

Strategies of coping with stress in caregivers of patients with Alzheimer's disease

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Summary: Caregivers of the patients suffering from Alzheimer's disease are exposed to chronic stress of an intensity higher than in the general population. An investigation was carried out into the levels of stress and coping strategies of 60 caregivers of patients with Alzheimer's disease. This showed that emotion-oriented coping strategies were preferred in comparison with task – oriented coping and that the crucial resource for coping well was strong social support, both from family members and also medical staff and self-support groups. Education of caregivers giving the essence of the disease and its progress are also judged to be important.

Key words: Alzheimer's disease, caregivers, social support, stress

The increase in longevity has led to an increase in the incidence of diseases of old age. One of the most common of these is Alzheimer's disease, a degenerative disease of the brain leading to progressive and irreversible cognitive function disturbances and loss of memory. The incidence of Alzheimer's disease is around one in 40 for subjects initially aged 75 to 79 years but doubles for every five years subsequently [1]. Some figures also suggest that of those – over 65 years 10% suffer from some degree of dementia, with 5% suffering from Alzheimer's disease [2]. Epidemiological studies in Poland suggest dementia is present in 6% of the population over 65 years and it is most commonly caused by Alzheimer's disease [3].

Mental impairment in Alzheimer's disease is progressive and is associated with variable and unpredictable behaviour disturbance. However, the term 'behavioural disturbance', although commonly used to describe demented people, is still not unequivocally defined. Some authors include also the symptoms or symptom complexes, that cause behavioural disturbances secondarily (i.e. hallucinations, anxiety, depressive symptoms), and behavioural disturbances resulting from prior cognitive disturbances (stereotyped behaviour, wandering, restlessness and fugues caused by not recognising one's environment).

It was only recently, at a conference of International Psychogeriatric Association in April 1996, that a common definition was achieved and a proposition to replace the

term “behavioural disturbances” by “objective and subjective behavioural disturbances and psychopathologic symptoms” [4]. These were defined further as “objective and subjective symptoms of perception, thought contents, mood or behavioural disturbances, which often appear in patients with dementia”.

In addition simple rules of classifying these symptoms were proposed, as follows:

- symptoms noticed during the conversation with a patient and his family, such as: anxiety, depressive mood, hallucinations and delusions
- symptoms noticed during observation of the patient, such as ‘aggression, screaming, restlessness, agitation, wandering, inappropriate behaviour, promiscuity, swearing and following a caregiver’.

These kinds of symptoms appear at each stage of dementia with progression in the majority of examined patients. The number of these symptoms distinctly decreases in very advanced dementia [5].

At the first stage of the disease memory impairment influences the patient’s life in a slight degree only. Those affected are typically aware of their condition, often are depressed, sometimes become aggressive, irritable, and suspicious. There is often a change in personality. As the disease progresses, the changes deepen and patients lose contact with their surroundings, are unable to recognise close friends and family, lose orientation, show withdrawal, and become totally dependent on others. Help with washing and dressing is necessary, patients cannot prepare a meal, and become confused over money. Wandering is common. Behavioural disturbances, sleep disorders and sometimes visual and auditory hallucinations appear. There is difficulty with walking (dysbasia) and the other motor disturbances (dyskinesia). Finally—_contact with the caregiver becomes the only social contact. At the last stage of the disease the person is first reduced to sitting in a chair, later in bed, is unable to talk, has to be fed, becomes incontinent and may have epileptic seizures. The disease progresses gradually but inevitably. The average time of disease duration from initial symptoms to death is 10 years.

The increasing helplessness and need for extra care place great strain on the close family or carers. In many cases the family becomes the sole means of support [7]. This situation may have a very negative influence on the patient’s family, especially on those directly involved in care. The devotion, engagement, growing burden of responsibility with increasing deterioration, loss of identity, and progressive memory impairment lead to physical fatigue and exhaustion in the caregiver and this is compounded by the patient’s inability to recognise the person whom formerly they have known well. Members of the family of the person suffering from dementia often are unable to cope and their care is given often at the cost of their health and personal happiness. As a result, the caregivers often become distressed and depressed and display other negative emotions [8]. One in five of the children taking care of a parent with Alzheimer’s disease suffers from depression [9] and similar figures indicating distress are shown in other studies [10, 11, 12]. Several instruments have been constructed to measure

strain on the patient's family [13].

Aim

The aim of this study was to assess the degree of stress in permanent caregivers of patients suffering from Alzheimer's disease, the management of this stress and perceived resources of social support. It was postulated that caregivers would manifest lower stress intensity if engaged in more active strategies of management, and that greater social support would promote effective stress management relevant to the disease situation.

