

Identification and referral of patients with refractory epilepsy from the primary to the tertiary care interface in New South Wales, Australia

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ABSTRACT

Objectives: This mixed-method feasibility study conducted in New South Wales (NSW), Australia, aimed to explore clinical practices around the identification of patients with refractory epilepsy and referral from primary care to Tertiary Epilepsy Centers. The perceptions of general practitioners, neurologists, and adults living with refractory epilepsy were considered.

Methods: Fifty-two data collection events were achieved through 22 semi-structured interviews with six neurologists and 12 adults who currently have, or have had refractory epilepsy, and four family members, 10 clinical observations of patient consultations and 20 surveys with general practitioners. A thematic analysis was conducted on the qualitative data alongside assessment of observational fieldnotes and survey data.

Findings: Two main themes emerged: 1) *Patient healthcare pathways and care experiences* highlighted the complex and deeply contextualized experiences of both patients and healthcare professionals, from first identification of people's seizures, in primary and community care settings, to referral to Tertiary Epilepsy Centers, shedding light on a fragmented, nonstandardized referral process, influenced by both individual and shared-care practices. 2) *Factors impacting referrals and patient pathways* indicated that onward referral to a Tertiary Epilepsy Center is affected by the knowledge, or the lack thereof, of healthcare professionals regarding treatment options. Barriers include limited person-centered care, shared decision-making, and refractory epilepsy education for healthcare professionals, which can delay patients' disease identification and can hinder speedy referral pathways and processes, in Australia for up to 17 years. In addition, person-centered communication around care pathways is affected by relationships between clinicians, patients, and family members.

Conclusion: This study has identified a noticeable lack of standardized care across epilepsy-related healthcare sectors, which recognizes a need for developing and implementing clearer epilepsy-related guidelines and Continuing Professional Development in the primary and community care settings. This, however, requires greater collaboration and commitment in the primary, community, and tertiary care sectors to address the ongoing misconceptions around professional roles and responsibilities to optimize shared-care practices. Ultimately, prioritizing person-centered care on both patients' and professionals' agendas, in order to improve satisfaction with care experiences of people living with complex epilepsy.

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1. Background

Epilepsy is the most common neurological condition impacting people of any age, with over 50 million people globally suffering from the disease, causing 0.6% of the total worldwide disease burden [1]. In Australia, over 250,000 people, about 0.6% of all Australian's, are currently living with epilepsy, and around 3–3.5% will experience epilepsy at some point in their life [2–4]. Most people with diagnosed epilepsy achieve 'seizure freedom' through antiepileptic drug (AED) therapy, but approximately one-third are living with refractory epilepsy, a difficult to treat, chronic and complex condition, where seizures are not controlled effectively by an AED regime alone [5–7]. Epilepsy management can be further complicated by significant adverse side effects from drugs that can add to the burden of disease [8]. Epilepsy surgery (resection of the focal part of the epileptogenic lobe of the brain) can be a 'life-changing procedure' [9:982] in epilepsy management. A median curative rate of 62.4% for focal seizures has significant benefits beyond the absence of seizures, including: reduced mortality, cognitive improvement, improved quality of life, and reduction in psychological comorbidities [9–11]. However, delays in obtaining an epilepsy specialist assessment can greatly affect attaining these benefits. These delays not only impact patients, but family members as well, who can also experience the disabling effects of complex epilepsy, including, but not limited to, social stigma, and a sense of frustration and isolation [12–14].

Nevertheless, surgical treatment for refractory epilepsy remains underutilized internationally, and there is a disparity between the proportion of suitable candidates for surgery and those that receive surgery [11,12,15,16]. In the United States there is, on average, a 22-year delay for epilepsy related surgery after initial disease presentation, and in Australia, a 17-year delay [7,9,17,18]. There are many factors contributing to this, including the following: a tendency among neurologists to consider surgery as the 'last resort' [19:39], the inability of nonspecialist healthcare professionals (HCP) to identify refractory epilepsy, a delayed onset of refractory epilepsy from initial presentation of epilepsy was estimated as nine years [20], lack of accurate knowledge and information about other nonpharmacological treatments, such as resective surgery, poor sharing of statistical information about surgical treatment outcomes and risk, and patients' fearful attitudes toward surgery [8,9,12,17,21].

Patients', family members', and HCPs' experiences have been noted as a valuable source of information about referral and care pathways as they provide clear insights into the current healthcare processes, which include clinical effectiveness, information sharing, shared decision-making (SDM), patient-centered care (PCC), and the best ways to 'build confidence and trust' [22:87,12,13, 23–25]. The significance of individual lived experiences and the broader social aspects of treatment are significantly underestimated in terms of PCC and patient involvement in decision-making [19,23,26]. Indeed, it has been argued that the lack of attention to the whole patient disease experience may be a clear contributing factor to patients' fears and anxieties around surgery, impacting on their decisions to avoid surgery [13]. However, refractory epilepsy is one neurological field where little research has been undertaken regarding consumer and HCP experience.

The fragmentation of epilepsy services, from primary to tertiary care, and lack of shared-care are also barriers to delivering and receiving effective care, affecting efficiency, timely access to services for patients and continuity of care [22,27]. Inefficient care management and miscommunication across settings can also delay identification and referral of patients with refractory epilepsy to epilepsy specialists in Tertiary Epilepsy Centers (TECs), where they have more chance of receiving an early surgical assessment [3]. Other contributing factors are 'poor clinical pathways and/or a lack of resources for candidate assessment' [5:14,17,27].

Using mixed methods, Rapport and colleagues [28] identified numerous gaps in service provision and delays in care for patients with refractory epilepsy within the Australian healthcare system. The program

comprised five study components, both qualitative and quantitative, identified a strong link 'between clinical, social, and personal factors impinging or promoting a willingness for surgery' [29:42,26,28]. Rapport et al. argue that there is poor continuity of care between general neurologists, general practitioners (GPs), and TEC specialists [29], and recommend further investigation into current clinical decision-making in the primary and community care sectors. Based on patient reported determinants of health and wellbeing, the Patient Reported Implementation SciEnce (PRIME) model identified limited patient and family member understanding of treatment and care options from primary and community care through to the TEC context [22:81].

1.1. Details of the current study aims and study objectives

This mixed methods study draws on the perceptions of GPs, general neurologist, epilepsy specialists and people living with refractory epilepsy. It aims to 1) assess the challenges and barriers to clinical decision-making in the diagnosis and management of patients with refractory epilepsy, and 2) examine the impact of decisions made on patient pathways, clarifying referral processes and shared care practices, particularly between primary and community HCPs but including tertiary epilepsy care specialists.

Study objectives:

- 1) Clarify patients', families', and treating HCPs' experiences of refractory epilepsy diagnosis, referral, and treatment in primary and community care;
- 2) Confirm care pathways from initial diagnosis to referral to specialists in TECs;
- 3) Reveal factors influencing referral decisions, both facilitators and barriers;
- 4) Disclose individual and shared-care practices at the care interface to inform the PRIME care model;
- 5) Explore ways of closing the 17-year gap in patients with refractory epilepsy identification and referral in NSW, Australia.

2. Methods

2.1. Study ethics

The qualitative component of this study took place in the North Sydney Local Health District (NSLHD), NSW, Australia. The quantitative component took place with the North Sydney Primary Health Network and the Hunter New England Central Coast Primary Health Network. The study gained ethics approval from the NSLHD Human Research Ethics Committee: reference number HREC/18/HAWKE/95.

2.2. Participant recruitment

2.2.1. General neurologists and epilepsy specialists

A clinical lead (GH) identified a range of general neurologists and epilepsy specialists managing patient care for those with epilepsy and other neurological diseases. Three general neurologists, affiliated to Royal North Shore Hospital (RNSH), working closely with people with refractory epilepsy and three epilepsy specialists providing specialist care across NSW consented to participate in the study, representing both community and hospital-based referral practices.

2.2.2. Patients

Patients, directly linked to the participating general neurologists, were recruited to the study using timeframe sampling [30]. This methodology allows potential participants to be approached in the order in which they attend a consultation, over a specific time-period, in this case, six months. Timeframe sampling reduces the chance of clinicians' or researchers' influencing recruitment. Patients with refractory epilepsy

were invited to participate, following informed consent, in the order in which they presented for their neurological consultation. While qualitative research does not seek a representative sample as a result of often small sample sizes involved, and while the team recognized that certain types of patients are sometimes seen at specific times of the day, they chose timeframe sampling to mitigate against clinician or researcher recruitment preference during neurological consultation. At the same time, the sampling framework encouraged, as much as was possible, equal opportunities for all of being recruited [31].

