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Perceptions of Life Burdens and of the Positive Side of Life in a Group of Elderly Patients with Diabetes: A Qualitative Analysis through Grounded Theory

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Abstract

The study focuses on discovering what the main concerns of frail elderly people diagnosed with diabetes are, in terms of perceptions of their lives burdens and their distinctive views on the positive side of life. In the study, there were included 57 individuals, of both gender, aged over 60 years of age (range = 60–91 years of age, mean = 76.42 years) and diagnosed with diabetes, from two primary care offices from the county of Iasi, Romania. For each of them, we conducted open interviews, and consequently we analyzed and coded the data accordingly to grounded theory. The management of diabetes implies adjustments of diet, non-pharmacological strategies, medication, caring, and also the choice of being compliant or not. Following the inductive theory, there have been identified the following concerns and expectations of elderly diabetic patients about everyday living and their remaining life: reducing their efforts accordingly to the cumulus of diseases and the decline of their quality of life, not being a burden for the family members, maintaining their dignity in front of younger generations, controlling the evolution of their diseases, conceptualizing life satisfaction. The

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concerns of frail elderly people are preserving their self-esteem and how they are perceived by the community, being useful to their closed ones. The emerging theory shows how the diabetic elderly individuals are coping with their illnesses, with medical support in order to induce positive changes in their remaining life.

Keywords: elderly diabetic patients; grounded theory; life satisfaction; compliance; life burden; social features.

Introduction

A cluster of factors helps physically and socially vulnerable elderly to cope with their everyday lives and burdens and feel quite well. A good quality of life may affect both self-reported health and the measured physical state (Benyamini et al., 2000). Diabetes mellitus is a complex condition, by its progressive character associating and inducing a cumulus of morbidities (Parry et al., 2004). Type 2 diabetes and secondary diabetes also are more often encountered in adults and elders. In this context, risk factor' management strategies in order to reduce the morbi-mortality rate have a wide range of variety (Croxxon, 2009: 21). From medical point of view, an important subject is the diagnosis of diabetes and the recognition of its type, because biochemical changes, metabolic abnormalities and finally hyperglycemia may develop gradually and silent, clinically unapparent, for many years until the symptoms and signs are detected and recognized. Undiagnosed diabetes is commonly met in the elderly population. The long subclinical diabetes evolution is associated with increased co-morbid conditions but also with a higher mortality (Van den Arendet al., 2000; Alexa et al, 2012). So at the moment of diagnosis the macro- and microvascular complications may already be developed (UKPDS, 1998a). It is important that disease management, pharmacologic and non-pharmacologic treatment, begins promptly once the diagnosis has been made (UKPDS, 1998b), a marked role being that of diabetes and its complications self-management.

Consistent with the WHO statements, 280 millions people are diagnosed with diabetes today, and 55.2% of these are living in Europe. In accord with prognosis, in the next 20 years, this number will augment to 380 millions. Some causes for this growing number are the multiplied number of cases in developing countries, the demographic burst, the growing process of getting old, vicious diets, obesity, and sedentary life. Till 2030, in developed countries, most of diabetic population will be 65 years of age and older, while in developing countries, most patients will belong to the active range between 45 and 64 years of age.

Geriatric means pertaining to old people, and WHO defined in 1963 people of middle-age as being 45-59 years, elderly as being 60-74 years and the aged being over 75 years of age. In developed countries, young old is 64-75 years of age,

aged are 75-84 years of age, oldest old are older than 85 years of age, while frail elderly are those older than 65 years of age with significant physical and cognitive health problems. In human terms, the elderly should be regarded by society as a useful resource because of their knowledge, skills and experience, but the aged most often need assistance. Applications of the psychosocial aspects of aging can assist the healthcare worker in providing compassionate, appropriate medical care for the aging individual. There are three major psychosocial theories of aging: disengagement, activity and continuity (Gavrilovici, Cojocaru & Astarastoe, 2012). These three theories focus on how elders deal with the *golden years*. The proportion of elderly grew considerably in the last decades, partly because length of life increases. Many of the elderly are quite healthy but several of the elderly living at home, in assisted care, or in the hospital have chronic and complex diseases, one or more disabilities, and/or multiple medical diagnoses (Helvik et al., 2011). In spite of serious debilitating physical conditions, elderly ones are often quite happy and comfortable with their lives. According to Eurodiab study, in 2010 the incidence rate of diabetes in Romania, for the group of age 10-14 yrs, was 7 cases/100,000 population per year, with a mean for 0-14 yrs of 5.4 cases/100,000 population per year; Romania exhibits one of the lowest rates in Europe (Soltesz, Patterson & Dahlquist, 2010). In the county of Iasi, in the last 20 years, there has been registered an increase of diabetes incidence, and the prevalence is 3.5% in 2011.

