

# **‘A systematic overview—a decade of research’. The information and counselling needs of people with epilepsy**

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This paper explores the background to epilepsy in terms of medical impact and psychosocial effects. The argument that information and counselling may be central to the person with epilepsy is explored.

The evidence from primary research published between 1990 and 2000 investigating the information and counselling needs of people with epilepsy is appraised and synthesized.

This paper seeks to answer the following questions:

- What are the information and counselling needs of people with epilepsy?
- What are the preferred formats, timing and delivery of information and counselling?
- What are the outcomes of information giving and counselling for people with epilepsy?

The review suggests that there are unmet needs for personal and general information about epilepsy which may include individual or group education and counselling. Information related to gaining control for people with epilepsy and targeted public education may contribute to improved quality of life for people with epilepsy. Information is required which is individually relevant and could be delivered in small groups or as part of an individual counselling service. Specialist epilepsy clinics and specialist nurses can improve patient knowledge and communication and provide an effective and high quality service for people with epilepsy.

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*Key words*: epilepsy; information; counselling; epilepsy clinics; specialist epilepsy nurses.

## **INTRODUCTION**

‘Epilepsy and the epileptic do not exist, epilepsies and people with epilepsy do’<sup>1</sup>.

Epilepsy is the most common brain disorder, apart from migraine<sup>2</sup>. It is estimated that at least 300 000 people in the UK have epilepsy<sup>3</sup>. The cost of epilepsy in the UK is in the region of £2 billion per annum<sup>4</sup>. The history of epilepsy has been described as ‘4000 years of ignorance, superstition and stigma, followed by 100 years of knowledge, superstition and stigma’<sup>5</sup>.

Epilepsy shares a similar prevalence with diabetes and also a number of features such as the need for long-term drug treatment and monitoring. Both epilepsy and diabetes can be hidden disorders which

may have a large impact on the quality of life of the individual and their families.

Epilepsy, however, carries with it the additional potential for stigmatization, misunderstanding and a number of psychosocial implications. It is often unpredictable in nature and is surrounded by many misconceptions and myths, both historical and cultural. A combination of these factors adds to the complex and unique difficulties people with epilepsy may experience sometimes leading to secondary handicaps.

A diagnosis of epilepsy can have wide reaching physical and psychosocial consequences which may be as difficult to deal with as the seizures themselves<sup>6</sup>. Having epilepsy can alter a person’s social status thus perpetuating social stigma and psychosocial distress<sup>7</sup>.

An effective service should therefore consider more than the potential for seizure control<sup>2</sup> and services are required which help people to deal with the physical, psychological and social consequences of epilepsy.

Services for epilepsy in general are often fragmented with audits continuing to show epilepsy care to be less than optimal<sup>8</sup>.

## EPILEPSY—THE POLITICAL FRAMEWORK

A recent study by the clinical standards advisory group (CSAG) highlighted six previous Government sponsored reports on epilepsy<sup>9</sup>.

These reports have detailed recommendations for the provision of services for people with epilepsy in the UK. Recommendations have included the provision of counselling for people with epilepsy and their families and highlighted the need for public and professional education on epilepsy.

A review of existing medical services in 1990, found that progress had been slow with many proposals remaining unimplemented. Contributing factors were suggested such as a lack of financial backing and divided opinions about the services required amongst health professionals<sup>10</sup>.

In 1978 The Commission for the Control of Epilepsy and its Consequences (US Department of Health), stated many people were ill informed about their epilepsy<sup>11</sup>.

The 'Epilepsy Needs Document'<sup>12</sup>, stated that medical services for people with epilepsy were often 'poor in quality, fragmented and poorly organised' (p 91). Detailed recommendations were made to improve service provision. Guidelines for optimum care covered areas such as initial referrals, assessment, investigations and treatment, care in the community, education, long-term care and training for health professionals. The provision of counselling and information for patients and families was recommended and the need for specialist epilepsy services and epilepsy nurse specialists highlighted<sup>12</sup>.

