

SOCIAL POLICIES REGARDING GERONTOLOGICAL SOCIAL SERVICES FOR ALZHEIMER PATIENTS AND THEIR CAREGIVERS

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Abstract

The present paper approaches a current social issue of the European contemporary society, from a general point of view, and for the Romanian society in particular. By synthesizing the main ideas resulted from the whole endeavor, the research aims at taking an account of the pertinent ideas related to the improvement of the activity in the Romanian environment for the Alzheimer patients, in favour of the persons involved but also of their caregivers and of the community, in general, starting from the gloomy premise according to which there is an obvious lack of preoccupation in what concerns the administration of social policies and of separate budgets for the Alzheimer disease. Method applied is observation, which was used as a base for the case study, respectively a questionnaire investigation. Results of the study, first of all, indicates the involvement of the family, services and community, the specialty investigation and thereof, the European actions regarding the Alzheimer dementia, the good practice methods etc., representing the main concern of gerontological social services. In conclusion, we managed to prove that all the informative and innovative steps approached in order to draw up the present research has reached its purpose, that is, to set up a social services outlook, in favour of a vulnerable category, less known, acknowledged and supported by means of adequate policies and services. The Research succeeds in reviewing the international purchase of knowledge and medical, psycho-social, juridic, organizational intervention, constantly bringing in close-up the role of interdisciplinarity, when approaching the complex problem of elderly people suffering from dementia.

Key-words: social policies, social services, gerontological intervention, Alzheimer dementia, European initiative

Introduction

Currently, in Romania, all the specialty literature regarding the Alzheimer dementia, goes for a medical approach in particular, more exactly, for the medical (Smith, 2000, p.119) and psychiatric pattern, except for the paper „Alzheimer: patient, family, society-assisting intervention, Morcan O., 2013” and other studies and papers published/translated from international literature.

Nevertheless, we can take into account another dementia pattern which is considered, by many specialists as being more practical (Smith, 2000, p.119) as it not only aims at the individual needs in the case of every person diagnosed with Alzheimer dementia, but it also looks for and provides personalized methods for complying with such needs, according to everyone's particularities.

The reason for such an intervention is to offer more opportunities of intervention for an extended, personalized model, in accordance with the individual needs of the collateral victims of this disease: the Alzheimer patients and their families, respectively their caregivers. Ever since the 70s, the Australians have been boasting with a non-medical intervention model while in Romania, in 1999, maybe even 2000, „the Alzheimer dementia was not even registered in the diagnosis nomenclature of Romania, being forced, we, the specialist doctors, to prescribe treatments for organic psychosis”; therefore, we can explain why, the interference of the social services occurred so late, in a field entitled from this practice point of view.

Ever since, Marry Marshall has been focusing on the importance of creating a "bridge" (Smith, 2000, p.119) between the services provided in the case of Alzheimer dementia and research.

Besides having managed to develop this intervention pattern, her greatest merit is the fact that she succeeded in implementing it as a distinct model „the other half, equally important” which she has used and disseminated as a distinct model of administration in comparison with the other patterns employed in the case of dementia at that time. Many authors consider that many of the problems and difficulties the Alzheimer patients go through could be minimized if the society was more benevolent and if it tried to understand that „Actually, the brain matter represents just half of the problem – in dementia, everything revolves around the patients' trials of communicating and coping with the situation.” (Smith, 2000, p.120) The rules for assisting the Alzheimer patient are the same as in the case of any service addressed to elder people; the only thing that is different are the individual needs.

The Alzheimer dementia has an outstanding impact not only upon the affected ones, but, to a troubling extent upon the entourage, their appartenance community as well as upon their caregivers. Most often, the first contact is not meant for therapy but for evaluation: what the family knows about the old man's situation and about his disease prognosis. According to the unified estimation of Vickery (apud. Colshed, 1993, p.22), the social services worker will have to take into consideration the weak points of the situation at individual, group, neighbourhood, organizational and environmental level, asking himself/herself questions.

Methodology

Being a qualitative research we used the observation, that served as a base for the case study, respectively, the questionnaire inquiry focused on the case study.

The Research Objective

Analyzing the specialty literature as well as the wide range of services and the legislation corresponding to this intervention segment, I can claim that this is the major discrepancy related to the intervention abroad and what is desired to be achieved and what is happening in our country at the moment. While in our country we can speak about primary intervention services at the most, the psychosocial dimension of the intervention and its multiple implications has been very well-perceived abroad.

