

Psychosocial outcome

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Epilepsy can have far reaching psychological and social ramifications and for some individuals these can be more debilitating than the seizures^{1,2}. Awareness of the psychosocial problems which may arise is essential for professionals working with people with epilepsy and their families. Such difficulties can have a profound impact on a person's mental health and also upon seizure control. Greater recognition of the wider impact of epilepsy is also needed to enable the development and targeting of appropriate services and support. This chapter reviews some of the potential areas of difficulty and, in particular, focuses on topics not addressed elsewhere in this volume.

Education

The majority of children with epilepsy attend mainstream schools, although evidence exists of underachievement in certain subject areas, including reading, spelling and arithmetic. Additionally, young people with epilepsy appear to do less well than their peers in terms of educational qualifications³.

Academic difficulties arise for many reasons and useful generalisations about children with epilepsy are difficult to make. Most attention has focused upon seizure-related factors, with poor educational prognosis being associated with early age of onset and a long seizure history, especially where seizure control has proved problematic. Seizure type also exerts an influence. Dominant hemisphere disturbances are more likely to affect language-related skills. Other factors which should be considered as possible causes of underachievement include the occurrence of nocturnal attacks, brief epileptic discharges, and high levels of medication and polypharmacy.

Other psychosocial variables have been implicated, including teacher and parental expectations, misconceptions about epilepsy, absence from school, low self-esteem, and anxiety due to stresses at home. Until recently these factors have been rather neglected⁴. Table I provides suggestions for minimising the impact of these factors on the schoolchild with epilepsy.

Employment (see also Chapter 53)

Existing evidence suggests that people with epilepsy experience high levels of unemployment and underemployment. Employment problems are not simply due to seizures, rather they may be a result of personal and social factors, including discrimination, stigma, passive coping styles and low self-efficacy interacting with one another in a complex manner^{5,6}.

Work has many functions aside from financial rewards. It provides a way of structuring time and, more importantly, contributes to a person's identity and feelings of self-worth.

Table I. Ways of maximising the academic and social development of the schoolchild with epilepsy.

1. Establish good communication channels between:
 - School
 - Doctor
 - Family

 2. Education about epilepsy for:
 - Teachers
 - Pupils
 - The family
 - The child with epilepsy

 3. Encourage a positive self-image:
 - Increase chances of success
 - Avoid unnecessary restrictions
 - Provide reliable career advice

 4. Minimise time off school for:
 - Clinic appointments
 - Seizure recovery

 5. Ensure full education:
 - Explore nursery places
 - Encourage tertiary education

 6. Sensitive monitoring:
 - Detect difficulties early
 - Detailed neuropsychological assessment
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Employed people with epilepsy experience fewer psychosocial problems than unemployed people with epilepsy⁷.

People with disabilities in general are vulnerable to employment difficulties, particularly at times of economic recession. If paid employment seems increasingly unobtainable, then alternatives should be sought to enable people to make a meaningful contribution to society. Unfortunately, in our experience of young people with intractable epilepsy, many have had no structured daily activity since leaving school and no prospects of such until they reach retirement age. Interventions focusing on vocational rehabilitation, increasing self-efficacy and coping skills have been recommended⁵.

Family life

People with epilepsy do not live in a vacuum; the attitudes and experiences of family members will greatly influence how someone copes. The potential impact of epilepsy on the family is difficult to gauge and is likely to be variable. Research studies have found lower parent-child relationship quality, higher rates of depression in mothers and problems with family functioning in association with epilepsy⁸.

Parents may be overprotective through fear of injury or death. Families may harbour misconceptions about epilepsy and thus become socially isolated for fear of adverse public reactions. The attitudes and understanding of families should therefore form a prominent part of any treatment programme. Provision of accurate information about a child's epilepsy may go a long way to allay significant anxieties, but the opportunity for emotional support may also be valuable. Support is particularly important within the first few months following a diagnosis⁹.

Little attention has been given to the possible impact on the family of a parent with seizures. Parents and potential parents with epilepsy often express doubts about their suitability for such a role and mothers may have the greatest concerns. Fears expressed include the potential inheritability of epilepsy and the possibility that antiepileptic drugs may lead to birth defects¹⁰. As children grow older, parental vigilance may intensify as a watch is kept for any behaviour or physical sign that might herald the onset of epilepsy in their child. Older children may behave over protectively towards the parent with epilepsy and may exhibit worrying behaviours, such non-attendance school.

Social networks

In a survey of young people with poorly controlled seizures, we found a major concern was lack of social contacts, particularly friendships, and activities outside the parental home or outside parental supervision. The ability to form friendships and develop social networks greatly influences how effectively we cope in society. Social support is an established positive mediating factor which irrespective of seizure control has been shown to be related to a better quality of life, life satisfaction and health status^{11,12}. Social isolation in people with poorly controlled seizures should therefore be a major cause of concern.

