Seizure 22 (2013) 472–475

Contents lists available at SciVerse ScienceDirect

Seizure

journal homepage: www.elsevier.com/locate/yseiz

Short communication

Epilepsy health consumer groups and charities; How representative of patients are they? The results of a pilot study

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ARTICLE INFO

Article history:
Received 11 June 2012
Received in revised form 23 September 2012
Accepted 25 September 2012

Keywords:
Epilepsy
Service user
Patient involvement

ABSTRACT

Purpose: In the United Kingdom all health care providers are encouraged to consult with user groups. The submissions of charities and patient advocacy groups to NICE and SIGN are considered reflective of the patient groups they purport to represent, yet little is known about how representative they are. This pilot study was designed to ascertain how many patients attending a hospital based epilepsy clinic were members of such advocacy groups.
Methods: Patients were asked to complete a brief 9-question questionnaire before they left the clinic.
Results: One hundred and twenty-five questionnaires were distributed, of which 101 were returned. Seventeen percent of patients were members of advocacy groups, with several being members of more than one charity/group. Only seven percent of the respondents had ever been contacted by an advocacy group to canvass their opinions. Seventy percent of patients questioned stated they thought a frank discussion with their physician, or specialist nurse was more likely to influence patient services. Patients with long duration of disease and taking multiple anti-epileptic drugs were more likely to be members of charity/advocacy groups.
Conclusions: As patient charities in the UK are often in receipt of public funds, and actively seek to influence public policy this raises the question of whether they should be required to consult more widely with the people they claim to represent.

1. Introduction

Health consumer groups (HCG) are a diverse group of voluntary organisations promoting the interests of patients and carers through a variety of means. They have proliferated rapidly in the last 30 years.[1] Although often small their impact on the organisation of health care is increasing, with the UK government strongly encouraging the National Institute for Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN) to incorporate the views of patient representatives into their discussions and recommendations. Both NICE and SIGN issue guidelines that determine practice in the United Kingdom, and are influential around the world. Professional members of these bodies are recruited because of their qualifications, experience and demonstrable expertise in their chosen field. Patient representatives who sit on these bodies, however, do not have to provide any evidence of how representative they are of the generality of patients suffering from the condition under scrutiny. The authors are unaware of any systematic examination of how many of our patients with epilepsy are members of patient representative groups, or how many of our patients have been consulted by such groups. Such an examination is timely as SIGN is about to revisit its guidelines on epilepsy, and NICE published new guidelines for epilepsy in 2012.

2. Methods

The study was undertaken between March and August 2010 in the Epilepsy Clinic in the Department of Clinical Neurosciences at the Western General Hospital Edinburgh. A total of 125 questionnaires were distributed and 101 were returned completed before the patient left the department. In the case of people with learning disabilities their carer/support worker was asked to help them complete the questionnaire.

The questionnaire comprised 7 questions which could be answered with a tick. The eighth question required the patient to state an order of preference. A free text box was included at the end

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http://dx.doi.org/10.1016/j.seizure.2012.09.016

Table 1

A		B	
Self reported employment status	Membership of HRG	Median years duration of epilepsy (interquartile range)	Membership of HRG
59 unemployed	11 members of HRG	12 (10–23)	Member ($N=17$)
23 full time employed	1		
14 part time employed	5	16 (6–22)	Not a member ($N=84$)
5 students	0		
Chisquare $P=0.06$		Mann–Whitney $P=0.28$	

C		D	
Self reported disability status*	Membership of HCG	Number of AEDs	Membership of HCG
Disabled $N=59$	$N=12$	No more than 2 $N=64$	$N=5$
Not disabled $N=30$	$N=2$	Three or more $N=37$	$N=11$
Chisquare $P=0.8$		Chisquare 0.003	

* 12 people did not reply to disability question.

of the questionnaire for comments. The study was sanctioned by the Lothian Research Ethics Scientific Office.

