

A meaning of well-being: from the experience of paraplegic Thai people[@]

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A meaning of well-being: from the experience of paraplegic Thai people

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Songkla Med J 2008;26(2):173-183

Abstract:

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. Twenty paraplegic adults from Songkhla participated in an in-depth interview that employed a natural inquiry methodology. Following the technique of Lincoln & Guba, the interviews were audio-taped, transcribed, and analysed.

[@]This paper was presented at 9th EAFON, at Convention Center, Chulabhorn Research Institute, Bangkok, Thailand, 2006 March 30-31

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Three commonly used meanings of well-being were identified and eight components in the three identified groups were included in the definition. The results also indicated that the meaning of well-being is an individual perception, which includes both objective and subjective values and experiences. The study provides information that is useful for health professionals in the development of specific programmes that will enhance the well-being of paraplegic patients.

Key words: well-being, paraplegia, in-depth interview

บทคัดย่อ:

การส่งเสริมความผาสุกเป็นเป้าหมายสำคัญในการดูแลผู้ป่วย ความผาสุกได้ถูกนำมาใช้มากขึ้น แต่ยังไม่มีความชัดเจน โดยเฉพาะความหมายตามการรับรู้ของผู้ป่วยอัมพาตท่อนล่าง ผู้ป่วยผู้ใหญ่ที่เป็นอัมพาตท่อนล่างซึ่งอาศัยอยู่ในจังหวัดสงขลา จำนวน 20 ราย (เป็นเพศหญิง 7 ราย และชาย 13 ราย) ได้รับการสัมภาษณ์เจาะลึกโดยใช้วิธีการที่เป็นธรรมชาติ ข้อมูลที่ได้จากการบันทึกเทปสัมภาษณ์นำมาวิเคราะห์โดยการจำแนกและจัดกลุ่มตามเนื้อหาตามกระบวนการเชิงคุณภาพของ Lincoln และ Guba ความผาสุกที่ผู้ป่วยอัมพาตท่อนล่างรับรู้และให้ความหมายมากที่สุดมี 8 องค์ประกอบที่จัดแบ่งเป็นกลุ่มได้ 3 ส่วนสำคัญ ผลการศึกษาสะท้อนให้เห็นว่า ความหมายของความผาสุกเป็นการรับรู้ส่วนบุคคลซึ่งมีคุณค่าและประสบการณ์ ทั้งที่เป็นรูปธรรมและนามธรรม อันเป็นข้อมูลที่มีประโยชน์สำหรับทีมสุขภาพในการพัฒนารูปแบบเฉพาะเพื่อส่งเสริมความผาสุกของผู้ป่วยอัมพาตท่อนล่าง

คำสำคัญ: ความผาสุก, อัมพาตท่อนล่าง, การสัมภาษณ์เจาะลึก

Introduction

Well-being is the most commonly used in philosophy, usually related to health, to describe what is ultimately perceived as good for a person.¹ With spinal injury rehabilitation, not only provides a focus for functional performance, but also incorporates the themes of independent living and sense of well-being. As highlighted by Inman,² the aims of spinal cord injury rehabilitation include: optimising physical functions; facilitating social independence; minimising 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 disablement. Enhancing the sense of well-being for people with paraplegia is therefore the goal of spinal injury rehabilitation practice.

Paraplegia results in changes not only physical and psychological but also socioeconomic, which taken together may had significant impact on an individual's "subjective well-being" (SWB). SWB is now receiving increased attention as an important long-term outcome following severe injury.³

There are several types of psychological outcome which include those that are clinically relevant, particularly depression,⁴ as well as the non-pathological outcomes, such as satisfaction with life and adjustment after spinal cord injury (SCI).⁵ Both these types of outcome are relevant to the SWB of people with SCI.⁶

