

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 Vaghholkar^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.vaghholkar@mq.edu.au (S. Vaghholkar), frances.rapport@mq.edu.au (F. Rapport).

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.

of twelve routine clinical consultations between the six epilepsy specialists and 12 of their patients, lasting approximately an hour; and 3) one-to-one interviews with each of the 12 patients, lasting between 45 min and an hour.

Data analysis involved the triangulation of data sets [32]. Triangulation is said to validate and enhance the rigor of the analytical process while adding to the richness and depth of understanding. Triangulation entails the examination and confirmation of convergence and complementarity across data sets. Following individual analysis, data sets are considered as a composite whole [33] to build a fuller and more accurate picture of the subject under review.

In this study, all three data sets were regarded as of equal weight, with one informing the other. For example, interviews with the clinicians clarified the clinical and procedural context of patient journeys through the system, and during these interviews, the study researcher asked about the process of presurgical investigation, patient throughput, and key concerns leading up to surgery. The clinical perspective, in turn, helped inform key topics for the observation of routine clinical consultations while observation fieldnotes contextualized the questions about patients' experiences collected through patient interviews. Interviews were specifically focused on patient perspectives to balance the clinical view.

By sequencing data collection in this way, the study was not wholly reliant on a single perspective, and while this article concentrates on patient experience, it draws on complementary perspectives and observations of others involved.

2.3. Data analysis

Interviews were audio-recorded and transcribed verbatim. Observation fieldnotes were written up. All qualitative data were de-identified to protect confidentiality and anonymity. Study participants were assigned pseudonyms (see Table 1) in order to differentiate the quotations and accounts belonging to each individual in any publically disseminated results. Interview data were thematically analyzed [34]. Six qualitative researchers worked together to discuss emergent issues of significance within interview data, contextualized by observation fieldnotes. Recurring concepts were identified and coded across all three data sets and organized hierarchically to ensure primary and secondary categories were revealed [34]. Group work encouraged a more rigorous approach to data analysis than individual analysis could achieve alone, according to the demands of consensus of opinion [35]. The three data sets were triangulated to enhance the rigor of the analytic method. The validation of data and analysis through the application of a triangulation method is said to assure "trustworthiness". In this case, trustworthiness was achieved when clear relationships between data sets were agreed upon by all six analysts [36], reducing individual researcher's interpretive 'bias' and enhancing peer-group support [33].

3. Results

Thirty data-capture events took place, comprising 12 interviews with patients, six interviews with epilepsy specialist clinicians, and 12 observations of consultations. The six key themes to emerge from data collection were 1) 'patient experience of poor seizure and AED management prior to TEC referral', 2) 'access to information about refractory epilepsy and treatment options', 3) 'seizure freedom and the pursuit of personal goals', 4) 'reconciling challenges of clinical workup', 5) 'understanding risks and taking odds', and 6) 'learning from the experiences of other patients'. Each theme is described in more detail in this section.

3.1. Chronic experience of poor seizure and AED management prior to TEC referral

On average, patients lived for 18 years with epilepsy. Patients recounted this protracted period as marked by inconsistent seizure control and poor AED management. The chronic nature of refractory epilepsy

and the length and difficulty of treatment saw patients being transitioned between primary care under general practitioners (GPs) and community-based general neurologists before finally being referred to a TEC.

During this time, patients recounted psychosocial and physical deterioration when they could only achieve irregular periods of seizure freedom, with poorly managed AED regimens in increasing doses and combinations.

[The AED] would last for a month or so, and then it would stop working... All I kept feeling was that my medication was just getting amped up and amped up, even more and more, which was just making me worse and worse.

[(Imogen)]

According to Kevin, "as far as I know, I've tried the lot" in terms of AEDs, and he reported psychological distress, including erratic behavior as the result of taking the antidepressants prescribed to counter AED side effects. For Charlie, "the medication just took over my life", and he believed this caused the development of kidney stones, weight loss, and suicidal thoughts. Ironically, AEDs that were intended to help patients gain control over unpredictable seizures were instead an additional source of uncertainty and ill health.

