ROCZNIKI PSYCHOLOGICZNE / ANNALS OF PSYCHOLOGY
2018, XXI, 1, 53-68

DOI: http://dx.doi.org/10.18290/rpsych.2018.21.1-4

KAROLINA SZATKOWSKA
MICHALINA SOŁTYS
Kazimierz Wielki University in Bydgoszcz
Institute of Psychology

PERCEIVED SOCIAL SUPPORT, SPIRITUAL WELL-BEING, AND DAILY LIFE FATIGUE IN FAMILY CAREGIVERS OF HOME MECHANICALLY VENTILATED INDIVIDUALS

Providing care to a chronically ill person is a stressful situation, which may lead to burden. However, personal and social resources such as social support and spiritual well-being can protect caregivers from these negative consequences. To assess the role of these resources in counteracting fatigue, we examined 55 caregivers of their home mechanically ventilated relatives. The variables were measured with the Perceived Social Support Questionnaire, the Daily Life Fatigue Questionnaire, the Spiritual Index of Well-Being, and a survey. The method of ventilation did not differentiate resources and daily life fatigue in caregivers. Perceived social support was not significantly correlated with fatigue, but spiritual well-being correlated negatively with physical, mental, and social fatigue. Spiritual well-being can partly protect from daily life fatigue in the physical and mental areas.

Keywords: perceived social support; spiritual well-being; daily life fatigue; family caregivers; home mechanical ventilation.

Address for correspondence: KAROLINA SZATKOWSKA – Kazimierz Wielki University in Bydgoszcz, Institute of Psychology, ul. Leopolda Staffa 1, 85-867 Bydgoszcz; e-mail: szatkowska_karolina @wp.pl

INTRODUCTION

The specificity of family caregiving and home mechanical ventilation

Family caregivers frequently have to manage multiple daily tasks, such as nursing, planning the day, preparing meals, and other household activities. They not only change their usual rhythm of functioning but also struggle with financial difficulties (stemming from increased medication or care treatment expenses), not to mention the simultaneous decrease in work activity or leaving a job altogether (Kawczyńska-Butrym, 2008). Therefore, providing care to a chronically ill person requires the skill of coping with various challenges, which, in the long-term perspective, often leads to physical and psychological burden (Stajduhar, 2003). Nevertheless, current progress in medical technology makes it possible to create safe and comfortable conditions for home treatment. Even individuals with a serious health condition have the chance to stay in the familiar environment of their homes (Tzu-Ting & Ji-Ming, 2010; Szkulmowski, 2016).

Home mechanical ventilation is a form of long-term nursing intervention for people with chronic respiratory failure. The treatment is provided via a ventilator which assists in or takes over the breathing process. Mechanical ventilation is executed as a non-invasive method by means of facial or nasal masks, or as an invasive method via an artificial airway passage – tracheotomy. Diseases most frequently leading to chronic respiratory failure are: neuromuscular diseases (e.g., ALS – amyotrophic lateral sclerosis, SMA– spinal muscular atrophy, DMD/BMD – Duchenne/Becker muscular dystrophy, myopathies), lung diseases (e.g., COPD – chronic obstructive pulmonary disease, CF – cystic fibrosis), restrictive diseases (kyphoscoliosis), and the obstructive sleep apnea syndrome (Simonds, 2003; Szkulmowski, 2016).

By embarking on home care giving the patient's family takes responsibility for this care. This entails a change of lifestyle in order to provide all day care and to perform multiple nursing and medicinal actions (Kózka, Wojtan, & Woźniak, 2011; Evans, Catapano, Brooks, Goldstein, & Avendato, 2012). As a result, taking care of mechanically ventilated relatives is burdening and stressful situation for the caregivers (Fernández-Álvarez et al., 2009), and in the long run it may lead to the experience of daily life fatigue (Urbańska, 2010).

DAILY LIFE FATIGUE IN CAREGIVERS

Fatigue is a multidimensional construct combining somatic and psychological processes. As regards the physiological component, fatigue is an objective state of exhaustion of the organism or its decreased ability to undertake activity (Chojnacka-Szawłowska, 2009). The understanding of psychological fatigue focuses on subjective sense of discomfort connected with a decrease in well-being due to cognitive and emotional activity and due to the influence of external factors (Chabowski, 2005; Jackson & MacLeod, 2016). A particular type of psychological fatigue is daily life fatigue.

Joanna Urbańska (2010) perceives daily life fatigue as a psychological phenomenon and defines it as a subjective state of general tiredness manifested in the unwillingness to undertake daily activities in the physical, mental, and social areas. It is a result of a mismatch between daily life requirements and the individual's psychosocial abilities (Urbańska, 2010).

The interpretation of one's situation plays an essential role in the perceived level of fatigue. It seems that daily life fatigue could be a consequence of subjective stress (e.g., Lazarus & Folkman, 1984) as well as an indicator of the depletion of resources (Hobfoll, 2006).