The CSAG study<sup>9</sup> evaluated existing services for people with epilepsy. Findings identified a lack of focus for services and lack of co-ordination and continuity between various health providers and specialist centres. The provision of information about epilepsy for patients and carers was identified as a continuing and presently unmet need.

More recently the national service framework (NSF) for long-term health conditions<sup>13</sup> identified the needs and service provision for people with epilepsy as a focus area. The European White Paper on Epilepsy<sup>14</sup> has called for action to improve public understanding of epilepsy throughout Europe, protection from

discrimination and increased investment in research to aid diagnosis and treatment.

In the light of past and current reports it would seem the time has come to implement the recommendations in order to ensure service provision for people with epilepsy meets the identified needs.

## Why do people need information about epilepsy?

Wide individual variations in adaptation to a potentially chronic illness exist<sup>15</sup>, with some people feeling stigmatized and debilitated by their epilepsy<sup>16</sup>.

Accurate medical information may help positive adaptation, it may also empower people with epilepsy to disclose their diagnosis and educate others<sup>1</sup>. Information seeking may be one of many coping strategies employed by some individuals, and as such may be an element of positive adjustment<sup>17</sup>.

Accurate and up to date information gives people the ability to make truly informed choices about their treatment and care.

Education of the general public has a role in reducing the stigma of epilepsy<sup>17</sup> and may subsequently improve the quality of life for people with epilepsy. Improved public understanding of epilepsy and its management will ensure that people have a better chance of receiving appropriate and safe intervention especially during seizures.

It is therefore suggested that potential positive outcomes of information giving include reduced morbidity and mortality, individual empowerment and the means to make informed health care and behaviour decisions to achieve the best quality of life possible. Cognitive outcomes include positive changes in opinions and attitudes<sup>19</sup>.

## THE REVIEW—RATIONALE, AIMS AND OBJECTIVES

The provision of accurate relevant information and counselling, to people with epilepsy, carers, health professionals and the general public, has the potential to reduce stigma, and promote a sense of control. In addition it may facilitate the development of positive coping strategies and ensure safe seizure management.

A lack of understanding and knowledge appears to exist despite information being freely available through specialist centres and networks. Information seeking may be a coping strategy employed by some individuals but it is not universal. Knowledge whether accurate or not may underpin the variables associated with quality of life such as attitude and stigma.

An understanding of the lay perception of illness<sup>20</sup> may facilitate health professionals to aid positive

adaptation. It has been suggested that patients do not receive adequate information because they do not ask questions or do not know what to ask<sup>21,22</sup>.

Anxiety may inhibit information processing and make new information feel threatening<sup>19</sup>. It is also recognized that patients in general often forget or are unable to process much of the information given by doctors<sup>23–25</sup>.

It is hypothesized therefore that personal and social barriers to receiving and utilizing information and counselling services may exist, existing knowledge may be inaccurate or outdated or there may be underlying prejudice, negative attitudes and perceived or actual stigma.

This paper aims to locate, appraise and synthesize evidence from key primary research published between 1990 and 2000 in order to answer the stated research questions and to highlight areas where little research evidence exists. Evidence to support action and facilitate change will be presented and implications for future practice considered.

### Research questions and methodology

The following three questions were formulated based on a preliminary examination of published literature and from practice.

- What are the information and counselling needs of people with epilepsy?
- What are the preferred formats, timing and delivery of epilepsy information and counselling?
- What are the outcomes of information giving and counselling for people with epilepsy?

### METHOD

The review is intended to be inclusive rather than exclusive, therefore the studies included incorporate diverse methodologies. Many have used qualitative methods to investigate the patients' perspective. For this reason a meta-analysis was not appropriate, therefore an 'overview' of the findings in a narrative and tabular form (Table 1) are presented.

A scientific design<sup>26</sup> is used to minimize bias and increase reliability and the evidence is examined using a recognized hierarchy<sup>27</sup>. Potential selection bias is addressed by using multiple reviewers and an agreed protocol.

