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Citation style: Wojtyna Ewa, Popiołek Katarzyna. (2012). Character of the relationship with Alzheimer patient and the psychological costs of care. "Polish Psychological Bulletin" (Vol. 43, no. 4, (2012), s. 244-252), doi 10.2478/v10059-012-0027-0



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Character of the relationship with Alzheimer patient and the psychological costs of care.

Abstract: *Alzheimer's disease is the most common form of dementia. The aim of this study was to determine the dependence between the quality of the caregiver-patient relationship and the psychological costs the caregiver bears during the caregiving period. This study encompassed 292 caregivers (104 partners, 117 children and 71 friends or others persons).*

The study indicated the greatest level of depression and caregiving-related burdens in the spouses group, and the least in the friends/others group. The most important predictor of the level of burden in the caregiving role turned out to be the nature of the caregiver-patient relationship; however, a varying set of the significance of individual elements of this relationship were indicated in different caregiver groups.

Keywords: *Alzheimer's disease, burnout, caregiver burden, depression*

Alzheimer's disease (AD) is the most common type of dementia and although its main symptom indicates cognitive impairment, the most inconvenient ones are the accompanying behavioural disturbances (e.g. Lanctôt, Herrmann, Rothenburg, & Eyravec, 2007; Parnowski, 2010). As the disease progresses patients begin to manifest aggressive behaviour, have reversed sleeping-waking rhythm, brood, have bladder and bowel incontinence, and/or pose a threat in their dwellings by turning on water or gas. They require increasingly more assistance when performing the most common activities of daily life such as dressing, bathing or feeding. Not infrequently, the disease's advancement is associated with disinhibition exhibited by sexual hyperactivity and idiosyncratic, offensive behaviour matched with a complete lack of criticism towards these activities (e.g. Cummings & Zhong, 2006; Parnowski, 2010).

As the population ages, more and more Alzheimer's disease cases are reported. It is estimated that by 2050 AD will affect between 11 and 16 million people (Thies & Bleiler, 2012). Despite this fact, support in caregiving for the patient continues to be insufficient and the main burden is placed on the closest relatives or friends (e.g. Bień, Wojszel, Wilmańska, & Sienkiewicz, 2001; Parnowski, 2010). The

problems of caregiving are generally recognized by society, but they are usually associated with organizational issues such as ensuring safe conditions for the patient and their environment or nursing care. Societal attention may also focus on financial or time-related strains, necessity-driven modifications to lifestyle or overload resulting from difficult contact with the patient as the process of psychophysical deterioration progresses (e.g. Parnowski, 2010).

What is less apparent to the casual observer are the psychological costs borne by the caregiver. Their lives are marked with significant changes concerning family relationships and social life. Lack of free time and rest result in loss of friends, giving up one's interests and loneliness. It entails a loss of control over one's time, the inability to engage in external activities and low self-esteem. The patient's impaired condition and degradation of the personality of the patient, as well as the lack of prospects for improvement cause frustration, anger, embarrassment and a sense of guilt in the caregiver. The caregivers of AD patients rarely have the possibility to rest so fatigue, exhaustion, sadness and grief develop over time (e.g. Kłoszewska, Szafranec, & Sobów, 2000; Raś & Opala, 2001).

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Exposure to long-term stress and negative emotions affects the immune system by causing hyp immunity (e.g. Raś & Opala, 2001). Over 40% of caregivers of AD patients report clinical depression (cf. Croog, Burleson, Sudilovsky, & Baume, 2006; Mausbach et al., 2012; Raś & Opala, 2001), a several times higher incidence of cardiovascular diseases, premature death and increased mortality in comparison with a population not suffering a similar type of long-term stress. These consequences have been measured many times and their scale is quite well known (e.g. Mausbach et al., 2012).

Less research, however, has been carried out on the psychological costs associated with the transposition of roles in close relationships with the Alzheimer's patient, a specific process of loss which can be defined as untimely long-term mourning, a change of social status and life balance of the spouse as well as problems generated by cultural norms and social expectations.

It seems reasonable to assume that the character and level of caregiving costs depend largely on the closeness with the patient, common pre-onset experiences, the emotional bond and a sense of loss. Emotional bonding has rarely been the subject of study within the area of issues regarding the costs of caregiving for Alzheimer's patients, and the results of such studies show the complex nature of relationships as well as the need for further research

(Fauth et al., 2012). The study presented in this article has therefore been devoted to this issue.

Purpose of the study

The purpose of this study was to define the correlation between the psychophysical functioning of the patient diagnosed with Alzheimer's type dementia, the quality of caregiver-sufferer relations and the psychological costs borne by the caregiver. Furthermore, an attempt was made to identify the predictors of caregiving burnout in spouses, children and others.

Material and methods

The design is a cross-sectional study.