Grounded theory was originally developed by Glaser and Strauss as a mean to make possible the ‘systematic discovery of theory from the data of social research’ (Tavakol, Torabi & Zeinaloo, 2006). The focus of grounded theory is on generation of categories by the subjects themselves, not on typologies à priori created by the researcher, being similar to phenomenology (Garson, 2012). In the last two decades, there has been an increase in the number of published papers using “grounded theory” as a research method in the health care system that provides a systematic way to generate theoretical constructs and concepts to illuminate human behavior and the social world and their interrelations (Jeon, 2004; Cojocaru & Cojocaru, 2011). Research on doctor – patient relationship has highlighted its importance, the communication between them, the reactions and attitudes of health professionals being essentials for the patient to understand the disease severity, in order to obtain the therapeutic and educative compliance (Dietrich, 1996; Cojocaru, Cace, & Gavrilovici, 2013). The aim of this grounded theory-study was to reveal concerns of frail elderly people diagnosed with diabetes in terms of perceptions of their lives burdens and their distinctive views on the positive side of life.

Method

The study included elderly outpatients of both genders diagnosed with diabetes and with a broad spectrum of other clinical problems including one or more disabilities. This elderly group, with a range of age between 60 and 91 years, with and without a declared stress, allowed a large amount of collecting data and patients' experiences. The grounded theory helped us to put in evidence particular characteristics of this group concerning behaviour, mood, and way of thinking and facing life changes due to diabetes, interrelated with their socio-economic status, variant occupational background and level of education, and their special place in the family and community. Qualitative study provided by grounded theory allows the patients to express their feelings, reactions and behaviour in their manner, and by generating concepts and theory from the data to study the ongoing processes (Glaser & Strauss, 1967). Symbolic interactionism focuses on how people define events and realities and how they behave based on their beliefs and experiences (Evans, 2001). Within human interactions, grounded theory has its place to explore the social processes. Through grounded theory, researchers develop explanations of key social processes that are grounded in empirical data (Hutchinson, 2001).

Choice of subjects for gathering rich data

Attendees in the research group

In the study, there were included fifty seven individuals, of both gender, aged over 60 years of age (range = 60–91 years of age, mean = 76.42 years) and diagnosed with diabetes, from two primary care offices from the county of Iasi, Romania. Among them, 34 are men with a mean age of 75.5 years old, ranging from 60-91 years old, half of men are at most 74 years old. Only two of them are widowers, of 82 and 91 years old. The remaining 23 persons are women with a mean age of 77.8 years old, ranging from 60-91 years old; half of them are at least 78 years old. Twelve women are widows, with a range of age between 67-91 years old. The majority presented a diagnosis of arterial hypertension years ago before the diabetes was discovered. Some of them developed chronic renal disease, peripheral neuropathy and retinopathy. There were 14 people diagnosed with depression and diabetes as well, 10 women and 4 men.

Sampling

Among the patients enrolled in a larger study, the first recruitment criterion was the age. Because of different definitions of geriatric age among countries,

first we entered people beyond 65 years old (retirement age in developed countries), but later we enriched data with the group of people with age range between 60-64 years old (a border of retirement age in developing countries). The most important criteria that splitted the initial group was the diagnosis of diabetes, and so it resulted in a group of 57 individuals aged over 60 years old. The goal was to compare the reactions, the main concerns and feelings of frail elderly people diagnosed with diabetes, in terms of perceptions of their lives burdens and their distinctive views on the positive side of life, and also the adapting changes in this group. The selection was guided by the idea to sketch a large image of the broader variability of experiences, by gathering elderly individuals with different marital status, level of education, somatic health problems, duration of illness, and psychological stress disclosed or not during his early life and adulthood.