3. Results

A total of 101 patients completed and returned the questionnaire. Seventeen (17%) were members of an epilepsy charity or patient self help group dedicated to people with epilepsy. These were Epilepsy Scotland, Epilepsy Action, The Epilepsy Society, Fife Epilepsy Network, Epilepsy West Lothian and Scottish Paediatric Epilepsy Network. Of the 17, 2 were members of three separate epilepsy associations. Seven of the sixteen (44%) had been contacted by the group of which they were members to ask for their opinion on services for people with epilepsy. Some of the topics included: nocturnal seizures, their opinion on an information leaflet, and views on medication. Two of the 101 patients had used services offered by these HCG's/self help groups. Fifty-nine of our respondents were unemployed, 23 were in full time employment, 14 were part time employed and 5 were students. Employment status did not appear to influence membership of an HCG (Table 1A).

There were no significant differences in duration of epilepsy between those who were members of patient groups (Table 1B), but there was a trend for those who had suffered from the condition for many years to be members.

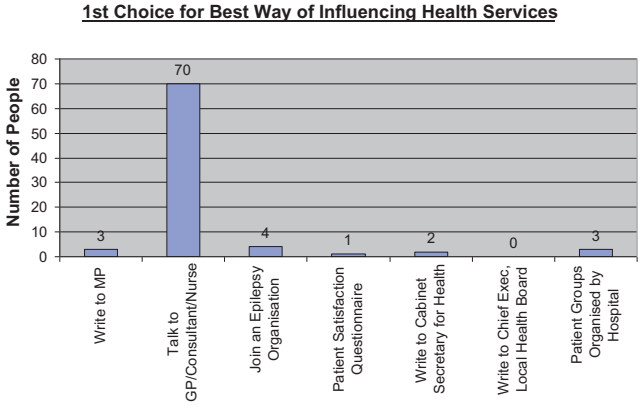
Thirty-four (34%) of the respondents took one anti-epileptic drug (AED) only, 30 (30%) took two AEDs and 37 (37%) took three or more AEDs. We divided the respondents arbitrarily into those taking no more than two AEDs, and those taking three or more, on the assumption that the latter group was much more likely to be intractable. Significantly more people who took three or more AEDs were members of patient advocacy groups than those taking one or two AEDs (chi-square 0.003) (Table 1D).

There was no significant difference in HCG membership between those who considered themselves disabled as opposed to those who did not (see Table 1C).

Respondents were asked to rank in order of preference how they thought they could best influence services for epilepsy. Seventy percent replied that a discussion with their general practitioner (primary care physician), hospital consultant or epilepsy nurse specialist was their preferred route (see Graph 1).

Four of the 17 people who were members of an epilepsy patient advocacy group wrote comments in the free text portion of the questionnaire. One said more information about patient support and advocacy groups was needed, two wanted more information about side effects of medication, one wanted information about mobility scooters.

Of those who were not members of any patient group, one wanted the population at large educated on how to deal with seizures, one wanted more support at the time of diagnosis, one complained about the difficulty in getting to see the consultant at short notice and another wanted to raise his concern about the stigma associated with epilepsy.



* 18 people did no answer this question.

Graph 1. First choice for best way of influencing health services. *18 people did not answer this question.

4. Discussion

The present study was limited in terms of patient details. This reflected the need to produce a short questionnaire that would cause minimal disruption in a busy outpatient clinic. We know nothing of the 19 people who did not return the questionnaires. Our aim was to examine the feasibility of doing a larger study with a more complex questionnaire in outpatients. The most obvious objection to our method of patient selection is that a specialist epilepsy clinic is perhaps not especially representative of the population as a whole. Yet quality of life and other data are routinely collected from this population.[2,3] Conversely in one study of patients recruited through patient groups the authors speculated about how representative these patients were.[4] In this area of research no sample group is perfect.

Another potential criticism of our study is that our population of patient's needs might not coincide with the stated aims and intentions of the epilepsy charity/self help groups, who purport to represent patient interests. In other words there may be another population of patients elsewhere whose needs are better aligned to those of various charities. To investigate this further we visited the charities websites of which our patients were members.