Participants

292 caregivers of patients suffering from Alzheimer's type dementia participated in the study, including 195 women (66.8%) and 97 men (33.2%). The prerequisite of participation was the duration of caregiving – at least one year. The participants formed three groups: 104 caregivers were life partners of the patient (marriage or steady, informal relationship), 117 were the patient's children and 71 – close friends ($n=46$) or distant relatives (grandchildren, nephews, sibling; $n=25$). The socio-demographic characteristics of the group are presented in Table 1.

Table 1 Socio-demographic characteristics of the caregivers of patients with Alzheimer's disease.

Caregivers (N=292)	Spouses (N=104)	Children (N=117)	Others (N=71)
Gender [n(%)]			
Male	43 (41.35)	31 (26.5)	23 (32.4)
Female	61 (58.65)	86 (73.5)	48 (67.6)
Age [years]			
Mean (SD)	70.31 (9.01)	49.85 (6.67)	47.75 (11.97)
Range	55-83	37-64	28-67
Marital status [n(%)]			
Married	104 (100.0)	81 (69.23)	41 (57.75)
Widowed	-	9 (7.69)	11 (15.49)
Single	-	19 (16.24)	15 (21.13)
Divorced	-	8 (6.84)	4 (5.63)
Level of education [n(%)]			
Primary school	22 (21.15)	2 (1.71)	1 (1.41)
Vocational school	49 (47.11)	28 (23.93)	13 (18.31)
Secondary school	23 (22.12)	48 (41.03)	36 (50.70)
University	10 (9.62)	39 (33.33)	21 (29.58)
Living with patient [n(%)]			
Yes	104 (100.0)	61 (52.14)	10 (14.08)
Sole caregiver [n(%)]			
Yes	89 (85.56)	84 (71.79)	48 (67.6)
Employment status [n(%)]			
Working	6 (5.77)	76 (64.96)	41 (57.75)

Measuring tool

Sufferer's functional status

In order to characterize the functional status of the sufferer, Mini-Mental State Examination (MMSE) and The Katz Index of Independence in Activities of Daily Living (ADL) were used. The first tool measures the level of cognitive impairment of the patient (Folstein, Folstein, & McHugh, 1975) and the second assesses the patient's level of independence in performing basic daily activities such as bathing, dressing or feeding (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963). In both instruments a higher score corresponds to a better functional status. While MMSE was carried out by one of the authors of the article, the ADL scale was filled in by the patient's caregiver.

Depression

In order to measure the level of depression in caregivers The Beck Depression Inventory (Beck, Steer, & Brown, 1996; Beck, Steer, & Garbin, 1988) was used. The higher the score, the stronger is the manifestation of depression symptoms. Cronbach's alpha coefficient of reliability for the BDI obtained in our study equals 0.91.

Caregiver Burden

To measure caregiver burnout the Caregiver Burden/Burnout Inventory (CBBI), designed for the purpose of the study, was used. The tool is based on C. Maslach's concept of job burnout (Maslach, 2004). It comprises 20 statements concerning burnout symptoms in the role of caregiver of patients with dementia. The tool indicates the general intensity of burnout and assesses three components itemized on the basis of the factor analysis: Emotional exhaustion (8 items), Depersonalization of the sufferer (5 items) and Self-esteem and personal accomplishment (7 items). On the subscales of Emotional exhaustion and Depersonalization a higher score indicates a higher degree of caregiver burnout and conversely, on the scale of Self-esteem and personal accomplishment a high score corresponds to a low degree of burnout. Cronbach's alpha coefficient of reliability, obtained in our study, equals 0.95, and ranges from 0.87 for the subscale of Self-esteem and personal accomplishment to 0.98 for the subscale of Depersonalization.

Emotional bond

In order to assess the caregiver-patient emotional bond, the participants answered three questions: 1) *How strong is your emotional bond with the sufferer?* (on a scale 0-10; 0 meaning no emotional bond, 10 indicating a strong one); 2) *What are your experiences with the sufferer from the pre-onset time?* (on a 0-10 scale; 0 means very negative and 10 - very positive); 3) *Do you feel a sense of loss associated with the deteriorating condition of the sufferer?* (on a 0-10 scale; 0 means no sense of loss and 10 corresponds to a very severe sense of loss).

Results

In all the groups - spouses (and steady relationships, falling under the same category as spouses), children and others, it is women who are the primary caregiver (cf. Table 1). The highest percentage of male caregivers is observed in the group of spouses - 41.35% and in the group of children, sons account for only 26.5%. No statistically significant variation was noted between the average age of children and others.

In the group of married children (69.23%), well-educated professionals were predominant. Similarly, in the group of others there were mainly Secondary School or University graduates, but with lower rates of employment than child caregivers. Furthermore 42.25% of others did not have a long-term relationship. In the group of spouse caregivers only 6 individuals (5.77%) were employed; the rest were retired or used disability benefits.

