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Patient perceptions of the referral of older adults to an epilepsy clinic: Do patients and professionals agree who should be referred to a specialist?

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ABSTRACT

The aim of this study was to establish whether older patients concurred with previously reported staff perceptions of why older adults may be underrepresented in epilepsy clinics. Fifteen interviews with older patients provided support for four of seven key factors previously suggested by professionals as leading to underreferral of older adults: unclear referral pathway, complex differential diagnosis, gaps in referrer knowledge, and the length of time since onset. However, the patients interviewed did not report that patient difficulties accessing the hospital, patient reluctance to attend clinics, or the particular characteristics of older patients (knowledge, awareness, and willingness to ask for help) made it less likely that older adults would want to attend a specialist epilepsy clinic. While recognizing the limitations of the study, particularly in relation to the number of participants, we believe that it provides valuable further insights into the age-bias apparent in referral patterns to specialist epilepsy services. Of particular concern are professional assumptions regarding older patients' willingness to attend appointments and about the impact of seizures on the life of an older adult.

1. Introduction

The risk of requiring treatment for epilepsy increases steadily with age in adulthood [1,2], and the number of older adults with epilepsy has been growing as life expectancy has increased [3]. A recent review highlighted that, despite this increase, there is a dearth of research on this patient group, and there are also gaps in service provision [4].

Prior work by our team exploring whether a specialist epilepsy service provides equitable access to patients with epilepsy regardless of age indicated that older people are less likely to be referred to specialist neurology services than younger adults, raising the possibility of inadvertent age discrimination [5], with number dropping consistently from age 50. Further, we reported that professionals (potential referrers from other hospital departments and primary care, together with neurologists and epilepsy nurses) suggested seven factors which may contribute to the underreferral of older adults. These were the following: patient difficulties accessing the hospital; patient reluctance to attend epilepsy clinics; complex differential diagnosis; gaps in referrer knowledge; the length of time since the onset of the seizure disorder; particular characteristics of older patients (knowledge, awareness, and willingness to ask for help); and an unclear referral pathway [6].

These views suggest that referrers may make judgements regarding the appropriateness of referral based on age-correlated factors (such as ease of traveling to hospital and the prioritization of seizures versus other coexisting conditions), and that there is a need to provide services via a different model if all patients, regardless of age, are to gain access to specialist epilepsy care. While the judgements made by health care professionals may well be justifiable on clinical grounds, our findings were consistent with the interpretation that inappropriate age discrimination, based on assumptions of older patients' wishes and priorities, is widely prevalent among the interviewees whose views we described in this study.

Of particular concern are potential assumptions regarding older patients' willingness to attend appointments and about the impact of seizures on the life of an older adult. The aim of the study reported here was to establish whether older patients concurred with the previously reported staff perceptions of why older adults may be underrepresented in epilepsy clinics to determine whether the assumptions made by health care professionals about the thoughts and wishes of older people with epilepsy were correct.

2. Method

Semistructured interviews using a predefined interview schedule were conducted between March and September 2012. In order to avoid leading questioning, patients were not asked specifically about the factors identified by professionals. Interviews lasted for 30 min to 1 h and were undertaken by an experienced researcher (LB) at the

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patient's home, at a general practitioner surgery, or by telephone where the patient preferred. Participants were purposively selected to be representative in terms of age, gender, and time since diagnosis. An inclusive definition of "older people" including those aged 50 and above was adopted to reflect the gradual decline in use of specialist epilepsy services from that age [5]. Potential participants were identified using local knowledge and networks (including Epilepsy Action and local GPs), with an invitation letter sent by the first author. Ethical approval for the study was granted by the local NHS Research Ethics Committee. All participants gave informed consent prior to data collection.

All interviews were audio-recorded and transcribed verbatim. The data were analyzed using NVivo, and thematic analysis was undertaken to identify recurring views and opinions [7]. Initial data analysis, undertaken by the first author, consisted of line by line reading of the transcript and assigning sections of data to a particular idea or theme. Emerging themes along with anonymized data were discussed with the rest of the research team to agree on categories and subcategories. Data assigned to each theme were reviewed to ensure consistency, with particular attention to any negative instances or variance of opinion. Illustrative quotes were selected for use in this report on the basis that they were representative of the views expressed by a range of participants. There has been minor editing of some quoted extracts to achieve clarity of meaning.

In the analysis, data from the interviews carried out with older adults with epilepsy for this study were compared with the findings of our previous study using a similar methodology but focusing on health care professionals [6].

