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Components of Quality of Life for Persons With a Quadriplegic and Paraplegic Spinal Cord Injury

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This investigation determined the themes that represented quality of life for persons with a spinal cord injury. Fifteen people (6 females, 9 males; 7 persons with quadriplegia, 8 with paraplegia) participated in this study, which used naturalistic inquiry methodologies. Results showed that quality of life for this population, regardless of severity of impairment, consisted of nine themes: (a) physical function and independence, (b) accessibility, (c) emotional well-being, (d) stigma, (e) spontaneity, (f) relationships and social function, (g) occupation, (h) finances, and (i) physical well-being. The themes of life quality were similar for quadriplegics and paraplegics; however, physical function and independence and physical well-being affected the quality of life of persons with a quadriplegic injury to a greater extent. These findings may provide health professionals with information necessary to assist in the development of programs to enhance quality of life.

Health care professionals have traditionally focused on disability assessment and management when working with persons with a spinal cord injury (Whiteneck, 1994). Much less attention has been directed to the evaluation of life quality, even though it has been suggested that the overall goal of most rehabilitation professionals is to assist patients to improve the quality of their own lives (Wood-Dauphinee & Kuchler, 1992). Raeburn and Rootman (1996) have stated that quality of life is a representation of how good life is for a person. Thus, a change in life quality for a person with a spinal cord injury should be viewed as an important indicator of the effectiveness of health promotion strategies (Lanig, Chase, Butt, Hulse, & Johnson, 1996).

The direct assessment of quality of life has been done infrequently in a rehabilitation setting. To date, quality of life has been routinely inferred from general measures of a person's health or functional status (Renwick & Friefeld, 1996), and it has been assumed that an improvement in an individual's health or functional status results in a direct improvement in his or her quality of life. However, this is not necessarily a correct assumption because health and functional measures are not based on well-developed conceptual frameworks of quality of life (Renwick & Friefeld, 1996). In addition, other tools that have purported to directly measure the quality of life of a person with a spinal cord injury have frequently been adapted from measures for able-bodied persons, without specific input from those with a spinal cord injury (Schulz & Decker, 1985). Thus, the validity of these measures in assessing life quality in the spinal cord-injured population may be questionable. To improve the

validity of such instruments, researchers need to gain a better understanding from individuals with a spinal cord injury of the various themes that should be included in the measurement of their life quality. Day and Jankey (1996) suggested it is essential that individuals who are being assessed have greater input into the determination of which aspects of their lives will be considered relevant to the ultimate representation of their quality of life. This statement is further supported by the work of Dijkers (1997), who suggested that "only the perspective of the patients/clients themselves is a useful guide to where resources can be utilized most effectively" (p. 839).

Two notable studies have used naturalistic inquiry methodologies to address some of the past concerns about measurement validity and to improve our understanding of quality of life issues with groups of physically disabled persons (Bach & McDaniel, 1993; Renwick & Brown, 1996). The findings from Renwick and Brown, who interviewed nondisabled persons as well as persons with various physical disabilities, showed that the components representing life quality were similar for all persons, regardless of a physical disability. In contrast, Bach and McDaniel (1993) found that some life quality themes, such as assertiveness and dependence/independence, were only important for individuals with a quadriplegic injury. These investigations provide preliminary information for the rehabilitation professional whose goal is to assist persons with spinal cord injury in improving the quality of their lives. However, further research may be warranted to attempt to replicate these findings and to investigate whether the issues related to quality of life for persons with a spinal cord injury vary according to the level of the impairment. Therefore, the purpose of this investigation was to determine the themes that represent quality of life for persons with a spinal cord injury. In addition, we examined whether there were differences between persons with quadriplegia and paraplegia in terms of the representation of their quality of life.

METHOD

Design

This investigation was a focused ethnographic study that examined the concept and experience of quality of life for a group of persons with a spinal cord injury. Ethnography is a "generalized approach to the developing of concepts and understanding human behaviors from the insider's point of view" (Morse & Field, 1995, p. 26). As an ethnographer, the researcher sets out to learn from people, as opposed to going out to study people (Morse & Field, 1995). In contrast to traditional ethnography, focused ethnography concentrates on a specific area of inquiry (Sabari, Meisler, & Silver, 2000), such as quality of life, and can be used to improve practice in health science settings (Morse & Field, 1995).

Participants

Purposive sampling technique was used in this investigation because it increased the range of data that could be uncovered (Lincoln & Guba, 1985). The sample was

TABLE 1: Semi-Structured Interview Guide

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1. What things are important to your life (your quality of life [QOL])?
 2. How does the spinal cord injury (SCI) affect these things?
 3. What are the things or aspects of your life that are affected by a SCI?
 4. How do these things affect how good your life is?
 5. Does the SCI prevent you from complete satisfaction in these areas (the areas they discussed that are important to their life)?
 6. Does a SCI affect how good your life can be? (Either negatively or positively.) How (in what ways)?
 7. What do you think QOL means?
 8. Does a SCI change what is important in your life?
-

selected from a list of persons with a complete spinal cord injury, between 3 to 30 years post injury, living within a 150-mile radius of the research institution (150 persons in total). This list was generated from the Canadian Paraplegic Association (CPA) database. The research assistant and an individual from the CPA examined the list and selected individuals who were representative of different age groups, duration of injuries, gender, and level of injury. These individuals were then telephoned by a representative of the CPA and asked if they would consider volunteering for a study. If consent was given, the research assistant for this investigation contacted the individuals and interview times were arranged.