Only studies written in the English language and carried out in developed countries were included for practical and comparative reasons. It is however acknowledged that much important work has been

done in other geographical areas, languages and cultures and their exclusion in no way negates their value.

Computer databases such as—Medline, Cinahl, Psyclit, Sociofile, BIDS, NHS CRD database (DARE), Cochrane Library, RCN Nurse Rom were searched with the aid of a search strategy to identify systematic reviews and randomized controlled trials<sup>26</sup>.

Subject search terms were—epilepsy, epilepsy and: health education, information, counselling, education, teaching, public education, knowledge, awareness, information giving, patient teaching and education, information needs, specialist epilepsy nurse.

Current publications were hand searched in specialist journals, reference lists of relevant papers and the Epilepsy Research Group's<sup>28</sup> publication were searched. Some grey literature and anecdotal evidence was considered but not included in the final overview.

### THE RESEARCH 1990–2000

Forty primary research papers, were reviewed, the sample, randomization, methods, reliability, validity and findings of these papers was considered. The selected studies are summarized and ranked in Table 1 and are discussed in the text in terms of the evidence provided relevant to the stated research questions.

#### What are the information and counselling needs of people with epilepsy?

Fifteen papers identified specific information needs of people with epilepsy<sup>8,9,29–41</sup>. Results from these studies suggest that patients require information on, epilepsy in general, diagnosis and treatment options, medication and side effects, seizures and seizure control, injury prevention, psychological issues (especially stress), social security, driving and insurance, employment, prognosis, life style and social issues. Counselling issues identified were anxiety, depression, emotional support and information.

Patients who had seen an epilepsy specialist nurse were more likely to have discussed a wide range of topics with their GP or hospital doctor, including causes of epilepsy, family and social life, side effects of medication and drug interactions<sup>41</sup>.

Sampling techniques varied, mostly adopting an opportunistic approach, the majority of participants belonged to a specialist epilepsy association or attended specialist epilepsy or neurology clinics. The findings cannot therefore be easily generalized to the whole epilepsy population.

Table 1: Summary the information and counselling needs of people with epilepsy.

