

## Disease- Based versus Patient- Based Approach in Epilepsy Management from the Patients' Point of View: A Qualitative Research

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**Abstract:** To investigate patient, family and the healthcare provider's perspectives on disease-based and patient-based management of epilepsy as one of the most common neurologic disorders. Epilepsy is a chronic disease with psychosocial and cultural ramifications unseen in any other condition. This study highlights the importance of holistic approach in medical management of epilepsy. In a qualitative study participants' perceptions of epilepsy and its medical management were explored. The purposely selected 33 participants were epileptic patients (23), family members (5) and healthcare providers (5). Recruitment sites were the Iranian Epilepsy Association, private practice offices and hospitals. Data were collected through semi-structured in-depth interviews and analyzed using arbitrary qualitative content analysis. Three main themes emerged as: 1) absence of holistic health views; 2) lack of therapeutic and healing approach; and 3) fragmented healthcare and communication systems. Results identified a need for patient-based approach to epilepsy along side medical management. Although healthcare systems recognize the importance of holistic patient care and disease management, epileptic patients in Iran with greatly benefit from a coherent and specialized team of healthcare providers who can address epileptic patient's concerns and communicate with their family members. Cultural taboos associated with epilepsy in countries like Iran, has not been explored and disease management by a neurologist is mainly focused on medical treatment. Thus, a cohort team familiar with holistic and patient-based approach can improve the quality of care for epileptic patients by enhancing their overall quality of life.

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### 1. Introduction

Epilepsy is one of the most common neurological diseases with impact on many aspects of a person's life such as financial, socio-cultural, physical and psychological. The influence of epilepsy as a chronic disease on the family and society is undeniable (1). Epilepsy is not just a simple clinical diagnosis -- it is a cultural phenomenon and in some parts of the world epilepsy can have a negative and life changing implication for the patient and the family as a whole (2). Thus, epilepsy could be considered a medical diagnosis with a significant social prognosis which at times could be worse than the disease itself (3). Epileptic patients are predisposed to a wide range of psycho-social maltreatments, more harmful and debilitating than the accompanied medical condition (4). Psychological and social consequences of epilepsy include high rate of mental health problems, mood disorders, suicide, social isolation (5); feelings of shame and guilt (6); family and social dishonor, low self-respect, anxiety, depression, and pessimism (7). About 50 to 60 percent of patients have clinical signs of depression,

anxiety, and psychological disorders (8). The disease also can lead to restriction and life style limitations in family life, marriage, occupation, education and learning, driving, economical and recreational activities for the patient (9, 10).

While most studies suggest that controlling the onset of epilepsy is a fundamental issue, some have stated that disease onset is just a part of the story, while many complex factors are involved. A multidimensional disease management can improve patient's lifestyle. Therefore, psycho-social aspects of the disease are as important as the medical management of epilepsy. A healthcare plan must be developed according to the patient's lifestyle and the acceptance of epilepsy as lifelong a medical diagnosis (11). Georgi (2010) reported that patient-based care is more necessary than disease-based approach by including patient's physical, psychological, social, mental, and spiritual needs for a holistic care. Patient-based care helps the patient to assume responsibility to effectively manage their disease (12). According to the results of several studies, the interaction between physicians and other

healthcare members would improve the continuity of patient care and disease management (11). Lawn and Schoo (2009) asserted that patient education and participation in treatment decisions and consultation could improve team efforts for the management of a chronic disease through a set of interactions with the patient and family members (13).

Although there has been some studies analyzing the concept of self-management for epileptic patients, other studies have mainly used quantitative approach with focus on the medical treatment and disease management. There has been no comprehensive study on patient-based management of epilepsy particularly for Iranian patients. Although medical management of epilepsy has been well investigated, the socio-economic and psychological problems associated with epilepsy have not been addressed for those suffering from the disease and many life challenges they face. Most studies discuss epilepsy as a disease and neglect to examine this life altering condition holistically.

