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## Personal resources and daily life fatigue in caregivers of persons with paraplegia

### Abstract:

Taking care of a paraplegic may contribute to the caregiver's fatigue. Sixty family caregivers participated in our study, out of which 30 provided care for paraplegics in hospital, and 30 for paraplegics at home. The Orientation to Life Questionnaire (SOC-29) was used to measure individual sense of coherence, The Life Orientation Test – Revised for dispositional optimism, The Polish Resiliency Assessment Scale for resiliency, and The Daily Life Fatigue Questionnaire for daily life fatigue. In order to collect data about caregivers an individual examination was applied. People with higher personal resource levels such as sense of coherence, optimism and resiliency are characterized by less severe daily life fatigue.

### Keywords:

personal resources, daily life fatigue, caregiver, paraplegia

### Streszczenie:

Sprawowanie opieki nad osobą z paraplegią może przyczyniać się do zmęczenia jej opiekuna. Badaniem objęto 60 opiekunów osób z paraplegią, w tym 30 opiekunów osób przebywających w szpitalu i 30 opiekunów osób przebywających w domu. Do pomiaru indywidualnego poczucia koherencji zastosowano Kwestionariusz Orientacji Życiowej SOC-29, dyspozycyjnego optymizmu – Test Orientacji Życiowej LOT-R, prężności – Skalę Pomiaru Prężności SPP-25 i nasilenia zmęczenia życiem

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codziennym Kwestionariusz Zmęczenia Życiem Codziennym KZZC. W celu zebrania danych o opiekunach zastosowano ankietę osobową. Osoby z wyższym poziomem zasobów osobistych takich jak: poczucie koherencji, optymizm i prężność charakteryzują się mniejszym nasileniem zmęczenia życiem codziennym.

**Słowa kluczowe:**

zasoby osobiste, zmęczenie życiem codziennym, opiekun, paraplegia

## **Introduction**

A growing number of car accidents, the most frequent cause of spinal cord injuries, appears to be one of the major problems we are facing today. As a result, those who sustain a spinal cord injury (SCI) suffer from many neurological complications, with paralysis to the lower extremities, so-called paraplegia, being one of the most common injuries associated with SCI, and very often become dependent on other people.

Caring for people with paraplegia can lead to increased daily life fatigue in caregivers. Research findings show that socio-demographic factors and personal resources that a person uses in coping with day-to-day problems are among key predictors of daily life fatigue (Sęk & Pasikowski, 2001; Hobfoll, 2006). Personal resources include, among others, a sense of coherence, dispositional optimism, and resiliency. Therefore, to investigate the relationship between personal resources and daily life fatigue in a group of caregivers appears to be warranted.

### **Daily life fatigue characteristics**

Since so many people in our modern society are becoming overwhelmingly tired, fatigue has come to be viewed as one of the most important sociological problems in the 21<sup>st</sup> century. Researchers have provided different perspectives and theoretical frameworks for fatigue (Jason at al., 2005; Carruthers at al., 2003). Chronic fatigue syndrome has been the most frequently described affliction in the scientific literature (Niloofer, & Buchwald, 2003). It is estimated that 5% of the world's population suffer from chronic fatigue syndrome. Major CFS symptoms include persistent fatigue lasting at least six months, sleep disorders, malaise, reluctance to undertake any activity and limited daily activity, plus a feeling of fatigue not relieved by rest or sleep. Other symptoms that characterize CFS may include dispersed pain and reduced intellectual ability (Schwid et al., 2002).

A Polish researcher, Urbańska, has suggested a new perspective on fatigue, with a view to more closely analyzing the psychological consequences involved in modern social life participation. She introduced the term daily life fatigue as a psychological phenomenon defined as an individual's subjective overall fatigue. Daily life fatigue

manifests itself in reluctance to undertake any daily activity (no matter what its type) and results from incongruity in life's day-to-day demands and a person's psycho-social abilities (Urbańska, 2010).

Daily life fatigue can occur due to exposure to a difficult situation experienced by an individual, viewed, in this case, as traumatic and exceeding the a system's capacity to adapt. An example can be a family member's spinal cord injury, a condition debilitating not only for the person suffering from paraplegia, but also for close relatives.

### **Caring for a chronically ill person**

A complete thoracic spinal cord injury results in totally losing sensory and motor functions of lower extremities, known as paraplegia (Kirshblum et al., 2011). Paraplegics preserve nerve sensation and functions in all their upper extremities. A T1 level paraplegia, so-called high paraplegia, is characterized by an impaired balance in a sitting position and frequent breathing problems. People with thoracic cord injury (T2-T5) have a better torso control, which enables better stability and preserves sensory functions of diaphragm muscles. Persons with a T6-T12 injury can use torso muscles for breathing and therefore are able to stand with the help of braces (Hagner, Kasprzak, & Sosnowski, 2002; Kirshblum et al., 2011). Individuals with paraplegia preserve nerve sensation and functions in all their upper extremities. Long rehabilitation and regaining functional independence after an injury along with unfavorable prognosis for completely recovering motor and sensory functions, make paraplegia a chronic condition.

