Transition from paediatric to adult epilepsy care: Patients' experiences of learning how to manage with epilepsy

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Abstract. Objective: the purpose of this study was to explore patient's experiences of learning how to manage with epilepsy during the transition process. Materials and Methods: a qualitative methodology, constructivist grounded theory, Charmaz version guided this study. Data collected in semi-structured interviews with 10 adults. Results showed that independent individual patient-physician communication starts in the adult epilepsy care. Family members are taking care of child and protection of risk, but transition to adult care is uncertain. Patient - physician communication differences between paediatric and adult epilepsy demands assistants during the transition. Conclusions: patients feel uncomfortable due to a lack of knowledge about process of transition in adult epilepsy care. Family members feel fear and responsibility for their child and restrict self-independence of their child. Knowledge about epilepsy, reconciliation depends on patient and physician connection.

Key words: grounded theory, epilepsy, transition.

1 Introduction

Epilepsy is a chronic, bio-psycho-social disorder of a neurological nature [1] with recurrent epileptic seizures, the timing and location of which are difficult to predict. This disease is often diagnosed along with others similar to this such as brain injuries, tumours, and mental retardation. Studies show that learning to diagnose epilepsy and living with it become a challenge to one's identity [2]. A person's identity changes not only because of changes in the biological body, but also due to persistent psychosocial factors such as stress, fear of seizures, inability to understand causes of the disease, uncertainty about the future [3]. Especially, if epilepsy appears in early life, parents take care and seek to create safe space for his/her and children seek for normalcy [4]. Parents' fears of seizures [4] complicate autonomy development and learning to live with epilepsy. Adolescents with epilepsy are unable to explain what it is epilepsy or how to manage it because all information were given to their parents and not to them [5]. Physicians communicate about illness more with parents not with patients with epilepsy during the paediatric epilepsy but transition means to become independent and responsible of epilepsy. Patient-physician communication difference between paediatric and adult epilepsy demands assistant during the transition.

According to Rajendran and Iyer (2016) transition from paediatric to adult epilepsy care is dynamic and structured process, which involves planning, preparation, and involvement of a skilled team in ensuring a seamless continuation of care from paediatric to adult services [6]. Risk and uncertainty is a part of routine transitional care [7]. The research question of the current study was to explore possible explanations for how patients learn to manage with epilepsy through physician-patient interaction during the transition process. Previous studies have shown a dyadic ratio in patients with epilepsy constructed with the doctor through language and social abilities [8, 9] when treated with antiepileptic drugs and seizures, making it often difficult for the physician to understand the patient's social behaviours that affect the course of treatment. Patient's narrative is contextual and personal because the physician through interaction with patients helps them to become independent and responsible during the transition process. The aim of the research is to construct grounded theory about patients learning to manage with epilepsy during the transition from paediatric to adult epilepsy care.

2 Materials and methods

2.1 Study design and participants

A qualitative methodology, constructivist grounded theory, Charmaz version guided this study. Grounded theory is an inductive method by which a theory is constructed from the obtained qualitative data [10]. According to Charmaz, the paradigm of social construction was applied in the formation of the constructivist underlying theory. The underlying theory is an inductive method enabling the construction of a theory from the obtained qualitative data [10]. Qualitative data are obtained following defined data collection procedures without recourse to other rigid constructions or theories about phenomena. In forming the constructivist underlying theory, the paradigm of social construction was applied. Constructivist Theory of Social Reality by P. Berger and T. Luckmann (1966) defines 'knowledge' and 'reality', where 'knowledge' is interpreted as certainty and 'reality' as a property of phenomena. According to the authors, self-reflection takes place only by consciously looking at oneself, at "who I am" [11]. The learning experiences of people with epilepsy are understood as a "reality" that is continually enriched by knowledge while interacting and recognizing each other's perceptions. Theoretical sampling principle was applied. Epilepsy patients were targeted for the study adults with epilepsy from childhood. Participants were required to have a diagnosis of epilepsy without cognitive dysfunction (as diagnosed by their treating neurologist). Ten people with epilepsy (4 men and 6 women) were selected based on the experience of previous, innovative projects in which subjects participated together with future doctors. The choice was based on trust between a researcher and participants regarding the confidentiality of the data and in depth-narrative. Epilepsy is very common and co-morbid conditions, in addition to various developmental disorders and severe neurological trauma, which selected subjects with no cognitive function disorders. The names of the study participants have been changed. The study was conducted in February of 2020 and in April of 2021. The principle of theoretical sampling [10] was applied in order to answer the research questions and understand the educational interaction of physicians-patients and to reveal negative and positive research cases.