Majority of studies have reported a disease-based approach and the paucity of information on patient perceptions was limiting to researchers in this study. Kersol, Green and Thorogod emphasized the importance of qualitative approach to highlight social processes and specify patient's lived experiences with various aspects of the disease and how it can change life meanings (14). We are hopeful the results of this study will provide information on the holistic management of epilepsy and introduce multidimensional perceptions of the Iranian patients, their families and the healthcare team. We focused on the subject from medical, social and cultural perspectives in Iran.

Finally, we urge healthcare providers to consider disease-based management with patient-based approach. A better patient perception of epilepsy and its medical management could help assess the effectiveness of treatment plans and improve patient's condition physically, socially, mentally and spiritually. Adequate holistic management of epilepsy can help control onset and therefore better life quality.

## 2. Material and Methods

Using qualitative research method, researchers aimed to investigate participant's perspectives on the management of epilepsy as a disease-based versus patient-based approach. The key participants in this study were 23 purposely selected epileptic patients from a list provided by the Iranian Epilepsy Association (IEA), neurology private offices, hospital neurology wards and the Isfahan Epilepsy Monitoring Ward (IEMW). Patients were identified by physicians according to the research

defined inclusion criteria consisting of at least 2 years diagnosis of epilepsy by a neurologist, being over the age of 18 years and having the ability to communicate. Twenty three (23) epileptic patients in different age groups and with various disease severities were selected. Researchers included 5 family members of the patients and 5 members of the healthcare team for a total of 33 participants.

In-depth semi structured interviews reached category saturation (no new information was revealed). The interviews occurred at home, in physician's offices, at the hospital epilepsy center, in the Iranian Epilepsy Association office, and at home according to the participant's preferences. Interviews started with general questions such as "tell me about your experiences with epilepsy. How have your disease been managed? What did they do for you?" and then asked follow up questions. Each participant was interviewed 1 to 3 times for 45 to 120 minutes according to their mental health state, as well as their ability to share information.

Participants signed a written informed consent and assured of respect for their privacy and confidentiality regarding personal and medical information. Voluntary participation was emphasized as interviews were recorded on an Mp3 player and later transcribed verbatim for optimum accuracy. Data were analyzed using arbitrary content analysis. Four qualitative research criteria of credibility, dependability, conformability, and transferability were considered when raw data were evaluated for accuracy and consistency. Content review by 10 external qualitative research specialists helped establish validity and reliability of data collection approach. Various views from a diverse group of faculty researchers and the major advisor verified method validity and reliability. The arbitrary content analysis method was used (14) and multiple reviews of the transcribed data helped categorize perceived expressions as stated by participants. Meaning units were extracted and 483 primary codes were recorded. Coded data were categorized according to their meaning and conceptual similarities. The categories were then summarized in interpretative levels so that they stated the main concept of each category. Finally, major themes and sub themes from abstract concepts were identified.

## 3. Results

The research participants were 23 patients (11 men and 12 women), 5 medical staffs (3 nurses, 2 physicians), and 5 family members of epileptic patients. Findings reached 3 major themes and 4 sub themes as follows (table 1).

Table 1: perception of participants about medical management of epilepsy

Theme	Subtheme
1. Absence of holistic health views	
2. Lack of therapeutic healing approach	a. lack of professional behavior
	b. mistrust
3. Fragmented healthcare and communication systems	a. inadequate professional competency
	b. incomplete course of treatment

### 1. Absence of holistic health views

Participants shared personal stories which indicated lack of holistic approach by the healthcare team. Expressed views revealed staff negligence to recognize patient's in social, psychological and cultural needs for an effective medical management of epilepsy.

The following statements are participants' expressions regarding disease-based approach:

Participant #11: ward nurses do not pay attention to us. They just take the blood pressure, give medications and take blood samples. That's it. Like other patients. Mom has told them several times about my severe headache but, they don't seem to care. They don't ask us how we are doing nor is there any problem. We don't say anything and they have no idea how we suffer (Patient).

Participant #2: my physician just would tell me to take medications regularly and doesn't even change the dose most of the times. I wish he would sometimes listen to my confabulations. They think the disease is just physical, while it has battered my soul and mind (patient).

Participant #4: my problem is much more than having convulsions. But I don't know whom to talk to. Medications do not relieve my pain. (Patient).