While all the spouses co-resided with the Alzheimer's sufferer, in the remaining groups the percentage of caregivers residing with the patient accounted for 52%, and 14% of the groups of children and others, respectively. In the group of others the co-residents were mainly grandchildren and in two cases - close friends.

The vast majority of caregivers looked after the patient single-handedly, without support from anyone else. The group of others reported quite a high rate of support offered, with 32.4% receiving help from other people caring for the patient.

No variation was noted as regards psychophysical functioning or duration of the disease in patients cared for by individuals belonging to different groups (Table 2).

Significant differences, on the other hand, were observed in the factors associated with the role of caregiver. Spouses spent the most time on caregiving activities, 17h/d on average, including night time care, which often resulted in disruptive sleep. Children and others spent much less time with the patient (on average 6-7h less). The highest degree of depression and burnout in each dimension (only in Self-esteem and personal accomplishment was it comparable to children) was reported in spouse caregivers, while in others the exposure to those psychological costs was the lowest.

With regard to the assessment of the caregiver-patient relationship, spouses declared the strongest emotional bond and the most severe sense of loss and child-caregivers reported the most positive experiences with the sufferer. By analyzing the results for caregivers residing with the patient and those living elsewhere it was found that the sense of loss and depersonalization of the sufferer were significantly more severe in the latter group ($U=-2.75$; $p<0.05$; Cohen's $d=0.34$).

The analysis of data regarding the level of caregiver burnout with respect to caregiver's and patient's gender revealed a few significant results. Wife caregivers reported a higher level of emotional exhaustion ($U=-2.10$; $p<0.05$;

Table 2 Clinical factors for caregivers and patients (ANOVA and Scheffe test)

Factors	Spouses <i>n</i> =104		Children <i>n</i> =117		Others <i>n</i> =71		<i>F</i>	Differences
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>		
Caregiver:								
Time spent caring (h/day)	17.08	7.27	11.15	10.14	9.88	9.32	17.39***	S > (Ch = O)
Depression	16.31	9.43	8.89	6.85	3.13	2.61	35.90***	S > Ch > O
Caregiver-patient relationship								
Emotional bond	8.85	0.72	7.48	0.98	7.50	0.51	3.83*	S > (Ch = O)
Positive experiences	7.08	0.93	7.62	0.79	7.13	1.29	4.96**	Ch > (S = O)
Sense of loss	8.89	0.88	8.04	1.09	6.16	1.17	10.54***	S > Ch > O
Caregiver burden								
Emotional exhaustion	13.54	5.57	10.02	6.46	6.86	4.82	12.17***	S > Ch > O
Depersonalization of sufferer	3.92	0.94	2.41	0.57	2.04	0.90	4.77**	S > Ch > O
Self-esteem and personal accomplishment	10.08	3.46	10.67	4.05	15.63	4.28	6.42**	O > (S = Ch)
Patient:								
Time since onset [months]	33.08	21.02	31.78	28.38	29.13	13.84	2.80	No differences
Cognitive impairment (MMSE)	11.62	7.57	11.89	5.45	12.75	6.46	1.53	No differences
Independence (ADL)	4.08	1.66	3.94	2.06	4.25	1.81	1.21	No differences

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; S – spouses; Ch – children; O – others caregivers

$d = 0.43$) and depersonalization ($U = -3.45$; $p < 0.01$; $d = 0.47$), compared with husband caregivers; conversely, in the group of children caregiving for a mother-patient (regardless of caregiver's gender) meant a higher degree of depersonalization ($U = -2.05$; $p < 0.05$; $d = 0.39$).

As for spouse caregivers, while the level of burnout in the dimension of depersonalization increased with the duration of care ($r = 0.44$; $p < 0.001$), increased time of daily care corresponded only to the levels of emotional exhaustion ($r = 0.38$; $p < 0.01$) and depression ($r = 0.44$; $p < 0.001$).

Child caregivers reported an intensification of burnout symptoms as the time of daily care grew, the most apparent being an increase in depersonalization ($r = 0.39$; $p < 0.001$) and a decrease in self-esteem and personal accomplishment ($r = 0.41$; $p < 0.001$). With respect to the duration of caregiving in the group of children, differences were observed between those who assisted the patient for less than a year ($n = 54$) and those who did so longer. In this case, the former group reported a higher degree of depersonalization ($U = -2.15$; $p < 0.05$) and emotional exhaustion ($U = -2.65$; $p < 0.01$), while the latter group displayed a bigger decrease in self-esteem and personal accomplishment ($U = -2.00$; $p < 0.05$).

On the other hand, in the group of others the growing duration of care correlated with an increase in depression ($r = 0.49$; $p < 0.001$) and emotional exhaustion ($r = 0.57$;

$p < 0.001$). Moreover, the tendency for depersonalization of the sufferer increased in the group with the growing time of daily care ($r = 0.32$; $p < 0.01$), similarly to child caregivers. At the same time, the group of others, unlike the remaining two, reported an increase in self-esteem and personal accomplishment as the time of daily care for the patient extended ($r = 0.67$; $p < 0.001$).

