

Review

Patient, caregiver, and health care practitioner knowledge of, beliefs about, and attitudes toward epilepsy

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Abstract

The medical literature related to knowledge of, beliefs about, and attitudes toward epilepsy was reviewed from the perspective of patients, caregivers, and health care providers. The literature points to a desire for enhanced epilepsy education by patients and caregivers; however, these needs have not been met by primary or specialty care. Surveys of general practitioners (GPs) point to limitations in knowledge and negative attitudes. GPs view their role in epilepsy care as primarily educational and tend to acknowledge their limitations by referring difficult cases. Ongoing education for GPs is important, as is an improved partnership in defining roles for care and education. Health care professionals specialized in epilepsy care acknowledge their own set of barriers to optimal care. Epilepsy education programs have been able to improve knowledge; however, long-term improvements in behavioral outcomes or quality of life are less documented. Suggestions for improvements are provided.

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1. Introduction

Epilepsy affects an estimated 50 million people worldwide. It is the most common serious brain disorder in every country, and it affects people of all ages, races, social classes, and countries [1]. Only in the past 15 years has the Centers for Disease Control and Prevention (CDC) in the United States recognized epilepsy as a public health issue [2]. In 2002, a global campaign organized by the International League Against Epilepsy was formed to bring epilepsy “out of the shadows.” Key campaign objectives were to increase awareness of epilepsy among health professionals, to improve education about epilepsy, and to identify the needs of people with epilepsy (PWE) [3]. Knowledge of, beliefs about, and attitudes toward (KBA)

epilepsy are common threads in these objectives. A review of the existing epilepsy literature may help define common areas of both deficiency and strength. It would also help to raise the understanding of the progress that has been made in epilepsy research, but, more importantly, provide direction as to where future efforts need to be focused.

2. Methods

A literature review was completed using electronic searches through the PubMed database (<http://www.ncbi.nlm.nih.gov>) using the subject term *epilepsy* combined with *knowledge*, *beliefs*, and *attitudes*. These searches resulted in 1669 hits for knowledge, 889 for attitudes, and 523 for beliefs. A review of these abstracts yielded 239 references relevant to the review topic. Only studies in English were included. The published papers were gathered through electronic and library resources. Five themes emerged: population research, patients, health professionals, schools (teachers and students), and educational programs. Additional papers were identified and gathered through the reference lists of reviewed articles. This review has an international focus on patients, caregivers, and health care providers and provides a discussion of relevant epilepsy educational interventions and recommendations for future directions.

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3. Patients

Epilepsy is a very unique medical problem when compared with other chronic illnesses. The unpredictability of when and where the next seizure might occur makes people with epilepsy (PWE) live in constant fear of the unknown. PWE not only have to cope with the complex demands of a chronic illness (doctors' visits, diagnostic tests, medications, etc.), but also have to deal with social stigma and prejudice in physical activities, employment, and education. As knowledge of one's health condition is an important factor in achieving better control of that condition, researchers have been interested in assessing knowledge, beliefs, and attitudes in PWE.

3.1. Knowledge, beliefs, and attitudes

Jarvie et al. developed two questionnaires to assess knowledge of PWE: the Epilepsy Knowledge Profile—General (EKP-G) and the Epilepsy Knowledge Profile—Personal (EKP-P) [4,5]. The questionnaires were derived from the medical literature and experts in the field. Both were validated and tested in groups of PWE (82 for EKP-G and 79 for EKP-P) attending an outpatient neurology clinic in Glasgow, Scotland. The EKP-G is a 55-item true/false questionnaire (34 medical knowledge items, 21 social knowledge items) that assesses general knowledge of epilepsy. The EKP-P is a 23-item true/false questionnaire that assesses an individual's knowledge of his or her condition. Five published studies used EKP-G, in addition to other tools, to assess knowledge in PWE [4,6–9]. All used the medical and social knowledge items, except for

Doughty et al. [9], who used the medical knowledge items only. Data from these studies in England and Europe, summarized in Table 1, show fairly consistent scores of 75% correct answers.