Patients were recruited by a neurologist not directly linked to an individual patient's care, to reduce the chance of any personal preference. Those recruited represented different stages in the epilepsy surgery pathway. Some had participated in presurgical evaluations resulting in surgery. Others had been deemed unsuitable for surgery. Those unsuitable were not evaluated. Some had only got to the stage in their patient pathway of discussing surgery as a potential option while one patient had never discussed surgery with a clinician. Patients were fully informed about the study through a Patient Information and Consent Form and completed written consent before researchers contacted them. Four from the final cohort of 12 patients requested family members attend consultations and interviews. A written consent form was also completed by each family member before researchers contacted them.

2.2.3. General practitioners

The GPs were either members of the North Sydney Primary Health Network or the Hunter New England Central Coast Primary Health Network. Recruiting from these two Health Networks ensured GPs represented practices across urban, regional, and rural areas. Research information was included in an online and paper survey via the Networks, and consent was obtained after an expression of interest. A flyer was produced to support GP recruitment, distributed online through Network newsletters, and posted with paper survey to 148 randomly selected GP practices across both Primary Healthcare Networks [32].

2.3. Study design

This study used a convergent, mixed methods design, merging both qualitative (interviews and observations) and quantitative (survey) data concurrently, to provide a rich and detailed database to better understand healthcare experiences, and professional knowledge from a range of different perspectives [33,34]. Qualitative research provided an opportunity to explore experiences and perceptions of healthcare practices, processes and procedures, illness courses, and to understand a range of views on health and wellbeing [33,35]. Quantitative research provided information about specific population groups' views and opinions and in this study, GPs' knowledge of refractory epilepsy, surgical treatment, shared care, and their management practices across urban, regional, and rural settings. The mixed methods design included an iterative approach to analysis, so that analysis began as soon as data collection commenced, and reviewed several times, to build knowledge over time.

Using the Qualtrics survey software [36], hosted at the primary university's site, a secure server handled data management. The Qualtrics survey content was designed through preparatory team workshops comprising health services researchers, a health economist, and a number of HCPs including a GP and researcher [35]. The survey questions were scrutinized by all members of the research team for consensus agreement on key topics and approaches to questioning. In addition, survey questions were informed by an in-depth literature search, examining a range of international and national refractory epilepsy studies, with due consideration given to the methods adopted by others. The online survey was piloted with GPs and researchers based at the primary university site, and questions were revised before being launched, to ensure relevance and clarity, enhancing face validity.

2.4. Data collection

Data collection included 10 observations of routine of consultations, in general neurologists' consulting rooms between patients, family members (if present), and general neurologists. All consultations were audio-recorded, and a dedicated study researcher (KH, PS, or EFA) took notes throughout, documenting interactions, procedures, and nonverbal communication. Directly after the consultations, ten patients and three family members participated in a semi-structured, audio-recorded interview with a study researcher which lasted approximately 1 hour. One patient, due to work and family commitments, chose to be interviewed by Skype, and another with restricted mobility, preferred to conduct the interview at home with a family member. Interviews were also completed with three consulting general neurologists and three epilepsy specialists in their workplace. Patient and neurologist interviews (Tables 1 and 2) involved two separate question schedules, in response to study aims and objectives. The semi-structured interview process, which allowed interviewees to expand on a topic, was aided by additional probing questions [33].

A GP survey was collected (see Appendix 1); GPs' views and practices in managing refractory epilepsy, alongside information on referrals, shared-care relationships, knowledge and understanding of refractory epilepsy, and views of surgical management, were gathered through 34 survey questions. Surveys returned by post had data transferred into the Qualtrics survey platform.

2.5. Data analysis

Following data collection, all qualitative recordings were transcribed verbatim and deidentified. Patients were assigned pseudonyms (see Table 2) while neurologists were assigned a code number (see Table 1). Observational fieldnotes embellished interview transcripts and were also analyzed thematically [37]. GP survey data were collated and analyzed in Qualtrics and Excel. The survey included demographic data from all responding GPs (see Table 3).

Framework analysis supported data management, ensuring a 'systematic and flexible approach' [38:1] to map qualitative data across datasets [39]. Following a period of familiarization with the data by a team of researchers (KH, FR, PS, and EFA), interpretation and coding took place, manually, to ensure consensus regarding key and incidental themes, and the alignment of themes, aims, and objectives [28]. The framework method identifies commonalities, differences, and relationships across qualitative data, taking thematic analysis to its conclusion by generating main themes and their concomitant categories [37].

Once all datasets were analyzed, data could be triangulated to compare findings across all datasets together. Triangulation adds credibility to the construction of a rich, holistic and precise representation of participant experience, and in this study, participants' perceptions of seizure identification, refractory epilepsy diagnosis, and primary and community referral practices [33,40]. Triangulation also revealed finer details regarding the management of patients as they were assessed by different HCPs, and considered for different treatments and procedural reviews, including information on informal shared care, clinical knowledge, and expertise.

3. Results

A total of 52 data captured events took place with three study participant groups: 1) general neurologists and epilepsy specialists (see Table 1), 2) patients and family members (see Table 2), and 3) GPs (see Table 3). Throughout this paper the collective term of HCPs refers to GPs, general neurologists and epilepsy specialist together.

Two major themes emerged from the data (see Fig. 1). The first — *Patient healthcare pathways and care experiences* — describes the patient pathway from initial seizure to referral to a TEC, and the primary, community and tertiary healthcare professionals' roles, informal shared care

Table 1
Characteristics of general neurologists and epilepsy specialists, n = 6.

Neurologist	Age range (years)	Years practicing as GN and/or ES	Epilepsy training	% of patients with refractory epilepsy	% of time seeing patients with refractory epilepsy	Location of work in NSW	Private/public practice
GN1	41–50	15	No	5	5	Urban	Private
GN2	51–60	18	No	10	<5	Urban	Public
GN3	61–70	30	Yes	>10	>15	Urban	Public & private
ES1	51–60	GN - 22 ES - 20	Yes	50	20	Urban	Public
ES2	41–50	GN - 14 ES - 10	Yes	90	90	Urban & regional	Public & private
ES3	61–70	GN - 30 ES - 25	Yes	80	40	Urban & rural	Public & private

Abbreviations: GN = general neurologist, ES = epilepsy specialist.

Public healthcare – Medicare – and public hospitals provide free or low-cost access for all Australians to most healthcare services. Private healthcare, in and out of hospital, is available with personal and private health insurance contributions.

Table 2
Patient demographic information, n = 12.

Pseudonym	Current age	Age diagnosed with epilepsy (years)	Marital status	Children	Work status	Currently managed on antiepileptic drugs	Presurgical evaluation completed	Planned or already had surgery
Ann	44	36	Married	Yes	Employed	No	Yes	Not a surgical candidate
Ian	26	23	Single	No	Employed	No	No (surgery not applicable)	No
Sam	25	17	Single	No	Student	Seizure-free	Yes	Yes
Trevor	36	35	Married	Yes	Employed	Yes	No (Surgery discussed only)	No
Bruce	60	48	Married	Yes	Retired	No	Yes	Not a surgical candidate
Craig	47	44/45	Married	Yes	Employed	Yes	No (Surgery not discussed)	No
Andy & family member	64	15	Married	Yes	Retired	No	Yes	Not a surgical candidate
Brian	60	4	Single	No	Retired	Seizure-free	Yes	Yes
Fred & family member	58	25–28	Married	No	Retired	Yes	No (Surgery discussed only)	No
Sarah & family member	20	10	Single	No	Student	Yes	Yes	Not a surgical candidate
Jim & family member	80	76	Married	Yes	Retired	No	No (surgery not applicable)	No
Faye	42	7/8	Married	Yes	Employed	Yes	Yes	No

practices, and perceptions of managing refractory epilepsy. The second – *Factors impacting referral practices and patient pathways* – demonstrates the impact of current knowledge and understanding on HCP

practice, and the importance of strong relationships between HCPs and with patients and families.

4. Theme 1: patient healthcare pathways and care experiences

The pathway of healthcare delivery for people living with refractory epilepsy is complex and nonlinear according to different healthcare sectors and professionals attending to patients' needs.

4.1. Diagnosis and identification of seizure type

The complexity and variability of seizure presentations and their severity can range from patients who have transitory periods of inattention, to those experiencing prolonged convulsions. In this study, patients who had had an initial convulsive seizure, presented at a hospital emergency department and were seen by a general neurologist at the time, and those with nonconvulsive seizures had initially contacted their GP due to the vagueness of their symptoms. At first presentation of a seizure, the consensus on usual practice among HCPs was to obtain a detailed history from the patient, conduct a physical examination, and then refer the patient for a variety of investigations and tests, undertaken either in a hospital or in the community setting. These investigations could include a computed tomography (CT) scan, a magnetic resonance imaging (MRI) scan, an electroencephalogram (EEG), blood tests. For patients with nonconvulsive seizures, such as 'generalized absences' (brief lapses in consciousness) or 'atonic' seizures (loss of muscle tone), there could be delays in diagnosis and treatment if the seizure was not identified as such. Bruce, for example, who was living with refractory epilepsy, highlighted how disparities in GP knowledge delayed his diagnosis,

Table 3
Characteristics of general practitioners' (GP) completing the survey, n = 20.

