



## Review

# Qualitative research and its methods in epilepsy: Contributing to an understanding of patients' lived experiences of the disease



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## ABSTRACT

This review paper makes the case for the usefulness of qualitative research methods in the context of epilepsy research. It begins with an assessment of the current state of epilepsy literature and identifies gaps especially in the following: research in 'developing' countries and research around surgery for adults with epilepsy. It makes the case that disclosure of people's behaviors, actions, and reactions in different, often complex health-care situations can indicate how they bring meaning to their disease experiences and support needs. It shows the value of encouraging work that clarifies how patients manage their illness and how they understand changes in their health and well-being over the life course of their illness and how health-care professionals and other stakeholder groups care for those with epilepsy.

The paper suggests a range of methods for addressing gaps in the literature and highlights a range of data collection, data analysis, and data interpretation and synthesis techniques that are appropriate in this context. It pays particular attention to the strengths of qualitative applications in mixed-methods research using an example from a recent ulcerative colitis drug trial that indicates how they can be integrated into study findings, add rich description, and enhance study outcomes. Ethnographic methodology is also presented, as a way of offering rare access to the 'lived experience' dimension, before the paper concludes with an assessment of the qualitative criteria of credibility, dependability, transferability, and confirmability for judging a study's 'trustworthiness'. The criteria evidence not only the trustworthiness of data and findings but also the ways in which a study has approached any challenges inherent in its research design.

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## Key questions

1. What topic areas have already been covered by the qualitative literature in epilepsy research?
2. Are there any clear gaps in the literature?
3. Are there qualitative methodologies that are not currently reported?
4. What qualitative assessments for rigor should be considered?

## 1. Introduction

This paper makes the case for the contribution of qualitative research to understanding the lived experience of patients with epilepsy. In this context, we use the term "lived experience" to mean a personal, self-reflexive awareness [1] and "qualitative research" to mean a way of disclosing people's behaviors, actions, and reactions in specific settings and exploring what causes those behaviors, actions, and reactions [2]. Qualitative research stresses social interaction, social construction, and the creation of meaning-laden notions that shape research enquiry. Quantitative research, on the other hand, relies on scientific measurements of processes and entities "in terms of quantity, amount, intensity, or frequency" ([3]: 8) (Tables 1 and 2). Using qualitative research techniques in epilepsy enables the clarification of meanings that are "not experimentally examined" ([3]: 8) and the exploration of the intimate relationships and lived experience of patients regarding how they 'know' their disease – how it feels to have epilepsy (the affect) – experientially. Looking at the impact of epilepsy on people's behavior, it is also possible to answer questions such as "What is it like to live with epilepsy?", "What can we do to improve patients' lives?", "Which services

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**Table 1**

Differences between qualitative research and quantitative research.

Source: Norman K. Denzin and Yvonna S. Lincoln (Eds). *The Sage Handbook of qualitative research*, Sage, Thousand Oaks, 2005.

Qualitative research	Quantitative research
Concentrates on the qualities of entities and the meanings that are not examined experimentally	Concentrates on the measurement and analysis of causal relationships between variables
Socially constructed nature of reality (experiential understanding) never fully captured	Objective nature of reality to be captured and understood
Intimate relationship between the researcher and researched dependent on trust and the building up of dialogical understanding	Distance between the researcher and researched must be upheld (positivistic approach to knowing and understanding)
Social sciences	Physical sciences
Rigor through the trustworthiness of data (transferability, credibility, dependability)	Rigor through validation, generalizability, and reliability
Assessment primarily through subjective interpretation of social worlds	Assessment primarily through statistical quantification
Expansionist embracing subjectivity, multivocal	Reductionist avoiding personal bias
Actor's perspective, dialogue, multiple truths to be revealed	Impersonal, third person, modeling, single truth to be discovered

should we be offering to ensure patients have optimum support from healthcare professionals?”, and “What form should that support take?”

This paper begins by identifying how qualitative research and its methods have successfully been used and reported in the epilepsy literature while highlighting two areas where more could be done to improve its visibility and impact. We discuss why qualitative research should be seen as a useful contribution to this field using an example from a chronic condition trial (CONSTRUCT) that utilized mixed methods, thereby indicating a range of opportunities for methodological applications in epilepsy.

