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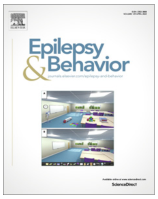

Meanings of quality of life among people living with epilepsy in Ghana; a qualitative exploratory study

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ABSTRACT

Purpose: The purpose of this study was to explore the meanings of quality of life among people living with epilepsy (PLWE) in Ghana.
Methods: An exploratory-qualitative study design was adopted. Face-to-face in-depth interviews, using a semi-structured interview guide, were conducted on 15 PLWE who were purposively selected for the study. The interviews were audio recorded and transcribed verbatim. The content analysis approach was then used to analyze the data.
Results: Four themes – "acceptance", "support", "seizure control", and "self-reliance" emerged from the study as meanings of Quality of life (QoL). Quality of life meant unconditional acceptance from family, friends, acquaintances at home, school, and work, and by the public despite epilepsy. Receiving support in the form of protection from injury during a seizure, financial assistance to meet individual and family demands, emotional warmth, and spiritual support through prayers and encouragement, was QoL for PLWE. Achievement of control over seizures and being self-reliant in terms of selfcare and daily activities in addition to having some form of financial independence meant QoL.
Conclusion: Meanings of quality of life among PLWE is associated with being accepted and supported by family and friends as well as being in control of seizures and attaining a status of independence.

1. Introduction

Quality of life is a broad term encompassing not just the absence of disease, but an individual's perception of his or her position in life within the perspective of one's culture and value system, goals, expectations, and concerns about health [1]. Patients with epilepsy are at increased risk of poor Quality of Life (QoL). This is due to the chronic and debilitating nature of the condition [2]. Increased seizure severity has also been reported to significantly reduce the QoL of People Living with Epilepsy (PLWE) in most sub-Saharan countries [3–5]. The debilitating nature of epilepsy interferes with school, work, and activities of daily living among PLWE [5,6] with a ripple effect on reducing the QoL of PLWE [7]. Although adherence to antiepileptic treatment has been found to provide some form of control over seizures [8], the side effects of these medications negatively affect their QoL [7,9].

Increasingly, studies on epilepsy are focusing on patient-reported wellbeing and psychosocial outcomes compared to the traditional clinical health outcomes such as effectiveness of antiepileptic medications [10–12]. Studies in sub-Saharan countries such as Uganda [13], South Africa [14], Sudan [15], and Zambia [16] have used both disease-specific and generic QoL tools to assess the quality of life among PLWE. Despite a high prevalence of active epilepsy in sub-Saharan Africa, estimated to affect 4.4 million people [17], none of these studies have explored the meaning of QoL among PLWE. [18,19]. In 2018, Ghana had approximately 22,171 people diagnosed with epilepsy [20]; however, most cases of epilepsy remain unreported. Persons diagnosed with epilepsy in Ghana are treated with contempt and avoided by those around them [6]. These negative public attitudes of avoidance and rejection of PLWE due to the stigma associated with epilepsy, is not only among Ghanaians [6] but, common in other sub-Saharan countries in Africa [21–23]; and contributes to low QoL among PLWE [24]. People living with epilepsy invariably need support

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from family, friends, and others to cope with these challenges. In Ghana, church members and family members play an active role in supporting PLWE financially in order for them to survive [8]. The show of love and emotional warmth for PLWE give them peace of mind, makes them less anxious, and improves their QoL [25]. Acceptance of PLWE depends on people's knowledge about epilepsy and the willingness to understand people living with epilepsy [7].

The negative impact of epilepsy [5,6] on the QoL of PLWE [24] cannot be underestimated. In order to promote the QoL of PLWE there is a need to understand, further, what quality of life means to the person living with epilepsy. The aim of this study was to explore the meaning of QoL from the perspective of PLWE, which is key to expanding the knowledge base on the concept of QoL among PLWE in Ghana.

2. Methods

2.1. Research design

This study employed a qualitative exploratory design to explore the meaning of QoL among PLWE in Ghana. The design aided the researchers in gaining an in-depth understanding of meanings from the experiences of participants [26].

2.2. Study population and sample

The study population comprised PLWE in Ghana with no comorbid mental illness or mental sub-normality. Fifteen PLWE participated in the study, which ensured satisfactory personal involvement by the researcher [27]. Purposive sampling was used to select only participants who were 18 years old and above. The identification and selection of participants were done in consultation with the community mental health workers in the Greater Accra Region of Ghana. Arrangements were made to interview participants who agreed to participate in the study at places of their choice, including their homes, churches, workplaces, and some offices of the community mental health workers.