Providing care to a chronically ill person can lead to a situation in which the caregiver is overburdened with work in trying to meet the dependent person's needs, and the balance is lost between the tasks undertaken and the caregiver's capacity to fulfill those obligations (Donelan et al., 2002). Consequently, these overlapping tasks may in the long run contribute to daily life fatigue (Urbańska, 2010). Differences regarding the capacity to adapt to an ensuing situation depend on an individual's worldview. Preserving minimum hope and optimism when faced with seemingly insurmountable life circumstances, preconditions successful adaptation and coping. According to Folkman and Moskowitz (2000), evaluating circumstances positively, focusing on constructive aspects and constructive fantasizing along with a strong sense of control over a difficult situation can enhance coping with stress, while negative orientation towards solving problems may lead to health impairments in caregivers (Elliott, Shewchuk, & Richards, 2001).

### **Personal resources and their significance in coping with daily life demands**

Factors contributing to better coping with difficult events can on the one hand facilitate control over life's adversity, counteract any negative health and psychological consequences resulting from it, and, on the other hand, increase the person's resistance to experiencing such events as harmful or negative. These factors are most often referred to

as personal resources. Anything can become a personal resource (object, energy, information), as long as it is used by an individual to satisfy their immediate need or realize their long-term objectives (Hobfoll, 2006).

Recently, there has been a tendency to view an individual's beliefs and expectations as particularly important. Many research studies have shown that such constructs as sense of coherence, optimism in life, and resiliency are crucial (Hart, Wilson, & Hittner, 2006).

Sense of coherence, according to the definition put forward by Antonovsky (1987), is a person's global dispositional orientation. It expresses their pervasive, enduring, though dynamic sense of confidence that (1) the stimuli coming from their internal and external environments are structured, predictable and explicable; (2) the resources are available to them to meet the demands posed by these stimuli; and (3) these demands are challenges, worthy of investment and engagement. There are three basic elements that constitute sense of coherence, namely: comprehensibility, manageability, and meaningfulness (Antonovsky, 1987). Since sense of coherence is a relatively stable and enduring disposition to perceive life as comprehensible, meaningful and manageable, it correlates with somatic and physical health and a higher resistance to stress and acceptance of unavoidable difficulty (Lundman, & Norberg, 1993; Basińska, & Andruszkiewicz, 2008). Therefore, it may be assumed that this positive influence also refers to adaptation in caring for paraplegics.

Dispositional optimism, viewed as a relatively stable personality trait, functions as a moderating mechanism, influencing the choice of goals and goal-oriented actions. It expresses positive expectations towards future events, and a conviction and belief that negative outcomes will be rather scarce or will not happen (Carver, & Scheier 1990, 1998; Scheier, & Carver 1992). Dispositional optimism helps to preserve persistence in action even when confronted with failure or a difficult and very slow change in life (Carver, & Scheier 1990, 1998; Scheier, & Carver 1992).

Resiliency consists in a set of personality characteristics and skills that help an individual to cope with difficult situations that are also significantly stressful. The ability to break away from negative experiences and evoke positive emotions is crucial here (Smith, Tooley, Christopher, & Kay, 2010).

Two research objectives were formulated based on the literature in the field. Firstly, we attempted to define the differences in the daily life fatigue levels in paraplegic caregivers in a rehabilitation ward in hospital and those caregivers who cared for paraplegics at home. Secondly, we examined whether there was any interaction between the personal resources, coherence and resiliency, and the daily life fatigue levels in these paraplegic caregivers. Hypothetically, we assumed that:

1. due to hospital-stay related stress, the daily life fatigue level is higher among caregivers when paraplegics remain in hospitals than when caregivers care for paraplegics at home, and that
2. paraplegic caregivers with high personal resource levels, such as sense of coherence, optimism and resiliency, experience less daily life fatigue compared to paraplegic caregivers with lower personal resource levels.

## Materials and Methods

### Participants

To test these hypotheses 60 study participants were examined, including 25 women and five men who cared for paraplegics in a rehabilitation ward in hospital and 25 women and five men who cared for paraplegics at home.

The average caregiver's age in hospital (N=30) was 45.07 years  $\pm$  12.35, the youngest person being 21 while the oldest was 64. In the sample of caregivers at home (N=30) the average age was 50.30  $\pm$  15.74, the youngest aged 24 and the oldest 78.