Participants' characteristics

Four women have duration of diabetes over 12 years, one of them being diagnosed 22 years ago, now aged 81 years old. She, a military widow, has a medium pension (1,000-1,500 lei/month), secondary education, and over the years developed hypertension, coronary artery disease, cardiac insufficiency, atherosclerosis, hypercholesterolemia, cerebral atherosclerosis, depression, gallstones, and cataract. She is under oral antidiabetic treatment for 14 years. Three women were diagnosed with diabetes in the last year; their ages are 91, 83, and 69 years old, the first being a widow. All of them have low retirement benefits (under 1,000 lei). The eldest graduated high school and the 2 others graduated the secondary school. Sixteen women from the group have diabetes without renal failure; ten of them did not developed peripheral polyneuropathy, and among these nine are free of retinopathy. Twenty-five men did not developed renal insufficiency; sixteen of them did not have a diagnosis of polyneuropathy, nor of retinopathy. Four diabetic men had developed stroke with secondary disabling, on a background of peripheral artery disease.

Open interviews

For each of them, we conducted an open interview, and consequently we analyzed and coded the data accordingly to grounded theory. M.G. F. conducted the interviews for one year and a half, covering the period from January 2011 until June 2012. The individuals are in the care of two general practitioners from two primary care offices from the county of Iasi, Romania. Each patient was interviewed twice, at the first the duration of questions and answers was of one hour, and the second one lasted almost half an hour, being taken after a mean period of 6 months. The anamnesis and the whole conversation was directed, as Lofland and Lofland, 1983, said it is the best way, but as the conversation developed the patient was encouraged to talk, such that the researcher could get

interesting leads and rich data, also depending on our theoretical perspectives. The way the conversation went on depended on patient's psychological and physical status at the moment, and on the perception of the empathic behavior showed by the interviewer. At the second interview, the patients were more cooperative, partly due to the trust that the researcher inspired to them previously. This good ambience was enhanced by the warm relationship and confidence patient – general practitioner. The interviews were recorded and transcribed word to word on computer, and at the moment of the interview M.G.F. annotated the reactions, mood changes, the opening to the interviewer, and differences in handling challenging situations.

Procedure and ethical considerations

The interviewer M.F. met the invited elderly individuals at their GP's office. She was not involved in their treatment. The patients were informed orally about the project and signed an informed consent.

Data analysis

Theme categories initially comprised symptoms related to diabetes and comorbidities, addressability to health care system, reaction to diabetes diagnosis. By developing the interview, we enlarged the area of interest to focus on patients' anxiety, concerns, the possible reliance on family, friends, the medical strategies and compliance to them, and changes to be done in adjusting to the new settings.

Practical coding in grounded theory

In the development of a grounded theory, coding is an essential step to accomplish (Charmaz, 2006: 46). The link between data and emerging theory is coding. It also helps you to stratify and categorize data and understand what it means. From the first data we began to deduce as many questions and ideas, and to encode them in an initial coding. The authors frequently got together and discussed coding systems, how to get the most of the collecting data, and tried to find the core categories.

Memo-writing

In her paper, Charmaz, 1990, suggested the following chain of feelings: Trusting - Encompassing / Accepting - Cooperating - Expanding / Growing = Changing/ Adapting? For example, how patients understand, integrate and intermingle the diagnosis upon their experiences, including the ordering and timing of events, the roles played by various specialists, patient degree of satisfaction with diagnosis delivery and perceptions of unmet needs. But what is the patient reaction? How

does he perceive disclosure of diabetes diagnosis? Is it the first burden on his shoulders; is it the second or one of the many problems that gathered along years? Does it make him/her depressive? Does he/she realize being depressive and address himself/herself a specialist for treatment? Do any healthcare care specialists, to whom they address for varia conditions and complications, apprehend that their patient would be depressive? Which are the positive factors that might help him/her living with this condition, without changing his/her life to 180°?

This new approach is put recently into practice, but in most countries is only part of the tertiary or secondary prevention. The new protocols on prevention of hypertension complications, of diabetes or diabetes co-morbidities are presented to general practitioners and specialists. A part of them, believing and thus embracing this concept, adapted and incorporated it in primary prevention.

Patients were asked whether they liked to be referred to a specialist, being addressed to hospital or private clinics, or they preferred to be checked out by their general practitioner after a lab exam. 'I want the best treatment' (some of them specified: 'that I can afford')... 'because I contributed to this country for so many years...', 'because all people in my family are very occupied, and I want to be helpful, so I don't have time to be sick'. During this choice process an important role is played by general practitioner personal features, preconceived notions, medical practice environment, and how GP combine patients' needs and expectations while making treatment decisions. Finding the balance between preventive non-surgical treatment (curing of disease) and rehabilitation treatment is an every moment challenge in a profitable general practitioner practice.

