A QUALITATIVE INQUIRY IN THE SOCIAL CONSTRUCTION OF CHRONIC ILLNESS. CASE STUDY ON DIABETES MELLITUS. DOCTORS' PERSPECTIVES

A. Sandu[1,3], R. Necula[2], A. Frunza[1,3], E. Unguru[3,6], S. Damian[4,5]

[1] Stefan cel Mare University of Suceava, Romania
[2] National College of Social Workers (CNASR), Iasi, Romania
[3] LUMEN Research Center in Social and Humanistic Sciences, Iasi, Romania
[4] Gr. T. Popa University of Medicine and Pharmacy, Iasi, Romania
[5] Institute of Forensic Medicine, Iasi, Romania
[6] University of Oradea, Romania

Antonio Sandu, *Professor PhD, Scientific Researcher*

Roxana Necula, *President of the territorial department*

Ana Frunza, *PhD in Ethics, Scientific Researcher*

Elena Unguru, *PhD Student, Scientific Researcher*

Simona Damian, *PhD, Postdoctoral researcher, Senior forensic pathologist*

ABSTRACT — The present paper is based on a secondary data analysis, and aims to identify the diabetologists' perspective on the relationship between the doctor and the patient in the (co)construction of the process of self-care of the chronic diabetic patient of type 1, in the context of the respect for the patient's autonomy, and of the (co)responsibility for the patient's state of health. The analysis starts from the data obtained within the project of exploratory research *Lifestyle and behaviour in health, for the chronic disease patient*, conducted by an interdisciplinary team in the program "Postdoctoral studies in the field of ethics of health-related policies", between 2012–2013, in a city in N.-E. area of Romania.
The data analysis method used is a qualitative one – the data-based constructionist theory – Grounded Theory, aiming at generating a model after following all the stages of inductive coding, specific for Grounded Theory, which may be the hypothesis for future research, that will validate the model.
The analysis shows the fact that the doctor-patient relationship is an important instance in the process of social construction of the idea of chronic disease, but also of the patient's autonomy in the process of self-care, while the responsibility for self-care is the result of a process of therapeutic education, on whose efficiency depends the state of well-being and the quality of life of the chronic patient.

KEYWORDS — ethical values; medical ethics; qualitative inquiry; social construction; chronic illness; Case study; diabetes mellitus; trust; medical sociology; public health

INTRODUCTION

The current article aims to answer the question "What is the role of the diabetologist doctor in the social construction of the autonomy and responsibility for the insulin-dependent, type 1 diabetic patient's health condition?". The discursive perspective analysed is that of diabetologist doctors. This study is based on

a secondary data analysis, obtained during the exploratory research "Lifestyle and behaviour in health, for the chronic disease patient", conducted by an interdisciplinary team in the program "Postdoctoral studies in the field of ethics of health-related policies".

The purpose of this research was to identify the mechanisms through which the responsibility for own health-condition and the autonomy [30] of the chronic patient are developed, in the process of care, at the interface with his family and the medical-social and religious institutions involved. The interest of the researchers was focused on the context specific for the diabetic disease, as a particular case of chronic disease, without limiting the research exclusively to this context.

SHORT CONTEXT OF HEALTH BEHAVIOUR OF PATIENTS WITH CHRONIC ILLNESSES

The health-related behaviour is a major issue of public health programs [1]; the health-related behaviour being connected to the decision of the autonomous individuals, who chose to responsibly act or not [2] in order to maintain their health state (health behaviour) [3];[28]; [1] in general, or as a response to a disease, especially a chronic one, which requires a particular lifestyle [3]. The benefits of an approach towards the chronic disease, based on respect for the patient's autonomy [4]; [5]; [6]; [7]; [9]; [10]; [12]; [13: 90-113]; [14: 17]; [15]; [16], the health-related behaviours of the individuals and their capacity of moral agent would, on one hand, be a part of their health-state improvement [17]; [18], and their quality of life, and on the other hand, of reducing costs [19]; [20] and lowering the pressure on the health system. The choice of type 1 insulin dependent diabetes in the context of studying the chronic patients' autonomy, and their responsibility for the their health-state is based on its incidence at global level and in Romania, the high costs for patients' care, but also the centrality of self-care in the management of the disease [21]. Kathryn Dean [22] defines self-care as being the fundamental level of health care in all societies [23]; [24]. The social construction of chronic disease is the analysis of the discursive particularities related to the health-state of different communicative agents involved in the process of care: patients, doctors, specialists, general medicine doctors, care institutions, families, etc [29]. One of the main axes of the social construction [25] of the idea of chronic disease is the doctor-patient relationship, the discourse of the doctors being the instance of social construction of the meaning offered to the term chronic disease. The phenomenon of medical life socialization drifts from the patients' internalization of the chronic health condition, taken from the discourse of caregivers, of which the most important role is that of doctors.