Characteristic of GP clinician	n	%
Gender		
Male	9	45
Female	11	55
Age groups (years)		
31–50	8	40
51–70	9	45
71+	1	5
No answer	2	10
Location		
Region 1 - urban	9	45
Region 2 - regional	6	30
Regional 3 - rural	5	25
Length of time practicing as a GP (years)		
0–5	2	10
6–10	3	15
11–20	3	15
21–30	6	30
31–40	3	15
41+	2	10
No answer	1	5
Sessions worked per week (1 session = 3–4 h)		
8 sessions or more	14	70
Less than 8 sessions	6	30
Specialist training in neurology		
No	20	100
Yes	0	0

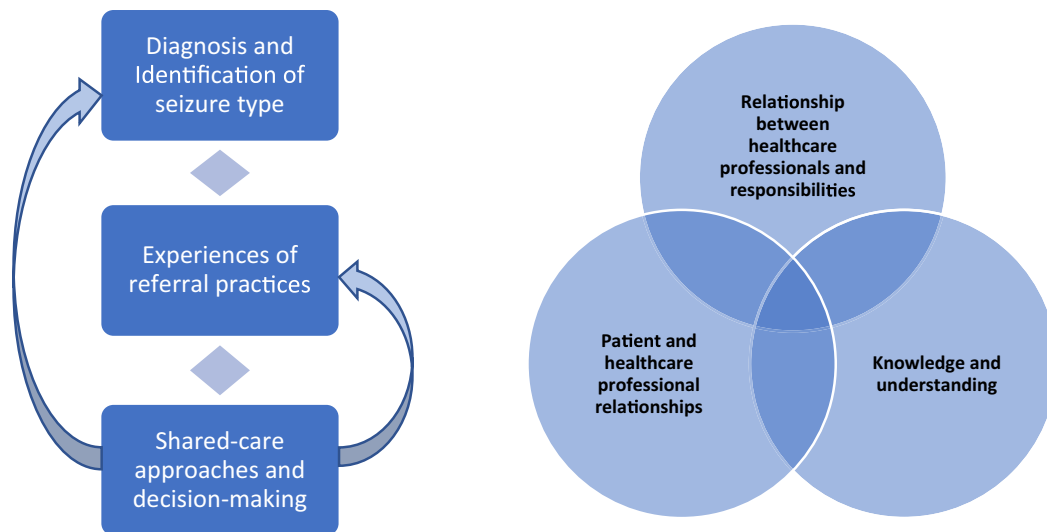


Fig. 1. Major themes and subthemes.

He (other GP) recognised it immediately, as soon as I said that I was having these butterflies in the stomach type feeling, the *déjà vu*, he (GP) said that they are all classic signs. I was disappointed that my regular GP, who is attached to that same clinic, was sending me for all these cardiac tests for that 12 months and not picking up on those things that I was telling him and not recognising that they were associated with epilepsy.

While Ann demonstrated a different diagnosis pathway,

I just randomly had a really bad seizure in the gym and really bashed up myself, and they thought a tumour had grown again, so I was rushed to hospital in an ambulance, spoke to the neurosurgeon, and then he put me on to (neurologist name) to treat me for the seizure.

In summary, the type of seizures and initial hospital or GP medical assessment can impact the timing of diagnosis and linked investigations. As highlighted in Ann's situation, a preexisting condition with an underlying risk of seizures can improve efficiency of diagnosis. Patients rely on HCPs' clinical knowledge and expertise to diagnose seizures, but challenges arise when HCPs are faced with a vague presentation or have limited expertise in this complex area.

4.2. Experiences of referral practices

As one epilepsy specialist noted there are 'no national guidelines' or 'set criteria' (ES2) for HCPs in Australia to follow regarding current referral practices for people diagnosed with refractory epilepsy. This limits the support available to GPs, general neurologists or epilepsy specialists, to guide referral practices. Guidelines, according to these HCPs, could assist with standardizing patient management and coordination of the referral process, to ensure patients are more promptly and consistently referred to epilepsy specialists.

From the survey, the three main reasons GPs refer patients to a general neurologist were as follows: 1) evidence of the first presentation of a seizure (15/19), 2) uncontrolled seizures (15/19), and 3) a patient experiencing worsening seizures (15/19) (see Fig. 2). Most GPs (15/19) referred a patient to a general neurologist or epilepsy specialist between one to six weeks following the patient's first seizure, but if the identification of seizures was delayed, they acknowledged that this could be a lot longer. Onward referral from a GP to a

general neurologist or epilepsy specialist was affected by: 'cost, waiting times' (GP3), 'patient can't travel' (GP15), 'patient preferences' (GP3), and 'lack of neurologist' (GP9), especially in rural and regional areas, where GPs themselves described their approach as 'closed books' (GP15), and commented that there are 'less services and (patients) have to travel/ miss work to see specialists to have tests done' (GP2).

To reduce waiting times, epilepsy specialists described how they only accept referrals from GPs within their local health district, having: 'a prime responsibility to manage them (patients) anyway in the hospital system because they're local, and they need neurology care' (ES1). They reported a three to four month waiting period for an appointment, even in the patient's own local health district. To reduce waiting times and travel from regional areas, some epilepsy specialists now host satellite clinics in a few areas in NSW.

Most patients reported being managed in the primary and community care setting for extended periods of time, with some experiencing a lack of information or choice of alternative treatment options. General neurologists validated the view of patients, explaining that the delays of up to four years were due to the complexity of diagnosing refractory epilepsy, excluding patients who were noncompliant with medications, or who indicated poor avoidance of seizure triggers, drug side effects, or intolerances. General neurologists' diagnoses of refractory epilepsy and/or their ongoing uncertainty of diagnosis then led to discussions with patients about referral to a TEC for more specialized investigations and potential assessment for resective surgery. However, general neurologists in this study explained that a referral could be delayed further when patients chose to transfer to other general neurologists. Several patients recalled many years with one general neurologist, to only then be referred to a TEC when they changed neurologist. An epilepsy specialist sensed that 'most doctors want to give it (treatment) a try before they want to move on' (ES2). However, the responses of patients (and families) could also be a barrier to TEC referral. Fred, for example, faced a dilemma in wanting to be better informed about his condition but not wanting, 'the medication withdrawn ... then getting back to being stable again,' and therefore delayed the referral himself.

General neurologists' referral practices and decision-making processes for referrals to a TEC are outlined in Fig. 3. Some general neurologists contacted a specialist directly for clinically complicated cases prior to putting forward a written referral. HCPs not attached to TECs were 'not quite sure how they (TECs) accept referrals' (GN2) and were unclear of any

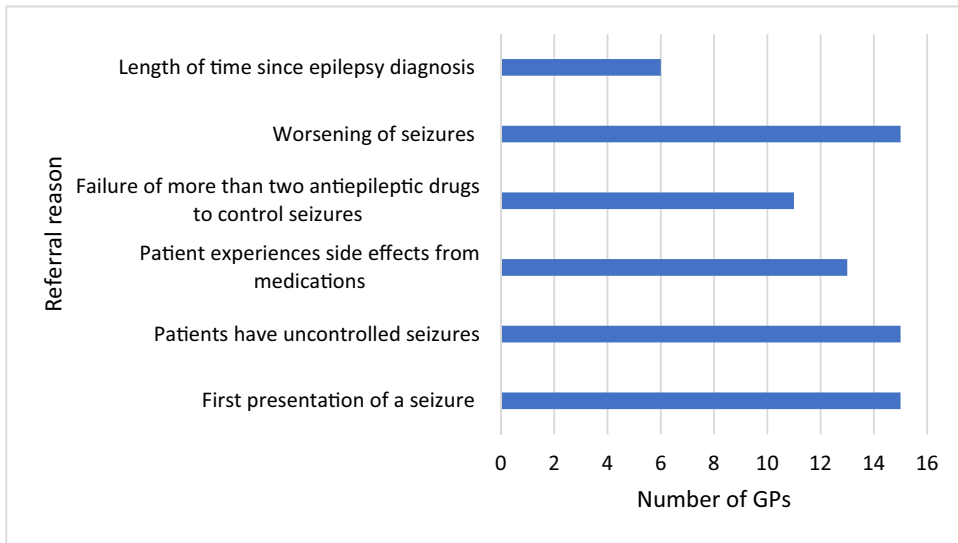


Fig. 2. Reasons for a GPs' decisions to refer to a general neurologist.

specific referral processes that they should follow to improve the process. The majority of HCPs in this study reported some challenges and even barriers to onward referral, particularly focused on the public health administration staffing and processes, and dissatisfaction with lengthy referral waiting times. Strong emotions were elicited, describing the 'organisational issue is irritating' (GN3), and frustration with 'poor communication' (GN3) practices between TECs, general neurologists and GPs. One GP reported their frustration at being excluded from 'postconsultation letters' (GP6).