PERSONAL AND SOCIAL RESOURCES IN CARING FOR A CHRONICALLY ILL PERSON

Personal and social resources as health potentials play a protective role against the negative effects of adverse situations such as long-term care for an ill person (Antonovsky, 1995; Juczyński & Ogińska-Bulik, 2003; Hobfoll, 2006). According to the conservation of resources theory (Hobfoll, 2006), people experience stress in situations of danger or actual loss of resources. Individuals with greater resources are less vulnerable to their reduction and more likely to increase them. People with inadequate resources are exposed to an accumulation of their losses. The mechanism of daily life fatigue shows that its level increases in people with low abilities to manage growing social requirements accompanied by a decrease in support offered by the environment. Thus, daily life fatigue should be reduced by sustained social support (Maghout-Juratli, Janisse, Schwartz, & Arnetz, 2010; Urbańska, 2010).

Social support. Social support is defined as help available in difficult situations or as a consequence of being part of social networks. Objective social support perceived as a resource (e.g., Antonovsky, 1995; Hobfoll, 2006) might be family, friends, neighbors, and professionals such as psychologists (Sęk & Cieślak, 2012). What is particularly important in coping with a difficult situation is the adequacy of support in relation to the need for it (Sęk, 2012), as well as perceived support understood as the individual's beliefs about where to go for help and who may provide it (Schwarzer, Knoll, & Rieckmann, 2004).

The results of multiple studies show the essential role of social support in a situation of caring for a chronically ill person (Suh & Oh, 1993; Au et al., 2009; Basińska, Kielnik, & Grzankowska 2014). The caregivers of people with multiple sclerosis perceive social support as beneficial to their general health, mood, experienced stress level, as well as to family life (McKeown, Porter-Armstrong, & Baxter, 2003). For the caregivers of people suffering from the Huntington disease, social support provided especially by healthcare personnel and efficient coping with stress are more important in their care giving than disease-related medical factors (Soltysiak, Gardiner, & Skirton, 2008). Social support, coping, and general well-being are recognized as factors with a significant influence on caregivers 'perceived burnout (Suh & Oh, 1993; Buck & McMillan, 2012). Mothers of children with ADHD who declare a higher level of social support show a lower level of chronic fatigue (Basińska et al., 2014). Parents of children with DMD who receive social support cope better with the child's disease (Thomas, 2014), while mothers of children with DMD and BMD suffer less stress and care burden and admit to experiencing greater life satisfaction (Kenneson & Bobo, 2010). Caregivers of individuals suffering from ALS who receive social support suffer less burden related to the care giving (Pagnini et al., 2010), and with the years passing by they report enhanced social support and improved general well-being (Roach, Averill, Segerstrom, & Kasarskis, 2009).

Spiritual well-being. Spirituality is another resource that provides ways of coping with health loss and the situation of taking care of a chronically ill person. It plays a regulatory role, influencing physical and psychological health (McClain, Rosenfeld, & Breitbart, 2003; Heszen-Niejodek & Gruszczyńska, 2004; Masters, 2008). Spiritual well-being is one of the constructs used in clinical practice for the purpose of evaluating the spiritual condition of adults, whose vertical dimension is defined as feeling well in relation to a higher power or God, and whose horizontal dimension is understood as a sense of purpose and meaning in life (e.g., Moberg, 1984; Frey, Daaleman, & Peyton, 2005). According to authors, spiritual well-being is a meaningful life scheme accompanied by self-efficacy in overcoming life challenges (Daaleman & Frey, 2004).

Research findings indicate that spirituality and religiousness help caregivers in coping with the illness of their relatives and can affect their physical and emotional functioning positively (Rabins, Fitting, Eastham, & Fetting, 1990; Delgado-Guay et al., 2013). The lower level of spiritual well-being is associated with inferior physical and psychological health in caregivers of cancer patients (Kim Carver, Spillers, Crammer, & Zhou, 2011; Pawl et al., 2013). Individuals with a higher level of spirituality tend to adapt better to the nursing situation with patients suffering from different diseases and cope better with burnout (Weaver & Flannelly, 2004; Pagnini et al., 2011). Caregivers with a lower level of spiritual well-being are characterized by a higher level of anxiety, a higher level of depression symptoms, denial, and lower quality of life; they exhibit less involvement in care and use maladaptive stress coping strategies (Pagnini et al., 2011; Delgado-Guay et al., 2013). Longitudinal studies on caregivers of people with advanced cancer reveal that social support and spirituality are predictors of higher quality of life (Leow, Chan, & Chan, 2014).

Studies on the resources of caregivers of mechanically ventilated people are rare. The official American Thoracic Society (ATS) standards regarding palliative care for patients with respiratory diseases and critical illnesses require that these patients and their families be provided with social support and that their spiritual needs be fulfilled (Lanken et al., 2008). Similar requirements can be found in Polish directives regarding care for people suffering from chronic obstructive pulmonary disease (Śliwiński, Górecka, Jassens, & Pierzchała, 2014) and in German directives concerning care for over mechanically ventilated people (Windisch, Walterspacher, Siemon, Geiseler, & Sitter, 2010).

Based on the above findings, we formulated the following research questions:

Do objective medical factors (the method and time of ventilation) differentiate perceived social support, spiritual well-being, and daily life fatigue in caregivers of mechanically ventilated people?