In the nursing discipline, Swanson⁷ has stated that well-being is an important phenomenon for concern and in particular, the individual's perception of well-being is a critical variable for nurses in terms of their ability to consider when to interact with the chronically ill and disabled. However, two major problems found in the well-being research were the lack of a clear definition of the term at start and the lack of consistency in the methods of measuring the phenomena. The research in Thailand on the well-being of individuals with SCI, in respect of both quadriplegia and paraplegia is limited. Most research related to well-being explored among different populations, particularly in Thai elderly and has also used various different analytical tools. For example, using "Cantril's self-anchoring ladder scale" to evaluate overall perception of

well-being,⁸⁻⁹ or using the "Life satisfaction Index A" to assess social activity participation and psychological well-being.¹⁰ Some used Dupuy's general well-being concepts that included physical activity, anxiety, depression, self-control, state of health, and energetic life to explore certain specific aspects of paraplegic well-being.¹¹ In addition, there has been a qualitative study among the Thai elderly on psychological well-being that identified five dimensions: harmony, interdependence, acceptance, respect and enjoyment.¹²

According to an intensive review of well-being of people with SCI in Southeast 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" (QOL) perceived by Chinese adults with SCI. The study indicated that physical, psychological, economic, social well-being and uncluttered environment were the spheres of influence of QOL.¹³ The second study, from Sri Lanka, noticed that SCI adults QOL 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.¹⁴

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. It has also been suggested by Duggan & Dijkers¹⁵ that an individual experience of well being occurs in a specific sociocultural context; hence, a qualitative research method appears to be the most appropriate tool for this type of investigation in so far as it helps provide the "insiders" view of the well-being of people with disabilities. As a result, this qualitative study has been designed to obtain the perceptions from adult Thai paraplegics of the meaning of well-being. This understanding should extend the knowledge of nursing and caring for Thai paraplegics.

Materials and methods

Objective

To describe the meaning of well-being as perceived by Thai people living with paraplegia.

Research question

How do Thai people living with paraplegia perceive and describe well-being?

Research participants

To increase the range of data that could be uncovered a purposive sampling technique was used in this investigation¹⁶ and the participants were selected from a list of people with paraplegia from both a regional hospital and the Songkhla Society of Disabled Persons (SSDP) database for the year 2005. Most participants, in the first instance, were approached by telephone; introduced to the research objective; and asked if they were willing to voluntarily participate in the study. If they consented then interview times were arranged. After contact, 13 males and 7 females ranging from 19 to 55 years volunteered to be interviewed. Most of them had a history of SCI longer than 10 years (mean=10.8). Fourteen people were diagnosed with complete paraplegic injuries (4 females, 10 males), and 6 people with incomplete paraplegic injuries (3 females, 3 males). Half lived in a rural setting, and 12 were unemployed. Looking at their Activities of Daily Living (ADLs), three were confined to their homes (defined as went out less than once a month), eight occasionally went out (defined as between once a month and once a week) and nine frequently went out (defined as more than once a week). Eighteen of the participants were fully independent in ADLs in their home but two of the participants who were confined to home still needed incomplete assistance from their primary caregivers for basic activities such as going to the toilet, and bathing.

Procedure

Approval to use human subjects was obtained from the Research Ethics Committee (REC) in the Faculty of Nursing at Prince of Songkla University. After consent, the in-depth interviews were conducted in a quiet setting of the participant's choice (mostly at home). 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 45 to 60 minutes, were audio-taped. Following methodologies from Lincoln & Guba,¹⁶ data collection was terminated after 20 complete interviews because it was felt there was a sufficient data to work from and "emergence of regularities" in the data could be observed. This meant no new information would be gained from further interviews.

Data analysis

The goal of the data analysis was to identify emerging themes in the data, which was achieved by first, identifying patterns then coding, and categorising them. Consequently, all verbal responses were recorded and archived on audiotape from which a verbatim transcription was made. The data were segmented manually and recorded in a computer data base by analysing the responses to questions which were summarised and coded by pattern coding. The coding enabled the researchers to group the data into large categories. Units of similar information were then grouped into provisional categories by either a close relationship to the same or similar content.¹⁶ Next followed a process of sorting and reducing these categories into preliminary themes by manually reading the content of the computer file folders and finding common ideas or concepts as well as the overall messages that were emerging. After the preliminary identification of the themes, an integrity check was performed on the data as well as an external audit was made to examine independently the product, results, and interpretations and enhance the validity and dependability of the analysis.¹⁶

Results

Responses concerning the meaning of well-being and the most important components of their well-being are presented below.

