

QUALITY OF LIFE FOR PEOPLE WITH ALZHEIMER'S DEMENTIA AND THEIR CAREGIVERS THROUGH THE EXISTING SPECIALTY SERVICES: "MORAL CAREER" OF THE PERSON WITH THE ALZHEIMER DISEASE

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Abstract

The theme identified, and taken into the research undertaken is not only new, and research in the field of psychosocial studies and social work from Romania, but, especially, which is required for theoretical and methodological Foundation of social policies and services for particular categories of vulnerable, growing.

The present paper is intended to provide the opportunity of making gerontology assistance, theoretical practices aiming at quality of life in the social services provided to people with A.D. and their caregivers, starting from a comparative study between them in non-specialized in residential centres and psychiatric hospitals as "total" institutions similar to detention spaces. The methods used in the research study were qualitative observation, and structured interview guide applied to staff in health centre personnel from Arad, concerned care centres intended for persons with dementia in Arad. The results of qualitative analysis, it helps us draw up some signals of alarm on daily "realities" of the disease, which has a large incident in Europe and Romania, namely social services not adapted yet, due to the "lack of" highly professionalized intervention, adapted to the new requirements of the psycho-social person with A.D. Unfortunately in Romania people with dementia often end up as psychiatric patients, while social assistance is "called" to be the main actor in the service of the person with A.D. and their caregivers through a generous range of services adapted to the type of day care centres, residential and weekend services, designed to relieve caregivers burden of medical care, contributing significantly to the quality of those two categories.

Keywords: Alzheimer's dementia, caregivers, social support, network security, quality of life, social services, medical care, intervention

INTRODUCTION

The aim of the present study is to lay the foundations of a sharper social work in the field of the quality of life of persons with dementia and their caregivers, the birth of a comparative study between caregiving and psychiatric intervention.

The literature points out that caregivers having oversight people with Alzheimer's dementia, performs loads heavier than other caretakers (A report by

the Alzheimer's Association and the National Alliance for Caregiving, *Families Care: Alzheimer's Caregiving in the United States 2004. Statement of the Alzheimer's Association and the National Alliance for Caregiving*).

Their sacrifice is aimed at multiple personal plans such as: personal time, hobbies, vacations, family time, profession, etc., sometimes going up to their own health, to respond to changing demands, needs care and other types of so-called "challenges".

In Romania, as in other countries, caregivers have a number of unmet needs, the most important being those of information and support-both for themselves and for the care recipient.

Although dementia does not affect only the elderly, the possibility of developing dementia increases with age. Because of the labour of the European Community concerning the epidemiology and prevention of dementia (EURODERM, 2009; EUROCODE, 2010) it is possible to estimate how many people in a country runs the risk of developing dementia. EURODERM gathers data on the prevalence of moderate-severe dementia in several European countries in order to achieve a set of prevalence rates for men and women in 9 different age groups, 30-59, 60-64, 65-69, 70-74, 75-79, 80-84, 85-89, 90-94, 95-99) (Munteanu, 2004)

Unfortunately, neither in this research, Romania was not mentioned at that time (2006). When we talk about quality of life, people with DA, the main concern of the specialist in social worker would have to differentiate the type of intervention that is imposed in their case, based on the person in question and their caregivers. This phenomenon has multiple consequences in economic and social plan, based on the financial status of the elderly population and continuing with the degradation of the physical and mental health. One of the greatest problems faced by a significant number of elderly persons and, consequently, their families is senile dementia.

In the medical literature and psychological, there can be found a multitude of definitions and descriptions of dementia: "Dementia is characterized by the development of numerous cognitive deficits (including damage to memory) that is due to the direct physiological effects of a general medical conditions continuing effects of a substance or to multiple etiologies (eg. the combined effects of cerebrovascular diseases and Alzheimer's disease)". (Smith, 2000). "Dementia (which signifies a significant regression of intellectual capacity, compared to the previously) is widespread during this ontogenetic period. As mentions R.D. Chiriceanu, a rate of 5-10% of the elderly over 65 years results in a regression of these cognitive, and approximately 50% will be affected by a degenerative dementia, the most widespread being Alzheimer's dementia ". (Erving, 2004)