What are the relationships between perceived social support, spiritual well-being, and daily life fatigue?

Which type of resources predicts the level of daily life fatigue?

METHOD

Participants and procedure

The participants in the study were 55 caregivers of mechanically ventilated people, aged 29 to 74 (*M* = 50.04, *SD* = 12.24). Forty-four of the caregivers (80%) were female and 11 were male (20%). The care recipients were aged 1 to 90 (*M* = 42.47, *SD* = 25.25). A considerable majority of the participants were married (*n* = 44, 80%); the others were single, widowed, or divorced (*n* = 11, 20%). A significant majority of the care givers (*n* = 47, 86%) remained unemployed, including those (*n* = 18, 33%) who received retirement or annuity benefits. Almost half of the caregivers were parents of the care recipients (*n* = 27, 49%), followed by spouses (*n* = 18, 33%), children (*n* = 8, 15%), and other family members (*n* = 2, 3%). The home mechanical ventilation application period ranged from four months to eight years (*M* = 2.86, *SD* = 2.13). Nearly half of the care recipients (*n* = 24, 44%) required 24-hour ventilation, 31% (*n* = 17) required ventilation at various times during the day and night, and 25% (*n* = 14) needed it only during the night.

The study was conducted among the caregivers of people included in the home mechanical ventilation program after receiving informed consent from the participant. Participation remained voluntary and anonymous.

MEASURES

Perceived Social Support Questionnaire (F-SozU K-22) by Fydrich and colleagues (Fydrich, Geyer, Hessel, Sommer, & Brähler, 1999), adapted into Polish by Juczyński (2001), measures subjective assessment of social support understood as the result of interactions between the individual and his or her surroundings. The questionnaire consists of three scales: Emotional Support (ES), Practical Support (PS), and Social Integration (SI). The short version of the questionnaire consists of 22 items rated on a 5-point Likert scale. The Cronbach's α reliability coefficient in the examined group was .85 for the whole scale, .80 for ES, .83 for PS, and .79 for SI.

Daily Life Fatigue Questionnaire (DLFQ) by Urbańska (2010) measures fatigue symptoms and consists of three subscales: Physical Fatigue scale (PFS), Mental Fatigue scale (MFS), and Social Fatigue scale (SFS). Each of the subscales consists of eight items with "yes" or "no" answers. In the research on the caregivers of people with home mechanical ventilation the Cronbach's α reliability coefficient was .85 for the whole scale and the coefficients for the subscales were as follows: .86 for PFS, .85 for MFS, and .71 for SFS.

Spiritual Index of Well-Being (SIWB) by Daaleman and Frey (2004), adapted into Polish by Sołtys and Basińska (Sołtys, 2016), measures the generally understood spirituality. The scale consists of 12 items rated on a 5-point Likert scale. The scale consists of two subscales: Self-Efficacy subscale and Life Scheme subscale. The Cronbach's α reliability coefficient in the examined group was .78, .87, and .85 for the Self-Efficacy subscale, the Life Scheme subscale, and the total spiritual well-being score, respectively.

The survey included: questions about sociodemographic data of the caregiver and care recipient, the duration of the illness, ventilation method, the amount of hours of ventilation per 24 hours, and the time of ventilation.

STATISTICAL ANALYSES

In order to determine the significance of differences in social support, spiritual well-being, and fatigue between caregivers depending on ventilation aspects, we performed Student's *t*-test and one-way ANOVA. The relationships between resources and fatigue were reported in the form of Pearson's *r* correlations. To verify which of the analyzed resources predicted daily life fatigue in caregivers, we performed multiple linear regression analysis.

RESULTS

Analysis of differences between caregivers of people with invasive and a non-invasive home mechanical ventilation

The analyses of results revealed that caregivers of people with invasive home mechanical ventilation (64%) did not differ significantly from caregivers of those using non-invasive (36%) mechanical ventilation in perceived social support, in any of its aspects, in the level of spiritual well-being, or in the level of physical, mental, and social daily life fatigue (Table 1). The average scores were similar in both groups of caregivers.

The results revealed no statistically significant differences, either, in perceived social support, spiritual well-being, and daily life fatigue in caregivers depending on the time of mechanical ventilation use.

Table 1

Differences in Perceived Social Support, Spiritual Well-Being, and Daily Life Fatigue Between Caregivers of Invasively and Non-Invasively Ventilated People

Variables	Caregivers of people with home mechanical ventilation								
		total *N* = 55		non-invasive *n* = 20		invasive *n* = 35			
	Range	*M*	*SD*	*M*	*SD*	*M*	*SD*	*t*	*p*
Social support	50–106	83.82	13.56	81.95	14.34	84.89	13.19	-0.769	.445
emotional support	14–35	25.60	4.83	24.75	5.01	26.09	4.72	-0.987	.328
practical support	17–40	31.71	6.17	31.15	6.12	32.03	6.26	-0.505	.616
social integration	13–35	26.40	4.58	26.05	4.63	26.60	4.61	-0.425	.673
Spiritual well-being	18–58	42.29	7.56	43.40	7.48	41.66	7.64	0.820	.416
self-efficacy	10–30	18.75	4.52	19.40	5.13	18.37	4.17	0.808	.423
life scheme	7–30	23.55	7.56	24.00	3.88	23.29	4.88	0.560	.578
Daily life fatigue	0–21	7.56	5.98	7.75	6.07	7.46	6.02	0.173	.863
physical fatigue	0–8	2.96	2.55	2.90	2.83	3.00	2.43	-0.138	.890
mental fatigue	0–8	2.76	2.49	3.15	2.46	2.54	2.51	0.869	.398
social fatigue	0–7	1.84	1.78	1.70	1.63	1.91	1.88	-0.426	.672