Nine males and 6 females volunteered to be interviewed. They ranged in age from 22 to 63 years and were a mean of 13 years post-spinal cord injury. Seven persons had complete quadriplegic injuries (1 female, 6 males), and 8 persons had complete paraplegic injuries (5 females, 3 males). Four of these persons lived in a rural setting, and the remaining 11 lived in an urban setting. Five participants were employed at least half-time, 2 were in school full time, and 8 were unemployed.

Procedure

The method of data collection in this study was semistructured interviews. Each person was interviewed on one occasion. The interviews were conducted by one of the authors, a researcher with 6 years of experience working with the spinal cord-injured population as a physical therapist. Prior to the interviews, the procedures were explained to each participant and a consent form was signed. Participants were interviewed individually in a quiet setting of their choice. The interviews were audiotaped and lasted approximately 45 to 60 minutes. The semistructured format of the interviews allowed the researchers to use predetermined open-ended questions that introduced the topic under study. These questions focused on what was important to our participant's lives, how the spinal cord injury may or may not have affected what was important, and finally how the participants would define the term *quality of life*. Examples of key questions used during the interview are provided in Table 1. Data collection was terminated after 15 complete interviews, because there was saturation of information and an "emergence of regularities" in the data (Lincoln & Guba, 1985, p. 350). Saturation of information is when the interviewer begins to hear the same information reported and hence is no longer learning anything new (Douglas, 1976; Lincoln & Guba, 1985; Rubin & Rubin, 1995).

Data Analysis

Data analysis was an ongoing process from the initiation of data collection to the completion of the study. The data obtained during the project were interpreted and analyzed using strategies suggested in the qualitative literature (Guba & Lincoln, 1981). The goal of data analysis in qualitative inquiry is to find emerging themes in the data. This is achieved by identifying, coding, and categorizing patterns in the data.

At the conclusion of each interview, the notes made during the interview were reviewed to determine emerging ideas and preliminary categories. These were recorded in the researcher's reflexive journal, a diary suggested by Lincoln and Guba (1985). The interviews were then transcribed verbatim from the audiotapes, and the manuscripts were reviewed several times by the research assistant and the principal investigator. While scanning the data, notes and comments were written on the manuscripts of the interviews to identify recurring thoughts and ideas of the participants. This information was cross-referenced with the notes made in the researcher's reflexive journal. The process of unitizing was then performed, which involved working with the data to find units of information that came directly from the transcripts and included phrases, sentences, or entire paragraphs.

The next stage of data analysis involved the formation of categories. The units of information gathered from the unitizing process were grouped into provisional categories when the units seemed to relate to the same or similar content (Lincoln & Guba, 1985). In this investigation, the file folder method was used (Bogdan & Biklen, 1982); following placement of the similar units of information into the file folders, researchers began to look for themes, concepts, or recurring messages that emerged from the data. The process of collapsing the categories into themes involved reading the content of the file folders and finding common ideas and concepts as well as the overall messages that were emerging.

Following preliminary identification of the quality of life themes, member checks were carried out. Lincoln and Guba (1985) stated that in naturalistic inquiry, member checks are "the most crucial technique for establishing credibility" (p. 314). Member checks consisted of distribution of a document that outlined the quality of life themes to persons who had been interviewed and to other stakeholders (i.e., employees at the CPA). Respondents were asked whether the documented themes captured what was discussed in the interviews. Also, they were questioned about whether they felt the components of their quality of life were represented by the themes. Some participants responded in writing, whereas other member checks were accomplished through discussion. Following the member checks and suggestions from the respondents, minor revisions and modifications to the quality of life themes were made.

Throughout the process of data analysis, a "critical friend" or external auditor was used to independently examine the product, data findings, and interpretations (Humbert, 1995). This person performs the audit by following the data trail from the interpretations of the themes back to the raw data, forming an opinion about whether methodological decisions and themes are logical and appropriate. The auditor also looks at researcher bias, completeness of data collected, and the sampling process (Lincoln & Guba, 1985). This individual is an important part of data analysis because he or she serves to enhance the validity and dependability of the analysis (Lincoln & Guba, 1985).

RESULTS

All of the participants in the study stated that quality of life was a subjective construct and that the only one who could comment on an individual's life quality was the person himself or herself. The respondents indicated that quality of life was what the spinal cord-injured person perceived it to be. For example, one respondent described quality of life as

basically doing what you want to do and enjoying it. I was thinking about quality of life, and you know it might look to a lot of people that there's not much going on in my life, but I like it.

Quality of Life Themes

Data analysis led to the establishment of nine themes that this group of persons with spinal cord injury felt composed their quality of life. These themes included (a) physical function and independence, (b) accessibility, (c) emotional well-being, (d) stigma, (e) spontaneity, (f) relationships and social function, (g) occupation, (h) financial stability, and (i) physical well-being.

Physical Function and Independence

Physical function and independence in this investigation represented a person's physical ability within his or her present limitations (i.e., level of injury). It consisted of the participant's ability to transfer and perform bed mobility and wheelchair mobility as well as his or her independence with activities of daily living. In general, the participants stated that it was very important to their quality of life to be as physically independent as possible within their limitations. One woman with a paraplegic injury stated,

I try to be as independent as I can. My husband fixed up the lawn mower for me so I was able to cut the grass. This thing about having to wait on people to do it for you is really a burden. It really doesn't go well with me. So I try to find a way to do it myself.