I consider that it is extremely important to focus all the efforts on the improvement of the services provided for the Alzheimer patients and for their families. According to Smith, (Smith, 2000, p.71) the first stage of the Alzheimer dementia is the period when the family should get into contact with the "local" support networks, which, unfortunately are not very popular in our country, with the exception of a few such centers from the country.

In 1997 and 1998, the first scientific preoccupations regarding this problem came from the European Commission which, approved a budget line for implementing certain measures for helping the people suffering from dementia in general and from Alzheimer dementia in particular, both in the case of patients and caregivers. Several projects have been launched: *Diagnosis and therapy*, *Performing a maintenance therapy for minimalizing the comorbidities associated with dementia (the example of depression)*, *the Control of distress-causing symptoms*, *Information and support for the caregiver*, *Sustained counselling and support*, *Support and counselling in the terminal stages of the disease*, *Periodic assistance with ADLs or IADL and full support for all ADL and IADLs*.

There has been another main project of the E.U. regarding rare diseases that emerge in case of rare forms of dementia. A new system of classification for such rare forms of dementia was created. The EU also supports EADC (European Alzheimer's Disease Consortium) that is, a full functional network of the European centers of excellence that operate in the field of Alzheimer's disease. They provide a scientific frame for a better understanding and development of some prevention, slowing down or improvement methods of the primary and secondary symptoms of BA.

A European consensus was achieved in what concerns the lack of a full package of care providing services for the patients with dementia. In that moment, the idea that offering support just to the patient's family would solve the problems triggered by the care providing methods in the case of dementia was totally rejected. In France for example, as almost everywhere in the world, the Alzheimer dementia affects a great part of population, that is, approximately 6% of the people over 65.

Nowadays, in France, the Alzheimer dementia diagnosis is put in an advanced stage and the treatment of the people with Alzheimer dementia varies considerably. In Romania unfortunately, up to this moment, the only institutional rapport is the one with the Romanian Association of Alzheimer, and other few governmental and private centers in the country; but we cannot consider the

existence of a legislative frame, of specialized services which to be useful both for the persons with dementia and for their caregivers, financial facilities, or a special attention from the state. The importance of such diseases was long ago, acknowledged at European level, both by the Commission and by the EU Parliament and Council. The action that resulted included the resolutions of the European Parliament, together with the budgetary funds allocated for projects that are specific for this field. The white book „Together for health: a strategic approach for the EU 2008-2013” of October 23rd, 2007 (COM, 2007-630) describes the health strategy of EU11 and identifies the need for a better understanding of neurodegenerative diseases such as Alzheimer dementia, in the context of the demographic aging process. The European Council has recently adopted two series of conclusions regarding the fight against neurodegenerative diseases, especially the Alzheimer dementia, requesting thus the Commission to take action.

The main fight against dementia falls under the responsibility of the member states. However, in the field of health, according to article 152 of the treaty, the Community must encourage the cooperation between the member states and, if necessary to support their actions. Moreover, article 165 of the treaty stipulates that both the member states and the Community coordinate their research and technological development activities, so as to make sure that the national and community policies are mutually compatible. In cooperation with the member states, the Commission may take any kind of initiative that may be useful for promoting coordination.

For these reasons, a joint action is necessary to be carried out between the European Commission and the member states, as they are defined in the working plan for enforcing a specific health programme. This work modality shall be turned into a contribution to the general objective - an improvement of the medical results and, therefore, an increase of a healthy life expectancy, a key indicator for the Strategy of Lisbon.

As mentioned in Gal, D., (coord.) 2012, p. 151 „as we were talking about an acute lack of research in this field, in Romania, two projects are about to be discovered by means of the newest application entitled ”*Assisting, counselling and taking care of the elderly. European models of professional training.*”, under the direct coordination of Conf.univ.dr.Denizia Gal, 2012”.

This book proves to be more valuable for the present study as it is aimed not only at old people in general, but at the old person suffering from dementia in particular.

