Understanding patients’ perspectives on communication and the patient-physician relationship: A qualitative study in the context of epilepsy and migration.

Degree project in Medicine

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Institute of Medicine
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Abstract
Background: Immigrated people who live with epilepsy carry a double vulnerability in society. They are more likely to have lower health status than the general population and barriers present themselves that complicate the care-seeking process. Patient- centred care has been recognised to improve health care through addressing patients’ personal preferences.

Purpose: To investigate patients’ perspectives on communication with physicians and valuable components that contribute to the process of building a trustful patient- provider relationship, from the perspective of foreign- born patients with epilepsy.

Method: 15 semi- structured in depth interviews with immigrated patients with epilepsy were held at Angered Hospital, recorded, transcribed verbatim and analysed according to the principles of content analysis.

Results: Three themes appeared: “Feeling safe with the physician”, “Being acknowledged as a whole person” and “Feeling like a normal person”. For patients to feel safe, physicians need to represent authorities and listening persons who involve patients in treatment management.

Due to migration, reduced social network and epilepsy- related stigma, conversations with physicians appear particularly important for patients’ wellbeing and feeling of safety.

Physicians seem to play an important role in verbalising, confirming and normalising patients’ symptoms. Daring to talk openly about epilepsy takes time and is still associated with a fear of negative reactions from others.

Discussion: Whether patient- centred care implies shared decision- making need to be assessed individually. Epilepsy disclosure might promote patients wellbeing. Taking responsibility and fulfilling social roles promote self- confidence and the feeling of being a normal person.
Practical implications: Trust is crucial for successful communication and treatment outcomes. While physicians should consider each patient in the specific context of the patient’s own life, a respectful and listening physician who shares information is fundamental for a trustful patient-physician relationship regardless of patients’ culture or country of origin.
Background
Migration

Sweden is today facing a challenging situation, with large quantities of immigrants and refugees arriving in continuous streams. According to the Swedish Migration Agency, 162,877 people applied for asylum in Sweden during 2015, which resulted in the introduction of temporary border controls (1). Sweden has today become a country with multicultural societies and diverse populations, with various needs and resources.

Immigrating and resettling in a new country means adapting economically, socially, culturally and even dietary to a new society, a stress for the individual who often experiences a decline in health within this process (2). Migration affects employment and personal economy.

Recent reports from the Swedish Public Employment Service show that unemployment increases among foreign born citizens, mainly among people born outside of Europe, while it decreases among the native born population. In October 2015 almost 50% of unemployed Swedish citizens were born abroad (3). Socioeconomic status, the individual’s attributes of income, occupation and education, is closely related to health and mortality (4). Other consequences of migration, for example the loss of contextual factors such as friends, family and a place like home, may disable emigrated persons from actively taking part in the community. This often results in isolation and further negative health effects (5). In Sweden, self-reported poor health is three-four times more common for immigrated citizens than for the native-born population (6). Reasons to migrate differ between different groups of immigrants and correlates to the degree of health decline from migration. Refugees belong to the most vulnerable group, a group that generally has significantly lower health status than the native-born population (7).
Angered

Angered is a suburban area in north-eastern Gothenburg in Sweden, where about 50% of citizens have immigrated from foreign countries, especially from countries outside Europe. In this multicultural population, incomes are lower, rates of unemployment are higher and the number of days with social financial support because of illness is significantly higher than in the general population of Gothenburg. Likewise, the proportion of families receiving social financial support is elevated in Angered in comparison to the city as a whole (8).

In 2007, the project that would result in the establishment and construction of Angered Hospital was started. The development took its point of departure in an analysis of the local population’s specific needs. Results from this analysis indicated that Angered’s diverse population had similar expectations on health care as residents in Gothenburg in general, concerning availability, respect, listening and effective care. However, the difference was presented in how health care staff had to work to reach this. In a transcultural context, health care professionals must put aside pre-existing understandings, work to improve listening skills and be prepared to widen their views. The analysis further points out the need for research to increase knowledge about patients’ specific needs in a multicultural context (8).

Migration and health communication barriers

Speaking the language of the destination country and understanding written health information is positively associated with good health (9). Meanwhile, migration and low socioeconomic status is related to low health literacy. Health literacy is described as “the ability to gain critical health knowledge needed for making informed decisions regarding disease management” (4) and facilitates health communication and patient comprehension (10). Physicians tend to overestimate health literacy of minority patients (10), which create gaps of misunderstanding in the communication between patients and physicians. Moreover,
learning a new language and a new health care system takes time and present additional barriers for the individual in the communication with health professionals.

Other possible sources of misunderstandings between patients and physicians derive from cultural differences in health care traditions. One example is the extent to which patients wish to take part of information and involve in decision making (11). Another example concerns perceptions of the meaning of preventive care (2) resulting in different expectations on and demand for medical interventions.

Many immigrated patients prefer to see physicians who speak their own mother tongue (2, 5, 10). Seeing a physician who is language- concordant with the patient has been associated with clear communication, feelings of trust and safety in the medical encounter (10). Medical jargon is reported as a communication barrier among low- income patients, a phenomenon that appears to be less prominent when translated to the immigrated patient’s mother tongue (10). In situations where interpreters are needed, physicians face additional challenges in the communication with the patient. Sufficient consultation time, cultural competence and trust between all parts in the patient-, interpreter- and physician communication is considered essential for a successful medical consultations (11). If no language concordant family physician is available, immigrated patients may consider to seek health care abroad (2).

Epilepsy

Epilepsy is one of the most common neurologic disorders, a global health issue with approximately 50 million people affected worldwide. Epilepsy is prevalent everywhere, but is more common in developing countries than in the “Western” world (12, 13). In developing countries where standards of health delivery systems are poor, diagnosing epilepsy is problematic and patients often lack access to adequate treatment, leading to considerable treatment gaps and increased suffering. In 2007, it was estimated that 9 out of 10 persons with
epilepsy in Africa were untreated for their epilepsy (13). In Sweden today, the total incidence of epilepsy is estimated to 50/100000/year and the prevalence to 0.7% (14). For the individual, undergoing an epileptic seizure for the first time is usually a terrible experience leading to emergency room visits (12, 15). Epilepsy not only affects physical and mental health by its seizures but in addition, affected persons often suffer from social consequences of epilepsy such as discrimination and epilepsy related stigma (16, 17).

Stigma has been defined as “the co-occurrence of labelling, stereotyping, separation, status loss and discrimination in a context in which power is exercised” (4). Negative attitudes and prejudicial behaviour towards people with epilepsy is common worldwide (4, 13, 17, 18), as a result of misperceptions and lack of knowledge about epilepsy in society.

For people with epilepsy, discrimination at work places as well as in accessing education is common. Violations of human rights are prevalent but often subtle, as being overlooked for promotion at work or denial of rights to participate in social activities in society (13). Existing myths about epilepsy, that it is contagious, that children with epilepsy cannot go to school, that women with epilepsy should not give birth and that it is caused by evil spirits, witchcraft etc. lead to isolation, default of education, economic disadvantage and have severe negative effects on health and wellbeing (13, 18). Social discrimination has been associated with affected mood and behaviour. Depression and anxiety are more common in epilepsy than in the population in general. Meanwhile, mental health problems are often as highly stigmatised as epilepsy, underdiagnosed and undertreated, especially in settings with poorer health delivery systems. Psycho-social complications of epilepsy have the potential to cause severe harm to health and quality of life, sometimes more than the seizures themselves (13). Reluctance to disclose epilepsy can be a result of having experienced discrimination and present a strategy to avoid stigma in the future (19). Meanwhile, a lack of disclosure can lead to social isolation and an absence of social support from friends and family members.
Increased knowledge about epilepsy in society is welcomed to raise awareness, increase understanding and help to diminish stigma (19).

In many cultures, where an idiopathic reason for epilepsy is likely to be explained by traditional beliefs, patients may seek help at local faith healers, not receiving effective medication. Thus, minority status can sometimes present a barrier to accessing effective health care and as a consequence, seizures can proceed, aggravate, and continue to fuel the situation of stigma and social isolation (18).

A person with epilepsy is not permitted to perform all kinds of work, such as handling certain machines or potentially dangerous tools. In Sweden, holding a driving licence demands a two-year seizure-free period of time (12), inevitably affecting those working with vehicles. Thus, epilepsy has extensive socio-economic consequences (4) and people with epilepsy more often have lower education, lower income, and lower health status compared with the general population. Moreover, those who reside in generally low socioeconomic status areas, are more likely to have uncontrolled seizures, negative side effects from medication, experiences of stigma and low quality of life (4). The co-occurrence of epilepsy, minority status and low socioeconomic status is associated with lower adherence to medication and higher rates of hospitalisation and emergency room visits (4). Immigrated persons with epilepsy must therefore be recognised as a, in a double sense, vulnerable group in society.

Epilepsy treatment focus on careful administration and monitoring of anti-epileptic drugs (AED) and life style changes, where patients are recommended to avoid alcohol, stress and sleep deprivation (12). Surgery is rarely but sometimes performed. There is no guarantee for when seizures will cease to occur (12) but more than 70% of epilepsy patients in developed countries achieve long term remission from seizures within 5 years after the diagnose (13).
Many patients fail to report missed doses, non-adherence or breakthrough seizures (20). Non-adherence to medication, missing doses or stopping AED medication, is related to loss of seizure control, breakthrough seizures, higher rates of emergency room visits and hospitalisation (15, 20). Non-adherence has also been correlated to being fired from work because of seizures or seizure related loss of driving ability, motor vehicle accidents, decrease of work-related productivity and decrease of mental and emotional wellbeing (15).

To facilitate for patients to talk about non-adherence, physicians must ask about this in a non-judgemental way (21). Reporting missed doses should through honesty and trust serve to strengthen the patient-physician relationship over time. Patients who report participating in open dialogue with their physician and feeling comfortable speaking to the physician have been found to be more likely to be adherent to medication (15, 20). Adherent patients report fewer breakthrough seizures and tend to trust their physicians to make the best decisions for them, more than non-adherent patients (15).

Efficient patient-physician communication is therefore crucial to optimise epilepsy treatment outcomes (20). Physicians should strive to increase patient understanding of their condition, increase patient empowerment and engagement in treatment management, as a means to improve quality of communication and optimise medication adherence (15). Epilepsy care and outcome is strongly influenced by multiple psychosocial factors, such as the patient’s degree of health literacy, attitudes, perceptions and trust towards the provider together with the provider’s communication skills and attitudes towards the patient (4).

The right to equal health care

All humans have the same right to enjoy adequate health care with good quality. As it is stated by the World Health Organization “The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race,
religion, political belief, economic or social condition” (22). According to the Swedish Health and Medical Services Act 2§ (1972:763) the objective for Swedish health care is a good health on equal conditions for the entire population. The person with the greatest need for health care should be prioritised (23).