Epilepsy specialists supported general neurologists' views that a major barrier was linked to resource constraints in TECs that impacted smooth referral, but also highlighted attempts to readdress this, for example, by outsourcing administration staff, ensuring that reports were sent within two weeks to GPs and general neurologists, and notes were dictated during appointments and given directly to patients. However, from the perspective of the epilepsy specialists, once assessment and treatment was complete, a big

problem was 'the accumulation of chronic care patients that will come here and won't go back to their referring doctor as they only want to see the specialist in the TEC system' (ES3). Ultimately, TEC clinics become blocked, creating overcrowding and an inability to cope with growing patient numbers. Subsequently, there are delays in receiving and processing new referrals, compounded by hospital resource constraints, such as lack of person-power or adequate finances to employ extra staff [22,41].

4.3. Shared-care approaches and decision-making

Patient care was viewed by HCPs 'as collaborative care' (GN3) (see Fig. 4). However, collaboration was not described as 'a formal shared care relationship' (GN1), but rather one that had 'no structure' (ES2). Importantly, HCPs recognized that patient-centered needs should be foremost in the shared-care agenda, though patients did not feel this was

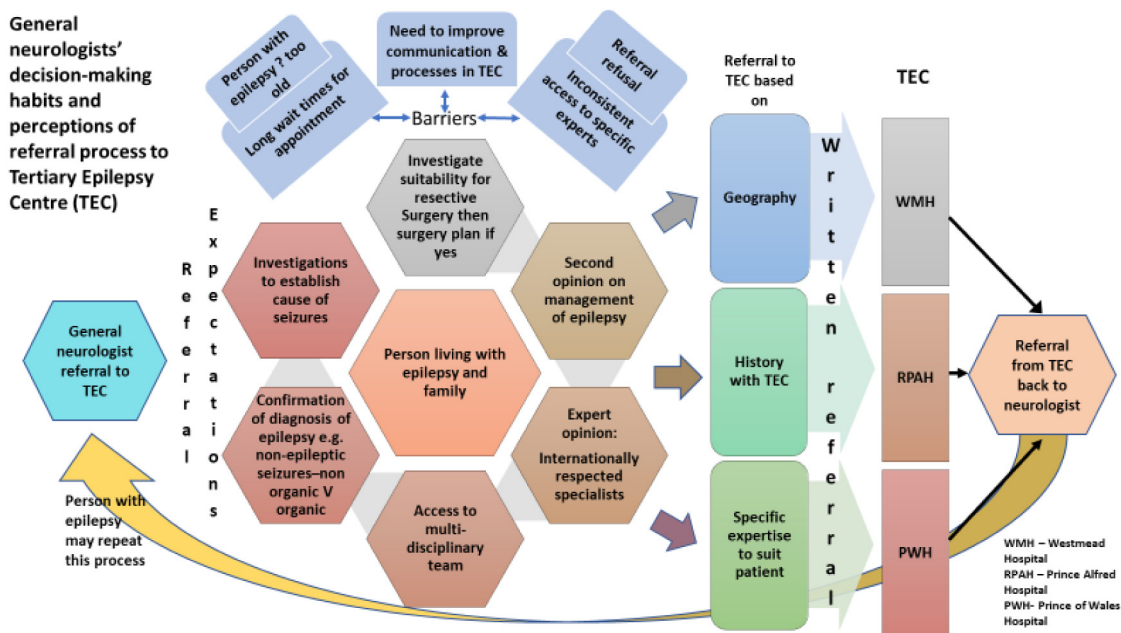


Fig. 3. Decision-making and referral between general neurologists and Tertiary Epilepsy Centre specialists (TEC).

happening. For example, Faye drew attention to unhelpful discussions with HCPs: 'sometimes I felt like I was put down ... I didn't know the terminology, like I was an idiot. I should have known what they were talking about.' Andy changed neurologists due to his 'appalling' manner but was 'taken aback' when 'very little medical information was passed on' even though requested by himself and his new neurologist.

Both general neurologists and epilepsy specialists considered the GP as the 'main manager' (GN2) of general medical needs in the community. The GP is, thus,

... pivotal. They're kind of like the gatekeeper, so if anything happens between when I see the patient ... the GP will be the one who has to do all the hard work, so they'll get in touch and email or ring (GN2).

In Australia, 'general neurologists would still be the people who treat refractory epilepsy more than speciality clinics ... because of access' (GN3). The general neurologist's role is to establish the 'right diagnosis first and foremost' (GN1), then aim 'to find the medications or group of meds that work to control seizures' (GN1). This is communicated to the GP by letter, then monitored by the GP and neurologist together (see Fig. 5). While 18 out of the 19 GPs surveyed reported that they received written information from neurologists after every appointment, one GP commented on this being 'variable,' with 'public clinics less reliable' (GP13).

Patients agreed that the GP is the HCP for 'any other issues' (Fred), for example, to 'get scripts' (Brian) and to support their mental healthcare needs, but the consensus among GPs, neurologists, and some patients like Ian was that general neurologists are 'pretty much the main guy in this (refractory epilepsy management)' (Ian). Neurologists believed some 'patients don't see their GPs that much. They seem to get dependent on the specialist care' (GN2). This was confirmed by many patients with refractory epilepsy, who preferred the neurologist as their primary contact for expert advice. This disparity between who is the 'main manager' of patients with epilepsy in the community and primary care context is an important issue in terms of misunderstandings and potential mismanagement of patients who need further investigation. The HCPs' ambiguity around who is responsible for patient management in this setting, is also shared with patients, and affected the HCPs' ability to work closely, communicate efficiently and share-care meaningfully.

Overall, GPs saw themselves as being in a supportive, secondary role to neurologists, both generalists and specialists. Fig. 6 outlines GPs' supportive roles as perceived by them, with prescribing medications as the top identified role (n = 18). All GPs surveyed prescribed AEDs, but from the patients' and neurologists' perspective this was mainly according to the direction of the neurologist. Most patients felt that while their GP wrote the prescription for epilepsy-related medications they relied on the general neurologist to manage medication changes. Ian explained this, saying, 'it's more like he's (GP) getting told what to do from (neurologist name)'. Nevertheless, patients and other HCPs confirmed that GPs have an essential role to play in the management of comorbidities for patients with refractory epilepsy. GPs in this study explained they prescribe antidepressant (12/20), antianxiety (8/20), and antipsychotic (7/20) medications.

General neurologists' decisions to refer to TECs were based on accessing 'a level of superiority, a level of training that is above that of a general neurologist' (GN3). However, patients and family members saw themselves as having an equally important role in the onward referral and decision-making process, but their involvement varied from being fully informed and supported in decision-making, to sensing a general disregard for their views and specific needs. The GPs' survey responses confirmed that patients were involved in the choice and timing of onward referrals, with their responses ranging from 'extremely' to 'moderately' involved (18/19). Neurologists recognized the importance of involving patients in the decision-making process, but felt it was their role to frame the discussions in such a way as to reduce potential resistance to referral, primarily associated with fear around 'brain surgery' (GN1) and temporary weaning off medications, even while monitored in hospital, as part of a presurgical evaluation or 'workup' (GN3). Consequently, they approached onward referral less directly, by saying things like 'it might be worthwhile getting a really truly expert opinion' (GN3). General neurologists believed by having a less-threatening discussion with patients, the likelihood of patients attending a TEC appointment was enhanced.

5. Theme 2: factors impacting referral practices and patient pathways

There are many different relationships involved in the movement of patients through the healthcare system. These relationships shape the effectiveness of collaboration and communication among HCPs and between HCPs, patients, and family members.

