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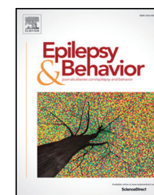
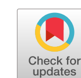


Leading up to saying "yes": A qualitative study on the experience of patients with refractory epilepsy regarding presurgical investigation for resective surgery



Patti Shih [a,*], Armin Nikpour [b,c], Andrew Bleasel [c,d], Geoffrey Herkes [c,e], Rebecca Mitchell [a], Rebecca Seah [a], Virginia Mumford [a], Jeffrey Braithwaite [a], Sanjyot Vagholkar [f], Frances Rapport [a]

[a] *Australian Institute of Health Innovation, Faculty of Medicine and Health Sciences, Macquarie University, Sydney, Australia*
[b] *Royal Prince Alfred Hospital, Sydney, Australia*
[c] *University of Sydney, Sydney, Australia*
[d] *Westmead Hospital, Westmead, Australia*
[e] *Royal North Shore Hospital, Sydney, Australia*
[f] *Primary Care & Wellbeing, Faculty of Medicine and Health Sciences, Macquarie University, Sydney, Australia*

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ABSTRACT

Objectives: Adult patients with refractory epilepsy who are potential candidates for resective surgery undergo a period of presurgical investigation in tertiary epilepsy centers (TECs), where they engage extensively with healthcare professionals and receive a range of treatment-related information. This qualitative study aimed to examine the experiences of adult patients with refractory epilepsy leading up to and during presurgical investigation and how their perceptions of resective surgery are shaped.

Methods: In-depth interviews with 12 patients and six epilepsy specialist clinicians and 12 observations of routine patient–clinician consultations took place at two TECs in Sydney, Australia. Data were thematically analyzed via group work.

Results: Patients reflected on prior experiences of poor seizure control and inadequate antiepileptic drug management and a lack of clarity about their condition before referral to tertiary care. Poor continuity of care and disrupted care transitions affected patients from regional locations. Tertiary referral increased engagement with personalized information about refractory epilepsy, which intensified during presurgical assessments with additional hospital visits and consultations. Experiential information, such as testimonials of other patients, influenced perceptions of surgery and fostered more trust and confidence towards healthcare professionals.

Conclusion: Qualitative inquiry detailed multifaceted effects of information on patients' overall treatment trajectory and experience of healthcare. Earlier patient identification for surgical assessments should be accompanied by access to good quality information at primary and community care levels and strengthened referral processes.

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1. Introduction

Fifty million people worldwide live with epilepsy, making it one of the most common global neurological diseases [1]. Over 250,000 Australians are currently living with epilepsy [2], approximately one-third of whom have refractory epilepsy, a complex and chronic condition where two or more antiepileptic drugs (AEDs) have failed to achieve seizure control [3,4]. Refractory epilepsy can cause diminished quality of life, poor psychosocial health, and comorbidities associated with uncontrolled seizures and side effects of ineffective AEDs [5–7].

Resective surgery, where the cortex in the brain responsible for the generation of seizures is resected or “disconnected”, can be an effective treatment for approximately one-third of patients with refractory epilepsy [4,7,8]. In recent years, there is increased efficacy of seizure control among carefully selected patients who undergo resective surgery, with a median of 62.4% seizure control reported in nine systematic reviews and two large case trials [6,7]. However, there remains a concern that patients who may benefit from the procedure are not being referred for surgery eligibility assessment in a timely manner or those who, despite being assessed as suitable surgical candidates, elect to not undergo the procedure [9–12]. Globally, studies suggest that eligible patients can

* Corresponding author.
E-mail addresses: patti.shih@mq.edu.au (P. Shih), armin@sydneyneurology.com.au (A. Nikpour), andrew.bleasel@sydney.edu.au (A. Bleasel), geoffrey.herkes@health.nsw.gov.au (G. Herkes), r.mitchell@mq.edu.au (R. Mitchell), rebecca.seah@mq.edu.au (R. Seah), virginia.mumford@mq.edu.au (V. Mumford), Jeffrey.braithwaite@mq.edu.au (J. Braithwaite), sanjyot.vagholkar@mq.edu.au (S. Vagholkar), frances.rapport@mq.edu.au (F. Rapport).

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live for up to 20 years or more before they receive surgical treatment [13–16].

In New South Wales (NSW), the most populated state in Australia, the burden of disease among patients with refractory epilepsy costs AUD$9.8 million per year [17]. Thus, there is much interest in ensuring that patients are referred for surgery eligibility assessment or other appropriate treatments. In NSW, presurgical investigations, or surgical “workup”, take place in one of four tertiary epilepsy centers (TECs), where patients typically arrive following failed prior treatment at primary care or community-based neurology clinics.

Presurgical investigation assesses patients' eligibility for surgery by determining the underlying epileptic zone (EZ) responsible for triggering seizures. The risks of other complications are also assessed, such as the chance of surgical failure in achieving seizure control and deficits such as memory loss, speech impairment, and death [18–21]. Assessment procedures typically include neurological and psychiatric examinations, neuroimaging, neuropsychological testing, and video-electroencephalography (video-EEG) [19,20,22].