**A physician’s duty**

The physician represents an important tool for patients in accessing health care. Due to knowledge and professional role, the physician has a great responsibility towards patients. One of those responsibilities is to see to that all patients receive the best possible care on equal grounds. As it is stated in the 7th ethical principle of the Swedish Medical Association, a medical doctor should never deviate from the principle of all human beings’ equal value and should never expose a patient to discriminating treatment or behaviour (24). In the Declaration of Geneva from 1948, the World Medical Association (WMA) states that a medical doctor should “not permit considerations of age, disease or disability, creed, ethnic origin, gender, nationality, political affiliation, race, sexual orientation, social standing or any other factor to intervene” between the physician’s duty and the patient” (25). Thus, the work of a physician must always include awareness of and actions against discrimination as well as promoting health care access for the most vulnerable groups in society with the goal to prevent health inequities in society.

One important strategy in the work against health inequities, that recently has reached increased recognition, is the concept of “culturally sensitive care” (26). The definition most commonly referred to, “cultural and linguistic competence”, is described by Cross et al and defined as ”a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals that enables effective work in cross-cultural situations” (27). Considering that Swedish health care is dealing with a patient population with diverse cultural backgrounds, and that the physician is ethically bound to promote health
equity, cultural competency should be acknowledged by physicians and prioritised in medical practice.

**Patient-centred care**

Patient-centred care was introduced in medicine in the 1950s’ as a concept intending to focus on patients’ individual identity. In 2001, patient-centred care was defined by the US Institute of Medicine as “healthcare that establishes a partnership among practitioners, patients and their families to ensure that providers and systems deliver care that is attentive to the needs, values and preferences of patients”. However, the precise definition of patient-centred care has changed over time as well as the suggested pathways to reach there. Originally, shared decision making was considered a significant indicator of patient-centred care (28). Later, attention has been drawn to the importance of encouraging patients’ narrative, and a physician’s listening skills, as a key to attain shared decision-making (21, 29). Some authors prefer the term “person-centred care” rather than “patient-centred care”, referring to the importance of acknowledging the person behind the patient, his or her preferences, values and beliefs, and not reducing the patient into a mere diagnose (29).

Regardless of the exact term, the concept intends to shift from a traditional health care model where a patient is an inactive consumer of health care services, to a model where the patient plays an active role in decision-making and management of their condition (28, 29). It is emphasised that health care systems need to take the whole person into consideration, including the person’s history, context, family, preferences, strength and weaknesses, in order to achieve effective care (29). Patient-centred care aims to turn the patient into a partner in managing and making decisions about their condition (21, 29). Patients who are included in forming their treatment plan are more likely to adhere to medication and turn up for their health care appointments (21). By sharing more information with the patient and asking about the patient’s thoughts and feelings, patient adherence and satisfaction will increase (21).
Nowadays, effective patient-provider communication is considered essential in achieving patient-centred care (28, 30). Studies have shown positive correlation between effective patient-provider communication and patient health outcomes (28) and that shared decision-making leads to better treatment outcomes where patients who participate in open dialogue about their treatment and take part in forming treatment plans tend to adhere better to medication (15, 21, 29).

Even though health care staff generally agrees to the importance and application of a patient-centred approach in health care, application in medical practice is challenging. The explanation is often to be found in perceived time pressure and in the inclination through habit to fall into an illness-centred approach (29). Physicians tend to fear that applying a patient-centred approach lead to prolonged appointments, decreased efficiency and raised costs in health care. An argument against this is presented by the high costs from hospitalisation following patients’ non-adherence to medication (21).

Perceptions of communication in the patient-physician interaction is often incongruent between the patient and the physician, why more attention has to be drawn to the patient’s own experience of communication in the meeting with the physician (30). Lack of language proficiency and low health literacy have been found to constitute observed significant communication barriers in health care (9), why it is crucial that information is adjusted to the patient’s interest, educational level and ability to take in new information. Physician’s should focus on what patients need to know to be able to actively take part in managing their health condition (21). In the work to promote patient-centred care, more education is needed to attain knowledge about cultural diversity, to increase understanding for different preferences (31).
Rationale

According to what is known today, migration and epilepsy both have negative effects on mortality, health and quality of life. Hence, people with epilepsy who have migrated should be considered carrying a double vulnerability in society and an increased risk for impaired health. In the context of epilepsy, efficient communication and a trustful patient-physician relationship have been recognised as key to better adherence and improved health for the patient. Meanwhile, culturally derived perceptions of health care can present communication barriers between patients and physicians that cause misunderstandings and communication gaps. With this in mind, striving to understand patients’ pre-existing understandings of health, disease and the meaning of cultural background, should be a priority for each physician in the work to improve communication, treatment outcomes, health care access and in promoting health equity. In order to adapt health care and change into a patient-centred approach, personal values, expectations and preferences in the context of a meeting with a physician need to be determined.

Previous research has described health effects of migration and epilepsy separately, as well as the importance of constructing a trustful relationship with the physician for optimal wellbeing and treatment outcomes. To our knowledge, little is known about foreign born patients with epilepsy and their expectations on physician-encounters from the patients’ point of view. What specific components that contribute to the process of building a trustful patient-provider relationship in the context of epilepsy and migration remains unknown and needs to be further investigated.

Aim

To explore pre-existing understandings and expectations on health care, and determine personal values in the context of a meeting with a physician, from the perspective of foreign born patients with epilepsy.
Patients and methods

Since the research question concerns patients’ personal experiences, thoughts and emotions in the context of their own lives, a qualitative method with individual in depth interviews was considered to be the most appropriate method for our purpose (32).

Participants

In this study, “maximum variation (heterogeneity) sampling” as it has been described by Patton (33), was applied as strategy for purposive sampling. Through a great diversity within the group of participants, the researcher aims to explore a certain phenomenon from multiple aspects and thereby determine and distinguish uniqueness and reoccurring patterns. When patterns reoccur and cut across interviews in a sample with great variation, it is of particular interest since it reflects a shared experience of that specific phenomenon. This shared experience represents a core value in human context. Personal characteristics that were accounted for in this study were age, sex, occupation and country of birth, and whether or not the patient had been absent from previously booked health consultations. Recruited patients had all lived with epilepsy more than one year. Informants were recruited to the study with help from health care staff at the neurology department at Angered Hospital.

Before entering this study, a meeting was held between the authors and the health professionals at the clinic. The health professionals’ ideas and points of views were taken into account and inclusion criteria for the study were stated. Health professionals were thereby actively engaged in recruiting informants by selecting patients from the time book matching the inclusion criteria: foreign- born patients, 20 years or older, with a registered epilepsy diagnosis. In connection with the booked health care appointment at the neurology department, health care providers informed about this study and asked patients to participate. Patients showing interest in the study were provided with information verbally as well as
through a participant information sheet. This information was provided both in English and in Swedish and translated by interpreter when needed. Health professionals stressed that participation in the study was on a voluntary basis. A signed informed consent form was then obtained from each participating informant before commencing the interview.

Information about participants’ demographics was collected through direct inquiry and from medical journals with the help from a nurse at the clinic. Participants ranged between 20-62 years old, with the median age of 32 years. Authors strived to collect data representing diverse perspectives of how it is to live with epilepsy as a migrated person in Sweden today, why participants with various backgrounds and characteristics were preferred.

Table 1.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Age</th>
<th>Occupation</th>
<th>Country of birth</th>
<th>Years lived in Sweden</th>
<th>Interpreter</th>
<th>Former absence</th>
</tr>
</thead>
<tbody>
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<td>1.</td>
<td>Male</td>
<td>31</td>
<td>sick leave</td>
<td>Turkey</td>
<td>15</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>2.</td>
<td>Female</td>
<td>20</td>
<td>student</td>
<td>Vietnam</td>
<td>5</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>3.</td>
<td>Female</td>
<td>35</td>
<td>unemployed</td>
<td>Lebanon</td>
<td>19</td>
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<td>No</td>
</tr>
<tr>
<td>4.</td>
<td>Male</td>
<td>27</td>
<td>working</td>
<td>Somalia</td>
<td>18</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>5.</td>
<td>Female</td>
<td>30</td>
<td>student</td>
<td>Tanzania</td>
<td>22</td>
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<td>No</td>
</tr>
<tr>
<td>6.</td>
<td>Female</td>
<td>27</td>
<td>student</td>
<td>Mexico</td>
<td>&lt;1</td>
<td>Spanish</td>
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<tr>
<td>7.</td>
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<td>40</td>
<td>sick leave</td>
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<td>1</td>
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</tr>
<tr>
<td>8.</td>
<td>Female</td>
<td>31</td>
<td>working</td>
<td>Poland</td>
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</tr>
<tr>
<td>9.</td>
<td>Female</td>
<td>27</td>
<td>student</td>
<td>Iraq</td>
<td>3</td>
<td>Kurdish</td>
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<td>10.</td>
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<td>11.</td>
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</tr>
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<tr>
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<td>No</td>
</tr>
<tr>
<td>14.</td>
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<td>retired</td>
<td>Iran</td>
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</tr>
<tr>
<td>15.</td>
<td>Female</td>
<td>46</td>
<td>working</td>
<td>Ethiopia</td>
<td>18</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Study participants’ characteristics

Interviews

A qualitative approach with in depth interviews was applied in order to explore each informant’s personal experiences from meetings with health professionals in Sweden and in
the informant’s country of birth. Striving to understand how personal experiences have shaped the informant’s pre-existing knowledge about their condition, attitudes towards and expectations of the physician and what personal values that the physician need to acknowledge to build a trustful relationship, the authors employed an interview guide specially designed for this study. Through semi-structured questions, authors aimed to derive informants’ personal narratives of previous meetings with physicians. Questions concerned how patients had experienced living with epilepsy originally and today, how meetings with physicians were experienced what factors that promoted trust in the medical encounter (see appendix).

Every in depth interview was carried out by the authors with each informant individually at the neurology department, Angered Hospital. Interviews were preformed both in Swedish, sometimes assisted by a professional interpreter, and once in English. This since informant number 6 preferred to continue the interview in English ten minutes into the interview upon which the Spanish interpreter could leave.

Interview lasted between 24-56 minutes, with a median interview time of 40 minutes. After each interview, the interviewer took notes on the content and the course of the interview, what happened and why, trying to improve the formulations of questions in the interview guide to deepen the content for following interviews.

