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**Title: 'A LIGHT IN A VERY DARK PLACE': THE ROLE OF A VOLUNTARY ORGANISATION PROVIDING SUPPORT FOR THOSE AFFECTED BY ENCEPHALITIS'**

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## **ABSTRACT**

Voluntary organisations are seen as contributing to the ‘democratisation’ of health and social care. Little, however, is written about their role and this paper, by focusing on the work of The Encephalitis Society, provides insights into the challenges facing voluntary organisations as they manage twin roles as service providers and advocates, of people with neurological disorders. Two studies are presented: a review conducted by the Society, focusing on patient’s experiences of neurological services; and an external evaluation of the Society’s current provision. The first, based on a postal survey of its members affected by encephalitis (n = 339), illustrates the Society’s advocacy role. The survey provided support for the Association of British Neurologists’ recommendation for nationally agreed standards of care. The second study, a postal survey of recent contacts (n = 76) and in-depth telephone interviews (n = 22), illustrates the Society’s value role as a service provider and supports its role in helping rehabilitate affected individuals and their families. These studies provided the Society with information for policy and service development. Importantly, providing the basis of informed action and partnership with stakeholders and informing the organisation’s sense of purpose, in the changing context of welfare provision in the UK.

**Key words:** encephalitis; patient-centred care; voluntary organisations; and welfare provision.

**Length:** 2883 words (excluding references)

## **‘A LIGHT IN A VERY DARK PLACE’: THE ROLE OF A VOLUNTARY ORGANISATION PROVIDING SUPPORT FOR THOSE AFFECTED BY ENCEPHALITIS**

In social democratic welfare systems, voluntary organisations have a long and successful history in helping mainstream health and social care agencies support disabled and chronically ill people (Williams, 1996; Crack, Turner & Heenan., in press). The relationships among voluntary and statutory organisations has assumed recent political significance, in which the State, by promoting active citizenship and community cohesion, recognises a plurality of interests, fostered through networks and partnerships (for a general account, see Boddy and Parkinson, 2004 and for a more pragmatic national approach, see Home Office, 2005).

This is why voluntary organisations are seen as contributing to the ‘democratisation’ of health care (Fox, 2001) and despite considerable heterogeneity among voluntary organisations, two distinct roles can be identified. First, as an advocacy movement, second as a provider of services. The advocacy role provides a ‘user-centred’ forum that by giving voice to the concerns of patients and their families (Crombie and Coid, 2000), contributes to participatory democracy (Taylor and Burt, 2005). By developing a broad commentary, voluntary organisations can become the ‘conscience’ of health organisations, reminding them of the importance of providing care, which meets the needs of specific service users (Dahlberg, 2006). As for provision, such voluntary organisations can develop and provide support in parallel with

mainstream organisations (see, Ross-Barnett, Pearce and Howes., in press). They, therefore, become a provider of care, part of the fabric of the welfare state.

Some voluntary organisations see no contradiction in combining these two roles, while others believe the functions of ‘advocate’ and ‘provider’ should be kept separate, as each compromises the other (Fyfe, 2005). Whatever their role, voluntary organisations face similar challenges: a lack of resources; short-term funding; managing user expectations; and developing ‘meaningful’ partnerships with mainstream agencies (see Coid, Williams and Crombie., 2003). Little, however, is currently published, particularly with evidence to base practice, on the role of voluntary organisations and in particular the types of support they provide, the circumstances in which they provide that support, and the views of those who receive this support. This paper, by focusing on The UK Encephalitis Society, presents two studies: (A) patients’ experiences of neurological services; (B) an external evaluation of the Society’s current services. These provide insights into the challenges facing a voluntary organisation as they maintain their relevance within the changing context of welfare (see Scottish Council for Voluntary Organisations, 2002).

## **THE CONSEQUENCES OF ENCEPHALITIS**

Describing what encephalitis is, not only provides an initial context in which to make sense of the findings, but also explains some of the organisational principles, informing the operation of The Encephalitis Society. Encephalitis can occur at any age, usually as a result of a viral infection or by autoimmune

diseases affecting the brain. It is a life threatening illness. The initial stages commonly manifest as a serious and acute neurological illness, which leaves many people with a long standing, acquired brain injury, the degree and severity of which will vary (Raschilas, Wolff, Delatour, Chauffaut, De Broucker, Chevret, Lebon, Canton and Rozenberg., 2002). Rates of recovery differ from individual to individual but are probably less than for other types of brain injury (Moorthi, Schneider, Dombovy., 1999).