### 2. Lack of therapeutic healing approach

Under this theme participant's perceptions formed 2 sub-themes as listed below:

#### a) Lack of professional behavior

Those who suffer from epilepsy have a delicate and fragile spirit due to abhorring nature of the disease which threatens their identity. They thrive on forming human relationships and seek respect for human values by the healthcare team. They expect educated people to be kind and respectful and treat them as a human being so that it would be ascertain they are not any different from others. Lack of professional behavior and poor temperament by

healthcare providers was a frequent voiced expression by patients:

Participant #16: nurses are ill-tempered. They don't come to see whether you're dead or alive. They take a blood pressure and give medications. They don't treat us as humans and don't think we have other problems. I'm devastated. I wish someone would ask why I am in low spirit or what has disturbed me? I convulsed yesterday. I didn't realize what happened. But after that, I was so sad. I wished somebody would ask about my grief (patient).

Another patient shared experiencing physicians' inattention and poor communication skills: Participant #13: as soon as you say hello, they start to prescribe without asking anything about the disease. They don't ask how long the attacks are, how they are, where do you occur, do I bite my tongue, do I bite my lips...? I don't know.... They don't ask how do you feel before and after an attack. Of course a good physician would ask such questions (patient).

A participant from the healthcare team stated the need for better relation with patients as stated below:

Participant #22: patients like to talk about themselves. It should matter what they do, where they are from, what's their occupation, and they want to be asked. They want to communicate. I believe the most important thing is that patients feel they are not dead bodies and treated as a living being with good temper (nurse).

#### b) Mistrust

Experiencing mistrust towards medical team and the given diagnosis inhibits the healing and therapeutic efforts between the patient and healthcare team. Lack of trust breeds pessimism among patients and their families. Participant #15: every time I went to my physician, he sent me for another EEG without any questions. There was no change. We just have to spend a lot of money each time. These repeated EEGs have just become their business. Yet we have seen no improvements (patient).

Discordance between the primary and the consulting physician for a second opinion often adds to patient mistrust in the diagnosis and medical management approach. A participant who felt a need to get a second consult was confused by the dichotomy of medical opinions as stated here:

Participant #10: how would I recognize whom to believe after a second consult? I talked with my physician who said no, no, no. don't go for a consult, they can't do anything for you. I got a consult and was told no, no, no. don't go back to your physician. The medications you are taking are ineffective and you are washing yourself out. What should I do here caught in the middle (patient)?

Despite sporadic patient education sessions, participants complained about being unaware of their health condition and treatments given by the staff as an expression of mistrust.

Participant #16: my husband asked a midwife about being pregnant and treated for epilepsy. Looking at the lab results and what medications I was taking, we were told of carrying a malformed fetus. From that day on, my fear started. I couldn't sleep at all that night. I cried often. I told my husband that if my child was to be malformed, I didn't want such a child. He told me to go to an obstetrician. I went and was assured of other similar patients having a child and they have no problems (patient).

### 3. Fragmented healthcare and communication systems

This theme evolved into 2 sub-themes as listed below:

#### a) Inadequate professional competency

An important factor for achieving the best treatment results is by developing a trusting relationship with the patient in order to provide education and partnership. When a patient and his family experiences an epileptic convulsion for the first time, they are in fear and eager to know everything about the disease, its etiology, triggering factors, physiology, what to do when an attack occurs, what to do after the convulsion subsides, what is the appropriate nutrition and much more as many participant expressed frustration with the healthcare team for not providing patient educate.

Participant #9: physicians immediately prescribe medication and they don't care or say anything about what to eat or not to eat. They just treat with medications. A good physician should try to tell the patient how they can be treated without medications as much as possible. They don't tell us a word about what to do or not to do (patient).

A healthcare provider described the significance of public and patient education regarding epilepsy to help remove the social stigma.

Participant #23: the conditions of epileptic patients are such that people fear them and wonder why they get convulsions and change instantly. Well, this is a real social stigma which can be removed through education (physician).

Beside public and patient education, epileptic patients need someone who can heal their injured spirit and identity due to people's rebukes. Psychological counseling is among strategies used to effectively deal with erroneous viewpoints and help patients talk about their perceptions.