Interviews were recorded and transcribed verbatim by the interviewing author the same day or the day after the interview was held. Thereafter, informants who agreed on receiving their respective interview were sent the transcript by email, which enabled each informant to correct their answers and potential misunderstandings. Nine participants agreed on receiving their transcripts via email. None sent comments or demands for changes in return.
Analysis

The analysis was conducted progressively during the performance of interviews according to the systematic principles of qualitative content analysis (34). In qualitative content analysis, the transcribed text from interviews constitutes the collected data, where each interview represents a unit of analysis. In the text, the researcher deals with both manifest and latent content. The manifest content deals with the direct message of words and what the text is saying. In contrast, the latent content represents a higher level of interpretation of the text and describes what the text is conveying as well as the underlying meaning of the text (32, 34).

Each interview was carefully read by the student and the supervisor separately. Words or phrases that related to each other through their inherent meaning were marked out as so called meaning units. Meaning units were then shortened in a process called condensation, where the aim is to shorten the text while preserving the core meaning of what is said (34). Condensed meaning units were then labelled with codes. The student and supervisor performed coding separately after which a comparing session was held with discussion of the text’s underlying meaning and most representative codes. Examples of how meaning units were taken out, condensed and labelled with codes, are presented in Table 2.

Table 2.

<table>
<thead>
<tr>
<th>Meaning unit</th>
<th>Condensed meaning unit</th>
<th>Code</th>
</tr>
</thead>
<tbody>
<tr>
<td>“And it becomes annoying that he all the time sends this invitation, I think. Because, I know that, it’s doctors, only the prescriptions she has written, there’s nothing else she can do. Because I know this, this disease, that no one can change.” - P12</td>
<td>Does not like to be invited to the hospital since the doctor is unable to do anything to change the disease other than to prescribe medication.</td>
<td>Absence</td>
</tr>
<tr>
<td>“For example, if a girl has epilepsy, if she meets a guy, than she’ll be afraid to tell him she has epilepsy. Because, then she’ll maybe think that, maybe he thinks, he doesn’t want to be with her anymore.” - P1</td>
<td>If you tell the person you are dating about your epilepsy, he or she might not want to date you anymore.</td>
<td>Stigma</td>
</tr>
</tbody>
</table>

Examples of condensing and coding
**Trustworthiness**

Reality can be interpreted and understood in multiple ways and the researcher’s interpretation will always be influenced by personal expectations, pre-understandings and professional background (32, 34). In qualitative research, the researcher’s personal influence, strategies for sampling and the process of analysis with interpreting and discussions are important factors that interfere with the validity of the study (35). The researcher’s background and perspective determine what certain view of a phenomenon that will be high-lighted and thereby what findings that visibly emerge from data. Instead of regarding this as a failure of reliability, as long as the researcher is aware of and discusses this influence, different perspectives lead to richer understanding of phenomena in qualitative research. Preconceptions are only considered bias in situations where researchers fail to mention them (35).

To raise awareness of personal experiences and pre-existing knowledge that could plausibly affect results and author’s interpretations within the study, a document with personal thoughts and expectations of possible results was presented in the form of a written document before commencing the interviews. This document was meant to serve as a reminder of personal influence and a reference throughout the process of interviews and the analysis in particular, to diminish the personal influence of pre-existing understanding. Also, results were compared with the initial project plan to better understand how the author’s perspective guided the course of interpretation with the aim to diminish this influence on the final results.

The first author, Klara Andersson, is a master student in medicine at the University of Gothenburg without any personal experience of migration or living with epilepsy. The student had never before performed a qualitative research study or a study with similar design. The
supervisor Susann Strang is a senior researcher in caring science with focus on qualitative research and she had extensive experience from caring for patients with epilepsy.

To diminish personal influence, interviews were read and coded by the student and the supervisor separately after which a session of comparing codes and interpretations followed, leading to discussions about adequate codes, most plausible interpretations and underlying meaning. This way, personal interpretations were questioned and criticised enabling new interpretations and understandings to emerge from the same material.

**Ethical considerations**

In the performance of this study, authors were guided by the ethical principles of the Declaration of Helsinki, adopted by the WMA General Assembly, Helsinki, Finland 1964. The health of patients should be the physician’s only concern, and the goal to generate new knowledge can never outweigh the rights and health of the individual research subject (36).

To safeguard participants’ integrity and confidentiality, authors considered the Swedish Personal Data Act (SFS 1998:204), an act serving to protect personal integrity and the processing of personal data based on common rules within the European Union (37), as well as the recommendations of the Swedish Research council (38).

In qualitative studies, the researcher must be attentive to particular risks for participants. Malterud highlights the risks of psychological anxiety, abuse, distortion and recognition (32). While interviewing patients, the researcher must balance own interests in accessing valuable information of the intended research focus with the participant’s integrity, health and well-being. While being encouraged to talk about life, participants might be reminded of traumatic events or hurtful memories. There is always a potential risk of causing participants emotional harm, while recalling these memories. Narratives may lead participants to draw new
conclusions of lived experiences, influencing participants in unpredictable ways. The researcher must never be negligent to the fact that all interviews potentially can cause psychological anxiety and emotional harm. To gain a rich material from interviews, the researcher must work to improve comfort for the participant and optimise closeness through creating a calm and trustful environment where the participant feels free to talk without judgment (32). The participant must feel ensured that the trust will not be abused. Since sensitive and emotionally provoking data can emerge from qualitative research, it is the researcher’s responsibility to safeguard objectiveness, ensure trustworthy interpretation and avoid distorting the information (32). In the documentation and presentation of results, the researcher must make careful considerations to safeguard confidentiality. In presenting citations, it is paramount that no such information is revealed that could make it possible for others to identify specific participants (32).

Before entering upon this study, possible risks were assessed and balanced against risks for participants. Patients recruited to this study were provided with information verbally and through participant information sheet, and an informed consent form in connection with their booked health appointment with a physician. Information provided included the aim and method of the study, expected benefits and possible risks with the study, how to access presented results further on and contact information to the responsible person for the study in case of questions (see appendix). Patients were carefully informed that participation was on a voluntary basis and their right to terminate participation at any time without any consequences for the individual whatsoever and without any influence on the patient’s care and treatment. Confidentiality of all personal information was reassured. All material was handled according to the principles of the Personal Data Act, safeguarded on a password-protected personal computer. Information about participants and demographics was kept separate from the texts during the analysis, to protect confidentiality at all times during the work process. The person
asking patients for participation was a nurse working at the neurology department, to whom the patients were considered less likely to be in a dependant position. An analysis of potential risks and benefits was carried through before the study begun.

The author considered the main risk to be that of causing the participants emotional harm from recalling painful memories. In case of negatively influencing participants’ emotional wellbeing during interviews, the student as well as the supervisor were well aware of available resources at the hospital, including psychological and medical care. When being encouraged to talk about life and actively listened to, interviews may also have a positive influence and relieving effects on the wellbeing of participants. No risks were identified for the student in performing the interviews. Experienced health professionals were available at all times in close connection to the place of the interview, in case of a need for assistance.

The benefits of the study in the form of new knowledge were assessed and considered superior to the potential risk for participants. Learning more about patients’ perspectives on communication in health care may potentially lead to improvements in communication and outcomes for both patients and health professionals.

Results

In order to optimise treatment outcomes and patient wellbeing, a trustful patient-provider relationship needs to be constructed. People with epilepsy need additional treatment than medication. The ritual of coming to the hospital and having a conversation with the physician appeared particularly to serve to support, motivate and encourage the patient in daily life. The physician acknowledges patients as persons in his or her personal context through listening, answering questions and confirming thoughts, symptoms, or worries. This has a reassuring effect on patients who experience a feeling of being recognised for the person they are, the specific nature of their problems and their meaning in the whole picture of patients’ lives.
When being listened to and acknowledged as a person, the patient can trust the physician’s good will to help and contribute to an honest patient-physician relationship. Within the process of building a trustful patient-physician relationship, three themes appeared: “Feeling safe with the physician”, “Being acknowledged as a whole person”, and “Feeling like a normal person”, presented below in Table 3.

Table 3.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Categories</th>
<th>Codes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feeling safe with the physician</td>
<td>A professional person</td>
<td>Authority, Gender, Confidentiality, Documentation</td>
</tr>
<tr>
<td></td>
<td>Attitude towards the patient</td>
<td>Welcome, Positive, Motivation, Absence</td>
</tr>
<tr>
<td></td>
<td>Availability</td>
<td>Not alone, Guidance, Delay</td>
</tr>
<tr>
<td>Being acknowledged as a whole person</td>
<td>Social background</td>
<td>Stress, Stigma, Culture</td>
</tr>
<tr>
<td></td>
<td>Co-morbidity</td>
<td>Respect, Constructivism</td>
</tr>
<tr>
<td></td>
<td>Religion</td>
<td>Stigma, Insignificant, Fast</td>
</tr>
<tr>
<td>Feeling like a normal person</td>
<td>Treatment</td>
<td>Medication, Conversation, Psychology</td>
</tr>
<tr>
<td></td>
<td>Self-perception</td>
<td>Same person, Capable, No secrets, Not alone, Responsible</td>
</tr>
</tbody>
</table>
Feeling safe with the physician

Feeling safe and secure in the meeting with the physician appeared to be one of the most basic needs for establishing trust in relation to the physician. In order to make the patient feel safe, the physician must appear professional, maintain a positive attitude and present accessible ways to contact the hospital whenever needed.

A professional person

It appeared to be important for patients that physicians demonstrate authority. The physician needs to make clear that epileptic seizures have been treated successfully before and that there is a developed program, a clear strategy with careful steps and measures to be taken. When the physician appeared confident, calm and clearly presented information, patients were reassured. Any sign of insecurity from the physician could immediately cause patients to doubt. When wanting to include the patient in decision-making by asking for the patient’s opinion, this could be perceived as insecurity and have adverse effects. While some felt included in a positive way when deciding together, others started doubting the physician’s competency and would, as a consequence, consult another physician for a second opinion.

“I would say -I don’t have any idea, that’s why I’m here, for you to make me a treatment, to give me some advice, I didn’t study (to become) a doctor. And I will, if I got some doubts I would probably want to speak to a second doctor.” -P6.

Primarily, the physician was identified as a professional person on duty, before patients considered any personal characteristics as of being a man or a woman. As a professional person, health is the physician’s only concern. Therefore, physicians were considered not to have the right to personal judgements that were not directly linked to the patient’s health status. Whether physicians were men or a women was said not to be of any importance.
"As long as the doctor is good and can help, that’s the point". -P7

For some patients however, it appeared easier to communicate personal thoughts or feelings together with a physician of the same sex. A female physician was thought to better understand the situation of a female patient, for example as a mother, and through recognition better understand the patient’s whole picture.

"With female doctors, it’s easier to talk to her. Maybe she’s a mother, maybe she understands." -P14

However, in the context of epilepsy, the need for help with controlling seizures was clearly emphasised prior to any personal preference of the physician’s characteristics as a man or a woman. When being in need of help, patients have no choice but to accept any physician available. It appeared that the worse the patient’s health condition, the less preferences they had regarding physicians’ personal characteristics.