The consequences of Encephalitis and its impact remain poorly understood. People may be left with cognitive, physical, emotional, behavioural and social difficulties (Dowell, Easton and Solomon., 2001; ). Prognosis, however, is uncertain (Tyrer and Lievesley, 2003; Bajo and Fleminger., 2002). For some, significant changes in personality as well as day to day functioning can occur (McAvinue, O'Keeffe, McMackin and Robertson., 2005). Coming to terms with this can be very distressing and challenging (MacNiven, Poz, Bainbridge, Gracey and Wilson., 2003; Ponsford, Harrington, Olver and Roper., 2006). Those involved have, in effect, suffered a complicated form of bereavement and in some cases, loss of self (see Bury, Newbould and Taylor., 2005 for a broader discussion of these issues). Following encephalitis, people may view themselves differently: they are not quite the person they were before. Memory problems may result in a disturbing lack of continuity and order to one's life (McAvinue et al., 2005). Changes in personality, especially those involving loss of control over emotions, thoughts or actions, can be particularly disturbing (Foster and Tilse, 2003), especially for the family (Chwalisz and

Stark-Wroblewski, 1996; Simpson, Mohr and Redman., 1999; Man, 2002; Ponsford et al., 2003).

Service delivery remains patchy and although there are examples of good practice (Simpson et al., 1999), mainstream provision struggles to accommodate the complexity of encephalitis (Association of British Neurologists 2002; Butcher., 2002; Foster and Tilse., 2003; Foster and Tilse., 2004). This struggle explains the foundation of The Encephalitis Society in 1994 (Dowell et al., 2001). By providing information and offering mutual support, the Society's goal is to improve the quality of life of people affected directly and indirectly by encephalitis.

## **METHODOLOGY OF EVALUATION STUDIES:**

*Background:* To ensure validity (Ryan, Scott, Reeves, Bate, van Teijlingen, and Russell., 2000) and reflexivity (Alvesson and Sköldberg, 2004) we begin by discussing the methods. In the first instance, in offering accounts of its members, it can be sometimes difficult to disentangle the self-interest of the Society from the need to 'objectively' represent the experience of those affected by encephalitis. The survey of members, which informs the first study, is based on self-reporting and does not locate these accounts within the context of service delivery and – in particular - the views of health and social care professionals. Nor can we be sure that the membership list of the Society is representative of those affected by Encephalitis. Nonetheless, their surveys do represent the 'patient's viewpoint' and as such have a valuable contribution to make (see Department of Health, 2005). Further, the

membership list is one of the largest registers of people affected by encephalitis and as such is a justifiable sampling frame, particularly since few published papers in this area can be regarded as 'representative'. (It is rare, for example, for research to reflect ethnic, cultural and socio-economic diversity. For a broader discussion of these issues, see Hussain-Gambles, Leese, Atkin, Brown and Mason., 2004). This is a general reminder that research is as much about interpretation and critical appraisal than straightforward representation (see Bourdieu, 1990). To this extent, providing an ongoing commentary on the framework in which health and social care occurs is where the work of The Encephalitis Society acquires specific value.

*(A) Study of patients' experiences of neurological services:*

This study illustrates the Society's role in advocating on behalf of its members. During 2002 and 2003 the Association of British Neurologists (ABN) published two articles documenting the current provision of neurological services in the UK and suggesting appropriate standards of care. The Society wished to ascertain whether its members' experiences of neurological services matched those suggested by the ABN and therefore conducted an evaluation study. Those affected by encephalitis received a structured self-administered questionnaire, with closed, fixed responses. Respondents were guaranteed anonymity and assured that a non-response, would not affect the support provided to them. One thousand and eighty-eight questionnaires were distributed of which 339 (28.5 per cent) were returned. Fifty six per cent were from women and 70 per cent were from people aged

40 years or over. Analysis focused on providing simple descriptive frequencies.

