurobehavioral Consequences of Acquired Brain Injury  
Contemporary Forums
- WHEN:** May 4, 2008
- WHERE:** Seattle, WA
- MORE INFO:** [www.contemporaryforums.com/](http://www.contemporaryforums.com/)
- 
- WHAT:** Brain Injuries Contemporary Forums
- WHEN:** May 5–7, 2008
- WHERE:** Seattle, WA
- MORE INFO:** [www.contemporaryforums.com/](http://www.contemporaryforums.com/)
- 
- WHAT:** National ADA Symposium and EXPO
- WHEN:** May 12–14, 2008
- WHERE:** America’s Center, St. Louis, MO
- MORE INFO:** <http://www.adasymposium.org/>
- 
- WHAT:** Spinal Cord Injuries Contemporary Forums
- WHEN:** May 15–17, 2008
- WHERE:** San Francisco, CA
- MORE INFO:** [www.contemporaryforums.com](http://www.contemporaryforums.com)

- WHAT:** Abilities Expo/Southern California  
**WHEN:** May 30–June 1, 2008  
**WHERE:** Anaheim Convention Center, Anaheim, CA  
**MORE INFO:** [www.abilitiesexpo.com](http://www.abilitiesexpo.com), or 1-800-385-3085
- WHAT:** United Cerebral Palsy Annual Conference  
**WHEN:** June 18–21, 2008  
**WHERE:** Hyatt Regency, Washington, DC  
**MORE INFO:** [http://www.ucp.org/ucp\\_generalsub.cfm/1/10/10/10-11912](http://www.ucp.org/ucp_generalsub.cfm/1/10/10/10-11912)
- WHAT:** 34th Annual Scientific Meeting of ASIA  
(American Spinal Injury Association)  
**WHEN:** June 19–22, 2008  
**WHERE:** San Diego, CA  
**MORE INFO:** [www.asia-spinalinjury.org/](http://www.asia-spinalinjury.org/)
- WHAT:** RESNA 2008 Annual Conference (Rehabilitation Engineering & Assistive Society of North America)  
**WHEN:** June 26–30, 2008  
**WHERE:** Hyatt Regency Crystal City, Arlington, VA  
**MORE INFO:** [www.resna.org/](http://www.resna.org/)
- WHAT:** 22nd Annual Conference of AASCIPSW (American Assn. of Spinal Cord Injury Psychologists and Social Workers)  
**WHEN:** August 11–13, 2008  
**WHERE:** Gaylord Palms Resort & Convention Center, Kissimmee, FL  
**MORE INFO:** [www.aascipsw.org](http://www.aascipsw.org)
- WHAT:** American Psychological Association Annual Meeting and Division 22  
**WHEN:** August 14–17, 2008  
**WHERE:** Boston, MA  
**MORE INFO:** [www.apa.org](http://www.apa.org)
- WHAT:** 21st World Congress Rehabilitation—Quebec 2008  
**WHEN:** August 25–28, 2008  
**WHERE:** Quebec City Convention Center, Quebec, Canada  
**MORE INFO:** [www.riquebec2008.org](http://www.riquebec2008.org) or [www.riglobal.org/](http://www.riglobal.org/)
- WHAT:** ISCoS 47th Annual Scientific Meeting & 3-Day Workshop on Spinal Cord Injury Management  
**WHEN:** September 1–4, 2008  
**WHERE:** Durban, South Africa  
**MORE INFO:** [www.iscos2008.org.za](http://www.iscos2008.org.za)

**WHAT:** Abilities Expo/Minnesota  
**WHEN:** September 12–14, 2008  
**WHERE:** Minneapolis Convention Center, Minneapolis, MN  
**MORE INFO:** [www.abilitiesexpo.com](http://www.abilitiesexpo.com), 1-800-385-3085

**WHAT:** Council on Social Work Education  
2008 Annual Program Meeting  
**WHEN:** October 30–November 2, 2008  
**WHERE:** Marriott Philadelphia, Philadelphia, PA  
**MORE INFO:** [www.cswe.org/](http://www.cswe.org/)

**WHAT:** Annual Assembly of the American Academy of Physical Medicine and  
Rehabilitation (AAPM&R)  
**WHEN:** November 20–23, 2008  
**WHERE:** San Diego, CA  
**MORE INFO:** [www.aapmr.org/assembly.htm](http://www.aapmr.org/assembly.htm)