A lower level of independence of the sufferer (measured on ADL scale, where a high score corresponds to a higher level of independence) related to a higher degree of depression in spouses ($r = -0.21$; $p < 0.05$), and in children - a greater tendency for depersonalization ($r = -0.25$; $p < 0.01$) and a larger decrease in self-esteem and personal accomplishment ($r = 0.15$; $p < 0.05$). In the group of others, apart from a weak negative correlation between independence of the patient and self-esteem and personal accomplishment ($r = -0.16$; $p < 0.05$), no other significant correlations between the patient's independence and caregiver's burnout were observed.

In order to specify the arrangement of the predictors of psychological costs – depression and burnout – borne by the caregiver, a multiple regression analysis was conducted. The conclusions are presented in Tables 3-6.

The analysis of the results shows a different arrangement of predictors of individual caregiving costs in the itemized groups of caregivers.

Table 3. Predictors of emotional exhaustion in the caregivers of patients with Alzheimer's disease (multivariate linear regression model)

Factors	Spouses (n=104)		Children (n=117)		Others (n=71)	
	adj.R ² =0.59		adj.R ² =0.30		adj.R ² =0.58	
	β	ΔR^2	β	ΔR^2	β	ΔR^2
Caregiver-patient relationship						
Emotional bond	-		-0.27**		-	
Positive experiences	-0.44***	0.54	-0.56***	0.30	-0.17*	0.47
Sense of loss	0.39***		-		0.61***	
Sufferer functional status						
Cognitive (MMSE)	-	-	-	-	-	-
Independence (ADL)	-		-		-	
Care						
Time in months	-	0.05	-	-	0.55***	0.11
Time h/d	0.26*		-		-	

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; adj.R² - adjusted R²

Table 4. Predictors of depersonalization in the caregivers of patients with Alzheimer's disease (multivariate linear regression model)

Factors	Spouses (n=104)		Children (n=117)		Others (n=71)	
	adj.R ² =0.68		adj.R ² =0.32		adj.R ² =0.61	
	β	ΔR^2	β	ΔR^2	β	ΔR^2
Caregiver-patient relationship						
Emotional bond	-0.44***		-0.20*		-	
Positive experiences	-0.46***	0.51	-0.29**	0.20	-0.57***	0.24
Sense of loss	0.22*		-		-	
Sufferer functional status						
Cognitive (MMSE)	-0.18*	0.14	-	0.09	-	0.22
Independence (ADL)	-0.42***		0.26**		-0.17*	
Care						
Time in months	0.27**	0.03	-	0.03	-	0.15
Time h/d	-		-0.21*		0.49***	

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; adj.R² - adjusted R²

Table 5. Predictors of self-esteem and personal accomplishment in the caregivers of patients with Alzheimer's disease (multivariate linear regression model)

Factors	Spouses (n=104)		Children (n=117)		Others (n=71)	
	adj.R ² =0.52		adj.R ² =0.49		adj.R ² =0.67	
	β	ΔR^2	β	ΔR^2	β	ΔR^2
Caregiver-patient relationship						
Emotional bond	-		0.24**		0.50***	
Positive experiences	0.46***	0.52	0.48***	0.42	-	0.48
Sense of loss	-0.42***		-		-0.19*	
Sufferer functional status						
Cognitive (MMSE)	-	-	-	0.05	-	0.12
Independence (ADL)	-		-0.19*		-0.18*	
Care						
Time in months	-	-	-	0.02	-0.23*	0.07
Time h/d	-		0.19*		0.34**	

Notes: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; adj.R² - adjusted R²

For emotional exhaustion (Table 3) the factors introduced into the model explain from 30% (for child caregivers) to 59% (for spouse caregivers) of the variance.

In all the itemized groups of caregivers, the character of caregiver-patient relationship is the biggest contributory factor in explaining the variance of emotional exhaustion. In children the factor accounts for the total variance (30%) explained in this model, and positive experiences ($\beta=-0.56$; $p<0.001$) and emotional bond ($\beta=-0.27$; $p<0.01$) are found to be the two components of this interdependence. Fewer positive experiences and a weaker emotional bond correspond to more severe symptoms of emotional exhaustion in child caregivers.

In the remaining two groups positive experiences also constitute a protective factor against symptoms of exhaustion, however emotional bond is not of special significance. What becomes an important risk factor is the sense of loss. It is also observed that in spouses the growth of emotional exhaustion corresponds to a growing time of daily care (but the factor explains only 5% of the variance of exhaustion), and in others there is a strong correlation between exhaustion and the total duration of care ($\beta=0.55$; $p<0.001$).

In all the groups factors relating to physical and cognitive functioning of the patient were found to have no significance as exhaustion risk factors.

As regards depersonalization of the patient the model explains from 32% to 68% of the variance, and, similar to emotional exhaustion, the factors connected with the caregiver-patient relationship contribute the most to explaining this variance (Table 4).

