Children with epilepsy and their families: Psychosocial issues

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Abstract

This article commences with the psychological effects of epilepsy on children, followed by the typical emotional problems experienced by parents of children with epilepsy. Subsequently the roles and responsibilities of parents during the various developmental stages of children with epilepsy are discussed. The effect of childhood epilepsy on family life as well as on the siblings is described. Coping strategies that could be helpful to parents of children with epilepsy are briefly discussed. Finally, the importance of a trusting relationship between the family with an epileptic child and their family practitioner is highlighted and recommendations are made in this regard.

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Introduction

It is estimated that 1 in every 100 South Africans suffers from epilepsy.[1] Although the prevalence rate of epilepsy in South African children could not be established, approximately half of the patients who develop epilepsy do so before the age of 15. [2] The mortality rate in patients with epilepsy is two- to threefold higher than in the general population, which makes treatment essential once epilepsy has been diagnosed.[2,3] The diagnosis and treatment of epilepsy in childhood are complex and the family practitioner will probably refer the child to a paediatrician or paediatric neurologist for basic decisions in this regard.[2] However, the family practitioner will probably remain closely involved in follow-up treatment as the primary care physician.[4]

Epilepsy has various negative consequences which involve many areas of the child's life. Many of these negative consequences are related to the stigma associated with epilepsy.[5,6] Research on lay attitudes towards people with epilepsy has revealed that they are perceived as sexually deviant, antisocial, aggressive, potentially violent, mentally ill and unattractive.[7,8] Being teased by peers is painful and humiliating and may leave deep emotional scars that interfere with the child's social and emotional development.[9]

Psychological effects of epilepsy on children

Research on children and adolescents with epilepsy has revealed a high incidence of psychiatric, psychological and behavioural difficulties.[10] Psychopathology is more than four times more prevalent in these children than in children in the general population.[11] Children with epilepsy are often overwhelmed by feelings of embarrassment, frustration and helplessness and display resultant fearfulness, dependence and demanding behaviour.[12] Anxiety, depression and concomitant social withdrawal are highly prevalent in these children.[13] Long-term follow-up studies of epileptic children showed an increased risk of unemployment, a significant possibility of completing only six or fewer years of school, social isolation, financial dependence, and less likelihood of getting married than a matched control sample.[14,15]

Typical emotional problems of parents of children with epilepsy

Most parents are extremely upset when their child is diagnosed with epilepsy, mainly because of the stigma associated with the condition. Typical parental responses are shock, devastation, anger, frustration, sorrow and depression.[16,17] Witnessing a seizure in one's young child, especially a tonic-clonic seizure, can be one of the most anxiety-provoking experiences for a parent.[9] It usually leads to feelings of helplessness and fear and often results in overprotection or overindulgence of the child.[4,18] Parents often fear divulging their child's epilepsy to their friends and relatives because they experience a sense of shame, self-blame and rejection. They consequently withdraw from their relatives and social circle. Mothers may fear that the child's epilepsy is due to neglect during pregnancy. Feelings of guilt and inadequacy develop, leading to further loss of self-esteem. Due to their anxious withdrawal from others, parents risk increasing isolation and loss of social support.[4,16,18] Parents may grieve the loss of a "normal" child and this bereavement process may become pathological.[17] Higher divorce rates have been reported among parents of children with epilepsy than in the general population.[9,12]

As the child grows older, parental stress is likely to increase due to management difficulties, financial demands and increased concern about the child's future. The addition of behavioural problems, a common occurrence in adolescents with epilepsy, may further increase stress and burden.[12] Parents of children with epilepsy and comorbid mental retardation experience even more intense stress because of the increased the risk of injuries. Parents may become physically and psychologically exhausted, having to provide almost constant care.[4,19] In a South African study among parents of children with Down Syndrome, it was found that depression was present in almost a quarter of a sample of these parents, and nearly half of them experienced above average anxiety levels.[20]

Roles and responsibilities of parents of children with epilepsy

The most basic role of parents is to provide a safe psychological and physical environment from which the child can explore the world and master the developmental tasks of childhood and adolescence. The unsuccessful negotiation of the stressors attached to epilepsy prevents the child from adapting successfully to his/her condition and hampers normal personality development. This leads to psychosocial adjustment problems throughout childhood, continuing into adulthood.[11] Parents play the most significant role in helping the child with epilepsy adapt to his/her condition. In practical terms their functions include seeking treatment, ensuring the child's compliance with treatment, facilitating the child's functioning in and outside the home, and regulating the impact of other people's attitudes on the child.[9,11,17]

The nature of parents' roles changes during the course of the child's developmental stages. During infancy and early childhood children need an environment where they can develop autonomy and initiative. If parents' response to the diagnosis of epilepsy is overprotection and overindulgence, the child is deprived of experiencing feelings of competence and developing life skills.[11]

The developmental tasks of middle childhood include becoming more independent of parents and more attached to peers. During this stage it is crucial for the child's psychosocial development to be actively involved in peer groups and to achieve success in the school environment. Epilepsy can interfere with these tasks. Unless the parents' attitude is positive, constructive and empowering, the child will feel different from peers, withdraw from peer groups and develop poor self-esteem.[11,17,21]

Adolescence is the period during which the child's identity as an individual in his/her own right should be consolidated. Achieving independence from parents, establishing healthy interpersonal relationships outside the family and choosing a vocation are essential developmental tasks of adolescence.[17] In a South African study of stress and coping among healthy adolescents, it was found that concern about a future career was one of their two most prevalent stressors.[22] For an adolescent with epilepsy, worrying about finding employment probably causes even more severe stress. Overprotection may result in failure to develop a sense of self-competence, which in turn leads to poor self-esteem and a self-perception of being "different". Seizures and having to take anti-epileptic medication may lead to a sense of physical incompetence. An adolescent with epilepsy may withdraw, become depressed or display behaviour problems in response to his/her condition.[17,21] In each of the three above-mentioned developmental stages, constructive parental responses to the child's condition is crucial to successful mastery of developmental tasks.