Some patients reported poor relationships with their community-based neurologists, which led to referral delays. Imogen, who was from a culturally and linguistically diverse background, felt racially discriminated and judged by her first neurologist, prompting a lengthy search for another who knew about resective surgery but was not convinced of its effectiveness. Charlie simply "didn't like the guy [neurologist]", which discouraged him from receiving treatment for several years. While other patients had a good relationship with their GPs or neurologists, the consensus was that the lack of specialist knowledge in epilepsy, particularly among generalists, greatly affected the quality of their care.

There were multiple pathways by which patients were referred to their current treating TECs. The eventual pathway was not always the result of an informed medical opinion from a referring doctor. Some patients experienced a sudden change in seizure patterns, such as Kevin, whose unexpected onset of daytime seizures led to specialist referral. By chance, Elaine had a seizure during a routine scan at her long-term neurology clinic, which revealed more information about her disease and therefore enabled her neurologist to make a referral. After years of frustration with poor treatment under her first neurologist, Jolene's visit to a second neurologist prompted an immediate TEC referral. For others, it was a chance social encounter with someone who mentioned surgery, a suggested medical professional who could organize a referral, or a patient's observation of a news item on television that led them to explore the resective surgical pathways.

In summary, this theme indicated that patients' lives were deeply affected by chronic, uncontrolled seizures and exacerbated by what they felt was poor disease management. This was also demonstrated through inconsistencies and delays in their referral to TEC specialist care.

3.2. Tertiary specialist care: accessing better information and continuity of care

In reflection of the difficulties of poor AED and seizure management, the opportunity to consider resective surgery at a TEC was perceived as a chance to consider new treatment options that patients were not previously aware of.

I don't really want to have to take these medications for the rest of my life, but if I have to and that's my only choice, then I will. But if surgery is an option — and I was seeking a little bit more information on surgery to see if I would be able to come off these tablets.

[(Elaine)]

Accessing better information about epilepsy and resective surgery was an important goal for attending a TEC. According to Belinda,

“surgery is probably the biggest step that I can take as regards to treatment”. Given this, the need to approach the intervention with caution and adequate information was crucial.

A number of patients described a notable difference under the care of tertiary epilepsy specialists, whom patients found to convey information in a relevant and individually tailored way. This helped patients gain clarity about their challenging and unpredictable health condition. According to Imogen, “it was the first time someone ever explained anything to me”. Jolene described the revelation of seeing a scan of the scarring on her brain for the first time in the 27 years since first experiencing debilitating auras. Previously, her long-term doctors had not been able to explain, nor justify, the increasing doses of medication prescribed, apart from “for 20 odd years I was told I had a virus in my brain”. Now Jolene could “actually give it a name, and tell people, *that’s* what it is”, after almost three decades of living with what she called “turns” and a “metal taste in my mouth”. Being able to access accurate and understandable information was important not only for patients themselves but also for the peace of mind of their family and friends.

For patients who lived more than 75 km away from the TEC in a regional location, an additional challenge is the lack of access and continuity of care. Belinda, originally from a regional area approximately 250 km from Sydney, was previously unable to access appropriate healthcare professionals who were knowledgeable enough about refractory epilepsy.

A lot more happened in that consultation with [epilepsy specialist at TEC], than in the consultations with [a previous community-based neurologist]. I’m not sure if that was because he was strapped for time or if he just didn’t have a big basis of knowledge of epilepsy and he was the only one that we had access to.

According to Kevin, who lived about 3 h by train from his current treating TEC in Sydney, previous neurologists visited his regional township on an irregular basis and changed constantly.

My biggest issue is with what I call fly-by people. So, doctors who were put into positions to just go from town to town until they decided to move off to a greater field. They just sit across a desk from you and they’re making life decisions for you within a ten or 15-minute consult and slap you with \$150 and you never see them again ... and I’ll need to explain to the next guy my story all over again and they’ll say: “Oh, well, if [the AED] is not working, fair enough, well, we might just try upping this, or we might try maybe putting you on that sort of drug”. But there was no explanation of what that drug could do [in terms of side effects].

