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**“Qualitative research and its methods in epilepsy: contributing to an understanding of patients’ lived experiences of the disease”**

**Frances Rapport<sup>1</sup>, Clare Clement<sup>1</sup>, Marcus Doel<sup>2</sup>, Hayley Hutchings<sup>1</sup>.**

Corresponding author:

Professor Frances Rapport  
Professor of Qualitative Health Research  
Director of the Qualitative Research Unit (QUARU)  
Director of Qualitative Enquiry Supporting Trials (QUEST)  
Patient, Population Health & Informatics (PPHi)  
College of Medicine  
Swansea University  
ILS2, Second Floor, Room 207  
Singleton Park  
Swansea  
SA2 8PP  
Wales  
T: 0044-(0)1792 513497  
T: Vicky Davies (PA) 0044-(0)1792 513407  
[F.L.Rapport@Swansea.ac.uk](mailto:F.L.Rapport@Swansea.ac.uk)  
<http://www.swan.ac.uk/>

1 Ms Clare Clement, Trial Qualitative Researcher  
[c.clement@swansea.ac.uk](mailto:c.clement@swansea.ac.uk)

1Professor Hayley Hutchings Associate Professor of Health Services Research  
[h.a.hutchings@swansea.ac.uk](mailto:h.a.hutchings@swansea.ac.uk)  
College of Medicine  
Swansea University  
Institute of Life Science<sup>2</sup>, Second Floor  
Singleton Park  
Swansea  
SA2 8PP  
Wales

2 Professor Marcus A Doel  
Professor of Human Geography  
Deputy Head of the College of Science & Deputy PVC  
Department of Geography  
Swansea University  
College of Science  
Room 220, Margam Building  
Singelton Park  
Swansea  
SA2 8PP  
[m.a.doel@swansea.ac.uk](mailto:m.a.doel@swansea.ac.uk)

## **“Qualitative research and its methods in epilepsy: contributing to an understanding of patients’ lived experiences of the disease”**

(3834 words minus abstract and refs)

**F. Rapport, C. Clement, M.A. Doel and H.A Hutchings**

### **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: research in ‘developing’ countries, and research around surgery for adults with epilepsy. It makes the case that disclosure of people’s behaviours, actions and reactions in different, often complex healthcare 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 wellbeing over the life-course of their illness and how healthcare 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-method 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.

### **Key words**

Qualitative epilepsy research, qualitative methods, ethnography, mixed-methods, trials, trustworthiness.

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## **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 behaviours, actions and reactions in specific settings, and exploring what causes those behaviours, 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]. 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 behaviour, 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 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, whilst 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 in this field, using an example from a chronic condition trial that utilised mixed-methods (the CONSTRUCT trial), 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 favour a more patient-focussed view of the world. We will describe c) data-analysis techniques that help with data interpretation, and d) suggest how qualitative or mixed-method study findings can be more nuanced than reporting patient-related clinical outcomes alone, notably through trials 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.

### **1. The research literature**

The qualitative research literature on the impact of epilepsy on patients’ lives presents multi-perspectival accounts from: children, adolescents, young adults, and adults [4]. Kerr and colleagues conducted a systematic review in 2011 of epilepsy research that used qualitative methods, identifying 20 publications of 18 studies fitting the criteria of: “impact of epilepsy on adult and paediatric 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 [4]. According to Kerr et al. [4] the adult perspective, which underpins the focus of our paper (due to our concentration later on in the paper on surgical treatment for adults who have had repeated seizures), presents experiential impact in relation to: stigma [5], QoL [6], patient decision-making [7], access to care [8,9], psychosocial adjustment to personal life [10], attitudes to epilepsy [11], emotional impact of treatment [12], and professional intervention [13].

In addition, we identified a number of mixed-method studies (qualitative and quantitative) that related to adults' knowledge and experiences of: information-seeking [14], shared experience following suboptimal treatment outcomes [15], psychosocial adjustment after surgery [16,17], and seizure post-surgery [18].

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 adult and adolescents in studies of epilepsy, including: qualitative-literature searching, semi-structured interviews, theoretical enquiry, focus groups, psychoeducational group interventions, and surveys with open-ended questions; and data analysis methods, including: thematic analysis [19,20], Grounded Theory analysis [21], content analysis [22], 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 [23-27]. Some of this research also introduced cognitive-behavioural strategies and other extended engagement approaches to link interventions with needs-based assessment.