Resources and daily life fatigue in caregivers

Considering the size of the sample and the fact that the analyses mentioned above did not reveal statistically significant differences in the examined variables, we performed further analyses jointly for all the sampled respondents. The analysis of correlations between perceived social support and daily life fatigue in caregivers (Table 2) showed a lack of statistically significant correlations.

Table 2

Correlations Between Perceived Social Support and Daily Life Fatigue in Caregivers of Home Mechanically Ventilated Patients

	Daily life fatigue in caregivers			
	total	physical	mental	social
Total	-.04	-.04	-.09	.04
emotional support	.01	-.06	-.10	.07
practical support	-.04	-.05	-.05	.02
social integration	-.08	-.10	-.08	.01

N = 55. All correlation coefficients are statistically non-significant.

Spiritual well-being	Daily life fatigue in caregivers			
	total	physical	mental	social
Total	-.54***	-.49***	-.55***	-.35**
self-efficacy	-.47***	-.38**	-.48***	-.36**
life scheme	-.60***	-.52***	-.61***	-.42**

Note. *N* = 55. ** *p* > .01, *** *p* > .001.

Table 3 presents Pearson's correlations between spiritual well-being and daily life fatigue in caregivers. The overall spiritual well-being score as well as life scheme and general fatigue scores showed a high negative and statistically significant relationship with physical and mental fatigue in caregivers. A lower positive correlation was also noted for the social aspect of daily life fatigue. A higher level of self-efficacy in caregivers moderately correlated with lower levels of all dimensions of daily life fatigue.

Determinants of daily life fatigue in caregivers

In order to identify the resources that protect caregivers from daily life fatigue, we performed stepwise multiple linear regression analysis (using the forward elimination method). The results of the analyses are presented in Table 3.

Table 3

Predictors of Daily Life Fatigue – Results of Multiple Linear Regression Analysis (Forward Elimination Method)

Predictors	Standardized coefficients		Unstandardized coefficients		*t*	*p*
	β	*SE*	β	*SE*		
Model 1 – daily life fatigue (total)						
self-efficacy	-0.39	0.115	-0.52	0.152	-3.42	.001
life scheme	-0.28	0.115	-0.37	0.152	-2.45	.018
$F(2, 52) = 13.63$; $p < .001$; Adj. $R^2 = .32$						
Model 2 – physical fatigue						
self-efficacy	-0.38	0.122	-0.21	0.069	-3.08	.003
life scheme	-0.21	0.122	-0.12	0.069	-1.69	.097
$F(2, 52) = 9.27$; $p < .001$; Adj. $R^2 = .23$						
Model 3 – mental fatigue						
self-efficacy	-0.39	0.11	-0.22	0.06	-3.45	.001
life scheme	-0.29	0.11	-0.16	0.06	-2.55	.014
$F(2, 52) = 14.26$; $p < .001$; Adj. $R^2 = .33$						
Model 4 – social fatigue						
self-efficacy	-0.24	0.129	-0.10	0.051	-1.88	.066
life scheme	-0.23	0.129	-0.09	0.051	-1.78	.081
$F(2, 52) = 5.24$; $p < .008$; Adj. $R^2 = .14$						

Note. Social support was not a significant predictor in any of the models.

Higher levels of both dimensions of spiritual well-being predicted the lowers level of general daily life fatigue and mental fatigue. Self-efficacy was the only one significant predictor of the physical dimension of daily life fatigue. Social support as well as spiritual well-being were not significant resources promoting lower social fatigue. The determination coefficients for all models were moderate.

DISCUSSION AND CONCLUSION

The psychosocial situation of caregivers of mechanically ventilated patients has rarely been the subject of scientific research in Poland (e.g., Kózka et al., 2011; Stodulska & Biłogan, 2016; Szatkowska & Szkulmowski, in press). The results of the present study showed that the method and time of mechanical ventilation use did not significantly differentiate the caregivers in terms of resources and daily life fatigue. This finding may be explained by the low sample size, which stems from the fact that in Poland home mechanical ventilation has-been conducted for only 16 years and is currently provided to approximately 3,000 patients (Szkulmowski, 2016). Yet, numerous reports (Pagnini et al., 2012) suggest that disease-related medical factors (e.g., general deterioration of health, especially mobility, increasing dependency, progressive difficulties in breathing, swallowing, eating, and expectoration) are relevant to caregivers' fatigue or burden. Caregivers might adapt to situational requirements regardless of the health condition of the patients (Zarit, Reever, & Bach-Peterson, 1980). The role of care time and intensity is equally important (Evans, Catapano, Brooks, Goldstein, & Avendano, 2012). Therefore, in subsequent studies, both patients 'medical characteristics and care factors should be investigated in detail.