Kevin relayed the relief he felt once he was referred to the TEC and experienced a continuity of care with the same epilepsy specialist who can be reached on the phone and discuss new developments if seizures and medication responses changed. He suggested that the referral to the TEC was “the best thing that’s happened to me”, despite having to make the three-hour train journey to Sydney on a regular basis.

In summary, this theme indicated the stark contrast between information provision and clarity at the TEC level while lack of information prior to referral highlighted frustrations for patients who were unable to turn to knowledgeable specialists for their care. Perceived lack of timely information also influenced the way in which patients formed expectations for better care once they finally arrived at a TEC.

3.3. Seizure freedom: an opportunity to pursue personal goals

Patients described their willingness to consider surgery as a potential treatment option in their desire to attain personal goals.

I feel like with the process of changing meds, changing doses, I kind of feel a bit tied down in terms of what and where I can go and what I can do. I’d like to live overseas while I’m still young and I don’t feel

comfortable doing that while I’m still juggling meds and not being stable.

[(Andy)]

As long as I have some quality of life, can drive and work, and travel and get married and all that sort of stuff. Being independent – not having to have someone caring for me so much.

[(Charlie)]

Fiona, a 24-year-old woman in a steady long-term relationship, was eager to start a family. Concerned with the risks of AED during pregnancy, Fiona felt that being seizure-free, on a low medication dosage, would allow her to achieve this important personal goal. Male participants such as Charlie, Dan, and Gareth also mentioned their desire to “get married and start a family”, although the barriers to this were defined more in social than biomedical terms as being seizure-free allows them to enjoy better psychological health and enhance their capacity to maintain relationships and be effective parents.

Imogen and Kevin were both parents of young children, and the role of being a capable parent was very central to their desire to explore surgery as a treatment option. As a mother, Imogen’s ability to look after her son and be a “good role model” had diminished, not only because of uncontrolled seizures but also as a result of her dependency on alcohol, which she suggested as her way of coping with the anxiety of living with refractory epilepsy. As the breadwinner of the family, Kevin saw his role as “the provider” and being able to return to work and have a better income than his current government sickness benefit would relieve his wife from caring for him and their three children.

In summary, this theme indicated that patients’ views of uncontrolled seizures contributed to their inability to achieve personal goals. These limitations to their personal life and aspirations in some ways shaped their desire to explore other treatment options offered at the TEC level.

3.4. Reconciling challenges of surgical workup

For patients who were motivated to pursue surgery as a treatment option, undergoing surgical workup was a necessary, albeit challenging, rite of passage towards becoming eligible for surgery. The sequence of medical assessments, from video-EEG and magnetic resonance imaging (MRI) to sleep tests and other scans, varied for each patient, depending on the complexity of each individual’s case. Undergoing surgical workup produced successive clinical data from which to inform medical decision-making. Results discussed with patients during clinical consultations led to new AED regimens or further investigations to ascertain eligibility for surgery. For Dan, electing for surgery was a chance that only became possible after undergoing these exhausting assessments, which resulted in some patients like himself being eligible for surgery, but not others.

During the last 18 months – I’ve probably had 12 or 15 different scans, MRIs and CT scans. That sort of thing ... I don’t mind. I don’t mind coming into hospital because it’s all part of being ready for surgery. It’s just part of life ... I know that I’m one of the lucky ones, so to speak – being able to have surgery. Because not all people are able to have surgery.

A hallmark of surgical workup is a one-week, in-hospital video-EEG, where antiepileptic medication is reduced in a monitored hospital environment in order to stimulate seizures and capture information about the size and location of the EZ. This is a demanding and time-consuming process, which patients can fear and resist. In NSW, a full-time, 24-hour “sitter” or carer for each patient is legally required to accompany them for the duration of the video-EEG because of the risks of injury and death during seizure onset. According to Andy, during his first consultation at the TEC:

[The clinician] offhand mentioned this inpatient [video-EEG], “can I get someone to sit with me”? But I felt ... like that was probably

one of the biggest deals, one of the biggest hurdles towards [surgery].

Not only was the process logistically challenging to organize, but being physically “wired-up” for a week and unable to leave the hospital bed was confronting to Imogen’s sense of dignity: “I didn’t know that I would look like Medusa!”