In spouses the tendency for depersonalization increases with fewer positive experiences ($\beta=-0.46$; $p<0.001$), a weaker emotional bond ($\beta=-0.44$; $p<0.001$), a lower level of independence of the patient ($\beta=-0.42$; $p<0.001$) and, to a lesser degree, with a longer total duration of care, a greater

sense of loss and more distinct cognitive deficits of the sufferer.

In children depersonalization grows with fewer positive experiences ($\beta=-0.29$; $p<0.01$), a weaker emotional bond ($\beta=-0.20$; $p<0.05$) and, what is interesting to note, a shorter time of daily care ($\beta=-0.21$; $p<0.05$) and a higher level of independence of the patient ($\beta=0.26$; $p<0.01$).

As regards self-esteem and personal accomplishment (Table 5) the model explains from 49% to 67% of the variance.

Again, the most powerful predictors are the factors connected with the caregiver-patient relationship. In the group of spouses these factors, especially positive experiences ($\beta=0.46$; $p<0.001$) and a sense of loss ($\beta=-0.42$; $p<0.001$) explain the total variance in the study ($adj.R^2=0.52$). In child caregivers the most significant predictors of increased self-esteem and personal accomplishment were positive experiences and a strong emotional bond with the sufferer (49% of the variance). The factors connected with the progression of dementia and the duration of care explained only 7% of the variance, jointly. In the group of others the strongest predictors of a high level of self-esteem and personal accomplishment were their emotional bond with the sufferer ($\beta=0.50$; $p<0.001$), a longer time of daily care ($\beta=0.34$; $p<0.01$) and, to a lesser degree, a shorter duration of care, a weaker sense of loss and a lower level of independence of the patient.

The variance of depression in caregivers (Table 6) was explained in 21-42 percent of the group.

In others, the total duration of care ($adj.R^2=0.21$; $\beta=0.48$; $p<0.001$) was found to be the only significant risk factor. In child caregivers the duration of care is also a significant risk factor, but it explains only 8% of the variance of low spirits. On the other hand, factors associated with the progression of the disease explain 19% of the variance. A higher level of cognitive impairment and a lower level of independence

Table 6. Predictors of depression in caregivers of patients with Alzheimer's disease (multivariate linear regression model)

Factors	Spouses (n=104)		Children (n=117)		Others (n=71)	
	<i>adj.R</i> ² =0.42		<i>adj.R</i> ² =0.27		<i>adj.R</i> ² =0.21	
	β	ΔR^2	β	ΔR^2	β	ΔR^2
Caregiver-patient relationship						
Emotional bond	-	0.33	-	-	-	-
Positive experiences	-		-		-	
Sense of loss	0.59***		-		-	
Sufferer functional status						
Cognitive (MMSE)	-	0.05	-0.36**	0.19	-	-
Independence (ADL)	-0.23*		-0.22*		-	
Care						
Time in months	-	0.04	0.12*	0.08	0.48**	0.21
Time h/d	0.25**		-		-	

Notes: * $p<0.05$; ** $p<0.01$; *** $p<0.001$; *adj.R*² - adjusted *R*²

of the sufferer correlate with more severe symptoms of depression in the caregiver. In spouses, (42% of the variance) depression increases with a growing sense of loss ($adj.R^2=0.33$; $\beta=0.59$, $p<0.001$), an extended time of daily care and a lower level of independence of the patient.

Discussion

The results of the study indicate the highest level of caregiver burnout in the group of spouses, a somewhat lower level in children and the lowest in the group of others. The data is consistent with the results of other studies (e.g. Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010).

The predictors of emotional exhaustion, depersonalization of the sufferer and self-esteem and personal accomplishment applied in the model enable a more subtle identification of probable sources of this difference. They are mainly located in the interrelation of roles binding the individual groups of caregivers to the sufferer and the significance of changes within this interrelation (cf. Kubacka-Jasiecka, 2002).

Marriage is characterized by the greatest complexity of the interrelation of these roles. The pre-onset life of the caregiver, which was a set of complementary behavior patterns and defined roles in a dyad, is now in ruins and it is necessary to build a new relation, by definition – unstable and temporary. The sufferer becomes unpredictable and is no longer able to fulfill spousal roles and obligations or share daily chores, so all the burden falls on the shoulders of the caregiver. The satisfactory mutual functioning of partners relates greatly to the quality of marriage. It concerns both occasional acts in difficult situations as well as a permanent function of maintaining the well-being of the partner, being always kind and considerate, offering reassurance. The patient with Alzheimer's disease fails to play such a supporting role in the relationship; just the opposite, becomes a source of concern and worry for the spouse and generates strong, negative emotions resulting from difficulty in communication. The sufferer can no longer be a stimulating partner in everyday life so the caregiver may feel lonesome and deprived of their original role and its privileges. Earlier, they had a sense of safety and love – and such was their perception of their environment. Presently, they have become stripped of it all and, what is more, become an object of compassion.

