

Research Articles

Communication Problems Within Families With Patients With Dementia

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Abstract

Dementia in later age is an extreme hardship for the affected families. More than 90% of these patients in Bulgaria live with their families. The results from the conducted study pointed out that a big share of the specific problems of these families is related to the lack of communication skills on the part of the relatives of the patient. This was to a great extent due to the lack of information on the characteristics of the process of dementia as well as on the concurrent personality changes in the patient. This article reviews the main difficulties of the families in taking care of patients with dementia as well as clarifies appropriate psychological forms of support aimed at lowering the family distress originating from the disease.

Keywords: patients with dementia syndrome, family, communication skills, psychological support, educational therapy

Psychological Thought, 2012, Vol. 5(2), 106–112, doi:10.5964/psyct.v5i2.21

Received: 2012-06-10. Accepted: 2012-08-19. Published: 2012-10-31.

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Actuality of the Problem

With aging, the medical and social care needs of the elderly increase, due to the high prevalence of chronic and degenerative diseases, loss of physical strength, psycho-social disadaptation, reduced social competency and increased dependence (Balkanska, 2003, p. 108; Balkanska, Mladenova, Chakarova, & Petrova, 2011; European Commission, 2005). All of these elderly people require not only specialized medical and social care, but also patience and understanding of their needs.

Conducted extensive studies of the team by the Department of "Gerontology" of the Faculty of Public Health, Medical University - Sofia /to 2000 - Clinical Centre of Endocrinology and Gerontology, Medical University - Sofia/ in the field of health care for older people and mental health in the period 1995 - 2009, ascertain the following major problems:

1. Insufficient adaptation of health and social systems to the specific needs of individuals in the elderly;
2. Manifestation of Ageism in public relations and health care for aging people;
3. Lack of specialized knowledge and skills for working with old people, which creates significant difficulties for medical staff or quality of geriatric care;
4. The early diagnosing and treating of the dementia is impeded because of:
 - ignorance or wrong assumption about the manifestations of the disease;

- disregarding the psychogeriatric problems;
- lack of comprehensive concept for covering, early diagnostics, therapy and prevention of the cognitive disturbances in people at advanced age

5. Lack of alternative and affordable forms of family support for care for older people and patients with dementia (Balkanska, 2003; Balkanska, 2008; Balkanska, Georgiev, & Mladenova, 2009; Balkanska et al., 2011).

Dementia is the family name for a number of disorders, all of which have in common a loss of memory and other intellectual functions, a reduction in the person's ability to care for himself or herself, often accompanied by emotional changes and disturbances of behaviour.

Dementia is a syndrome representing nearly 100 different diseases. The Alzheimer's disease (AD) and vascular dementia represent a majority of diagnosed dementia cases.

The various clinical symptoms of dementia occur very differently according to the type of dementia.

Alzheimer's disease is often associated with anomic aphasia, characterized by word-finding and naming difficulties. Other types of dementia, e.g. vascular dementia may show very small signs of aphasia, or the opposite; showing signs of global aphasia, according to which parts of the brain that are most inflicted (Ridder, 2005, p. 63).

In general, loss of conversational skill is likely to be an early marker of dementia syndrome. In the later stages of the different dementia diseases it seems very troublesome or even impossible to maintain conversation or dialogue. Language deterioration is a serious problem and might cause secondary consequences of dementia (in Ridder, 2005, p. 63).

Studies that consider communication-related stress show that communication breakdown is perceived by caregivers to be a primary problem in coping with the disease, and that communication problems increase the risk of early institutionalization of the individual with Dementia of Alzheimer type (in Ridder, 2005, p. 63).

The following symptoms of dementia disturb the communication:

- Semantic anomic aphasia;
- Expressive speech deficits;
- Speech comprehension deficits;
- Attention and orientation disturbances (Ridder, 2005, p. 63).

Orange and Colton-Hudson suggest that caregivers must show attention to the communication breakdown that might lead to isolation, depression and agitation (in Ridder, 2005, p. 63).

Tom Kitwood (1997) focussed his research into the subjective world of dementia and defined a cluster of five great psychosocial needs – comfort, attachment, inclusion, occupation, and identity – which come together in the central need for love. He sees that the first psychological task in dementia care is to generate interactions of a really positive kind, and the second to enable the interactions to continue. For caregivers this means that the more severe the dementia, the greater the need for special interactive competencies will be (Kitwood 1997, pp. 96-97; in Ridder, 2003, p. 26).

Great understanding, patience, and strength are required to reconcile with the illness and live together with the patient with dementia. Most of these patients live with their families and the care for them is provided by their relatives (Butler & Lewis, 1982; Balkanska, 2003; Hybels & Blazer, 2003).

Objective

The aim was to explore the main difficulties of the families in the care of patients with dementia as well as to find out appropriate psychological forms of support aimed at lowering the family distress originating from the disease.

Object of Study and Methods

Psycho-social investigation was conducted among 178 families with patients with dementia in Sofia. The patients with dementia included in the study were aged from 60 to 94 years.

The following methods were used: clinico-psychopathological method, clinico-behavioural scale of Haycox (Haycox, 1984), clinical scale for study of cognitive functions of Gil (Gil et al., 1986), and interview. 181 subjects aged from 39 to 75 years have been inquired representing those most engaged in taking care of their ill relatives.

Results and Discussion

Among the patients studied, the most numerous was the group of persons with vascular dementia (by ICD-10) – 50.2%, followed by the group of patients with Alzheimer's disease – 43% and patients with dementia originating from other diseases – 6.8% (World Health Organization, 2003).

Nearly half of the studied patients were relatively autonomous, while 1/3 were entirely dependent on others' assistance.

