The Consequences of Encephalitis

**Report of a Postal Survey (Year 2000 survey)
carried out by the Encephalitis Support Group**

Elaine Dowell[1], Ava Easton[1], Tom Solomon[2]

[1] *Encephalitis Society, Malton, UK*
[2] *Department of Neurological Science, University of Liverpool, UK*

Background

Encephalitis is inflammation of the brain tissue. It can occur at any age in any part of the world and is caused by a variety of viruses, including the herpes simplex virus. The current identified incidence is 7.4 per 100,000 (Beghi E., Nicolosi A., Kurland L. T., Mulder D.W., Hauser A. and Schuster L. (1984) "Encephalitis and aseptic meningitis, Olstead County, Minnesota 1950-1981." Annals of Neurology, 283-294).

When untreated, the mortality rate for those acquiring encephalitis is high, but the development of antiviral and other supportive treatments means that many more patients are now surviving.

In spite of this, there is little data on the long-term consequences of viral encephalitis for patients and their families, though it is known that these include muscle weakness, epilepsy, speech and communication disorders, and difficulties with memory, learning, concentration and understanding.

Introduction

The Encephalitis Support Group was established in 1994, the name was changed in 2003 to The Encephalitis Society. It is a UK based charity with international links.

The Aim of the Society is to improve the quality of life of all people affected directly and indirectly by encephalitis.

It fulfils this aim by -

- Supporting individuals, both adults and children, and families of people affected by encephalitis; and promoting better services;
- Raising awareness about the condition and its subsequent problems - among relevant professionals, statutory agencies and the wider public; and
- Promoting research into encephalitis.

To address these aims the group operates a telephone advice service; provides direct support to individuals; produces and disseminates written information about encephalitis; arranges regular meetings and conferences across the UK; and raises funds for research into the disease.

Aims and Methodology

The purpose of the research described in this report was to investigate the consequences of encephalitis and their impact on the quality of life of people affected, their families and carers.

A questionnaire was designed by the Encephelitis Support Group, and distributed to all its 1200 members in January 2000.

Groups were compared using the Chi squared test, taking $p<0.05$ as statistically significant.

Findings

A total of 400 (33%) of the questionnaires were returned, relating to the experiences of 261 people who had contracted encephalitis as adults and 139 who had contracted it as children.

Diagnosis

38% of those who had contracted the disease as adults and 24% of those who had contracted the disease as children reported that their encephalitis had been diagnosed as due to herpes simplex virus.

Resuming a 'Normal Life'

The majority of both groups reported that they did not feel they had been able to 'fully resume their normal life'. This included 72% of those who had contracted the disease as children, and a slightly lower number (69%) of those who had contracted the disease as adults.

Financial Impacts

Nearly two-thirds (61%) of those who had contracted the disease as adults reported that their illness had resulted in a fall in income for them or their families.

Almost twice as many adults were unemployed after their illness as were prior to it. Two-thirds of those who were in employment before their illness reported that they were not working at the time of the survey.

Educational Impacts

44% of those who contracted the illness as children had a statement of special educational needs and/or attended a school or college for young people with special educational needs.

Almost a half (47%) of those who had contracted the illness in childhood reported epilepsy resulting from the encephalitis. These respondents were well over twice as likely to have a 'statement of special educational needs' and/or to attend a school or college for children / young people with special educational needs (62% compared to 27%, $p<0.001$)

Relationship Breakdown

208 respondents reported that they had been either married or in a stable relationship before their illness. Of these 20% had experienced breakdown of that relationship since the illness.

Other Difficulties

53% of those who had contracted the disease as children and 39% of those who had contracted the disease as adults were in receipt of Disability Living Allowance (DLA), indicating that they required significant assistance or regular supervision with personal care tasks and/or had very limited mobility.

Those who had been diagnosed with herpes simplex encephalitis were significantly more likely to be in receipt of DLA than those who were not (48% compared to 34%, p=0.05), suggesting that herpes simplex encephalitis is more likely to cause long-term disability than other forms of the disease.

Respondents were given a list of 23 problems potentially experienced by people who have contracted encephalitis.

The most common problem for those who had contracted encephalitis as adults, reported by over 80% of the respondents, was tiredness/fatigue. This was followed by concentration and attention difficulties; frustration and anger; anxiety; specific memory problems; mood swings and depression.

Over half of these respondents also reported difficulties with one or more of the following:

- planning and problem-solving
- short-term memory
- word-finding
- headaches
- balance

Those who had contracted encephalitis during childhood repored a slightly different pattern of problems and difficulties. It should be noted that it was usually their parents who completed the questionnaire rather than the children themselves.

Psychosocial difficulties

The findings showed that concentration and attention problems were seen as the most common problem for those who had contracted the disease as children. This was closely followed by tiredness/fatigue; mood swings; and frustration and anger. Significantly more difficulties with new learning were reported for children than for adults ($p<0.001$), but significantly fewer problems with short term memory, planning and problem-solving ($p<0.05$ for each).

Problem	% of Adults	% of Children
Short-term memory	57	44
Long-term memory	45	40
Specific memory	61	37
Planning/problem-solving	57	47
Word-finding difficulties	56	58
New Learning	44	60

Similar levels of difficulties with concentration and attention, and with frustration and anger, were reported for children and adults. However, initiative and motivation problems appeared to effect over twice as many children as adults:

Problem	% of Adults	% of Children
Concentration/attention	70	72
Initiative/motivation	19	46
Frustration/anger	68	65

Important emotional impacts related to the condition were reported for both children and adults. However, whereas mood swings were the most common manifestation for children, more adults suffered from depression and anxiety:

Problem	% of Adults	% of Children
Depression	58	35
Mood swings	59	66
Anxiety	67	55

Physical impairment

With regard to sensory and motor function, significantly more difficulties with fine motor function were reported for those who had contracted encephalitis as children than as adults ($p<0.05$), (though gross motor function was almost at the same level), and with co-ordination ($p<0.05$) - but fewer problems with impaired senses and balance.

Problem	% of Adults	% of Children
Impaired senses	30	22
Gross motor function	38	39
Fine motor function	19	40
Co-ordination	42	50
Balance	52	45
Vision	31	32
Light/sound sensitivity	46	48

There were significant differences in the physical impacts of the condition. Those who had contracted the condition as children were almost twice as likely to be affected by epilepsy ($p<0.05$), while reporting of tiredness/fatigue was much higher for adults:

Problem	% of Adults	% of C hildren
Epilepsy	26	47
Headaches	55	49
Tiredness/fatigue	80	68

Conclusions and Recommendations

This study shows that survivors of encephalitis have severe psychological and social impairment, in addition to physical disability. Our study was limited by the fact that it relied on self reporting, or reporting by a family member, nevertheless it suggests that the consequences of encephalitis may differ according to the age of the patient, and the cause of the encephalitis. Adults who survived encephalitis suffered not only in terms of employment, but also in terms of relationship breakdowns. Encephalitis had a marked impact on children's education, especially those who had also developed epilepsy. More work is needed to define further the consequences of encephalitis. Those involved in the rehabilitation of survivors of encephalitis need to be aware of the specific difficulties they are likely to suffer.

Correspondence should be sent to: Elaine Dowell - Information Coordinator

Encephalitis Resource Centre · 7B Saville Street · Malton · North Yorkshire · YO17 7LL · United Kingdom
Information: +44 (0)1653 699 599 · Administration: +44 (0)1653 692 583 · Fax: +44 (0)1653 604 369
Email: mail@encephalitis.info · Website: www.encephalitis.info

The Year 2000 survey was funded by the friends and family of Gordon Graffin.