The outcomes of our research reveal a lack of statistically significant differences between the respondents in perceived social support, spiritual well-being, and daily life fatigue. This is an unanticipated outcome. Similar studies have not been reported before; it is therefore necessary to compare the results of the present study to results obtained for other groups of caregivers.

Social support proved to be one of the factors reducing the experienced fatigue and burnout and contributing to more effective coping with stress in caregivers (Grabowska-Fudala, Jaracz, & Górna, 2009; Maghout-Juratli et al., 2010). The results were acquired among 4,717 dyads of Danish caregivers and their elderly charges, showing that social support has a protective function, contributing to lower stress severity through care and shortening stress duration (Verbakel, Metzelthin, Gertrudis, & Kempen, 2016). Caregivers of people suffering from Alzheimer's disease who declared higher level of social support showed a lower level of daily life fatigue, particularly physical fatigue (Basińska, Lewandowska, & Kasprzak, 2013). Furthermore, almost half of the responders in the Polish sample of caregivers of mechanically ventilated individuals reported increasing fatigue and burden. They coped with difficulties by using family help and support (Stodulska & Biłogan, 2016). The lack of relationship between perceived social support and daily life fatigue in the examined group of caregivers can be explained by the fact that their sense of burden and fatigue might require different resources, both personal and social. This is An example of this can be found in the study by Agnieszka Woźniewicz and colleagues (Woźniewicz, Kalinowska, Basińska, Pietrulewicz, 2014), who reported a higher level of personal resources such as sense of coherence, optimism, and resilience in those caregivers of people with paraplegia who experienced lower daily life fatigue. Furthermore, the caregivers who have the opportunity to use the help of other people are described as having a lower level of daily life fatigue (Woźniewicz & Basińska, 2014). The help providing by family members is a protective factor against chronic fatigue among mothers of children with ADHD (Basińska et al., 2014).

Spiritual well-being understood as having a well-defined life scheme and a sense of self-efficacy has comparable meaning to the sense of coherence (Antonovsky, 1995; Daaleman & Frey, 2004; Frey et al., 2005). Therefore, the acquired results indicating a strong relationship between spiritual well-being and physical as well as emotional fatigue in caregivers are consistent with the aforementioned Polish research reports (e.g., Woźniewicz et al., 2014).

Other studies confirmed that spiritual well-being fosters higher quality of life in various groups of caregivers of people with chronic illnesses – for example, in caregivers of people suffering from ALS (Pagnini et al., 2011) and in caregivers of cancer patients (Delgado-Guay et al., 2013; Leow et al., 2014). Moreover, the existential well-being of those suffering from ALS is related to lower burnout, anxiety, and depression in caregivers (Boerner & Mock, 2012). Burnout in caregivers of people with dementia is related to the need for spiritual support (Wright, Pratt, & Schmall, 1985).

It seems that spirituality can play a significant role in conditions which are objectively difficult to alter, such as the situation of care giving to a chronically ill person. When the possibility of controlling some aspects of the individual's life is minimal, efficient adaptation mostly involves intra psychological mechanisms (Park, Sacco, & Edmondson, 2012). Social support can act as an important resource preventing excessive burden in caregivers, although severe illness often requires a response and stimulates them to reflect on the meaning of human life (Frankl, 2009). In this respect, the abilities to recognize a meaning under the circumstances, to flexibly reformulate life goals, or reconstruct the system of beliefs, which are manifestations of spiritual well-being, seem to be very helpful (e.g., Taylor, 2003; Frey et al., 2005). Caregivers who do not see the purpose of their actions and their life experience spiritual challenges and unfulfilled spiritual needs. Consequently, they feel incompetent to cope with difficult situations and might be more susceptible to daily life fatigue in the physical, mental, and – partly – social areas (Buck & McMillan, 2012; Salins, Deadhar, & Muckaden, 2016). For this reason, the concern about spiritual well-being in caregivers seems to be as relevant as their psychosocial functioning. It is important to continue research in this group of caregivers and to extend the scope of the research to include a greater number of caregivers ‘personal resources as well as intrapsychological characteristics of individuals using home mechanical ventilation.

REFERENCES

Antonovsky, A. (1995). *Rozwikłanie tajemnicy zdrowia. Jak radzić sobie ze stresem i nie zachorować* [Unraveling the mystery of health: How to cope with stress and stay well]. Warsaw, Poland: Fundacja IPN.

Au, A., Lai, M. K., Lau, K. M., Pan, P. C., Thompson, L., & Gallagher-Thompson, D. (2009). Social support and well-being in dementia family caregivers: The mediating role of self-efficacy. *Aging & Mental Health, 13*(5), 761-768.

Basińska, M. A., Kielnik, J., & Grzankowska, I. (2014). Wybrane wyznaczniki zmęczenia chronicznego u matek dzieci chorych na ADHD [Selected indicators of chronic fatigue in mothers of children with ADHD]. *Pediatria Polska, 89*(1), 21-26.