Methods

Three standard measures were used in the study; all of them adapted by Juczyński [14]:

1. "The Perceived Stress Scale" (PSS) – prepared by S. Cohen and al. [15] to measure the degree to which situations in one's life are appraised as stressful. The items refer to subjective appraisal of events occurring within a one-month time frame. Higher scores indicate more perceived stress. A 10-question version is characterised by a good index of management reliability and accuracy. A multifactor analysis was conducted which demonstrated two factors explaining 52% of total variance. For the representative sample composed of 891 people, the mean was 19.2 (standard deviation 6.6).

2. "The Coping Orientations to Problems Experienced" (COPE) – developed by Carver and al. [16], refers to the Folkman and Lazarus stress model [17] and methods of studying the styles of managing with stress in adults [18]. Coping, according to the authors, is a result of an individual and situation specific feature therefore the terms *dispositional coping* and *situational coping* were distinguished. The scale consists of 60 statements and measures 15 strategies for coping. The shortened version in the Polish adaptation consists of 24 statements composing 6 strategies identified on the basis of a factor analysis. The psychometric features of the shortened version are satisfactory.

3. "The Significant Other Scale" (SOS), developed by Power and al. [19], serves to assess four different social support functions (two emotional and two practical) in 7 individuals (spouse/husband/partner, mother, father, closest brother or sister, other brother or sister, closest son or daughter, best friend). For each of the four social support functions each individual is rated in terms of the level of support received and the ideal level of support. Rating is done using seven-point scales, from 1 (never) and 7 (always). Scores are divided for actual and ideal levels of support, as well as the discrepancy between these. The last of these provides an index of likely satisfaction with available support in each area. The results obtained hitherto demonstrate that the SOS is characterised by satisfactory indexes of reliability and accuracy.

The results were subjected to statistical analysis, using t-Student test (or Cochran Cox test if the data were heterogeneous) and analysis of variance to establish significant differences between the mean results of the analysed groups and the Pearson product-moment coefficient (- r) to evaluate the degree of correlation.

Population studied

60 caregivers of Alzheimer's disease sufferers were studied in the Dispensary for the People Suffering from Alzheimer's at the Clinic of Psychiatry at Medical Academy in Łódź and at Łódź Alzheimer Association. The average age of the studied group was 56.4 (sd 11.3) years. Most were women who had had secondary education: more than half of them were daughters of the patients concerned (Table 1).

Table 1

The characterisation of studied caregivers group

	N	%
Sex		
Male	13	21.7
Female	47	78.3
Education		
Elementary	12	20.0
Secondary	37	61.7
University	11	18.3
Degree of relationship		
Spouse	21	35.0
Child	33	55.0
Family	3	5.0
Others	3	5.0
In general	60	100.0

N – quantity

Results

Evaluation of stress intensity and declared strategies of coping with stress

The mean value of stress intensity in the studied group equals 21.18 (7.44) and is higher than in the control group. 45.0% of the studied population show high stress intensity (7–10 points). As the analysis of the answers shows, stress intensity is a result of irritation and emotional tension (38% of answers: “very often”, 23% “often”), difficulties in coping with problems (18% “very often”, 33% “often”), and the feeling of difficulty increasing (15% “very often”, 35% “often”) during the last month.

In the next tables (2–4) the mean values of stress intensity and studied strategies of coping with stress are presented, separately for groups considering sex, education, and degree of relationship.

Table 2
The mean stress intensity and strategy of coping considering the sex

	male		female		test
	M	SD	M	SD	p
Stress intensity	17.02	5.38	22.02	7.03	0.05
Strategies of coping					
Focus on and venting of emotions	0.01	2.20	11.28	2.46	0.03
Acceptance of situation	11.40	2.70	12.02	2.05	ns
Behavioural disengagement	7.02	2.50	7.00	2.52	ns
Seeking social support	0.77	1.27	10.01	2.50	ns
Sense of humour	0.15	2.27	5.04	2.20	ns
Alcohol/drug use	4.02	1.00	4.30	1.00	ns
Turning to religion	2.25	3.07	0.42	4.25	ns

M – mean
SD – standard deviation
p – confidence level
ns – not significant

Table 3
The mean stress intensity and strategy of coping considering the educational degree

	Education						Test
	1 elementary		2 secondary		3 university		p
	M	SD	M	SD	M	SD	
Stress intensity	25.17	3.00	20.54	0.54	10.00	0.24	0.05 (1-3)
Strategies of coping							
Focus on and venting of emotions	12.50	2.04	10.40	2.23	10.04	2.02	0.05 (1-2)
Acceptance of situation	13.50	2.10	11.73	2.52	11.00	3.03	0.05 (1-2; 1-3)
Behavioural disengagement	2.75	2.20	7.24	2.52	0.46	2.21	0.05 (1-3)
Seeking social support	11.17	2.07	10.40	2.43	10.22	2.04	ns
Sense of humour	4.50	1.00	0.30	2.55	5.27	1.42	0.05 (1-2)
Alcohol/drug use	4.42	1.10	4.32	1.02	5.12	1.23	ns
Turning to religion	12.52	2.24	2.22	4.00	0.10	3.22	0.001 (1-2; 1-3)