2.2 Data collection

The data collection method is a semi-structured interview. The study included 10 interviews with epileptic patients without cognitive disorders. Interview data were transcribed and coded, categories were formed. Memos were used during the study to use the data during the analysis. The collection of research data was carried out until the data became saturated [10] and no new semantic units were formed during the analysis of the research data. The search for subjects was related to the deepening of knowledge about the formation of theoretical categories. The data collection method used is a semi-structured interview. Charmaz (2006) recommends that the researcher asks open-ended questions and allows the narrative to unfold during interaction and conversation. Following Charmaz's (2006) recommendations, participants were asked to recall past and future events thus encouraging reflection and detailing their previous experience. People with epilepsy often tell their medical stories to doctors, relatives and other patients, so study participants were asked to remember how they were telling about their illness to physicians. Participants often mentioned specific details, so they were asked to explain the meaning of them. Memos were written throughout the study. The notes written by the researcher from the beginning of the research help clarify the codes, i.e. identify codes that can be assigned to analytical processes. Coding was done by looking for similarities in the information and assigning it to a category or code and naming it by a word or a phrase. If an idea or phenomenon did not fit the formed category, a new category was formed. After forming the categories, the data was generalised and the phenomenon explained. Focused coding of the data was performed in two steps. In the first phase of focused coding, the codes and notes of the subjects (patients with epilepsy) were reviewed individually. In the second stage, the obtained data was passively reviewed and a comparison was made between the research experiences. The interviews were reviewed during focused coding and comparisons between subjects' experiences, actions, and interpretations of the same experiences were made [10]. The code comparison was carried out based on Charmaz's recommendations to answer questions such as which of these codes best represents the data, what the comparisons show, what theoretical categories the codes indicate and whether they complement the resulting study data. In the last, deductive stage, the two researches independently analyzed interviews transcripts to use an agreed coding framework and code definitions.

3 Results

Three core categories emerged from the data: differences between paediatric and adult epilepsy, family members and individual patient-physician communication.

3.1 Differences between paediatric and adult epilepsy

In the narratives, time seems to divide a person's epilepsy "I" into the first context of acquaintance with the disease (childhood) and the second context (adulthood). When you become ill as a child, you and your loved ones are expected to have the hope that the seizures will pass away, but they experience chaos when they reach adolescence and epilepsy seizures had not disappeared:

"I was hoping I wouldn't have it at all and I would be like a healthy person, let's start with that… and work and everything else, and here...it's like someone something put in the wheel, and I have to go with broken wheel." (Participant 6).

People with epilepsy often discuss the causes of the disease and note that it was only as adults that they learned that the seizures could be due to fear of ongoing domestic violence:

"It simply came to my notice then. Father comes to me, drinking was." (Participant 7).

Epilepsy in childhood was understood different:

"Later, I was concerned about family members care. In the childhood, family members supervised me. I ... in the childhood, when I had seizures I didn't know why I am using medication and later, when I grew up, I understood that's epilepsy, I have this diagnose and I have to use medication<…>it was hard to accept" (Participant 9).

People with epilepsy see the difference in communication with doctors in paediatric and adult departments:

"One of the last meeting in paediatric, I remember, I left tearfully. I don't know. They are talking in very simple way, they don't use any terms any talk is simple. They always find time for me, of course you have to wait, but it was so natural <…> in the adult care department no one looks into you like a child. They do assessments, cardiography and other, and that's all. Quickly. Be healthy. I think they know that adults have more patience" (Participant 3).

The doctor's language is difficult for the young patient to understand, so he/she simply follows the instructions and seeks to understand what is going on:

"We didn't realize it was a seizure, it was, I say, the first time I went to the doctor, but I found it, but I didn't realize it yet." (Participant 1)

People with epilepsy who only became aware of the disease in adolescence experience anger at immediate family members:

"As a teenager, when I found out... because I found hidden documents and read them. I was looking for something, so I found it, but I didn't understand what I was looking for, but I also found those medical extracts <…>. Then I told my mother that I still had a right to know what was hiding the disease. " (Participant 10)

In childhood, seizures are remembered differently and relatives only teach how to prevent them, but do not explain what the disease is:

"It simply came to our notice then. I was very nervous, nervous, and then my grandmother told me not to be nervous, because there was still an attack, and I found ways to stay calm after all, and if I try to stay calm, then I will recover." (Participant 9)

People with epilepsy after transition process to adult department talk about the disease as an object they do not want to recognize and know which seems to disappear if it is not addressed. Learning about the disease helps to perceive it as a part of life that is not a separate, somewhere floating object, so the change in the "I have epilepsy" relationship is observed - the transformation of an epileptic seizure into a subjective experience.

3.2 Family members

Family members' efforts to protect themselves from the disease, fears about the child's future, are linked to a lack of knowledge about the course and treatment of the disease:
"I've been sick since four years of age, I don't really remember it, but when after many years I started to understand, I started to be interested in it myself. As a child, there were many seizures and I walked in a cuddly way, so when I grew up I asked mother and... she explained a lot ... It's just…" (Participant 7).