In terms of education, the majority of caregivers had higher education while those who declared vocational secondary education were in the minority.

### Measures

The following measures were used in the research study:

1. The Orientation to Life Questionnaire SOC-29 by Antonovsky, is used to define sense of coherence (SOC) in adults. The Cronbach coefficient alpha value for the Polish version was .87 (Sęk, & Pasikowski, 2001).
2. The Polish Resiliency Assessment Scale (SPP-25) is used to examine the resiliency levels in adults. The Cronbach's alpha reliability coefficient was .89 (Juczyński, & Ogińska-Bulik, 2008a).
3. The Life Orientation Test – Revised (LOT-R) is used to measure dispositional optimism in adults. Reliability of the Polish version is close to the original test and is .87 Cronbach's alpha (Juczyński, 2001).
4. The Daily Life Fatigue Questionnaire consists of 24 statements grouped in eight subscales: physical fatigue scale (PFS), mental fatigue scale (MFS), and social fatigue scale (SFS). Each scale consists of eight statements. Study participants answer *Yes* if the statement applies to them or *No* if it does not. Total score for the daily life fatigues is the sum of all three subscale scores and ranges within 0-24 points. A high score means a high level of daily life fatigue, while a low score indicates a low level. In its original form, the Cronbach alpha value was calculated as .89 for the entire scale while in the present study the Cronbach alpha value is .88.

The psychometric properties indicate that the Daily Life Fatigue Questionnaire is a reliable instrument, and individual scale scores correlate highly with the total score (Urbańska, 2010).

5. A personal questionnaire was used in order to collect socio-demographic data.

### **Statistical Analyses**

In order to answer the research question posed in our study, firstly, basic statistics were calculated for the entire sampled caregivers, preserving the distinction between care settings: hospital and home. Next, statistically significant differences in the average severity of daily life fatigue among the caregivers were computed. Interaction between daily life fatigue and personal resources as well as caregiving settings was also examined. The analyses were conducted with Statistica 10.0.

### **Results**

In both groups of caregivers (N=60), the majority declared low or average daily life fatigue severity. Concerning sense of coherence among caregivers in hospital, the majority showed low and average sense of coherence levels. Concerning optimism levels in the entire sample, the majority of subjects displayed optimism, and the fewest number showed pessimism. At the resiliency level, the majority showed high resiliency, the fewest number showed low.

#### **A comparative analysis of caregivers**

Since The Daily Fatigue Questionnaire variable lacked normal distribution, the non-parametric U Mann-Whitney testing procedure was used to estimate statistically important differences in the daily fatigue levels among paraplegic caregivers staying in hospital and those staying at home ( $z=-0.185$ ;  $p=0.853$ ). The answer to the first research question was negative; the place where care is provided was not a variable differentiating daily life fatigue severity.

#### **The analysis of daily life fatigue severity interacting with paraplegic caregivers' personal resources**

In order to verify the research hypothesis about interaction between daily life fatigue levels of personal resources, namely sense of coherence, optimism and resiliency, a two-factor analysis of variance was implemented with the first degree interaction, which showed a significant relationship between coherence, optimism, and resiliency levels, and the severity of a daily life fatigue. Significant interaction was found between coherence level and place where care was provided (Table 1).

**Table 1.** The significance of interaction between daily life fatigue, personal resources and care settings.

Resources	PR		PI		PRS	
	F	p	F	P	F	P
SOC	14.739	< <b>0.0001</b>	3.791	<b>0.029</b>	0.126	0.724
Optimism	13.649	< <b>0.0001</b>	0.117	0.890	0.113	0.738
Resiliency	7.626	<b>0.001</b>	1.051	0.357	0.099	0.754

PR= The probability of a relationship between a given personal resource included in the variance analysis model and the level of daily life fatigue

PI = The probability of an interaction of a given personal resource included in the model and caregiving settings

PRS = The probability of a relationship between caregiving settings (the second variable included in the variance analysis model) and daily life fatigue

F= F (variance analysis) score

The Duncan test (Table 2) uncovered a statistically significant difference in daily fatigue severity in individual levels of every factor. The study showed that individuals with low sense of coherence levels are significantly different from individuals with average and high levels, and persons with average levels differ significantly from persons with high sense of coherence. Therefore we observed a general tendency towards a decrease in daily life fatigue in paraplegic caregivers who demonstrated an increased level of coherence (Table 2).

**Table 2.** A statistically significant difference between the level of daily life fatigue and the examined personal resource levels across the entire caregiver group ( $p \leq 0.01$ ).