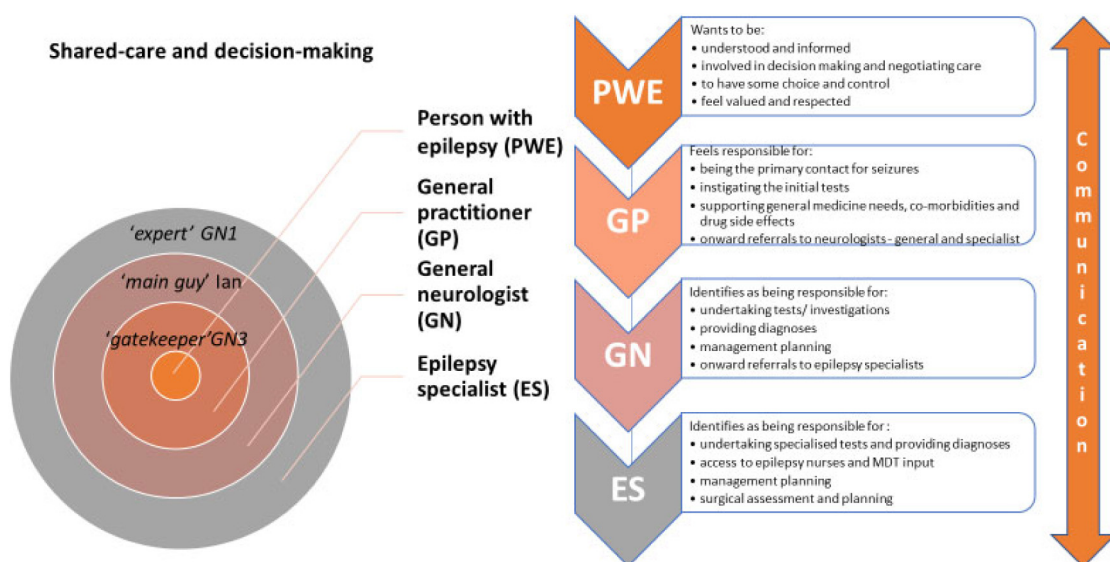


Fig. 4. Informal shared-care, and patient and HCP roles in decision-making.

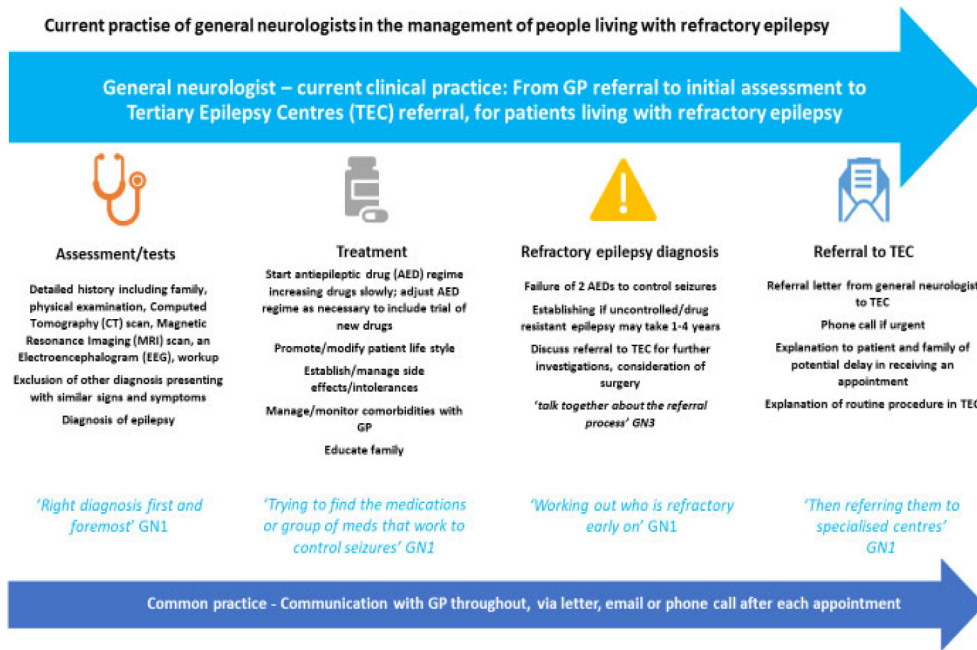


Fig. 5. Current practices of general neurologists from assessment to TEC referral.

5.1. Relationships between healthcare professionals, and professional responsibilities

There is an expert identity reserved for epilepsy specialists. This was confirmed by GPs and general neurologists regarding a patient referral 'to get a second opinion or a more expert opinion' (GN2). However, reputation, trust, and confidence between HCPs, and established 'good relationships' (GN3) ultimately influenced timing of referral and referral choices. There was a consensus among HCPs that 'If I know of, and am familiar with them (HCP), I will be more inclined to refer to them' (ES2).

This study identified an implicit agreement across HCPs that they cannot interfere in each other's clinical practice or judgment.

Consequently, communicating feedback or knowledge directly to a referrer, to help improve the standard of their referrals and reduce 'inappropriate referrals' (ES1), is not deemed appropriate and may jeopardize relationships with referrers. It was noted that this would appear to be questioning another clinician's expertise and would not be viewed favorably. Providing information in patient postappointment communications between HCPs was considered the best option, if this was done in a nonjudgmental way. It was preferable that communication and shared knowledge did not challenge professional clinical autonomy and followed the 'clinical etiquette' [42:693], where knowledge was provided between HCPs only when requested.

When an epilepsy management plan or any advice was communicated to another HCP, often the responsibility remained with the

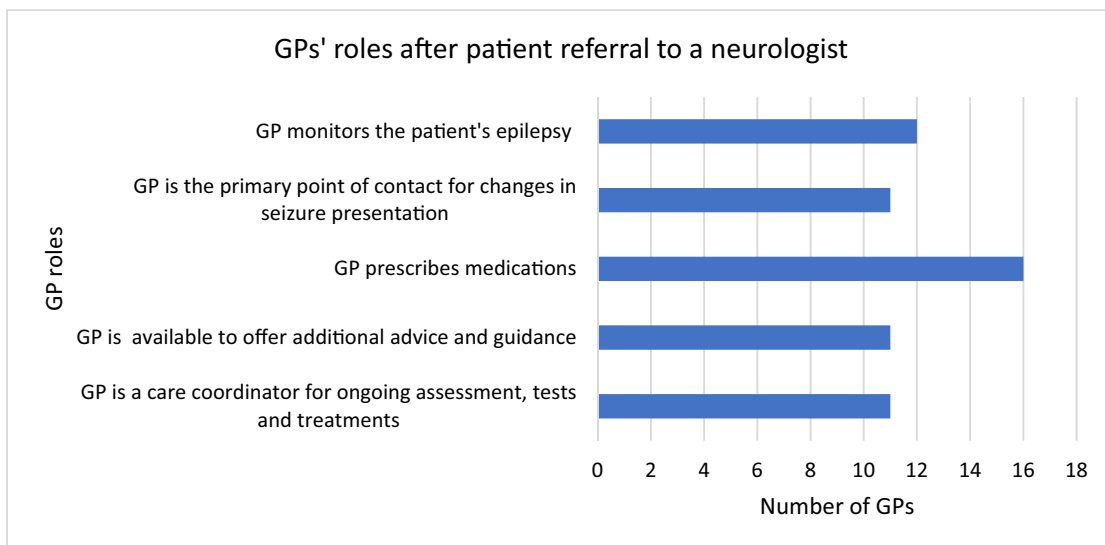


Fig. 6. GPs' roles after referral to general neurologist.

professional providing the plan, so professional identity would not be affected by another's involvement. However, this acceptance of another's treatment plan could also be perceived, on occasion as being 'more passive' (GN2), indicating disinterest in learning about the condition. In receiving expert advice, general neurologists and GPs accepted and followed the plan provided, especially if they trusted the individual specialist's expertise. The GPs generally followed what 'general neurologist advises' (GP17). General neurologists and GPs appeared aware of their clinical limitations concerning refractory epilepsy and acknowledged the benefit of patients being informed by an expert. However, there was an awareness from patients, general neurologists, and epilepsy specialists that some HCPs do not refer on, and do not change patient treatments, using the same medications for long periods of time.

5.2. Patient and professional relationships

Relationships between patients, family members, and HCPs can influence decision-making and patient throughput in the healthcare system, timely access to epilepsy specialist care, and knowledge of treatment options. Fig. 7 outlines some enablers and barriers identified by the patients in this research study, impacting the quality of the relationship between patient and HCP. Having a positive relationship created confidence and trust in the HCPs' ability to manage individual needs, which quickly dissipated when things went awry.

5.3. Enablers

Positive relationships with HCPs were described by patients as being based on the development of trust and confidence in their relationship, and the sense of being fully understood. As a result, patients felt valued and respected, which supported shared decision-making toward effective epilepsy management. Having a HCP who is understanding and responsive to need was described by Bruce in positive terms, who perceived his general neurologist as: 'a very approachable man and very knowledgeable', who embraced the whole medical and social experience. According to Bruce and others, this was deemed vital, especially at times of crisis or uncertainty over epilepsy treatment management plans, or when epilepsy complications arose.

Moving from pediatric to adult services was perceived as particularly challenging for patients who had established a good relationship with a pediatric neurologist, like Faye (see Fig. 8), who had lived with generalized seizures (tonic-clonic, convulsive) from about nine years old. The transition was made smoother with the support of the pediatric neurologist to find a neurologist with the 'right fit' (Faye). Bruce was at the complete opposite end of the scale to Faye (see below), suddenly having seizures at the age of forty-seven.