3. Results

We interviewed fifteen older patients aged between 49 and 84 (median age: 67), including seven males and seven females (Table 1). Of these, five were currently under specialist care for their epilepsy, and seven had active epilepsy (seizure within the last 12 months). The median duration of their seizure disorders was 12 years (range: 2–67/"lifelong"). Details on the professional participants previously interviewed have been reported separately [6].

Older patients reported four of seven key factors previously suggested by professionals as leading to underreferral of older adults: gaps in referrer knowledge, complex differential diagnosis, unclear referral pathway, and the length of time since onset. However, no respondents felt that patient difficulties accessing the hospital; patient reluctance to attend clinics; or the particular characteristics (knowledge, awareness, and willingness to ask for help) of older patients influenced their preferences or behavior in response to referral.

Table 1
Details of interviewees.

Patient number	Age (years)	Gender	Currently under specialist care	Ever seen a specialist	Seizure within last year	Epilepsy duration (years)
1	84	M	Y	Y	Y	3
2	70	F	Y	Y	Y	>30
3	76	M	N	Y	N	12
4	56	F	Y	Y	Y	43
5	61	F	Y	Y	Y	4
6	69	F	N	Y	N	56
7	72	F	N	Y	N	5
8	78	F	N	Y	Y	10
9	59	M	N	Y	N	8
10	66	M	Y	Y	Y	10
11	71	F	N	Y	Y	63
12	67	M	N	Y	N	67
13	49	M	N	Y	N	15
14	57	F	Y	Y	Y	21
15	54	F	Y	Y	Y	2

3.1. Referrer knowledge

Concern over poor referrer knowledge was reported as one reason why older patients may not be referred to specialist clinics in the previous study with professionals [6]. Many participants were in agreement, reporting a lack of faith in their general practitioner (GP) regarding epilepsy knowledge: ["*I have not got a great deal of faith in GPs when it comes to my condition actually. Well they have got so many things to cover. They are a general practitioner when it comes down to it but then that's exactly what they do.*" (PT10)], ["*I'm not sure about GPs' ability overall with epilepsy… in something as complex as epilepsy… you know GPs don't actually know enough about epilepsy to advise in any meaningful way.*" (PT9)]. In addition, one patient reported a concern over inappropriate treatment in primary care: ["*I did have tablets for eight years and they were the wrong tablets. It was [neurologist] that found out that they were the wrong tablets that had been given me. So they perhaps could have helped me better, but didn't.*" (PT8)].

3.2. Complex differential diagnosis

Previously, practitioners reported the presence of other illnesses as presenting challenges for the diagnosis (and that diagnostic uncertainty might lead to cause doctors not to refer patients to a specialist service) [6]. Most patients concurred with practitioners: ["*There was an awful lot of shunting round different departments at the beginning you know. I don't know what it was really. It was kind of, I seemed to end up in just about every single department in the hospital, thinking what the heck is this?*" (PT9)], ["*I think it was a kind of the jury is still out on whether it was a stroke, a heart attack or an epileptic seizure.*" (PT7)]. However, it was acknowledged that diagnosis was difficult, and that other conditions had to be "ruled out": ["*But I mean it is such a difficult thing to pin down. Then I had breathing tests which didn't work very well. You know maybe that is a common experience. What surprised me was how long it took to sort of because there were so many things that could actually be causing fits. I think they are quite careful before you get a formal diagnosis.*" (PT6)].

3.3. Unclear referral pathways

Practitioners previously described the referral pathway for older patients as often being complex, with some uncertainty regarding roles and responsibilities for care provision and referral to a specialist service [6]. This view was also reflected by many patients who commented on the initial referral being inappropriate: ["*Is it a breathing problem, is it a chest problem. I don't know, I just seemed to be referred around quite a bit.*" (PT9)], although perhaps unsurprisingly, they had no suggestions as to how referral could be better managed: ["*But I don't know. I am not sure what they could do, or what they could offer.*" (PT12)]. The complexity of the pathway is likely to be related to the coexistence of conditions as discussed above.

3.4. Time since onset

The fact that the condition could be longstanding and well-controlled in older patients was mentioned by professionals as potentially contributing to lower referral rates [6]. Patients with longstanding conditions agreed: ["*As you get older you think I have had it this long I think I know what I am doing.*" (PT14)]. There was also agreement that as patients become confident in managing their condition, they became less likely to seek services: ["*I suppose after sixty seven years I have got so used it…. I feel as though my life will continue now in a good way and that I won't need any advice.*" (PT12)], although patients also felt that their experience would give them confidence to ask for the services they needed: ["*I have had this condition for quite a long time and I have made it such that I know a fair bit about the condition and if I don't think I am*