An important aspect of physical function and independence was energy expenditure for everyday activities, and it was mentioned frequently by the participants as something that affected their quality of life. The respondents stated that if a person could perform an activity independently yet expended so much energy that he or she unable to do anything else for the rest of the day, then that activity would not be functional for that person and satisfaction in this domain would decrease. One participant discussed energy expenditure for daily activities in this way:

After all these years, I still find it very frustrating to do some of the things that should be so simple yet they take so much energy. An incline that is a little too steep is just hard, hard work to get up to the top. And yet if you're walking, you'd take the stairs or the incline, I mean there is just nothing to it. I think a person in a wheelchair or whatever disability expends a whole lot more energy, in relation to somebody who can just jump up and do whatever.

Physical function and independence was one of two themes (the other being physical well-being) that affected the quality of life of persons with quadriplegia to a greater extent than those with paraplegia. Hand function was specifically identified as decreasing physical function for quadriplegic persons. This limited function had implications for (a) writing in school and work settings, (b) mobility in terms of opening doors and wheeling, and (c) activities of daily living such as eating and grooming. Respondents with a quadriplegic injury stated that they frequently required adaptive equipment and that tasks usually took more time and effort than for a person with a paraplegic injury. One man with quadriplegia discussed some of these issues:

I've often thought how much easier things would be, even if I were a para. Even if I had use of my hands. . . . How useful they are, they're great, everyone should have working hands.

Accessibility

The theme of accessibility refers to the physical accessibility or inaccessibility of the environment (i.e., at home, work, or leisure facilities) and the effect that it has on quality of life. Accessibility affected the quality of life for many of the participants. One respondent with quadriplegia stated, "The environment is your barrier. If everything was set up for me perfectly, then my quality of life would be absolutely wonderful. You know I could go anywhere I wanted, and everything would be just perfect for me."

Seasonal accessibility was an issue for all of the participants in the present study. The respondents reported that cold temperatures and snowy sidewalks in winter made mobility and accessibility very difficult. One individual reported, "It's almost like come spring, I get out of jail and I've been in jail for the last 7 months, and I haven't done a damn thing to be in jail, but I have been." Another participant discussed the difficulties related to accessibility that a person with spinal cord injury faces when deciding whether to live in an urban or rural setting:

It's something that I still struggle with—how long I want to stay here [in the city]. But then I look at the issues that I think a lot of people with spinal cord injury look at, as far as being able to get out and get around independently. You don't have a choice. If I want to access a gym that's accessible with equipment, then I have to live in the city. If I want to go for a wheel at night, I have to live in the city. I can't go wheeling down a gravel road, it's just not practical. So it's kind of a toss up.

All participants felt that physical accessibility was becoming less of an issue in recent years, although it still continued to be a factor that affected their quality of life. Throughout the interviews, the participants reported that there were still many places an able-bodied person could access that they could not. For example, one woman discussed how she was unable to get into the post office in her town because even though there was a ramp to the door, she could not open it without help.

The respondents also mentioned that ease of accessibility was a concern for them. They suggested that there was a difference (although not always recognized by the general population) between something being technically accessible and something being realistically and easily physically accessible to the majority of persons in a wheelchair.

Emotional Well-Being

The theme of emotional well-being was represented by two subcategories: (a) the participants' emotional health and (b) the behaviors the participants engaged in that enhanced or detracted from their emotional health. The first subcategory represented the respondent's actual state of emotional health, which included self-esteem, self-image, and self-confidence. Most participants reported that these issues affected their quality of life at some point in their adjustment to the spinal cord injury. As one individual stated, "You just don't feel whole sometimes."

Respondents also reported that at one time or another, they had varying degrees of depression following their spinal cord injury, which had affected their quality of life. One man talked about how he continued to feel depressed at times.

You dream. There are nights when I don't sleep good. I still fight depression sometimes, not every time but sometimes. It's not as often as it was, but there are bouts of it that are just as bad as if it [the injury] just happened.

Some of the participants stated that depression negatively affected their quality of life by making it difficult to get up in the morning and to find something to look forward to. Others, however, reported that although they may have been depressed following the injury, depression or depressive feelings were no longer as common or did not affect them at all. One young man who was injured when he was 15 years old reported that he now was just like everyone else: "You feel pretty down sometimes, but pretty much like everybody else. You get a bad day and you sit there and kind of mope. I don't really get depressed about anything any more." Another participant stated, "I'll tell you, I had good days and bad days when I was walking, and I have good days and bad days now."

The second subcategory of emotional well-being was made up of behaviors that had an impact on the emotional well-being of the participants. In the present study, these behaviors were related to coping, adjustment, and outlook following a spinal cord injury. This area was very important to the participant's quality of life and was discussed frequently during the interviews. Many individuals were proud of how they had survived and enjoyed discussing their methods of coping. Examples of coping methods included possessing a sense of humor, not worrying about the things that cannot be controlled, and being able to recognize individual strengths and abilities. One respondent stated, "Yes, there are certain things that I know I just can't do and, it just comes to a point that it just doesn't bother you. You just can't let it bother you; that's the main thing, acceptance." Although the ability to accept one's injury was expressed by some of the participants, other persons reported that coping with the spinal cord injury was more of an adjustment to the disability as opposed to acceptance of that disability. This was expressed by one respondent who stated,

It's not that you accept it. People say you sure accept your disability, but you know, it's not that I accept it, it's that I live with it and I do the best with what I have. I wouldn't say that I will ever accept it.