Yet, despite these challenges, patients who underwent the video-EEG week spoke of it as a necessary step towards achieving their goal of seizure freedom.

My PET scan was on [date], and after that, they took my medications off [during video-EEG] and I had a lot of seizures. I think one day I had 16 seizures...it was a good thing, because it means that my epilepsy is actually there. Yeah, it was a good thing because it was leading up to saying “yes” to surgery.

[(Fiona)]

Likewise, according to Dan, “I wasn’t excited about [video-EEG]. I knew it had to happen in order to do the testing.” The trade-off of the physical and psychological trauma of enduring seizures and the indignity of having to toilet in a hospital bed pan was part and parcel of the personal sacrifice some patients felt was necessary to be eligible for surgery. According to Kevin:

I bit my tongue to shreds when I had those seizures [during video-EEG]. I couldn’t talk for two days after that. But it had to be done. They [healthcare professionals] do their bit, I do my bit.

Having to endure the physical discomfort and logistical inconvenience of various assessments, though in particular the one-week video-EEG, were seen as a necessary step in reaching their health and life goals.

During a consultation, Andy’s clinician explained the number of possible assessments required for presurgical investigation and the several months it might take for the process to complete. Asked if he was concerned with this delay, Andy said that being given a bit more time during a protracted process of presurgery investigation was in fact helpful.

I might be in two minds about [having surgery]. I think if anything that timeline reassures me that there’s a lot of time in which I can reconsider and if I ever want to be like: “no I don’t want you cutting up my brain,” I’d have plenty of time and opportunity to say that. If it was happening all of a sudden, I would feel anxious about it. At the same time, it is also frustrating that it is a long process, and that I wouldn’t see results for what I’m doing now.

As presurgical investigation progressed, there was an increased build-up of personalized clinical data, which clinicians routinely conveyed back to patients as they returned for consultations. These added to patients’ knowledge about their own conditions, suitability for surgery, and the potential risks and deficits they needed to consider before deciding to undertake surgery. Jolene said she was initially fearful when the topic of surgery was broached by her clinician when she first visited the TEC.

I was in tears when I heard, I was so scared, just the idea that they are going to cut into my brain.

Eight months later, and after undergoing a number of neurological assessments, the increased knowledge Jolene gained about resective surgery and understanding her own potential for achieving seizure freedom helped her form a more positive perception towards surgery.

In summary, this theme indicated that despite the protracted and convoluted process of surgical workup, patients understood that clinical assessments would provide the best data by which clinicians could confirm their eligibility for surgery and would be vital in informing clinicians about surgical procedure and thus optimize surgical outcomes.

3.5. Understanding risks and taking odds

Surgery would only be offered to patients who were determined to be suitable candidates after extensive assessments, where the odds of a beneficial outcome outweigh the risks. The risks of surgery, including the chance of surgery failure and other potential complications and deficits, are nevertheless routinely discussed between clinicians and patients. There were a number of different ways patients articulated their understanding of these risks.

Despite being presented with the risks, Fiona preferred to take an optimistic view based on her hopes for achieving her goal of starting a family.

I know there are risks, but I don’t really want to think about it. I’m just excited for it. I’m just thinking of the positives, and I am going to have a child.

Harry, too, was willing to undergo surgery because he was given clinical information that pointed to good odds.

We had the understanding that there was no 100% guarantee of success, but the odds are still well and truly in our favour and so, it was worth taking the odds.

His willingness to do so was particularly influenced by his confidence in the professional expertise of his clinician, who had a nationwide reputation.

People told me that he was the best in Australia, so I thought, he’ll do me, thank you!

Indeed, having a sense of confidence and trust in healthcare professionals was important when faced with risks and uncertainties of treatment. For Charlie, this came from the knowledge and expertise demonstrated by his neurosurgeon.

He seemed to me, really up to date. And he knew all the new technologies, all the new medications. He basically knew everything about what you’d possibly want somebody to know about brain surgery.

For Kevin and Jolene, it was about the degree of improvement that mattered in the face of potential risks.

