SELF - NEGLECT IN ELDERS: A WORLDWIDE ISSUE IGNORED IN ROMANIA

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Abstract

Purpose: This paper reports the partial results of a study which aims to compare medical, social, psychological and behavioral self-neglected elderly hospitalized in three geriatric units from Finland, Greece and Romania. In this paper we sought to identify the particularities of the self-neglected elders from North-Eastern part of Romania. Methods: Patients were assessed using data from their medical files and questionnaires that included comprehensive geriatric assessment tools, economic and social details, psychological and behavioral elements. Results: Data obtained from 30 patients has been analysed; the average patient age was 76,84 years, 60% of them were women. Further analysis showed that 60% were brought to hospital by ambulance and only 16,67% benefited from a good family support. The monthly income in more than half of elderly (53,33%) was less than 1000 RON 83,33%. Patients had comorbidities, most frequent cardiovascular and psychiatric disorders. Starting from the results of this study we analyzed the ethical dilemmas which are raised in elderly patients, based on the principle of doing no harm, the principle of autonomy, family's responsibility of protecting its members, society's responsibility of protecting its citizens and also the topic of clinical and legal competence. Conclusions: Due to various factors involved in self-neglect in elders the intervention must be complex involving family, community, social and medical services and also considering the ethical principles, civil and privacy rights of every elderly patient.

Keywords: *self-neglect, elderly, abuse, ethics.*

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Introduction

Self-neglect is a behavior of an elderly person that threatens his/her own health and safety. This condition is diagnozed in persons who refuse to adequately feed, water, shelter or clothe him/herself, refusing medications or medical care and personal safety measures. Studies from United States, Canada and Western European countries [1-3] draw attention to the fact that in elderly people self-neglect is the most frequent form of abuse. In a population-based study of Texas adult protective services [4], 62, 5% of the clients were referred for self-neglect, with 90% of the self-neglect cases occurring in persons aged 65 years and older.

The self-neglected elders frequently live alone, are socially isolated, suffer from physical or psychiatric illness (e.g. Alzheimer's disease), and severe depression. This form of abuse is found more frequently in those with advanced age, in women, those with a low educational level and low income. [5]

First described in 1960 in the United States and Great Britain, self-neglect was called the "Social Breakdown Syndrome" or "Senile Breakdown". Some authors use the term "Diogenes Syndrome" for those who live in squalor, a specific feature being the fact that they gather useless things and deposit them in their home; but this illness is also identified in youngsters with psychiatric problems and personality disorders. [5-8]

Given the increased number of cases of self-neglected elders, the problem had to be reglemented by law. In 1987 the American legislation through Older Americans Act Amendments defined three types of elder abuse: domestic abuse, institutional abuse and self-neglect - the abuse to him/herself. This subject has an increased importance because it has an ongoing growth (is mentioned an increase of 34% from 2000 to 2005) and because self-neglect is a marker for increased mortality independent of cognitive function or physical condition. [1,9-11]

Worldwide, many studies have been published on self-neglect, such as CHAP (*Chicago Health Aging Project*), which is the most quoted in the medical literature, but we have not found reliable data relating this issue to medical, social, economic and population realities in Romania.[12,13]

This paper reports the partial 12-months results of a study which aims to compare medical, social, psychological and behavioral self-neglected elderly hospitalized in three geriatric units from Finland, Greece and Romania. In this paper we sought to identify the particularities of the self-neglected elders from North-Eastern part of Romania, the causes that lead to self-neglect and the medical, social, psychological and behavioral state of self-neglected elderly.

Material and method

Patients were assessed using data from their medical files and questionnaires that included comprehensive geriatric assessment tools, economic and social details, psychological and behavioral elements. The Romanian study was conducted in the Geriatric Department of "Dr. C.I.Parhon" Hospital, Iasi.

Our study was conducted on 30 patients who were hospitalized in the last 12 months for severe medical conditions either due to self-neglect or inability to comply with medical recommendations. These patients were selected according to one of the following criteria based on the Pavlou and Lachs definition of self-neglect [14]:

1. Persistent neglect to personal hygiene and/or compliance to medical recommendations;

2. Repeated refusal of receiving medical/social services which can be expected to improve quality of life;

3. Self-endangerment through the manifestation of unsafe behaviors (e.g. persistent refusal to care for a wound, creating life-hazards at home, alcohol abuse).

As part of the comprehensive geriatric assessment we collected demographic data (including age, gender, urban or rural area), medical data (chronic concomitant diseases, chronic medication, and alcohol consumption), social data (non-self sufficient or complete dependent person, family support, existence of caregivers), and economic data (monthly income, personal hygiene, living condition and household). [15,16]

The dates about family support were collected though a cross questionnaire applied to caregivers, patient, family members and even medical staff which accompanied the patient at admission.

All elderly self-neglected were evaluated in terms of personal appearance and environment status taking into account that self-neglect is associated with defective personal hygiene and deficient living condition and household.

We assessed general appearance and specific aspects as skin, nails and hair condition, oral cavity aspect including teeth and even clothes appearance.