Many factors may underlie social isolation including anxiety, parental over-protectiveness and lack of employment and a dearth of activities outside the home. Anxiety may make people with epilepsy not only fearful of making social contacts but it may adversely affect social presentation. A very anxious person can appear awkward, and even rude, in social situations. Where anxiety underlies social difficulties, stress management programmes may be offered which can improve social functioning.

Stigma can also negatively impact on the development of friendships. People with epilepsy may avoid socialising for fear of having seizures in front of others. In a survey of almost 20,000 young people in the USA two-thirds stated they would not date a person with epilepsy and the authors concluded that the social environment for adolescents with epilepsy is characterised by stigma and lack of accurate knowledge about the condition¹³.

People with epilepsy should be encouraged to reap the benefits of social networking sites, epilepsy forums and support groups. These outlets can provide emotional support, contacts and information, and may help to reduce isolation. However, on their own they may not be enough and some people may benefit from cognitive behavioural therapy (CBT) and other interventions aimed at reducing social anxiety and developing social skills.

Neuropsychological deficits (see also Chapter 41)

People with epilepsy are at increased risk for disorders of cognitive function and memory impairments are the most frequently voiced¹⁴. Cognitive difficulties will reduce the chances of academic success and reduce employment opportunities. For individuals experiencing academic or employment problems, a thorough assessment as early as possible is advised to help identify any cognitive difficulties which may exist. The results enable the setting of

realistic employment and educational goals. Furthermore, when difficulties are found it may be possible to devise strategies to improve functioning in daily life¹⁵. Memory problems also impact on self image and in turn self-esteem. Our memories define our sense of who we are and our relationships with other people. Memory deficits may lead to a loss of confidence in social settings and feelings of inadequacy.

Emotional adjustment

Living with epilepsy means coping with an uncertain prognosis regarding seizure control.. Epilepsy carries increased risks of mortality and morbidity. Having epilepsy may mean coping with additional hidden deficits such as language and memory problems, or with a dual diagnosis, a learning disability being the most frequent co-morbidity.

Diagnosis and prognosis aside, individuals have to cope with ongoing seizures. For some, these may be rare, short-lived episodes, but for others, epileptic attacks may involve bizarre behaviours, distorted awareness and perception, and embarrassing aspects such as incontinence. The unpredictability of the majority of seizures is sufficient to erode self confidence and self-esteem, even when events are infrequent. Public misunderstandings and stigma cause additional stress.

Individuals also have to adjust to long-term drug treatment and accompanying side effects which may include weight gain, acne, unwanted facial hair, irritability and cognitive disturbances. These aspects may become more stressful at certain times of development, with adolescence being a vulnerable period. Many with poorly controlled seizures have to endure successive treatment failures and the accompanying emotional highs and lows as hopes are raised with the introduction of a new drug only to be dashed when seizures return. Potentially more damaging psychologically is the failure of surgical treatment (which can arise in approximately one-third of cases), particularly when this follows several years of freedom from seizures.

Anxiety and depression are over-represented in individuals with epilepsy but undertreated^{16,17} (see Chapter 16). A recent survey of professionals working with people with epilepsy identified managing psychological and emotional effects of epilepsy as one of the greatest challenges¹⁸. NICE guidelines recommend CBT to treat depression and anxiety and recent studies indicate potential benefit in epilepsy^{19,20}. A recent pilot study combining cognitive therapy with mindfulness utilising the telephone and internet has shown some promise regarding mood improvements and in promoting the development of social support networks²¹.

Recommendations

Greater awareness is needed of the broader impact of epilepsy. Improved training of health professionals is required, as are resources for public awareness campaigns²². Anxiety and other negative reactions are more likely to develop when people have partial and/or inaccurate information. People need pertinent, individually tailored information about seizures, treatment and lifestyle. Research has indicated that many issues could be resolved by better information, the availability of counselling and other emotional support²³. Input is needed not only at the time of diagnosis. Epilepsy is a complex disorder and the need and nature of support will change over time. In the UK there has been an expansion of the role of the epilepsy nurse specialist to provide education and information and this has been positively received by people with epilepsy and their families.

Approaches developed need to encourage people with epilepsy and their families to form social networks and local support systems. Active participation in this process is essential to

increase feelings of control and to reduce the feelings of passivity that having epilepsy can engender. Awareness of, and early identification of, emotional disorders will hopefully enable quick referral to agencies trained to deal with problems of psychological adjustment.

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