Level of SOC			Level of optimism			Level of resiliency		
	M	SD		M	SD		M	SD
Low	<b>11.00</b>	5.55	Low	<b>12.58</b>	5.03	Low	<b>11.50</b>	5.29
Mean	<b>6.57</b>	4.43	Mean	<b>7.59</b>	4.95	Mean	<b>6.63</b>	5.00
High	<b>3.85</b>	3.91	High	<b>4.23</b>	3.81	High	<b>5.22</b>	4.60

It can also be concluded from the test that there is a tendency towards decreased levels of daily life fatigue with an increase in optimism. The study showed that individuals disposed toward pessimism differ significantly from individuals with an average level of optimism, and persons with an average level of optimism differ significantly from optimists (Table 2).

The test also shows that a relation emerges between decreased daily life fatigue severity and increased resiliency levels in caregivers. Therefore it can be observed that caregivers with a low level of resiliency are significantly different from caregivers with

average resiliency levels and caregivers with high levels (Table 2). Thus these findings allowed us to positively answer the second research question.

## **Discussion**

The analyses of factors that determine the severity of daily life fatigue showed that these personal resources are important: sense of coherence, optimism, and resiliency of paraplegic caregivers. This means that high personal resource levels lessen daily life fatigue levels. Such a result is completely understandable when viewed by the conservation of resources theory (Hobfoll, 2006). According to this theory, a person with more personal resources is able to better cope with adversity in life and continuously strives to manage their resources so that they can apply them to survive, ensure their well-being, avoid illness and maintain social interaction on an optimal level.

The above relationship confirms the salutogenic theory propounded by Antonovsky, according to which sense of coherence is one of the key personal resource in coping with stress and difficult events in life (Antonovsky, 1995). A high level of optimism enables individuals to look into the future optimistically and without fear or anxiety (Seligman, 2005). Consequently, they are more likely to positively assess their chance for successful performance. This in turn increases their motivation so necessary in lessening the consequences of paraplegia (Juczyński, & Ogińska-Bulik, 2008b). Resiliency, on the other hand, facilitates the flexible adaptation to life's demands in the form of increased social competences, fulfilled developmental tasks and without any emotional or behavioral disorders (Smith et al., 2010).

According to previous research on caregivers of persons with spinal cord injuries, elevated levels of physical stress, emotional stress, burnout, fatigue, anger and resentment, and depression have been reported (Boschen, Tonack, & Gargaro, 2005; Lucke, Coccia, Goode, & Lucke, 2004; Elliott, Shewchuk, & Richards, 2001). Since daily life fatigue is a relatively new concept in the literature, and no research has been conducted as yet into daily life fatigue in paraplegic caregivers, the findings in our study will refer to similar research samples. Until now research has shown similarly that a high level daily life fatigue and a low level resiliency allow one to predict that mothers of children with ADHD will develop chronic fatigue (Basińska, Kielnik, & Grzankowska, 2014). A statistically significant negative relationship has been found between daily life fatigue and satisfaction with life in an entire group of parents and mothers who have children with cerebral palsy. Such a correlation has not been identified in a group of fathers under study (Basińska, & Wędzińska, 2014). The literature provides substantial evidence that attending to the chronically ill seriously burdens family caregivers and may be understood in

terms of costs and negative consequences in providing care by family caregivers (Grad, & Sainsbury, 1966), or tension that has built up in trying to cope with persistent problems associated with caregiving demands (Pearlin, & Schooler, 1978). The experienced burden has a negative influence on caregivers' health, finances and social life, causing mental deterioration and tiredness.

Research on the burden experienced by family caregivers of the chronically ill has found that among its most significant predictors are: sense of coherence, health status, time spent on caregiving, emotional status and social support (Pearlin, & Schooler, 1978). The experienced burden has a negative influence on caregivers' health, finances and social life, causing mental deterioration and tiredness.

Research on the burden experienced by family caregivers of the chronically ill has found that its most significant predictors are: sense of coherence, health status, time spent on caregiving, emotional status and social support (Grabowska-Fudala, Jaracz, & Górna, 2009).

Research findings obtained in the present study proved to be comparable with the findings related to factors determining the burden level in family caregivers of chronically ill persons.

Our findings show that factors conditioning daily life fatigue levels of paraplegic caregivers are diverse. The importance of sense of coherence, optimism and resiliency in explaining the caregivers' functioning, enables them to understand and explain the essence of their need to live their own lives despite the close one's adversity. High level personal resources contribute to reevaluating their own experiences, having a positive view on life, and consequently accepting and learning to live with their condition; lower fatigue intensity caregivers in spite of all adversities learn to appreciate and notice life's positive aspects. These findings further suggest that personal resources buffer caregivers against difficult events in their own lives.

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