A Meaning of Well-Being: From the Experience of Paraplegic

Hina Aman¹, Atifa Aslam²

¹Career Counseling Division, Gulf Medical University, Ajman, United Arab Emirates

²Rehabilitation Department, Federal Ministry of Health Pakistan, Islamabad, Pakistan

Study Design: Retrospective study.

Purpose: The goal of care for paraplegic people is the enhancement of their “well-being”. However, despite the frequent use of the term “well-being”, its definition remains unclear and there is little information in the literature concerning the paraplegic’s own perspective. The study was conducted to explore the Pakistani paraplegia’s perspective of well-being.

Overview of Literature: Studies have shown that paraplegia changes not only physical and psychological, but also socioeconomic, states, which have significant impact on an individual’s “subjective well-being”, however there is no clear definition of well-being and the methods of measuring the phenomena.

Methods: Fifty paraplegic adults from different rehabilitation centers of Pakistan participated in an in-depth interview using natural inquiry method. The interviews were audio-taped, transcribed, and analyzed.

Results: Three commonly used meanings of well-being and eight components were identified and included in the definition. The results indicated that the meaning of well-being is an individual’s perception, which includes both objective and subjective values and experiences.

Conclusions: The study provides information that was used to develop specific rehabilitation program for the paraplegic Pakistani adults to enhance their well-being.

Keywords: Rehabilitation; Perception; Activities of daily living; Spinal cord injury; Well-being

Introduction

Spinal injury rehabilitation, not only focuses on functional performance, but also incorporates the themes of independent living and sense of well-being. The aims of rehabilitation include: optimizing physical functions; facilitating social independence; minimizing medical complications; enhancing emotional adaptation and promoting reintegration into the community; enabling individuals to function with optimal physical, emotional;

and social potential in spite of the existing disability. Paraplegia changes not only physical and psychological, but also socioeconomic, states, which have significant impact on an individual’s “subjective well-being” (SWB); concept of well-being is universally used to describe what is ultimately perceived to be good for a person.

There are several types of psychological outcome which include those that are clinically relevant i.e., depression, as well as the non-pathological outcomes, such as satisfaction with life & modification after spinal cord injury

Received Apr 2, 2012; Revised Jul 9, 2012; Accepted Jul 9, 2012

Corresponding author: Hina Aman

Career Counseling Division, Gulf Medical University, Ajman, United Arab Emirates

Tel: +971-6-7431333, Fax: +971-6-7431222, E-mail: researchdivision2@gmail.com

(SCI). Both these types of outcome are relevant to the SWB of people with SCI. Swanson [1] has reported that individual's perception of well-being is a important factor to be considered with regards to chronically ill and disabled patients. However, two major problems encountered during the research on well-being included lack of a clear definition of the term at initiation of study and the lack of consistency in the methods of measuring the phenomena. No major research in Pakistan on the well-being of individuals with SCI, in respect of both quadriplegia and paraplegia has been conducted so far. According to an intensive review of well-being of people with SCI in Asian countries, two studies of the quality of life specific to well-being were found. The first, a qualitative study, explored the components and meaning of the "quality of life". The study indicated that physical, psychological, economic, social well-being and uncluttered environment were the spheres of influence of quality of life; Hampton and Qin-Hilliard [2]. The second study, noticed that in SCI adults, quality of life was affected if they received rehabilitation; giving them a more positive and realistic outlook on life as a result of increased individual self-esteem and community support; Chappell and Wirz [3]. Most of the literature suggests that when assessing or evaluating any intervention aimed at paraplegics the perceptions of people with disabilities, including paraplegia, should be included. Duggan and Dijkers [4] suggested that qualitative research method appears to be the most appropriate tool for this type of investigation as far as it helps to provide the "insiders" view of the well-being of people with disabilities. As a result, the present qualitative study was designed to obtain the perceptions from adult Pakistani paraplegics perspective of well-being, with the aim to design and develop rehabilitation program for them.

Materials and Methods

1. Research question

What is Pakistani paraplegia's perspective of well-being?

2. Research participants

Purposive sampling technique was used in this investigation; participants were selected from the three different rehabilitation centers of Rawalpindi and Islamabad,

Pakistan. Participants were directly approached and the research objective was introduced and explained to them. The consent in-depth interviews were taken from 32 males and 18 females ranging from 20 to 45 years in age. Based on the interview, 20 males and 16 females were found to have complete paraplegia, while 12 males and 2 females were found to have incomplete paraplegia. Most of them become paraplegic after 2005 earth quack in Pakistan. Since then they were in the rehabilitation centers. Looking at their activities of daily living (ADLs), it was observed that they occasionally went out (once in a month) of their centers. Eighteen of the participants were fully independent in ADLs; 32 of the participants always required complete assistance from their primary caregivers for basic activities such as going to the toilet, and bathing.