Authors	Method/sample	Level	Findings/conclusions
Archibald, J. 1993	Interviews, n10, Leeds	V	50% next of kin seen by doctor, 7 unaware of driving ban, patient education and nurse knowledge inadequate
Averis, A. K. 1996	Questionnaire, n200, Australia	IV	41.5% unaware of type of epilepsy, 6.5% received epilepsy education, 71% received medication education 69% received treatment advice
Baker, G. & Jacoby, A. 1995	Two postal surveys. Mersey, n696, Europe, n5000	IV	Patient satisfaction with services, gap in level of information, quality of life may be improved by education
Beech, L. 1992	Questionnaires, n67 families, controls 4. Cheshire	III	Experimental group had more knowledge of epilepsy, advice/counselling recommended for families
Buck, D. 1996	Questionnaire, single region. Community, n1024	IV	67% received sufficient information from GP (N677), 55% (n215) received sufficient information from hospital doctor, 62% (n126) received right amount of information from neurologist/epilepsy specialist 45% (n76) received the right amount from general hospital doctor
Chappell, B. 1992	Postal survey, n437, BEA	IV	More information needed, especially medication
Chappell, B. & Smithson, H. 1998	Questionnaire n178, BEA, general practice, secondary care	IV	44% given information by GP, 58% rarely/never given enough by GP, 80% no recollection of first aid information being given, information provision poor
Collings, J. A. 1990	Survey n392, epilepsy support groups	IV	Information linked to effective coping and overall well being
CSAG 1999	People with epilepsy, postal survey, n2394. Interviews, n79	IV	Face to face contact/information wanted on variety of topics, public education recommended, 46% thought they knew enough about their condition, 51% (n1109–1393) had information on their type of epilepsy, 54% on side effects, specialist nurses helped by providing advice/support
Dawkins, J. L. <i>et al.</i> 1993	Experiment n29 & 32, questionnaires, two general practices	IV	Poor knowledge, both groups, more personally relevant information wanted
Dilorio, C. <i>et al.</i> 1993	Questionnaires, nurses n85, patients, n59, physicians n38. USA	IV	Nurses and physicians ranked patient learning needs similarly, medication issues ranked higher by health professionals, gaining control issues higher for patients, information may reduce fear, personalized information preferred
Dilorio, C. <i>et al.</i> 1995	Questionnaire, as above	IV	Physicians preferred for all categories, nurses preferred for lifestyle issues, pharmacists for medication
Epilepsy Association of Scotland 1994/5	Questionnaires & focus groups, n12 members of EAS	V	Public education should be increased, more information and support needed
Hartshorn, J. C. & Byers, V. L. 1994	Descriptive study, n150, USA.	V	Correlation between information, understanding and quality of life, multiple unmet needs identified
Hart, Y. M. & Shorvon, S. D. 1995	Questionnaires, n1628	IV	Improvement in patient education and knowledge of general population suggested, poor recall, self-reported data difficult to verify
Hayden, M. <i>et al.</i> 1992	Postal questionnaire, tertiary Care, n517. Australia	IV	26% did not know their type of epilepsy, 68% seek help/advice from family, 46.4% from doctors, 39.6% from friends, 14.8% from epilepsy associations, provision of information does not always allay concerns
Helgeson, D. C. <i>et al.</i> 1990	Intervention study, n23, controls n20, USA	II	Intervention group—reduced fear, reduced hazardous medical self-management, misconceptions and improved AED levels
Goldstein, L. H. <i>et al.</i> 1996	3 questionnaires, n70 epilepsy clinic	IV	Minority knew names for their seizure types, majority did not know test results, most knew their AED's, 25% gave incorrect doses, 40% would like epilepsy information, 33% had received some but not enough information, high demand for specialist nurse service
Hills, M. D. & Baker, P. G. 1992	Survey and interviews, n28. New Zealand.	IV	AED dose and knowledge of epilepsy correlates with self esteem, education to include families