## **2. Gaps in the literature**

The literature reveals a rich vein of information regarding qualitative research that has identified: the characteristics of genetic generalised epilepsies [28], patient symptomatology [15], the effects of epilepsy treatments on patients' health related QoL [17], and issues surrounding clinical efficacy, absence of physical symptoms, seizure reduction, and seizure freedom [18,29]. 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 programmes.

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: [16,17], 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 context of medical treatment success" [29:13]. However, research could be undertaken to examine the experience of patients undergoing surgery for severe epilepsy,

particularly in relation to changes in health, and expectations for health improvement over time. Resective epilepsy surgery, for example, where patients come into contact with a large team of healthcare professionals may be an area ripe for qualitative investigation. In this area we could clarify different stakeholder-groups' perspectives on the battery of tests and therapeutic assessments these patients undergo to gauge a patient's suitability for surgery, all of which may have a unique impact on patient wellbeing in the longer-term.

### **3. Qualitative data-collection and data-analysis methods and their strengths**

Qualitative data-collection and data-analysis methods are widely adaptable, and can be applied across research-subject areas and disease types. Qualitative data-collection methods can help researchers understand not only patients' healthcare experiences, but also their views on service provision. Researchers can mine further into primary data sources, according to various criteria linked to: disease type, patients' socioeconomic status, patient-professional interaction, communication channels, care delivery, use of new healthcare technologies and devices, and current working practices, all of which can be considered in terms of pathways to better health.

Qualitative methods are supportive of high-quality study designs, assessment of research decision-making around study outcomes, and evaluation of dissemination channels for study findings. Enlightening sources of data include but are not restricted to: documentary evidence, focus groups, oral testimony, interviews of all types, and observation [30] and robust methods of analysis include: content, conversation, framework, narrative, and thematic analysis [31].

Different analytic approaches suit different data-capture methods. Thematic analysis [3,19], for example, suits semi-structured interviews. It allows researchers to consider not only the questions asked but also people's responses to them and the extent to which they change their views during an interview. Coding is according to an open-ended coding structure that can be amended and fine-tuned over time to reveal patterns and themes in the data, and participants' responses. In this respect, coding is: "a method for conceptualising research data and classifying it into meaningful and relevant categories for participants in the study" [19:769].

Schema analysis suits large, dense datasets, such as those created from focus groups, where many people speak together and at times across one another [32]. Schema analysis can identify patterns and themes across participant groups, in line with a broader assessment of the topic area and study aims. Schema analysis is adaptable to the groups involved, and depends on the creation of succinct accounts of each unit of data, dataset or participant group view, taking into consideration not only key emergent themes, but also patterns of speech and word usage.

Framework analysis [33] is useful with longitudinal studies, where data may be collected on more than one occasion. Framework analysis is pertinent to the study of chronic conditions such as epilepsy, where patients' views and experiences may change as their illness or treatment regime changes, and where they face new challenges for ongoing care. It can capture data to show the challenges that people face over the life-course of an illness, and is dependent on a group of researchers creating a framework together as a template. The framework is refined, expanded, or contracted by the group, and finally related back to the study's aims and objectives.

Thematic and schema analysis can be undertaken individually or through group-work (framework analysis is dependent on group-work), according to the study design, study protocol and agreed working practices. Once completed, findings can stand alone or be considered alongside other study findings, whether quantitative methods or mixed-methods were used.

Data-integration tools such as the 'MATRICS tool' are useful towards the end of mixed-method studies, and MATRICS (a Method for Aggregating The Reporting of Interventions in Complex Studies) [34,35] is a particularly effective tool for synthesising findings from complex, multi-method studies. It is based on a three-layered table that tabulates: 1) the effects of the intervention explored (in relation the study aims and objectives), 2) the methods used (to investigate the effects) and 3) the findings (that the study reports), using alphanumerical coding. Using a MATRICS tool, mixed methods findings can be synthesised for ease of reporting.

#### **4. Strengths of qualitative approaches: an example from an Ulcerative Colitis study**

Researchers who wish to incorporate qualitative methods into epilepsy research might like to consider methods that suit a mixed-method study, with data-analysis techniques aligned to pragmatic research designs. An example of this comes in a recently completed clinical trial that compared two drugs, Infliximab and Ciclosporin, for the treatment of Ulcerative Colitis (UC) – the CONSTRUCT Trial (COMparison of iNfliximab and ciclosporin in STeroid Resistant Ulcerative Colitis Trial). CONSTRUCT was chosen as an example for this paper, for the many comparative features between UC and epilepsy. UC is one of a number of gastroenterological diseases which, like epilepsy, is chronic, debilitating and affects a wide population group, about 150,000 people in the U.K. [36,37]. Like epilepsy, UC can affect patients' health and wellbeing over an extended period of time, and can lead to substantial changes in treatments and drug options, though little is known of patients' longer-term treatment responses [38]. Like epilepsy, as indicated by a recent World Health Organisation review, ([www.who.int](http://www.who.int)) UC can lead to social isolation, depression, and stigma.