Results

The main concerns of frail elderly people in our study was to adapt to changes induced by diabetes and other associated morbidities, and we end up underlying perceptions of their ongoing life burdens. Our findings are summarized in *Table 1*.

Reducing their efforts accordingly to the cumulus of diseases

Education for varia diseases and, in addition, the diabetes needs time both from GP and the patient. For some, his/her wife/husband or other family members were involved in educational process. The relatives were asked and they accomplished the task of pursuing the drugs administration. Sometimes, for the long distance sons or grandsons there was sufficient one phone call for the patient to be psychically reassured and to remember to take the pills. The educational process is made difficult by patient's conceptions. She /he would rather take her husband/wife or neighbor's medication than going to specialist. In this group there is

another characteristic: since they are listed to their GPs, their education improved and every time they have a problem they address to the GP asking for advice or demanding hospitalization. Probably, this improvement of attitude is due to the fact of cohabitation with sons and/or grandsons, also with the contribution of new technologies like internet, and the strong connections between the family members in sharing health information, thus showing a constant interest in their relatives' well-being.

Table 1. Core categories and coping efforts

Core categories	Coping efforts
<i>Reducing their efforts accordingly to the cumulus of diseases</i>	Education for varia diseases and in addition the diabetes needs time both from GP and the patient.
	Leaning on family, friends, neighbors, and primary care givers
	Terms of comparison with known people
	Coping to depression and other diseases associated to diabetes.
<i>Adapt to changes induced by diabetes and co-morbidities</i>	Family support
	Self-care
	Primary care addressability
<i>Diminishing the decline of their quality of life</i>	Having daily or future tasks to accomplish
<i>Not being a burden for the family members</i>	Rely on people close to them
	Family relationship
<i>Maintaining their dignity in front of younger generations</i>	Sharing life experience
	Inspiring respect to the younger
<i>Controlling the evolution of their diseases</i>	GP's support
	Family contribution
<i>Conceptualizing life satisfaction</i>	Filling the spare time
	Feeling like still existing

Leaning on family, friends, neighbors, and primary care givers. They are waiting impatient for their loved ones to come to them.

Terms of comparison with known people. Living in urban area, most of the interviewed people socialize with their neighbors as they lived in the same block of flats for more than forty years. So in a positive way, they are feeling 'much better, than ...', or some of them are complaining all the time about their social condition and 'how miserable' they feel comparative to others. They also described some good experiences during the hospitalization

Coping to depression and other diseases associated to diabetes. At the moment of diagnosis, the psychological status is imbalanced, so what they reckon to be a positive push up is the empathic attitude and prompt response to their physical or emotional problems coming from their GP. As realizing they have a support,

amazingly, they face their problems easier, and adjust their daily task to a medium or lower level, redimensioning the effort and getting happy by finishing what they started. They learn to ask the younger to help with the more demanding tasks.

Adapt to changes induced by diabetes and co-morbidities

Family support. Because of reduced mobility and equilibrium, visiting the closed ones needs assistance, so they are waiting impatient being visited by their loved ones, or to be brought to their friends or ex-neighbors.

Self-care. When they change place for a short period of time (staying with grandsons, traveling), they pay attention to get their medication and medical records in case they would need medical care. They practice self-determination of blood pressure and glycemia.

Primary care addressability. They address more frequently to their GP. From this group, men who had a military career, tend to maintain an active status and thus their medical and psychical condition, by walking daily for at least half an hour.

Diminishing the decline of their quality of life

Having daily or future tasks to accomplish. It's like a mind therapy/ occupational therapy. If they keep their mind occupied with things they believe that matters for them or for the others, even if they are or not in depression, they are more cooperative with therapeutic strategies. Most of them are dealing with bills and money, so they need to keep up with mental calculation.

Not being a burden for the family members

Rely on people close to them. When they need to confront ideas, either there are conversations husband-wife, or for widows/widowers there is of real help sharing opinions with people of same age, or cultural and religious background.

Family relationship. 'I'm happy with my family, they show a constant interest on my condition... They bought me an automatic blood pressure monitor, which I can easily use... ?'