While not all patients will eventually be offered surgery, or decide to go ahead with the procedure, presurgical workup provides an opportunity for patients to undergo medical assessments under multidisciplinary specialist care. The results of assessments can provide a more comprehensive picture of a patient's medical conditions, including individually relevant short- and long-term risks and benefits of surgery [12,18,21,23]. Undergoing presurgical investigation is therefore a pivotal point in time in the clinical pathway of many patients. The healthcare- and treatment-related information patients receive during presurgical workup can shape their perceptions towards surgery utilization and thus impact on treatment decisions that lead to future health outcomes.

Understanding patients' experiences leading up to and during presurgical investigation can reveal detailed insights about the personal journey and logistical processes they undergo, as well as the information they receive before deciding to utilize surgery. Indeed, previous studies suggest that patients' attitude and perceptions, including fears and mistrust towards surgery, are changed by the provision of information [24,25]. The support or discouragement from healthcare professionals at any stage of care can also affect surgery utilization [21,23,25]. Broader issues in the healthcare system also add to patients' challenges, such as inconsistent referral processes and lack of linkage and coordination between primary and tertiary clinics [12,26].

Clearly, a number of systematic, clinician, and patient factors add to the complex way in which patients come to the point of preparing and considering surgery [27]. However, few studies have examined the interplay of these multilayered issues, particularly during the stage of presurgical investigation, where patients arrive after having faced a range of health-related challenges for some time.

Qualitative research methodology, in the context of a health services research study, aims to elicit in-depth insights into the social world of study participants, examining people's perspectives on everyday clinical practice and the actions, interactions, and reactions that take place in different clinical environments [28]. To add to the understanding of resective surgery treatment, in this instance, this study assessed the views of patients as they progressed along different patient pathways and examined their experiences as they underwent clinical and therapeutic interventions. This study aimed to understand how patients made sense of their illness and the clinical services that were provided, how they engaged with healthcare professionals, and how they managed routine clinical consultations in order to disclose insights about the assessment process and care continuum.

Currently, the literature on refractory epilepsy is limited. We know little of patients' perspectives in terms of their views of treatment and care options over the longer term as assessments progress, with studies concentrating on quantitative assessment to examine incidents of treatment and psychosocial impact of the disease [28,29]. Furthermore, few studies have captured the fluidity of changing perceptions and decisions during assessment and over time. In order to better understand these aspects, and the build-up to surgery, as a progressive and highly contextualized process, and to adequately clarify the meaning and significance of resective surgery for patients, a qualitative approach was necessary [28–30].

This qualitative study aimed to reveal the experiences of adult patients with refractory epilepsy leading up to and during presurgical assessment and investigation stage and to examine how patients' perceptions of resective surgery are shaped. Qualitative inquiry can offer a much needed, in-depth view of this complex topic [28,29] and help fill the gap in our knowledge base regarding the experiences of being assessed for surgery in Australian adult patients with refractory epilepsy.

2. Methods

2.1. Study ethics and participant recruitment

This study took place between January and December 2017 in two TECs, based in two large public hospitals in Sydney, Australia, which receive a substantial proportion of patients referred for resective epilepsy surgery from across NSW. The study obtained ethical approval from the North Sydney Local Health District Human Research Ethics Committee (HREC/17/HAWKE/22) and site-specific assessment approvals at each hospital.

Thirty data-capture events were planned with six epilepsy specialist clinicians and twelve patients with refractory epilepsy who were recruited to the study. Three clinicians from each study site, who worked most closely with patients with refractory epilepsy, were identified by a clinical lead at each hospital and invited to attend a study information meeting where they were fully briefed about the study before written consent was obtained. To remove the possibility of researcher coercion, a dedicated clinical liaison officer was appointed at each site to identify eligible patients. Patients were identified from each clinic's appointment lists in the order in which they attended the clinic. This avoided choice bias, with patients included according to the following criteria: patients who underwent presurgical assessment during the study period, aged 18 years and older, and whom their clinician felt were physically capable of participating. These patients were given a study information sheet and consent form, and written consent to participate was obtained prior to any data collection taking place (Table 1).

2.2. Study design

The study utilized an intramethod (or “within-method”) qualitative approach [31], which refers to the use of more than one qualitative method of data collection to build a rich picture of the topic under review. Three sets of data were collected sequentially by a dedicated study researcher: 1) one-to-one interviews with the six epilepsy specialists, lasting approximately 30 min; 2) nonparticipant observations

Table 1
Participating patients who underwent presurgical investigation for resective surgery between January and December 2017 in two tertiary epilepsy centers in Sydney, NSW.

Patient pseudonym	Sex	Age	Years since reported first known seizure onset	Long-distance patients[a]
Andy	M	26	12	
Belinda	F	23	7	✓
Charlie	M	33	14	✓
Dan	M	39	37	
Elaine	F	47	29	
Fiona	F	24	14	
Gareth	M	33	12	
Harry	M	64	27	✓
Imogen	F	31	10	
Jolene	F	49	27	✓
Kevin	M	38	21	✓
Lance	M	40	4	
			Mean: 17.83	

[a] Long-distance patients are defined as patients residing more than 75 km away from the treating TEC clinic.

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