The CONSTRUCT trial was a two-armed, open label, pragmatic randomised trial. The mixed-methods were: quantitative, qualitative, health economics, and analysis of routinely collected data [39]. CONSTRUCT's primary outcome measure was quality-adjusted survival, with secondary outcomes including two generic QoL measures (EQ-5D & SF6D), emergency and planned colectomy rates, adverse events, and mortality. The qualitative component was fully integrated into the trial design from the outset (see Figure 1), and the results were considered alongside a clinical effectiveness assessment of the two drugs and a health economics analysis of resource utilisation, each reported separately and integrally, using the MATRICS tool. CONSTRUCT included semi-structured and telephone interviews with patients and healthcare professionals analysed through a combination of thematic and schema analysis [2,3,19,27] as an integral part of the trial's mixed-methodology.

The qualitative component involved multiple, semi-structured interviews with patients in both drug groups, at three- and twelve-months post-treatment, with similar questions asked on both occasions about people's health, drug-taking practices, views on UC, and support received from healthcare professionals and others. In addition, a separate interview was conducted for patients who had undergone a colectomy operation. The interviews at twelve-months also explored changes to

people's health, wellbeing and healthcare needs, and changes to people's experiences of support and care.

In this trial, group-work followed individual analysis, and ensured that a multidisciplinary group from the wider trial team accessed aspects of the data to familiarise themselves with its content. By combining analyses and triangulating outputs, and with the support of consensus-building activities, qualitative researchers were able to confirm the 'trustworthiness' of the data [40,41] and the veracity of outputs and working methods. Group-work also enabled others to consider the key qualitative findings and make connections with other trial outcomes for which they were personally responsible.

The CONSTRUCT trial involved not only interviews with patients, but also with a sample of healthcare professionals from across trial sites (consultants, surgeons and nurses), to consider: acceptability of the two trial drugs, drug administration and ease of handling, drug management, personal preference and others' preference, views on the trial itself, and opinions about others' familiarity with drug handling. Professional interview transcripts were analysed using framework analysis [30,31]. Analysis involved the study Research Associate, Trial Qualitative Researcher and Trials Qualitative Lead, in developing a framework template together. This was followed by wider team-work to discuss data interpretation to provide a group view. The final, unified coding framework was a distillation of extensive data that did not lose nuance.

Following analysis, qualitative findings were integrated with other study findings using the MATRICS tool described above. In this trial, layer three of the MATRICS tool created a clear and succinct summary of study findings according to the methods employed and a synthesis of all analogous findings. This was presented descriptively when findings from each method were individually realised. In this way, findings were understood across the range of mixed-methods, and referred back to according to individual methods and effects.

The kind of detailed analytic activities described above can lead to the production of high-quality publications and reports, containing not only verbatim quotations from participants but also "thick descriptions" [42] of the main analytic processes. In a large, pan-U.K., multi-centred trial like CONSTRUCT, with strict protocols, analysis planning and reporting requirements, value can be added through collaboration between trial members. In addition, whilst a drug trial may indicate clinical equipoise, even at the reporting stages, qualitative data can add understanding to that, even throwing the findings into sharp relief, through details of personal preferences and a more nuanced understanding of clinical behaviour. Group-work can involve people with little qualitative knowledge or a great deal of expertise, with everyone preparing to familiarise themselves with the data and become *au fait* with proceedings. In CONSTRUCT, most importantly, this enabled the creation of new knowledge, which would otherwise have been lost to the trial.

## **5. Ethnographic methodology in the context of epilepsy research – accessing the lived experience of others**

This section builds on the two preceding sections by introducing a new element, "Ethnographic methodology" [43], which provides rare access to the lived experience dimension. This clearly has



its strengths in the context of epilepsy research, and is dependent on very different data-collection and data-analysis techniques to those exemplified by the CONSTRUCT trial.