In addition to the EKP-G, Goldstein et al. evaluated the EKP-P along with patient satisfaction with medical services [6]. Seventy percent did not know the name of their seizure type, 75% did not know the results of their EEG assessments, 65% did not know the results of their brain scans, and 25% gave incorrect dosages for all or some of their antiepileptic drugs (AEDs). In addition, 40% of patients reported they were never given information about the side effects of AEDs, and 88.6% preferred attending an epilepsy clinic rather than a general practice one.

Duthie et al. assessed EKP-G in PWE and people without epilepsy in the general population (control group) and found no statistical difference in medical or social knowledge between the groups [7].

Ridsdale et al. found that younger age, older age at leaving school, possession of a General Certificate Examination (high school diploma), and membership in self-help groups were independently associated with higher EKP-G scores [8]. EKP-G questionnaires were completed by participants twice, approximately 6 months apart. Stage 1 consisted of completion of the EKP-G (see Table 1). During stage 2, patients who completed stage 1 were randomized. Approximately half received an intervention consisting of 45–50 minutes with a special nurse at a “neurology clinic” in their general practice with follow-up 3 months later (intervention group). The remaining half served as a control group. The nurses tailored information and advice provided according to patients' expressed needs and according to

Table 1
Epilepsy knowledge profile scores across studies

	Jarvie et al., 1993 [4,5] ^a	Goldstein et al., 1997 [6]	Duthie et al., 1998 [7] ^b		Ridsdale et al., 1999 [8] ^c	Doughty et al., 2003 [9]
<i>Study sample description</i>						
Country	Scotland	England	England		England	10 European countries
Type	Single neurology clinic	Single neurology clinic	Population sample		37 general practice clinics	Epilepsy support groups
<i>Description of subjects</i>						
Type	PWE	PWE	PWE	Controls	PWE	PWE
Total number	82	70	287	383	251	6,156
% Females	53	61	NA	NA	46	50
Mean age (range)	33 (16–75)	42 (18–76)	NA	NA	51 (17–90)	37 (16–98)
Mean age at epilepsy onset (range)	17 (1–65)	NA	NA	NA	NA	18 (1–78)
<i>Mean EKP-G score (% correct)</i>						
Medical knowledge (max 34)	26.2 (77%)	25.9 (76%)	25.6 (75%)	25.6 (75%)	Median 26 (76%)	24.3 (71%)
Social knowledge (max 21)	15.4 (73%)	15.6 (74%)	14.5 (69%)	14.3 (68%)	Median 15 (71%)	Not done
Total knowledge (max 55)	NA	40.9 (74%)	40.2 (73%)	39.5 (72%)	Median 42 (76%)	Not done

Note. PWE, people with epilepsy; NA, not available; EKP-G, Epilepsy Knowledge Profile—General.

^a For Jarvie et al., 1993 [4,5], mean scores were calculated from the frequency distribution because EKP-G scores were normally distributed.

^b Data from an abstract.

^c For Ridsdale et al., 1999 [8], only median scores were reported.

their individual needs for advice on diverse topics such as driving, contraception, and pregnancy. When it seemed appropriate, nurses provided topic-related pamphlets and lent books or videotape recordings. Knowledge scores were analyzed for both groups at both stages. The intervention made no difference in knowledge scores. The authors attributed this to the fact that the patients had chronic epilepsy for an average of 23 years and had likely acquired information from other resources during this time. Patients expressed that the intervention might have helped if it was provided earlier in their illness.

Doughty et al. found that only 7% of responders scored ≥ 30 and more than half scored < 25 on medical items on the EKP-G ($< 74\%$ correct) [9]. The four items most frequently answered correctly were: (1) drugs must be taken regularly to work, (2) an EEG detects electrical brain activity, (3) an EEG helps to diagnose epilepsy, and (4) alcohol can increase seizure occurrence (96, 92, 92, and 91% of responders, respectively). The four items most frequently answered incorrectly were: (1) if you forget to take your seizure medication for a day it is okay to take two doses together, (2) people have been taught to control seizures by psychological methods, (3) brain damage is the only reason for epilepsy, and (4) most women taking AEDs can breastfeed (82, 56, 55, and 53%, respectively).