I understand that there’s going to be risk involved but I’ll be honest with you, I’d rather have surgery than not and as [treating clinician at TEC] said, “you can go through the surgery and you come out just the way you are now, no harm lost. Or you could come out and we could find that there’s major differences.” They’ve already had six or seven patients this year that have walked away medication-free and seizure-free. Well, I’ll take those odds any day. I’ll even take the odds to go, okay, yeah, it’s just nocturnal now or, we’ve only had to cut back your drugs by half. So, as far as I’m concerned, right now I’ve got nothing to lose, I’ve got everything to gain and that’s the way I see it.

[(Kevin)]

If they can fix it to an extent where it’s not going to bother me with anything and it’s going to give me a better quality of life, that’s what I want.

[(Jolene)]

In summary, this theme indicated that each patient had their own understanding of the risks of surgery and the odds for and against surgical success. Some of this was shaped by their encounters with other patients and some by the information they received from the clinicians. Overall, patients who trusted, and had confidence in, the healthcare professionals managing their treatment tended to think more positively about surgery.

3.6. Learning from the experience of others

While clinical data, such as the odds of success, were important in informing decision-making about surgery for both clinicians and patients, the chance to meet other patients who had undergone similar experiences provided a different kind of perspective.

With the frequent visits to hospital for various assessment procedures, patients often met each other in waiting rooms. Charlie had met another patient who had undergone brain surgery and whose initial health was worse than his and felt encouraged that the other patient survived and recovered. Jolene had also met another patient returning for postsurgery follow-up while she was waiting to see her neurosurgeon. The patient was from the same local area as Jolene and also had to travel to Sydney to seek medical care, and this became a bond for them. The other patients' recommendation and affirmation of the neurosurgeon's skills gave Jolene an overwhelming sense of confidence about her pending surgery.

[The other patient] could not speak more highly of [neurosurgeon], so that made me feel really good about [going ahead for surgery].

Kevin also had a chance meeting with someone who underwent resective surgery but only achieved partial seizure reduction. Rather than being discouraged by this, Kevin felt that partial improvement to his health would still be a worthwhile outcome.

I met someone just in the last two weeks who had the brain surgery, and he's now only got nocturnal seizures and he's on one drug, which in my eyes is progress, because his quality of life changed, and he's got a [driver's] license, and he can live life. So, it was just interesting that I keep finding these people all of a sudden, never, ever before, and now all of a sudden, I'm meeting them and all it does is it just keeps on giving me hope that these things are possible.

[(Kevin)]

In summary, the testimonial of others, integrated with personal experiences of illness and treatment, culminated in a powerful and convincing form of information that complemented clinical data communicated by healthcare professionals. However, experiences of other patients can also have a negative impact and can lead to misleading information for patients, particularly if others are speaking from the experience of a different kind of epilepsy or neurological condition or a different type of procedure. Thus, some clarity and guidance should be offered to patients when they use the testimonials of others to inform them about treatment decision-making.

4. Discussion

Presurgical investigation is a significant and a unique stage in the clinical pathway of patients with refractory epilepsy. In this study, patients made sense of this process by reflecting on a prior period of failed AED treatment and projected their hopes for successful surgical treatment around their personal goals. The often lengthy and convoluted pathway many took to arrive at this point of treatment showed marked differences and shifts in experiences overtime as patients transition from primary and community-based neurology care to the TEC and engage more extensively with a range of information and healthcare professionals with specialist expertise.

The results of the study is summarized and developed into a Venn diagram in Fig. 1. It shows how patients' perceptions towards the potential benefits of surgery are influenced by accumulative gathering of information (Box [1]) and their engagement with healthcare professionals (Box [2]), which is enabled when adequate knowledge and referral processes at primary care and community-based neurology clinics allow for timely care transition (Box [3]).

4.1. Accumulative opportunities to engage factual and experiential information

While a number of previous studies highlight the role of information and knowledge in alleviating patients' fears and anxiety associated with the refusal of surgery [23,25,37], this study details a more complex view of the multifaceted effects of information on patients' overall trajectory and experience of healthcare. The progression into tertiary care gave rise to more opportunities to receive personalized information about their illness that was previously lacking.