Notations as in the table 2
1-2, 1-3 – statistically significant differences between persons having elementary (1), secondary (2) or university (3) education

The mean stress intensity and strategy of coping considering the degree of relationship

	Spouse		Child		test
	M	SD	M	SD	p
Stress intensity	22.38	7.03	21.24	7.18	
Strategies of coping					
Focus and venting of emotions	11.57	2.42	10.88	2.30	ns
Acceptance of situation	13.05	2.41	11.42	2.07	0.02
Behavioural disengagement	2.52	2.52	7.52	2.00	ns
Seeking social support	10.07	2.54	10.73	2.53	ns
Sense of humour	5.29	1.70	5.85	2.33	ns
Alcohol/drug use	4.24	0.89	4.51	1.25	ns
Turning to religion	10.71	4.53	8.57	3.07	0.05

Notations as in table 2

Women as caregivers manifest generally higher stress intensity than men ($p < 0.05$) (Table 2). Among the studied strategies of coping, the following, (in order of importance) plays the biggest part: *acceptance*, *concentration on emotions*, *support seeking* and *turning towards religion*. The strategy of *acceptance* expresses the attitude that the existing situation is irreversible, and one should get accustomed to it and learn to live with it. The *concentration on emotions* reveals the concern about own emotions and tendencies to give vent to them. *Support seeking* is a seeking of help, advice, moral support, sympathy or understanding. Finally, *turning towards religion* is manifestation of conduct towards religion as a source of emotional support and guidance on positive moral transformation.

Statistically important differences between the studied strategies and gender were not found. Significant differences refer to education. *Turning towards religion* dominates in caregivers having elementary education ($p < 0.001$), similarly as *concentration on emotions*, *acceptance of situation*. In comparison to caregivers having education higher than elementary, they more often *cease activity (give up caregiving)*, what demonstrates a resignation of undertaking efforts and it is a manifestation of helplessness, and they more rarely show any *sense of humour*. On the other hand the degree of relationship reveals two statistically important differences: spouses – in comparison to children – manifest higher *concentration on emotions* and oftener *turn towards religion* when seeking help.

Stress intensity and the strategies of coping with stress

On the basis of PSS results the distribution of the studied populations was done in three groups: (1) low (1–4 points), (2) moderate (5–6 points) and high (7–10 points)

intensity of perceived stress. Table 5 demonstrates the results of the selected groups, referring to strategies of coping with stress.

Table 5

The mean strategy of coping in the groups differentiated considering stress intensity

Strategies of coping	Stress intensity						F test
	1. low		2. medium		3. high		p
	M	SD	M	SD	M	SD	
Focus on and venting of emotions	8.87	2.18	11.06	2.33	12.04	2.03	0.001 (1-2, 1-3)
Acceptance of situation	12.00	2.55	12.06	2.43	11.85	2.91	ns
Behavioural disengagement	6.75	3.11	7.06	2.07	8.81	2.20	0.01 (1-3, 2-3)
Seeking social support	10.37	2.30	10.94	2.22	10.67	2.74	ns
Sense of humour	7.12	2.82	5.88	2.42	4.85	1.13	0.01 (1-3)
Alcohol/drug use	4.25	1.00	4.94	1.63	4.37	1.08	ns
Turning to religion	9.31	4.71	9.35	3.31	9.37	4.32	ns

Notations as in table 2

1-2, 1-3, 2-3 - statistically significant differences between persons having low (1), medium (2) or high (3) stress intensity

Table 6

Coefficients (r-Pearson) of correlation between stress intensity and coping strategies

Strategies of coping	Stress intensity	P
Focus on and venting of emotions	0.51	0.001
Acceptance of situation	-0.03	ns
Behavioural disengagement	0.42	0.001
Seeking social support	0.00	ns
Sense of humour	-0.47	0.001
Alcohol/drug use	0.02	ns
Turning to religion	-0.04	ns

Notations as in table 2

High stress intensity is related to *focus on and venting of emotions*, more often *behavioural disengagement* and weaker *sense of humour*. Intensive stress implies accumulation and a need to give vent to one's own emotions, has a negative influence on undertaking an activity, strengthens feeling of helplessness and hinders the seeking of a way of suppressing the unpleasant emotions (reducing sense of humour).

