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‘A light in a very dark place’: The role of a voluntary organisation providing support for those affected by encephalitis

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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 valuable insights into the challenges facing voluntary organisations that represent the needs of those with neurological disorders. Two empirical studies are presented: a review conducted by the Society, focusing on patients’ 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 specifically supports the Association of British Neurologists’ recommendation for nationally agreed standards of care. The second study, based on a postal survey of recent contacts (n = 76) and in-depth telephone interviews (n = 22), demonstrates the Society’s value as a service provider and its role in helping to rehabilitate affected individuals and their families. In responding to these findings, the Encephalitis Society is reminded of the importance of maintaining credibility among its members as well as health care providers. Developing strategies, on the basis of informed action and partnership working with service champions, continues to inform the organisation’s sense of purpose, as it responds to the changing context of welfare provision in the UK.

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INTRODUCTION

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, & Henan, in press). The relationships between voluntary and statutory organisations have 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 & 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, they provide a “user-centred” forum that, by giving voice to the concerns of patients and their families (Crombie & Coid, 2000), contributes to participatory democracy (Taylor & Burt, 2005). By developing a broad commentary, voluntary organisations can become the “conscience” of health organisations, reminding them of the importance of providing care that meets the needs of specific service users (Dahlberg, 2006). Second, voluntary organisations can develop and provide support in parallel with mainstream organisations (see Ross Barnett, Pearce, & Howes, in press). They, therefore, become a provider of care, part of the fabric of the welfare state (see Wistow, Knapp, Hardy, & Allen, 1994).

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, & Crombie, 2003). Little, however, is written about 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 empirical studies: an external evaluation of the Society’s current services and a review of patients’ experiences of neurological services. Both examples provide valuable insights into the challenges facing a voluntary organisation as it struggles to maintain its 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 of the studies, but also explains some of the
organisational principles that inform 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 et al., 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, & Solomon, 2001). Prognosis, however, is uncertain (Tyrer & Lievesley, 2003). For some, significant changes in personality as well as day-to-day functioning can occur (McAvinue, O’Keeffe, McMachin, & Robertson, 2005). Coming to terms with this can be very distressing and challenging (Ponsford, Harrington, Olver, & Roper, 2006). Those involved have, in effect, suffered a complicated form of bereavement and in some cases, loss of self (see Bury, Newbould, & 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 & Tilse, 2003), especially for the family (Chwalisz & Stark-Wroblewski, 1996; Man, 2002; Ponsford, Olver, Ponsford, & Nelms, 2003; Simpson, Mohr, & Redman, 1999).

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 & Tilse, 2003). 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.

DATA COLLECTION

To ensure validity (Ryan et al., 2001) and reflexivity (Alvesson & Sköldberg, 2000) we begin by discussing the methods. In the first instance, in offering accounts of its members, it can sometimes be 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 that 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, & Mason, 2004.) This is a general reminder that research is as much about interpretation and critical appraisal as it is about 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 has specific value.

The first 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. 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. In total 1088 questionnaires were distributed of which 339 (28.5%) were returned. Of the responses, 56% were from women and 70% were from people aged 40 years or over. Analysis focused on providing simple descriptive frequencies.

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 with encephalitis, as parents of affected children, or as partners or family members. Data were 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 people’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 were returned directly to the evaluators in prepaid envelopes. A total of 141 questionnaires were sent out and 76 returned, giving a response rate of 55%. The respondents included 29 adults with encephalitis, 19 relatives/family carers of adults (including partners) and 28 parents of children with encephalitis. Unfortunately, no details are available for those who did not respond.
The postal survey also asked respondents if they were willing to be interviewed by telephone. Twenty-two 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, particularly 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 links between concepts, and offered explanations for patterns or ranges of responses or observations from different sources (see Silverman, 2001).

THE STUDIES

Advocating on behalf of members

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%) 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%) said a neurologist had seen them within 24 hours of hospital admission. Further, only 39% 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% had been given an encephalitis-related diagnosis and 9% 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%) 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%) of those responding could remember having had a discharge-planning meeting and a third (33%) said they received no out-patient follow-up.

Evaluating the Society’s support

The second study explored the Society’s role in providing support. During the three month period covered by the research 130 people contacted the Society
and included similar proportions of adults with encephalitis (42%) and family/friends (40%) and a lower proportion of parents (18%). Many people (70%) said their contact with the Encephalitis Society was often their only source of comprehensive information about encephalitis. Satisfaction was high with 89% 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.”

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 also there are several examples of how advice and information have resulted in tangible outcomes, in terms of new treatment programmes, improved relationships and more confident self-management of the condition.

One of the services, the “Link-Up” scheme, provided by the Society specifically enables its members to support each other. 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

The first study suggests that the Encephalitis Society performs a valuable advocacy role in presenting patient experience in ways that can help develop neurological support services. This aspect of the Society’s 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 the 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 that provide 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 they gain reassurance from talking to someone who understands. This emphasises the importance placed by people and their families on understanding the cause of their difficulties (see Moorthi et al., 1999; Pisecky & Freund, 2003). Ongoing support, which responds to changes in a person’s circumstances, was equally valuable (also see O’Connor, Cano, Thompson, & Playford, 2005). More generally, this suggests the Encephalitis Society has an important role in supporting the rehabilitation of affected individuals and their families.

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 that enables the Society 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, & 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, & Anionwu, 2006). The Society, with its user-centred focus, can help support mainstream “service champions” to 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 innovatory 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 precedence 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 (Atkin & Chattoo, in press). 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.

REFERENCES
