

ORIGINAL PAPER**Health-related Quality of Life in caregivers of patients with spinal cord injury (SCI). A Greek review****Venetia Notara, BSc, MSc, RHV**

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Correspondence: Notara Venetia, Thivon Av. 274, Athens Greece E-mail address: venotara@yahoo.gr**Abstract**

Background: Health – related quality of life and spinal cord injuries are two parameters that are becoming a key concept in research due to medical and rehabilitative care advances resulting in extended life expectancies for those with SCI. People with SCI often have significant functional limitations and lack of independence according to their level of injury. In such cases, help from others is needed, and this is often provided by a family member. The responsibility of caregiving can lead to physical injury and emotional distress not only for the caregiver but also the person with SCI.

Aim: The objective of this study was to review the data associated with the Health-related Quality of Life in SCI patients and their family caregivers.

Methodology: A literature review of national and international studies was performed in databases of PubMed and Scopus using keywords such as spinal cord injury, caregivers, quality of life, physical activity, subjective well-being, health promotion, depression.

Results: Several studies indicate the positive impact of health promotion/wellness interventions and of social support services that could be provided for both patients and their caregivers.

Conclusions: Caregiving has been studied extensively among those providing services to elderly or cognitively impaired people. On the contrary, there has been relatively little focus on caregiving in SCI patients. Further research is needed to address strategies that could effectively optimize, support and increase not only caregiver's but also patient's quality of life.

Keywords: Spinal cord injury, caregivers, quality of life, health promotion.

Introduction

Spinal Cord Injury (SCI) remains a major public health issue in developed countries as well as worldwide (Jia et al 2011). A significant increase of the SCI incidence has been observed due to the increase of road traffic accidents. Furthermore, the number SCI survivors has been increased due to treatment improvements.

Greece has the highest car accident rate in Europe, with 32,000 injured, of whom 3200-3500 resulting in permanent disability (Batsiou et al 2008, Koutsodontis et al 2011), followed by

accidents from falls, sports and those caused in the workplace. A study in China, in which medical records of 239 patients with traumatic SCI admitted to a general hospital were reviewed, showed that in accordance with other developing countries car accidents and falls are the two leading causes of traumatic SCI (Feng et al 2011). According to the World Health Organization report "The Global Burden of Disease" 2004 Update, road traffic accidents are expected to take third place in the rank order of disease and injury

burden by the year 2030 among men aged 15-44 years. (WHO 2008) (Table 1)

Greek crash rates for sex and age groups indicate an excess risk for men of over 60%, while the average age is between 18 and 40 years. The financial burden because of increased health care costs (prolonged hospitalization and rehabilitation), state benefits and productivity loss, is estimated at 1 billion euros per year, whilst the psychological consequences of both patients and caregivers should not be underestimated (Batsiou et al 2008).

Methodology

A Pubmed and Scopus database search was performed in order to identify studies of QoL in patients with SCI and their caregivers. Keywords such as spinal cord injury, caregivers, quality of life, physical activity, subjective well-being, health promotion, depression were used.

Studies revealing a relationship between spinal cord injury survivors, caregivers' burden, depression and the enhancement of their quality of life were selected while, mainly, a ten year time frame was set in order to include the most recent studies.

Other important issues, that the international search yielded a large number of papers, like employment, racial disparities and SCI were not selected because of not meeting our inclusion criteria.

Medical complications following Spinal Cord Injury

Patients with spinal cord injury (SCI) usually have permanent neurologic deficits and disabilities including, chronic pain (usually neuropathetic pain) or dysesthesia, motor or sensory disorders, muscle flaccidity or spasticity, urinary and gastrointestinal complications, sexual disorders, frequent infections (urinary or pulmonary system) and pressure sores.

Studies indicate that people living with constant pain are four times more likely to suffer from depression or anxiety, and more than twice to report difficulty in dealing with the working and social environment, compared to those without pain (Pender, Murdaugh & Parsons 2006). Generally, chronic pain interferes with daily activities and consequently can have a negative impact on all aspects of quality of life of the patients and their caregivers (Carragee 2001, Arnold et al 2000). However, it has been revealed that patients with SCI showed less depressive

symptoms compared to patients with other neurological disorders (stroke, multiple sclerosis) (Hassanpour, Hotz-Boendermaker & Dokladal 2011). According to the research data, it is very well stated that secondary medical complications represent a major cause of mortality and morbidity which can lead to increased re-admissions to hospital and rehabilitation units and simultaneously to the loss of employment opportunities and decreased quality of life.