Basińska, M. [A.], Lewandowska, N., & Kasprzak, A. (2013). Wsparcie społeczne a zmęczenie życiem codziennym u opiekunów osób chorych na Alzheimera [Social support and daily life fatigue in caregivers of patients with Alzheimer’s disease]. *Psychogeriatria Polska, 10*(2), 49-58.

Boerner, K., & Mock, S. E. (2012). Impact of patient suffering on caregiver well-being: Thecase of amyotrophic lateral sclerosis patients and their caregivers. *Psychology, Health & Medicine, 17*(4), 457-466.

Buck, H. G., & McMillan, S. C. (2012). A psychometric analysis of the Spiritual Needs Inventory in informal caregivers of patients with cancer in hospice home care. *Oncology Nursing Forum, 39*(4), 332-339.

Chabowski, M. (2005). Zmęczenie jako kategoria definicyjna w badaniach psychologicznych [Fatigue as a definitional category in psychological research]. In R. Koc, & Ł. Mazur (Eds.). *Zmęczenie – psychospołeczny punkt widzenia* [Fatigue – A psychosocial perspective] (pp. 5-11). Bydgoszcz, Poland: Social Psychology Students’ Association Press, Kazimierz Wielki University.

Chojnacka-Szawłowska, G. (2009). *Zmęczenie a zdrowie i choroba* [Fatigue, health, and illness]. Kraków: Oficyna Wydawnicza Impuls.

Daaleman, T. P., & Frey, B. B. (2004). The Spirituality Index of Well-Being: A new instrument for health-related quality of life research. *Annals of Family Medicine, 2*, 499-503.

Delgado-Guay, M. O., Parsons, H., Hui, D., De La Cruz, M. G., Thorney, S., & Bruera, E. (2013). Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. *The American Journal of Hospice & Palliative Care, 30*(5), 455-461.

Evans, R., Catapano, M., Brooks, D., Goldstein, R., & Avendano, M. (2012). Family caregiver perspectives on caring for ventilator-assisted individuals at home. *Canadian Respiratory Journal, 19*(6), 373-379.

Fernández-Alvarez, R., Rubinos-Cuadrado, G., Cabrera-Lacalzada, C., Galindo-Morales, R., Gullón-Blanco, J. A., & González-Martín, I. (2009). Home mechanical ventilation: Dependency and burden of care in the home. *Archivos de Bronconeumologia, 45*(8), 383-386.

Frankl, V. E. (2009). *Człowiek w poszukiwaniu sensu* [Man's search for meaning]. Warsaw, Poland: Wydawnictwo Czarna Owca.

Frey, B. B., Daaleman, T. P., & Peyton, V. (2005). Measuring a dimension of spirituality for health research: Validity of the Spirituality Index of Well-Being. *Research on Aging, 27*, 556-577.

Fydrich, T., Geyer, M., Hessel, A., Sommer, G., & Brähler E. (1999). Social support questionnaire (F-SozU): Norms of a representative sample. *Diagnostica, 45*, 212-216.

Grabowska-Fudala, B., Jaracz, K., & Górna, K. (2009). Obciążenie opiekunów chorych po udarze mózgu – wyniki wstępne oceny retrospektywnej [The burden of the caregivers of patients after stroke – Preliminary results of retrospective assessment]. *Nowiny Lekarskie, 81*(1), 3-9.

Heszen-Niejodek, I., & Gruszczyńska, E. (2004). Wymiar duchowy człowieka, jego znaczenie w psychologii zdrowia i jego pomiar [The spiritual dimension of man, its significance to health psychology, and its measurement]. *Przegląd Psychologiczny, 47*(1), 15-31.

Hobfoll, S. E. (2006). *Stres, kultura i społeczność* [Stress, culture, and society]. Gdańsk, Poland: Gdańskie Wydawnictwo Psychologiczne.

Jackson, H., & MacLeod, A. K. (2016). Well-being in chronic fatigue syndrome: Relationship to symptoms and psychological distress. *Clinical Psychology & Psychotherapy, 24*(4), 859-869.

Juczyński, Z. (2001). *Kwestionariusz Wsparcia Społecznego F-SozU K-22* [Social Support Questionnaire F-SozU K-22]. Łódź, Poland: unpublished study.

Juczyński, Z., & Ogińska-Bulik, N. (2003). Zdrowie najważniejszym zasobem człowieka [Health as the most important human resource]. In Z. Juczyński & N. Ogińska-Bulik (Eds.), *Zasoby osobiste i społeczne sprzyjające zdrowiu jednostki* [Personal and social resourses conductive to the individual's health] (pp. 9-16). Łódź, Poland: University of Łódź Press.

Kawczyńska-Butrym, Z. (2008). *Wyzwania rodziny: zdrowie, choroba, niepełnosprawność, starość* [Family challenges: Health, illness, disability, oldage]. Lublin, Poland: Wydawnictwo Makmed.

Kenneson, A., & Bobo, J. (2010). The effect of caregiving on women in families with Duchenne/Becker muscular dystrophy. *Health and Social Care in the Community, 18*, 520-528.