On the meaning of well-being

Well-being is a subjective observation on an individual's quality of life. The various meanings of well-being in the study were eventually reduced down to three major headings based on a definition from the well-being indicators to enable

assessment and evaluation of well-being and also establish interactions between the components for enhancing the well-being of paraplegic Thai people. The groups contained eight components that had common properties (Table 1).

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, facilities available for participating public activities and livelihood. Each of the components is presented following sample case quotes.

Performing physical functions for themselves

This first component represents the 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 a concern here because they are basic human functions. All the participants felt a loss of independence and freedom as a result of the injury and did not want to be a burden to their family or society. Most reflected on their own living and working constraints as quoted by the case of a single-male who had been a complete paraplegic for fifteen years, "well-being is an ability to do activities of daily living by myself...without increasing my parent's burden" (ID15). A single woman of fourteen years complete paraplegia, who was unable to transfer by herself and needed personal assistant stated that, "to improve my ability to do or perform activities by myself is my main concern. My hope is to live as independently as much as I can. It will be fine if I can go to the toilet or move from my bed by myself" (ID5).

Facilities available for participating public activities

Many participants commented on the ability of the disabled to join in with social activities in the community. They shared numerous examples of how an inaccessible physical environment limited their ability to participate in public activities, and the affect on them. According to their responses, public transportation was virtually inaccessible to wheelchairs. Some participants did use power tricycles or modified vehicles as a means of transportation while others utilised a tricycle

operated by hand mechanisms. Many public places, such as the street, hospitals, primary care units, toilets, restaurants, and cinemas, are not accessible. As a male participant; a complete paraplegic for seventeen years and who was constantly in and out of hospital stated, *"I am able to drive a car by myself... however, there are some limitations. As I drove into the hospital yesterday, I could not park my car because there were no parking places for the disabled. I had to use my wheelchair for a long distance. Although legislation for the disabled has been recommended, we still cannot gain access to all the public places we would like to go to by ourselves"* (ID18). Other paraplegic patients also discussed how they were unable to get into the toilet in a public hospital. The accessibility of public places for wheelchair bound people was then a concern for them.

Livelihoods

The third 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. The participants stressed that an occupation contributed fundamentally to income generation, and that this supported independent living. In addition, other main concerns were the cost of living and having reserve funds for emergency situations particularly of those participants who earned a low

income (500–2,000 baht per month). A single woman, of three years incomplete paraplegia, currently living with her aunt and grandmother could walk with short-leg braces and crutches, reflected on her idea of well-being in the following: *"My well-being could be related to...first, I can survive from earning my own wage. Second, I can support my family; I don't want to be a burden to my family...I feel good enough if I can do both"* (ID3). The same experience is also reflected by a complete paraplegic married woman for the last nine years, who had her own work and stayed with her husband nearby her parent's home: *"Economic status is important... I mean that it has to be sufficient to live in daily life. We will suffer if I have no income. If the family is in poverty; no food; no income then it will lead to suffering...that will prevent us from reaching happiness as well"* (ID9). There was no difference in gender perspective in terms of earning a living. As a complete paraplegic male for ten months who received a living allowance from the monthly social security fund stated, *"I hope to earn my living wage, and then my parents won't be in trouble"* (ID1). This was similar to a single man who had been complete paraplegic for ten years, lived alone and was temporarily employed. He stated that *"I need a better life and to get money for a good living. How do we get food? I have to do a job then I can get money and can buy the food. This would help to make my life better"* (ID11).

Table 1 Major groupings and components of well-being of paraplegic Thai people

| Major group | Components |
|-------------------------------|--|
| Living with independence | <ul style="list-style-type: none"> - Performing physical functions for themselves - Facilities available for participating public activities - Livelihood |
| Living with self-esteem | <ul style="list-style-type: none"> - Being recognised by society and gaining opportunities to do things as if normal - Being able to contribute to family and social functions |
| Living well without suffering | <ul style="list-style-type: none"> - Being satisfied with their condition - Being free from unpleasant problems - Having positive support from family and friends |

Living with self-esteem

All 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 important here.