Spinal Cord Injury and demographic characteristics

A study conducted in 87 patients (victims of SCI) admitted to a university hospital, in Portugal concluded that the group at higher risk of injury to the spinal cord is the young adult male (Brito et al 2011). Another study conducted in the USA in 2010 showed that males were nearly three times more likely to be hospitalized for SCI than females. Falls and motor vehicle accidents were the leading cause of SCI-related hospitalizations (WellFlorida Council 2010). It is worth mentioning that compared to western countries in which motor vehicle accidents are the commonest cause of injury in 18-25 years age group and falls are the leading cause of injury after the age of 45, in India the leading cause of injury even before the age of 45 are falls. (Gupta, Solomon & Raja 2008) In the same study, the majority of the SCI victims had secondary education who were most likely to be engaged in high-risk occupations. This result comes in accordance with the study conducted in Brazil (Blanes et al 2009) concluding that patients with paraplegia were young males with low education level. It is stated that developed and developing countries share some similarities with the age groups of SCI incidents, but there are many important differences as well regarding the leading causes of death, the cause of non traumatic SCI, the availability of data, etc.

Marital status is rather more complicated issue meaning that either can enhance or weaken well-being, since several dynamics are involved in human relationships. (Kalpakjian et al 2011) Certainly, as a disease itself, SCI is a difficult experience for the whole family, but still there is a need for more research on this matter since very little is known about the burden of caregiving on the children or even the parents of the injured patients (Wise Young 2006). And on this subject there are cultural differences that can interpret the varying results. i.e. the divorce rates after SCI are not as high in developing countries compared to those in the developed countries.

Spinal Cord Injury and addictions

There is a great interest on how SCI interferes with alcohol abuse and internet addiction. Regarding alcohol consumption and abuse, there is a great evidence that patients with SCI who were heavy drinkers before the injury, they continue their drinking habits even after that which in turn affects the rehabilitation progress (Stephanie et al 2002). At the same time, most at-risk drinkers frequently intend to change their post-injury alcohol use which can be countered as an opportunity to improve rehabilitation interventions (Stroud et al 2011, Bombardier & Rimmele 1998).

Internet and computer use can be a potential benefit tool for people with disabilities provided that it can facilitate their daily activities including shopping, communication, access to services, job searching without physical limitations (Goldner 2006). On the other hand, it is suggested by other researchers that frequent use can lead to negative activities such as internet dependence, social isolation, depression, gambling, pornography, and seeking immoral material (Houlihan et al 2003). Nevertheless, the association between internet use and SCI needs further research.

Health-related Quality of Life (HRQOL) and SCI

Health-related Quality of Life is a multidimensional concept which includes subjective perceptions on psychosocial, mental and physical health. Self-rated health has been proved a useful predictor of future mortality and morbidity and if combined with the clinical objective information can help public health researchers to define a more improved health policies and community interventions (Idler & Benyamini 1997). Thus, HRQOL surveys provide useful information in evaluating the effectiveness of health care interventions for chronic diseases, but they can also be used in the general population for comparing the disease burden in different groups. Patients with SCI in their majority, experience important barriers to physical and social activity and lack of independence resulting in a poorer quality of life (Vall, Braga & de Almeida 2006, Dijkers 2005, Migliorini & Tonge 2009). Stevens et al (2008) & Vissers et al (2008) also noted a positive correlation between physical activity and quality of life in adults with SCI. The everyday physical activity helps patients to improve self-care skills and life satisfaction, to

decrease the risk of depressive symptoms and to prevent the occurrence of other complications which limit the patient to bed or a wheelchair. Depressive disorder is also one of the most common secondary health condition associated with physical disability and chronic illness (Krause & Saunders 2011). The limitations of their bodily capacity in their daily activities e.g. access to shops, services, personal hygiene, strongly emphasize the need of a psychological support at an early stage of their illness.

Caregiving and QOL of patients with SCI

Patients with SCI require permanent health care provision, including monitoring, treatment and home health care training of the family caregivers. People who take on the role of caregiver, in their majority, have little or no preparation for the new requirements of such an effort. Since care for patients with SCI is a life-long process, it can be easy for caregivers to feel overwhelmed and neglect their own health and well-being therefore their concern for their patients is decreased leading to negative impact of the care recipient's life. Thus, caregiving in patients with SCI is associated with physical, psychological, and financial burdens. As mentioned above, many individuals with SCI have no option other than to rely on a family member for daily assistance (bathing, dressing, transportation, bladder management, etc). In 2009, a survey conducted in the USA (Collins & Swartz 2011) reported that 3 in 10 households have at least one person providing unpaid care as a family caregiver.

It is interesting to point out the Greek cultural care-giving tradition, meaning that family members (caregivers) provide also informal in-hospital care spending almost the whole day at their patients' bedside since they want to participate and be present in the whole treatment process (Sapountzi-Krepia et al 2006). Thus, additional support and anticipatory guidance for the caregiver are particularly helpful during care transitions.

According to a Greek study (Sapountzi-Krepia et al 1998), health education interventions should be provided in both rehabilitation centres and home settings by health visitors and community nurses to improve patient's self-care and to alleviate "informal" carers burden. Moreover, Rosland & Piette (2010) supported that, new family support programmes need to be structured so as to have a more successful result on patient management.