The demand for engagement in supportive activities which are an inherent part of the caregiver's role often triggers off a state of reactance – a compulsion that limits the sense of freedom. The price for winning societal approval and having satisfaction for fulfilling the caregiving role is incredibly high. In order to be well-perceived, caregivers have to abandon their goals for the sake of dedicated care, because otherwise, they can be stigmatized as bad and heartless (cf. Wirga & Wojtyna, 2010). That is why their manifestation of pain and heroic self-sacrifice with regards

to the patient are reinforced by the factor of societal approval. Yet it has been found that meditating on one's loss and focusing on a negative affect lead to the strengthening of non-adaptive coping strategies (por. Stroebe et al., 2007; Shear et al., 2007).

Furthermore, focusing solely on the sufferer deprives the caregiver of other roles – as a person who likes to socialize, is successful and engages actively in the local community, which additionally undermines self-judgement (e.g. Ott, Sanders, & Kelber, 2007; Rinaldi et al., 2005; Sanders & Adams, 2005; Sanders, Ott, Kelber, & Noonan, 2008).

Subsequent stages of the disease continually bring adverse changes in behavioural patterns of the spouse. The cherished spouse is still present, but their previous identity disintegrates gradually, as if they were present and absent at the same time. However, the distress of losing the pre-onset partner cannot be expressed, as the sufferer is still alive. Therefore, the most subjective emotions are concealed, as contradictory to the culturally-accepted pattern of reactions relating to the illness of a close person.

The emotional bond with the sufferer is largely based on positive experiences from the pre-onset time, therefore it is not surprising that they are found to be an essential predictor – a protective factor against caregiver's burnout (cf. Raś & Opala, 2001). However, as the study shows, the caregiver's present life is dominated by a sense of loss and it is this manifold sense of loss that becomes the predictor of depression in this group of caregivers.

The status quo is different for child caregivers. In most cases the children of Alzheimer's patients live separately and their everyday reality centres around functioning in a procreative family. As a result, the emotional bond with the parents weakens and relations become more casual. The change of roles is associated mainly with shifting from the position of being taken care of to the position of being the caregiver. It entails facing challenges of being authoritative and in charge of a person who has so far occupied a higher position in the family hierarchy. This change proves to be the most painful in the first year of caregiving, demanding from the caregiver the greatest effort to adapt. Within this period most evident is also the strongest tendency towards depersonalization of the patient. When the change is finally made, relations with the parent stabilize. That is why child caregivers with a longer duration of care may show a weaker tendency towards depersonalization. The stabilization of the radically altered relationship with the parent can explain the lack of a predictor of a sense of loss for all the costs of caregiving.

Caregiving for the sufferer, although absorbing and strenuous, gives the child a chance to reward the parent for their own upbringing. The relationship with the patient is based on a long-lasting emotional bond and positive experiences from childhood. It corresponds to the results of the study which indicate a lower level of caregiving burden

in the case of numerous positive experiences with the patient from the time prior to the onset. It can also explain the seemingly paradoxical result that shows a weaker tendency towards depersonalization as the level of the patient's dependence grows. The rewarding, as numerous empirical sources quote (e.g. Wood, Joseph and Linley, 2007), fosters well-being, positive re-interpretation and growth as well as more active ways of coping with stress. At the same time it protects against a decrease in engagement, self-blame, embarrassment, avoidance (understood as a protective mechanism) and psychoactive substance abuse. The need to reward is therefore a construct worth further study in the context of the burden of caregiving for the patient with Alzheimer's disease.

The average age of adult-child caregivers was 50. It is a time of the so-called middle age crisis, and so the deteriorating psychophysical condition of the parent can arouse fears of one's own aging and disability, reinforced by the risk factor for Alzheimer's disease (cf. Witusik & Pietras, 2007). This can explain the predictive force of the factors associated with psychophysical functioning of the sufferer for the level of depression in child caregivers.

In the group of others, including mainly friends and distant relatives, relations with the patient manifested themselves through occasional rather than regular contact, which is the case for spouses and children. The relationship between the sufferer and others can be defined as friendly and based on mutual emotions. Such individuals make the decision about caregiving independently, as a goodwill gesture, which means they don't act under compulsion. The sense of loss in this case is caused by the fact that their friend has abandoned their old role. However, positive past experiences help the caregiver to achieve satisfaction from performing friendship duties, which enhances their self-esteem and personal accomplishment. That is why this group not only reports the lowest costs but even some benefits of caregiving. Numerous positive experiences characteristic for friendship (otherwise it is discontinued) protect the caregiver mainly against demeaning treatment of the patient and, to a lesser extent, against emotional exhaustion during the course of care.