## 2009

**WHAT:** American Counseling Association and the  
American Rehabilitation Counseling Assn.  
**WHEN:** March 19–23, 2009  
**WHERE:** Charlotte, NC  
**MORE INFO:** [www.arcaweb.org](http://www.arcaweb.org)

**WHAT:** American Psychological Association Annual Meeting  
and Division 22  
**WHEN:** August 6–9, 2009  
**WHERE:** Toronto, Ontario, Canada  
**MORE INFO:** [www.apa.org](http://www.apa.org)

**WHAT:** 2009 Annual Program Meeting of the  
Council on Social Work Education  
**WHEN:** November 6–9, 2009  
**WHERE:** Grand Hyatt, San Antonio, TX  
**MORE INFO:** [www.cswe.org](http://www.cswe.org)

## 2010

**WHAT:** American Counseling Assn. and  
American Rehabilitation Counseling Assn.  
**WHEN:** March 18–22, 2010  
**WHERE:** Pittsburgh, PA  
**MORE INFO:** [www.arcaweb.org](http://www.arcaweb.org)

**WHAT:** American Psychological Association Annual Meeting  
and Division 22  
**WHEN:** August 12–15, 2010  
**WHERE:** San Diego, CA  
**MORE INFO:** [www.apa.org](http://www.apa.org)

## **Top Papers and Posters at the 2007 AASCIPSW Conference**

### ***Papers***

**#303 Unique Programming in Pediatric Spinal Cord Injur**

*Heather Russell, PhD, and Sara J. Klaas, MSW, C-ASWCM*

**#204 Pain Following Spinal Cord Injury, Classification, Assessment and Novel Interventions**

*J. Scott Richards, PhD, ABPP; Trevor A. Dyson-Hudson, MD, and Margaret M. Scmitt, PhD*

**#106 From War Theater to Community Re-entry: Challenges of Polytrauma Rehabilitation**

*Jay M. Uomoto, PhD, and Glenn Curtiss, PhD*

**#307 Reflection and Conversation on Psychotherapy**

*Stephen T. Wegener, PhD, ABPP, and Lester Butt, PhD, ABPP*

**#212 Obstacles to Overcome in the Quest to Cure Spinal Cord Injury**

*Wise Young, MD*

### ***Posters***

**#7 The Effect of Nicotine Use on Spinal Cord Injury Pain: A Pilot Study**

*Elizabeth J. Richardson, MA (Ms. Richards also received the Best 2007 Research Poster Award)*

**#5 The Effect of Alcohol Use on Unintentional Injuries Post-Spinal Cord Injury**

*Sherry L. LaVela, MPH, MBA*

**#3 Experimental Treatments for Spinal Cord Injury: What You Should Know**

*Maria J. Amador, BSN, RN, CRRN*

**#11 Girls Just Gotta Have Fun: The Creation of GLAHM Camp**

*Sara J. Klaas, MSW, C-ASWCM*

**#20 Family Intervention Utilizing the Functional Independence Measure: A Marine's Acute Polytrauma Rehabilitation**

*Kristi S. Van Sickle, PsyD*

## **2007 AASCIPSW AWARDS**

At the annual meeting of the American Association of Spinal Cord Injury Psychologists and Social Workers in Kissimmee, Florida on August 28, 2007, the Association presented the Essie Morgan Excellence award to Daniel Rohe, PhD, of Rochester, MN; the James J. Peters Distinguished Service Award to Kathlene Chadband of Seattle, WA; and the Clinical Performance Award to Sara J. Klass, MSW of Chicago, IL.

### **Essie Morgan Excellence Award**

#### ***Daniel Rohe, PhD***

The Essie Morgan Excellence Award is given to an active member of AASCIPSW who has demonstrated outstanding leadership in the areas of psychosocial adjustment and rehabilitation of persons with SCI in service delivery, research, education, or administration.

This year's recipient, Dr. Dan Rohe, Associate Professor of Psychology at Mayo Medical School and Rehabilitation Psychologist at the Mayo Clinic in Rochester, Minnesota exceeds in all of these areas. Dr. Rohe has spent over 25 years on the staff of the renowned Mayo Clinic. He holds Masters and Doctoral degrees in Counseling Psychology, with a specialization on rehabilitation psychology from the University of Minnesota. He is recognized by his peers as one of the most knowledgeable clinicians, educators and researchers in the field of rehabilitation psychology.