Participant #10: I believe if a physician tells me that I might have psychological issues without any other problem, then, it would be better to consult

with a psychologist rather than a neurologist (patient).

Participant #1: people like us need lots of counseling. We should go through emotional counseling every now and then – in some situations, going through counseling is cool. Counseling can be comforting and helpful in finding a way to solve the problems... it is good to talk to someone who understands you (patient).

Physicians are aware of the patient's needs for psychological counseling but, they don't want to or have the time for it.

Participant #23: since I can't afford the time to do counsel my patients myself, I send them for psychotherapy. Three of my patients have achieved good results. I just couldn't afford the time to do it (physician).

#### b) Incomplete course of treatment

Adding a psychiatrist to the healthcare team for managing epileptic patients seems to be a prudent decision and yet, the neurologists do not consider it as being necessary unless a patient develops severe psychiatric problems to obligate a referral. However, the devastating psychological effects of a chronic disorder such as epilepsy frequently necessitates a psychiatrist consult. The following description by participants reveals sub-standard and incomplete course of treatment for those who were not referred for psychiatric consult despite having major depressive disorder.

Participant #11: my problem is mostly my temper. I've become brainsick. I want to kill myself. I'm so depressed, and do nothing but crying. However, all they do for me is just increasing the medication dose, and there is no use. Tell them to do something else for me (patient).

Participant #18: I am losing my temper and feel frustrated. These medications do not calm me. I'm tired of life and everything. I think I've become more depressed. I don't know if I really need a psychiatrist or I should go to the neurologist. I talked to my physician but there was no improvement (patient).

Participant #30: with my experiences in Canada a healthcare team working with epileptic patients consists of a clinical psychologist, psychiatrist, physician, neurologist, nurse, and a social worker (physician).

Although patients did not state their expectations of nurses, and unaware of nurse's significant role, the inconspicuous role of nurses in care management of epilepsy is inferred from the following statements:

Participant #24: there's a vacant place for epilepsy nurse in treatment team, (it mean we need more nurses) (physician).

Participant #25: nurse is a good example of someone who cares. Having a clinical nurse specialist or a graduate nurse would be very good. Also, having psychologists with knowledge of epilepsy would be helpful. Studying medicine and knowing psychology of epilepsy will help provide appropriate consult for patients. Frankly speaking, I prefer nurses to counsel patients (physician).

The healthcare team members believed an admission, discharge and follow-up system would be necessary, especially to educate, counsel, and support patients and their family.

Participant #24: unfortunately, our standard care system is weak and our follow-up system non-existent. We have a long way to go to reach an efficient level of care. However, talking to patients and educating them would improve their awareness. But it would be much better if there was a follow-up system (nurse).

Participant #22: unfortunately, in Iran we don't have a patient followed up system. This is a plan I've proposed, which consists of two parts with patient education and patient follow up (nurse).

#### 4. Discussions

Participants in this study expressed their viewpoints openly to inform healthcare providers that disease-based approach is insufficient without a holistic patient-based plan of care for patients suffering from epilepsy. In a study by Sample and et al (2006), epileptic patients reported receiving healthcare service including mental health and spiritual care but, services had limited accessibility (9). George (2010) believes that management of a chronic disease such as epilepsy requires holistic care by a team of experts and medical treatment alone does not satisfy patient's need for emotional, psychological, spiritual, and social support (12).

Considering epilepsy as a cultural shame and embarrassment to self and family has been a neglected issue in many studies. The Iranian epileptic population receives medical treatment without holistic care. Similarly, Jacoby, Wang and et al (2008) stated that in clinical medicine, the treatment team uses its all powers to diagnose epilepsy, its related signs and symptoms, and the healthcare providers don't care about the negative social stigma associated with the disease (15). Likewise, Mc Evan, Espie et al (2004) believed services focused on medical treatment may decrease disease onset but, remain sub-standard for not offering a holistic approach with consideration for psychological and social effects of epilepsy. Perhaps inattention to comprehensive care of a patient remains unforeseen for many other life changing chronic conditions throughout the global healthcare systems (16).