Kózka, M., Wojtan, S., & Woźniak, E. (2011). Funkcjonowanie psychospołeczne opiekunów osób wentylowanych mechanicznie w domu [The psychosocial functioning of caregivers of home mechanically ventilated people]. *Problemy Pielęgniarstwa, 19*(2), 185-193.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping.* New York, NY, US: Springer Publishing.

Lanken, P. N., Terry, P. B., DeLisser, H. M., Fahy, B. F., Hansen-Flaschen, J., Heffner, J. E., Levy, M., & Yankaskas, J. R. (2008). An official American Thoracic Society clinical policy statement: Palliative care for patients with respiratory diseases and critical illnesses. *American Journal of Respiratory and Critical Care Medicine, 177*(8), 912-927.

Leow, M. Q., Chan, M. F., & Chan, S. W. (2014). Predictors of change in quality of life of family caregivers of patients near the end of life with advanced cancer. *Cancer Nursing, 37*(5), 391-400.

Maghout-Juratli, S., Janisse, J., Schwartz, J., & Arnetz, B. (2010). The causal role of fatigue in the stress-perceived health relationship: A MetroNet study. *Journal of the American Board of Family Medicine, 23*(2), 212-219.

Masters, K. S. (2008). Mechanisms in the relation between religion and health with emphasis on cardiovascular reactivity to stress. *Research in the Social Scientific Study of Religion, 19,* 91-116.

McClain, C. S., Rosenfeld, B., & Breitbart, W. (2003). Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. *Lancet, 361,* 1603-1607.

McKeown, L., Porter-Armstrong, A., & Baxter, G. (2003). The needs and experiences of caregivers of individuals with multiple sclerosis: A systematic review. *Clinical Rehabilitation, 17,* 234-248.

Moberg, D. O. (1984). Spiritual well-being: Background and issues. *Review of Religious Research, 25*(4), 351-364.

Pagnini, F., Banfi, P., Lunetta, C., Rossi, G., Castelnuovo, G., Marconi, A., . . . Molinari, E. (2012). Respiratory function of people with amyotrophic lateral sclerosis and caregiver distress level: A correlational study. *Biopsychosocial Medicine, 6*(1), 14-18.

Pagnini, F., Lunetta, Ch., Rossi, G., Paolo, B., Gomi, K., Cellotto, N., Castelnuovo, G., Molinari, E., & Corbo, M. (2011). Existential well-being and spirituality of individuals with amyotrophic lateral sclerosis is related to psychological well-being of their caregivers. *Amyotrophic Lateral Sclerosis, 12*(2), 105-108.

Pagnini, F., Rossi, G., Lunetta, C., Banfi, P., Castelnuovo, G., Corbo, M., & Molinari, E. (2010). Burden, depression, and anxiety in caregivers of people with amyotrophic lateral sclerosis. *Psychology, Health & Medicine, 15*(6), 685-693.

Park, C. L., Sacco, S. J., & Edmondson, D. (2012). Expanding coping goodness-of-fit: Religious coping, health locus of control, and depressed affect in heart failure patients. *Anxiety, Stress & Coping, 25*(2), 137-153.

Rabins, P. V., Fitting, M. D., Eastham, J., & Fetting, J. (1990). The emotional impact of caring for the chronically ill. *Psychosomatics, 31*(3), 331-336.

Roach, A. R., Averill, A. J., Segerstrom, S. C., & Kasarskis, E. J. (2009). The dynamics of quality of life in ALS patients and caregivers. *Annals of Behavioral Medicine, 37,* 197-206.

Salins, N., Deodhar, J., & Muckaden, M. A. (2016). Intensive care unit death and factors influencing family satisfaction of Intensive Care Unit care. *Indian Journal of Critical Care Medicine, 20,* 97-103.

Schwarzer, R., Knoll, N., & Rieckmann, N. (2004). Social support. In A. Kaptein & J. Weinman (Eds.), *Health psychology* (pp. 158-182). Oxford, UK: Blackwell.

Sęk, H. (2012). Rola wsparcia społecznego w sytuacjach stresu życiowego. O dopasowaniu wsparcia do wydarzeń stresowych [The role of social support in stressful life situations]. In H. Sęk & R. Cieślak (Eds.), *Wsparcie społeczne, stres i zdrowie* [Social support, stress, and health] (pp. 49-67). Warsaw, Poland: Wydawnictwo Naukowe PWN.

Sęk, H., & Cieślak, R. (2012). Wsparcie społeczne – sposoby definiowania, rodzaje i źródła wsparcia, wybrane koncepcje teoretyczne [Social support: Ways of defining, types and sources of support, selected theoretical conceptions]. In: H. Sęk & R. Cieślak (Eds.), *Wsparcie społeczne, stres i zdrowie* [Social support, stress, and health] (pp. 11-28). Warsaw, Poland: Wydawnictwo Naukowe PWN.

Simonds, A. K. (2003). Home ventilation. *European Respiratory Journal, 22*, 38-46.