The ethnographic paradigm is epitomised by the image of a researcher immersed in a field of study. As Wallace [44] illustrates, in his seminal description of the famous anthropologist, Franz Boas, who, on stepping off a boat “in an Eskimo village” with his suitcase in hand, prepared for: “a long stay in residence” [44: 469]. Wallace [44] encapsulates the ethnographic pursuit in his example – “this image is the paradigm” [44:469]. Ethnographic methodology promotes a data-collection approach that runs counter to the scientific pursuit, where the research is wholly restricted to laboratory experiments or the examination of library documents. Ethnographic data are collected *in-situ*, through participant or non-participant observation of people’s activities and behaviours. Ethnographic methodology emphasises: “social interactions, behaviours and perceptions that occur within groups” [43:512], demanding relative submersion in the study setting to ensure that researchers can produce: “holistic insights into people’s views and actions” [43:512], by getting “inside” the way people see the world [45].

Ethnographic study predominantly concentrates on a single setting, with a mix of intense observation and interviews supported by notes from a researcher’s diary. It tends to be lengthy, due to the necessity to become familiar with the setting over time, whilst directly engaging with study subjects to gain their confidence: “since thick descriptions of the participants and setting may only be acquired from sufficient exposure to them” [42:4]. With such working practices, an epilepsy study employing ethnographic methods might usefully: a) map people’s behaviours to healthcare practices, b) consider patients’ actions and interactions with others across the healthcare setting, c) shadow patients prior to, during and following surgery, and d) observe changes in patients’ attitudes towards their own, and others’, bodies.

Ethnographic interviews, often running alongside participant- or non-participant observation, provide supplementary information gathered as a result of the trust that can be gained over time through close working practices. Research conversations or more formal interviews become part of the trusting relationship, and can be woven into data of observed life events, enabling the researcher to have confidence in their textual interpretations. Ethnographic interviews are frequently supported by notes taken about non-verbal gestures and other visual stimuli [46].

In the context of resective epilepsy surgery, research that employs ethnographic methods could provide detailed understandings of: patients’ fears and concerns in the lead in and pre-surgery periods, family members’ reflections on intra-family dynamics according to specific time-points in a patient’s clinical trajectory (such as pre-assessment, assessment for surgery, preparation for surgery, post-surgical investigation, longer-term clinical and psychological follow-up), and patients’ and family members’ views on what is seen as important clinical information. Furthermore, data collection could take place at multiple time points to evaluate: the longer-term impact of resective epilepsy surgery, shared decision-making with therapeutic teams, and preparations for surgical follow-up.

With the scope to observe, discuss, reflect and involve others in participatory activities, and with methods that lend themselves to expanding understanding beyond the clinical outcome of seizure reduction, ethnography could hold the key to clarifying: the impact of surgery on QoL, family dynamics, post-surgery emotional states, and longer-term effects. It could also shed light on

whether or not professionals aim to match their clinical expectations with patient expectations for a healthier and more fulfilling life, once seizure-free.

## 6. Challenges of applying quantitative assessment criteria to qualitative data

This paper has highlighted the strengths of employing qualitative methods for data-collection and data-analysis of extensive, qualitative datasets. It has also provided an example of a recent chronic conditions trial, where a mixed-method approach supplemented the work of the trials group.

But how can we judge the validity – or as it is more commonly described qualitatively, the ‘trustworthiness’ – of data and study outputs? In this respect, whilst critical assessment applies across paradigms, using similar positivistic criteria to those applicable to quantitative research, such as external and internal validity, reliability and objectivity, is unhelpful. Rather, qualitative researchers consider whether an explanation of the study and its outcomes fits the study description [35,42]. They ask whether explanations are “credible” [3:69], and look to demonstrate not the objectivity of findings, their predictability and truth, but their authenticity, sound creation, understanding and coalescence around consensus [48]. For explanations to be considered in their fullness it must be possible to scrutinise a study in terms of whether it is appropriate, credible and convincing; producing outputs that are congruent with reality – a clear and realistic picture of the work that was undertaken, through its fulfilment of the following criteria:

- a) Credibility (in preference to internal validity) ‘congruence of findings with reality’;
- b) Transferability (in preference to external validity or generalisability) ‘application of findings to other situations’;
- c) Dependability (in preference to reliability) ‘processes in the study reported in enough detail that others can repeat the work’;
- d) Confirmability (in preference to objectivity) ‘findings that are the result of participants’ experiences and ideas, and not researcher preference’. [40]

**Credibility** can be assured if the operational methods applied to the concepts are applied correctly [45]. Full and detailed reporting of the processes, clearly specified question schedules, complementary data-capture methods, information collection on more than one occasion, and data that can be considered by multi-disciplinary teams, clearly linking to a study’s aims and objectives, can all enable credibility to be assessed and assured.