All patients underwent a complete geriatric assessment. An international accepted battery of assessment tools was used as part of the global geriatric assessment. All subjects underwent cognitive evaluation using *Mini Mental State Evaluation* (MMSE), nutritional evaluation using *Mini Nutritional Assessment*® (MNA®) and evaluation of the existence of depression using *Geriatric Depression Scale* - 4 (GDS - 4). The assessment tools were carried out in collaboration with both the patient and family or caregivers (wherever necessary). Data were collected by the personnel involved in the study and statistically analyzed.

Results

Our patients were aged between 65 and 88 years old with an average of 76,84 ± 7,15; 50% were aged between 75 and 85 years, 33,33% were part of the "young-old" group (65 to 75 years) and 16,67% part of the "oldest-old" group (over 85 years). There is a definite predominance of rural-belonging patients (73,33%) versus urban, a fact according to demographic distribution in our region. The patients were brought to our hospital mostly by ambulance (60%) or by family/caregivers (36,67%). Only 3,33% came by themselves. Even though almost half of them were brought by their family, only 16,67% benefited from a good family support, i.e. moral and financial support, and help with the activities of daily living. One of the selected patients held a university degree, but most of them graduated a primary school or gymnasium (43,33% and 33, 33% respectively) and only 6,67% graduated from high school.

The most frequent cause for hospitalizations was acute de-compensation of various cardiovascular disorders: heart failure (46,67% cases), arrhythmias (46,67% cases), hypertension 43,33%), ischemic heart disease (16,67%). All these patients had several comorbidities, including mental disorders such as depression and dementia 43,33% and 46,67% respectively and metabolic disorders (diabetes mellitus in 16, 67% of all

patients and malnutrition in 43,33% of cases); 13,33% of patients were chronic alcohol consumers, being equally distributed in the age groups.

Data about chronic medical treatment were available only in 50% patients who were following at least partially the prescriptions. The drugs frequently taken were cardiovascular agents (40% of patients), medicines for respiratory and pulmonary conditions (20% of patients), diabetes (6,67% of patients) and neuro-psychiatric agents (13,33% of patients).

Patients' general appearance was various at first evaluation: 60% were confused, 50% agitated, 26,26% with dementia, 13,33% depressed, 10% aggressive and normal or with no response 3,33% each. At admission personal hygiene was poor and very poor in 70% of participants (36,67% and 33, 33% of patients respectively) and in 10% of the enrolled elderly patients lack in personal hygiene even endangered their life. We have found following aspects: the skin was dirty and dry in approximately even percentage of patients 76,67% and 80%respectively, was wounded in 20%, inflamed and with bruises in 36,67% of elderly and 10% of patients had pressure sores. Nails (from hands and feet) were long, untrimmed and very dirty in over half of the assessed elderly (56,67%), trimmed but dirty in 40%and only one patient had trimmed and clean nails. Oral hygiene was deficient in all subjects, 70% were having profuse cavities and 30% cavities, reflecting also social and economical status even medical education. Hair was dirty and very dirty in most patients in approximately even percentages 40% vs. 50% respectively and in 3,33% pediculosis was detected; clothing aspect revealed following aspects: soiled in half of patients (46,67%), very soiled with odor (e.g. incontinence) in 36,67% and the rest had torn and soiled clothes.

Environment status of subjects could not be evaluated in all participants; data was collected from either the family or caregivers or ambulance crew in 70% of participants. The general condition was poor and very poor in 33,33%and 9,52% respectively, moderate in 28,57% of cases. Our questionnaire included a series of questions about household and house condition; these were answered by the persons who accompanied the patient into the hospital. After analyzing the questionnaire, data obtained suggested an important deficiency in house hygiene. In 62,55% of subjects house insides was dusty, unpleasant odor and sordid; in 56,25% the sheets were yellowed and filthy and the bed corrupt, dirty and with an unpleasant odor. In 68,75% of cases the walls had holes in sheet-rock and in 81,25% the windows were unwashed.

We collected data about the monthly income in 86,67%of patients; the rest of the patients (13,33%) either had no income or had an income but we could not appreciate the amount (equally divided). The monthly income in more than a half of the elderly (53,33%) was less than 500 RON; 30% had an income between 500 and 1000 RON and only 3,33% an income more than 1000 RON. Noteworthy that only one of the enrolled patients had an income greater than 1000 RON. The monthly income is an important variable in our study as the economic factors along with the social status and the social and familial support contribute to the phenomenon of elderly self-neglect.

Results of Geriatric Assessment Measures

Our results showed that 76,67% of patients achieved an abnormal score on Mini Mental State Examination (normal ≥24), 36,67% scored for moderate

dementia, 10% for severe dementia and 23,33% for mild cognitive impairment.

Evaluation of nutritional status revealed nutritional disorders in the majority of the patients, only 4 patients had a normal nutritional status and the rest were either malnourished (36,67%) or at risk of malnutrition (50%).

Approximately half of patients who underwent the Geriatric Depression Scale - 4 (GDS - 4) had scores significant for depression and they were subsequently psychiatrically evaluated.