DATA COLLECTION

The data were collected in a city in the N.-E. area of Romania, between 2012–2013, through 5 focus group interviews with diabetologist doctors, general medicine doctors, insulin-dependent patients with type 1 diabetes and other persons involved in the process of care, and of 3 semi-structured individual interviews with patients. The sampling was achieved through the snow-ball method, the saturation of the sample being verified through the saturation grid. The selection criterion for the research sample was the involvement in the care/self-care of type 1 diabetes patient. The research was not considered gender-sensitive, which is why the interviewees' gender was not taken into account. For this article, we only analysed the diabetologist doctors' answers, the rest of the collected data being the object of other papers [26]; [27]; [32].

DATA ANALYSIS

The data analysis was conducted starting from the Grounded Theory methodology. This methodology aims to identify certain discursive categories, identified during the reading of the individual and group interviews, and applying certain three-step data coding processes: open coding — a first level of coding through which we identify keywords that give meaning according to the interviewees of the studied phenomenon; axial coding — aims to group the keywords in semantic categories; analytical coding — which aims at the relationships between the identified semantic categories; generating the model with exploratory nature — the conclusions of the model generated after following all the coding steps, representing hypotheses for future research, which will validate the model.

ABBREVIATIONS

[FG01.D2012] – focus group with Diabetologists

MAIN RESULTS

After conducting the inductive-type analysis, we have produced a series of semantic categories, relative to the perspective of the diabetologist doctors on the doctor-patient relationship in the context of supporting the construction of the type 1 diabetic chronic patient's self-care, whose process of construction we will not present in this article, due to limited editorial space. We will present the main semantic categories identified following the secondary data analysis obtained through focus group interview with diabetologist doctors [FG01.D2012].

The main inductive identified semantic categories were:

Normality and exceptional in the doctor's life. The clutter in the clinic was considered a leitmotif of the professional life of doctors — diabetologist specialists. Every day there is an exceptional situation, an emergency, a special case. *Each day there is an exceptional situation, or each person can be regarded as so.* With all these, the interviewed doctors couldn't describe the exceptional situations they have faced, precisely due to the exceptionality and uniqueness of each case. The chronic condition involves long-term care, and the patient's empowerment for self-care being *the diabetes, unfortunately, lasts — so to speak —, every day, for a lifetime*. The specific of chronic patient's medical care doesn't reside in the spectacular and imminent, like in the case of surgery, but in the tact and the art of convincing the patient to care for himself in order to lead an almost normal life, with the life expectancy and quality similar to the same-aged non-diabetic person. The exceptionality in the doctor's life is given by the choices he makes, both in the everyday life, and in specially chosen moment, such as changing the type of practice from the public system to the private on, for example. A feature of this category would be the everyday exceptional: *From a professional point of view, it wasn't special that we spent 5 years in the country-side, nor that we had a birth-house there and I was trembling... like so... when two twins were born*. The professional status of the doctor [8] is perceived as being exceptional, one of the diabetologists interviewed showing that in the decision of medical career choice, the *opinion of the group of equals* mattered, and who consider that *if you don't go to medicine, you are inferior*.