In contrast, Robinson, Callister et al (2008), reported a group of physicians participating in disease management by increasing holistic care and patient-based approach. Another study reported the difference in medical management by additional patients participate in treatment decisions (17). Also, Pittz and Phillips (1998) stated that one reason for patient dismay with the healthcare plan was lack of attention to patient's psychological and social needs and too much focus on the medical treatment. As suggested, there is a need to add holistic care to medical management of patients diagnosed with epilepsy (18).

The healthcare team's lack of attention to patient's cultural values, and need for respect and exhibiting no interest to communicate with the patient or poor communication skills were among many concerns and complaints expressed in this study. Patients voiced their mistrust in the healthcare team. In their qualitative study, Campbell, Scot et al (2011) reported patient perceptions of those suffering from AIDS with respect to the way nurses provided care, introduced themselves with regards for confidentiality, showed mutual understanding, treating them the same as other patients, and offered kindness as an important part of treatment and care components (19). While in our study, epileptic patients found emotional barriers and disconnect with the healthcare team as a prohibiting factor to healing. Although patients in our study expressed non-existent relation with physicians, their perceptions of nursing staff were positive. However, nurses in other studies have received higher patient satisfaction score in particular with communication skills, providing information and patient guidance (20-23). The difference might be due to the significant differences in nurses' role and autonomy when caring for epileptic patients in other countries. In Iran, professional autonomy for nursing role is minimal and there are no specialized epilepsy nurses to be a more active part of the healthcare team.

According to the patient's views in a study by Mills, Bachmann et al (2000), effective relation with clinicians are more effective than epilepsy control and the clinical demonstration(24). Therefore, establishing staff communication skills along with emotional awareness can improve healing of patients' pains.

Sub-standard performance and incomplete course of treatment caused disruption for everyone involved. Holistic approach to patient care required patient involvement in their care through education and counseling and most participants in this study complained about the missing essential components of care. They viewed holistic and comprehensive care as a significant part of epilepsy management. In their

study Dickert and Kass (2009) discussed patients' perceptions on respect where patients considered informing on their condition a form of respect for personhood (25). Wells in Moyer (2007) stated that families and patients need correct information and unfortunately we as neurologist neglect by proxy due to professional restrictions to provide sufficient and direct information to patients (26). Meanwhile, Wagner, Semple et al (2009) expressed that physicians and the healthcare team can make a difference by establishing a coherent team for the care of epilepsy patients in a specialized epilepsy clinic run by expert epilepsy nurses to care, inform and educate patients and their family members (27).

Although patients in this study did not have the opportunity to experience the benefits of individual consults, participants were very open and hopeful that expert consultation could offer them a chance to better understand the disease process, communicate their concerns, have someone listen to their life changing experiences and help their stress levels to be able to live a normal life. Also Campbell and Scott (2011), Taylor, Readman et al (1994), Clark, Stoll et al (2010) in their studies on the management and treatment of epilepsy wrote, it necessary to refer patients for psychological consult (19, 28,29) while this important need has not been considered by many epilepsy management teams in our study. Mental and psychological care of epileptic patients require expert consultation and yet, they are not considered as a regular part of the team by Iranian physicians.

Charyton, Elliott et al (2009), stated that epileptic patients should be counseled for their emotional needs by a psychologists and a social worker while medically managed by a neurologists (30). In their study, they found that participating physicians rarely considered psychologists as a suitable choice for consultation due to their insufficient medical knowledge on epilepsy, and proposed a specialized epilepsy nurse as a better choice to counsel patients suffering from epilepsy. In another qualitative study, patients were satisfied with nurses' level of competence to decrease their fear, elevate their depressed mood, reduce their anxiety and majority of general practitioners in Britain would refer epileptic patients to nurses for consultation (31-32). Thus, a well prepared and educated nurse can serve on the healthcare team as epilepsy consult to provide comprehensive and holistic care.

This study identified a broken chain in the Iranian management of epilepsy where patients are offered incomplete care without consideration for their psychological, social, cultural and financial needs by a group of neurologists who resist change. Vahey, Aiken (2004) wrote, according to research

evidence, apart from the prescribed medication by a physician, other care modalities seem significant (33). Mills, Bachman et al (1999) stated that multidisciplinary team of healthcare professionals should be involved in the care epileptic patients, among which are the physicians and nurses responsible for establishing and maintaining partnership with epileptic patients as a team approach (24).