**Transferability** is the notion that a particular study can become one example within a broader group [49,50]. Transferability can come into effect if sufficient contextual information is provided about sites or constituencies involved [51]. Details such as those surrounding sampling and recruitment may boost confidence that a study is an example within a broader group, where ideas can be transferred to other settings and other participants.

**Dependability** suggests that the working processes underpinning a study can be reported in enough detail for other researchers to confidently extend knowledge and understanding. When this is the case, the research design can be seen as a “prototype model” [41:71]. Shenton [41] reminds us that this kind of detail allows those assessing a study’s dependability to be sure that ethical principles were upheld.

**Confirmability** is the “qualitative investigator’s comparable concern to objectivity” [41: 72], allowing findings to be clearly linked back to participant data, rather than to an individual researcher’s set of assumptions. This is encouraged by: team-working during analysis stages, researcher involvement in other data assessment activities, and consultation with topic experts and patient groups, during planning, dissemination, and delivery. Data can also be returned to participants for ‘member checking’ [52].

## **7. Conclusion**

Qualitative research methods can be usefully employed to support epilepsy research studies, and this may fill some of the gaps identified in the literature, as well as the current dependency on quantitative research methods that lack experiential enquiry.

We have noted two areas in particular where more qualitative research could be undertaken to add to the data already reported in the epilepsy literature. Here, other research methods could be applied, such as ethnographic methods, to complement a current predominance of psychosocial methods. In terms of identifying gaps, we have particularly noted opportunities in research in ‘developing’ countries, including comparative cross-border studies and have suggested studies into the needs of patients undertaking surgery such as resective epilepsy surgery.

We have emphasised not only the value of using qualitative research methods such as those used in ethnographic studies ‘in the field of investigation’, but also those aligned with mixed-method studies, supporting pragmatic research designs, and multi-stage work. We have offered an example from a chronic condition trial to illustrate how the work of wider teams can add to the trustworthiness of data and study outputs.

This paper makes a case for judging qualitative methods, study design and the study outputs by using a set of criteria that complement a qualitative research paradigm. Qualitative research is both a discipline and a way of working, cutting across fields and topic areas. If qualitative methods are to become sufficiently recognised and embedded into epilepsy research, they should add to the knowledge-base of not only how reality is socially constructed, but also how important relationships can best be supported in the interest of a patient’s good health.

## **Disclaimer**

There are no conflicts of interest for any of the named authors of this paper.

## **References**

[1] Husserl E. Ideas pertaining to a pure phenomenology. Collected works Vol. 1. Translated by Pohl, W.E., Klein, T.E. The Hague: Martinus Nijhoff Publishers; 1980.

