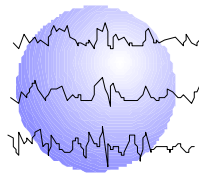


THE IMPACT OF CARING FOR A CHILD WITH EPILEPSY: A PARENT'S PERSPECTIVE

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REVISED ABSTRACT

RATIONALE

Although many parents encounter stressors while raising a child with epilepsy, little is known about how parents are impacted by this experience. The objective of this investigation was to explore parents' perceptions of the social, emotional, financial and spiritual impact that results from caring for a child with epilepsy.

METHODS

Participants were 25 parents (7M; 18F) whose child was admitted to a children's inpatient epilepsy unit for evaluation and treatment. Parents ranged in age from 25 to 48 years. Most participants who completed the questionnaire were married (n=18) including six married couples. The participants' children with epilepsy (10M; 9F), ranged in age from 1 to 18 years (median=7 years). Time since seizure onset ranged from newly diagnosed to 15 years (median=4 years). The children experienced one to multiple seizure types. Seizure frequency ranged from one to hundreds per week. Children were treated with mono- or poly-anticonvulsant therapy. Parents were asked if they were willing to complete a survey that included checklists, open-ended and scaled score questions regarding family demographics, stressors, and the impact of caring for a child with epilepsy. Parents were excluded if medical staff reported that comprehension of the questionnaire may have been difficult due to language or cognitive abilities.

RESULTS

Many parents (48%) noted an increase in tension with their spouse/partner due to caring for their child with epilepsy, while 28% noted that their relationship had been strengthened. Similarly, 32% reported feeling a close relationship with their child; however, parents tended to treat their child with epilepsy differently (e.g., overprotective). Of those parents with additional children, 44% noted fewer opportunities to provide them time or attention. Relationships with extended family members were primarily described as supportive (52%), yet a majority of parents (84%) reported a marked change in their social life (e.g., less free time, spend most time with their family). Taking time off from work was the most frequently cited change noted by parents employed outside the home (57%). A majority of parents (60%) also noted a change in their family's financial circumstances due to expenses related to the child's care. 72% reported that caring for a child with epilepsy resulted in increased stress or symptoms of depression or anxiety; however, most parents (80%) described themselves as doing "OK" or able to cope with stress more effectively. Of those parents who noted a change in their spirituality, 57% stated their experiences had deepened their faith. When asked to describe the most stressful part about caring for their child with epilepsy, 32% noted the uncertainty associated with their child's illness. Finally, 60% of parents reported feeling moderately overwhelmed with the care their child with epilepsy requires.

CONCLUSION

These results suggest that parents of children with epilepsy experience marked social, emotional, financial and spiritual changes as a result of caring for their child with epilepsy. Although these results are based on a limited number of participants and are considered preliminary, these findings have implications for the types of services these families may require. In addition, these results may help healthcare providers appreciate the experiences of families.

INTRODUCTION

Many parents of children with epilepsy experience stress associated with caring for their child; however, little is known about what aspects of their child's care parents perceive as stressful and how this experience alters a caregiver's life. Thus, the present investigation explores parents' perceptions of how caring for a child with epilepsy impacts their lives socially, emotionally, financially and spiritually and what parents identify as the most salient stressor associated with their child's care.

METHODS

Participants: Participants were 25 parents (7 males; 18 females) of patients from the Minnesota Epilepsy Group, P.A. whose child was admitted to the inpatient Pediatric Epilepsy Unit of Children's Hospital and Clinics (St. Paul, Minnesota) for evaluation and treatment. Parents ranged in age from 25 to 48 years (median=36.5 years). Most of the parents who completed the questionnaire (n=18) were married, including six married couples. Within the family home, the number of siblings living in the same household ranged from zero to four.