In addition to these skills, Dr. Rohe has been involved in developing standards in the field. These efforts include the Consortium on SCI Medicine Clinical Practice Guidelines and the CARF National Advisory Committee for Spinal Cord Rehabilitation Systems of Care. Dr. Rohe has also served on the Boards of the American Board of Rehabilitation Psychology and the American Psychological Association Division of Rehabilitation Psychology. He was one of a group of 10 clinicians who established Board Certification for Rehabilitation Psychologists in 1995.

Dr. Rohe has also contributed to the body of knowledge in spinal cord injury psychology through his research, particularly in the areas of personality characteristics, vocational interests and substance abuse issues. He is a dedicated educator, frequently presenting at national and international professional meetings,

including AASCIPSW, as well as to medical and allied health students about psychological adjustment after SCI.

Dan Rohe's multifaceted contributions to the field of SCI psychosocial care certainly merit his award as our 2007 Essie Morgan Excellence Award recipient. His colleague, Dr Mitchell Rosenthal, who passed away tragically before the award could be made, nominated Dr. Rohe. Dr Stan Ducharme and Dr. Kris Hagglund presented the award.

## **James J. Peters Distinguished Service Award**

***Kathlene M. Chadband, Administrative Officer in the Veterans Administration  
SCI Central Office at the VAMC at Puget Sound***

The James J. Peters Distinguished Service award is given to a person who has demonstrated exceptional accomplishments in the area of psychosocial rehabilitation of persons with SCI. This award may be given to a person who is not a member of the AASCIPSW. This year, the award was given to Kathlene M. Chadband, Administrative Officer in the Veterans Administration SCI Central Office at the VAMC at Puget Sound.

Ms. Chadband has served as the Administrative Officer for the VA-Puget Sound Health care System—SCI Center for over 19 years. In this capacity, she serves as the frontline contact for the national SCI program. Ms. Chadband's long tenure in the SCI program has made her an expert in VA SCI policy and she has used this experience to assure that important elements of psychosocial care of the spinal cord injured veteran is included in the VA SCI handbook. Ms. Chadband has worked nationally to advocate for numerous services on behalf of the SCI veteran, including those that impact quality of life, travel, fee-based care, and program funding and staffing, pharmacy, and site visit reviews. She was also integral to improving social work support for SCI clients.

Ms. Chadband has worked closely with VA Healthcare Administration SCI/D Chief Margaret Hammond who describes her services as "invaluable." Ms. Chadband listens to veterans, recognizes needs, and solves problems and has a positive impact on the quality of life of SCI veterans and their families. In addition, Ms Chadband has provided support for SCI Coordinators, including the development and administration of an SCI Coordinator mentoring program within the VA system. She has also coordinated annual SCI Coordinator meetings in conjunction with the AASCIPSW annual meeting.

SCI Coordinators Ellen Cloyed, LIW and Virginia Hartwich, MSW, nominated Ms. Chadband and also made the presentation at the conference.

## **Clinical Performance Award**

### ***Sara J. Klaas, MSW, C-ASWCM***

The Clinical Performance award is given to an active or associate member of the Association who has demonstrated outstanding performance in the area of clinical skill related to the psychosocial adjustment and rehabilitation of persons with SCI. This includes outstanding clinical contributions and expertise and exceptional performance in the nominee's work environment as well as in the community.

Sara J. Klaas, MSW, C-ASWCM is Director of Care Coordination and the Spinal Cord Injury Care Coordinator at Shriners Hospitals for Children in Chicago, where she has worked for more than 18 years. She is also a member of the Board of Directors of AASCIPSW and a member of the Clinical Practice Committee. The award recognizes her outstanding performance in the area of clinical skills related to psychosocial adjustment and rehabilitation of children and adolescents with SCI.