5.4. Barriers

Bruce shared an experience where he felt disempowered, and became confused by 'medical jargon', seeing few opportunities to ask questions or be listened to (see Fig. 8). This kind of situation led to a general sense among many patients that there was an overall disinterest in their condition. Patients also expressed a strong sense that, if the HCP was predominantly focusing on their medical management, he or she would fail to adopt a person-centered approach that included recognizing their social or psychological concerns. This could result in a medically driven, clinical outcomes-orientated relationship that might further disempower the patient.

Another area of substantial concern for patients was the manner adopted by HCPs and their lack of understanding about the confronting and complex situations faced by patients. Ann recalled, for example, that her specialist neurologist 'was quite rude. His bedside manner is appalling', which added to her overall distress going through a 'tortuous' and emotional five-day 'workup'. Ann felt that her specialist neurologist 'didn't respect – I mean, they should respect the patient. The patient knows what the patients go through'. This led to Ann receiving no further consultations with this specialist.

5.5. Knowledge and understanding

The overall lack of knowledge and understanding around epilepsy, especially refractory epilepsy, was a concern for many HCPs, patients, and families. Different perspectives on information sources and understanding are explored.

Enablers	Barriers
Supported/ shared in decision-making	Feeling misunderstood
'Approachable' (Sam)	Rude/abrupt communication, lack of communication
Communicating in 'layman terms'	Using medical jargon 'baffled me with medical terminology' (Bruce)
Respectful	Loss of confidence and trust
Personal recommendation increase confidence	Limited knowledge and understanding of epilepsy
Empathic	Failure to recognise signs and symptoms of epilepsy
Interest in personal experience	Disrespectful/ disconnected and disinterested
Responsive to need	Lack of interest in comorbidities
Knowledge of history/family and comorbidities	Changing HCPs
Choice and control	No choice and lack of control
Communicates well with other HCPs and family	Lack of understanding of the impact on the person and the whole family

Fig. 7. Enablers and barriers to patient relationships with healthcare professionals.

Faye	Bruce
<i>She (paediatric neurologist) said that she would put me in contact with a doctor and see how that goes, but if it didn't work out, come back to her, and she would refer. We'd get the right fit. So, she was awesome the way she helped ... Well, it was definitely scary. The first guy that she put me in contact with, he told me that it was all caused by my mother. He was a total idiot ... That was a reality check. Like going from having her (paediatric neurologist) so caring and so nice and then to a total idiot.</i>	<i>I suddenly have epilepsy at 47 years of age, I don't understand any of this, I have got to learn all about it, and I wanted the best care I could possibly get, and because of the referrals, how approachable these people were, they would take the time to explain things to you and not become frustrated with you because you ask too many questions.</i>

Fig. 8. Patients' quotes.

5.6. Views of general practitioners

Among the GPs surveyed, 88% said that they needed more information on epilepsy, and none had specific neurology training. Continuing Professional Development (CPD) was, according to 60% of GPs surveyed, the most common way they could obtain epilepsy information, followed by accessing information through journal articles (55%). Other opportunities for gaining information were professional conferences (20%), pharmaceutical agencies (20%), online courses (25%), and other approaches (20%), including getting information from the 'treating neurologist' (GP2), 'specialists' (GP4) and 'therapeutic guidelines' (GP1).

5.7. Views of neurologists, patients, and epilepsy specialists

Neurologists also identified themselves as useful sources of information for GPs. This view was shared by patients, who felt that GPs learned a lot from being part of a team managing their epilepsy, as Andy stated: 'it keeps him (GP) up to date'. However, one specialist commented that 'the average GP's knowledge about where they can get help is also not great' (ES1). It was also felt that HCPs could learn a lot from patients' experiences, which was deemed by Ian as particularly beneficial.

The first time going to see him (GP), it'd be like you know, an uphill battle, but after spending a lot of time with me and my case and everything, like he (GP) probably would have learnt a lot.

5.8. Epilepsy specialists' engagement with GPs

Attempts made by epilepsy specialists to engage with GPs, to offer training and support and to develop potential GP subspecialties in epilepsy, fell by the wayside. They described a lack of response and general disinterest among both GPs and primary healthcare networks to get more involved, resulting in training events not going ahead and the need to refocus on targeting individual referring GPs. For many HCPs, there can be an overwhelming number of lectures to attend during CPD, but for some, learning from the experts, through routine clinical practice is beneficial, as one epilepsy specialist stated over the years: 'I've never learnt from lectures, I've learnt from doing' (ES1).

5.9. Views on the use of international guidelines

According to the International League Against Epilepsy (ILAE) guidelines, a patient should be identified as having refractory epilepsy if seizure freedom is not achieved after trialing two AEDs [21,43]. However, according to this study's investigation, only

35% of GPs were aware of this definition, with 65% believing it was a failure of 1 AED (5%), or 3 AEDs (40%), or four or more AEDs (20%). General neurologists in this study reported that identifying someone who has uncontrolled or drug-resistant epilepsy may take between one and four years.

Furthermore, as an epilepsy specialist highlighted, general neurologists do not always communicate well to patients or know that the chance of success after trying two or three AEDs for seizure freedom 'is less than 10%, and in an appropriate population, the chance of success with surgery is 50–60%' (ES3). A general neurologist remarked that, at the mention of brain surgery, 'people panic' (GN1), and the conversation that follows needs to include an explanation of the journey and process involved, including selection criteria and risks. However, this conversation is not routinely undertaken in the primary and community healthcare setting and depends on the level of the HCPs' own knowledge and understanding. As a result, people appeared more inclined to refuse or delay referral to a TEC, feeling ill-informed.

6. Discussion

This study is unique in its application of mixed methods to examine primary and community neurology care contexts for diagnosis and referral of patients with refractory epilepsy in NSW, Australia. The paper provides insights into factors facilitating effective PCC and challenges and barriers that lead to what the authors have previously defined as 'convoluted pathways of healthcare delivery' for patients with refractory epilepsy, 'within an everchanging adaptive healthcare system' [44:2], from initial seizure presentation, to the transition through primary and community neurology, to an eventual referral to a TEC [22].

This study offers clear examples of PCC in the primary and community neurology context and at the interface with specialist services, such as being respectful and responsive to specific patient preferences, beliefs and needs, which supports SDM, in effect, the 'active two-way participatory collaboration' between HCPs, and patients and families [25:78]. However, it also illustrates the degree to which PCC is not routinely practiced, and the effect this has on SDM [25], with patients feeling uninformed, at times exacerbated by limited HCP knowledge, and disengagement from their care and decision-making. This conflicts with the understanding of collaborative and coordinated shared-care [23,45] and with the global aim to ensure that health outcomes are underpinned by integrated PCC [24,46].

Adopting an integrated PCC approach ensures 'individuals have timely access to safe and efficient quality health services that meet their life-course needs and are coordinated across a continuum of care' [24:87]. This can cultivate partnerships in shared-care

practices across healthcare to address the varied needs of people living with refractory epilepsy [8,9,13,18,19]. However, as this study has indicated, there are intraprofessional, contextual, structural, and physical boundaries that mitigate against collaboration, all of which continue to exist across healthcare settings, adding to the complexity of shared clinical practices in this field [47]. These boundaries are 'socially constructed demarcations' [48:32], which add to problems of healthcare professional competency and the 'mutual exchange of practices' [48:32], and can detract from knowledge-sharing.

The authors draw attention to three key areas from this study that together help account for delays in refractory patient identification, and for gaps in shared-care practices in NSW, Australia.

The first key area, effective, collaborative communication between HCPs and patients is central to 'building a therapeutic' dynamic relationship that allows patients to be informed and involved in SDM around their PCC needs and treatment options [49,50:38]. However, some patients in this study demonstrated dissatisfaction in the quality of relationships, which led to poor exchange of information [49]. For example, some HCPs paid limited attention to patients' social situation and experiences, leading to misinterpreted information, compounded by the HCPs use of unfamiliar 'medical terminology' [51:552].

According to Thapar and Roland, taking a non 'person-centered communication' [52:5] approach, can be a barrier to identification, diagnosis, and treatment of epilepsy as it impacts mutual understanding. Patients wish for more HCPs to consider their thoughts, experiences and ideas, and communicate in a way that reflects their needs. Failure to do so could result in patients' and families' misunderstandings around instructions, which can be perceived as noncompliance with treatment and advice, causing delays in onward referrals to epilepsy specialists, and additional anxiety and distress [50,51]. In this study, adopting a person-centered communication approach was associated with the patient's greater sense of value, satisfaction in care and more compliance in treatments.