2.3. Data collection

Written consent was sought from participants to conduct and record participant interviews. A semi-structured interview guide was used to conduct face-to-face, individual, in-depth interviews with participants. One main question was asked with probes: "What does quality of life mean to you?". The interviews lasted 45 to 60 minutes, were audiotaped and field notes were taken.

2.4. Data analysis

Data analysis was conducted concurrently with the interviews. All interviews were transcribed verbatim. Interview transcripts were read several times to obtain full understanding of participants' accounts. The content analysis approach of preparation, organisation, and reporting of results [28] was used to analyze data using the MAXQDA qualitative data analysis software. Coding and categorization of data [28] were carried out and verified by the second author, and the third author serving as an adjudicator in the event of any discrepancy. The results were described based on the content of the categories of the phenomenon under study in the reporting phase. Data from field notes were also reviewed and added up to the results to enhance the meaning of the information gathered. Segments of data that best suited the themes identified were sorted appropriately and used to support findings. Identification codes were used instead of participants' names to ensure anonymity.

2.5. Methodological rigor

The trustworthiness criteria recommended by Lincoln and Guba [29] were employed in this study. To ensure credibility, the researcher through his experience with caring for PLWE had prolong engagement during each interview. Participants were also given the opportunity to see the final report to verify correct representation of their views [30]. Dependability was ensured through detail reporting of the processes involved in the study [31]. Independent co-coding of data was also done by the second author and results compared. Credibility and dependability were also met through triangulation of data sources (combination of field notes and interviews) [31] and, the use of probes during the qualitative interviews. A detail description of the research setting, the participants and methods involved were also presented to ensure confirmability and transferability [31].

2.6. Ethics

Ethical approval for the study was obtained from the Postgraduate and Human Research Ethics Committee (Medical) of the University of the Witwatersrand (M180946) and the Ghana Health Service Research Ethics Review Committee (GHS-ERC004/12/18).

3. Results

The results consist of a description of the demographic characteristics of participants and thematic presentation of the findings supported by verbatim quotes. The interviews ended with the fifteenth participant after data saturation was achieved. Identification codes (1F1, 2F2, 3 M1, 4 M2. 5F3, 6 M3, 7 M4, 8 M5, 9 M6, 10 M7, 11 M8, 12F4, 13F5, 14F6, 15 M9) were used, instead of the respondents' real names, to conceal their identity.

3.1. Demographic characteristic of participants

A sample of fifteen PLWE (n = 15), comprising six females (40%) and nine males (60%), aged from 20 to 56 years, participated in the study. Five participants (40%) had tertiary level education and two (13.3%) had basic level education. Three participants were self-employed while, one was a private employee. Thirteen of them were Christians and 11 were single. Among them, eight had lived with epilepsy not more than 10 years and three have had epilepsy for 22 to 28 years (Table 3.1).

The findings from the study are described under four themes namely; "support", "acceptance", "seizure control", and "self-reliance", with their corresponding 14 sub-themes (Table 3.2).

3.2. Support

Among the PLWE, QoL meant receiving support from family, friends, and significant others. These included physical, emotional, financial, and spiritual support.

3.2.1. Physical support

Physical support comprised support provided to PLWE in the form of first aid or assistance from bystanders or from teachers in school during seizures, in order to protect them from injury and suffocation.

> '*... they have to help anybody living with epilepsy that gets an attack by holding them up and protect them from getting injured*'. (1F1)

Table 3.1
Socio-demographic characteristics of participants (n = 15).

№	Code	Sex	Age (Years)	Level of Education	Marital Status	Employment Status	Religion	Duration of Illness (Years)
1.	1F1	Female	42	Secondary	Married	Unemployed	Christian	28
2.	2F2	Female	27	Tertiary	Single	Unemployed	Christian	22
3.	3M1	Male	23	Secondary	Single	Unemployed	Christian	18
4.	4M2	Male	52	Secondary	Married	Self Employed	Christian	13
5.	5F3	Female	41	Basic	Married	Unemployed	Muslim	10
6.	6M3	Male	56	Secondary	Single	Unemployed	Christian	38
7.	7M4	Male	22	Secondary	Single	Private Employee	Christian	22
8.	8M5	Male	21	Tertiary	Single	Student	Christian	8
9.	9M6	Male	35	Tertiary	Married	Unemployed	Christian	8
10.	10M7	Male	20	Tertiary	Single	Student	Muslim	1
11.	11M8	Male	32	Basic	Single	Unemployed	Christian	12
12.	12F4	Female	32	Secondary	Single	Unemployed	Christian	8
13.	13F5	Female	28	Tertiary	Single	Student	Christian	5
14.	14F6	Female	30	Secondary	Single	Self Employed	Christian	8
15.	15M9	Male	32	Secondary	Single	Self Employed	Christian	10

Table 3.2
Themes and sub-themes.