In addition to the medical knowledge items of the EKP-G, the authors used three other scales to evaluate the knowledge and attitudes of PWE. Based on the Impact of Epilepsy Questionnaire, 13% reported that they did not worry at all. More than 50% reported that epilepsy affected their relationships with significant others, family members, and friends. Based on the Adjustment to Epilepsy Scale, 50% reported that they miss things they liked to do and 49% felt more dependent on others than they would like. Fifty-four percent did not feel they were a burden to family and 55% did not feel that others were uncomfortable with them. Only 17% perceived a high level of stigma and half did not feel stigmatized by epilepsy based on the Epilepsy Stigma Scale.

3.2. Other patient knowledge studies

Other researchers have assessed knowledge and attitudes of PWE using different questionnaires/tools that they developed; however, these questionnaires vary and cover a wide range of topics, which makes it very difficult to compare and draw general conclusions about the overall attitude and degree of knowledge of PWE.

Both Long et al. and Al-Awadi et al. used the Epilepsy Patient Knowledge Questionnaire (EPKQ) to assess patients' knowledge of their epilepsy [10,11]. EPKQ is a nonvalidated, three-page, 13-item questionnaire that includes a variety of multiple-choice, true/false, and "fill in the blank" questions. Long et al. developed EPKQ and collected data from 175 PWE newly referred to a tertiary care academic center in the United States [10]. Fifty-seven percent of male and 58% of female patients

answered questions correctly. Thirty percent believed that epilepsy was a mental disorder or a contagious disease. Only 31.6% responded correctly to questions concerning social issues. Twenty-five percent thought that pregnant women should discontinue AEDs. Forty-one percent of PWE believed placing an object in a person's mouth was an appropriate safety precaution. The mean scores were 84.7 and 57.5% on questions related to compliance and safety. The lowest scores were related to legality of driving (13.6%) and employment (47.5%).

Al-Awadi et al. adapted the EPKQ and collected data from 107 patients in a tertiary care center in Oman [11]. The EPKQ was translated into Arabic and modified to accommodate some sociocultural aspects of Oman. A majority of patients gave incorrect responses to most questions regarding safety, legality of driving, employment, and compliance. The only exception was that all patients agreed that hospital medication was the most effective treatment for epilepsy.

Danesi surveyed 117 PWE in a neurology clinic at Lagos University Hospital in Nigeria [12]. Although all patients admitted they had seizures, 35.9% did not accept the diagnosis of epilepsy. Sixty-two percent of patients reported they were satisfied with medical treatment, and 32.5% combined medical treatment with native medicine or spiritual healing.

Dawkins et al. compared responses from 29 PWE and 32 persons in a control group from two general practices in the United Kingdom [13]. PWE knew little more than the control group about types of epilepsy, etiology, and seizure-triggering factors. PWE regarded their disease as a minor illness, whereas the control group considered epilepsy a major illness. Sixty-two percent of the control group said they would let their children marry someone with epilepsy. More than half of the control group gave proper responses when asked what to do if they witnessed a seizure. Only 22% of the control group reported that placing an object in the person's mouth during a seizure was appropriate. Fifty-nine percent of PWE reported participating in fewer activities because of their condition, 49% told their employers about their epilepsy, and 55% thought that they were eligible to hold a driving license.

Desai et al. surveyed 80 PWE in a rural clinic in India [14]. The majority of the patients believed that epilepsy was a disease of the brain; only 9% believed it was due to evil spirits; however, more than half had tried alternative treatments. Patients lacked knowledge of appropriate treatments and the goals of treatment, and 64% expected a cure from treatment. Fifty-five percent of patients had tried spiritual, Ayurvedic/indigenous medicines or voodoo at some point during their disease. The authors stressed the need for education to clear up misconceptions and to ensure treatment compliance.

3.3. Information needs

Patients from the United Kingdom in the general practice setting indicated their perceived needs most related to:

concealment (100%), stigma (97%), cause and prognosis (95%), need for more public education (87%), fear and depression (74%), driving (61%), and AEDs (whether to stop medication) (53%) [15]. In a study of 493 patients attending a hospital clinic, 90% indicated they wanted to receive more information about epilepsy than what had already been given to them, with 61% reporting they wanted to talk to someone about epilepsy [16]. Qualitative research in the United Kingdom points to such topics as why treatments are changed, long-term side effects, newer drugs, and childbearing concerns in women as key information needs from the patient's perspective [17].