Maintaining their dignity in front of younger generations

Sharing life experience. Living with children and grandsons, they had the possibility to educate them and give them examples from their own life experiences.

Inspiring respect to the youngers. During the entire period of childhood and adolescence, the presence of grandparents was a benchmark equilibrium and

guidance for good behavior in every stage of the younger's development. Therefore, over the years, old people inspire respect that is reckoned when younger became adults. From the face to face interviews, we apprehended this sense of satisfaction and fulfillment of the very old people with children and grandsons who turned into fine and reliable individuals. This accomplishment was made possible by grandparents' contribution.

Controlling the evolution of their diseases

GP's support. Elderly patients from this group addressed every 2 or 3 months to general practitioner to get their medical prescription and went to pharmacy to get their pills. Once or twice a year they have their lab check up, including blood sugar, biochemical and hematological analysis, and risk factors evaluation. Some of them needed frequent in-hospital admission for intercurrent infections and diabetes complications.

Family contribution. In case of financial problems, due to the high costs of medication, family or relatives meet the needs. Sometimes family intermingle in the relation doctor-patient when it comes to reveal a worsening situation or another co-morbidity that affects the patient well-being.

Conceptualizing life satisfaction

Filling the spare time. Sudden changes in their lives opened up periods of free time that they didn't have or didn't allowed for themselves previously. Filling their free time with useful pursuits is a way by which they increased their creativity, energy, enthusiasm, and sense of fulfillment in life. '...to create something and finish it well'. 'To put an idea into practice and follows its course'. . . In view of local religious believes, they are more preoccupied in the later part of their life to go to church.

Feeling like still existing. '...feeling quite good/healthy and enjoying life as it became'. 'Still being of some interest' for the others. Having a partner and receiving frequent help from family contribute to this feeling of life satisfaction.

The quality of life is given by the individuals' perceptions over their social status, in the context of the cultural systems values they live in and depending on their own needs, standards and aspirations (OMS, 1998). By the quality of life in medicine, it is comprehended the physic, psychic and social wellness, as the patients' capability to accomplish their 'jobs' in their daily living activities.

Conclusions

Humans construct theories in order to explain, predict and master phenomena. The theoretical orientation of grounded theory studies is symbolic interactionism, underlying that human conduct is developed through human interactions, through a continuing process of negotiation. Within human interactions, grounded theory has its place to explore the social processes.

The development of age-related criteria for treating a specific population must address not only the chronological age, but also the emotional state and physical condition of the individual at the time of medical treatment. Assessment of the specific needs of elders is performed on a case-by-case basis. This assessment must be made each time the individual is treated. Rapid physical and/or mental deterioration may be occurring and could significantly impact on an individual's ability to comprehend and tolerate the treatment process. Some degenerative mental conditions may impart a variety of emotions and memory loss that manifests itself in different ways each time the patient is treated. It is important for the health care practitioner to do a rapid assessment and match the treatment to the developmental level of the patient.

The patients' perception and the avalanche of feelings raised by finding out the diagnosis are involved in the understanding and the self-management of diabetes.

As Cummins argues life satisfaction tends to stabilize around certain levels, from the societal (around the society's average) to individual level. Indicators for objective life conditions are health (self-rating of health, long-term illness/disability), education (level of), family (help from family, marital status) (Cummins, 2003).

As realizing they have their GP's support, surprising, they face depression and diabetes easier than younger people. Another psychological support is represented by the priest and church, individuals, as they age, described an inclination to religion. There is a difference between the individuals: women are more inclined to this religious behavior, and men aged before 1945 were raised by their parents in these beliefs, but younger elders attended the religious services some years after the revolution in Romania.

The cultural pattern of this group of elders is *traditionalism*, but because of cohabitation with the new generations, in most cases, the 'modernism' intermingles. People's priority is focused on satisfying basic needs, things happen 'as God wishes' or 'as the chief orders', the society is more religious, more obedient and has more respect for authority, work is seen as an obligation towards the society to make it grow and have a contribution to that, opposition to change is extremely high, family values are very important, intolerance to deviant groups is also higher; *a change in mentality* modifies the relation between social and economic determinants and dominant values and people get worried about the

future in this new political and socio-economical context that face the old individual (Asandului, Ceobanu & Baci, 2012).

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