Themes	Sub-themes
Support	(1) Physical support (2) Emotional support (3) Financial support (4) Spiritual support
Acceptance	(1) Acceptance from partner (2) Acceptance by friends (3) Acceptance by family (4) Acceptance at work (5) Acceptance from general population
Seizure control	(1) Nature of seizures (2) Medication (3) Disease outcome
Self-reliance	(1) Economic self-reliance (2) Self-care

> *'The teachers also have to assist by giving some first aid because during an attack . . .'* (13F5)

One participant was satisfied with the way his family constantly provided physical support and protection for him during seizures.

> *'To my family . . . anytime I get the seizure, they are the people who protect me form injury and hold me up and tell me what happened.'* (9M6)

3.2.2. Emotional support

Quality of life meant receiving love, a show of concern and emotional warmth from others. Having the reassurance that someone will be there to provide care or assistance during a seizure episode also gave them some emotional comfort.

> *'. . . knowing that someone will care for me when I have a seizure makes me feel ok.'* (13F5)

Being reassured, counseled, pampered, and talked to in a nice and respectable way by their wives meant QoL for two male participants who were married.

> *'Maybe I would like my wife to talk to me nicely or pamper me after the seizure.'* (11 M8)

3.2.3. Financial support

Financial support for upkeep of self and family and to cater for one's needs meant QoL to PLWE.

> *'I want help with money so that I can take care of myself and my family.'* (6 M3)

Two participants mentioned that they wish to have financial support to buy medicines to treat their epilepsy through sponsorship from government or from any philanthropist.

> *'I would be happy if government helps us out a bit there with some sponsorship. . . to help and perhaps buy some of my drugs'.* (12F4)
> *'I'll be very glad if we get help not only from our families but from others in the form of small funds . . . I will like it.'* (7M4)

3.2.4. Spiritual support

Spiritual encouragement and support in terms of prayers were linked to QoL among PLWE.

> *'When I go to church, I pray. My husband always encourages me . . .. So, I am praying and waiting for the day God will actually heal me.'* (1F1)

Other participants indicated that being in a good relationship with God, having a fulfilling spiritual life and being able to pray were satisfying moments that represented QoL. It also served as a means of connection to God for healing.

> *'. . . I can pray to God anywhere at any point, . . . I am satisfied that I have a fulfilling life with God.'* (14F6)
> *'My spiritual aspect too is very important. . . so that God will help me through my prayers.'* (3M1)

3.2.5. Acceptance

Quality of life was associated with being accepted by family, friends, colleagues, and acquaintances as a person, irrespective of one's epilepsy status.

3.2.5.1. Acceptance from partner. Unconditional acceptance and getting attention from a partner were stated as attributes of QoL.

> *'To me quality of life is when the person (partner) is not rejecting me when I come to her because of the situation I am in.'* (10M7)

Being accepted by the family of the partner or being able to marry was satisfying for PLWE and represented QoL for them.

> *'. . . my husband to be is scared to sit his mum down and say this is what my wife to be is going through; and it's scary . . . She might even decide . . .. you are not going to be a part of their family.'* (12F4)
> *'It's nice and satisfying to marry. If you stayed all your life and you didn't marry it will be very uncomfortable.'* (6M3)

3.2.5.2. Acceptance by friends. Participants expressed frustration and heartbreak at instances where people withdraw from them because of their condition (epilepsy).

> *'. . . And it is heart breaking to know that because somebody knows this is what is wrong with you, they have withdrawn from you.'* (2F2)

Being welcome and accepted by friends despite epilepsy was QoL to the PLWE.

> *'Despite my state, I want them (friends) to come around me because the more they come around me, the more I feel that I am at home.'* (8M5)

3.2.5.3. Acceptance by family. Quality of life also meant having a family that cares, recognizes, and accepts one as a family member irrespective of the diagnosis of epilepsy.

> *'Okay, if you say quality of life, to me it means all the family showing you love by accepting you as you are. . .'* (12F4)

Quality of life meant not being regarded as a burden to the family because of epilepsy but, rather to live in harmony with ones' family.