"Doctors, they’re doctors. There are some, they’re muslims, they think that, it’s not good if there’s a woman, it’s better from a man. /…/ But I don’t listen. It doesn’t matter, it’s doctors. Maybe I don’t find no one else, what should I do? It doesn’t work that way." -P3

Thinking about the physician as a professional person appeared as a mental strategy to facilitate emotionally in the exposed and vulnerable situation of being a patient. A professional person has no right to prejudice or negative thoughts and is by the strict rules of confidentiality prevented from talking to people about what they see or hear. Confidentiality seems to be a basic condition for trusting the doctor. In the context of epilepsy, confidentiality was mentioned to be particularly important since many patients concealed their epilepsy to avoid stigma and discrimination in society.

“I think when you meet a doctor and everything that you say is anonymous and no others or no other doctor who can know about that you have some problem with what happens it is
more confidential with epilepsy. So no one can know about this. So that I can trust that all I say, it’s only my doctor and my nurse who know about this.” -P2

Another way for the physician to prove professionalism to the patient was by presenting documentation from test results. Many patients reported an initial difficulty to accept having epilepsy. Depending on the country of birth, the culture and previous experiences, epilepsy as a diagnosis often had a strong negative meaning for the individual. Actively taking part of test results and other documentation was said to be a way of understanding and helping to accept having epilepsy. Test results might not explain for the patient why the epilepsy happened to them of all people, but can be important for the patient to be able to trust information and the physician.

"I trusted the doctors who examined me because they showed everything on paper too, from the documentation and they told me everything straight, direct, without lying.” -P8

Attitudes

Authority and competence in medicine was told to be important but not sufficient for patients to create a trustful relationship with the physician. The attitude towards the patient, as welcoming, warm and positive, appeared not only to make the patient feel safe in the meeting with the physician, but also serve to motivate the patient in overall treatment and gain hope for the future. When patients feel insecure about seizures, feel alone and the situation is experienced as hopeless, the physician needs to project the opposite attitude for patients to feel secure. A positive attitude motivates the patient to believe in improvement, attending booked consultations and perceiving in the work with life style changes.

A warm welcome at the first encounter with the physician settles the patient’s attitudes for future encounters. Showing that the patient has come to the right place and that the physician is positive about finding a solution to the problem was reported as crucial in enabling a
trustful relationship and gain hope for the future. Being realistic about the chronic nature of epilepsy does not prevent optimism regarding improvement. A negative point of view was even reported as a reason for wanting to change physician.

“They visited a doctor and he said that this disease is not possible to cure, with that you will die. He was all negative. So then they felt like -what kind of doctor is that?” -P7

A positive view appeared also crucial to motivate the patient to attend health consultations. Patients told of tiresome situations when repeatedly receiving the same instructions from physicians about maintaining a healthy life style. These repeated lectures about how to live life to prevent seizures was often negatively perceived and mentioned as a reason to cancel booked appointments.

"We talk about same things every time we meet. The same thing! I can guarantee, 100%, they ask you same things. You have to take it easy, you’re not allowed to stress, you can’t be stressed, you can’t do this, you can’t do this.. Same thing every time.” -P1

After many years with treatment, motivation can be difficult to convey to the patient. Overall, patients seemed to agree on that it takes time to accept epilepsy as a condition. At first, especially for patients without obvious injury preceding the epilepsy, patients were wondering about the reason for its onset. Accepting epilepsy without not knowing the reason could take many years. Afterwards, especially young patients told of reluctance to life style changes that kept them from living like any other young persons. Finally, the chronic nature of epilepsy and many years of treatment even when seizures no longer occurred, lead to a lack of hope for the situation to improve. In these situations, meetings with the physician was experienced as useless for some patients, which resulted in absence from booked appointments.
“And it becomes annoying that he all the time sends this invitation, I think. Because, I know that, it’s doctors, only the prescriptions she has written. There’s nothing else she can do. Because I know this, this disease, that no one can change.” -P12

Availability

Knowing that you are not alone with your epilepsy, and that health professionals are aware of your symptoms, promotes the feeling of safety and turn epilepsy into a less heavy burden in everyday life. In some cultures, epilepsy is still heavily stigmatised, why patients conceal their condition to family and friends. Thus, physicians and nurses can be the only ones to talk to and turn to for social support.

As it turns out, direct access to the neurologist and the nurse by phone was reported to be an important factor for patients’ wellbeing and feelings of trust towards the clinic. If something happens to the patient outside the hospital, new symptoms appearing or negative side effects from medication, there is a need for guidance on what to do. Maintaining a frequent contact with health care providers on a weekly basis was reported essential for the feeling of safety and wellbeing of people with epilepsy.

“When you feel sick and you call to the nurse, that makes you calm. Only the fact that you call them -I’m feeling this, and then they can just tell you, -that’s normal or isn’t normal you should reach the hospital or.. That makes you calm too. Like, now I know what to do.” -P6

However, calling the hospital for advice and not receiving help within expected time can drastically damage the patient- provider relationship. A delay of any kind was experienced as unprofessional and hurtful for patients who would consider changing neurologist or hospital.

“If I call in saying I feel bad, like that time when I felt bad from the Keppra, if she wouldn’t call me the same day, then I would have changed doctor. If it would take some day, the day
after or two days, then I would change. I would not keep the same doctor. Or I would change the local hospital maybe. I would look for another hospital. Yeah.” -P5.

Being acknowledged as a whole person

Once patients have approved of the physician as a professional person with whom patients can feel safe, a key to trust and successful communication appeared to be that of the physician acknowledging all relevant aspects of patients’ lives. Relevant, in the sense of somehow affecting patients’ health. When physicians’ approach the patient’s point of view, efficient communication can begin. While a mere diagnose does not tell anything about a person, personal circumstances will decide what place and meaning epilepsy come to fill in patients’ lives. Understanding epilepsy from patients’ point of view, is a time-consuming process, but appeared nevertheless crucial for mutual understanding and successful communication.

Background and social situation

Epileptic seizures are strongly connected to patients’ overall wellbeing, why any factor impairing the patient’s health is important for the physician to acknowledge. Knowledge about the patient’s past and current living situation helps physicians understanding the whole context and what measures that need to be taken to help. Acknowledging every day struggle and showing interest will reassure the patient that the doctor understands the whole situation and will do what is possible to help. Additionally, it facilitates for patients to talk about problems otherwise experienced as shameful.

Some patients’ shared lived experiences of war from the home country, experiences of being victims of aggravated assault in intimate relationships, of being married as a child, dangerous living situations or other substantial stress factors. When the physician had insight into the patient’s life it appeared less stigmatised for the patient to ask for help, as for example a wish to see a psychologist. Seeing a psychologist was told to be difficult to talk about and nothing
that you would share with a physician that you did not trust. This since, in some cultures, a
person that wished or needed to see a psychologist would be seen as crazy.

“I feel that if I wasn’t in the same situation I wouldn’t be sick. I think about that sometimes. If
I don’t stress I don’t faint. That means my situation. It’s good that she (the physician) thinks
of this. /…/ Sometimes you feel like you might not need help, but you need to talk.” -P3

Experiences of stigma and social isolation earlier in life appeared to affect attitudes and
degree of openness towards the physician. Through experiences of being avoided by friends
and acquaintances, causing rumours with negative consequences for the family, being
dismissed from work or not being hired because of epilepsy, patients had developed a strategy
to avoid stigma through concealing their epilepsy symptoms. Knowledge about what social
consequences epilepsy had caused in a patient’s life appeared to facilitate for physicians to
understand the patient’s situation, to connect and gradually build a trustful relationship.

Patients shared diverse cultural views of epilepsy and an extensive span of experienced
negative consequences as a result. People with epilepsy could for example be considered
dangerous, possessed with voodoo witchcraft, mentally ill, retarded or handicapped. In
consequence, people with epilepsy lost social status, lost rights to participate in society, were
avoided, isolated or locked in. A man undergoing an epileptic seizure on the street would
most likely be avoided and left to his fate. Rumours spread and negatively affected whole
families and it was told that a person with epilepsy might never find a job or a spouse.

“We have kept the silence, it’s only my mum and the family who knew that I had those
seizures, she didn’t dare to leave me if I get seizures and faint and so on. My siblings knew
about it, but no other people.” -P9
When the physician speaks the same mother tongue and share the same culture as the patient, the patient finds it easier to communicate, relax and trust the physician. This seemed to have a great impact on patient satisfaction initially, during the first encounter with the physician.

“First, I start, I feel -Oh my god he is so nice, he is so.... It was good that he’s same language as me. /.../ For example if you’d been a Persian doctor, Persian, for example you know Persian language, maybe easier for me to tell you what happened, or I don’t know. You can talk easier.” -P14

However, in the context of epilepsy, when the patient had experienced social isolation or discrimination in the home country, seeing a physician from the same culture appeared to remind the patient of feelings of shame and distress. This resulted in diminished disclosure towards the physician.

P14: "But if it was my doctor, Persian, maybe I’m ashamed to say some words to him, peeing for example, or ..” -P14

Interviewer: Is this less embarrassing with a Swedish doctor?

P14: “Yes.”

Because of stigma, patients told they had not always told physicians about seizures or other symptoms, why diagnosing epilepsy sometimes turned into a time consuming process and delayed the insertion of adequate medication. Within this process, patients saw physician after physician, tried vitamins or other ineffective medications until finally meeting a physician who would interpret the symptoms told as epilepsy. A culture discordant physician appeared then to reduce stigma for patients and facilitate communication in the medical encounter.

”In the home country they have, it takes a long time until they know what we have, where we are, it takes a very very long time. But here (in Sweden) there’s a possibility that you tell also,
so they can understand a little faster. /../ Here in Sweden you can describe everything that you’ve gone through, yes." - P9

Problems with economy, relationships, finding a place to live, or an employment can be apprehended by the patient as more urgent threats to their health than epilepsy. In some cultures, social problems are considered shameful and cannot be discussed among friends and acquaintances. The physician is sometimes the only person to talk to and there seemed to be a strong belief in physicians’ ability to help, for example through written certifications.

“It was really hard for me to walk the stairs and there is no apartment and so. I don’t know, it.. if there’s a doctor for example, maybe write that in a letter or so, she has problems, or so. It is better that I show, maybe find little easy or with elevator.” -P14

Co-morbidity

Co-morbidity, with for example visible injuries, appeared to amplify the degree of stigma. In addition to the fear of having seizures in front of people, a fear was expressed of being judged for other visible injuries or deviating features, which added on to social isolation and internal stress.