In the United States, patients indicated they preferred to receive education about medication, risks, and lifestyle issues from their physician, rather than other health professionals [18]. It is much more likely that nurses are providing such education in the clinical setting. Patients, nurses, and physicians rank ordered areas for learning very similar for overall topics such as medication information, seizure information, psychological factors, anatomy/physiology, and general lifestyle [19]. However, the perceived importance of individual items differed dramatically within each topic.

4. Caregivers

Although most adult patients with epilepsy live and manage their epilepsy on their own, significant proportions are dependent on family members and partners for medical care. Caring for epilepsy is emotionally demanding and caregivers are at a greater risk for depression [20]. The provision of better care for PWE requires not only better knowledge of and attitudes toward epilepsy, but also better information resources for caregivers.

4.1. Knowledge, beliefs, and attitudes

Beech developed a 23-item questionnaire to assess awareness of the basic facts about epilepsy among relatives of PWE based on published surveys, pamphlets from the British Epilepsy Association, and the opinions of expert judges [21]. Data were collected from 67 control individuals and 74 individuals who were close family members of PWE. The control group scored 14.46 ± 3.94 (63% correct) and family members of PWE scored 17.01 ± 2.78 (74% correct) ($P < 0.001$). Although, family members of PWE had more knowledge than the control group their scores are fairly consistent with the knowledge scores of PWE listed in Table 1. Importantly, 15% of the family members had a score lower than the mean of the control group, suggesting that a portion of family members of PWE lack basic knowledge of epilepsy.

The largest study to evaluate the knowledge of and attitudes toward epilepsy of caregivers was done by McEwan et al. [22]. An 18-question assessment of knowledge of epilepsy and attitudes was developed and administered to 651 caregivers. With respect to knowledge, authors found that caregivers were well informed about epilepsy, the causes

and different seizure types (80.3% attributed epilepsy to a disorder of the brain, a majority expected to see a convulsion during seizures and 82% thought a seizure might take the form of a blank stare, 12% described epilepsy as a mental problem and 46% as a physical problem). The majority of caregivers agreed that PWE were as intelligent as everyone else, could be as successful as others in their careers, and could lead a normal life. Eighty-one percent of caregivers, however, felt that PWE are treated differently by society. The majority of caregivers felt that PWE should not hold many of the jobs that can put the lives of PWE or others at risk. Younger people and those with higher levels of education tended to hold more positive attitudes.

4.2. Information needs

Lu et al. interviewed 84 families of children with epilepsy who were followed in a neurology clinic at a tertiary care center in Alberta, Canada [23]. Families were asked about the sources of information they seek and the perceived accuracy of the information. Families assessed an average of 3.5 sources that were recommended by health care providers and clinics and an average of 4.1 sources outside these areas. Families with higher education accessed a greater number of resources. Surprisingly, clinic handouts were not accessed highly because the families felt that they were "too general." The accuracy of information provided by the clinic and health care providers was perceived to be the highest. The authors concluded that parents of children with epilepsy seek information sources both within and outside where they get medical care.

Kendall et al. developed a questionnaire to assess the information needs of caregivers of adult PWE after in-depth interviews with 12 caregivers [24]. Results from 70 caregivers indicated: (1) a preference for individualized information delivered by the most competent person, typically a neurologist; (2) a preference for face-to-face delivery of information over written information; (3) a lack of enthusiasm for epilepsy organizations and the information they provide; (4) a confidence to seek information from a range of resources including neurologists and general practitioners. However, caregivers felt that physicians were not interested in their information needs.

5. Health professionals

5.1. General practice

Most research about knowledge, beliefs, and attitudes related to epilepsy in health professionals has focused on general practitioners (GPs). It is estimated that in the United States, more than 80% of patients with new-onset seizures are examined by GPs [25]. Studies of the neurological content of family practice have found that epilepsy ranks consistently among the top five most frequent diagnoses [26]. GPs, however, are less likely to be aware of newer diagnostic and therapeutic measures [27].