The persons who felt they were coping well stated that they were able to do so because of their efforts to adjust to the changes caused by a spinal cord injury. They

reported that they had found a way to appreciate what they were still able to do. One respondent who had a quadriplegic injury discussed how he coped with the spinal cord injury and overcame depression by recognizing that there were others who were worse off than he was.

There was a woman that had a heart attack or a stroke. She used to really make me so mad when I was in the hospital. My door was right at the buzzer, and she'd drive her wheelchair up there and make that buzzer squawk, and she'd just sit there and they'd go and get her and bring her back, and she'd drag that chair up there again and sit there and make that buzzer squawk. And after about 2 weeks of that I thought, I can't walk and I can't do a heck of a lot but at least I ain't that mixed up, sitting there and making that buzzer squawk. And that really helped. She was kind of my savior as far as my head because before that I was really depressed.

Other individuals who appeared to be having some difficulty coping with their injury frequently compared themselves to nondisabled persons or to where they thought they should have been had they remained nondisabled. For example, one respondent stated, "I really would have gone nuts if I couldn't drive. That's one thing I can do almost equivalent to anybody else . . . and in most circumstances, it's pretty clear cut that you're not [equivalent]."

The respondents also stated that one's attitude and outlook were important factors related to a spinal cord-injured person's quality of life. One participant demonstrated his positive attitude toward his injury when he said,

My thing is, it's about 5 minutes slower than what I would be doing if I was walking. Like to go somewhere, it would take me 5 minutes longer. So it's not a huge change, I just get around with wheels. That's about it. Don't get the old feet working.

One respondent further stated, "I'm the same person that I was before the accident except that now I have to get around a little bit differently."

The majority of the participants also reported that they had somehow found the strength to find reason and purpose in their lives. Some individuals stated that their quality of life had actually improved since the spinal cord injury, as was evident in this quote:

The injury makes you think about what's important and what's not important. Before my injury, a lot of things just really didn't concern me or I didn't think of them as big issues. Whereas after my injury, all of a sudden you had to, you learn to appreciate a lot of different things. It [the injury] tested me as a person. It makes you a little bit stronger, I guess.

Many participants said that they had no choice but to adjust and carry on. A number of persons talked about how the spinal cord injury forced them into a personal growth they would not otherwise have achieved. It was apparent that emotional well-being and the behaviors that one used to maintain or enhance it were very important to overall quality of life.

Stigma

The theme of stigma represented the perception that persons with a spinal cord injury have of other's attitudes toward them as people with spinal cord injury. The

respondents stated that if stigma was present or was perceived to be present, it had a negative effect on quality of life. The participants reported that stigma affected them to the greatest extent in the first 2 to 3 years after their injury. It then generally lessened over the years as they adjusted. One participant stated,

I really had a problem with that [stigma] when I was first injured. It's not so bad now that I had a baby because people don't look at me as being disabled. You know, she can have a baby or she can keep up her yard. People don't look at me like that around here because they know that I can do things and try before I'll say, "No, you better do it."

The spinal cord-injured person's reaction to stigma determined to a large extent how it affected his or her quality of life. One woman discussed people's attitudes and her changing reactions to them over the years:

It's really interesting, other people's perspectives. And I must admit, early on once I was back to work, I found it very frustrating and quite demoralizing in that lots of people seem to almost dismiss you. In that, oh, well, if you're legs are paralyzed, your brain must be too. That sort of thing drove me crazy. . . . It doesn't happen nearly as often anymore, probably because people are a lot more educated or whatever. But it was really tough to begin with. Like, you just wanted to go somewhere and cry. So it's interesting, that whole transition. Now I think, well, all people make mistakes. If some people haven't been around a person in a wheelchair, what do they know?

Some respondents also commented that they had to overcome not only the perceptions of others but also their own perception of people in wheelchairs, the perception that they held when they were nondisabled. One respondent commented, "I don't seem to notice people notice the chair now. I mean, I'm just who I am. It was probably that way 10 years ago, except I perceived it to be different."

Spontaneity

Spontaneity (or lack of it) in all daily activities was frequently reported as something that affected the quality of life of the participants. The respondents stated that it took longer to do things and that much more planning was needed for all activities. One individual, when asked about how the spinal cord injury affected his life, summed up the group's feelings about spontaneity when he stated,

Spontaneity. You have to plan a lot more. You can't just up and go wherever with whoever, whenever. There's gotta be some routine. Whether it's for personal care, whether it's for accessibility, whatever. I mean, you might not be able to just up and go to the lake for the weekend if you need personal care, if you've got personal care staff coming in, or if it's not accessible and you don't have the transportation.

Relationships and Socialization

The theme of relationships and socialization included relationships with family, friends, and significant others. Some of the participants reported that their relationships with family actually improved following the spinal cord injury, because they no longer took them for granted. They came to recognize the importance of their relationships and cultivated them to a greater extent.