3. Procedure

The study was initiated by Pakistani Psychologist working in Federal Ministry of Health, Pakistan to develop rehabilitation plan for Pakistani people living with paraplegia. After obtaining consent from patients, in-depth interviews were conducted in a quiet setting. A set of interview guidelines with open-ended questions to focus on what was important to the participant's life, and how the participants would define the term well-being was used. The interviews, which lasted approximately for 60 to 120 minutes, were audio-taped.

4. Data analysis

Consequently, all the verbal responses were recorded and archived on audiotape. The obtained information was manually segmented and grouped into large categories by using pattern coding. Units of similar information were grouped into provisional categories, followed by the process of sorting and reducing these categories into preliminary themes by manually reading the content and finding common ideas and concepts as well as the overall emerging messages. After the preliminary identification of the themes, an integrity check was performed on the data.

Results

Responses concerning the meaning of well-being and the

Table 1. Major groupings and components of well-being of paraplegic Pakistani adults major group components

Major group	Components
Living with independence	Performing physical functions for themselves
	Facilities available for participating public activities
	Livelihood
Living with self-esteem	Being recognized by society and gaining opportunities to do things as if normal
	Being able to contribute to family and social functions
Living well without suffering	Being satisfied with their condition
	Being free from unpleasant problems
	Having positive support from family and friends

most important components of their well-being are listed below.

1. Meaning of well-being

Well-being is a subjective observation of an individual's quality of life. Based on their common properties various meanings of well-being are grouped into three major headings, containing eight sub components (Table 1).

2. Living with independence

This category describes the patient's ability to perform day-to-day activities and to have freedom of movement. It includes performing physical functions for themselves, and the available facilities for participating in public activities and livelihood.

The details of individual components are listed below:

1) Performing physical functions for themselves

This component represents an individual's physical ability to perform functions within their current limitations (i.e., level of injury). The ability to perform bed and wheelchair mobility as well as their independence in daily living activities was of a concern here because they are basic human functions. About 99% of the participants felt a loss of independence and freedom because of the injury and did not want to be a burden on their family or society. Whereas, 90% of the participants reflected on their own living and working constraints.

2) Facilities available for participating in public activities

Typically, 78% of participants commented on the ability of the disabled to participate in social activities in the community. According to their responses, public transportation was virtually inaccessible to wheelchairs. The public places in Pakistan, such as the streets, hospitals, primary care units, toilets, restaurants, and cinemas, are not accessible to wheelchairs. This fact was a matter of concern for 78% of the participants.

3) Livelihoods

This component represents a person's ability to take financial care, particularly in having an occupation and/or enough money to support certain basic needs such as food, clothing, housing, transportation and supporting the family. About 75% of the participants stressed on the issue that an occupation contributed fundamentally to income generation, which supported independent living. In addition, other main concerns were the cost of living and having reserve funds for emergencies particularly of the participants with lower income (even before the initiation of the problem).

3. Living with self-esteem

About 98% of the respondents described their well-being as having a relationship with their society and acceptance in order to gain self-esteem. They felt that they needed to overcome the stigma of their condition, self-pity and establish their confidence.

Two components are of importance here.

1) Being recognized by society and gaining opportunities

to do things as if they are normal. Society's beliefs and perceptions about disability is one of the participants' concerns. In Pakistani culture, others have generally viewed paraplegics as being useless, pitiful, and dependent on others. The social reaction to this stigma determines largely the individual's sense of well-being.

2) Being able to contribute to family and social functions. This component revealed strategies for the improvement of an individual's attitude or outlook for being a part of the family and taking part in social functions. About 72% of the participants expressed a strong desire to work and participate in the welfare of the family. Contribution beyond family matter was important for 3% of the more assertive participants. For example, a single man with incomplete paraplegia indicated that, *"It is important to be able to contribute something to society"*.

4. Living well without suffering

Living well in the family without any suffering consisted of three components as follows:

1) Being satisfied with their condition

About 83% of the participants discussed the importance of their personal attitude in relation to achieving well-being by accepting themselves as they are, and moving forward for the benefit of their own future. Typically, 57% of the participants felt that well-being was related to being mindful and happy.

2) Being free from unpleasant problems

According to 100% of the participants, being free from unpleasant problems meant the absence of bad health or medical problems, and the absence of negative emotions. In terms of health problems, 99% reported pressure sores, 82% urinary tract infections, 95% spasticity, and 84% pain with a negative effect on their functional abilities and emotions.