The participants' children with epilepsy (10 males; 9 females), ranged in age from 1 to 18 years (median=7 years). Time since seizure onset ranged from newly diagnosed to 15 years (median=4 years). The children with epilepsy experienced up to four seizure types (i.e., infantile spasms, simple partial, complex partial, generalized tonic-clonic, myoclonic, absence, and tonic seizures). Seizure frequency ranged from one to hundreds per week. Children were treated with mono- or poly-anticonvulsant therapy (up to five anticonvulsants). In addition, 12 of the children (63%) were taking up to three additional medications for other health-related issues (e.g., gastrointestinal difficulties, allergies, sleep problems).

Procedures: Parents were approached during their child's hospitalization and asked if they were willing to complete a survey that included checklists, open-ended, and scaled score questions regarding family demographics, the impact of caring for a child with epilepsy, and stressors the parent may have experienced in the past year. The current study reports responses to a subset of questions from the survey (Table 1). All parents approached agreed to participate; however, the number of questionnaires returned was approximately 63%. Some parents were not invited to participate if medical staff reported that comprehension of the questionnaire may have been difficult due to language or cognitive abilities of the parent. With the exception of one parent, all caregivers completed the questionnaire prior to their child's discharge from the hospital.

RESULTS

The most frequent responses to questions concerning the social impact of caring for a child with epilepsy are illustrated in Figure 1. 48% of participants noted an increase in tension with their spouse/partner. Factors identified as contributing to increased tension included disagreements related to the child's care (e.g., amount of supervision, discipline) or stress associated with the child's treatment (e.g., long-term hospitalizations). In contrast, 28% of participants noted that their relationship with their spouse/partner had

been strengthened. Many parents (32%) described themselves as closer to their child with epilepsy; however, often parents treated this child differently (e.g., more tolerant of misbehavior, overprotective). Of those parents with other children (n=18), 44% reported fewer opportunities to provide sibling(s) time and attention. A majority of parents (52%) perceived their relationship with extended family members as supportive or closer as a result of their child's illness. Finally, most parents (84%) reported that caring for their child with epilepsy had altered their social life (e.g., fewer opportunities to socialize outside the family because of less free time or reluctance to leave their child with epilepsy).

Figure 2 presents frequent responses regarding the career and financial impact of caring for a child with epilepsy. 57% of employed parents (n=21) noted an increase in time away from work. Interestingly, 3 of the 4 parents not employed outside of the home stated that they were not employed because of the care their child for epilepsy requires. A majority of parents (60%) also experienced a decrease in their family's disposable income due to illness-related expenses (e.g., insurance deductibles, uncovered services) and time away from work without pay. Please see Table 3.

Common responses relating to emotional impact are presented in Figure 3. 72% of parents reported that caring for a child with epilepsy is often stressful. In addition, some parents (36%) reported feeling frequent symptoms commonly associated with mood and anxiety disorders (e.g., feel "depressed," "worry a lot,"). When asked how overwhelmed parents feel about caring for their child with epilepsy, 60% (n=15) reported feeling at least moderately overwhelmed. Despite an apparent increase in stress, 80% of parents described themselves as coping "OK" or able to cope with stress more effectively.

Of those parents who described a change in their spirituality, religious beliefs or faith as a result of caring for their child with epilepsy (n=14), 57% described their faith as "deeper" or "stronger" while 36% reported having questioned or doubted their religious or spiritual beliefs.

When asked to identify the most stressful part of caring for their child with epilepsy, 32% of parents noted the level of uncertainty associated with their child's illness. For example, parents wonder what is causing their child's seizures and whether their child's seizure control will improve. Parents also experienced stress due to concern that their child may have a seizure at "any time." An additional 20% of parents identified the care their child requires (e.g., level of supervision, following treatment recommendations) as the most salient stressor while 16% of parents described their child's lack of or decrease in seizure control. Finally, 8% of parents identified a decrease in disposable income as the most stressful aspect of caring for their child with epilepsy (Figure 4).