Table 1—continued

Authors	Method/sample	Level	Findings/conclusions
Hoch, D. B. <i>et al.</i> 1999	World Wide Web survey. 155 posts, 342 responses	IV	Principal users—caregivers 49%, patients 34%. Responses by patients 38%, caregivers 34%, treatment questions most frequent, 6% of information inaccurate
Jain, P. <i>et al.</i> 1993	Patient survey, n493. Belfast	IV	90% wanted more information, 61% wanted to talk to someone, specialist nurse felt most appropriate
Jarvie, S. <i>et al.</i> 1993	Three stage trial, n79. Glasgow	III	48% patients happy with level of knowledge, assessment scale could be used for patient education To aid diagnosis and assess seizures
Long, L. <i>et al.</i> 2000	Knowledge questionnaire, n175, USA	IV	30% believed epilepsy is a mental disorder, 41% thought an object should be placed in the mouth during a seizure, patient knowledge poor, need for education to prevent injury and on legal issues
MacDonald, D. <i>et al.</i> 2000	Nurse intervention study, patient survey n64, interviews n175, Scotland	IV	32% had not been informed of driving regulations, 92% would return for annual appointment with nurse, nurse specialist can provide knowledge and support to health professionals and people with epilepsy
Millet, C. <i>et al.</i> 1997	Survey n364, London	IV	Perceived risk of video games 2–3 times higher than actual risk, media increased perceived risk, test results not discussed with patients, individual information needed
Mills, N. <i>et al.</i> 1999	Postal questionnaire, n394 Bristol	IV	69.8% wanted contact with specialist nurse, 50% wanted to discuss epilepsy, poor communication identified
Mills, N. <i>et al.</i> 1999	Follow up study, n240	IV	Service users more likely to discuss epilepsy issues, specialist nurse increased communication and monotherapy, improved access for most needy, may have adverse effect on patients perception of psychosocial effects
Morrow, J. 1990	Comparative trial, epilepsy clinic n130, neurology clinic n102	III	Improved seizure control both groups, epilepsy group had less side effects, were given or retained more information, more satisfied with service
Ridsdale, L. <i>et al.</i> 1996	Questionnaire, GP's n35 patients n251. S. Thames	IV	35% of patients felt insufficient information given, advice preferred in GP setting, poor record keeping identified
Ridsdale, L. <i>et al.</i> 1997	Randomized controlled trial. General practice. Nurse run clinic n106, usual care n124. S. Thames	II	Improved level of advice by nurse demonstrated, nurse run clinics feasible and well attended
Ridsdale, L. <i>et al.</i> 1999	Patient interviews n44, S. Thames	IV	Specialist nurse highly valued in providing support and advice especially social aspects, doctors perceived to not have enough time, specialist nurse input at diagnosis perceived to be helpful
Ridsdale, L. <i>et al.</i> 2000	Intervention study. n90 Questionnaires specialist nurse/usual care	III	Knowledge linked to general education, nurse intervention helped those with least epilepsy knowledge, patient satisfaction with advice given increased with nurse input
Scambler, A. 1996	Intervention study, questionnaires. S. Thames primary care. N251 N168 randomized intervention/control. N50 interviews	II	More satisfaction with nurse input, especially in communication of information and advice giving
Scambler, G. 1994	Literature review n37	V	Three themes—felt stigma, rationalization, action/coping; need for trained counsellors and specialist nurses identified, some patients do not want active involvement
Taylor, M. P. <i>et al.</i> 1994	Survey and interviews. Clinic staff & GP's n5, care workers n3, Patients/relatives n12. Doncaster	IV	Patients more able to raise issues and identify psychosocial needs in home setting, liaison nurse service popular and effective, explanations by doctor valued
Tedman, S. <i>et al.</i> 1991	Interviews and survey. Patients with epilepsy n52, non epilepsy n48. Mersey	IV	People with epilepsy were more depressed and anxious and had little knowledge of medical and social aspects of epilepsy, correlation between self-efficacy and depression and knowledge and anxiety

Table 1—continued

Authors	Method/sample	Level	Findings/conclusions
Thapar, A. K. 1996	Literature review, n50 approximately	V	Communication barriers, poor patient knowledge/education identified, evaluation of effectiveness and acceptability of patient education methods needed, patient education has role in reducing psychosocial consequences of epilepsy, education in small groups and tailored use of leaflets may be effective and efficient
Usiskin, S. C. 1993	Analysis of counselling, n83. London	V	Main issues raised—anxiety and depression, need or emotional support and information identified, counselling related to emotional adjustment and adjustment to seizures most common need, problems not related to seizures identified, intervention by skilled counsellor can help patients with epilepsy
Wallace, H. K. <i>et al.</i> 1996	Survey—neurologists, n209 54 epilepsy clinics, general neurology, n385 other n19. UK	IV	Additional counselling sessions significantly more likely at epilepsy clinics, more written information given. Epilepsy clinics provide improved access to investigations, specialists and support services
Wilde, M., & Haslam, C. 1996	Qualitative study, interviews, n24	V	2/3rds felt epilepsy not discussed enough generally, stigma increased on leaving school, epilepsy education could improve attitudes. 33% received advice from doctors, 37% felt employment hindered by epilepsy, employer ignorance blamed for discrimination. Lack of communication by medical profession identified

The finding that many patients feel they lack information about epilepsy and its treatment is surprising given that many of the samples were selected in the tertiary setting.

Many studies identified a general, but unspecified, need for more information by people with epilepsy, not necessarily identified directly by the patient<sup>8, 18, 29, 33, 34, 36, 42–54</sup>.