At the beginning of learning how to live with the disease, people with epilepsy try to understand what is going on, so the help of loved ones is valuable, but when they start understanding what happens to the body, they try to control seizures and learn to live with the disease. However, study participants notice that surviving the seizure itself is a difficult process, regardless of time or place, so it is important to learn to wait:

"I can't remember the first seizure, mother was coming with me. The first year…They are asking about seizure but I was unconscious, I can't remember anything. I said that I didn't know…I didn't remember anything I could not feel anything" (Participant 2)

Relatives limit the independence of people with epilepsy. Due to excessive care, the people lose the opportunity to create a dialogical conversation on their own, because their relatives try to do everything for them:

"I had seizure once which is not registered anywhere. I didn't want to know because my mother feels stress and something like this. My mother often goes with me …she thinks that I am small. When you are not going alone…another person has his/her interest, questions and then... I am going alone I am asking what's important to me" (Participant 3).

"I was angry because my mother didn't tell me that it is epilepsy because I was in hospitals very often <…>They always talk with parents, I had to wait behind the door <…> after years when epilepsy renewed I went alone" (Participant 8).

The formation of a subjective attitude is determined by a system of values that depends on the cultural space of the subject with epilepsy at that time. The loss of loved ones who need to be cared for requires a self-consultation and a problem due to a lack of knowledge about the disease, treatment, and communication with the doctor:

"For as long as I was a teenager, after my mother's death, there were no such attacks. It had already passed, after which such attacks came again. What was I doing then?" (Participant 10).

3.3 Individual patient-physician communication

Patients, even those with long-standing epilepsy, are constantly learning to tell their doctor about their illness, and it is an ongoing process, as the need for information changes along with treatment and lifestyle change. At the beginning of the treatment, they want to know what the disease is, and then how to live with it: how to study, work, start a family, have children, and get involved in community life. Patients look for answers to these questions in articles, specialist books, and during visits to the doctor:

"Mainly from a doctor, from a book, from literature in a foreign language. Those latest technologies, however, are advancing in terms of treatment. ...And those topics are very interesting here, you can find something all the time, of course, not in Lithuania, you won't read it in magazines or articles, but in foreign literature it's really a lot of that information." (Participant 5)

"There were residents at the doctor's office, they did such tests there, it even surprised me that I was sick for so many years, but I still don't know what type," he explained." (Participant 4)

During an epileptic seizure, a person may not understand what is going on and what to do, so the support of those around them is also very important. Relatives are also involved in treatment, learning how to help after a seizure and how to recognize that it is a seizure. Developing awareness of those around them helps the patient feel safe and encourages self-care, to follow their doctor's instructions. During meetings with other patients with epilepsy, the doctor is seen as a person, so another relationship with the doctor is formed:

"You know how it stays with the doctor that we don't meet so often anymore, but still our communication is so different as the doctor and patient started purely from those meetings in our group." (Participant 1)

The study also revealed the need for help in people with epilepsy not only after starting to see a doctor, but also after learning to live with epilepsy:

"He recommended a psychotherapist who worked for us. Well, I visited her purely in the beginning on an individual basis to accept the disease and understand what it is and to live with it… It helped a lot." (Participant 4)

The interviews reveal the importance of providing information about the disease and individual interviews in reconciling and understanding the disease: "...for a long time I could not acknowledge, could not reconcile and it was extremely difficult" (Participant 6). The importance of multi-professional cooperation is also highlighted. When epilepsy is diagnosed for the first time, patients experience anxiety because they are not familiar with the necessary tests, the treatments: "I used to go so anxious at first because you don't know what you will hear. Especially when research started. For the first time, I was most afraid because I did not realize ...” (Participant 4). Patients lack information about the illness that could be provided by a psychologist, psychotherapist, or social worker as a member of a multi-professional team with communication skills.

People with epilepsy did not understand epilepsy in childhood. People with epilepsy do not openly state their problems at the beginning of the disease to the doctor because they feel anxious about the future, fear of seizures and the uncertainty of how to learn to live with the disease. Reflecting on life with the disease and successful treatment, a picture of a professional doctor is gradually formed. A doctor who has not only acquired specialized knowledge but is also sensitive to patient’s problems and willing to help. Learning to manage the disease begins with the formation of the perception of the disease as an inevitable part of reality, which is important not only to know, to recognize but also to learn to live sick. During the dialogue with the doctor, trust in the doctor is formed, and understanding of the patient’s responsibility for the effectiveness of treatment. Patients, albeit for a long time, are constantly learning to tell their doctor about their illness. It is an ongoing process because of the change of treatment, lifestyle, and the need for information.

4 Conclusion

Results showed that independent individual patient-physician communication starts in the adult epilepsy care. Independent transition process depends on family members’ decisions to let go patient with epilepsy to visit the doctor. People with epilepsy loose support under other circumstances and they have to start manage with epilepsy alone, only with doctor’s help. Transition to adult care is uncertain. Patient - physician communication differences between paediatric and adult epilepsy demands assistants during the transition. Patients feel uncomfortable due to a lack of knowledge about process of transition in adult epilepsy care. Family members feel fear and responsibility for their child and restrict self -independence of their child. A patient with epilepsy has a lack of knowledge not only how to communicate with the doctor but also about seizures, medications, medical procedures, about factors, which provoke seizures and psychological problems solutions. Knowledge about how to manage with epilepsy, reconciliation depends on patient- physician interaction.

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