Primary care was designed to provide quick access to care for patients with varied and acute issues [28]. Persons suffering from chronic conditions such as epilepsy are therefore not likely to find their needs met in primary care. In the United States, the current model of the primary care physician (PCP) as “gatekeeper” is believed to run the risk of suboptimal evaluation and treatment of persons with seizures within the framework of the managed care organization [27]. A U.S. study by Moore et al. found a majority of primary care physicians prefer to refer their patients with seizures to a neurologist [29].

5.1.1. Knowledge, beliefs, and attitudes

In England, 60% of GPs perceived themselves as “the most important therapist” in epilepsy care [30,31]. However, 67% of GPs in Australia nominated the neurologist as the most important practitioner in epilepsy management [32]. GPs in both countries tend to see their roles as: monitoring patient response to AEDs, educating patients about epilepsy, giving practical advice about work and lifestyle, and advising about driving restrictions [32]. GPs have indicated they are less comfortable in the roles of stopping AED therapy, initiating AED therapy, changing AEDs, and managing patients through pregnancy [30,32,33].

Ninety-three percent of surveyed GPs stated they would welcome guidelines for epilepsy care [34]. However, a recent review of the failure to implement epilepsy guidelines in primary care in the TIGER trial revealed there was little perceived need for change [35]. A lack of knowledge of the existence and content of the guidelines, as well as a perceived difficulty in implementing the guidelines due to resource constraints and patient resistance, was noted. This trial highlights that not involving GPs as key stakeholders in the development of such guidelines was a major flaw. The European Working Party on Quality in Family Practice (EQUIP) recommends that patient perspectives be included in guidelines to improve quality of care: “all providers need to be able to see the care system from the patient perspective if they are to be able to help patients make sense of and benefit from an increasingly complex system” [36].

In the United Kingdom, 55% of GPs agree that care of people with epilepsy should be based in general practice; however, a significant lack of confidence about knowledge of epilepsy, unfamiliarity with new drugs, and a lack of time were considered major impediments to optimal care [37]. A survey of health care professionals (98% were non-neurologists) about knowledge of women’s issues and epilepsy found that few understood the effects of hormones on seizure threshold and that women with epilepsy have an increased incidence of female sexual dysfunction [38]. More than 70% were familiar with the effects of AEDs on contraception, bone health, and pregnancy, whereas less than half knew women on AEDs could safely breastfeed. One survey found GPs have a relatively low level of interest and most believe care should be coordinated with a hospital [39]. GPs, for the most part, perceive an established role and, based on the relatively low prevalence of epilepsy,

believe the more complex patient issues should be left to specialists [35].

Research from Australia in the 1980s revealed the negative attitudes of GPs toward psychological instability for those with controlled uncomplicated epilepsy and mixed opinions on personal relationships [30]. GPs did, however, have positive attitudes toward education, intelligence, and employment for PWE [30]. A follow-up study by the same investigators found some improvement in attitudes, with the exception of attitudes toward emotional and behavioral problems [40]. Similar attitude patterns were noted for physicians in Oman [41].

5.2. Health professionals in epilepsy care

5.2.1. Knowledge, beliefs, and attitudes

A recent needs assessment of health care professionals in epilepsy to identify perceived barriers to achieving optimal care was grouped into: attitudes toward persons with epilepsy, treatment, management, referral, health care system, and continuing educational development. Top attitudinal barriers identified included managing patients with multiple comorbid conditions, managing families with unrealistic expectations, patients who do not adhere to treatment, cultural attitudes, access to care, patients who refuse to accept the diagnosis or are skeptical of treatment, and negative attitude toward health care professionals [42]. Professionals identified management and referral barriers such as a lack of awareness about social services, stigma associated with epilepsy, practice profitability/protection, and difficulty with referrals. Epilepsy specialists believed that GPs have limited knowledge and take on more responsibility than they should. The three greatest health system barriers to positive outcomes were: lack of public awareness, availability of social services, and the cost of AEDs [42].