In contrast, Taylor, Readman(1994) supported a participatory approach. They suggested development and creation of a care network in epilepsy clinics to include general practitioners, neurologists, general physicians, pediatricians, British Epilepsy Association, social workers, school nurses, social workers, specialized epilepsy nurses, regional nurses, nursing supervisors, and psychological healthcare team in collaboration with self-help organizations of nursing faculties, hospital wards, epilepsy nurses association, and supporting groups to help improve epilepsy management and treatment in the region. Finally, the need for specialized epilepsy clinics and extensive society-based services by specialized nurses are highly recommended (34). Therefore, providing a cohort team with a clear job description seems necessary to improve the quality of care for epileptic patients.

Participants' views of epilepsy medical management highlighted the need for comprehensive and holistic approach to the treatment of epilepsy to address patient's physical as well as mental, psychological, and social components. Our results indicate disease-based management in Iran should be revised to include a patient-based approach. Patient mistrust of healthcare team is disruptive to achieving best health outcomes and Iranian physicians should consider a holistic approach and see their patients as a human being with mental and psychological pains associated with the disease.

On the other hand, medical management should not be void of patient education and consultation. A healthcare team with specific role designation may include healthcare professionals in partnership with the patient and family members. It seems reasonable to form a cohort team of experts to offer the best comprehensive health services including education on medical treatment, mental, psychological and social consultation and follow up. As proposed, Iranian nursing leadership may establish a coherent team of specialized epilepsy nurses, develop job descriptions and help improve the quality care for patients with epilepsy. As well, a sub-specialized educational program may be developed with an emphasis on professional communication skills to educate and consult in a patient-based model of care. Also, a suitable solution may be found to

educate physicians on a more competent epilepsy management. Lastly, a nationwide campaign should be formed to educate the Iranian public about epilepsy to eliminate the social stigma.

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#### References

- 1- Livneh, H., L. M. Wilson, et al. (2001). "Psychosocial adaptation to epilepsy: the role of coping strategies." *Epilepsy & Behavior* 2(6): 533-544.
- 2- Aydemir, N., D. Trung, et al. (2009). "Multiple impacts of epilepsy and contributing factors: Findings from an ethnographic study in Vietnam." *Epilepsy & Behavior* 16(3): 512-520.
- 3- Jacoby, A., D. Snape, et al. (2005). "Epilepsy and social identity: the stigma of a chronic neurological disorder." *The Lancet Neurology* 4(3): 171-178.
- 4- McCagh, J., J. Fisk, et al. (2009). "Epilepsy, psychosocial and cognitive functioning." *Epilepsy Research* 86(1): 1-14.
- 5- Baker, G., J. Taylor, et al. (2009). "How can cognitive status predispose to psychological impairment?" *Epilepsy & Behavior* 15(2): S31-S35.
- 6- Rätty, L. K. A., B. A. Söderfeldt, et al. (2007). "Daily life in epilepsy: Patients' experiences described by emotions." *Epilepsy & Behavior* 10(3): 389-396.
- 7- MacLeod, J. and J. Austin (2003). "Stigma in the lives of adolescents with epilepsy: a review of the literature." *Epilepsy & Behavior* 4(2): 112-117.
- 8- Marsh, L. and V. Rao (2002). "Psychiatric complications in patients with epilepsy: a review." *Epilepsy Research* 49(1): 11-33.
- 9- Sample, P., P. Ferguson, et al. (2006). "Experiences of persons with epilepsy and their families as they look for medical and community care: A focus group study from South Carolina." *Epilepsy & Behavior* 9(4): 649-662.
- 10- Al-Rashed, H., D. Al-Yahya, et al. (2009). "Knowledge of, perceptions of, and attitudes toward epilepsy among university students in Kuwait." *Epilepsy & Behavior* 14(2): 367-371.
- 11- Shafer, P. and C. DiIorio (2004). "Managing life issues in epilepsy." *Continuum Epilepsy* 10: 138-156.
- 12-George, N. (2010). "The science of holistic nursing" *Journal of Community Nursing* 24(5)
- 13- Lawn, S. and A. Schoo "Supporting self-management of chronic health conditions: Common approaches." *Patient education and counseling* 80(2): 205-211.
- 14-Sharkawy, G., C. Newton, et al. (2006). "Attitudes and practices of families and health care personnel toward children with epilepsy in Kilifi, Kenya." *Epilepsy & Behavior* 8(1): 201-212.
- 15- Jacoby, A., W. Wang, et al. (2008). "Meanings of epilepsy in its sociocultural context and implications for stigma: findings from ethnographic studies in local communities in China and Vietnam." *Epilepsy & Behavior* 12(2): 286-297.
- 16- McEvan, M. J., C. A. Espie, et al. (2004). "A systematic review of the contribution of qualitative research to the study of quality of life in children and adolescents with epilepsy." *Seizure* 13(1): 3-17
- 17- Robinson, J. H., L. C. Callister, et al. (2008). "Patient-centered care and adherence: Definitions and applications to improve outcomes." *Journal of the American Academy of Nurse Practitioners* 20(12): 600-607.
- 18- Pitts, M. and K. Phillips (1998). *The psychology of health: an introduction*, Psychology Press.
- 19- Campbell, C., K. Scott, et al. "A [ ] good hospital': Nurse and patient perceptions of good clinical care for HIV-positive people on antiretroviral treatment in rural Zimbabwe--A mixed-methods qualitative study." *International journal of nursing studies* 48(2): 175-183.
- 20- Couldridge, S. (2001). "A systematic overviewa decade of research'. The information and counselling needs of people with epilepsy." *Seizure* 10(8): 605-614.