Analyzing all collected data we found that in 60% of cases the patient understand and recognized his/her status and even wanted qualified help (40%). The main problems and disorders which correlates with self-neglect as noted by the examinators are: cognitive disorders (26,67%), mood disorders (23,33%), financial problems (23,33%), lack of family or social support (13,33% and 30% respectively) and decline in executive function (as percentage of total patient)

Ethical considerations in the case of self-neglected elderly

The ethical dilemmas frequently raised in cases of self-neglected elderly relate to the family's responsibility of protecting its members, society's responsibility of protecting its citizens and also the topic of clinical and legal competence. Many times the principles of autonomy, beneficence and doing no harm are to be carefully balanced in evaluating each particular case.

Perhaps the most frequent ethical dilemma in practice is the effort to respect the expressed wish of the patient (autonomy) while respecting the principle of nonmaleficence and protecting the patient from harm. It is not uncommon for elders to act in ways that place themselves at risk or to choose to remain in risky circumstances. In such cases the professionals, society and even family confront themselves with a dilemma. Professionals may consider that respecting the autonomous wishes of such an individual may be in direct conflict with their judgment of what is in the patients' best interest. We also have confronted with this dilemma because some of our patients refused our qualified help. In those cases we assessed their cognitive status, we discussed the matter with their family, with a psychologist and even with a priest to search the best way to resolve the matter. This also raises the question of whether society's role changes when elderlys experience a high degree of functional loss which endanger their lives. Perhaps the correct mode to resolve this problem is to determine if the patient is competent and, if confirmed, his/her right to refuse any intervention is to be respected. [17,18]

The assessment of the decision making capacity both clinically and legally is a challenging task in assisting these patients. The assessment can be imprecise, a person's legal and clinical capacity can vary over a period of time, even a few hours, making difficult a decision that can have secondary implications involving not only the patient, but the family and the society. The health care professionals must look for reversible causes that may lead to an impaired decision making capacity as severe depression, social or economical stresses which treated or resolved may lead to an totally transformed elder who is no longer a danger for himself or for the others. We identified some of these reversible causes in our group of patients such as lack of family or social support, financial problems and even depression.

The actions of the elderly may have consequences for other people and may put themselves and others in danger.

Such case is when a competent and sound minded elder wish to live in squalor, his home is infected with animal and rodents and so the harms are present either to the neighbors or to the community directly. This situation generates a new conflict, namely the respect for the individual rights versus the respect for the the rights of the community affected by squalor and other negative aspects from a self-neglectful neighbor. What is the appropriate solution in this case because this case not only brings ethical dilemmas, but also civil and legal issues. [9,17-21] In our study we did not confront with this circumstances because our patients were brought in for acute medical problems which were the top priority.

Discussion

The partial data obtained from the Romanian part of the multinational ongoing study emphasizes the importance of self-neglect among the hospitalized elderly, especially as we have not find any significant data regarding self-neglect in Romanian elders. The great risk and severity of self-neglect was associated with an abnormal cognitive and executive function and a poor economical and social status. Many of our patients were having a poor or absent family support and/or financial problems (54,17% of self-neglected elders had an income less than 500 RON). This emphasizes the importance of a good family support (moral support, financial support, help with the activities of daily living) especially since nowadays we are dealing with migration of young population to highly developed countries with increased living standards, thus elders are left alone and neglected. Here should intervene social self-help policies for elders, providing not only financial help but also social and medical help (from help for daily activities once or twice a week to institutionalization).

Each and everyone has an important role in the severity and prevalence of self-neglect in elders therefore the team who participated in the study was complex and gathered geriatrics, emergency doctors, nurses, psychologists, social workers, emergency crews. These all contributed not only to identify but to diagnose, help with the treatment and social assistance after hospitalization.

This is the first study on this topic in Romania in the last 20 years and it is meant to open the way for further studies because this subject of self-neglect in elders has an increased importance, self-neglect being a marker for increased mortality independent of cognitive function or physical condition.

It is not known yet how to manage self-neglect without interfering with ethical principles, individual's, personal values, civil and privacy rights. Whenever possible, after patient's acceptance the intervention should be complex (there are involved: family, community, social and medical services) and multifactorial in order to influence the multiple causes that lead to self-neglect. We believe that the patient's family should be the center of the therapeutical approach, highly sustained by social services and voluntary societies. However, recent changes in social and economical status of Romanian population decreased family role in assisting their elders, while social services are still not coping with the increasing number of self neglect population.

Limitations

There are a number of limitations of this study. We present only the Romanian results, therefore we have a

small size of the sample. The subjects included only elderly who were brought by the family or ambulance to our hospital for medical problems. There are no data about elderly self-neglected in general population - in our region or our country - because the lack of the studies.

Some information - i.e. information about living condition and household - were collected from the third parties not directly, but, when possible, were questioned two or more caregivers and the results confronted.

It was difficult for us to imagine a control group because of the lack of previous Romanian studies and the complexity of the problem and the studied group. Our study reveals that there is no medical/social protocol for identifying people at risk for self neglect; this explains why our study group contained only hospitalized patients.

And finally, we could not perform a full statistical analyze because of the lack of the data from the other centers, therefore when all data is collected new analyze will be performed and will be published in a new paper.

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