“I didn’t dare for I should have that seizure in front of people. And at the same time burn injuries, I was ashamed also. I wasn’t outside a single time.” -P9

What role epilepsy played in life was inevitably related to potential co-morbidity. For physicians to understand patients’ prioritisations and motivation in treatment, it seemed crucial to know how other physical or mental conditions influence patients’ everyday life. It appeared central for patients that the physician focus on what is perceived as the real problem, conditions likely to improve with medication. Commenting on circumstances less likely to improve, or expressing pity for the patient, was perceived much condescending and hurtful.
“There are ways that doctors express themselves that feels condescending. /../ -Oh poor you. or something like that. Comments like that make me more angry than, you know. It has opposite effect when they all the time remind me of something that I live with 24 hours a day.”

-P13

Religion

Despite the private and sensitive character of personal beliefs, the question of religion sometimes needs to be brought up during health consultations. Besides the privacy status, a fear of being discriminated appears to contribute to a reluctance to talk about religion. A reoccurring example mentioned was the fear of being discriminated for being Muslim and the repulsion and fear of being associated with terrorists. Another concerned the veil and whether or not wearing the veil and exposing religious belonging would influence the physician’s attitude towards the patient. It was reported that women wearing veils were afraid to be discriminated and not receive health care of equal quality as women not wearing veils, why some women chose to remove the veil exceptionally for health care consultations.

However, when religion is likely to interfere with patients’ medication, it needs to be brought up in medical consultations. Some patients considered religion as an important aspect of their life that physicians needed to be aware of and account for when providing health care.

Examples mentioned were female patients not wanting to remove the veil with a male doctor or male patients with preferences for male physicians for physical examinations, relating to religious beliefs. Meanwhile, many patients experienced interrogation of religion as upsetting, especially if not clearly relating the question to health or epilepsy. Fast was mentioned as an acceptable reason for discussing religion. Adjusting time for administrating the medication during Fast was discussed with the physician without the patient feeling exposed.
“I’m a Muslim, and she asked me a while ago if, the doctor, when I was, about Fast for example. Cause she said there are some who stop taking their medication during the Fast period. But I said, I usually take. /…/ If you feel that it can interfere with your medication, then it’s important to tell.” -P4

However, when being asked if religion could sometimes be of value for the physician to acknowledge, a majority of patients denied any importance of religion in the context of epilepsy.

“My religion says that if I’m about to do something religious that can have negative effects on my health, then I shouldn’t do it. /../ That’s why I don’t think it’s important that my doctor knows if I’m religious or not.” -P10

Feeling like a normal person

Epilepsy changes the course of life in an unpredictable way, while patients long to lead their life as before and feel like normal persons again. The need for patients to feel like normal persons emerged as a reoccurring theme across interviews, to restore patients’ confidence and health.

In order to lead a normal life, seizures must cease to occur. In this first important step towards a seizure-free life, the physician plays an obvious role. But whether or not seizures cease to occur, patients need to regain confidence in themselves and feel like independent persons again, capable of taking responsibilities and fulfilling their expected roles. Negative reactions from others often damage patients’ self-confidence. In establishing a trustful relationship with the physician, where the patient dare to talk openly of main concerns without feeling stigmatised, the physician represents a useful tool to promote normality.

Treatment

Patients seemed to be highly aware of the importance of medication and cautious adherence to prevent seizures. However, negative side effects from medication signified great issues, as a
loss of appetite, weight loss, feeling tired, aggressive or not feeling quite like yourself. Not only did this cause harm to the patient but also, resulted in devastating effects on the patient-provider relationship. Patients who had noticed a great deal of negative side effects, appeared to easily lose confidence in the physician as well as belief in their progress. Negative side effects were commonly interpreted by patients as a mistake by the physician, prescribing the wrong medication and a lack of competency. This conclusion was shown to motivate patients to take own initiatives, for example by deciding to stop taking medication, changing physician or cancel, alternatively simply not showing up for booked health care appointments.

“Every time I took the medicine I became aggressive. Fighting with my friends... Then I told them -It’s not me, it’s the medicine that does this. One day, I was just like- It’s enough, I’m not gonna use this. I through them away. I didn’t use them and I noticed I felt better.” -P1

Besides medication, the conversation with the physician appeared to serve as a great motivation for patients. As it seems, talking to the physician about life and feelings has in itself positive effects on how patients perceive their physical condition. Epilepsy was said to be different from many other medical conditions in the sense that epilepsy patients often deal with worries and fears and therefore have a more urgent need to talk with their physicians. Additionally, migration was mentioned as a reason for smaller social support why the conversation with the physician became even more important. For many patients, conversations about personal circumstances, thoughts and feelings appeared to be an equally important component in treatment as the medication, it was said to raise the patient’s morale and diminish the mental burden of epilepsy.

Interviewer: “-What do you think would happened if you felt that you couldn’t talk about everything with your physician?”

P12: “At that moment I feel that my disease would be much worse.”
Patients commonly told that seeing a psychologist was considered shameful in their cultures. A fear of being disregarded by others had driven people to keep psychosocial problems to themselves. By actively asking the patient if he or she would like to see a psychologist, while underscoring that it has been of great help to many people before, the physician can bring up the subject and make it possible for patients to ask for help without the feeling of being judged. A majority of patients confirmed that they would not have asked for a psychologist themselves and that it was the physician who had first brought up the subject.

By facilitating for patients to ask for help, the physician seems to help reducing stigma and promotes trust in the relationship with the patient. In the long run, establishing a trustful relationship appears to facilitate for patients to ask for help earlier in the process, before the condition is aggravated to the point that the patient no longer has a choice. Recognising and addressing the frequent need for psychological support appeared to be crucial.

“In my thoughts, not only me, most of us immigrants, when you say psychologist, it means that something’s wrong. You think like that. It’s the way we look at it. /.../ You’re getting crazy, that’s the way you’re heading, that’s why you end up there (at the psychologist). That’s our interpretation.” -P15

Self-perception

In the process of feeling like a normal person again, patients need to recover both physically and mentally and regain confidence in themselves as capable individuals. In the context of epilepsy, patients lose control over their lives in various ways. The extensive consequences from epilepsy, physical, social, economic etc., have strong influence on confidence and self-perception. Through the eyes of other people, patients interpret their own reflection, why other people’s judgments shape the patients’ perception of themselves. Taking medication every day is a constant reminder of disease that follows patients in everyday life, whether or
not seizures occur any longer. The physician appears to play an important role in confirming the patient as a normal, capable individual, in order to calm, support confidence and increase wellbeing for the patient.

Secrets

One reason for keeping sensitive information to oneself was explained by feelings of being wrong or different. Many patients explained how discrimination and social diminishment had led to decreased disclosure about epilepsy as an efficient strategy to maintain their social role. At the same time, keeping epilepsy secret had caused increased levels of stress. It appeared paramount that physicians anticipated and asked for symptoms, and confirmed symptoms as frequent and normal in the context of epilepsy. The physician seemed to play a crucial role in the process of normalisation by verbalising and confirming patients’ symptoms.

“The first time I’m very ashamed, cause I didn’t want to say to him -I pee, or so. And he asks me.. Do you remember knowing that someone told you that after that maybe you pee or so? We had an interpreter, I was more ashamed than usual.” -P14

Many patients reported having felt alone with their epilepsy and thinking that they were unusual or different. Through interaction with other patients with epilepsy, patients realised they were not exceptional, which was told to have a relieving effect. By meeting others in similar situations, patients felt reassured by the fact that they were not alone and felt more normal. Furthermore, when realising how many people there were with the same problem, patients seemed to feel more legitimate talking about their epilepsy.

“Before I thought maybe only I was like that and so. But when I came to Lundby, I saw that, woohh! There are many just like me (laugh). They come every time, I meet them, they sit and wait for the doctor and so. They know me, I know them and yes, it helps. It helps, you get a little, little more calm and like, not think why only me it’s like that.” -P14
Being the same, capable person.

Patients need to feel that they are still the same persons as before the onset of their epilepsy. In fact, social support from family and friends was told to sometimes have adverse effects on the patient’s wellbeing. A strong wish was expressed to not be pitied by others and it was commonly stressed by patients that they felt healthy and that they did not feel like they had a disease. Reactions from friends and family members and a change in behaviour towards the patient were told to negatively influence the patient. This change in behaviour, other persons’ pity and being regarded as a sick and weak person, strongly affected self-perception and confidence. Patients experienced a feeling of being reduced from the person they were, to someone who could no longer perform the same tasks or fulfil the same roles. To support the patient’s confidence and emotional wellbeing, the physician has a great responsibility to confirm patients as independent and capable persons. It appeared crucial not to pity the patients, to not add on to this diminishing process. Instead, the physician must focus on the patient’s abilities and respect the patient’s integrity. Privacy was mentioned as a right that was partly taken away from a person when becoming sick. Maintaining privacy seemed of great importance for patients’ self-esteem and wellbeing.

Interviewer: “What do you think other people think of epilepsy, your family for example?”

P5: “That it’s a terrible disease. That you can die from it. The often say ‘‘-Don’t stay on your own, don’t stay on your own. You must always have people around.’’ But you can’t have people around all the time, it’s just not possible. You want to have a private life too.”

Besides acknowledging the patient as a capable person, it is the physician’s responsibility to provide the patient with tools necessary to engage in their epilepsy management. Managing epilepsy seems to be an important contributor to the patient’s feelings of being capable. The physician was acknowledged as an important help in learning epilepsy management even
though patients generally seemed to understand the importance of their own contribution to achieve satisfactory treatment results. Many witnessed of non-adherence at a younger age and explained that it can take a long time to realise what great importance adherence has to seizure control and wellbeing. Learning to take responsibility for medication and life style appeared not only to improve seizure control, but also to give the patient confidence in managing other aspects of their life. By educating patients how to manage epilepsy, the physician encourages patients to take other responsibilities, whereby they can succeed to fulfil social roles and feel like normal persons again.

“It took me long time to understand that, you can have fun as everyone, but in a different way. Probably go to the bar or.. but drink a soda, but don’t drink probably shots straight to your system.” - P6

Discussion

In this study, 15 interviews were conducted with foreign born patients with epilepsy. Results highlight what appeared as important themes in the process of constructing a trustful relationship with the physician as “feeling safe with the physician”, “being acknowledged as a whole person” and “feeling like a normal person”. Our findings suggest that physicians are not only expected to prescribe a medication that prevent seizures, but also to be professional and available authorities, who positively greet and motivate the patient, acknowledge all aspects of the patient’s life, health and wellbeing and confirm the patient as a normal person, in discussing the patient’s symptoms, thoughts and feelings. Foreign born people with epilepsy, with diminished social network and support as a result from migration, and sometimes other co-existing morbidity, seem to be in particular need for being recognised and respected by the physician.
To strengthen self-perception, patients need to feel capable of performing tasks and fulfil roles, to gain respect from others. The physician is responsible for actively involving patients in managing their own treatment. If the physician succeeds in educating patients, not only can this improve seizure control, but also encourage the patient in taking other responsibilities, managing other tasks in life, that will strengthen the feeling of being a capable person.