The book, which introduces the projects, mirrors two major projects, that seem to come in succession, as if in a total symbiosis. *The Leonardo da Vinci Project i-ADEM ”Qualification of Multipliers for the Education of Specialists for Handling Persons with Dementia”*, DE/08/LLP-LdV/TOI/147076 or in translation “Calificarea formatorilor pentru educarea specialiștilor care lucrează cu persoanele cu demență”, is continued by the second *Leonardo da Vinci Project-DUKOM, ”Improvement of vertical and horizontal permeability of competencies in the field of geriatric care”* DE/10/LLP-LdV/TOI/147359, respectively “Creșterea

permeabilității competențelor, pe orizontală și pe verticală, în domeniul îngrijirilor geriatrice”.

From a scientific and didactic point of view, the volume succinctly presents the results of two European projects Leonardo da Vinci ”ADEM” and ”DUKOM”, projects that were carried out between 2008 and 2012 at Babeș- Bolyai University and at the Foundation for the Elderly Care, of Cluj-Napoca, in partnership with other four European countries: Germany (country that initiated and coordinated the projects), Bulgaria, Poland and Spain.

The purpose of the **Project Leonardo da Vinci - ADEM ”Qualification of Multipliers for the Education of Specialists for Handling Persons with Dementia”**, DE/08/LLP-LdV/TOI/147076 (Calificarea formatorilor pentru educarea specialiștilor care lucrează cu persoanele cu demență) as the author informs us, was to draw up a curriculum (education plan/training programme) for the qualification of caregivers, counseling and assisting personnel for the patients with dementia and their families.

The book presents in detail, by means of a series of edifying exemplifications, the matrix pattern suggested for the formation of competences that are specific for the dementia patients care. It presents the development manner of the matrix pattern, under the form of learning modules, on fields of activity. The second chapter of the book is focused on the educational patterns – structured this time, on concrete activities; while, the third chapter presents plans for forming specific competencies for taking care of dementia patients; the author chooses to render the plan for specific competencies training, in detail (for Romania). In the annex of the book, there are two patterns presented for those who want to analyze the topic in detail and that is: the Romanian and Spanish pattern.

The second part of the book illustrates the **Leonardo da Vinci Project-DUKOM, ”Improvement of vertical and horizontal permeability of competencies in the field of geriatric care”** DE/10/LLP-LdV/TOI/147359 (Creșterea permeabilității competențelor, pe orizontală și pe verticală, în domeniul îngrijirilor geriatrie) being structured on three chapters.

The first chapter presents an exploratory micro-research regarding the current situation for training the caregivers and assistance personnel for patients with dementia of Romania. The next chapter draws up a transdisciplinary approach for providing care and assistance in the gerontological and geriatric field, by means of a description of the professions and competences, while in the annex the author illustrates „Plans for professional training focused on competences”. Presentations of the national teams: Romania, Bulgaria, Germany, Spain, Poland in English, in PowerPoint format.

The last chapter systematizes in a comprehensive manner, proposals for “Thematic plans/education units” in two modules, as follows: “Module 1: Knowledge and research and “Module 2: Professional intervention and methodology”.

The target group of the exploratory study was aimed at by professionals and trainers in the assistance and healthcare field for dementia elderly people

(AIPVD). The reason for such a selection was the fact that, these population categories are regarded as experts or, at least, as having knowledge/partial or specific competence for one or another field of interest: medical and psycho-socio-cultural-spiritual.

An extremely interesting aspect is represented by choosing the proportions in what concerns the specialists included in the study: therefore, we are discussing about a group of 16 respondents out of which 8 social assistants, 1 psychologist, 2 theologians, 1 doctor and 4 nurses.

With respect to the research in professional fields, the third question (A3) of the questionnaire, asks the respondents to include the training institutions of reference into one of the known fields of interest for gerontology/geriatrics. In Denizia, Gal (coord), 2012, p. 132 the author discusses the increased share and importance of social services, in comparison with the medical field. Although, under such circumstances, this fact may be due to the professional structure of the group and not necessarily to an authentic reflection of the situation on the training markets, the researcher attributes to the results, a relative value motivated by the appartenance to the initial professional training of the respondents; the necessity of a systematic training in gerontological social services is obvious and clear, with a sub-specialization in the field of assisted intervention in the case of Alzheimer disease.

I am glad to notice that this project scientifically proves the importance of transdisciplinarity within this segment of intervention and the process suggested for the transdisciplinary construction of the training programme for the care of the elderly was started off as part of the project **Leonardo da Vinci-DUKOM**, by taking an account of the geriatrics and gerontological professions encountered in the partner countries of this project.