Being recognised by society and gaining opportunities to do things as if normal

Society's beliefs and perceptions about disability is one of the participants' concerns. In Thai culture, paraplegics have generally been viewed by others as being a "cripple," a concept which includes the states of uselessness, being pitiful, and dependent on others. The social reaction to this stigma determines to a large extent the individual's sense of well-being. For example, a married woman who has been a complete paraplegic for four years stated, *"I don't want to be stereotyped as crippled but I want to be thought of as normal (able to walk). I want community acceptance of my disability without stigmatisation"* (ID4). A similar attitude was also indicated by a single man who had been paraplegic for six years and who had previously been a national sportsman. His concern was related to social opportunity: *"Our group needs opportunities for us to do things, more than to feel pitied. Well-being then means that society gives a chance to the disabled group to do as many activities as possible"* (ID6).

Being able to contribute to family and social functions

This component revealed strategies for the improvement of the individual's attitude or outlook for being a part of the family and taking part in social functions. Many of the participants usually expressed a strong desire to work and participate in the family. As a married woman with nine years of complete paraplegia, who earned her own wage from a mushroom farm stated, *"I was proud of being able to support my family from the mushroom farm although I am unable to walk"* (ID9). In addition to earning for the family, being able to support their children in terms of higher education gave a person a sense of self-esteem. A married paraplegic man for the past eleven years, who had three children, said, *"I am*

happy to be able to take care of my children until they have finished their higher education and are earning their own living. This is a part of being a parent" (ID13). However, the contribution beyond family is important for some of the more assertive participants. For example, a single man with twelve years of incomplete paraplegia indicated that, *"It is important to be able to contribute something to society. I gain value not only from having a job but also from helping people in society. Now, I work for the Provincial Social Development and Human Security (PSDHS) Office to help the disabled and now people look at me in a more positive way"* (ID14). Similar experiences were reflected by another man who had seventeen years of complete paraplegia and worked for the Songkhla Society of Disabled Persons (SSDP) committee: *"It is my happiness to be able to earn a living for my family and help other disabled people. I give much useful information in order to motivate them to open up to society and also to facilitate their needs"* (ID18).

Living well without suffering

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

Being satisfied with their condition

Many participants discussed the importance of their personal attitude in relation to achieving well-being by accepting themselves as they are, and moving forward for their own future. One of the participants was a ten year complete paraplegic man and had chronic spasticity, but who could move independently with the use of a wheelchair. He was a member of the SSDP committee and had the following to say: *"Currently, I don't think too much. I believe in our king who said that we should do thing in a sufficient way or do as we believe we can do. I always do things in "my way" such as; I do what my body can tolerate, help my mother to earn living as much as possible, I do not hope to have more money to spend unnecessarily"* (ID12). Nevertheless, some participants felt that well-being was related to being mindful and happy, as a participant, a paraplegic of 20 years, stated: *"Don't*

keep everything in our mind, doing just fifty percent. If we have too much hope, it would be hopeless. We should think positively. If our mind has no stress, we will not suffer" (ID19).

Being free from unpleasant problems

According to the participants, being free from unpleasant problems means the absence of bad health or medical problems, and the absence of negative emotion. In terms of health problems, the most common reported were pressure sores, urinary tract infections, spasticity, and pain and negatively affected their functional abilities and emotions. Ten paraplegics still had pressure sores and six had neuropathic pain. In terms of negative emotions, stress and worry concerning the consequences of SCI were the most prevalent psychological impacts reported by nine of the participants; four of them worried about the complications of SCI; and three of them felt frustrated about their limited activities and being unable to work while the rest of them felt helpless and powerless or had lost their self-confidence. One woman who had fifteen years of incomplete paraplegia and a history of several illnesses ranging from: periodic attacks of neurophatic pain, five years previously had had TB lymph node, seven months before suffered chronic pressure sores and currently had a lump on her left breast, and reflected her experiences for us. *"I need to get rid of the pressure sore. If I have nothing to do, I will think about it (pressure sore)...when will it heal? When will I be free from karma (bad action). I feel hurt and I suffer when thinking about it and that makes me feel stressed and unhappy...I wish my health were strong without stress from this breast lump. That would be enough and that would mean well-being"* (ID16). Another married man, completely paraplegic for 17 years, reflected on his well-being in relation to his symptoms in the following way: *"Pressure sores cause my suffering. A person like me (paraplegia) who has a pressure sore cannot sit for a long time because of the pain. People usually want to be free from serious health problems"* (ID18). So, health problems concerning chronic conditions, pressure sores, and pains caused them to feel that they lacked a sense of well-being.