**Challenging the concept of patient-centered care**

In this study, results indicate that authority can serve to reassure immigrant patients with epilepsy of being in the safe hands of a competent doctor. Furthermore, patients seem to expect physicians to carefully listen to and seriously consider all problems in life. The need to be listened to and informed appeared more urgent for patients in this study than to share decision making, even though there were also patients stressing this as important. In general, the physician was recognised by patients for making the most appropriate decisions for them. A decisive physician seemed to have reassuring influence on patients and promote trust in the patient-physician encounter.

Findings from this study could somewhat be seen to contradict previous research in the field of patient-centered care. Encouraging the patient to talk, listening and sharing decision-making have earlier been described as fundamental components in establishing a trustful patient-physician relationship and a starting point for patient-centred care (21, 29, 39).

Previous studies have shown that shared decision making leads to better treatment outcomes where patients that participate in open dialogues about their treatment and take part in forming treatment plans tend to adhere better to medication (15, 21). Since improved adherence is positively associated with treatment outcomes and quality of life for patients with epilepsy (15), achieving good patient adherence is an important goal in epilepsy treatment. With this said, it can be argued that shared decision-making should have a natural place in medical practice and be applied as a general strategy to improve quality health care.
for people with epilepsy. This however, is contradicted by our results that indicate that many patients prefer authority and a physician that takes the responsibility for decision-making.

Considering shared decision-making, studies showing correlation with patient satisfaction and positive treatment outcomes have mainly been carried out in Western countries (21, 28, 29, 40). Whether shared decision-making leads to better treatment outcomes and health for people from other cultural traditions and health care settings is little investigated and discussed in the literature.

A qualitative study of diabetes type 2 patients’ expectations of patient-physician communication, performed in Oman (41), revealed that patients had similar expectations on communication with physicians as patients in Western countries. These aspects concerned warm welcoming, making eye contact and not staring into the computer while talking to the patient, attentive listening and occasions for patients to ask questions and express concerns. Encouraging the patient to ask question was suggested as a way to encourage patient involvement and management and had positive effects on treatment outcomes and the patient-physician relationship (41). In the same article it is further discussed that in many Muslim countries, it is common for leaders to separate themselves from the rest of the population and that physicians are seen as sources of knowledge and security which give them power and responsibility (41).

The above mentioned article offers an alternative view of patient-centred care, that better corresponds to our findings in this study. As was discussed before, persons from different cultures often have different expectations on communication with the physician, what information and how much information the physician should share with the patient (11). A certain cultural view and tradition inevitably influences the degree to which patients tend to involve in decision making.
The concept of patient-centered care is developed in Western countries with strong traditions of individualism in society. In many other countries around the world, people are used to a sort of dependent collectivism, where people are born into a group, formed by family and relatives, that protects the individual in exchange for loyalty (41). Traditional perspectives on social roles may explain something about differences in preferences among individuals concerning involvement in decision-making. Cultural heritage is likely to influence preferences for decision-making. However, there is research that have found that cultural explanations can mask social inequities (42), as for example a lack of education, why this explanation for reluctance to shared decision-making should be questioned before it is accepted by caregivers. Physicians must therefore pay careful attention to patients’ personal level of health literacy and provide information adapted to this level that is necessary for the patient to be able to involve in treatment management. But whether shared decision-making actually can be defended as a contributor to trust in the patient-physician encounter and improved seizure control need to be assessed individually. This, however, does not imply that discussions and open dialogues about treatment management should not be promoted for all patients. On the contrary, research shows correlations of effective patient-provider communication and patient health outcomes (28) regardless of who takes the final decisions. Results from this study show that patients need to be greeted with positive attitude and respect, given room to talk, to be listened to and provided with information, regardless of culture and origin. These results stand in line with above mentioned literature, indicating that being respected, listened to and encouraged as a patient to share narratives, is universally important to feel safe and construct a trustful patient-physician relationship, while preferences for shared decision-making might actually depend on context and cultural traditions.
Epilepsy-related stigma and disclosure

In this study, an overall knowledge of patients’ lives appeared both as a condition for and a result of building a trustful relationship with the physician. An insight into the complexity of combined factors that influences patient’s health takes time for the physician to develop. Nevertheless, this knowledge appears necessary for physicians, and probably also for other health professionals, to understand a patient’s point of view. By approaching patients’ perspectives, the physician has a better chance to understand what place and meaning a disorder like epilepsy takes in patients’ lives, to reach agreement over treatment and provide adequate health care. In our findings, personal history of war experiences, experiences of aggravated assault, struggle with economy, co-morbidities, discrimination, work situation, relationships, and belief were mentioned as important factors affecting patients’ health.

Recognising the complexity of social factors and characteristics that together form human beings and influence health have been presented in the literature through the concept of intersectionality (43), as a strategy to prevent social injustice and health inequities in the context of migration. Intersectionality acknowledges ethnicity, gender, class, poverty, disabilities, minority status and religion, as important dimensions that through individual combinations have great impact on social status, economic status and health (43). According to the concept of intersectionality, no human being could be identified or described due to a single characteristic. In contrary, a person with his or her lived experiences need to be understood in the light of complex, personal circumstances (44).

Our findings correspond well to the concept of intersectionality, indicating that epilepsy must be understood in a personal context, that physicians must acknowledge the whole person and all pertinent aspects of patients’ lives, in order for mutual understanding, efficient communication and a trustful patient-physician relationship to develop. Considering the complicated and sometimes dangerous living situations told of in our study, it is likely that the
importance of epilepsy treatment and medical encounters is sometimes overshadowed by other problems in life, perceived more urgent to the patient. Frequent absence from medical appointments should therefore be registered by physicians as a warning flag. Instead of declaring patients unreliable or hopeless, awareness must be raised that social support might be needed.

Among our findings, a reoccurring phenomenon was that of stigmatic experiences derived from various context, as in finding employment, a spouse, maintaining social roles and status. Social isolation and not talking about epilepsy with others, was described as a common strategy to safeguard epilepsy as a secret within the family and protect the individuals from stigma. At the same time, this strategy that aims to protect persons from epilepsy-related stigma, seem to provoke stress in itself. In the end, living with the secret, unanswered questions and solitude, appear to present a severe form of stress for persons with epilepsy, even when seizure control has been achieved.

Hiding epilepsy symptoms is widely described in the literature as a result of stigma caused by unawareness and lack of knowledge of epilepsy in society (4, 13, 18, 19). Due to economic, medical, and informational development in low-income countries, knowledge of epilepsy, of cause and conventional treatment, is increasing, progressively leading to improved health for persons with epilepsy (45). As a reflection of this development, fewer young persons with epilepsy in low- and middle income- countries are likely to consult traditional treatments than elderly (45). But despite increased public awareness, it has been shown that negative attitudes regarding prejudices, schooling, occupational choices of people with epilepsy still exist and contribute in maintaining marginalization and discrimination of people with epilepsy (45). Additionally, epilepsy-related stigma is associated with depression, anxiety, negative feelings and low self-esteem, where people with epilepsy consider themselves unsuccessful, non-independent or handicapped (46). Reports of negative attitudes towards people with epilepsy
as well as social consequences are frequent (19, 45, 46) and show likewise to our results, that they not only affect employment and restrictions in career development, but furthermore, social relationships and the chance to find a spouse. In a recent study in Turkey, approximately a third of married persons that were diagnosed before their marriage reported not disclosing their epilepsy to their partner before the wedding (46). It is clear that many people with epilepsy still today hide their epilepsy as a means to avoid discrimination.

Our findings from this study unfortunately seem to correspond to confirm results from previous research (4, 19, 45, 46), indicating that epilepsy have extensive social consequences, and that many people that live with epilepsy still today have low disclosure about their condition. However, in our study, patients claimed that talking openly about epilepsy had a relieving, motivating effect that promoted wellbeing. Trusting the physician enough to confide the most sensitive subjects, as for example a need to see a psychologist, appeared to be decisive for patients to dare asking for help, and thereby to receive adequate health care. Trust and openness about epilepsy appeared essential for efficient communication and the establishment of a trustful patient-physician relationship. Furthermore, when patients were enough confident to talk to other people about their epilepsy, disclosure about epilepsy had positive effects on overall perceived health and wellbeing.

While our results emphasise the positive health effects for patients practicing disclosure about their epilepsy, indicating that physicians should encourage patients to disclosure as a strategy to prevent stigma and promote health and wellbeing, previous research is somewhat ambiguous. Whether or not disclosure of epilepsy should be promoted to reduce stigma is discussed in a review of disclosure strategies for children with epilepsy and their parents (47), where it is stated that some studies have indicated that disclosure about epilepsy have positive effects. At the same time, concealing epilepsy or applying selective disclosure have been reported as useful protective strategies to avoid discrimination, social exclusion and safeguard
wellbeing. However, while protecting the person with epilepsy on short term, it is pointed out that a lack of disclosure adds on public unawareness and lack of knowledge which contributes to stigmatization on long term (47). Since increased knowledge of epilepsy in society has been associated with more positive attitudes towards people with epilepsy and has been recognized, together with maintained organized epilepsy care and seizure control as an important strategy to reduce epilepsy-related stigma (48), it can be argued that openness should indeed be encouraged by physicians to promote health in a larger scale. Concealing epilepsy might fuel the unawareness and the vicious circle of epilepsy-related stigma in society.

Increasing awareness and public knowledge of epilepsy is crucial to diminish epilepsy related stigma and improve health for persons with epilepsy. However, physicians must always prioritise health and wellbeing of individual patients. Depending on the extent of lived experiences of stigma, it may take many years for patients to be able to practice disclosure about their epilepsy. It might be so that each patient need to reach a kind of readiness, acceptance of the condition and trust towards the society to treat them well, before being able to talk openly about their epilepsy. If not yet ready, disclosure could instead have reversed effects, possibly causing the patient harm. A good insight into patients’ medical history and social context, including co-morbidities, social resources, values, consequences and struggle, would facilitate an assessment of individual readiness and whether disclosure should be encouraged as a means to support patients. As it seems, acknowledging the whole person and applying the strategy of intersectionality are effective enhancers for good communication which provide physicians with keys to better understand how to deal with disclosure in order to promote health for each individual patient.
Striving for normality

The question of feeling capable, capable of managing epilepsy, work, maintaining social relationships and status, driver’s license, capable of taking responsibilities for one self and for others, all seem to be crucial for patients’ self-perception and confidence. Results from this study indicates that the physician plays an important role within this process, first of all to anticipate, verbalise and confirm patients as normal persons, and secondly, through educating the patient in epilepsy treatment management. Actively asking for epilepsy-related symptoms and confirming that no phenomenon is unique, but also experienced by many others in similar situations, have relieving effects on patients and facilitates communication. Stigma appear much present here, in the sense that patients often hide symptoms from family to prevent loosing respect and esteem as capable persons. Not being considered the same person anymore as well as being pitied, were reported as reasons to hide epilepsy from the family. Managing epilepsy appeared to serve not only to improve seizure control but furthermore, to encourage patients in taking responsibilities, regaining confidence in managing other tasks in their life. In addition, by supporting patients in self-management of their epilepsy, in addition, physicians encourage patients in fulfilling expected roles in family or society, taking responsibilities that make them feel like normal persons again.