By identifying gaps in the epilepsy literature, we also bring attention to the value of employing a) a qualitative methodological paradigm and b) data capture methods that favor a more patient-focused view of the world. We will describe c) data-analysis techniques that help with data interpretation and d) suggest how qualitative or mixed-methods study findings can be more nuanced than reporting patient-related clinical outcomes alone, notably through trial work and ethnographic research. We will show how this provides a more expansive understanding of living with a chronic condition and changes in patients' quality of life (QoL) arising from treatment.

## 2. The research literature

The qualitative research literature on the impact of epilepsy on patients' lives presents multiperspectival accounts from children, adolescents, young adults, and adults [3]. Kerr and colleagues conducted a systematic review in 2011 of epilepsy research that used qualitative methods, identifying 20 publications of 18 studies fitting the following criteria: “impact of epilepsy on adult and pediatric patients' lives” ([4]: 765). From these, 8 studies concentrated on the experiences of children, adolescents, and young adults. The remaining 10 studies concentrated on the adult perspective.

The majority of studies were with mixed ethnic groups and were undertaken in the U.K. However, a small number of studies were conducted in Canada, Sweden, and Australia [3]. According to Kerr et al. [3], the adult perspective, which underpins the focus of our paper (because of our concentration later on in the paper on surgical treatment for adults who have had repeated seizures), presents experiential impact in relation to stigma [4], QoL [5], patient decision-making [6], access to care

[7,8], psychosocial adjustment to personal life [9], attitudes to epilepsy [10], emotional impact of treatment [11], and professional intervention [12].

In addition, we identified a number of mixed-methods studies (qualitative and quantitative) that related to adults' knowledge and experiences of information-seeking [13], shared experience following suboptimal treatment outcomes [14], psychosocial adjustment after surgery [15,16], and seizures postsurgery [17].

The qualitative literature identified in Kerr and colleagues' systematic review and our own further searches highlight a variety of data collection methods used with both adults and adolescents in studies of epilepsy, including qualitative literature searching, semistructured interviews, theoretical enquiry, focus groups, psychoeducational group interventions, and surveys with open-ended questions, and data analysis methods, including thematic analysis [18,19], grounded theory analysis [20], content analysis [21], and theoretical framework analysis [2]. The work with adolescents and children, in particular, concentrated on data gathering through focus groups and interviews and used psychosocial interventions supported by in-depth consultation in order to encourage children to share their views and experiences of the disease and other complex issues such as stigma [22–26]. Some of this research also introduced cognitive-behavioral strategies and other extended engagement approaches to link interventions with need-based assessment.

## 3. Gaps in the literature

The literature reveals a rich vein of information regarding qualitative research that has identified the characteristics of genetic generalized epilepsies [27], patient symptomatology [14], the effects of epilepsy treatments on patients' health-related QoL [16], and issues surrounding clinical efficacy, absence of physical symptoms, seizure reduction, and seizure freedom [17,28]. However, two areas appear to need qualitative investigation. The first relates to studies outside the “developed” world ([4]: 765). Here, clarification of the experiences of people could provide global comparison and illuminate differences in information provision, knowledge of services, resource availability, and cross-border treatment programs.

The second area relates to “surgical treatment” ([4]: 765), one of Kerr and colleagues' specific exclusion criteria (although the reason for this is unclear). Wilson et al. have written about the psychosocial issues involved in having surgery (see for example [15,16]) and postulated that the “burden of normality” exists following seizure surgery ([29]: 13), which they see as partly accountable for the wide variety of “paradoxical clinical effects, such as worsening patient psychosocial functioning in the

**Table 2**

Combining qualitative and quantitative research methods.

Source: John W. Creswell. *Research Design, qualitative, quantitative and mixed methods approaches*. 2nd Edn., Sage, Thousand Oaks, 2003.

Permissive rather than restrictive
Embraces knowledge development on pragmatic grounds (consequence-oriented, problem-centered, pluralistic)
Various qualitative and quantitative data collection strategies are employed to best understand the problem in hand, either sequentially or simultaneously
Enables both closed measures and observational work and qualitative questioning for more inclusive data capture
People's views stand alongside experimental data to test theories, hypotheses, and interventions
Enables a concept or phenomenon to be understood in its fullness in terms of meanings afforded by others and variables appropriate for assessment
Encourages mixed methods, mixed data analysis modes, intertextual analysis, and data synthesis for study reporting
Data integration improves triangulation of datasets and corroboration of materials and leads to richer outputs

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