Having positive support from family and friends

A strong relationship with a special person or group was identified as contributing to the experience of quality of life and provided an important resource in reconstructing the feeling that life was worth living, and also in re-affirming the value of and motivation for life. A married male participant, complete paraplegic for 16 years but who was able to move about independently by wheelchair, said that his well-being was related to family support: *"For me, well-being is the family's well-being; husband and wife must listen and understand each other. When my children, my wife and I accept each other, it is our support..."* (ID17). Children were also identified as important for both the male and female participants. For example, one married woman, with four years of complete paraplegia and who had two daughters, emphasised that *"The important thing in my life is my children, husband, and parents. These are my will power... if I don't have will power from them I may not be well. Having will power is an important part of living for me and I receive will power from my familyA lot of friends also come to see me. We talk and laugh all day"* (ID4). Whether married or unmarried, the responses tended to be the same.

At this stage, friends are important human sources of support for both younger and older paraplegics. To quote one paraplegic interviewed, *"I think that friends are very important. They give me will power by helping and advising me. I think will power is a very important and major source of my support. When I feel discouraged but have friends or good people around me, I can think about the future or what I should do tomorrow and can go forward"* (ID6). Support groups or peer support are therefore important factors in well-being as reflected by members of the SSDP and a self help group of paraplegics. A single woman with incomplete paraplegia for four years was able to walk with a brace and crutches; she indicated that *"previously, I could not accept my being disabled, but now I accept myself as disabled. I usually consult my friend for emotional support. We (disabled people) have similar feelings and experiences, so we consult each other because we understand each other better than normal people"* (ID3).

Discussion

The 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.

Living with independence

A person with paraplegia that is dependant on care lacks many choices in their every day life and mourns for the ability to perform activities that were once taken for granted. The findings showed that people with paraplegia, who can manage their affairs or physical functions of daily living, such as dressing, moving about, and using the toilet, gain a sense of well-being. In a review, physical independence was a major factor in positive social and emotional adjustments. However, most participants complained that they lacked support facilities such as ease of access to buildings, had difficulties with public transport or some facilities were not available. These situations cause most Thai paraplegics to have a problem with reentering the community or living, which in turn affects their sense of well-being. These findings from the current study are similar to those of a previous study which identified a barrier-free environment as one of the four components of QOL.¹³ A suggestion has been made that mobility equipment and transport are major areas of need among a large proportion of people with SCI living in the community¹⁷⁻¹⁸ particularly so for those who are employed and require transportation. 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 Thai people with paraplegia reflected on their need to live independently in relation to their ability to earn a living. Regarding Thai society, economic problems or unemployment were seen as important obstacles for people with disabilities for which the main reasons are related to the labour laws and currently high numbers of unemployed. An unpublished report from Mongkolsawadi¹⁹ indicates that in respect to the national employment levels of people with

disabilities, "more than one million and thirty thousand Thai adults with disabilities are not employed". In this study, approximately two thirds of the participants (60%) had no career, which was close to the data of other studies,²⁰⁻²¹ where it was found that 58-70.9% of SCI patients were unemployed after hospital discharge. The reasons given for not working were: physical disability, inconvenient location of the work place, and lack of transport. So, financial security and jobs emerge as important for living as they can be translated into basic condition factors, such as food, clothing, medication, housing, and family expenses. This is supported by evidence from people with SCI, not only living in Thailand but also in other countries, such as China,¹³ Taiwan,²² the USA²³ and Canada.²⁴ In addition, a job was seen as important for Thai people with disabilities because it could reflect capability, self-esteem and a healthy life, particularly in terms of minimising physical or psychological dependence on others.¹⁹

Living with self-esteem

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 described for gaining esteem; those of having social recognition and being able to contribute to both the family and social functions. In Thai culture Buddhism also can influence people's attitudes towards a person with a disability. A study of community self-help for disabled people in north-eastern Thailand found that community attitudes toward disabled people was similar to that of normal people (43%); pity them and sympathise with them (41.5%); and look down on them and dislike them (14.6%).²⁵ Paraplegia is a visible condition of the disabled which affects how individuals feel about themselves and how others who do not have the illness perceive and value them.²⁶ Hence, the participants in this study needed to overcome the stigma of being disabled and also 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.²⁷⁻²⁸ Moreover, self-esteem comes from being able to make a contribution to the community.