In the materials disseminated by the Romanian Society of Alzheimer's, dementia is defined as a chronic neuro-degenerative disorder with progressive and irreversible in nature, characterized by cognitive decline that interfere with multiple individual's ability to cope with daily activities. And World Health Organization experts have the attention of the mental health problems of older people. Thus, they presented in a language more accessible to the broad mass of the

characteristic symptoms of dementia: "A decline in memory that leads to poor functioning in everyday life; decrease of intellectual faculties that lead to a deterioration of thinking and processing information, to a degree that interferes with adaptability to everyday life; disorders of the conscious state, the results of which are sleepiness, apathy, etc.; the decrease in emotional control, leading to behaviour change or social motivations; the symptoms must be clearly present for at least six months."(Morcan, 2012) research is intended to be a qualitative study on the quality of life of people living with DA and their caregivers respectively*(family members, caregivers) in relation to existing specialty services.

The motive of this study took me to the institutional character of the patient, specifically, from psychiatric hospitals, which let's not forget, before they became patients "institutional/hospitalized", had a social life, a good perception of the surrounding reality, which now they only "imagine" through the reality of medico-social perspective. It is desirable that reform brings about a system centered on the customer's needs, yet when it comes to the these needs we resort to only basics without approaching the matter as a whole. This study is intended to be a reflection on this matter, which subsequently to result in a qualitative research social policies developed in this area, especially on the socio-economic development of the community psychiatry for people with AD, and the specialized services of the type «social respite centres, day, weekend residential. Boldest Studies in Psychiatry talk about a "big gap" (Revista Română de Sănătate Mintală, (2007) between Romanian psychiatry and that of other European countries.

In a context where psychiatric patient benefit from basic services, I say as I represent in a pyramid of needs after Abraham Maslow, that often the basic needs are met (food, shelter and basic health care), including medication, all happen under the jurisdiction of same authorities, often without detail, all as a *routine* around same persons, hours, after a treatment often not different from others in the presence and under the attention of their roommates, "colleagues".Unfortunately, the most important activity of the staff of psychiatric hospitals represent in the end, the supervision of patients. The departure from the objective reality is almost imminent. Health care services in the long term, have been long fought in the European countries. Social Policies in Romania should develop an intervention model, centered on the integralist sufferer mental (psychiatric problems) and his family.

The main *objective of social work in psychiatric sector should be geared to the rehabilitation of the individual in the socio-professional and familial plane*, enabling individual to be more independent, based on own capacities and discouraging institutional dependency.

The importance of this issue should emphasize the fact that unlike the vast majority of somatic diseases, the presence of mental illness to the individual represents an altered source of equilibrium, to the balance of social microgrup, by which we understand: family, surroundings, professional sphere. All forms of discrimination, sometimes due to lack of knowledge, sometimes deliberately cast will put on the patient's psychic in a position of inferiority, or even social isolation.

The principles that should guide the intervention of social services in working with psychiatric sufferer should focus on several areas involving interventions; development of roles and tasks: *Remove the label* (the role of the mediator intervention, advocacy); *Manager* -coordinates and facilitates access to medical and social services are important therapeutic process and in the interests of sound social reintegration; *Educational Role*- relationship between patient/beneficiary and his family; forming groups of self-support, organizing recreational activities, creative workshops etc; *Family orientation* -as the main element of the connection with the social life; a polyvalent intervention with the patient-as client of social work and family which in many cases can be equally affected, or need help with the same, or even better than the psychiatric patient-client. Size of family support is very important, because even from the economic point of view, is less expensive than if the State takes over entirely to these responsibilities; *Representation and promotion* of the rights of persons with mental disorders; *Intervention centered on medium*-escorting the patient relationship with the State, with civil society; *Shape* the relationship of the patient in relation to psychiatric social environment (State/governmental); *Determine the person's autonomy* -oriented dimension of social reintegration; *Representation (advocacy)*-social, family, legal, community; *Develop, propose and implement*- effective policies for persons with mental disorders; *Identify, access and attract financial support* - and for this segment of activity; *Facilitator* -to develop independent living skills; Offers free legal advice-good knowledge of the rights and facilities provided to this category of persons; *Counselor*- Counseling in social assistance-(disease management) is much different, however no less important to that psychological, because man must be regarded as a complexity, is no longer just a simple individual but a social entity. In this report the social worker play several roles including the confidant, advisor, support, the relationship can in certain circumstances bypass "boundaries" of a strictly professional relationship to interpersonal relationship; so the social worker will be invested with more confidence; the one that will lead to success. (Morcan and Trancă, 2012).