My family is a lot more important than they were. I mean, they were always important, but I depend on them more. Not as much as I did in the beginning, but just to know that I always know they're there. I just feel like they're more important.

The respondents, however, reported that forming new friendships and relationships with potential partners was more difficult now with a spinal cord injury. Some of the respondents made successful adjustments in this area, whereas for others this difficulty negatively affected their quality of life. One man discussed his lack of a relationship and how he felt it stemmed solely from the spinal cord injury.

I guess I can compare the situation I'm in now with where I should have been if I wouldn't have ended up in this thing [the wheelchair]. I would have been married, I would have had three kids and a dog or two. Things would have just been totally different than they are now.

Peer support was also identified as an important factor in the quality of life of a number of the participants in the sample. The respondents identified the National Paraplegic Association and friends and associates in wheelchairs as being the major sources of peer support. One participant talked of the importance of support from peers and how it was easier for her to find such individuals in a bigger center.

Actually, I think the one thing I find about being in a smaller center is I'm not around other people that are spinal cord injured, and that's really hard. I mean, it's not that they don't try to understand, but they can't. I think that's hard. Why I really like living in a larger center is that, like, I'm around my friends and stuff, because they know what it's like. If you have a bladder or bowel accident, you don't have to explain it, they know. It's a comfort zone. They also know if you're out of shape what that means to your whole life. Whereas if you get out of shape if you're not disabled, you can still walk. So I think that being around people that understand or can relate to you is a really big part of it.

Occupation

Another quality of life theme that arose from the interviews was the importance of having an occupation. This included not only paid employment but volunteer work, school, and housework. One respondent described the importance of having a job in this way:

I don't know if having a job is more for financial reasons or if it's just something to get you up and going. I was off [work] for about 13 months, and I just kind of hung around the house. You get pretty bored when you don't have much—you just get up and do nothing again all day. At least having a job makes you get up and gives you something to look forward to—even if you don't really like it some days.

Other participants felt that having an occupation was important because it had a positive effect on self-worth and self-esteem. One respondent reported that the sole reason she was looking for a job was her self-esteem. Because she did not have a job like a lot of other women her age, she felt it negatively affected feelings of self-worth. The persons who were able to go back into the working environment they were in prior to their injury seemed to have an easier time adjusting than those who had to change their vocation in addition to all the other changes caused by spinal cord injury.

Finances

All persons interviewed reported that their financial situation affected their quality of life. The respondents stated that health care costs and the price of equipment and services, such as home care or housekeeping, were substantial. One participant discussed the issue of driving and how for some people it just was not an option because of the cost of the equipment needed:

Finances play a big part, especially when you need a vehicle that's equipped. All that stuff costs money. . . . I've talked to a lot of people who say, "Well, I would go and get my license, but I can't afford the vehicle and all that equipment." It's the same for me. But having a vehicle makes you so much more independent. I would sell my left leg for that van.

The need for outside help to assist in the care of a person with a spinal cord injury can be costly in many situations. One man described one of the common problems a lot of families face when one member has a spinal cord injury. He discussed why his wife no longer worked: "She did for a while, but that didn't make any sense. She was getting paid less than what we were paying them to look after me. What the hell's going on here?"

Lack of finances or financial difficulties were also noted to have an impact on leisure activities or simply the option to be involved in those health-promoting activities. Respondents stated that for someone with a spinal cord injury, playing a sport or participating in a recreational activity was no longer simply a case of buying a pair of running shoes. One participant discussed these issues:

That's the thing with sports and stuff. I play in this chair [her everyday chair], but it gets banged up and bumped out of whack, and plus it's just not set up to be a sports chair. Everyone else on my team has a rugby chair. I mean, it's like you can't do the stuff you want to do without that modified equipment that costs much. So that's a big thing.

Physical Well-Being

This theme encompassed two aspects of physical well-being: (a) the participant's physical health and (b) the behaviors and actions of the participants that promoted their health or detracted from it. The first subcategory of this theme, physical health, represented the presence or absence of physical symptoms, including physical illness, obesity, or physical injury. The respondents reported that pain, spasticity, urinary tract infections, and pressure sores were common health problems that had negatively affected their quality of life.

Health behaviors, in contrast to actual health, referred to what the respondents did to enhance their health or detract from it. Participants discussed health behaviors such as eating a healthy diet, physical activity and recreation, and adequate rest as having a positive effect on their quality of life. They also discussed the importance of being proactive with regard to common health problems related to spinal cord injury. Some of these behaviors included pressure relief while up in the chair to avoid pressure sores and maintenance of a regular bowel and bladder regime so that infections could be prevented. One respondent also talked about physical

activity as a health behavior that played an important role in the prevention of obesity and in his quality of life.

I gain weight if I haven't been doing things, and that tires me out more, I know it does. I get more sluggish and transfers get harder and I think it's harder on the shoulders when I'm at a stage where I'm not doing things [exercising]. Yeah, I just feel better [with activity].

Another respondent talked about lifestyle choices and health behaviors, commenting on the potential they have to affect a person's physical health and function and, in turn, their quality of life.

Mostly I think its lifestyle things that impact our health. And so it pays to pay attention to your lifestyle because you're gonna pay for it sooner or later. So, I mean, eat properly so you don't get high cholesterol. Don't gain pounds and pounds and pounds, 'cause I know it would tire me out. I've seen quite obese people, and I have no idea how they would get in and out of the wheelchair by themselves or in and out of a vehicle.