The effect of childhood epilepsy on family life

Childhood epilepsy impacts on the entire family, because the demands for change and the use of family resources increase. This may lead to an increase in family stress and disruption. A chronic illness with unpredictable characteristics like epilepsy puts a family at risk for poor communication, poor cohesiveness and poor integration. The burden of care may fall more heavily on one member, which may lead to resentment and increased family tension. Plans for the future are often placed on hold. The family may spend less time enjoying activities outside the home, fearing that the child may have a seizure, and inviting friends to the home may come to an end.[18,23] One parent may have to end his/her employment outside the home to take care of the child, which may lead to a reduced income for the family and therefore the reduction of pleasurable activities. Having a child with epilepsy incurs many expenses, since specialist consultations, medication and special investigations are costly. For parents who live in rural areas, transport to and from the hospital or medical centre and the cost of child care for the children left at home bring additional expenses.[9,24,25]

Siblings in families with an epileptic child have been found to be more disturbed than siblings in a control group and appear to be at greater risk for psychiatric disturbances.[9,12,18] It is common for parents of a child with a chronic illness to neglect their other healthy children. As a result siblings often have difficulty adapting and sibling rivalry may be exacerbated.[4] Siblings may miss out on school activities and face many disappointments, since activities in which the epileptic child may not participate may be terminated.[18,23]

Coping strategies

Previous South African studies in other research populations revealed significant positive correlations between avoidant coping strategies and anxiety as well as depression, in contrast with significant negative correlations between problem-solving coping strategies and anxiety as well as depression in parents of children with Down Syndrome [20] and in adults caring for depressed spouses.[26] In parents of children with epilepsy, effective problem-solving coping strategies as opposed to avoidant coping strategies should likewise help to diminish psychological distress. Parents who feel able to handle their child's illness and who feel that they have the necessary skills to deal effectively with seizures, experience less burden and stress.[27]

Conclusion and recommendations

Childhood epilepsy has serious and far-reaching psychosocial sequelae for the patient and his/her family. In this regard the family practitioner can play an invaluable role by providing useful knowledge, guidance and support. Without a collaborative relationship of mutual trust between the family practitioner, the parents and the child, compliance is compromised and treatment outcome is often less successful.[17,21] Especially while the child is still young, the parents are the essential source of collateral information and feedback about the number and severity of seizures, the efficacy of medication and its side-effects. Parents attach great value to advice and suggestions from their family practitioner, who should therefore form a key component of the family's support system throughout.

The child's first seizures and the initial consultations with specialists, which necessarily involve unfamiliar vocabulary, perplexing questions and intimidating procedures, often leave the parents with feelings of fear, inadequacy and helplessness. Parental anxiety may interfere with their ability to comprehend and recall information and instructions about treatment.[17] During this period of confusion and uncertainty, consultations with the family practitioner are invaluable and should provide parents with the opportunity to share feelings that are causing them distress without fear of rejection or minimization of their pain and anguish. It is advisable for the family practitioner to adopt a primarily person-centered approach in his/her encounters with the child and the parents. [28] This approach, with its core characteristics of acceptance, empathic listening and genuineness, has the optimal chance of establishing a relationship of credibility and trust.[29] Acceptance of the parents' emotional reactions of grief, anger, fear or guilt is essential to facilitate parents' coming to terms with their situation. Parents also need the emotional support of their family practitioner when having to negotiate appropriate restrictions on their child's activities and when being faced with difficult decisions such as whether new treatment options, e.g. surgical treatment which to them may seem terrifying, should be explored.[30,31]

Whenever possible, both parents should accompany the child during consultations, so that they can have a shared understanding of what has been said.[21] The family practitioner should explain all aspects and implications of the condition and treatment to the parents on their level of comprehension. A sense of crisis should be avoided and discussion time should be maximized. [17] Verbal information can be supplemented with written information. Valuable guidebooks for parents are available and can be recommended.[4,16,21] The family practitioner should not hesitate to refer the child, the parents or the entire family for individual, marital or family psychotherapy if indications of psychological problems in coping with the situation are evident. A team approach with close cooperation between the family practitioner, the psychotherapist and the family will greatly benefit treatment outcome.

The family practitioner should encourage active involvement of the whole family from the outset. Knowledge about epilepsy and its implications and taking shared responsibility for treatment promote a sense of control and competency among family members. When the child is five or six years old, he/she can be encouraged to develop an attitude of scientific adventure about his/her condition.[17] If parents perceive themselves as capable of dealing with the demands and challenges of caregiving, they will experience a greater sense of well-being, less dysfunction and less life stress.[4,12] The family practitioner remains one of the family's major resources in coping with the inevitable stress attached to caring for a child with epilepsy.

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