

Psychosocial outcome

PAMELA J. THOMPSON

National Hospital for Neurology and Neurosurgery and UCL Institute of Neurology,
Queen Square, London, and Epilepsy Society, Chalfont St Peter, Gerrards Cross,
Buckinghamshire

Increasingly epilepsy is being viewed as a spectrum disorder that carries a high risk of co-morbidities and negative psychosocial ramifications¹. Good seizure control does not necessarily confer positive outcomes². Awareness of potential psychosocial problems is essential for professionals working with people with epilepsy and their families. Such difficulties can have a profound impact on 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 areas where difficulties may arise 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 impoverished academic progress^{2,3}. Academic difficulties arise for many reasons and useful generalisations about children with epilepsy are difficult to make. Low educational attainments have been associated with an early age of onset and poor seizure control. Focal epilepsy affecting the dominant hemisphere may impede the development of language-related skills such as reading and spelling. Other factors of likely significance include nocturnal attacks disrupting sleep, frequent brief epileptic discharges and a high medication load.

Psychosocial variables are also potential disrupters of educational progress. These include teacher and parental expectations, misconceptions about epilepsy, high absence rates from school, low self-esteem, and anxiety due to stresses at home. Table 1 provides suggestions for minimising the impact of these factors on the child and adolescent with epilepsy.

Employment (see also Chapter 53)

Rates of unemployment and underemployment are elevated in people with epilepsy. Poor seizure control is one cause but employment difficulties also arise due to personal and social factors, including discrimination, stigma, passive coping styles, low self-esteem, mood disorders, cognitive difficulties and an inability to drive⁴.

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. Unemployment is associated with an increased risk of psychosocial problems.

People with disabilities in general are vulnerable to employment difficulties, particularly at times of economic recession. If paid employment is not a current option, then alternatives should be sought to enable people to make a meaningful contribution to society. Research has demonstrated the efficacy of vocational rehabilitation programmes for people with epilepsy but unfortunately these are not widely available⁵.

Table 1. 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 careers 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
-

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 functioning⁶.

Parents may be overprotective through fear of injury or death. Families may harbour misconceptions about epilepsy and may become socially isolated due to concerns about adverse public reactions. The attitudes and understanding of families should be a prominent part of epilepsy management. Provision of accurate information about an individual's epilepsy may go a long way to allay anxieties but emotional support may be needed, particularly when the person or family are socially isolated.

Little attention has been given to the possible impact on the family of a parent with epilepsy. Parents and potential parents often raise doubts about their suitability and mothers express

the greatest concerns. Fears expressed include the potential inheritability of epilepsy and the possibility that antiepileptic drugs may lead to birth defects⁷. 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 as non-attendance school.

Social networks

Children and young people with epilepsy report concerns regarding difficulties forming friendships⁸. The ability to develop effective social networks greatly influences how 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. A recent population-based study found that the people most debilitated by their epilepsy were those that had limited social support⁹.

Many factors may underlie social isolation, including anxiety, parental over-protectiveness, lack of employment and limited activities outside the home. Anxiety may impact on social presentation; a very anxious person may appear awkward, and even rude. Where anxiety underlies social difficulties, stress management techniques may have a role.

Stigma may impede the development of social networks. 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 condition¹⁰.

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 feelings of isolation. In addition, some people may benefit from cognitive behavioural therapy (CBT) and other interventions aimed at reducing social anxiety and developing social skills¹¹.

Neuropsychological deficits (see also Chapter 41)

People with epilepsy have an increased risk of cognitive deficits. Much attention has been focused on memory impairments but more recently disorders of social cognition have been highlighted¹². Cognitive difficulties will reduce the chances of academic success and reduce employment opportunities. For individuals experiencing problems, a neuropsychological assessment may help to identify cognitive difficulties and may assist in the setting of realistic employment and educational goals. Memory deficits may lead to a loss of confidence in social settings and feelings of inadequacy. Memory rehabilitation that addresses the broader impact of memory disorders may prove beneficial¹³.

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 other co-morbidities.

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 seizures may erode self confidence and self-esteem. Public misunderstandings and stigma cause additional stress.

Individuals also have to adjust to long-term drug treatment and accompanying side effects such as 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 as damaging psychologically is the failure of surgical treatment, particularly when this follows several years of freedom from seizures.