Eighty-one percent of neurologists in another study believed that the public was not adequately informed about epilepsy, and frequent misperceptions still focus on epilepsy being primarily hereditary or a mental illness. A television campaign was most often suggested as the best method for public education by practitioners [43].

A recent survey of neurologists about “bothersome patient behaviors” (not specific to epilepsy) highlighted five key concerns: no-show appointments, verbal abuse of staff, poor compliance with medications or treatment, late for appointments, and not knowing the medications they take [44]. Although this may be a realistic assessment of some practitioners’ experiences, at least for concerns such as treatment compliance and knowing your medications, the health care system needs to take responsibility for improving patient education.

6. Patient education

Patient education has been shown to be effective in improving health outcomes such as reducing the need for medication; in reducing duration of treatment and hospital

stays; in improving risk-reducing behavior; and in reducing risk factors [45]. However doctors express doubts about their success in patient education and tend to be pessimistic about their ability to change their patients' lifestyles [46,47]. There is also evidence that physicians overuse ineffective patient education methods and underuse more effective behavioral and psychological methods [48].

Medical training teaches health professionals to organize knowledge according to disease history, etiology, symptoms, treatment options, and side effects. Therefore, most clinic-based patient education is based in this "medical model" format. However, written materials for patients that focus on facts only and use medical terminology unfamiliar to the general public are less effective [49]. Lack of clear instructions or patient misinterpretation of instructions has been suggested as a primary cause of noncompliance in epilepsy [50].

6.1. Educational interventions for epilepsy

The Modular Service Package for Epilepsy (MOSES) program, which uses a total of 14 one-hour sessions over 2 days, showed improvement in patient knowledge, coping, seizure outcome, and treatment/therapy satisfaction 6 months after the intervention for those in the intervention group [51]. MOSES was designed around nine areas: living with epilepsy, epidemiology, basic knowledge, diagnostics, therapy, self-control, prognosis, psychosocial aspects, and network. Both groups had roughly 54% incorrect answers on the Epilepsy Knowledge Scale at the start of the program. Although both the intervention group and the control group had improvements in knowledge at follow-up, only the intervention group had a statistically significant improvement. Knowledge levels increased more in patients with intermediate levels of education.

The study authors recommend that educational programs such as MOSES become a standard service in specialized epilepsy centers. Although successful, the MOSES program is limited in its ability to be replicated, as it was developed in German and, currently, no manuals or materials are available in other languages. In addition, because of the length of the program, it may be suitable only for patients who are highly motivated and have no or only slight cognitive and learning deficits [52].

A shorter 6-hour program was developed in Norway [52]. The two main aims were: (1) to provide general information about epilepsy focusing on individual problems of the patient, and (2) to allow the participants to share their own experiences of coming to terms with the diagnosis/living with epilepsy. This nurse-led intervention followed by 2 years of extended nurse follow-up and counseling was studied in a randomized, controlled trial [53]. The program was shown to improve quality of life (based on the QOLIE-89) in areas specific to health discouragement, medication effects, and physical role limitations for the intervention group, but not the control group. No outcomes related to knowledge were evaluated or reported.

A 2-day psychoeducational program from Nigeria found a significant decrease in level of depression, a significant increase in knowledge, and a significant decrease in psychoneurotic traits based on the Crown–Crisp experiential index [54]. The program focused on three modules: (1) background, (2) diagnosis and management, and (3) living with epilepsy. This is the only educational program to document an influence on psychopathology. The program also has limited ability to be replicated as it was developed in a specific culture.

In the United States, only one educational program has documented improvements in patients. The Sepulveda Epilepsy Education program, now known as the Seizures and Epilepsy Education (SEE) program, demonstrated increases in knowledge, a significant decrease in fear of seizures, and a significant decrease in hazardous medical self-management practices in the treatment group compared with those on a wait-list control group [55]. The SEE program, a 2-day weekend seminar, is designed to provide medical education and psychosocial therapy. No changes in outcome measures related to seizure frequency, mood, anxiety, and self-efficacy or on subscales of the Washington Psychosocial Seizure Inventory were seen in the original study.