> *'In the past when I have seizures people think that I am a burden to the family. The family members start to neglect me. But . . .. I should be living in harmony with my family.'* (8M5)

3.2.5.4. Acceptance at work. Participants, particularly those working, perceived quality of life as being able to get along with colleagues at work, and employers listening to them, and treating them as any other person.

> *'They (colleagues and employers) should treat me as every other normal person without fear because, there is nothing to be afraid of at the end of the day. Just treat me as you would treat somebody who is not living with epilepsy.'* (2F2)

3.2.5.5. Acceptance from general population. Quality of life meant not bothering about when or where a seizure episode might occur in public without fear of being stigmatized and people relating with PLWE just like any other person.

> *'Quality of life would be having to live without looking over your shoulder, knowing that you can have a seizure anywhere and nobody would use it against you and there would be no stigma. . .'* (14F6)
> *'All that I want to say is that people should see us as normal people . . .'* (7M4)

3.2.6. Seizure control

Control of seizures comprised control of the frequency and severity of the seizures, having access to quality medications for the treatment of seizures in addition to the control or cure of seizures.

3.2.6.1. Nature of seizures. For some participants, having less severe seizures and less frequent seizures of not more than six times a year were described as determinants of quality of life.

> *"I'm okay if it at comes least ones every two or three months."* (2F2)
> *"Okay, I think the attack going away for about three, four to five months for me to see that it's fading away is what will really make me happy."* (1F1)

The participants explained that quality of life meant having milder seizures without any injuries despite epilepsy. They expressed satisfaction with seizures with minimal or no falls.

> *"I want it come such that I will not fall down and hurt myself. Not falling down and getting injured."* (12F4)

3.2.6.2. Medication. A few participants reiterated they will be happier and more satisfied if they had continuous access to antiepileptic medicines that were effective and also affordable.

> *"I always want to have access to the medicine. If every day I get access to it and take it every day as prescribed by the doctor."* (7M4)

> *"For me I want just medication that I can live on that can take away this sickness."* (9M6)

To others quality of life was associated with having access to quality antiepileptic medication with minimal or less side effects.

> *"I think finding a medication that is suitable and has a very minimal side effect for this condition will be satisfying for me."* (2F2)

3.2.6.3. Disease outcome. Quality of life was described as expectations for cure from seizures and the reassurance of no risk of transmission of epilepsy to their children.

> *"I want to be healed . . . If I could get healed, I'll be very happy."* (6M3)

> *"I will be happy that my children to be born will not carry the illness."* (3M1)

Quality of life meant being physically fit and seizures not interrupting with work and academic activities among PLWE.

> *"I expect that I will live a healthy life . . . because this is the reason, I am not able to advance in my education. . . I want to be strong, healthy and have work doing."* (3M1)

3.2.7. Self-reliance

To be self-reliant was perceived as a determinant of quality of life for the participants. The sub-themes under self-reliance were economic self-reliance and self-care.

3.2.7.1. Economic self-reliance. Quality of life meant gainful employment, less stressful work, and the ability to meet personal financial needs.

> *"So, ... I will be satisfied to work and make money to take care of myself."* (1F1)

> *"I don't need to stress myself too much with work to prevent it (seizures) from occurring. . . .Our employers should provide suitable and less stressful environment to prevent it from occurring or reduce the severity."* (7M4)

Secondly, being in the position to provide for one's family's financial needs was seen as a fulfilling state of quality life for PLWE.

> *"I would love that I could work and bring money home . . . to help the family."* (1F1)

3.2.7.2. Self-care. Participants described quality of life as being able to carry out activities of daily living independently, and to move around without the need for an escort or someone watching out for the person.

> *"At first, I couldn't go out alone to buy something without anybody escorting me but now, I am happy I can do things on my own."* (1F1)

Secondly, quality of life meant having some form of self-control where one is able to sense impending seizures and avoid any injury by getting to a safe place before the seizures begin.

> *"This is when before an attack, I can tell and be able to control it… Like I can control myself during an attack and know when to stand or sit somewhere safe."* (3M1).

4. Discussion

Among PLWE, QoL means receiving physical and emotional support from family, friends and others. Injuries are sometimes associated with seizures as some PLWE fall unconscious and injure themselves in the process [6]. Therefore, physical support is considered as positively contributing to the QoL of PLWE. At school, PLWE prefer teachers to act as role models in protecting them from injury and preserving their dignity. This is because in school, teachers wield powerful influence to change the way classmates treat another with epilepsy [7]. Emotional support in the form of counseling, reassurance, and the expression of love and continual support from spouses and family members, meant QoL for the participants. Similarly, Lu et al. [25] found that the show of love and emotional warmth for PLWE in China gave them peace of mind, reduces anxiety, and improves their QoL. Receiving emotional support is likely to relieve any feelings of depression, which is known to be a key predictor of poor QoL among PLWE [24,32].