Physical well-being was the other domain that affected those with a quadriplegic spinal cord injury more so than the paraplegic group. Primarily, the differences seem to reflect the belief of many of the participants that persons with quadriplegic injuries had to work harder at the health-promoting behaviors to maintain their physical health. The most common example was in relation to body weight. The importance of maintaining an optimal body weight was frequently discussed by both persons with quadriplegia and persons with paraplegia with respect to the effect it could have on a person's overall health and function. However, it was apparent that the persons with quadriplegia had to work harder in terms of nutrition and physical activity (health-promoting behaviors) to maintain an optimal body weight.

Physical well-being was frequently discussed during the interviews, and all participants felt that it had a big impact on their quality of life. Physical well-being was something that they were no longer able to take for granted, and as a result, many were very cognizant of it and anxious to learn more about the positive behaviors that may enhance their health.

Impact of Quality of Life Themes on Each Other

All of the themes discussed in the previous section directly affected the participants' overall quality of life. However, the findings also showed that satisfaction (or lack of satisfaction) in one or more of the quality of life themes often had an effect on other themes. Figure 1 illustrates the potential crossover effects, both negative and positive, from the themes exclusive to persons with disability to the quality of life themes that are frequently described in the literature as being common to all people. With the exception of the physical well-being theme, crossover effects within the themes typically described for nondisabled persons will only be discussed briefly. Physical well-being, for our participants with spinal cord injury, affected or was affected by a number of quality of life themes. Good health allowed opportunities for maximization of functional potential and for relationships and social function. A number of our participants indicated that health also had had an impact on their

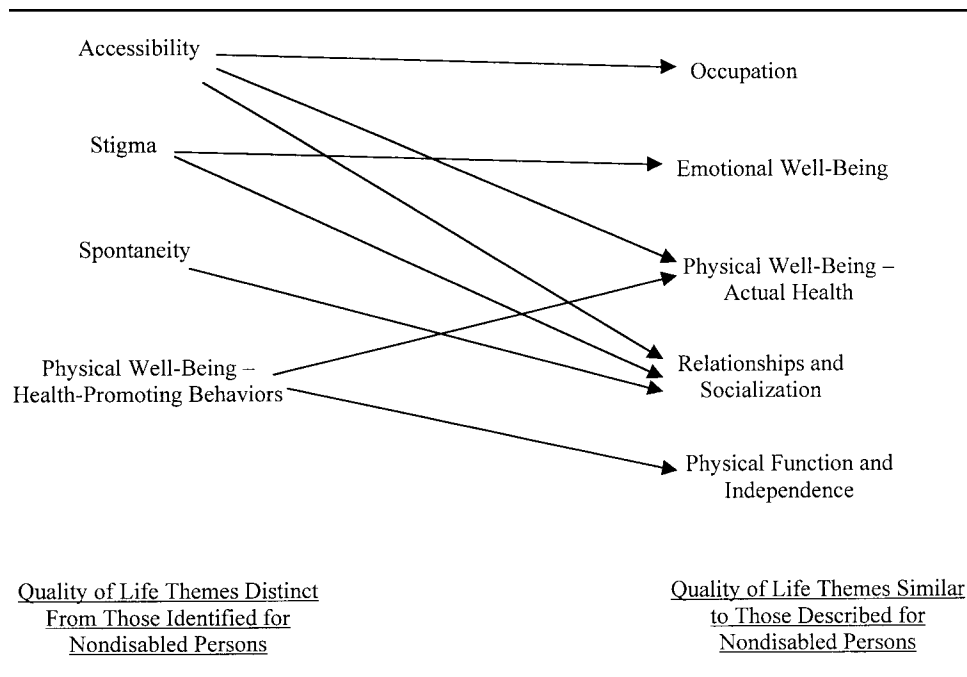


FIGURE 1: Visual Representation of the Quality of Life Themes and the Potential Crossover Effects Between Themes

NOTE: The physical well-being theme has been split into its two components (actual health and health-promoting behaviors) for the purposes of this figure.

ability to work. One person spoke of a pressure sore she had at one time that made it impossible for her to work for 6 months. Poor physical well-being also crossed over and had negative effects on physical function and independence. Persons who were less healthy indicated that they had more difficulty completing their functional tasks (as compared to when they were healthier). Other crossover effects more obviously affect all people, both disabled and nondisabled. For example, a person's occupation often has an effect on finances and thus on quality of life. Emotional and physical well-being likely have an impact on each other and affect quality of life both directly and indirectly through their effect on each other.