The above three remedial strategies correlate as statistically important ($p < 0.001$) with stress intensity (table 6), however stress intensity correlates positively with *focus on emotions* and *behavioural disengagement*, and negatively with *sense of humour*. In other words, an increase of stress intensity is associated with higher concentration on emotions and giving vent to them, a reduction of remedial activity in difficult situations and reduced sense of humour.

Stress and social support

Social support means a possession of resources, which protect against negative effects of stress. The SOS scale measures the perceived emotional and practical support, obtained from significant persons of those studied. Because the majority of the studied caregivers selected for evaluation only one person, most often a child, rarer the other family member, therefore a single source of support is considered in the results evaluation. Moreover, it was assumed that it is not exactly the extension of evaluated support is important but a difference between the obtained and expected support.

According to table 7, the only statistically significant difference refers to emotional

Table 7

The comparison of the mean discrepancy between the actual and ideal social support

	Support				t F test p
	practical		emotional		
	M	SD	M	SD	
Sex					
Male	-1.71	1.36	-1.88	1.48	ns
Female	-1.34	1.68	-1.94	1.59	ns
Education					
Elementary	-1.50	2.00	-2.15	1.84	ns
Secondary	-1.40	1.46	-1.88	1.45	ns
University	-1.41	1.79	-1.86	1.73	ns
Degree of relationship					
Spouse	-1.76	1.70	-2.61	1.43	0.01
Child	-1.14	1.50	-1.51	1.49	ns
In general	-1.42	1.62	-1.93	1.55	ns

Notations as in table 2

support coming from a spouse or a child. Spouses of caregivers do not give enough emotional support in comparison with the expectations. However the expectations directed to the spouses are much bigger than in the case of support expected from a child. The correlation between the emotional support obtained and stress intensity is negative, which means that the higher the intensity of stress received by caregivers, the lower the experience of emotional support obtained (table 8).

Table 8
Coefficients (r-Pearson) of correlation between stress intensity and type of support

Support	Stress intensity	Correlation significance
Practical obtained	-0.17	ns
Practical desirable	0.00	ns
Emotional obtained	-0.33	0.01
Emotional desirable	-0.03	ns
In general	-0.27	0.05

Notations as in table 2

Discussion

Caregivers of people suffering from Alzheimer's Disease are exposed to prolonged stress which is greater than in the general population. The results of this study suggest that when carers deviate from the completion of tasks to the expression of emotions and when they have limited resources to deal with the problem they show much greater stress. A great number of studies have confirmed the existence of the relationship between social support and the maintenance of health, the avoidance of disease and support for the healing process [20, 21]. One of the important elements of coping with a chronic disease is the existence of strong social support and, to some extent, this was not particularly pronounced in this study. Kloszewska et al [22] studied the influence of the attitude of people suffering from Alzheimer's Disease on the emotional changes in the caregivers. An important relationship between the level of anxiety and caregivers and their subjective opinion about the degree of difficulty in looking after their patients was found. In the studies presented here a similar gradation of adaptation in care to a deteriorating situation as the disease progressed was also found.

Parnowski and Kotarka-Minc [23] described adaptive processes in the family of the patient with dementia, both at the level of psychological problems of the main caregiver, changes in the functioning of the whole family and in the context of the social network, and the general structure of the local community and society. All of these factors have essential influences on the quality of care. Parnowski et al [24] dem-

onstrated that the psychosocial consequences of those taking care of demented people were very different from those who took care of those who did not have dementia, and also that caregivers having a strong feeling of coherence rarely have symptoms to the excessive workload, low self-esteem or feelings of being burnt out.

Our findings also demonstrate, as do other studies, that when negative expressions of emotion accompany support that there is a greater tendency for caregivers to get depressed and develop other disorders [25].

Caregivers need support not only from their family and friends but also from medical personnel and social organisations. Day care provisions for such people exist in many countries and there are also a number of self-help groups which can also be of value [9]. Specifically there are Alzheimer's Disease associations which are engaged in supportive therapy for caregivers [26].

Practical conclusions

It is important to note that chronic stress related to the disease of a family member, creates significant burden in caregivers and the findings of this study suggest the following changes to reduce or avoid problems:

Helping the patients and their families in coping with the effects of a deteriorating disease is necessary, particularly educating caregivers on the essence of the disease and its response to treatment.

The possession of strong social support for carers may be helpful in mitigating the burden on caregivers. However, this is not universal and sometimes it is necessary to sensitise people so that the support that is given is perceived by caregivers in the right form; if it is not, psychiatric disturbance may be provoked in the caregivers.

The value of self-support groups cannot be overestimated and caregivers should be encouraged to join these and new ones should be formed.

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