*(B) An external evaluation of the Society's current services:*

The second study offers an evaluation, conducted by an independent organisation, of the Society's services. The evaluation focused primarily on the views and experiences of those using the support service: whether as adults affected; as parents of children affected; or as partners or family members. Data was collected through a postal survey and telephone interviews with a selected sample. All respondents were guaranteed anonymity.

The postal survey was targeted at people who had recently used the service and included 130 contacts made between February and April 2005. Contacts made in January, were used to pilot and refine the questionnaire. The questionnaire, containing 'closed' pre-coded responses, asked about the person's satisfaction with their contact with the Society, their views on the support they received, and the outcome of the contact. For reasons of confidentiality, the questionnaires were mailed out with a covering letter by the Society, but they were returned directly to the evaluators in prepaid envelopes. One hundred and forty-one questionnaires were sent out and 76 returned, giving a response rate of 55 per cent. The respondents included 29 adults with encephalitis, 19 relatives/family carers of adults (including partners) and 28 parents of children with encephalitis. Unfortunately, we do not have details on those who did not respond.

The postal survey also asked respondents if they were willing to be interviewed by telephone. Forty-one respondents volunteered for telephone interviews of which 21 people were theoretically sampled to reflect the range of people contacting The Society. The eventual sample included nine adults with encephalitis, six partners/ relatives/carers of adults with encephalitis and seven parents of children with encephalitis.

A topic guide, with open-ended questions, organised according to specific themes, was used to inform semi-structured telephone interviews, which asked people what they thought about their contact with the Society, particular in relation to their own experience of encephalitis. The topic guide also explored any outcome occurring because of their contact. Analysis, combining the quantitative and qualitative data sources (see Adamson, 2005), explored concepts; established linkages between concepts; and offered explanations for patterns or ranges of responses or observations from different sources (see Silverman, 2000).

## **Results**

### *(A) Study of patients' experiences of neurological services:*

Findings from the first study support the ABN's observation that the provision of neurology services is far from adequate. Further, the frequency and range of complications experienced by those with encephalitis highlight the importance of establishing nationally agreed standards of care.

In summary, over a half (54 per cent) of those who responded said that, when they were first diagnosed, their hospital treatment had been under the care of a neurologist, although fewer than half (45 per cent) said a neurologist had seen them within 24 hours of hospital admission. Further, only 39 per cent of those responding thought they had been cared for on a neurology ward. Sixty-five per cent of respondents had been given a definite diagnosis and of these 91 per cent had been given an encephalitis-related diagnosis, although nine per cent had been given other diagnoses, such as brain tumour, dementia, epilepsy, multiple sclerosis, and stroke. Thirty-four per cent of people, who have had encephalitis, however, say they leave hospital without a diagnosis. Moreover, for those with a diagnosis of encephalitis, fewer than one third (31 per cent) said they remembered being given information or advice about their condition. Ninety-six per cent of people reported they left hospital with ongoing complications, although less than one quarter (23 per cent) of those responding could remember having had a discharge-planning meeting and a third (33 per cent) said they received no out-patient follow-up (see Easton 2005).

*(B) An external evaluation of the Society's current services:*

The second study explores the Society's role in providing support. One hundred and thirty people contacted the Society during the three month period covered by the research and included similar proportions of adults with encephalitis (42 per cent) and family/friends (40 per cent) and a lower proportion of parents (18 per cent). Many people (70 per cent) said their contact with the Encephalitis Society was often their only source of

comprehensive information about encephalitis. Satisfaction was high with 89 per cent saying they had received all or most of the advice they had hoped for. Respondents particularly felt that clear explanations of how the condition may affect personality had been vital in restoring relationships within the family. One person with encephalitis commented: 'All [the] pieces of the jigsaw fell into place'. Another remarked: 'It was like the first hand that came out to us...I was so lost and frightened' (see Hare, 2005).