The study also showed differences in caregiving burden according to the patient's and caregiver's gender. In the group of spouses female patients generated lower costs for the caregiver than male patients. Conversely, in the group of child caregivers looking after the mother was associated with a stronger tendency towards depersonalization. The data is consistent with the results of other studies (e.g. Conde-Sala et al., 2010). With respect to spouses, the explanation can be found in the deeply rooted stereotypes concerning male and female roles as well as different standards of care that men and women endeavor to fulfill (e.g. Oleksy, 1995). The stereotype of a male role (internalized in childhood) makes it easier to take over the burden of caregiving, especially in the sphere of providing for the family, being the decision-

maker. On the other hand, the standard of caregiving role assumed by women involves numerous obligations, increasingly difficult to meet as the disease progresses and the caregiver's resources shrink with age. As a result, women feel the burden of caregiving more than men, which is accompanied by a higher level of frustration leading to depersonalization and increased emotional exhaustion.

In child caregivers a higher cost of caregiving for the mother can be related to the fact that prior to the onset it was her role to shoulder the responsibility for daily chores (stereotype of the Polish Mother; e.g. Oleksy, 1995). The necessity to take over this role and assume her position in the hierarchy of the family may increase frustration in the child caregiver and activate the protective mechanism of depersonalization.

Conclusions

The results of the study show clearly the differences in the level of psychological costs such as burnout and depression in the three itemized groups of caregivers for Alzheimer's patients. The greatest percentage of the variance of the costs was explained by factors associated with the emotional bond between the caregiver and the sufferer.

The fact that the group of spouses was found to be the most affected by the burden of care indicates the need to provide them with help. One of the most significant predictors of caregiving burnout in this group is a sense of loss. Therefore the identification of losses associated with the change in the interrelation of life roles could facilitate the effectiveness of support provided for spouse caregivers. As the results of the study indicate, positive experiences with the sufferer from the pre-onset time are an important protective factor in all the groups of caregivers. Therefore it seems reasonable to assume that refreshing and nurturing such memories could also enhance the caregiver's ability to cope with the current situation, in which negative experiences and emotions predominate.

Furthermore the significance of positive experiences with the sufferer, shown in the study, can be an indicator for professionals preparing to assist the caregiver in the strenuous task of looking after the patient. Institutional caregivers usually meet the care recipient during the stage of severe impairment. Communicating to such caregivers the knowledge about who the patient used to be, their good sides, reasons to reward them can counteract demeaning treatment of the patient, foster better patient-caregiver relations (which become a protective mechanism against exhaustion) and show the patient due respect.

Popularizing the knowledge about the scale of costs borne by the caregivers of Alzheimer's patients could help build a better and more varied network of support for these distressed people, including voluntary support. The group of supporters is still too narrow and, as the study shows, the

majority of caregivers, especially spouses and children, can only rely on themselves.

The significance of the emotional bond between the caregiver and the patient is an incentive to conduct further studies within this field. It might prove interesting to investigate the costs of duty-related and reward-related caregiving. The problem concerns mainly children of Alzheimer's patients. Another issue requiring an in-depth analysis is specifying the character of support offered to caregivers in comparison with the expected and most effective one. The results of such a study should lay the foundation for adequate supportive activities in the area of caregiving.