Robert Mittan, Ph.D., presents the SEE seminars primarily in North America and hosts a website, <http://www.theseeprogram.com>, documenting current SEE program outcomes. No program-specific manuals or materials are currently available, but a set of six articles published in *Exceptional Parent* magazine in 2005 are available on the website. Mittan (personal communication) stated these articles follow the general scope of the SEE program and that a great deal of the program is devoted to AEDs using highly sophisticated materials for laypersons. Mittan states the program is able to enhance comprehension about complex concepts such as pharmacokinetics, drug interactions, side effects, toxicity, half-lives, and steady state by participants. Although the recent SEE outcomes listed on the website are impressive, no description of participant demographics is provided. Therefore, it cannot be determined how the SEE program works in specific patient groups, such as minorities or those with low levels of education and income. Currently, the SEE program costs \$75 per person.

At present, little evidence is available to identify the best timing of educational programs or if needs change over time. Patient education in epilepsy typically focuses on disease knowledge and self-care, but much less on medication knowledge [56]. A systemic review of the information and counseling needs of PWE completed by Couldridge et al. stated there was a lack of outcome studies investigating the long-term impact of education or counseling from the patient perspective or of measurable health outcomes [57].

6.2. Computer-based patient education

A recent evaluation of the medical literature found significant improvements in knowledge and self-care

behaviors in various conditions through the use of computer-based patient education. That computer-based education can improve social support, adherence, confidence, and satisfaction is, however, much less supported [58]. In addition, there is little published research in epilepsy using computer-based education. Persons with epilepsy are using the Internet to share information about their challenges and experiences. Twenty percent of webforum users remarked that a health care provider had not met their information needs [59]. In addition, a recent review of the Epilepsy Foundation website found that less than 6% of the health education content in English was written at the Institute of Medicine's recommended sixth-grade level or below [60]. This suggests that the currently available information is written well above established health literacy levels in the United States.

7. Suggestions for improving knowledge, beliefs, and attitudes

7.1. Medical education of epilepsy

A survey of Welsh physicians indicated they acquired most of their epilepsy knowledge at the undergraduate level, followed by postgraduate, general reading, and personal experience [33]. GPs in Spain reported their primary experience with epilepsy was in residency [61]. Lack of effective teaching about epilepsy in medical schools was identified more than 30 years ago [62], and this effect seems to have persisted [63]. Epilepsy seminars designed for medical students have improved knowledge but not attitudes [64]. It has been recommended that in addition to providing adequate knowledge and skills for managing epilepsy, medical education should address students' beliefs and attitudes [64].

A recent study confirms that targeted education for medical students improves knowledge and confidence while decreasing stigma in the primary setting. A 1-year follow-up found this improvement was maintained [65]. A similar program for health professionals that focused on the biopsychosocial aspects of epilepsy was able to improve knowledge, attitudes, and perceptions [66]; however, knowledge was still below 50%, stressing the need for ongoing educational programs. GPs report their preferred ways to earn continuing education were through weekday semi-

nars, away from practice, through lectures given by multidisciplinary professionals [39].

7.2. Provider-patient communication

Poor communication between providers and patients has often been reported [64]. The medical interview tends to be viewed as primarily a data collection exercise in which psychological and social issues are typically avoided [67]. It has been found that physicians, on average, interrupt their patients within the first 18 seconds [68] of the interview and that they frequently overlook significant psychosocial issues [69]. Many physicians seem not able to communicate information clearly to patients or in a way that leads to adherence to treatment plans [70].

Patient care is influenced by physicians' knowledge, but also by physicians' attitudes toward the condition of patients under their care. A discussion of psychosocial issues in epilepsy is more related to a doctor's communication skills than to seeing the same doctor in a group practice [15]. However, there is no generally accepted procedure by which epileptologists and primary care doctors take responsibility for providing advice and counseling to persons with epilepsy [71]. Previous research has found that patients without epilepsy forget half of what they have been told in a medical consultation after 5 minutes; only 20% retain such information [72], and improvements of 50% in retention occur when supplemental printed information is given to patients [73,74].