The experiences of the diabetologist doctor in the relationship with the chronically ill patient. The main element of the practice of diabetologists is to educate the patient for self-care. Their *participation* to self-care is essential. The therapeutic compliance, essential from the first phase of the disease, must be transformed in a therapeutic alliance, the doctor empowering the diabetic patient with the management of self-care. Another characteristic is the very high volume of patients, which leads to a certain level of automatism of the practice, considered to be beneficial by the interviewees. We make a clear distinction between the medical practice from the clinic of diabetology, where there is the necessary equipment and relatively enough time for the investigations conducted on the patient, and the medical practice in the polyclinic where it acts under the pressure of small time available at each meeting with the patient and the need for professional craftsmanship which involves the capacity to make a fast diagnosis and propose the necessary therapy (in our opinion, in the lack of certain investigation instruments, although the medical practice is less fit here).

Medicine as a vocation, not just a profession. The socialization of the doctor in the role of specialist is done both in the formal medical education system, and in the continuous one, as well as through the communication with other specialists in the field. When compared with the experience of practicing medicine in the country of origin, with that in other countries, we emphasize on the respect that the doctor, even debutant, is enjoying in the medical team, along with the technical-material equipment that the clinics have at their disposal. The experience of the international clinic is appreciated and recommended especially by debutant doctors. The acknowledged vocation of the doctor is helping people in distress. The choice of medical career is generally based on vocation, sometimes following the already existing tradition in the family, other time due to the *chance by accident*. Regarding the choice of the diabetologist specialty, the motivations discovered in the discourse of the interviewees targets the passion for nutrition, but also the complexity of the diabetology specialty among the clinical specialties. In all situations, however, the vocation is updated through practice and learning. The personal experience as diabetic chronic patient is also mentioned as a source of motivation for choosing the diabetologist career. The model of the experienced doctors is also very important, especially of professors and clinical chiefs. The satisfaction of the doctor is maximal when he managed to save a life through his work and due to his own experience: *you experience such a great joy when you saved that person's life (...). Nothing can compare with that*. In the care for chronic patients, the professional satisfaction of the doctor is connected to the *relationship with the patient*, the *therapeutic alliance* that was created, and the increase in the quality of life due to the chronic patient's involvement in self-care. Changing the beliefs and attitudes of the patient on the chronic (diabetic) disease is a source of professional satisfaction [11]. It is mentioned the special responsibility of the specialist doctor in the patients' care, especially when conducting practice in the clinic, where the doctor doesn't have the possibility of daily control of the patient's situation.

Portrait of the good professional. Patience in the relationship with the diabetic patient is one of the qualities of the good professional in diabetology. Due to the responsibility of the medical act, the doctor has the tendency to approach his relationship with

the patients in a paternalist way, trying to control all the therapeutic moments, even if this is impossible to achieve totally.

Limits of the system of care for the diabetic chronic patient. The main limitations of the system of care of the diabetic patient noticed by the doctors participating in the focus group, are: insufficient time with the patient, due to the small number of specialists compared to the number of patients, the lack of financial resources, both the patients' resources necessary for adopting the necessary lifestyle for self-care, but also the lack of resources in the medical system. The doctors' overload with cases may lead to a decrease in the quality of care. The lack of resources in the system is signalled despite the existence and functioning of a *National program of diabetes*, which provides for ensuring free insulin for all insulin-dependent patients, ensuring the necessary glucometers for self-care for this category of patients. Another limitation is strictly correlated with the financing of care and the doctor-patient relationship in case of diabetologist doctors. One doctor shows that he finds it impossible to go on strike and not sign the contract with the Health Insurance Company, since the lack of such a contract directly influences the patients whose insulin cannot be provided for free.

Particularities of the diabetic chronic disease. The particularities of the diabetic chronic disease requires an orderly lifestyle. *The patients must learn to live with the disease and not be dependent on the environment*. The intervention in the type 1 insulin-dependent diabetes patients are provided with, besides free insulin shots, also glucose measuring devices, glucometers and necessary tests. There are signalled situations in which the patients never use, or use incorrectly the measuring devices, which is considered a failure of the therapeutic education and an impossibility to develop certain options of management of self-care. The correct use and adequate self-care makes the diabetic patient be autonomous: express his moral agency, make decisions regarding his own health condition, and it also makes him responsible.