This study reinforced the different yet complementary role played by *factual* and *experiential* information. According to Choi et al. [24], factual information includes clinical facts around resective epilepsy and the statistical odds of risk versus benefits of surgery applicable to each individual patient while experiential information refers to the testimonials of other patients who have undergone similar procedures who can provide a personal account of treatment. This study suggests patients not only value the role of statistical and clinical data in informing them and their clinicians in progressing towards a treatment decision but they also recognize the importance of undergoing successive medical assessments in order to produce such factual information. Therefore, despite the logistical challenges and the physical and mental discomforts of assessments, such as video-EEG, patients were willing to continue participating in presurgical investigations.

In turn, attending the hospital for multiple assessments provided more chances to meet with other patients and the wider multidisciplinary healthcare team, including allied healthcare workers and nursing staff. These interpersonal situations gave rise to opportunities for patients to receive social support and share experiences. The results suggest that experiential information is not just a complementary source of knowledge about treatment procedures. Positive accounts of treatment as told by others can help patients feel more comfortable about undertaking surgery, when previously, patients may have been discouraged by a sense of mistrust and anxiety.

However, different types of resective surgery, such as lesional versus nonlesional surgery, are different procedures and with different odds of success [38]. Thus, it is important that patients are guided by the experience of others who have had the same type of procedure to obtain a more comparable case. Also, patients in the current study seem to be meeting each other on an ad hoc basis. More guidance from the TEC can ensure that patients meet others more systematically and are matched with those who have the same type of epilepsy and proposed surgery.

4.2. Building trust and confidence towards healthcare professionals

Receiving adequate information is highly associated with trust-building, and together, these two important factors deeply shape the perceptions of patients towards surgery. Previous studies suggest healthcare professionals as key facilitators of patients' knowledge and perceptions of surgery [12,23]. The lack of encouragement from clinicians, a sense of mistrust of the procedures, and lack of willingness to follow professional advice are all factors associated with patients' likelihood to refuse surgery [12,21,23]. This study shows that the limited knowledge among some nonspecialist clinicians in responding to AED resistance exacerbated patients' lack of confidence in healthcare services. However, patients had more clarity once epilepsy specialists were able to provide well-needed and personalized information. At the same time, experiential testimonials from other patients and healthcare professionals about individual clinicians' professional competence added to patients' trust and confidence. These increased the likelihood of more optimism towards treatment success and thus greatly influenced patients' positive perceptions towards utilizing surgery.

Having a strong, trusting clinician–patient relationship in turn underscores the communication needed in reaching a shared decision