There is evidence that information should be tailored to the individual's needs and circumstances [57]. Communication and health education need to be tailored to the patient's stage of emotional adjustment to the diagnosis of epilepsy [75]. Based on the stages outlined in Table 2, PWE are more cued for treatment recommendations and educational messages when they are in stages 3, 4, and 5. Information seeking is an element of positive adjustment in persons with epilepsy [76]. Once cued, epilepsy patient education needs to focus on many factors as depicted in Fig. 1. This model depicts the interaction of knowledge, power/control, self-management, and improved quality of life in epilepsy patient education [77]. Asking patients open-ended questions about their epilepsy concerns acts as a simple yet powerful "needs assessment" for which targeted education can then be provided.

Table 2
Emotional stages after diagnosis of epilepsy

Stage	Description
1	Shock: characterized by disbelief, confusion, irrationality, and emotion disorientation
2	Need for understanding and emotional support: feelings following stage 1 are likely grief and sorrow, followed by disappointment, anger, anxiety, aggression, guilt, depression, and, in some cases, denial
3	Adaptation: the person looks for a realistic appraisal of what can be done; information seeking, consideration of future decisions
4	Direction: start organizing and seeking help, need for advice and practical guidelines
5	Acceptance: preparation to get on in the process of living

Source. Adapted from Cochrane [75].

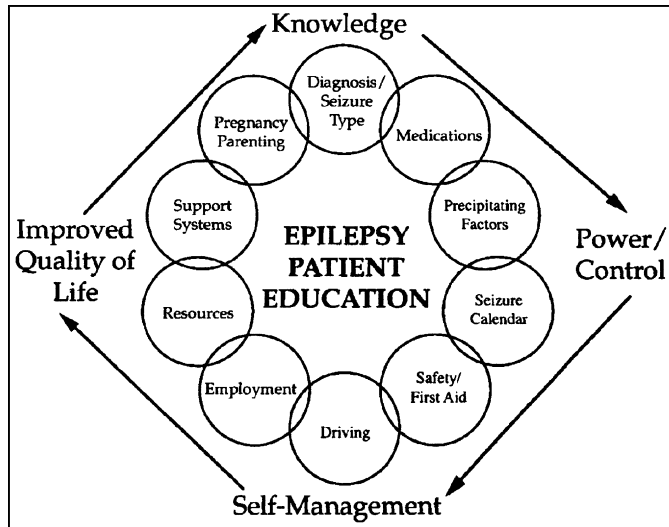


Fig. 1. Diagram depicting important aspects and outcomes of a comprehensive epilepsy educational process. *Source:* Mayo Clin Proc [77], with permission.

The use of case managers has been suggested as a way to enhance patient flow for those with chronic conditions through the health care system [28]. Patient navigator programs have been successful in improving screening for cancer, as well as in reducing delays in receiving care, especially for those in poor or minority populations [78,79]. Such programs use community members hired by the health care system to assist patients with everything from arranging appointments to providing social support throughout the treatment process. Patient navigator programs could be adapted to epilepsy care and education.

8. Conclusions

This review has provided the unique perspectives of stakeholders in epilepsy care. For patients, knowledge falls woefully short of what health care practitioners and epileptologists would like to see, especially considering such information is typically available through specialists and patient advocacy organizations.

Studies of GPs and where they gain exposure to epilepsy in their training point to a need for earlier targeted education to improve attitudes toward and beliefs about epilepsy and confidence in managing epilepsy. GPs recognize and claim an important role in the care of PWE and, for the most part, acknowledge their limitations through a preference to refer difficult cases. Both GPs and specialists report significant time constraints in clinical care settings. These constraints tend to force clinical-based education into a low priority.

Educational programs to enhance epilepsy self-management have often shown improvements in knowledge, but limited outcomes for quality of life or documented changes in behavior. By matching clinic education to a person's stage of adjustment to the diagnosis of epilepsy may work

to improve knowledge, beliefs, and attitudes. There is greater appreciation of the difficulties faced by general practitioners in dealing with chronic illnesses, and programs such as patient navigation and case managers that have been successful in patients with other conditions may be useful for PWE. Such changes would likely take time, as studies of patients and caregivers indicate they prefer to receive education primarily from their physicians.

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