Of particular interest in this article are the quality of life themes that are exclusive to persons with disability and the way these themes affect the quality of life themes that are more typically representative of all people. For example, stigma, an aspect of life that many nondisabled persons do not deal with on a day-to-day basis, had both negative and positive crossover effects on emotional well-being and relationships and socialization. If participants perceived that they were coping well with the stigma society places on persons with disability, emotional well-being was positively affected. For others, stigma was difficult to overcome and negatively affected their emotional well-being, their relationships, and thus their quality of life. Participants also reported that inadequate accessibility restricted opportunities for physical health (not able to access a gymnasium or appropriate place to wheel), occupation, and relationships. Many disabled persons face obstacles related to accessibility when considering a job. Participants indicated that these obstacles can

be overcome with work and perseverance, but nonetheless, they are obstacles that are not necessarily present for a nondisabled person pursuing a career. In addition, one man talked about how he missed social opportunities because he could not access his friends' houses. Many of the participants indicated that spontaneity (or lack thereof) had crossover effects to relationships, especially sexual relationships. Persons participating in health-promoting behaviors such as healthy eating or exercise reported that those activities had a positive effect on physical well-being and ultimately on their quality of life. Healthy eating and exercise also affected physical function and independence because persons were stronger and less obese and thus able to carry out their functional activities with less effort and greater independence. These examples illustrate that the quality of life themes do not necessarily represent themselves in isolation but may have a significant indirect impact on overall quality of life through crossover effects to other themes.

DISCUSSION

The objective of this study was to determine the themes that represented quality of life for persons with a spinal cord injury. The results showed that regardless of the severity of the impairment, life quality encompassed nine areas: physical function and independence, accessibility, emotional well-being, stigma, spontaneity, relationships and socialization, occupation, finances, and physical well-being. It is not unexpected that these quality of life themes were similar between quadriplegics and paraplegics, because both groups live their life from a wheelchair and, as a result, deal with common issues. Although all of the participants identified the same parameters encompassing quality of life, the themes of physical function and independence and physical well-being had a greater impact on the life quality of persons with a quadriplegic injury. This finding is not surprising, because research has shown that a quadriplegic injury has more serious implications for a person's health and function than does a paraplegic injury (Bauman & Spungen, 1994; Noreau, Shephard, Simard, Pare, & Pomerleau, 1993). In addition, because a person with a quadriplegic injury will typically expend more energy performing activities of daily living than a person with a paraplegic injury (Janssen, Van Oers, Van Der Woude, & Hollander, 1994), this may also impact their physical function to a greater extent.

Previous qualitative investigations have reported mixed results when determining whether similar quality of life parameters apply for all populations. Renwick and Brown (1996) found that quality of life for an individual with a spinal cord injury could be evaluated using the same conceptual framework used for all people, disabled and nondisabled. The work by Bach and McDaniel (1993), however, showed that some quality of life themes were exclusive to the spinal cord injured population, indicating that using measures based on other populations may not be valid. In the present study, the themes of emotional and physical well-being, relationships and socialization, occupation, physical function/independence, and finances were also identified by Renwick and Brown (1996) and Bach and McDaniel (1993) as factors important to the life quality of physically disabled persons. These themes have also been found to be significant factors in the representation of quality of life for nondisabled populations (Flanagan, 1982). Although there has been general consensus in the literature that these themes are important to quality of life for

all persons, satisfaction in areas associated with work, finances, health, and social relationships has generally been lower for the spinal cord-injured population (Dijkers, 1997). This may be due in part to the stigma and problems associated with mobility and accessibility that were evident in the present study. Overcoming the real or perceived barriers of stigma as well as the limitations of accessibility and mobility may make it difficult to find employment and to be proactive with regard to health concerns related to the physical disability. In addition, even in a country with a universal health care system, there are financial burdens that are incurred by the person with the spinal cord injury and their family in order to fulfill the health needs of the person with spinal cord injury. This suggests that even though there are several quality of life themes that are similar between nondisabled and spinal cord-injured persons, some of these may have a greater impact on the quality of life of the spinal cord-injured population.

The results from the present investigation also identified four themes of quality of life (accessibility, stigma, spontaneity, and health-promoting behaviors) for the spinal cord-injured population that have not typically been included as components for nondisabled persons (Flanagan, 1982). In addition, these themes have not been previously identified in the literature as quality of life themes for persons with a spinal cord injury (Bach & McDaniel, 1993; Renwick & Brown, 1996). Renwick and Brown (1996), however, did identify the issue of accessibility as an important part of an individual's physical belonging within the environment and with others. Even though most participants in the current study agreed that accessibility was improving and that stigma was decreasing, the respondents reported that these issues continued to affect their quality of life. This finding was reinforced by Renwick and Friefeld (1996), who stated that "environmental factors (e.g., social, political, cultural, and physical) continue to pose significant obstacles to their [persons with disabilities] opportunities for participating in and contributing to society" (pp. 28-29). Spontaneity was another quality of life theme that was frequently discussed by our participants. Stensman (1994) similarly reported that one of the negative effects of a spinal cord injury was "not being able to do things 'at once'" (p. 420). Adjustment to this change determined to a large extent how quality of life was affected for the participants in the present study. Some were well adjusted and reported that lack of spontaneity was just a "fact of life."

Health-promoting activities or behaviors can be defined as "activities directed toward increasing the level of well being and actualizing the health potential of individuals" (Stuifbergen & Rogers, 1997, p. 2). Although this theme has not been specifically identified in the past as an important quality of life theme for nondisabled persons (Flanagan, 1982) or for those with a spinal cord injury (Bach & McDaniel, 1993; Clayton & Chubon, 1994), Flanagan (1982) and Renwick and Brown (1996) do recognize recreation and leisure as an important part of quality of life. A recent qualitative investigation with persons with multiple sclerosis also identified physical and emotional health-promoting behaviors as important to that population's representation of quality of life (Stuifbergen & Rogers, 1997). Participants in that investigation reported that they needed to be more careful in order to maximize their physical and mental capabilities because their health status was already vulnerable (Stuifbergen & Rogers, 1997). The participants in the present study expressed similar sentiments when discussing why health-promoting behaviors, both physical and emotional, were important to their quality of life.