Besides social worker roles in working with the sufferer with the dementia should further outlines several principles of work, of which the most relevant would be: responsibility at Community level, the participation of entire community, ensuring a continued level of caregiving services, with emphasis on rehabilitation, customized care, a specialization of the family as the main pillar in the process of care and rehabilitation, population desensitization and its emphasis on rehabilitation.

It talks about an era of ' social psychiatry "in which the patient is being looked at as a whole, as a" bio-psycho-social".(Morcan, 2012) It should shape up more and more of a profile of psychiatric social worker, who takes up multiple duties from a psychiatric doctor, thus providing social assistance at a more advanced level, both at the hospital level, community (protected homes), but mostly on an outpatient basis — that support intervention and prevention.

The social worker must be involved in the process of rehabilitation, recovery, as a go-between between services and individuals, ensuring all this time the patient is provided the ability to work, to establish relations, to take actions and make decisions by themselves, and not rely on familiar climate of support, but gain the confidence of self-dependence.

Social worker mediates, and intervenes in the natural environment; get in touch with the surrounding etc., offering psycho-social approach to the conditions of individual life of an individual, being non-directive and non-manipulative. Orientation towards social intervention in psychiatry has evolved from "suffering social body" as defined in the first institutionalized forms of intervention, with a pronounced religious character, towards a "society created social person" concept that appeared with the birth of a new science-anthropology. New Social Policies should aim at the introduction of a social work specialties on this dimension. Action plan for implementation of the mental health reform, although it has already laid down clear objectives on short and long term; from the dictum "to improve the mental health caregiving situation" the expected costs on human resources, does not highlight the "necessity" of social worker positions creation. Real connection between the mental health system and social services is weak and often non-productive.

Dissemination of alternative services, and information about where they can be accessed using a professional is often available "served" on the internet, on the website offered by various services where the recipient (client/patient) has not always access; far from being one competitive to admission in a psychiatric hospital.

Tagging is a serious problem with which a person with dementia is confronted. In the most serious cases it is equivalent to discrimination. It is a phenomenon that often occurs in people with mental disorders or those with a disability, when faced with situations of refusal to care or social services. Lack of or weak representation places these individuals in situations of inferiority; unable to lodge complaints, and most of the time not having knowledge of their rights. Unfortunately many recipients of psychiatric services are labelled because their disabilities and most of the times amid preconceptions from the population, a fact that determines the limitation or fenced in access to medical assistance in, education, jobs, social services. Research in this domain (Hategan, 2008) "Alternative community care needs for institutionalized patients in psychiatric hospitals") and others in the field, identify the main barriers in the prolonged stagnation in psychiatric hospitals as social factors.

The size of the ethics of the gerontologic practices in addition to professional practice comes in the field of social work, where "compulsory therapeutic approach associating factor" family "it is necessary to always, at any moment that the family is the natural environment for the elderly, one of the vital tone or" (Gal, 2006) although one of the obligations of a social worker, is to defend the rights and interests of the recipient or (Rutman, 1997), sometimes even of his own, and own family respectively .

“The morale career” of the person with dementia sends me to think of the identification of the main "ethical dilemmas in the nursing/institutionalization" of the person with dementia.

PRELIMINARY RESULTS OF A QUALITATIVE STUDY. PROPOSALS FOR FUTURE INTERVENTION

On the basis of evaluations carried out, following the interviews of specialty care/staff from residential care centres intended for people with DA in the municipality and County of Arad, a percentage of 76% appreciate that it is not normal to tell the person with dementia the "truth" about the diagnosis, while only 34% believed that "prolonged institutionalization of periodic"/person with dementia, is a solution for the patient with dementia considering a rather "a reaction to the overloading of the caregiving family ."Network of social support in working with people with DA and their families, has an essential role" (Morcan, 2012) To understand that, the size of the practice in social care for people with dementia in general, or in particular, must pursue the improvement of the quality of life of people with dementia, regardless if they are in a health care institution, or in a family environment.