Living well without suffering

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. These were also seen as a barrier to the well-being by disabled people in other countries.²²⁻²⁴ Complications are additionally seen as a frequent cause of morbidity and mortality and lead to increased rates of re-hospitalisation 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, which is similar to a previous study in the central part of Thailand.²⁹

Regarding emotional health, the participants emphasised the significance of negative emotions in terms of well-being. The emotions discussed included stress and worry as well as feeling fear, frustrated, helpless, and powerless as Lazarus & Folkman³⁰ have previously defined. This is congruence with a previous study which has shown that several factors were related to suffering and have negatively affected paraplegic's lives such as 1) becoming dependent, 2) loss of self-esteem, 3) not having their own income, and 4) inability to protect themselves and their families.³¹

There was a statistically significant relationship between socioeconomic status, health status and suffering level. Support from close relatives and loved ones is the most usual needs identified by people with paraplegia, while community rehabilitation and nursing home care systems are not well-established at the time of study. All participants indicated that having positive support from family and friends was an important component of their well-being. So, having support from family and significant people, providing positive opinions, consoling them, and explaining the value they have for the family does help people with paraplegia in terms of their sense of well-being.

Conclusion and recommendations

The findings confirm that direct experiences after SCI affect a paraplegic's expression and response to a definition of well-being. Although eight components in the three identified groups of well being are similar to other disabilities, it appears to have resulted in meaningful improvements in the care of people with paraplegia at various levels. At the individual level, the ability to perform functions independently and reduce physical health problems are important for enhancing well-being particularly for those who confined at home or had less access to SSDP. There is a need for further study to examine strategies which best suited for patients according to relevant meaning of well being. In terms of the community, the findings showed the importance of having positive social interactions where people felt they were valued and supported by friends, family, and neighbours is essential. As a result of this, developing a network of peer groups, promoting family perceptions and the ability to face the situation should be explored. In addition, there is a real requirement to enhance well-being by increasing access and accommodations in the physical environment, improving services of integrative medicine, assistive technology, welfare, education, useful occupations, and promoting good attitudes via public relations. Although the applicability is limited, the findings derived from the participants' own responses show the importance of understanding both the individual's identification and weighting of specific areas of life which influence well-being.

Acknowledgments

We are grateful to the people with paraplegia that participated in this study. We would also like to acknowledge all the communities and hospitals that gave personal support and for the funding support from Prince of Songkla University. Our appreciation would also go to Bruce Leeds for editing paper.