In addition, many studies support the benefits of wellness and health promotion interventions for patients with chronic conditions which at the same time can alleviate the burden of their caregivers (Alexa et al 2010). Health Promotion is a process which focuses on the enhancement of self-management, healthful behaviours and self efficacy. It can be applied simultaneously at the patients and their caregivers so as to enable them to increase control over, to cope with their circumstances and create environments conducive to health, in which people become more able to take care of themselves (Pender, Murdaugh & Parsons 2006).

Physical activity, stress-control, healthy eating, good interpersonal relationships, functional independence, are some of the "health promotion" behaviours which contribute significantly to QoL, and how the person perceives health as a broader concept. (Marge 1988, Stuijbergen & Becker 2001).

Although there are several studies for caregivers of people with cognitive disabilities, but for caregivers of people with SCI, the bibliographic reference is almost nonexistent. Moreover, several studies (Collins & Swartz 2011, Kathleen et al 2004, Grehl et al 2011) suggest that further research is needed to identify strategies to offset caregiver stress, depression, and poor health outcomes.

Instrumentss for measuring Health-related Quality of Life (HRQOL) in patients with SCI

The rapid development of quality of life measurements in health care is due to the growing recognition of the importance of understanding the impact of healthcare interventions on patients' lives rather than just on their bodies. This is especially important for patients with chronic diseases who live without the expectation of cure and thus attention should be paid to their physical and psychosocial well-being (Addington-Hall & Lalit 2001).

Even though it is difficult to define the aspects that constitute HRQOL. which range in several studies, its content originates from the definition of WHO "... A state of complete physical, mental and social wellbeing and not merely absence of disease" (WHO 1958). The terms "wellbeing" and "quality of life" encompass a wide range of contexts, including the fields of healthcare, equality, environment, education, infrastructure, entertainment, economics and other issues associated with these. This broad "biopsychosociological 'perception of health has

several supporters (Keith 1995) and has led to the creation of multidimensional questionnaires or assessment tools to outline of define the health status. Certainly the patient's or caregiver's perspective is as valid and should not be abandoned

The few studies that have investigated the relationship between HRQOL and patients with SCI (Ku 2007, Leduc & Lepage 2002), have used different methodological approaches and assessment tools therefore many questions remain unanswered. For this reason it was intended to create reliable assessment methods to record specific problems that characterize a particular disease.

The most widely used instruments for the study of QOL in patients with SCI (Meyers, Andresen & JHagglund 2000) is the SIP (Sickness Impact Profile) Overview of the Impact of Illness (Bergner et al 1981, Yfantopoulos & Sarris 2001), the original version contained 136 questions, while there is a new version of 68 questions and the SF-36 (Medical Outcomes Study-Short Form 36) (Yfantopoulos & Sarris 2001, Ware & Sherbourne 1992).

Other questionnaires such as the NHP (Nottingham Health Profile) (Hunt, McEven & McKenn 1985) or the WHO Quality of Life Questionnaire (WHOQOL-100; WHOQOL-BREF) (WHOQOL 1998, WHOQOL 1998) are very rarely used for the certain disease.

Conclusion

Following the SCI, the patient is confronted with a great challenge in adjusting to physical, social and psychological sectors. The burden of the disease is substantial and high with a long-lasting profile which is not limited to the patients but also extending to their caregivers. Data reveal that both parties are not merely passive recipients but are directly affected in a great number of life aspects which should not be underestimated. Research endeavours should be directed toward the evaluation of the caregivers' QOL mainly of spinal cord injured people. Priority should be given to the care-giving burden, depression, social and psychological support.

Nevertheless, further research is required into identifying people at risk and exploring effective intervention strategies so as to alleviate the impact to the family members as well as to the patient itself.

Table 1

Projected change in the ranking of the 10 leading causes of death and disease (DALYs) worldwide, 2004-2030

2004 Disease or injury	As% of total DALYs	Rank	Rank	As% of total DALYs	2030 Disease or injury
Lower respiratory infections	6.2	1	1	6.2	Unipolar depressive disorders
Diarrhoeal diseases	4.8	2	2	5.5	Ischaemic heart disease
Unipolar depressive disorders	4.3	3	3	4.9	Road traffic accidents
Ischaemic heart disease	4.1	4	4	4.3	Cerebrovascular disease
HIV/AIDS	3.8	5	5	3.8	COPD
Cerebrovascular disease	3.1	6	6	3.7	Lower respiratory infections
Prematurity and low birth weight	2.9	7	7	2.9	Hearing loss, adult onset
Birth asphyxia and birth trauma	2.7	8	8	2.7	Refractive errors
Road traffic accidents	2.7	9	9	2.5	HIV/AIDS
Neonatal infections and other	2.7	10	10	2.3	Diabetes melitus
COPD	2.0	13	11	1.9	Neonatal infections and other
Refractive errors	1.8	14	12	1.9	Prematurity and low birth weight
Hearing loss, adult onset	1.8	15	15	1.9	Birth asphyxia and birth trauma
Diabetes melitus	1.3	19	18	1.6	Diarrhoeal diseases

WHO "The Global Burden of Disease" 2008

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