Concern of the occupational healthcare giver should be to respect the issue of the values and fundamental principles of intervention of social assistance through a structured model of intervention in this area relatively new, in specialized practice of the social worker, by eliminating ethical concerns outlined: "to tell the truth to the person with dementia/ allow freedom of/action/motion of person with dementia with detrimental security/a demented person institutionalize against his desire/promotion/failure of human values which underlie the profession of social worker, as well as providing dignity and keep, the term "self-determination"; respecting the individuality of the person and the treatment differentiated in the context of their disease., the independence and individuality of the person "; correct management the support network (family, work, friends, medical or social services, but also access to active life and own resources); the risk of stigmatization/exclusion (due to, loanliness, others mentality, the difficulty accessing of services, understanding special needs); in making treatment, forcing use of force/restricting tethering or isolation; in case of self-harm etc.

The principals regarding ' Ethics and morality in the profession of social worker in the area of intervention "but not only could find answers answers in supervision. Supervision in social work in the case of persons with dementia, could help relieve and streamline solutions which impede, results of specialized analysis, aimed to bring ethical solutions to the problem.

Supervisor in social assistance, is the specialist capable to manage, coordinate and propose tailored intervention models, respecting both the best interests of the beneficiary, but preventing at the same time the abuse from employee or a burn-out social worker, a result of overloaded responsibility, accountability, workplace conflict unmanaged.

The involvement of specialists in social work in an ethical research on intervention in the case of person with dementia, is considered as being vital in all centres destined persons with dementia; in order to identify the principal dysfunctions, needs in a supervisory capability to provide appropriate advisory to create accurate, professional relationships to develop a code of ethics, but also to manage work conflicts and to form the correct skills in working with people with DA. As partial results of a singular approach to the level of a County like Arad, alarm signals "pulled" shows still in such a moment seemingly talking about legislation that appear and follow standards of quality "in theory" the best interest of the beneficiary as the starting point in the intervention of a "vacuum" in this personalized intervention scope of intervention.

At present, the reality studied indicate that existing rules and laws regulating rather a "frame of reference" and not a law clearly with useful guides that you can access both specialist and caregivers; it is required specialization of the entire staff, from the caregiver to the medical doctor who treats palliative, without emphasis on the individuality and uniqueness of the person, often treating the client/patient, depersonalized. Supervising staff involved, to follow the counselling and support for them, this imposing them at each level of care/service centre.

To initiate a code of ethics at the level of each unit of caring for persons with dementia that will provide principles and models of intervention that will respect the ethics and professional conduct processed and assumed by each employee.

It is established an overloaded "workload" for caregiving personnel, which can impede caregivers, contributing to situations of abuse.

Social work as a profession, i.e. professional social worker, is responsible for ensuring the well-being of the person and of the family support network, namely in health care institutions; "starting from the premise of a higher level of requests, taken up to depression for caregivers-after some studies up two times higher than among the general population), the inclusion of people with Alzheimer's type dementia in specialized programs: in-home care, up from day care centres, or respite centres, will allow families to relieve a number of tasks of care, and an increase in the quality of life and for them (Ory, et al., 2003).

In conclusion, it is necessary to shaping a highly specialized interventions in gerontologic social care assistance in the case of persons with dementia and their caregivers/staff respectively, to have fundamental model of personalized intervention (Krogsrud, et al., 2006), a supervised activity designed to facilitate the protection of the rights of the beneficiaries (the sick, or caregivers) and adapting ethical models of intervention for personnel use.

Specific specialization, qualification in social gerontological nurse at the level of higher education institutions, will allow the formation of highly qualified experts, ready for a specialist intervention (Karen-Ashman, et al., 1997), (Karen-Ashman, et al., 2001), thus avoiding proper ways to act under the aegis of own moral or ethical subjectivity.

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