Soltysiak, B., Gardiner, P., & Skirton, H. (2008). Exploring supportive care for individuals affected by Huntington's disease and their family caregivers in a community setting. *Journal of Clinical Nursing, 17*(7B), 226-234.

Sołtys, M. (2016). *Prace nad polską adaptacją Duchowego Wskaźnika Dobrostanu. Raport z badań* [Work on the Polish adaptation of the Spiritual Index of Well-Being: A research report]. Bydgoszcz, Poland: Unpublished materials.

Stajduhar, K. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care, 19*, 27-35.

Stodulska, M., & Biłogan, L. (2016).Wybrane aspekty jakości życia chorych wentylowanych mechanicznie w warunkach domowych oraz ich opiekunów [Selected aspects of the quality of life of home mechanically ventilated patients and their caregivers]. *Nursing in Anaesthesiology & Intensive Care, 2*(2), 33-40.

Suh, M. H., & Oh, K. S. (1993). A study of well-being in caregivers caring for chronically ill family members. *The Journal of Nurses Academic Society, 23*(3), 467-486.

Szatkowska, K., & Szkulmowski, Z. (in press). Zmęczenie życiem codziennym a strategie radzenia sobie ze stresem opiekunów osób wentylowanych mechanicznie w domu [Daily life fatigue and stresscoping strategies in caregivers of home mechanically ventilated people]. *Medycyna Paliatywna w Praktyce.*

Szkulmowski, Z. (2016). Szczególne problemy wentylacji w domu chorego [Special problems of patient ventilation at home]. In D. Maciejewski & K. Wojnar-Gruszka (Eds.), *Wentylacja mechaniczna – teoria i praktyka* [Mechanical ventilation: Theory and practice] (pp. 533-583). Bielsko-Biała, Poland: Alfa Medica.

Śliwiński, P., Górecka, D., Jassem, E., & Pierzchała, W. (2014). Zalecenia Polskiego Towarzystwa Chorób Płuc dotyczące rozpoznawania i leczenia przewlekłej obturacyjnej choroby płuc [Recommendations of the Polish Lung Disease Society concerning the diagnosis and treatment of chronic obturatory lungdisease]. *Pneumonologia i Alergologia Polska, 82*(3), 227-263.

Taylor, E. J. (2003). Spiritual needs of patients with cancer and family caregivers. *Cancer Nursing, 26*, 260-266.

Thomas, P., Rajaram, P., & Nalini, A. (2014). Psychosocial challenges in family caregiving with children suffering from Duchenne muscular dystrophy. *Health & Social Work, 39*, 144-152.

Tzu-Ting, H., & Ji-Ming, P. (2010). Role adaptation of family caregivers for ventilator-dependent patients: Transition from respiratory care ward to home. *Journal of Clinical Nursing, 19*, 1686-1694.

Urbańska, J. (2010). *Zmęczenie życiem codziennym. Środowiskowe i zdrowotne uwarunkowania oraz możliwości redukcji w sanatorium* [Daily life fatigue: Environmental and health determinants and the possibilities of reduction in a sanatorium]. Poznań, Poland: Faculty of Social Sciences Press, Adam Mickiewicz University.

Verbakel, E., Metzelthin, S. F., Gertrudis, I. J., & Kempen, M. (2016). Caregiving to older adults: Determinants of informal caregivers' subjective well-being and formal and informal support as alleviating conditions. *Journals of Gerontology: Social Sciences*, Series B, 1-13.

Weaver, A. J., & Flannelly, K. J. (2004). The role of religion/spirituality for cancer patients and their caregivers. *Southern Medical Journal, 97*(12), 1210-1214.

Windisch, W., Walterspacher, S., Siemon, K., Geiseler, J., & Sitter, H. (2010). Guidelines for non--invasive and invasive mechanical ventilation for treatment of chronic respiratory failure. *Pneumologie, 64*, 640-652.

Woźniewicz, A., & Basińska, M. A. (2014). Charakterystyka zmęczenia życiem codziennym opiekunów osób z paraplegią ze względu na zmienne społeczno-demograficzne i bytowe [The characteristics of daily life fatigue in caregivers of patients with paraplegia according to sociodemographic and standard-of-living variables]. In H. Liberska, A. Malina, & D. Suwalska-Barancewicz (Eds.), *Współcześni ludzie wobec wyzwań i zagrożeń XXI wieku* [Contemporary people in the face of 21st century challenges and threats] (pp. 231-243). Warsaw, Poland: Difin.

Woźniewicz, A., Kalinowska, J., Basińska, M. A., & Pietrulewicz, B. (2014). Personal resources and daily life fatigue in caregivers of persons with paraplegia. *Polish Journal of Applied Psychology, 12*(4), 29-40.

Wright, S. D., Pratt, C. C., & Schmall, V. L. (1985). Spiritual support for caregivers of dementia patients. *Journal of Religion and Health, 24*(1), 31-38.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates offeelings of burden. *The Gerontologists, 20*(6), 649-655.

The preparation of the English version of *Roczniki Psychologiczne* (Annals of Psychology) and its publication in electronic databases was financed under contract no. 753/P-DUN/2017 from the resources of the Minister of Science and Higher Education for the popularization of science.