Ms. Klaas helped develop three innovative programs at Shriners Hospital, Chicago. The first is a sports and conditioning weeklong camp for adolescents with SCI that includes rock climbing, sailing, sled hockey, scuba, tennis and other sports. This has become an annual event at the hospital. Second, she and a colleague developed a scuba adventure program for teens with SCI. This is also an annual event that teaches scuba and includes a wonderful scuba diving trip to exciting places like the Florida Keys or the Caribbean. Thirdly, Sara was instrumental in developing GLAHM (Good Life and Healthy Mind) Camp for teenage girls with SCI. This camp includes spending several days in a downtown Chicago hotel with a program that focuses on regaining self-confidence, self-esteem, and a sense of empowerment. Activities include personal training, nutrition education, skin care essentials, makeovers, salon treatments, meditation, healthy living seminars, and a night at the theatre. All of these programs are provided free of charge to adolescents through Sara's fund-raising efforts and donations.

Ms. Klaas's contributions are not just with adolescents with SCI.

She has reached out to the community as a member of the Board and an officer of the Spinal Cord Injury Association of Illinois. She was selected for the Governor's Advisory Council for Spinal Cord and

Head Injuries. Ms. Klaas has made more than 50 presentations at national meetings on children and adolescents with SCI, including those at AASCIPSW meetings, and has numerous peer-reviewed publications. Dr Heather Russell nominated Sara and was on hand to make the presentation.

## Save the Date!

### **International Federation of Social Workers World Conference 2008 *The Challenge of Ensuring Rights in a Global and Unequal Society***

Salvador de Bahia, Brazil,  
August 16–19, 2008.  
<http://www.socialwork2008.com>

IFSW General Meeting will taking place in Salvador de Bahia,  
August 13–15, 2008

#### **Contact:**

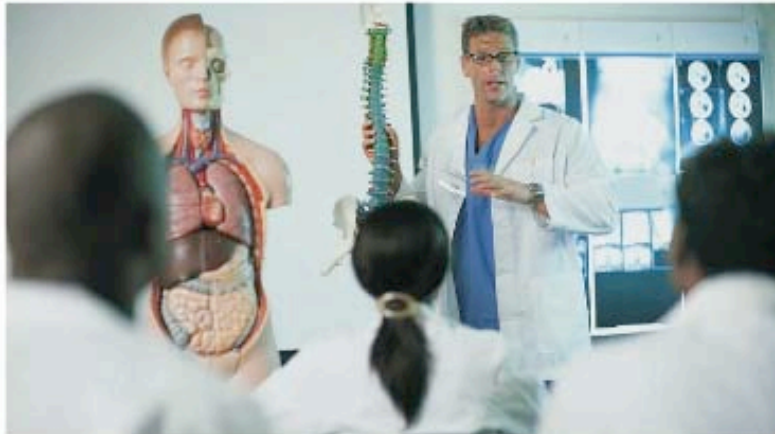
**Tom Johannesen**  
**Secretary General**  
**International Federation of Social Workers**  
Postfach 6875, Schwarztorstrasse 22  
CH-3001 Berne, SWITZERLAND  
Tel (41) 31 382 6015  
Fax (41) 31 382 1125  
**E-mail: [global@ifsw.org](mailto:global@ifsw.org)**  
**Web: <http://www.ifsw.org>**



#### ***Bring Home a Souvenir!***

*Join us at the 2008 Congress of  
Spinal Cord Medicine & Rehabilitation  
August 11-13, Gaylord Palms Resort &  
Convention Center, Kissimmee, Florida  
[www.spinalcordcongress.org](http://www.spinalcordcongress.org)*

# Congress of Spinal Cord Medicine & Rehabilitation

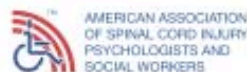
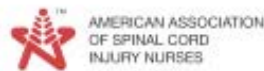


This is the largest annual gathering of professionals working in the field of spinal cord injuries and disorders in North America. Sponsored by American Paraplegia Society, American Association of Spinal Cord Injury Psychologists and Social Workers, American Association of Spinal Cord Injury Nurses, Therapy Leadership Council in Spinal Cord Injury, and hosted by United Spinal Association.

- Qualified attendees are eligible for continuing medical education credits

**Congress highlights include:**  
**Polytrauma and War Injuries**  
 by renowned experts: Paul E Pasquina, MD  
 Lauren G. Doloresco, MN, RM, CNA, BC  
 Steven G. Scott, DO

**Wheelchair Fall Risk Assessment**  
 featuring: Audrey L. Nelson, PhD, RN



Therapy Leadership Council  
in Spinal Cord Injury

**August 11th-13th, 2008**

**Gaylord Palms Resort & Convention Center**

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