References

- Beck, A.T., Steer, R.A., & Brown, G.K. (1996). *Manual for the BDI-II*. San Antonio, TX: The Psychological Corporation.
- Beck, A.T., Steer, R.A., & Garbin, M.G. (1988). Psychometric properties of the Beck Depression Inventory: Twenty-five years of evaluation. *Clinical Psychology Review*, 8, 77-100.
- Bień, B., Wojszel, Z., Wilmańska, J., & Sienkiewicz, J. (2001). *Starość pod ochroną: opiekunowie rodzinni niesprawnych osób starych w Polsce: porównawcze studium środowiska miejskiego i wiejskiego*. Kraków, Białystok: Oficyna Wydawnicza Text.
- Conde-Sala, J.L., Garre-Olmo, J., Turró-Garriga, O., Vilalta-Franch, J., & López-Pousa, S. (2010). Differential features of burden between spouse and adult-child caregivers of patients with Alzheimer's disease: An exploratory comparative design. *International Journal of Nursing Studies*, 47, 1262-1273.
- Croog, S.H., Burlerson, J.A., Sudilovsky, A., & Baume, R.M. (2006). Spouse caregivers of Alzheimer patients: problem responses to caregiver burden. *Aging and Mental Health*, 10(2), 87-100.
- Cummings, J.L. & Zhong, K. (2006). Treatments for behavioural disorders in neurodegenerative diseases: drug development strategies. *Nature Reviews Drug Discovery*, 5, 64-74.
- Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tschanz, J. (2012). Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging and Mental Health*, 16(6), 699-711.
- Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- Katz, S., Ford, A.B., Moskowitz, R.W., Jackson, B.A., & Jaffe, M.W. (1963). Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychological function. *JAMA*, 185, 914-919.
- Kłozewska, I., Szafraniec, L., & Sobów, T. (2000). Wpływ zachowania osób z chorobą Alzheimera na zmiany emocjonalne u ich opiekunów. *Rocznik Psychogeriatryczny*, 3, 25-33.
- Kubacka-Jasiecka, D. (2002). Psychologia wobec problematyki zmiany. In: D. Kubacka-Jasiecka (ed.). *Człowiek wobec zmiany. Rozważania psychologiczne*. Kraków: Wydawnictwo UJ.
- Lancôt, K.L., Herrmann, N., Rothenburg, L., & Eyrave, G. (2007). Behavioral correlates of GABAergic disruption in Alzheimer's disease. *International Psychogeriatrics*, 19(1), 151-158.
- Maslach, C. (2004). Wypalenie – w perspektywie wielowymiarowej [Burnout – in a multidimensional perspective]. In: H. Sęk (ed.), *Wypalenie zawodowe. Przyczyny, mechanizmy, zapobieganie [Occupational burnout. Causes, mechanisms, prevention]* (pp.13-31). Warszawa: PWN.
- Mausbach, B.T., Chattillion, E., Roepke, S.K., Ziegler, M.G., Milic, M., von Känel, R., Dimsdale, J.E., Mills, P.J., Patterson, T.L., Allison, M.A., Ancoli-Israel, S., & Grant, I. (2012). A longitudinal analysis of the relations among stress, depressive symptoms, leisure satisfaction, and endothelial function in caregivers. *Health Psychology*, 31(4), 433-440.
- Oleksy, E.H. (1995). Selected proceedings of the Women's Studies Conference, Łódź, Poland, May 17-21. *Women's Studies International Forum*, 18(1), 3-8.
- Ott, C., Sanders, S., & Kelber, S. (2007). Differences in the grief and personal growth experience of spouses and adult children of person's with Alzheimer's disease. *The Gerontologist*, 47, 798-809.
- Parnowski, T. (ed.) (2010). *Choroba Alzheimera [Alzheimer's disease]*. Warszawa: PZWL.
- Raś, P. & Opala, G. (2001). Obciążenie opiekunów osób z otępieniem [The burden in caregivers of demented patients]. *Wiadomości Lekarskie*, 1-2, 94-99.
- Rinaldi, P., Spazzafumo, L., Mastriforti, R., Mattioli, P., Marvardi, M., Polidori, M.C., Cherubini, A., Abate, G., Bartorelli, L., Bonaiuto, S., Capurso, A., Cucinotta, D., Gallucci, M., Giordano, M., Martorelli, M., Masaraki, G., Nieddu, A., Pettenati, C., Putzu, P., Tammaro, V.A., Tomassini, P.F., Vergani, C., Senin, U., & Mecocci, P. (2005). Predictors of high level of burden and distress in caregivers of demented patients: results of an Italian multicenter study. *International Journal of Geriatric Psychiatry*, 20(2), 168-174.
- Sanders, S. & Adams, K.B. (2005). Grief reactions and depression in caregivers of individuals with Alzheimer's disease: Results from a pilot study in an urban setting. *Health and Social Work*, 30, 287-295.
- Sanders, S., Ott, C.H., Kelber, S.T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of person with Alzheimer's disease and related dementia. *Death Studies*, 32, 495-523.
- Shear, K., Monk, T., Houck, P., Melhem, N., Frank, E., Reynolds, C., & Sillowash, R. (2007). An attachment-based model of complicated grief including the role of avoidance. *European Archives of Psychiatry and Clinical Neuroscience*, 257(8), 453-461.
- Stroebe, M., Boelen, P., van den Hout, M., Stroebe, W., Salemink, E., & van den Bout, J. (2007). Ruminative coping as avoidance: A reinterpretation of its function in adjustment to bereavement. *European Archives of Psychiatry and Clinical Neuroscience*, 257(8), 462-472.
- Thies, W. & Bleiler, L. (2012). 2012 Alzheimer's disease facts and figures. *Alzheimer and Dementia*, 8(2), 131-168.
- Wirga, M. & Wojtyna, E. (2010). Udręki zdrowego umysłu. Neuropsychologia cierpienia [Suffering of healthy mind. Neuropsychology of suffering] In: J. Binnebesel, J. Bleszyński, & Z. Domżał (eds.), *Wielowymiarowość cierpienia [Many-sidedness of suffering]* (pp.31-51). Łódź: Wydawnictwo Naukowe WSEZ.
- Witusik, A. & Pietras, T. (2007). Lęk i depresja u opiekunów osób chorych na otępienie – badanie pilotażowe [Anxiety and depression among caregivers of demented patients – the pilot study]. *Psychogeriatrya Polska*, 4(1), 1-6.
- Wood, A.M., Joseph, S., & Linley, P.A. (2007). Coping style as a psychological resource of grateful people. *Journal of Social and Clinical Psychology*, 26(9), 1076-1093.