Participants also commented that information helped reduce feelings of isolation and helped them come to terms with the illness, adjust to the condition, accept its after-effects and come to terms with their future. A person with encephalitis remarked how contact with the Society helped him understand the after-effects of the illness and adopt a 'workable style of living with it'. Many respondents said they tended to use the service a number of times, coming back when they reached transitional points in their lives or when things were particularly difficult. A partner of a person with encephalitis remarked: 'It's given us a place to go'. Not only do the service users feel reassured and comforted by 'just talking to someone' but there are several examples of how advice and information have resulted in tangible outcomes; in terms of new treatment programmes, improved relationships or more confident self-management of the condition.

One of the services, provided by the Society, specifically enables its members to support each other, through its 'Link-Up' scheme. For many respondents this offered a reminder that they 'were not alone'. Such contacts also provide

a social purpose, particularly since one person with encephalitis pointed out 'all my friends seemed to have gone'. Such schemes, however, do not appeal to everyone. Individual context is important. One mother said she had not joined because she did not wish to 'compare' her son with 'others'. A husband said his wife had always been a private person and would not like to talk about her problems. A person with encephalitis said she wanted to move on from seeing herself as an 'ill person'. Another commented: 'I am frightened of coming across those who have progressed more'.

## **CONCLUSION**

Our first study suggests the Encephalitis Society performs a valuable advocacy role in presenting patient experience in ways that can help develop neurological support services. This aspect of their work helps ensure that health care agencies take seriously the needs of those affected by encephalitis. Presenting the experience of its members is especially useful in response to specific initiatives, such as those of the ABN as well as the more general provision of the National Service Framework for Long-term Conditions in their call for establishing standards of care.

Evidence from our second study suggests The Society's own support services are well thought of by those who use them and to this extent it shares many similarities with other voluntary organisations, providing support to those with long standing chronic conditions (see, Bury et al., 2005). Service users especially value information that helps them understand the condition and its

consequences; and gain reassurance from talking to someone who understands. This emphasises the importance placed by people and their families in understanding the cause of their difficulties (see Moorthi et al., 1999; Pisecky and Freund., 2003). Ongoing support, which responds to changes in a person circumstances was equally valuable (also see O'Connor, Cano, Thompson and Playford., 2005). More generally, this suggests the Encephalitis Society has an important role in supporting the rehabilitation of affected individuals and their families. In particular this may include rehabilitation frameworks that embrace the complex nature of acquired brain injury, for example a biopsychosocial model of rehabilitation (Williams and Evans., 2003).

Despite these successes, the Society faces ongoing challenges, as it constantly needs to re-interpret its role in relation to the needs of its members and the changing context of health and social care provision.

An immediate challenge is how to facilitate a meaningful relationship with health and social care professionals who provide care, while still maintaining a distance, which enables them to comment on existing provision. The Society is not especially interested in developing a critique of medical practice, in a way sustained by organisations influenced by a more social model of disability (see Barnes, Mercer and Shakespeare., 2000). Partnership working with enlightened practitioners is fundamental to the work of The Encephalitis Society and there is good general evidence to support this role. Successful service development often occurs as a consequence of such partnerships especially when such partnerships are used to remind health and social care

agencies of their obligations to provide care for ‘forgotten’ service users (Atkin, Rodney, Cheater and Anionwu., 2006). The Society, with its user-centred focus, can help support mainstream ‘service champions’ develop quality requirements associated with the National Service Framework for Long-term Conditions (Department of Health, 2005).

Further, the Society is not constrained by the bureaucracies associated with statutory provision and, therefore, has the potential to develop innovative forms of provision, particularly given the diversity of need among those who have had encephalitis. Resources, of course, remain a problem and ultimately limit activity. The Society is entirely contract funded and this sometimes means short-term expediency takes precedent over long-term strategy. This dilemma, faced by most voluntary organisations, can reduce effectiveness and requires careful management (see Coid et al., 2003; Ross-Barnett et al., in press).

Maintaining credibility and legitimacy among users and welfare providers is at the heart of a successful voluntary sector organisation. Philosophically, the society’s goal is to develop ‘communicative competence’ (see Habermas, 1987), which enables the organisation to speak with legitimacy and have this legitimacy recognised by others involved in the struggle to provide accessible and appropriate care for those affected by encephalitis (see Bourdieu, 1990). Developing strategies, on the basis of informed action, to contribute to this struggle continues to inform the role and purpose of the Encephalitis Society.

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