Some patients in this study also reported what Dimopoulos-Bick and colleagues have termed an 'expert culture' [50:494], primarily dominating general neurologists' and epilepsy specialists' relationships with patients, making patients feel disempowered, and their needs and opinions disregarded in relation to their epilepsy management. This power imbalance exists between HCPs and patients, even though the 'principal enabler to SDM is having informational needs met at an appropriate level for the individual' [53:307], medical information should not be considered in isolation, and patients should be supported to convey their individual preferences and 'promote their self-efficacy' [53:307]. Enduring an unsatisfactory relationship with HCPs was not tolerated by some patients in this study, who terminated the relationship and went in search of HCPs that were responsive and empathic to their needs. Taking this action to ensure they received PCC necessitated, for some, seeing multiple HCPs and ongoing delays in management of their epilepsy, until they were satisfied with interpersonal relationships, and the HCP's expertise in epilepsy.

Further, patients reported greater satisfaction with their care when information and treatment choices were communicated in a way they could understand, their concerns were validated, and they were actively encouraged to participate in SDM, which are all fundamental to good 'doctor-patient communication' [49:38], as supported by the literature [54]. Adopting a collaborative communication approach with patients is therefore important for timely, appropriate referrals and treatment interventions. These should essentially be underpinned by a strong interpersonal relationship with a HCP, based on trust and confidence in the HCP's expertise to manage epilepsy effectively, while being respectful

and empathic to patients' needs, and treating them in accordance with their wishes.

The second key area highlighted the importance of shared-care practices being underpinned by strong clinical knowledge and understanding. It is well documented in the literature that identifying, diagnosing and managing refractory epilepsy is complex and involves specialist knowledge of the area [8]. This is simply beyond the scope of some HCPs' current knowledge and working practices in the primary and community healthcare setting. Ultimately, as Byrne et al. also noted, this requires a 'collaborative practice' [24:87,55,56]. Although our study disclosed how 'pivotal' (GN2) GPs are considered in the management of epilepsy, they were also seen to be the HCP group with the most limited expertise, also lacking knowledge of 'newer diagnostic and therapeutic measures' [57:550]. This view concurs with other research inside and outside the epilepsy field [51,55]. However, in this study, GPs acknowledged their gaps in knowledge and management of epilepsy, and as a result their decision not to take the sole responsibility for care, favoring direction from HCPs with more expertise, supports this [24]. However, taking this approach to epilepsy care and management was viewed poorly by some patients and other HCPs, who described it as taking a passive rather than an active practice role in patient care. Thapar and colleagues noted the importance of GPs accepting a 'key role in management' and said that patient health outcomes improve if the GP takes a 'special interest' in the condition [52:4]. This resonated with patients living with epilepsy, in relation to their mental health, who, in accordance with Minshall and Neligan report more positive outcomes when GPs take on the primary management of their care [55]. But conversely, this study shows that when patients lack confidence in their GP's clinical knowledge and expertise, they often attempt to bypass the GP and access general neurologists or epilepsy specialists for all or most epilepsy-related care.

However, patients' timely access to specialist advice also seems to be dependent on the individual HCP, rather than the routine practice of HCPs, highlighting individual inconsistencies and potential tensions in clinical practice roles. Although patient choice of HCP could be considered a way of delivering PCC, it creates a service model that is expert-dominated, which is neither cost-effective nor efficient in the use of healthcare resources, and based predominantly on patients' unmet needs in the primary care setting (and, in some instances, in the community care settings too, as some general neurologist failed to respond to patient needs).

The ILAE have developed guidelines [58] that reclassify epilepsy, and offer details of how to respond to patients with epilepsy, but according to HCPs in this research, and resonating with the views of Sharobeam et al. [57], many GPs remain unaware of these changes, which affects their accuracy in communicating with patients and referrers, and ongoing referral delays, or referrals being deemed 'inappropriate' (ES1).

In addition, this research has revealed that there are no established, formal shared-care practices in refractory epilepsy. This is exacerbated by a lack of clinical practice guidelines (CPG) for epilepsy care in Australia. The CPGs could help bridge the gap between different levels of clinical knowledge among HCPs; they contain evidence-based recommendations that can optimize patient care and improve quality of care [56]. Consequentially this could facilitate better clinician communication, more timely referrals, and formalized shared-care practices, to 'increase patient throughput' [7:5] to presurgical assessment. The ILAE taskforce, containing 14 international members, have provided expert guidance on the methodology for developing quality epilepsy-related CPGs; however, international uptake has been challenging as a consequence of poor implementation strategies being adopted [56]. Epilepsy-related CPGs have predominantly been developed across

Europe and North America, but issues have been identified around quality, priority areas for inclusion and currency, which need addressing [21].

The third key area considered the impact of professional responsibilities on integrated shared care. It has been said that building stronger relationships among HCPs is a way of transforming 'fragmented practices', but that this 'requires active change management to create spaces for communication and to build the alliances required for integrated PCC' [24:91]. While more extensive integration of care between medical practitioners and professionals allied to health is beyond the remit of this paper, it has nevertheless been made clear that current medical practices do not support shared or integrated care between primary, community and tertiary care sectors across the care continuum. Intraprofessional boundaries and clinical hierarchies contribute to patient experience of service fragmentation, which resonates with other research [24,48]. Furthermore, the focus in this study on epilepsy knowledge, and the limited opportunities for generalists to engage and integrate with specialists in mutual knowledge-sharing, has been described by others as 'impeding knowledge flow' [59:813].

Peterson et al. describe the GP as the 'missing link' [60:132] in interdisciplinary PCC for patients living with epilepsy, but in this research, GPs are believed by some to be missing in action as an active healthcare provider, based on their lack of clinical knowledge and limited sense of responsibility in epilepsy treatment, which concurs with other research [42]. Nevertheless, crossing intraprofessional boundaries to improve 'knowledge flow' [59:813] to nonepilepsy specialists is negatively affected by the need expressed by some medical clinicians to retain clinical autonomy and specialism, which, while an important part of professional identity, ultimately hampers collaborative clinical practice. Although deferring to the specialist knowledge preserved clinical autonomy, it could also provide a learning opportunity for other HCPs to witness patient experiences of interventions or learn from the expert practitioner [42]. This research has highlighted the careful consideration that is being adopted in this vein by all HCPs when they communicate with each other. They are clearly being careful not to compromise clinical autonomy by commenting on, judging or interfering with each other's practice. Adopting this kind of professional etiquette to ensure clinical autonomy is common across the medical profession [42], but this study highlights how, in the epilepsy context, this can impede effective communication, education and training, and opportunities for changing clinical practice to be more PCC.

7. Strengths and limitations

Our mixed methods study is one of the few in Australia or internationally, to explore identification, referral and care pathways for people living with refractory epilepsy. Important knowledge was gained on the implicit rules around how HCPs interact and communicate with each other, which is relevant to improving epilepsy care and changing clinical practice. However, a major limitation of the study is that it only recruited from within the Sydney region, recruiting a small sample (as is the practice in qualitative research), and therefore, it does not represent patients and neurologists' perspectives and experiences of healthcare, living in regional and rural areas, or areas outside of NSW, nor does it consider a wide population group. Although survey data were obtained from GPs across urban, regional and rural areas in NSW, the numbers of responses were limited. For a more comprehensive representation of epilepsy referral and care pathways, other healthcare professionals working within the area of epilepsy, across the whole of NSW, and wider populations beyond NSW could be usefully engaged in future studies.

8. Conclusion

This study makes an important contribution to understanding various stakeholders' experiences and views on challenges and barriers in the management of refractory epilepsy. The evidence demonstrates the need for HCPs across the primary, community and tertiary healthcare sectors to collaborate and commit to new ways of working together, driven by further knowledge and information on the disease and its treatments, to better coordinate the management of care for patients with refractory epilepsy. Current barriers include limited PCC models, or SDM, and limited refractory epilepsy education within primary and community contexts. Endeavoring to upskill healthcare professionals and ensure greater knowledge and understanding of this highly disabling disease has the potential to reduce delays to patient disease identification and enhance speedier referral pathways and processes. Exploring ways to break down professional boundaries and build alliances across sectors may also optimize shared-care practices and information sharing. Ongoing misconceptions of HCP roles and responsibilities are clearly obstructing progress in integrated care. Investing in the development and successful implementation of epilepsy-related CPD and clearer guidelines in routine clinical practice could be an effective way to influence a more positive patient experience and guide collaborative and coordinated shared-care HCPs to actively involve patients in more integrated, shared-care.