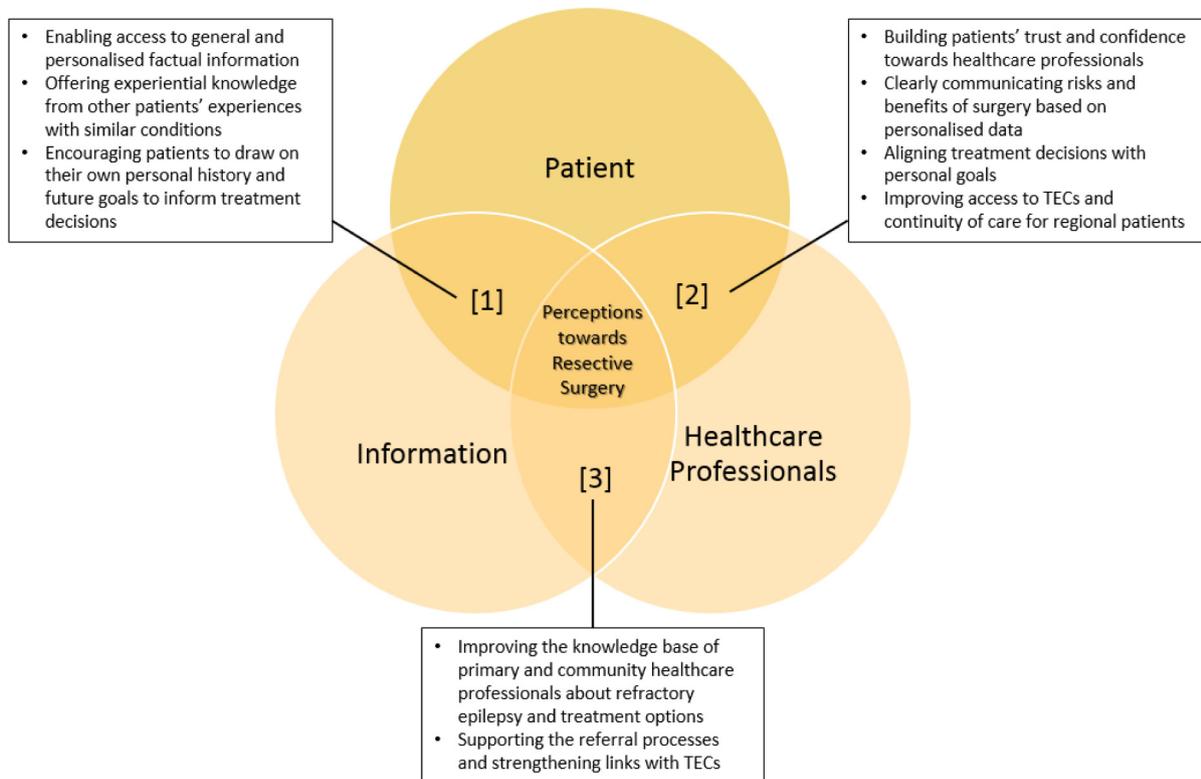


Fig. 1. Shaping patients' perceptions of resective surgery: engagement with healthcare professionals and information provision.

about undergoing surgery. Conveying and discussing the benefits and risks of surgery based on personalized clinical data is important but only one part of the concern. Personal goals and aspirations for a better quality of life are clearly central motivators for patients in considering surgery. How these personal goals and aspirations could be met by surgery, and with strategies that go beyond surgery, such as through the support of psychologists and personal social networks, should also be considered by TEC clinicians and the network of healthcare professionals available to patients.

4.3. Earlier information and referral: primary care and access challenges

The importance of information and trust invariably highlight areas where these are lacking or inconsistent. Patients in this study tended to receive adequate information and gained better trust after TEC referral. Both general information about refractory epilepsy and factual information about their personal conditions were lacking for a number of patients while under primary and community-based neurology care. Some community-based healthcare professionals were able to identify drug resistance more quickly than others, and some had access to better neuroimaging technology and referral networks. Overall, these challenges were more pronounced for patients from regional locations to overcome.

4.4. Study significance and limitations

This qualitative study details the experience of a small group of patients from two TECs in one state in Australia. While individual patients' experiences are limited in generalizability, the insights regarding the complex and intersecting role of information, trust-building, and referral processes are relevant healthcare issues that can be applied to other social and geographic contexts. The findings portray predominantly positive perspectives about undergoing surgery. This may be partly influenced by the exclusion of patients who were not offered presurgical

investigation or have refused when offered. However, the focus on the experience of patients who are motivated for surgery revealed that they share many similar challenges as those that do not go to surgery. Therefore, the results of this study can complement the preexisting literature on patient and clinician barriers of surgery utilization by showing how patients can, in some cases, overcome challenges and become motivated towards accessing appropriate treatment.

5. Conclusion

This Australian study has examined the experiences and views of patients with refractory epilepsy in undergoing surgical evaluation and assessment in the context of a prolonged and often delayed assessment process. Patients' experiential motivation for, and concerns about, surgery reveal a deep connection between clinical, social and personal factors that impinge or promote a willingness to have surgery. These findings also reflect wider healthcare system issues that impact on patients' treatment and care transitions. The study points to the need for further research, across regional and urban healthcare clinics in Australia and beyond, to gain a fuller understanding of the referral and treatment challenges for patients living with this chronic disease. Given patients' hopes for seizure freedom, this study can help to inform future research about patients' postsurgical and prereferral expectations and their desire for optimal progress to successful surgical intervention.

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Conflict of interest

None declared.

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