The dramatism of the chronic disease. For the patient suffering from a chronic disease, his condition may or may not be fully dramatic, based on the emotional burden projected on the disease, and the way in which he discursively develops his vision on his own health condition. At the time of the diagnosis, some patients go through real emotional shocks, being also noticed situations in which the patients feel stigmatized and excluded from the society. The lifestyle is the key for an almost normal life of the patients. Such examples of situations are also present in the specialists' discourse, when a good self-care management has led to a quality of life close to that of a normal person.

The medicalization of the patient's social life. The diabetic patient has a lifestyle that is adequate to the need for self-care, represented by the permanent measuring of glucose with the glucometer, and adapting the dosage of self-administered insulin. Also, the medical diet must also be strict in order to maintain the values of glucose within normal parameters. These conditioning lead to an increase in the medicalized dimension of the patient's social life, who tends to extend his self-care management from the elements that are strictly necessary for maintaining his health condition, to the most aspects of his social life. The patient should be involved — either while he is hospitalized after the diagnosis [31], or in the outpatient clinic — in courses of nutrition, glucose control, lifestyle, possible complications and avoiding them. These courses are available in certain university clinics in the country, but not in the region we have studied, the training activity being conducted by the medical nurses or interns.

It is also mentioned the need for a psychologist to participate in the therapeutic education of the diabetic person, at least in the first stages, when the patient is getting acquainted with the disease. A particularity of the life of the diabetic patient is represented by its spiritual dimension. If in the state of shock, many patients consider the illness as a result of divine punishment, in the stage of self-care, the spiritual practice can contribute to the tonus and trust of the patient, to the positive attitude and motivation for self-care. The role of support of the family is considered overwhelming for the efficiency of self-care of the diabetic patient. The local cultural model may lead, in certain situations, to the marginalization of the diabetic patient, who is considered guilty for his disease, being a risk for his family and the social environment, despite the fact that under the condition of an adequate treatment, the patient's life can be absolutely normal, including from the family and social-professional point of view.

THE MODEL OF THE SOCIAL CONSTRUCTION OF THE DIABETIC CHRONIC DISEASE FROM THE PERSPECTIVE OF THE DIABETOLOGIST DOCTORS' PERSPECTIVE

Analysing the results and their structuring into discursive categories, we could deduce, through successive induction processes, a series of statements which may constitute key elements of the descriptive model

of the social construction of diabetic chronic disease from the perspective of the diabetologist specialists:

- self-care of the chronic patient is of overwhelming importance in the therapeutic process, meant to maintain the patient's quality of life as closer to that of a healthy person;
- in the success of self-care, the doctor-patient therapeutic alliance is extremely important, the doctor being requested to prove a series of special communicative competences;
- the life of the diabetic patient suffers from an advanced process of medicalization, the medical model of the self-care management impinging on other aspects of the patient's life, including the family, professional or social one;
- the practice of medicine is, beyond the side of professions, an activity which requires a special vocation;
- the process of self-care is the framework in which the social construction of the autonomy and the diabetic patient's responsibility, both from the point of view of the social functionality, as well as of the moral (ethical) agency.

DISCUSSIONS

The requests concerning the ethics of research on human subjects were fulfilled, the research receiving the approval of the Commissions of Ethics in Research of the Gr. T. Popa University of Medicine and Pharmacy from Iasi, Romania. Being an exploratory research, based on qualitative data analysis, we don't talk about the data validity, but of the adequacy of the interpretative model created, as well as the potential of generalization widely. We consider that although the model is not a local one, through the particularities of the interviewed sample, there is a potential of generalization of the model, especially regarding the importance of self-care management, of the doctor-patient relationship in the construction of the therapeutic alliance. In order to increase the credibility of the analysis, the data interpretation involved the triangulation of the researchers involved in the process of coding and re-coding.

CONCLUSIONS

The doctor-patient relationship is an important instance in the process of social construction of the idea of chronic disease, but also the patient's autonomy in the process of self-care. The responsibility for self-care is the result of a process of therapeutic education, on whose efficiency, the well-being and quality of life of the diabetic patient depends on.

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