3) Having positive support from family and friends

Typically, 75% of the participants felt that a strong relationship with a special person or group is a contributing factor to experience the quality of life and provided an important resource in reconstructing the feeling that life was worth living, and in re-affirming the value of life.

Moreover, 77% of the participants reported that friends are important source of support.

Discussion

The present study has identified that the "well-being" of people living with paraplegia reflected three major areas with eight components. The content of each area in terms of the meaning of well-being was discussed to reflect multiple challenges in physical and psychosocial adaptation after a SCI.

A person with paraplegia that is dependent on caregiver, lacks many choices in their everyday life and mourns for the ability to perform activities that were once taken for granted. The findings from the present investigation demonstrates that people with paraplegia, who can manage their physical functions of daily living, such as dressing, moving about, and using the toilet, gain a sense of well-being. However, most of the participants complained, that they lacked support facilities such as ease of access to buildings, had difficulties with public transport or some other facilities were not available. These situations cause most of the Pakistani paraplegics to have a problem with rehabilitation process, which in turn affects their sense of well-being. It was suggested by the Rehabilitation Psychologist that the mobility equipment and transport are one of the major requirements for the people with SCI, so that they can get employment. In addition, access to the environment is important for individuals with paraplegia so that they can live independently and thereby attain a feeling of well-being.

Most of the people reflected on their need to live independently in relation to their ability to earn a living. Regarding Pakistani society, economic problems and unemployment were seen as important obstacles for people with disabilities for which the main reasons are related to the labor laws and higher rate of unemployment. After discharge from the hospital, patients were left with unemployment. The reasons given for not working were physical disability, inconvenient location of the work place, and lack of transport. Therefore, financial security and jobs emerge as important factors for living as they can be translated into basic condition factors, such as food, clothing, medication, housing, and family expenses.

Gaining self-esteem is related to social acceptance, and refers to the beliefs that a person has about themselves in terms of respect and worth and involves both positive

and negative attitudes. In this study, two components were dealt with for gaining esteem; the ones having social recognition and being able to contribute to both the family and social functions.

In another study (comparison of Pakistani paraplegia and normal earth-quack population in terms of their psychological well-being) it was found that paraplegia was a visible condition of the disabled, which had an effect on as how individuals feel about themselves and how others who do not have the illness perceive and value them. Hence, the participants in this study needed to overcome the stigma of being disabled and self-pity and to establish their confidence by becoming a part of society. On the other hand, successful or greater community reintegration or participation may promote productivity; better overall adjustment; and physical and mental well-being. Moreover, self-esteem comes from being able to contribute to the community.

Patients who have sustained a SCI are often physically and psychologically devastated. This study found that medical complications (i.e., pressure sores, urinary tract infections, pain and spasticity) were the most commonly mentioned problems that negatively affected the patients' functional abilities and well-being. Complications are additionally seen as a frequent cause of morbidity and mortality and leads to increased rates of re-hospitalization and care costs, along with loss of employability and decreased well-being. As a result, being healthy or not suffering from health problems was perceived as well-being.

Regarding emotional health, the participants emphasized the significance of negative emotions in terms of well-being. The emotions discussed included stress and worry as well as feeling of fear, frustration, helplessness, and loss of power.

Support from close relatives and loved ones is the most usual needs identified by people with paraplegia.

Conclusions

The findings from the present study confirm that direct experiences after SCI affect a paraplegic's expression and response to the definition of well-being. Although eight components in the three identified groups of well-being were found to be similar to other disabilities, it appears to have resulted in meaningful improvements in the care of people with paraplegia at various levels. At an individual level, the ability to perform functions independently and reduction in physical health problems is important for enhancing well-being.

In terms of the society, the findings showed the importance of having positive social interactions where people felt that they were valued and were supported by friends, family, and neighbors. At governmental level, a rehabilitation plan was designed and implemented to improve the standard of living of these people. As a researcher, I hypothesize that this research will lead to many other researches, which will enhance the in-depth knowledge about psychological states of paraplegia.

Conflict of interest

No potential conflict of interest relevant to this article was reported.

References

1. Swanson KM. Nursing as informed caring for the well-being of others. *Image J Nurs Sch* 1993;25:352-7.
2. Hampton NZ, Qin-Hilliard DB. Dimensions of quality of life for Chinese adults with spinal cord injury: a qualitative study. *Disabil Rehabil* 2004;26:203-12.
3. Chappell P, Wirz S. Quality of life following spinal cord injury for 20-40 year old males living in Sri Lanka. *Asia Pac Disabil Rehabil J* 2003;14:162-78.
4. Duggan CH, Dijkers M. Quality of life after spinal cord injury: a qualitative study. *Rehabil Psychol* 2001;46:3-27.