The findings from this investigation reinforce the theory that quality of life should be represented by subjective measures, if not totally, at least in combination with objective measures (Rapheal, 1996). Direct input from persons with spinal cord injury about what is important to their quality of life can assist in the appropriate selection of a quality of life measurement tool and help establish the validity of that chosen measure. By increasing our knowledge about what is important to the quality of life of a person with a spinal cord injury, the results of this investigation may provide a basis for the development and implementation of programs for persons with spinal cord injury that are aimed at enhancing quality of life.

REFERENCES

- Bach, C. A., & McDaniel, R. W. (1993). Quality of life in quadriplegic adults: A focus group study. *Rehabilitation Nursing, 18*, 364-374.
- Bauman, W. A., & Spungen, A. (1994). Disorders of carbohydrate and lipid metabolism in veterans with paraplegia or quadriplegia: A model of premature aging. *Metabolism, 43*, 749-756.
- Bogdan, R. C., & Biklen, S. K. (1982). *Qualitative research for education: An introduction to theory and methods*. Newton, MA: Allyn & Bacon.
- Clayton, K. S., & Chubon, R. A. (1994). Factors associated with quality of life of long term spinal cord injured persons. *Archives of Physical Medicine and Rehabilitation, 75*, 633-638.
- Day, H., & Jankey, S. (1996). Lessons from the literature: Toward a holistic model of quality of life. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation* (pp. 39-50). Thousand Oaks, CA: Sage.
- Dijkers, M. (1997). Quality of life after spinal cord injury: A meta analysis of the effects of disablement components. *Spinal Cord, 35*, 829-840.
- Douglas, J. (1976). *Investigating social research: Individual and team field research*. Beverly Hills, CA: Sage.
- Flanagan, J. C. (1982). Measurement of quality of life: Current state of the art. *Archives of Physical Medicine and Rehabilitation, 63*, 56-59.
- Guba, E., & Lincoln, W. (1981). *Effective evaluation: Improving the usefulness of evaluation results through responsiveness and naturalistic approaches*. San Francisco: Jossey-Bass.
- Humbert, M. L. (1995). On the sidelines: The experiences of young women in physical education classes. *Avante, 1*, 58-77.
- Janssen, T.W.J., Van Oers, A.J.M., Van Der Woude, L.H.V., & Hollander, A. P. (1994). Physical strain in daily life of wheelchair users with spinal cord injuries. *Medicine and Science in Sports and Exercise, 26*, 661-670.
- Lanig, I. S., Chase, T. M., Butt, L. M., Hulse, K. L., & Johnson, K.M.M. (1996). *A practical guide to health promotion after spinal cord injury*. Gaithersburg, MD: Aspen.
- Lincoln, W., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- Morse, J., & Field, P. A. (1995). *Qualitative research methods for health professionals*. Thousand Oaks, CA: Sage.
- Noreau, L., Shephard, R. J., Simard, C., Pare, G., & Pomerleau, P. (1993). Relationship of impairment and functional ability to habitual activity and fitness following spinal cord injury. *International Journal of Rehabilitation Research, 16*, 265-275.
- Raeburn, J. M., & Rootman, I. (1996). Quality of life and health promotion. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues and applications* (pp. 14-25). Thousand Oaks, CA: Sage.
- Rapheal, D. (1996). Defining quality of life: Eleven debates concerning its measurement. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues and applications* (pp. 146-165). Thousand Oaks, CA: Sage.
- Renwick, R., & Brown, I. (1996). The Centre for Health Promotion's conceptual approach to quality of life: Being, becoming and belonging. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues and applications* (pp. 75-86). Thousand Oaks, CA: Sage.

- Renwick, R., & Friefeld, S. (1996). Quality of life and rehabilitation. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues and applications* (pp. 26-38). Thousand Oaks, CA: Sage.
- Rubin, H. J., & Rubin, I. S. (1995). *Qualitative interviewing: The art of hearing*. Thousand Oaks, CA: Sage.
- Sabari, J. S., Meisler, J., & Silver, E. (2000). Reflections upon rehabilitation by members of a community based stroke club. *Disability and Rehabilitation, 22*, 330-336.
- Schulz, R., & Decker, S. (1985). Long term adjustment to physical disability: The role of social support, perceived control, and self blame. *Journal of Personality and Social Psychology, 48*, 1162-1172.
- Stensman, R. (1994). Adjustment to traumatic spinal cord injury. A longitudinal study of self-reported quality of life. *Paraplegia, 32*, 416-422.
- Stuifbergen, A. K., & Rogers, S. (1997). Health promotion: An essential component of rehabilitation for persons with chronic disabling conditions. *Advanced Nursing Science, 19*, 1-20.
- Whiteneck, G. G. (1994). Measuring what matters: Key rehabilitation outcomes. *Archives of Physical Medicine and Rehabilitation, 75*, 1073-1076.
- Wood-Dauphinee, S., & Kuchler, T. (1992). Quality of life as a rehabilitation outcome: Are we missing the boat? *Canadian Journal of Rehabilitation, 6*, 3-12.

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