Anxiety and depression are over-represented in individuals with epilepsy but are under-treated^{11,14,15} (see also Chapter 16). A survey of professionals identified managing the psychological and emotional effects of epilepsy as one of the greatest challenges¹⁶. NICE guidelines recommend CBT to treat depression and anxiety and there are studies that support its value in epilepsy^{17,18}. In the UK the Improving Access to Psychological Therapies programme has resulted in an expansion in the numbers of CBT therapists available. These can be accessed via the GP and other health professionals, with most services accepting self-referrals.

Recommendations

Greater awareness is needed of the wider impact of epilepsy. Improved training of health professionals is indicated, as are resources for public awareness campaigns. Emotional adjustment difficulties are more likely to develop in the context of incomplete and inaccurate information. People need pertinent, individually tailored information about seizures, treatment and lifestyle. 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.

References

1. QUINTAS R, RAGGI A, GIOVANNETTI AM et al (2012) Psychosocial difficulties in people with epilepsy: A systematic review from 2005 until 2010. *Epilepsy Behav* 25, 60-67.
2. CAMFIELD PR, CAMFIELD CS (2014) What happens to children with epilepsy when they become adults. *Pediatr Neurol* 51,17-23.
3. SILLANPAA M, CROSS H (2009) The psychosocial impact of epilepsy in childhood. *Epilepsy Behav* 15, S5-S10.
4. SMEETS V, VAN LIEROP B, VANHOUTVIN J, ALDENKAMP A, NIJHUIS F (2007) Epilepsy and employment: literature review. *Epilepsy Behav* 10, 354-362.
5. THORBECKE R, MAY TW, KOCH-STOECKER S, EBNER A, BIEN CG, SPECHT U (2014) Effects of an inpatient rehabilitation program after temporal lobe surgery and other factors on employment two years after epilepsy surgery. *Epilepsia* 55, 725-733.
6. RODENBURG R, MEIJER AM, DEKOVIC M, ALDENKAMP A (2005) Family factors and psychopathology in children with epilepsy: A literature review. *Epilepsy Behav* 6, 488-503.
7. PENNEL PB, THOMPSON PJ (2009) Gender-specific psychosocial impact of living with epilepsy. *Epilepsy Behav* 15, S20-S25.
8. KERR C, NIXON A, ANGALAKUDITI M (2011) The impact of epilepsy on children's and adult patients' lives: Development of a conceptual model from qualitative literature. *Seizure* 20, 764-774.
9. LU B, ELLIOTT, JO (2012) Beyond seizures and medications: Normal activity limitations, social support and mental health in epilepsy. *Epilepsia* 53, e25-e28.
10. AUSTIN JK, SHAFER PO, DEERING JB (2002) Epilepsy familiarity, knowledge and perceptions of stigma: report from a survey of adolescents in the general population. *Epilepsy Behav* 3, 368-375.
11. KIMISKIDIS KK, VALETA T (2012) Epilepsy and anxiety: epidemiology, classification, aetiology and treatment. *Epileptic Disord* 14, 248-256.
12. THOMPSON P (2014) The importance of theory of mind in epilepsy. *Epilepsy Behav* 39, 143-144.
13. KOORENHOF L, BAXENDALE S, SMITH N, THOMPSON P (2012) Memory rehabilitation and brain training for surgical temporal lobe epilepsy patients: a preliminary report. *Seizure* 21, 178-182.
14. RAI D, KERR MP, McMANUS S, JORDANOVA V, LEWIS G, BRUGHA TS (2012) Epilepsy and psychiatric co-morbidity: A nationally representative population based study. *Epilepsia* 53, 1095-1103.
15. KWON OY, PARK SP (2014) Depression and anxiety in people with epilepsy. *J Clin Neurol* 10, 175-188.
16. CLARK N, STOLL S, YOUATT E, SWEETMAN M, DERRY R, GORELICK A (2010). Fostering epilepsy self-management: The perspectives of professionals. *Epilepsy Behav* 19, 255-263.
17. MACRODIMITRIS S, WERSHLER J, HATFIELD M et al (2011) Group cognitive-behavioural therapy for

- patients with epilepsy and comorbid depression and anxiety. *Epilepsy Behav* 20, 83-88.
18. CARBONE L, PLEGUE M, BARNES A, SHELLHAAS R (2014) Improving the mental health of adolescents with epilepsy through a group cognitive behavioural therapy program. *Epilepsy Behav* 39 130-134.