- 21- Scambler, G. and A. Hopkins (1996). "Being epileptic: coming to terms with stigma." Sociology of health & illness **8**(1): 26-43.
- 22- Mills, N., R. Campbell, et al. (2002). "What do patients want and get from a primary care epilepsy specialist nurse service?" Seizure **11**(3): 176-183.
- 23- Ridsdale, L., I. Kwan, et al. (2003). "How can a nurse intervention help people with newly diagnosed epilepsy?: A qualitative study of patients' views." Seizure **12**(2): 69-73.
- 24- Mills, N., M. Bachmann, et al. (1999). "Effect of a primary care based epilepsy specialist nurse service on quality of care from the patients' perspective: results at two-years follow-up." Seizure **8**(5): 291-296.
- 25- Dickert, N. and N. E. Kass (2009). "Understanding respect: learning from patients." Journal of medical ethics **35**(7): 419-423.
- 26- Moyer, P. (2007). "Advice on How to Help Children Overcome the Stigma of Having Epilepsy". Neurology today **7**(3):32.
- 27- Wagner, J.L., P. L. Sample, et al. (2009). "Impact of pediatric epilepsy: voices from a focus group and implications for public policy change". Epilepsy & Behavior **16**(1): 161-165.
- 28- Taylor, M., S. Readman, et al. (1994). "A district epilepsy service, with community-based specialist liaison nurses and guidelines for shared care." Seizure **3**(2): 121-127.
- 29- Clark, N. M., S. Stoll, et al. (2010). "Fostering epilepsy self management: The perspectives of professionals." Epilepsy & Behavior **19**(3): 255-263.
- 30- Charyton, C., J. Elliott, et al. (2009). "The impact of social support on health related quality of life in persons with epilepsy." Epilepsy & Behavior **16**(4): 640-645.
- 31- Goodwin, M., S. Higgins, et al. (2004). "The role of the clinical nurse specialist in epilepsy. A national survey." Seizure **13**(2): 87-94.
- 32- Ridsdale, L., I. Kwan, et al. (2003). "How can a nurse intervention help people with newly diagnosed epilepsy?: A qualitative study of patients' views." Seizure **12**(2): 69-73.
- 33- Vahey, D. C., L. H. Aiken, et al. (2004). "Nurse burnout and patient satisfaction." Medical care **42**(2): II57.
- 34- Taylor, M., S. Readman, et al. (1994). "A district epilepsy service, with community-based specialist liaison nurses and guidelines for shared care." Seizure **3**(2): 121-127.

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