Other studies focused on assessing the existing level of knowledge of people with epilepsy<sup>29, 31, 33–35, 39, 43, 45, 49, 50, 54–57</sup>. Areas of knowledge found to be lacking were, driving regulations, type of epilepsy, photosensitivity, new treatments and medications and medication issues generally. These studies primarily followed survey designs of varying quality and adopted a variety of sampling procedures.

Two studies reviewed<sup>49, 56</sup> showed that only 48% of the subjects were happy with their level of epilepsy knowledge, in addition there was a significant difference between perceived and real risk of photosensitivity, due to inadequate information received. A significant number of people with epilepsy did not know the reasons for various tests being carried out.

Of note is the finding that the majority of people were unaware of new treatments and medication despite publications available to the study population (British Epilepsy Association members), this raises questions relating to the effectiveness of newsletter type publications to transfer information<sup>29</sup>.

Nine studies concluded that there was a need for

counselling for people with epilepsy and their families which was currently unmet, however the precise nature of the counselling role was not adequately described<sup>9, 29, 33, 40, 42, 43, 45, 50, 52</sup>. Advice and support was identified as an area of need, with 61% wanting to talk to someone about epilepsy<sup>33</sup>, 50% wanted someone to talk to and 69.8% wanted contact with an epilepsy specialist nurse<sup>50</sup>.

Twelve studies identified a need for specialist epilepsy nurses<sup>8, 9, 33, 37–39, 47, 50–52, 58, 59</sup>. Specialist epilepsy clinics are recommended as beneficial to patient care<sup>41, 47, 55, 58, 60, 61</sup>, however, only 4% of respondents suggested, without prompting, specialist clinics as an improvement to medical care<sup>46</sup>. This could be due to lack of knowledge or experience of specialist clinics.

Large gaps between doctors' estimates of advice given and written records of advice given were identified<sup>51</sup> with patients' estimates of advice received being greater than that recorded in patient notes. Recommendations were made for improvement in the systematic recording of advice given to patients by the training and appointment of specialist nurses. This study highlights poor record keeping relating to advice or information given, and the limited validity of some responses.

The introduction of a specialist epilepsy nurse was shown to improve communication generally between patient and health professionals, but could also have an adverse effect on the patients' perception of the impact of epilepsy on everyday life<sup>41</sup>.

## WHAT IS THE PREFERRED FORMAT, TIMING AND DELIVERY OF EPILEPSY INFORMATION?

Little evidence was found to identify the best timing of education programmes or whether needs changed over time, although some researchers highlighted a need for counselling at the time of diagnosis<sup>45</sup>.

There is evidence to suggest that information tailored to individual needs and circumstances is the preferred method<sup>36,45,57,62</sup>. The findings from these studies appear to echo those with findings that patients would like contact with epilepsy specialist nurses and counsellors as they too suggest a desire for an individual approach.

Two studies focused on the effects of health education sessions and provide Level II evidence<sup>58,62</sup>: A study evaluating a 2-day patient/family treatment and education programme (sepulveda epilepsy education, SEE)<sup>62</sup>, hypothesized that patient ignorance and psychosocial problems impacts on successful adaptation and compliance.

In addition it was hypothesized that the treatment group would show an increased understanding of epilepsy management, blood anti-epileptic drug (AED) levels, depression, anxiety, self-efficacy and acceptance of epilepsy. Subjects were randomly assigned to either treatment or waiting list control groups.

Results demonstrated trends in the treatment group towards improved emotional, interpersonal and vocational adjustment, improved adjustment to seizures and overall psychosocial functioning. These trends were still present 4 months later.

It was concluded individual therapy may be more effective than group therapy and that the SEE programme was effective in improving drug compliance. The effect of monitoring AED levels or other confounding variables were not discussed.

Overall the study offers considerable evidence that an intensive two-day education programme was beneficial to people with epilepsy, a decrease in hazardous self-management was demonstrated and an improvement in blood AED levels, although no evidence of seizure reduction was found. Further research is necessary to establish any long-term benefits and clarify the effectiveness of individual drug monitoring on seizure frequency.