Among the professions mentioned are: General Practitioner, geriatrician, nurse, community nurse, nutritionist, kineotherapist, professional masseur, psychologist, psychotherapist, ergotherapist, logopedist, social services worker, social pedagogue, spiritual counsellor, cultural animator, nurse for disabled people, caregivers for elderly people/geriatrics caregiver, personal guide and attendant, personal assistant, household helper, operator in residential centers. And for the subsequent analytical steps the professions that benefit from higher qualifications in the key fields have been taken into consideration: medical, psychological, social, cultural and spiritual (see the unabridged content competences as illustrated by the author in the two modules above-mentioned, *ibidem*, pp.140-144).

One should understand that the two European projects that included Romania, represent materials used in the school plannings, in the teaching-learning process, “the process in itself of drawing up these materials being one of qualitative didactic research, with international character” as the author specified.

The most interesting and innovative form of approach regarding the Alzheimer dementia of Romania is represented by the launching of a new concept. The concept known as the “**Alzheimer Café**” was also launched in Romania, on May 11th, 2012. It set off in 14 countries and extended worldwide. Only in the

Netherlands for example, in 1997 a single support group existed while in 2012 their number increased to 200 such support networks, according to doctor William van der Eerden, of the Alzheimer Café, the Netherlands.

The Alzheimer café represents a new innovative method for educating the population in what concerns dementia, for discussing with such patients and with their families, for supporting them. According to dr. Gemma Jones, consultant in dementia care within the Alzheimer café of the UK, the purpose of this concept is *to reduce the tendency to stigmatize Alzheimer patients* and to let them know that they are not alone and that there are support networks to help them.

The concept of the Alzheimer café reached Romania because it is desirable to include Romanian doctors, patients and patient organizations. Moreover, the response of the Romanian specialists is a positive one.

Many development projects do not comply with their objectives or even fail completely because of the fact that the problem they are trying to solve has not been well-defined or understood; because it has not been perceived by a sufficient number of persons, as representing a problem; because it may stem from complex causes which have not been taken into account when drawing up plans and which shall not be therefore considered by the chosen strategy.

More than anything, it is important to train communities or groups that are working in order to analyze and define the problem, as this represents the first step in the development of a civic consciousness. Understanding the structural causes of the existing problems represents the first important step in the opposed direction of apathy or self-blaming that discourages the action. An idea used for conceptualizing the community in connection with the practice has been put forward by Netting, Kettner and McMurtry (1993), idea that includes a number of tasks which the social services worker should sort out in order to get information focused on the following topics: identification of the target population, determination of the community characteristics, acknowledging the differences (oppression/discrimination), correct identification of the structure (existing resources, supplying resources etc.)

When we discuss about generalist practice we notice that it represents: “the application of an eclectic knowledge base, professional values and a wide range of abilities aiming at changes of any system, irrespective of size, in the context of three primary processes”. (Karen-Ashman and Hull, 2001, pp.2-3).

Prefiguring the research carried out in 2013 by Morcan, O., we confirm the fact that there are just a few state funds allocated to the Alzheimer field, both for the Alzheimer dementia healthcare centers and for granting access to the community services for Alzheimer patients. The funds provenance situation is an uneven one; therefore the private funds have an important role, with 65 responses, followed by the mixed funds (state and private) with a score of 41 points. The state funds do not exceed 20 points; the personal funds obtained by the centers are in the same situation. Among the funds that got 7 points we mention: members’ financial contribution, annual funds raising events, urns from shops.

Considering the fact that little money is spent for the Alzheimer dementia research worldwide, (approximately 1% of the world's Gross Internal Product, according to Alzheimer's Disease International) and nationally speaking, the allocated funds represent 3% of the health expenses (according to the Romanian Society of Alzheimer) one can draw the conclusion that within the researched area, the situation favours the private funds. The main financing resources for Alzheimer patients healthcare facilities are closely connected to the private segment; the state does not represent a real financial support in this respect, if considering that, nationally speaking there is no legal frame regarding the Alzheimer dementia.

As part of the responses categories an important place is occupied by social services, having a majority score of 65 points, consisting of financial transfers under the form of rights and of social services, by ample participation of non-governmental organizations and local partners. The second place belongs to the private payment methods with a score of 52 points, consisting of the pensions and other income resources of Alzheimer patients but also of their family members. An average level is represented by the medical insurances and charity funds with a score of 38/40 points. A very weak representation is provided by the state and local special programmes, the programmes for war veterans with scores under 20 points.