The greatest percentage was of the patients with moderately manifested cognitive disfunctions – 33.4%, while severe cognitive disfunctions were found out in 26.1% of the respondents.

In more than half of the observed families, the patient was taken care of by his/her spouse – 56%, in 36% the cares were provided by the grown-up children and in 8% – by other relatives.

The data from the performed study point at the patient with dementia as a source of various stress situations in the family life with all the resulting consequences for the relatives. They are due mostly to the specific development of the disease (Altshuler, 2002; Balkanska, 2003; Ballard, Lowery, Powell, O'Brien, & James, 2000).

According to data derived from the interviews, major sources of emotional strain and chronic distress were:

1. The offspring from the progression of the destructive brain process in the patient:

- memory disturbances (89%);
- reactions of anger and aggression (78%);
- anxiety reactions (73%);
- disturbed sleep and nutrition (67%);
- physiological incontinence (61%);

- communication problems (58%);
2. Unavailable or insufficient information on the disease as well as skills to manage the behavioural disturbances of the patient (76%);
 3. Inadequate or insufficient support and empathy on the part of the relatives (69%).

The results from the study pointed out that a substantial proportion of the specific problems of these families were related to the lack of communication skills on the part of the relatives of the patient (Balkanska & Georgiev, 2010). This was to a great extent due to the lack of information on the characteristics of the process of dementia as well as on the concurrent personality changes in the patient. It has been shown that only 43 (24%) of the interviewed 181 family members were informed about the realities of the dementia syndrome.

In the studied 178 families with member with dementia, we found extremely serious communication problems related with the manifestations of aggressiveness, anxiety, uncertainty and fear on the part of the patient which were often provoked and fostered by the inappropriate behaviour of the other family members, the unavailable or insufficient information on the nature of these symptoms as well as their inability to avoid them when possible in the everyday life with the patient.

Significant communication problems were proved between the patients and the caretakers that extremely aggravated the everyday life of these families.

It was proved that the patients sensed at a various extent their increasing communicative embarrassments. Some experienced them painfully and at the beginning they tried to hide them, e. g. they talked less. There was an impression during the course of the study that they were mainly patients who have been more differentiated personalities before the onset of the disease and their profession and social environment had been related with more verbal expressions. Patients suffering from moderate dementia can understand simple everyday questions and conversations. The comprehension of complex information, e. g. TV program is distinctly disturbed and lacks totally with the progression of the disease. The patients suffering from severe dementia possess very limited abilities to express themselves in a sensible way. Clear, short, and simple verbal expression can be understood even by patients in an advanced stage of the disease.

The non-cognitive mental disturbances accompanying the syndrome of dementia and including states of fear, anxiety, "fuss", aggressive behaviour, depression, etc. appear as specific events in the individual picture of dementia in every single case. But their incidence and severity depend much on the behaviour of the others as well (Balkanska, 2003; Balkanska, 2009, p. 178).

They may be overcome to a great extent provided that the caretakers of such a patient learn HOW to communicate with him/her, i. e. if they adapt themselves to the communicative skills of the patient determined by the illness.

The disturbances of verbal and written speech can be differentiated at the early stages of dementia during the psychological examination of the patients. This offers the chance to determine the individual problems of the patient and recommend case-appropriate behaviour (Cummings et al., 1994; Balkanska, 2003; Balkanska, 2009).

The analysis of the results of this study as well as my long-standing experience in the contacts with the patients with dementia pointed out that the extreme embarrassments in the everyday communication with the patient could be overcome at a considerable degree by the ability of the relatives to assess correctly the arising crisis situations and react accordingly.

Learning practical skills for adequate reaction to certain situations arising from the disturbances of patient's behaviour is one of the major objectives of the group therapy for education of the subjects taking care for patients with a syndrome of dementia (Balkanska, 2009b).

In the groups for psychological and educational therapy, we discuss with the family members psychosocial approaches for reduction of the non-cognitive morbid symptoms; their administration leads to the reduction of the family distress. Many "peculiarities" in patient's behaviour become understandable for the others provided that they are informed for them beforehand and attempt with greater tolerance to peer into the alien, confused by dementia world of the patient.

In order to alleviate the verbal communication of the patient and lessen the care he/she needs, it is necessary to observe some verbal and non-verbal forms of communication.

Some of them are the following:

- The style of expression must be simple and clear: short and simple words and clauses should be used.
- Low speed of utterance and benevolent tone. The slow speech helps for the comprehension of the verbal expressions directed to the patient.
- Corrections and critique of the patient do not help but rather impede his/her comprehension, confuse him/her and cause him/her to experience uncertainty.
- Gestures and mimics accompanying verbal expressions should be clear for the patient. The live emotional expression helps the comprehension.

Our examinations and observations confirmed by other authors showed that these approaches preserve for a longer period the speech comprehension in such patients (Balkanska, 2003; Lee, Volans, & Gregory, 2003; Nolan, Davies, Brown, Keady, & Nolan, 2002; Nolan, Davies, & Grant, 2001; Mintz & Marosy, 2000).

Conclusion

Substantial communication problems were proved between the patients with dementia and the caretakers that extremely aggravated the everyday life of these families. They may be overcome to a great extent provided that the caretakers of such a patient learn HOW to communicate with him/her, i. e., if they adapt themselves to the communicative skills of the patient determined by the illness.

The psychological and educational therapy with the relatives in the groups for support is the actual form of psycho-emotional and social support to the families with close person with dementia in Bulgaria.

For overcoming the specific problems in the families with patients with dementia in Bulgaria, a complex therapeutic programme was developed, based on the concept of early diagnostics, therapy of the affected by the disease and socio-psychological support to the patients with dementia and their families.

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