Declaration of Competing Interest

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

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Appendix 1. GP epilepsy referral survey

Welcome

As a general practitioner (GP) and member of the Sydney North Primary Health Network or Hunter New England Central Coast Primary Health Network, you are invited to complete this survey examining GP's views and practices on epilepsy, including refractory (drug-resistant) epilepsy, treatment and care. Approximately 1/3 of people living with epilepsy are resistant to antiepileptic drug treatment. The anonymous survey will take approximately 10 minutes to complete. This research is being led by Professor Frances Rapport, at the Australian Institute of Health Innovation, Macquarie University (frances.rapport@mq.edu.au, 9850 2320). The results of the study may be published in a final study report, and we may present anonymized data in peer-reviewed journals, and at presentations at academic conferences. We may also use data for teaching purposes and to develop research methodologies.

This study has been approved by the Northern Sydney Local Health District HREC (HREC LNR/18/HAWKE/95). Complaints may be directed to the Research Office on Level 13, Kolling Building, Royal North Shore Hospital, St Leonards NSW 2065. Phone 02 9926 4590 | email NSLHD-research@health.nsw.gov.au

Consent by Ticking 'I agree to participate' you are providing your consent for the research team to collect and use the information you provide for the study. You may withdraw your consent to participate at any time, by discontinuing the survey.

I agree to participate (1)

Q1 What is your age (in years)? _____

Q2 What is your gender?

- Male (1)
- Female (2)
- Other (3)

Q3 How many years have you been working as a GP? _____

Q4 Have you had any specialist training in neurology?

- Yes (1)
- No (2)

Q5 How many sessions (of between 3 – 4 hours) do you work per week?

- 8 sessions or more (1)
- Less than 8 sessions (2)

Q6 What is the postcode of your general practice? _____

Q7 How many other clinicians do you share your practice with? _____

Q8 How many of your patients have a diagnosis of epilepsy?

- None (1)
- 10 patients or less (7)
- Between 10-30 patients (8)
- 30 or more patients (9)
- Don't know (6)

Q9 How often do you see a patient with a diagnosis of epilepsy?

- Never (1)
- Once or twice a year (2)
- Once or twice every three months (3)
- Once or twice a month (4)
- Once a week (5)
- More than once a week (6)

Q10 What percentage of your patients diagnosed with epilepsy are adults/children?

- Adults, aged 18 years and above (please specify the percentage) (1) _____
- Children, aged under 18 years (please specify the percentage) (2) _____

Q11 Currently, for what percentage of epilepsy patients do you take on the following roles in epilepsy management?

I am the sole healthcare professional for epilepsy treatment (_____)

I play a supportive role to a general neurologist (_____)

I play a supportive role to a hospital specialist neurologist (_____)

I manage epilepsy related co-morbidities such as depression and anxiety (_____)

Q12 Which epilepsy-related medications do you prescribe for your patients who are diagnosed with epilepsy? (please select all that apply)

- Anti-epileptic drugs (AED) (1)
- Anti-depressant medication (2)
- Anti-anxiety medication (3)
- Anti-psychotic medication (4)
- Other medication (please specify) (5) _____

Q13 What do you understand to be the definition of refractory (drug-resistant) epilepsy? Note: A failure to respond to an AED (anti-epileptic drug) is a failure to control seizures.

- Failure of 1 AED (anti-epileptic drug) (1)
- Failure of 2 AEDs (2)
- Failure of 3 AEDs (3)
- Failure of 4 or more AEDs (4)
- Don't know

Q14 Where do you get your information about treatment for epilepsy, including refractory epilepsy? (please select all that apply)

- Continuing Professional Development events (please specify) (1)

- Professional conferences (2)
- Pharmaceutical agencies (3)
- Online courses (4)
- Journals (5)
- Other (please specify) (6) _____

Q15 How often do you feel you need more information about epilepsy treatment, including refractory epilepsy to ensure evidence-based care?

- All the time (1)
- Most of the time (2)
- About half the time (3)
- Sometimes (4)
- Never (5)

Q16 When a patient first reports having seizures, what steps do you go through to diagnose or investigate the condition?

Q17 If you prescribe AEDs for epilepsy patients, what are some of challenges you have encountered? (please select all that apply)

- Side effects (1)
- AEDs provide ineffective control of seizures (2)
- Drug interactions with other medications (e.g. oral contraceptive pill) (3)
- Compliance (4)
- Other challenges (please specify) (5) _____
- I do not prescribe AEDs (6)

(continued).

Q18 What do you feel are your patients' key concerns about managing their epilepsy?

Q19 Do you feel these key concerns would differ between patients who live in urban, rural and remote areas?

Q20 Under what circumstances do you refer patients to a general (community) neurologist, in regard to epilepsy care? (please select all that apply)

- At first presentation of a seizure (6)
- If patients have uncontrolled seizures (1)
- If patients experience side effects from medications (2)
- Failure of more than 2 AEDs to control seizures (3)
- Due to worsening of seizures (4)
- Length of time since epilepsy diagnosis (please specify) (5) _____

Q21 Under what circumstances do you refer patients to a epilepsy specialist neurologist (in a hospital)? (please select all that apply)

- At first presentation of a seizure (6)
- If patients have uncontrolled seizures (1)
- If patients have side effects from medications (2)
- Failure of more than 2 AEDs to control seizures (3)
- Due to worsening of seizures (4)
- Length of time since epilepsy diagnosis (please specify) (5) _____

Q22 What factors influence your choice of a general neurologist for referral? (please select all that apply)

- Travel distance for patients (1)
- Reputation of the neurologist (2)
- Personal knowledge and previous working relationships with the neurologist (3)
- Reputation and personal knowledge of the clinic or hospital (4)
- Appointment waiting times (5)
- Other factors (please specify) (6) _____
- I don't refer to a general neurologist (7)
- I don't know (8)

(continued).

Q23 What factors influence your choice of a specialist neurologist for referral? (please select all that apply)

- Travel distance for patients (1)
- Reputation of the neurologist (2)
- Personal knowledge and previous working relationships with the neurologist (3)
- Reputation and personal knowledge of the clinic or hospital (4)
- Appointment waiting times (5)
- Other factors (please specify) (6) _____
- I don't refer to a specialist neurologist (7)
- I don't know (8)

Q24 What are the barriers to onward referral of epilepsy patients? (please select all that apply)

- Don't know who/where to refer to (1)
 - Not confident about the reputation of the clinic or hospital (2)
 - Not confident about the reputation of the specialist (3)
 - Patient concerns (please specify) (4)
-
- Other barriers (please specify) (5) _____

Q25 How long do you wait before you refer a patient for specialist epilepsy care (e.g. average number of years with diagnosis of epilepsy before referral)?

- Weeks (please specify how many weeks) (2) _____
- Months (please specify how many months) (3) _____
- Years (please specify how many years) (4) _____
- Other (please elaborate) (5) _____

Q26 How involved are your patients generally in the choice and timing of onward referrals?

- Extremely involved (1)
- Very involved (2)
- Moderately involved (3)
- Slightly involved (4)
- Not involved at all (5)

Q27 How frequently does the neurologist (community or hospital) communicate with you after you have referred a patient on to them?

- Never (1)
- Only after the patient's first specialist appointment (2)
- After every specialist appointment (3)
- Other (please specify) (4) _____

(continued).

Q28 After patients are referred to a neurologist, what is your role in epilepsy treatment and care? (please select all that apply)

- I'm a care coordinator for ongoing assessment, tests and treatment (1)
- I'm available to offer additional advice and guidance (2)
- I prescribe medications (3)
- I'm a primary point of contact for changes in seizure presentation (4)
- I monitor the patient's epilepsy (5)
- Other (please specify) (6)

Q29 Are you aware of resective brain surgery as a treatment option for refractory epilepsy?

- Yes (1)
- No (2)

Q30 What are your perceptions of surgery in refractory epilepsy? (please specify high or low)

- Likelihood of seizure control (1) high low
- Risk of complications of surgery (2) high low
- Likelihood of reduction in AEDs (3) high low

Q31 Do you ever discuss brain surgery with epilepsy patients?

- Yes (1)
- No (2)

Q32 If so, who initiates the conversation?

- I do (1)
- The patient does (2)
- Both. I have brought up brain surgery with some epilepsy patients, and other epilepsy patients have raised the subject with me. (3)

Q33 Do you have any other comments or suggestions about improving the treatment and referral process for patients with refractory epilepsy?

Q34 Are you willing to be contacted to participate in further data collection, to help us better understand your responses to this survey, and further discuss your views about refractory epilepsy treatment and referral? Your contact details will not be linked to your response to the survey.

- Yes, I am willing to be contacted to participate in further data collection (1) Please email Professor Frances Rapport (details below)
- No, I am not willing to be contacted to participate in further data collection (2)

End of survey

Thank you for your responses to this survey.

For more information and if you want to attend a focus group, please contact: **Professor Frances Rapport at frances.rapport@mq.edu.au**

(continued).

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