- [2]Denzin NK, Lincoln YS. The SAGE handbook of qualitative research. 3rd ed. Thousand Oaks, CA.: Sage Publications; 2005.
- [3]Denzin NK, Lincoln YS. Strategies of qualitative inquiry. 2nd ed. Thousand Oaks, CA.: Sage Publications; 2000.
- [4] Kerr C, Nixon A, Angalakuditi M. The impact of epilepsy on children and adult patients' lives: Development of a conceptual model from qualitative literature. *Seiz* 2011; 20(10):764-74.
- [5] Kilinc S, Campbell C. "It shouldn't be something that's evil, it should be talked about": a phenomenological approach to epilepsy and stigma. *Seiz* 2009; 18(10):665-71.
- [6] Bishop M, Allen CA. The impact of epilepsy on quality of life: a qualitative analysis. *Epilepsy Behav* 2003; 4(3):226-33.
- [7] McCorry D, Marson T, Jacoby A. Understanding routine antiepileptic drug decisions: a qualitative analysis of patients' accounts of hospital consultations. *Epilepsy Behav* 2009; 14(1):210-14.
- [8] Paschal AM, Ablah E, Wetta-Hall R, Molgaard CA, Liow K. Stigma and safe havens: a medical sociological perspective on African-American female epilepsy patients. *Epilepsy Behav* 2005; 7(1): 106-15.
- [9] Sample P, Furguson P, Wagner J. Experiences of persons with epilepsy and their families as they look for medical and community care: a focus group study from South Carolina. *Epilepsy Behav* 2006; 9:649-62.
- [10] Velissaris SL, Wilson SJ, Newton MR, Berkovic SF, Saling MM. Cognitive complaints after a first seizure in adulthood: Influence of psychological adjustment. *Epilepsia* 2009; 50(5): 1012-21.
- [11] Rhodes P, Small N, Ismail H, Wright J. 'What really annoys me is people take it like it's a disability', epilepsy, disability and identity among people of Pakistani origin living in the UK. *Ethnicity Health* 2008; 13:1–21.
- [12] Raty L, Larrson G, Starrin G, Larrson L. Epilepsy patients' conceptions of epilepsy as a phenomenon. *J Neurosci Nurs* 2009; 41:201–10.
- [13] Ridsdale L, Kwan I, Morgan M. How can a nurse intervention help people with newly diagnosed epilepsy? *Seizure* 2003; 12:69–73.
- [14] Prinjha S, Chapple A, Herxheimer A, McPherson A. Many people with epilepsy want to know more: A qualitative study. *Fam Prac* 2005; 22(4):435–441.
- [15] Fernando DK, McIntosh AM, Bladin PF, Wilson SJ. Common experiences of patients following suboptimal treatment outcomes: implications for epilepsy surgery; *Epilepsy Behav* 2014; 33:144-51.
- [16] Wilson SJ, Bladin PF, Saling MM. The "burden of normality": concepts of adjustment after surgery for seizures. *J Neurol Neurosurg Psych* 2001; 70:649–56.
- [17] Wilson SJ, Wrench JM, McIntosh AM, Bladin PF, Berkovic SF. Profiles of psychosocial outcome after epilepsy surgery: The role of personality. *Epilepsia* 2010; 51(7):1133-38.

- [18] Shirbin CA, McIntosh AM, Wilson SJ. The experience of seizures after epilepsy surgery. *Epilepsy Behav* 2009; 16:82-5.
- [19] Ryan GW, Bernard RH. Data management and analysis methods. In: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research* 2nd ed. Thousand Oaks, CA: Sage; 2000, p.769-802.
- [20] Denzin NK, Lincoln YS. Introduction: the discipline and practice of qualitative research. In: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research*. 2nd ed., Thousand Oaks, CA.: Sage Publications; 2000, p. 1-28.
- [21] Glaser BG, Strauss AL. *The discovery of Grounded Theory: strategies for qualitative research*. 7th ed. UK: Aldine Transaction; 2012.
- [22] Neuendorf KA. *The content analysis guidebook*. Thousand Oaks, CA.: Sage Publications; 2002.
- [23] Snead K, Ackerson J, Bailey K, Schmitt MM, Madan-Swain A, Martin RC. Taking charge of epilepsy: the development of a psychoeducational group intervention for adolescents with epilepsy and their parents. *Epilepsy Behav* 2004; 5:547-56.
- [24] Mcewan MJ, Espie CA, Metcalfe A, Brodie MJ, Wilson MT. Quality of life and psychosocial development in adolescents with epilepsy: a qualitative investigation using focus group methods. *Seiz* 2004; 13:15-31.
- [25] MacLeod JS, Austin JK. Stigma in the lives of adolescents with epilepsy: a review of the literature. *Epilepsy Behav* 2003; 4:112-7.
- [26] McEwan MJ, Espie CA, Metcalfe J. A systematic review of the contribution of qualitative research to the study of the quality of life in children and adolescents with epilepsy. *Seiz* 2004; 13:3-14.
- [27] Elliot IM, Lach L, Smith ML. I just want to be normal: a qualitative study exploring how children and adolescents view the impact of intractable epilepsy on their quality of life. *Epilepsy Behav* 2005; 7:664-78.
- [28/23] Kay B, Szaflarski JP. EEG/fMRI contributions to our understanding of genetic generalized epilepsies. *Epilepsy Behav* 2014; 34:129-35.
- [29/24] Wilson SJ, Bladin PF, Saling MM. Paradoxical results in the cure of chronic illness: the “burden of normality” as exemplified following seizure surgery. *Epilepsy Behav* 2004; 5:13–21.
- [30/25] Silverman D. *Doing qualitative research*. 2nd ed. London: Sage; 2005.
- [31/26] Rapport F. Shifting sands in qualitative methodology. In: Rapport F, editor. *New qualitative methodologies in health and social care research*. London: Routledge; 2004.
- [32/27] Rapport F, Iredale R, Jones W, Sivell S, Edwards A, Gray J, Elwyn G. Decision aids for familial breast cancer: exploring women’s views using focus groups. *Health Expect* 2006; 9:232-44.
- [33/28] Gale NK, Heath G, Cameron E, Rashid S, Redwood S. (2013) Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013; 13:117.