A randomized controlled trial of nurse run clinics versus usual care<sup>58</sup>, offers strong evidence that nurse run clinics significantly increased the level of advice given to patients with epilepsy. However, some effect is likely to be attributable to the structured recording of advice given in the intervention group. Recommendations were made to develop an instrument to measure changes in patients' knowledge which

would give valuable information on the outcome of advice/information given.

Other researchers have suggested that written information is appropriate, especially as recall of verbal information given by health professionals is often poor<sup>47</sup>. Patients preferred verbal and written information which was personally relevant<sup>45</sup>. Written epilepsy information was a low priority in overall patient satisfaction with services. The sample was randomly selected from patients attending a specialist epilepsy service, levels of knowledge and information received were found to be good overall, although many patients could not identify what type of epilepsy they had. Patient suggestions for improvements included more epilepsy reading material, more medication information and a 24 hour epilepsy hotline<sup>55</sup>.

A literature review<sup>53</sup> concluded that education in small groups was less time consuming but equally as effective as one to one education combined with the use of tailored leaflets. Strategies used for asthma and diabetes education were recommended.

Low levels of knowledge were identified in people with epilepsy, but appear to be based on only one study, it is not clear whether this reflects the methodology of the review or a dearth of studies. Some key issues in epilepsy care were addressed, although the aims and questions were very broad. The methodology had limitations in that it was not systematic and therefore reliability was poor, selection criteria or search strategies were not described which further reduced reliability and increased potential bias.

Other researchers have highlighted the need to assess existing knowledge, lay beliefs, attitudes and perceptions and target information accordingly<sup>43,52,56,63</sup>. Young people with epilepsy felt that support groups were inappropriate and perpetuated negative attitudes<sup>54</sup> whereas other groups have reported feelings of isolation and lack of support<sup>29</sup>, this highlights the need to assess individual and group preferences.

## WHAT ARE THE OUTCOMES/BENEFITS OF INFORMATION GIVING?

There is an underlying assumption that information is beneficial but evidence as to the precise outcomes of epilepsy education is limited. From a psychosocial point of view there is evidence that information and understanding is related to well being, quality of life, coping, control, self-efficacy, and self esteem<sup>18,36,46,48,57,63</sup>. Provision of technical information can reduce fear and uncertainty<sup>36</sup> and reduce potential harmful self-management<sup>35</sup>.

The outcomes of information giving on attitudes is not clear, although there is some evidence however to

suggest that information giving can have a positive or negative impact on attitudes towards epilepsy and may also affect perceived or actual stigma.

Evaluation of a 2-day psycho-educational programme found that levels of misinformation and misconceptions were reduced as was fear of death or brain damage<sup>62</sup> however, long term evaluation is needed to ascertain if changes persist over time.

No studies were located which demonstrated a decrease in seizure frequency or severity as a result of educational programmes, although it was suggested that non-adherence may be linked with lack of knowledge about medication but there was no conclusive evidence to support this<sup>45</sup>. No evidence of seizure reduction was found after a two day educational programme but AED blood levels were improved, there was however a decrease in hazardous medical self-management<sup>62</sup>.

Patients randomized to either a neurology clinic or epilepsy clinic were shown to have improved seizure control in both groups, the reasons for this are not clear and cannot therefore be linked to improved education<sup>60</sup>.

## CONCLUSIONS AND DISCUSSION

Evidence from fifteen studies identified specific and varied information and counselling needs for people with epilepsy, their families and carers, and nineteen studies identified a general but unspecified need for more information for people with epilepsy. In some cases the perceived needs were identified by health professionals rather than the person with epilepsy. Eight studies specifically identified counselling as an unmet need.

Eleven studies identified the epilepsy specialist nurse could meet some of the unmet information needs of people with epilepsy and helped the general communication process between patient and health professionals.