Once again we observe limited resources that the state has to offer in order to help the Alzheimer patients; nevertheless, the administration of the funds obtained out of subsidiary resources falls under the responsibility of the Departments of Social Services and of the Local Administration.

The greatest problem in Romania is that, in most cases the disease is diagnosed late, and therefore we cannot speak about an early intervention, of prevention of a sudden and difficult decline. Under such circumstances, an institutional caretaking programme is more valued, in the case of people with serious mental health problems, and the care offered to the patients is a rather medical one. Even if people are talking about a reform, about social policies that promote community care alternatives, about the shaping of a pretty large number of social service workers, the reality is completely different with respect to the practices from hospitals and mental health centers, as they are currently functioning.

Discussions

The reports carried out in the field of mental health revealed the fact that the monitoring procedures carried out before the European integration proved to be beneficial only „on paper” and the great programmes were buried by the authorities indolence. „...most of the specialty literature about psychiatric patients has been written from the psychiatrist's point of view – and the psychiatrist, socially speaking, is situated on the opposite side of his patients”. (Goffman, 2004, pp.15-23) The main problems is that the legal liability of the civil servant for damages produced to the public authority or institution, „according to art. 85 (1) of the Law no. 188/1999 shall be ordered by the issuance by the head of the public authority or

institution of an order or a provision of imputation within 30 days from the establishment of the damage.” (Iovănaș, 2014, p.50; Iovănaș, 2008)

The social policies of Romania should develop an integralist intervention model, centered both on the mentally ill person (with psychiatric problems) but also on his/her family. Fazio, S., (1994) provides a good example from media, according to which a cancer patient is regarded as a fighter, while the Alzheimer dementia patients and their families are called ”non-winners” (losers).

According to another reference survey conducted in 2008 by the Alzheimer’s Association in cooperation with the Gerontology Institute of University of Massachusetts, Boston, they started the research under the aegis of a dictum: ”if the disease represents a reason for the families to get worried then it also represents a reason for us to get worried”, in order to sensitize the society in what concerns the implications of this disease.

Conclusions

The main *objective of social services in the psychiatric sector should aim at re-establishing the individual in the socio-professional and family environment*, giving him/her the opportunity to lead an independent life, in accordance with the individual abilities, and by no means to encourage dependance and addiction by relapsing/returning to a medical/institutional addiction. All these arguments are meant to be a preamble for stating the dementia represents a priority of the E.U. in the field of health and in order to urge the member states to draw up national strategies to provide services and assistance to the dementia patients and to their families.

This fact is rather desirable in our country where the lack of a specific legislation, of some specialty services and of some governmental programmes at national level, has been reflected in the level of knowledge in this field, in the whole country.

In the current Romanian system, there is the tendency of placing these persons on the second place. Only by acknowledging the complexity of the dementia confrontational situation shall we be able to reach an equitable approach which to take into consideration all the affected individuals.

As the Parliamentary Report related to the European initiative regarding the Alzheimer dementia and other dementias (2010/2084(INI)) stipulates, after having gone through these fundamental stages, the different countries should adopt integrated measures moving from research to supplying services of medical, social, psychological and psychiatric assistance. It is important to cover the existing voids in the field, such as professional training, family support (both in what concerns the healthcare and the psycho-social support) and to act so as to sensitize more and more the population with respect to the problems associated to a life affected by dementia.

According to the surveys carried out by Patrick, D.,L., Starks, H., E., Cain, K., C., Uhlmann, R., F., and Pearlman (1994), the general perception of the society

regarding the Alzheimer patients is negative and it is not differentiated at all in the majority population.

The population education is necessary to set forth the obstacles these patients and their families have to cope with. A better understanding of their behaviour and needs would lead to an improvement of their life quality, especially for those who live in the middle of a community and it would also increase the acknowledgement degree for the work carried out and for the limited capacity of the local centers. Ideally, this type of education would lead to more financing and support resources. Although a minimum financial compensation is being granted on condition the person's health situation corresponds to a certain degree of disability „In reality, community care means family care, more exactly care provided by daughters to their old parents” (Prelici, 2001, p.112), or, in other more serious cases, by the old and sick spouse.” (Gal, 2012, pp.158-159)

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