This somewhat corresponds to the findings of another Swedish study performed by Santos Tavares Silvia I, where strategies to participate in society through occupation and social interactions were explored through interviews with persons with disabilities having immigrated from eastern Africa. In this study, it was shown that fulfilling tasks and obtaining results that are valuable to others is an important strategy to gain respect. Hiding special needs or physical limitations was another strategy mentioned. While striving for normality, being recognised, valued and respected by others is crucial in the construction of the person’s self-perception as a person that actively participate and contribute in society (49). Immigrated
disabled persons are considered carrying a double vulnerability in society, often invisible, that need to be acknowledged (49). It appeared in this study, that taking responsibility in managing epilepsy contributes to the patient’s feeling of being capable, increases confidence and emotional wellbeing. Physicians should therefore prioritise working to actively engage and empower patients to manage their epilepsy.

Another study corresponding to these findings, a qualitative study inquiring self-managing goals for older people with epilepsy in the US, describes how patients were striving for normalcy in social roles (family, friends, work), physical and cognitive health and in satisfaction with life. Attaining seizure-freedom was considered important to achieve normalcy, but not exclusively. A main issue for patients with epilepsy is to lead a normal life and carry on as before (39). This same study further indicated that patients’ personal goals regarding managing epilepsy have been shown often to be incongruent with those of the physician who mainly focuses on seizures and medication. (39). Since a mutual agreement of and shared perspective on the patient’s condition is positively associated with the patient’s adherence to medication, patient satisfaction and trust towards the physician (30), the physician needs to form an idea of the patient’s view of their condition. Listening is an important step for the physician to promote a patient-centred approach (21).

Thus, striving for normality, feeling capable of taking responsibilities and maintain social roles appears to represent one of the main issues for people with epilepsy. Physicians can thereby be argued to have two main responsibilities towards patients with epilepsy. First, the obvious part where physicians prescribe, follow up and monitor medication, inform and involve patients in treatment management. Second, as our findings indicate, facilitating for patients to talk about symptoms is crucial for good communication and honest information between patient and physician, in particular when patients have suffered from stigma. Depending on culture, norms and knowledge in society, a phenomenon that is generally not
provoking any social reactions in one country can be perceived much stigmatic in another. Hence, a physician can never know beforehand what are the sensitive matters from the patient’s point of view. When entering upon a medical encounter without assumptions, certitude or prejudice, unexpected discoveries are made possible. Discoveries that may in fact present the keys to comprehension and efficient communication with the patient. In efficient communication, patients and physician stand on common ground, agreeing on the issue and most appropriate treatment. When sharing the same logic, physicians and patients can compensate each other’s resources and co-operate in solving the problem. Working to improve the patient-centred approach in every medical encounter, in the sense of increase listening, encourage patients’ narratives and share pertinent information with patients, fundamental to clear communication and to ensure common grounds in discussions. When treating all patients equally concerning attention and room for narratives, an actively listening physician is provided with information that can explain culturally derived differences.

**Methodological considerations**

Typical for qualitative research is that samples are purposefully selected to permit in depth understanding and inquiry into the subject the researcher wishes to explore (33). The sample size may therefore seem small in the eyes of a researcher from a quantitative research tradition. In contrast to probability sampling in quantitative studies, purposive sampling in qualitative research does not intend to permit generalisation to a certain population. That is why randomisation is neither the logic, nor the ideal strategy to recruit samples in a qualitative study design. Instead, since the study’s purpose is to gain insight into a certain phenomenon through participants’ personal experiences, the power and logic in qualitative purposive sampling comes from the emphasis on in-depth understanding. The adequacy of samples should therefore be judged due to information-richness instead of number of participants. Information richness should together with the researcher’s observational and
analytical skills constitute the most conclusive factors when judging validity, meaningfulness and the study’s presented results (33).

The reliability of the material as well as the authors interpretations can, and should, always be questioned. Since interviews were performed in Swedish, English or in another language that was translated to Swedish by a professional interpreter, transcribed in Swedish or English, analysed in Swedish and finally presented in English, the exact meaning of words is likely to have been modified throughout the process. Citations translated in two or three steps do change in their exact content, which may influence, and in worst case change, the meaning of what has been said. Careful considerations were therefore made throughout the whole process of translating, to safeguard both direct and underlying meanings. Authors received help from colleagues fluent in both English and Swedish to look over translations of citations as a measure to diminish the risk of modifying the meaning of the text. Regarding citations from interviews translated in the first step by a professional interpreter, there is always a risk of misconceptions. However, the alternative would have been to exclude participants who did neither speak Swedish nor English. By choosing not to include those participants, important perspectives would have been excluded and important knowledge lost. Including such perspectives was judged more important, overweighing the shortage of certitude concerning how well the interpreter’s translated message corresponded to the meaning of what the participant actually said.

Since the nature of narratives change with feelings of trust towards the interviewer it is likely that data would have become more true to the informant’s personal experience as it was actually perceived, if the setting had been different. First of all, since interviews took place at the neurology department directly following the informants’ health consultations with the physician or the nurse, informants were surely less likely to express negative feedback
concerning the consultation. Even though the interviewing student carefully informed informants of confidentiality and that information would not be shared with other health care staff, it is possible that the student/interviewer was associated with health care staff which further motivated participants to express loyalty towards the physician/nurse and carefully select which experiences to share. Finally, the interpreters assisting some of the interviews were the same interpreters that assisted during the preceding health consultations. This presence of an additional person in the room, a witness from the health consultation and a person who often share the same cultural background as the informant, might limit the extent to which the informant feels free to talk openly without being judged. This is also likely to influence the character and content of narratives.

Finally, demographic characteristics of the interviewer, as a Swedish born woman of 26 years of age, surely influenced the degree of trust that was established with different participants and the character of narratives. There is always a possibility that male participants would have answered differently to a male interviewer and that all participants would have answered differently to an interviewer with different age and origin.

Further research

Interventions to improve patient-physician communication and physicians’ listening skills need to be evaluated in a multicultural context. Further research is needed to increase knowledge of how to adapt patient-centeredness to culturally different settings. Research need to focus on development and evaluation of strategies on how to apply patient centeredness and promote increased attentiveness among physicians in medical practice.

In this study, narratives of aggravated assault in intimate relationships reoccurred across interviews with female participants, indicating a possible association of ill treatment and higher prevalence among migrated women with epilepsy. Whether this finding is related to
the vulnerable situation of having immigrated, cultural aspects, epilepsy or if this finding occurred randomly need to be further looked into, to identify risks for and take measures against physical violence.

Practical implications

Trust is decisive for successful communication and treatment outcomes. While physicians should consider each patient in the specific context of the patient’s own life, a respectful and listening physician who practices openness and shares information with the patient is fundamental for constructing a trustful patient-physician relationship, regardless of patients’ culture or country of origin.
Att bygga en förtroendefull patient- läkarrelation: En kvalitativ studie om hur utlandsfödda patienter med epilepsi upplever kontakten med läkaren

Bakgrund: Utlandsfödda svenskar har generellt sett sämre hälsa och större sjukvårdsbehov jämfört med den övriga befolkningen, samtidigt som de ofta möter svårigheter i att söka vård. Utlandsfödda svenskar som dessutom har epilepsi kan ur ett hällopspektiv beskrivas som en grupp med dubbel sårbarhet i samhället. Epilepsi orsakar inte bara fysiska skador till följd av anfallen, utan påverkar livet i stort med utbredda ekonomiska, psykologiska och sociala konsekvenser. Pga en rädsla för att bli diskriminerad i olika sammanhang kan det vara väldigt svårt att prata öppet om epilepsi. En strategi för att förbättra kommunikation och förståelse mellan patienter och sjukvårdspersonal, och därigenom öka kvalitet på given vård, är att tillämpa ”Patient- centrerad vård”. Patient- centrerad vård är ett koncept som syftar till att lyfta fokus från diagnosen och sätta patientens egna perspektiv i fokus.

Syfte: Syftet med den här studien var att utöka förståelsen för utlandsfödda patienter med epilepsi och viktiga faktorer som bidrass till att skapa en tillitsfull relation i mötet med läkaren.

Metod: 15 semi- strukturerade djupintervjuer med utlandsfödda patienter med epilepsi på Angereds Närsjukhus, spelades in digital, transkriberades och analyserades enligt principerna för innehållsanalys.

Resultat: Tre teman framkom: ”Att känna sig trygg med sin läkare, ”Att bli sedd som en hel människa” och att ”Känna sig som en normal person”. För att patienter ska känna sig trygga måste läkare representera auktoriteter, lyssna och involvera patienterna i behandlingsplan och utförande. Till följd av migration, reducerat socialt nätverk och epilepsi- relaterad stigma, verkade konversationen med läkaren särskilt viktigt för patienternas känsla av välbefinnande och trygghet. Läkare spelar en viktig roll i att sätta ord på, bekräfta och normalisera patienters
symptom. Att våga prata öppet om epilepsi tar tid och är fortfarande associerat med en rädsla för negativa reaktioner.

Slutsats: Förtryende är avgörande för framgångsrik kommunikation och behandlingsresultat. Medan läkare ska beakta varje patient i sitt eget specifika sammanhang, så är en respektfull och lyssnande läkare som delar med sig av information, fundamentalt för en tillitsfull patient-läkarrelation, oavsett patientens kultur eller födelseland.
Acknowledgements

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Appendix

Approval from the Ethical board of Angered Hospital

http://www.vgregion.se/sv/Vastra-Gotalandsregionen/startsida/Pressrummet/Diarium/

Registration number 34-2016

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Forskningsetisk ansökan

Beslutsdokument

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Dagens datum

2016-02-10

Studentens namn och epost

Klara Andersson, alva.klara.andersson@gmail.com

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Projektets titel

Erfarenheter, förståelse och förväntningar hos utlandsfödda patienter med epilepsi, som möjliga barriärer i kontakten med svensk sjukvård

Handledare

Susann Strang, Henry Ascher

Berörda verksamhet(er) på Angereds Närsjukhus

Specialistcentrum Vuxna

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Beslut

☐ A. Projektet får genomföras då forskningsetiska aspekter anses vara tillfredsställande beaktade.