There was little evidence to identify the best timing and format of information although overall an individualized approach was supported whether information was written or oral. A literature review<sup>53</sup> suggested group education was effective especially if combined with the use of tailored leaflets.

Four studies supported the need to assess existing levels of knowledge, attitudes and perceptions and target information appropriately. Fourteen studies focused on assessing the existing level of knowledge of people with epilepsy and identified many areas where knowledge was lacking, many of which such as driving regulations and medication could have detrimental health outcomes.

There are a lack of outcome studies investigating the long-term impact of information giving or counselling from either the patients' perspective or from measurable health outcome perspective. Six studies linked information and understanding to psychosocial well-being. One study linked non-adherence to a lack of knowledge about medication and one suggested reduced morbidity.

As a result of this overview it is clear that there is a considerable need for both personal and general information about epilepsy and for individual or group education and counselling. These needs are not currently met within the existing system.

The precise information needed is a complex and often individual matter. Evidence exists, however, to suggest that information related to gaining control, both physical and psychosocial, in addition to targeted public education would contribute to improved well-being and quality of life for people with epilepsy.

The evidence also suggests that advice, support and information, which is individually relevant and tailored to identified needs, is considered most effective, with small group discussions or individual counselling being favoured.

For information giving and education to be effective an assessment of need, existing knowledge, beliefs and learning style is necessary.

The use of scales to assess knowledge of epilepsy<sup>55</sup> could be used to plan individualized education programmes, but scope exists to develop new methods of assessment. Information, education and counselling given should be accurately documented to enable the process to be evaluated.

Specialist epilepsy clinics and nurses have been highlighted as being popular with patients with the potential to improve patient knowledge and provide an effective and high quality service for people with epilepsy. Three studies<sup>37,58,62</sup> provided Level II evidence of improved information giving. Further research however is necessary to provide evidence of precise and long-term outcomes.

The evidence presented suggests that the format and timing of epilepsy education needs further research. It is of relevance that researchers have found that both personal and general knowledge of epilepsy and its treatment is lacking, this appears to be true in primary, secondary and tertiary care.

The outcomes of information giving and counselling are not well researched, this may in part be due to the methodological problems of measuring something which is processed and utilized in very individual ways and has many variables. However, some outcomes are described such as improved quality of life, the ability to develop effective coping strategies, an increased perception of control, and reduction in feelings of fear and uncertainty.



Poor patient recall of information received, memory impairment, and poor recording and record keeping threaten the validity of some findings, especially in retrospective studies, further research is therefore necessary.

Sampling techniques have an inherent bias by focusing on people who are in contact with health professionals, receiving treatment, or belonging to epilepsy associations. Those excluded are likely to those most in need, such as families, friends and lay carers of people with chronic epilepsy and those with special needs, further research is needed to highlight the needs of these groups.

## Conclusions

The hypotheses/assumptions made were supported to some degree by the primary research examined, evidence exists to suggest that the information and counselling needs of people with epilepsy are largely unmet despite various recommendations in the last 10 years, the precise reasons for this require investigation.

There are many areas requiring further research, such as how information needs vary over time, which format is most effective, acceptable and cost efficient, what the long term outcomes are. It would also appear that there is scope for improved inter-professional communication to ensure patient information needs are identified and met in the most effective way and at the most appropriate time.

Despite the limitations, and in a climate of evidence based practice, this overview has highlighted some of the difficulties in attempting to identify and define the evidence relating to the information and counselling needs of people with epilepsy. Whilst there are some important pointers for practice, it is important to be aware of the methodological limitations of the studies under review, especially in the light of the limited number of controlled studies. In addition it is acknowledged that there may be a publication bias and that much valuable work remains difficult to access.

Given the prevalence of epilepsy and the evidence from this review of continuing unmet needs, it would appear to be an optimal time for quality standards to be implemented in epilepsy care.

A collaboration between primary, secondary and tertiary care services, and an increase in the number of specialist epilepsy nurses, could ensure improvements in epilepsy care with a focus on the psychosocial aspects are implemented.

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