- [34/29] Thorne K, Russell IT, Williams JG, Cheung W-Y, Cohen C, Seagrove AC, et al. Method for aggregating the reporting of interventions in complex studies – the matrices tool, HTAi 2010 Conference Maximising the value of HTA, RDS, Dublin, Ireland, June 6-9, 2010.
- [35/30] Thorne K, Jerzembek GS, Cheung WY, Cohen D, Hutchings HA, Rapport FL, et al. MATRICS: a method for aggregating the reporting of interventions in complex studies. *Clin Trials Methodol Conf* 12(S1):A147 <http://www.trialsjournal.com/content/12/S1/A147>, 2011.
- [36/31] Rubin GP, Hungin AP, Kelly PJ, Ling J. Inflammatory bowel disease: epidemiology and management in an English general practice population. *Ailment Pharm Ther* 2000, 14(12):1553-9.
- [37/32] Carter MJ, Lobo AJ, Travis SP (2004) Guidelines for the management of inflammatory bowel disease in adults. *Gut* 2004; 53(5):1-16.
- [38/33] Turner D, Walsh CM, Steinhart AH, Griffiths AM. Response to corticosteroids in severe ulcerative colitis: a systematic review of the literature and a meta-regression. *Clin Gastro Hepatol* 2007; 5(1):103-10.
- [39/34] Seagrove AC, Alam F, Alrubaiy L, Cheung W-Y, Clement C, Cohen D, et al. Randomised controlled trial to compare infliximab and ciclosporin resistant ulcerative colitis: trial design and protocol (CONSTRUCT). *BMJ Open* 2014;
- [40/35] Guba EG. Criteria for assessing the trustworthiness of naturalistic inquiries. *Ed Commun Technol J* 1981; 29:75-91.
- [41/36] Shenton AK. Strategies for ensuring trustworthiness in qualitative research projects. *Edu Info* 2004; 22:63-75.
- [42/37] Goodson L, Vassar M. An overview of ethnography in healthcare and medical education research. *J Educat Eval Heal Prof* 2011; 8(4):4.
- [43/38] Reeves S, Kuper A, Hodges BD. Qualitative research methodologies: ethnography. *BMJ* 2008; 337:512-14.
- [44/39] Wallace AFC. Paradigmatic processes in culture change. *Amer Anthrop* 1972; 74:467-78.
- [45/40] Hammersley M. What's wrong with ethnography? Methodological explorations. Routledge: London; 1992.
- [46/41] O'Reilly K. Ethnographic methods. 2nd ed. Oxford: Routledge; 2012.
- [47/42] Denscombe M. The good research guide for small-scale social research projects. Buckingham: Open University Press; 1998.
- [48/43] Lincoln YS, Guba EG. Paradigmatic controversies, contradictions, and emerging confluences. in: Denzin NK, Lincoln YS, editors. *Handbook of qualitative research* 2nd ed., Thousand Oaks, CA.: Sage Publications, 2000, p. 163-89.
- [49/44] Yin RK. *Case Study Research: Design and Methods*. 2<sup>nd</sup> ed. Thousand Oaks: CA.: Sage; 1994.

[50/45] Stake RE. Case studies. In: Denzin NK, Lincoln YS, editors. *Handbook of Qualitative Research*, Thousand Oaks, CA.: Sage Publications; 1994, p. 236–247.

[51/46] Lincoln YS, Guba EG. *Naturalistic inquiry*. Beverly Hills: Sage Publications; 1985.

[52/47] Creswell JW. *Research design: qualitative, quantitative, and mixed methods approaches*. 2nd ed. Thousand Oaks, CA.: Sage Publications; 2003.

### **Key questions**

What topic areas have already been covered by the qualitative literature in epilepsy research?

Are there any clear gaps in the literature?

Are there qualitative methodologies that are not currently reported?

What qualitative assessments for rigor should be considered?

### **Key answers**

Experiential data on epilepsy suffering is already available particularly in the form of psychosocial measures that covers both adolescents' and adults' views

Gaps in the literature exist in studies outside the "developed" world, and studies of patients undergoing surgery for severe epilepsy including changes to lived experience perceived over time

Ethnographic studies are particularly under-reported, as are in-depth, group analysis techniques supporting schema and framework analyses

Trustworthiness of data needs assessing supported by descriptions of a study's credibility, transferability and dependability.