Financial support from family and friends in addition to spiritual support are some of the aspects that were expressed by participants as helping PLWE to live a meaningful and happy life. In Ghana, some church members and family members are known to play active role in supporting PLWE financially for them to cope with living with epilepsy [8]. This underscores the importance of financial stability in the meaning of quality of life for PLWE. Some participants perceived spiritual support in terms of prayers and hope in God for healing as important in the quality of their lives and living with epilepsy. These spiritual activities are some of the known coping strategies adopted by PLWE in Ghana [8]. These spiritual coping measures confirm the belief in Ghana and sub-Saharan Africa that epilepsy has a spiritual cause [6,33]. Participants in this study considered quality of life as being recognized and accepted unconditionally as a person and not seen as a person with "epilepsy". This is demonstrated in studies in Japan [34] and Tunisia [35] where acceptance of disability of PLWE contributed to higher QoL among PLWE ($p < 0.01$). Being rejected by a partner and the family of the partner makes it difficult for the PLWE to establish a stable love relationship. This negatively affects their mood and further contributing to low QoL [24].

In this study, PLWE expressed feelings of not being accepted at work, being disrespected and in some instances, being laid-off work. Behaviors of such people or employers who disassociate themselves from PLWE, mirror the misconceptions and myths around epilepsy in Ghana and other sub-Saharan countries [6,36,37]. The rejection of PLWE at the workplace may be linked to disruptions that seizure episodes may cause [6]. Instead of treating PLWE badly and laying them off from work, employees and co-workers should rather create a welcoming environment for PLWE and show some interest in their treatment to improve their QoL. Therefore, acceptance is an essential component of adaptation among PLWE, which is required to attain good QoL [7].

Seizure severity and seizure impact have significantly negative correlation with QoL of PLWE [3–5]. In this study, QoL meant having the frequency and severity of seizures under control. To achieve this requires strict adherence and commitment to antiepileptic treatment regimen [8]. Ease of access to quality antiepileptic medication was also considered as QoL by PLWE. However, access to quality antiepileptic medications is affected by financial constraints and inadequate insurance cover for antiepileptic medications. The low health insurance cover is likely to increase out of pocket hospital expenditure, which is known to reduce QoL [38]. To others, QoL means having antiepileptic medication with minimal side effects because the side effects negatively affect the QoL of PLWE [7,9].

The expectation to be physically healthy, and not experience seizures any longer, was important in the meaning of the quality living for PLWE. This confirms findings of Deegbe et al. [6] that PLWE in Ghana have expectations for cure. However, some of these hopes are shattered because significant improvement in seizure control is not apparent, after long periods of treatment. According to Deegbe et al. [8], achievement of seizure control elicits feelings of happiness and reduces anxiety. In the absence of complete cure, PLWE expect their seizures to be under control so that episodes of seizures do not affect their work, schooling, and other activities. This is because seizures are known to interfere with work, schooling, and activities of daily living while engendering negative emotions among PLWE [5,6].

Furthermore, quality of life for PLWE means to be self-reliant financially and independently carry out activities of daily living. Fulfilling the need to also provide for one's family was QoL for the PLWE. However, these desires are hampered by negative attitudes that have contributed to unemployment among PLWE in many SSA countries including Ghana [39] and Nigeria [40].

5. Conclusion

The findings from this study have contributed to understanding the meaning of QoL among PLWE in Ghana. Being accepted and receiving support from relatives and the community members meant QoL to PLWE in Ghana. Expectations of support to improve the QoL of the PLWE, in the form of protection from injury during seizures, financial assistance, emotional warmth, and spiritual support, points to the need for a multidisciplinary approach to the care of PLWE. There is also the need for community mental health nurses to engage family members of PLWE and community members in education, first aid training, and sensitization programs on epilepsy in order to create more awareness of the need to support PLWE. In addition, the achievement of control over seizures was identified as quality life to the PLWE, which underscores the need for effective epilepsy treatment interventions to control seizures. Therefore, the Ghana Health Service must ensure easy and regular access to quality and effective antiepileptic medications that have fewer side effects, to reduce the severity and frequency of seizures, if not a complete cure from seizures.

6. Limitation

The subjective nature of qualitative approaches in research makes is difficult for researchers to be objective. However, co-coding and triangulation of data sources helped to ensure objectivity in the study.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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