References

1. Crisp R. Well-being. In: Zalta EN, editor. The stanford encyclopedia of philosophy [monograph on the internet]. California: The Metaphysics Research Lab; 2005 [cited 2007 Jan 18]. Available from: <http://plato.stanford.edu/archives/win2006/entries/well-being/>.
2. Inman C. The effectiveness of spinal injury rehabilitation. *Clin Rehabil* 1999;13 Suppl 1:S25-31.
3. Hicken BL, Putzke JD, Novack T, Sherer M, Richards JS. Life satisfaction following spinal cord and traumatic brain injury: a comparative study. *J Rehabil Res Dev* 2002;39:359-66.
4. Kemp BJ, Krause JS. Depression and life satisfaction among people aging with post-polio and spinal cord injury. *Disabil Rehabil* 1999;21:241-9.
5. Krause JS. Changes in adjustment after spinal cord injury: a 20-year longitudinal study. *Rehabil Psychol* Spring 1998;43:41-55.
6. Krause JS, Coker J, Charlifue S, Whiteneck GG. Depression and subjective well-being among 97 American Indians with spinal cord injury: a descriptive study. *Rehabil Psychol* 1999;44:354-72.
7. Swanson KM. Nursing as informed caring for the well-being of others. *Image J Nurs Sch* 1993;25:352-7.
8. Klin-ual A. Effects of exercise program on physical fitness and well-being among the elderly [thesis]. Chiang Mai: Chiang Mai University; 2001.
9. Pangjai R. Spousal support of well-being of the elderly [thesis]. Chiang Mai: Chiang Mai University; 1999.
10. Pattarakantakul P. Social activity participation and psychological well-being of the elderly [thesis]. Chiang Mai: Chiang Mai University; 2001.
11. Chotikacharoensuk P. Physical activity and psychological well-being among the elderly [thesis]. Chiang Mai: Chiang Mai University; 2002.
12. Ingersoll-Dayton B, Saengtienchai C, Kespichayawattana J, Aunguroch Y. Psychological well-being Asian style: the perspective of Thai elders. *J Cross Cult Gerontol* 2001;16:283-302.
13. 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.
14. Chappell P, Wirz S. Quality of life following spinal cord injury for 20-40 year old males living in Sri Lanka. *Asia Pacific Disabil Rehabil J* 2003;14:162-78.
15. Duggan CH, Dijkers M. Quality of life after spinal cord injury: a qualitative study. *Rehabil Psychol* 2001;46:3-27.
16. Lincoln YS, Guba EG. *Naturalistic inquiry*. London: Sage publications; 1985.
17. Cox RJ, Amsters DI, Pershouse KJ. The need for a multi-disciplinary outreach service for people with spinal cord injury living in the community. *Clin Rehabil* 2001;15:600-6.
18. Dunn M, Love L, Ravesloot C. Subjective health in spinal cord injury after outpatient healthcare follow-up. *Spinal Cord* 2000;38:84-91.
19. Mongkolsawadi S. Promotion of employment for people with disabilities [thesis]. Bangkok: Huachiew Chalermprakiet University; 2000.
20. Kovindha A, Yawila K. Status and problems of spinal cord injured patients after discharge. *Chiang Mai Med Bull* 1998;37:49-57.
21. Kuptniratsaikul V, Kaewnaee S, Leurcharusamee A, Chavasiri C. Vocational and avocational activities after traumatic spinal cord injury. *Siriraj Hosp Gaz* 1999;51:77-85.
22. Lin KH, Chuang CC, Kao MJ, Lien IN, Tsauo JY. Quality of life of spinal cord injured patients in Taiwan: a subgroup study. *Spinal Cord* 1997;35:841-9.
23. Putnam M, Geenen S, Powers L, Saxton M, Finney S, Dautel P. Health and wellness: people with disabilities discuss barriers and facilitators to well being- barriers and facilitators to well being. *J Rehabil* 2003;69:37-45.
24. Manns PJ, Chad KE. Components of quality of life for persons with a quadriplegic and paraplegic spinal cord injury. *Qual Health Res* 2001;11:795-811.

25. Ramasoota P, Pramanpol S, Taveesit S. The community self-help group for the disabled: Sriboonruang district, Udon Thani province. *J Prim Health Care Dev* 1994;7: 20-35.
26. Joachim G, Acorn S. Stigma of visible and invisible chronic conditions. *J Adv Nurs* 2000;32:243-8.
27. Allen SM, Ciambone D, Welch LC. Stage of life course and social support as a mediator of mood state among persons with disability. *J Aging Health* 2000;12:318-41.
28. Miller WC, Forwell SJ, Noreau L, Jongbloed L, Procter ES, Abramson C. Community reintegration following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, Wolfe DL, Townson AF, Aubut J, et al, editors. *Spinal cord injury rehabilitation evidence* [monograph on the Internet]. Vancouver: online publisher www.lulu.com; 2006 [cited 2007 Jan 18]. Available from: <http://www.icord.org/scire>.
29. Satyawiwat W, Kaewchantr M, Musikhasung C. The study of quality of life of paraplegic patients. *Nurs J* 1995;13:60-9.
30. Lazarus RS, Folkman S. *Stress, appraisal, and coping*. New York: Springer Publishing; 1984.
31. Waikittipong W. Factors related to suffering in paraplegic patients [thesis]. Songkhla: Prince of Songkla University; 2003.