**Table 1. Differences between qualitative and quantitative research**

<b>Qualitative Research</b>	<b>Quantitative Research</b>
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, outwith the researcher, to be captured and understood
Intimate relationship between researcher and researched dependent on trust and the building up of dialogical understanding	Distance between researcher and researched must be upheld (positivistic approach to knowing and understanding)
Social sciences	Physical sciences
Rigour through the trustworthiness of data (transferability, credibility, dependability)	Rigour through validation, generalisability and reliability
Assessment primarily through subjective interpretation of social worlds	Assessment primarily through statistical, quantification
Expansionist embracing subjectivity, multi-vocal	Reductionist avoiding personal bias
Actor's perspective, dialogue, multiple truths to be revealed	Impersonal, third person, modelling, single truth to be discovered

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

**Table 2. Combining qualitative and quantitative research methods**

Permissive rather than restrictive
Embraces knowledge development on pragmatic grounds (consequence-oriented, problem-centred, pluralistic)
Data collection strategies are employed to best understand the problem in hand, either sequentially or simultaneously
Enables both closed measures and observations, questions for more inclusive data capture
People's views stand alongside experimental data, to test theories, hypotheses, interventions
Enables 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 analyses modes, inter-textual analysis and data-synthesis for study reporting
Data integration improves triangulation of datasets, corroboration of materials, and richer outputs

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

**Table 3. Methodologists and methodologies**

<b>Qualitative methodologists</b>	<b>Methodology</b>	<b>Features and Uses</b>
Erving Goffman (Asylums, 1961) (Stigma, 1963)	Social Constructionist Theory	Social interaction and importance of face-to-face interaction, 'agency-and-structure' divide, rituals of communication (performance)
Yin (2009) (Sage 4 <sup>th</sup> Edn.)	Case Study	Social research method, explanatory, current social phenomena, in-depth, descriptive
Greg Guest (Applied Thematic Analysis, Sage) (2012) Boyatzis, RE (1998) Transforming qualitative information: Thematic analysis and code development)	Thematic Analysis	Examining and recording patterns or 'themes' within data, defining thematic categories for analysis, coding qualitative data to clarify and hone understanding
Bronislaw Malinowski (Argonauts of the Western Pacific 1922)	Ethnography	Direct and participant observation, extended time 'in situ', cultural knowing and belonging, intensive personal fieldwork
Barney Glaser and Anselm Strauss (1967)	Grounded Theory	Inductive, systematic generation of theory from systematic collection of empirical data, withholding of personal preconceptions and assumptions
Edmund Husserl (Logical Investigations) (1901)	Descriptive Phenomenology (cf. Amedeo Giorgi )	The science of phenomena, study of structures of consciousness, objects of direct knowledge and experience, that which appears from first

		person perspective
Martin Heidegger (Being and Time) (1927)	Interpretive Phenomenology (cf. Max van Manen 1990)	Examination of our engagement with and in the world, 'Being in the world', interpretation of perceptions of events/experiences/behaviours and one's response to them
Rapport (2010) (IJQM)	Summative Analysis	Rich investigation of complex, difficult or sensitive materials, from disparate population groups, disenfranchised populations, group-working activities towards consensus-building, hierarchies of data

**Table 4. Some examples of epilepsy research and linked qualitative methods**

<b>Authors and topic</b>	<b>Adults, adolescents or children</b>	<b>Methods used</b>	<b>Analysis</b>
Walker et al. (2014) Perspectives of adults regarding self management	Adults	In-depth interviews	Grounded theory techniques with 30 participants
Moffat et al. (2009) Impact of childhood epilepsy on QoL	Children	Focus groups	Grounded theory techniques with 22 participants
Elliot et al. (2005) Impact of epilepsy on children's views of QoL	Children and adolescents	Interviews (semi-structured, open-ended)	Computer-assisted analysis (QSR NUD.IST 4.0) of interviews with 51 participants
McEwan et al. (2004) QoL and psychosocial development in adolescents	Adolescents	Focus groups	Computer-assisted analysis (QSR NUD.IST 4.0) of 6 focus groups with 22 participants
Prinjha et al. (2004) Information needs of epilepsy sufferers	Adults	Interviews	

**Figure 1. Layer 1 of the MATRICS: Outcomes being investigated in CONSTRUCT according to an integrated approach to the methods and outcomes.**