☒ B. Projektet får genomföras efter att följande ändringar har gjorts och forskningsetiska aspekter anses vara tillfredsställande beaktade:
1. Bifoga tilltänkt samtyckesblankett.
2. Ta bort ordet ”kursansvariga” från samtliga dokument.
3. Ändra ”Angered närsjukhus” till ”Angereds Närsjukhus” med stort N.
4. Ändra ”Angered’s Hospital” till ”Angered Hospital” i brev till potentiella deltagare.
5. Lägg till Angereds Närsjukhus logotyp på samtliga dokument till deltagare.

☐ C. Projektet bör inte få genomföras då forskningsetiska aspekter ej anses kunna bli tillfredsställande beaktade.

Klicka här för att ange text.
Hello,

My name is Klara Andersson and I am a student in medicine at the University of Gothenburg.

I am writing my master thesis about how it is to live with epilepsy. The purpose of this study is to interview patients connected to Angered Hospital to describe and better understand how life is with epilepsy. I am hoping that this study will lead to new knowledge and better understanding for patients with epilepsy and that this could improve communication with Swedish health care.

You have received this letter because you are being treated for epilepsy at Angered Hospital. I write to ask if you would be interested in an interview, answering questions about how it is to live with epilepsy.

Participation is voluntary. If you accept to participate I guarantee your confidentiality and after the interview you will be compensated with two cinema tickets.
Research personnel information

To live with epilepsy

You have been asked to participate in a study about how it is To live with epilepsy and how it is experienced from an individual perspective. The study is carried out as a master thesis at the University of Gothenburg, in cooperation with Angered Hospital.

What is the purpose of this study?
This study is carried through to investigate how the participants have experienced To live with epilepsy.

How will this study be carried through?
Persons that agree to participate will be interviewed. Interviews will focus on your experience of how it is to live with epilepsy. Conversations will be recorded in order to be transcribed as text afterwards. Interviews are carried out by Klara Andersson, medicine student at University of Gothenburg, and estimated time for each interview is 30-60 minutes.

Will it be possible to identify my participation in this study?
No, in the final report of this study it will not be possible to identify the participants, who was there or who said what. All personnel involved in this study guarantee your confidentiality, which means that no such information will be available for unauthorized.

What will happen if I change my mind?
To participate in this study is voluntary and you can choose to interrupt your participation at any time without any consequences whatsoever. All you have to do is to inform the responsible personnel for this study.

How can I access to the results of this study?
Results of this study will be presented in a report available at the FoU secretariat at Angered Hospital.

To whom could I address myself for more information?
This study is performed by Klara Andersson supervised by Susann Strang. You are welcome to contact us at any time!

Klara Andersson, medicine student at the University of Gothenburg: gusandklb@student.gu.se
Susann Strang, senior lecturer at the University of Gothenburg: susann.strang@gu.se
Henry Ascher, senior lecturer at the University of Gothenburg/chief physician at Angered Hospital: henry.ascher@gu.se

Research questions

An example of questions that could occur in the interview is presented below.

• How is it to live with epilepsy?
• What are your expectations on a physician?
• What factors are important in order to trust a physician?
Informed consent
To live with epilepsy

I have received oral and written information about what it means to participate in this study. I am aware of that my participation in this study is completely voluntary, that my name and other personal information will not be seen in the study and that I can choose to interrupt my participation at any time without any consequences whatsoever. I agree to take part in this study.

............................................................
Signature

............................................................
Printed name

............................................................
Date
Intervjuguide

- Hur var det för dig att få epilepsi?
  - Vad visste du sedan innan?

- Vad tror du är orsaken till att du fick epilepsi?
  - Vad tror du? Familjen? - Kan ni prata om det?

- Hur är det att leva med epilepsi?
  - I Sverige vs hemlandet, finns det några skillnader?

- Hur har ditt liv förändrats sedan du fick epilepsi?
  - Din syn på dig själv?
  - Saker du inte gör längre?
  - Något som du saknar att kunna göra?
  - I vardagen?
  - Nya situationer?

- Hur tror du att andra ser på epilepsi?
  - Fördomar? Tankar?
  - Någon skillnad i Sverige vs hemlandet?
  - Hur påverkar det dig?

- Hur är det att berätta för någon att man har fått epilepsi?
  - För vem berättar/berättar man inte?
  - Hur reagerade familjen/vännerna på att du hade fått epilepsi?
  - Finns det någon gång som du har valt att inte berätta att du har epilepsi?

- Hur tycker du att det är att gå till en läkare?
  - I Sverige vs i hemlandet, är det någon skillnad?

- Vad gör att du känner att du kan lita på en läkare?
  - Finns det någon gång då du tappat förtroendet?
  - Vad skulle kunna göra att man inte kan lita på en läkare?
  - Skillnad i Sverige vs hemlandet?
  - Finns det något som läkaren skulle kunna göra som gjorde att du skulle vilja byta läkare?

- Känner du att du kan prata öppet med din läkare?
  - Är det viktigt? Varför?
Vad är det som gör att man kan prata öppet?
-Finns det saker man inte pratar om?

- Spelar det någon roll om läkaren är man eller kvinna?
  - Finns det saker som är lättare att berätta om läkaren har samma kön?
  - Kan du komma på en situation där det skulle vara svårare att prata öppet med en läkare av motsatt kön?

- Är det viktigt att din läkare känner till din kultur och dina traditioner?
  - Kan du komma på en situation då det skulle kunna vara viktigt?

- Är det viktigt att din läkare känner till din sociala situation?
  - Varför?

- Finns det någon situation då det kan vara viktigt för läkaren att känna till om en patient är religiös?

- Har det hänt att du har gått ifrån ett besök och känt att läkaren inte har förstått vad du menar? -Har det hänt att du har velat få information om något utan att du har fått det?

- Finns det något som skulle kunna göra att du inte kom tillbaka till läkaren? Vad skulle kunna göra att du valde att inte komma på ditt inbokade besök?

- Vem är det som bestämmer om din behandling?
  - Hur viktigt är det för dig att få vara med och bestämma om dina mediciner och behandling?
Feeling safe with the physician

A professional person

“Bara läkaren är bra och kan hjälpa, för det är det som är syftet”. -P7

“Med kvinnoläkare, kvinnor man är lättare att prata med henne. Kanske hon är mamma kanske hon är förstör.”-P14


”Jag tror att om man träffar en läkare och allt som man säger det är anonymt och inga andra eller ingen annan läkare som får veta om att man har något problem med vad som händer det blir starkare anonym med epilepsi. Så ingen får veta om detta. Så jag kan lita på att allt som jag säger, det är bara min(!) läkare och min(!) sjuksköterska som vet om detta.” -P2

”Jag litade på de läkarna som undersökte mig för de visade allting på papper också, på dokumentationen och de berättade allting rakt, direkt, utan att ljuga.” -P8

Attitudes

”Exempel, de besökte en läkare och han sa att den här sjukdomen kan man inte bota, med den kommer du att dö. Han var helt negativ. Då kände man ju sig -vad är det för läkare?” -P7

”Alltså vi pratar om samma grejer varje gång vi träffas. Samma sak! Jag kan garantera, 100%, de frågar samma sak. Du måste ta det lugnt, du får inte stressa, du får inte vara stressig, du får inte göra det här, du får inte göra det här.. Varje gång samma sak.” -P1

”Och det blir jobbigt att han hela tiden han har skickar inkallelse, jag tycker om. Därför att jag vet att, det är läkare bara de här recepten som hon har skrivit. Det är ingen annat som hon kan göra. Därför att jag vet det här, den sjukdom, som ingen ändrat. -P11”

Availability
“When you feel sick and you call to the nurse, that makes you calm. Only the fact that you call them - I’m feeling this, and then they can just tell you, - that’s normal or isn’t normal you should reach the hospital or... that makes you calm too. Like, now I know what to do.”  -P6


**Acknowledging the whole person**

**Social background**


**Culture and Stigma**

"Vi har ju hållit tystnaden, det är bara mamma och familjen som visste om att jag hade de här anfallen, hon vågade inte lämna mig ifall att jag får anfall och svimmar och sånt. Syskonen visste om det men ingen annan folk.”  .... “De pratar ju det är riktigt, kommer den här personen som har epilepsi man kan inte umgås med, man kan inte vara hos dem eller de kan inte vara, kanske de svimmar och pratar och rykten kommer gå runt.”  -P9


"Men i hemlandet de har ju, det tar ju väldigt lång tid tills de vet vad vi har, var vi befinner oss, det tar väldigt väldigt lång tid. Men här det finns möjlighet att man berätta ju också, så kan de förstå lite snabbare. ./../Här i Sverige, man kan ju beskriva allt som man har varit med om ja. I hemlandet när jag sökte läkare i början, det var svårt för dem att veta vad jag har problem, tex ont i huvudet, de säger du har blodbrist, sådana grejer, gick jag fram och tillbaka till läkare tills jag hittade riktiga som förstod mig vad jag har problem.”  -P9

**Social problems**

Co-morbidity

"I början var det väldigt tufft och jobbigt, speciellt med epilepsi, det var första gången jag får, jag vågade inte för att jag ska inte få det anfallet framför folk. Och samtidigt bränskada, jag skämdes också, jag var inte ute någon gång. Men efter ett tag, jag fick modet tillbaks, att jag måste ju leva vidare.” - P9


Religion


"I min religion taf så, även om läkaren vet eller inte, så säger min religion att om jag ska göra någonting religiöst som kan skada min hälsa då ska jag inte göra det. Om jag ska ta en medicin och det kan vara livsfarligt om jag inte gör det så måste jag ta den ändå. Det är därför jag tycker inte det är viktigt för mig att min läkare vet att jag är religiös eller inte.” - P10

Feeling like a normal person
Treatment


Intervjuare: 

"-Vad tror du skulle hända om man inte kände att man kunde berätta allt för sin läkare?"

P12: 

"-I det ögonblicket känner jag att det skulle vara mycket värre med min sjukdom."


Self-perception


"Innan jag tänkte kanske bara jag var så, eller kanske då och då. Men når jag går till Lundby, jag såg att wooh! Det är många är samma som jag(skratt), dom kommer varje gång jag träffar dom, dom sitter och väntar läkare och så. Dom känner mig, jag känner dom och ja, det hjälper. Det hjälper, man blir lite, lite lugnare och som tänker inte bara varför bara jag det var så." -P14

Intervjuare: Vad tror du att andra, din familj tex, vad tror du att de tänker om epilepsi?


"It took me long time to understand that, you can have fun as everyone, but in a different way. Probably go to the bar or.. but drink a soda, but don’t drink probably shots straight to your system." -P6