CONCLUSIONS

- Parents of children with epilepsy reported a marked emotional impact including increased stress and feelings of being overwhelmed; however, most parents feel able to cope
- The social impact of caring for a child with epilepsy includes increased tension with spouse/partner, less time to spend with other children, and fewer opportunities to socialize with friends
- A majority of parents reported increased time away from work and less disposable income
- Coping with the uncertainty associated with their child's illness is the most salient stressor for many parents

Figure 1 SOCIAL IMPACT OF CARING FOR A CHILD WITH EPILEPSY

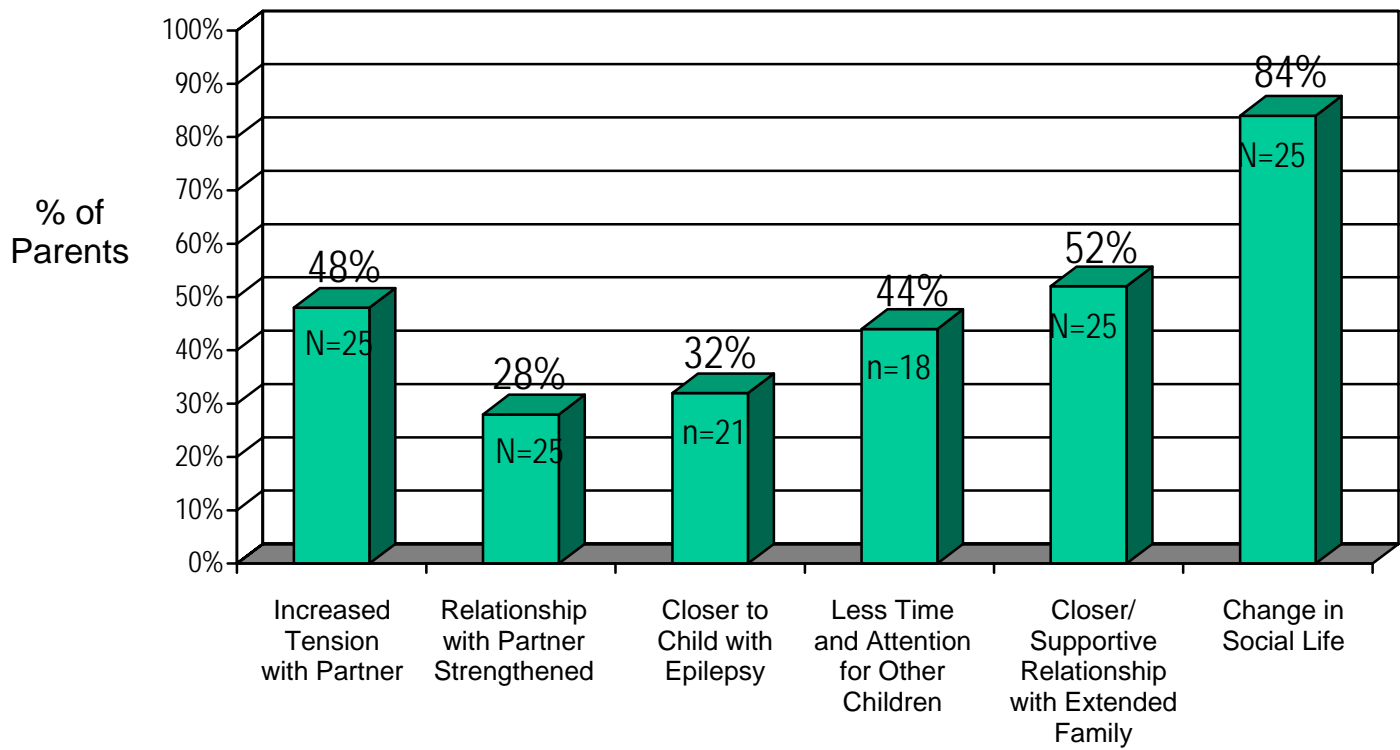


Figure 2 CAREER AND FINANCIAL IMPACT OF CARING FOR A CHILD WITH EPILEPSY

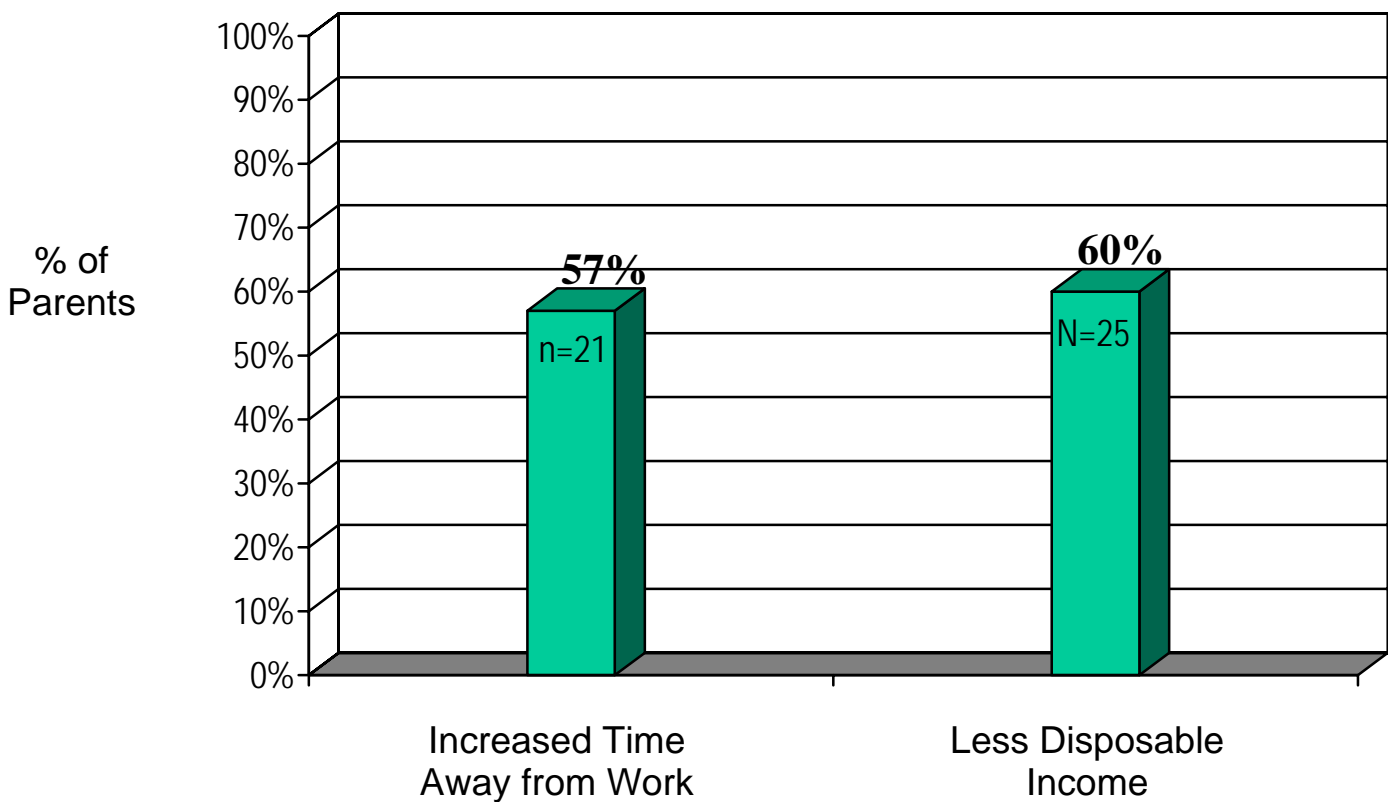


Figure 3

EMOTIONAL IMPACT OF CARING FOR A CHILD WITH EPILEPSY

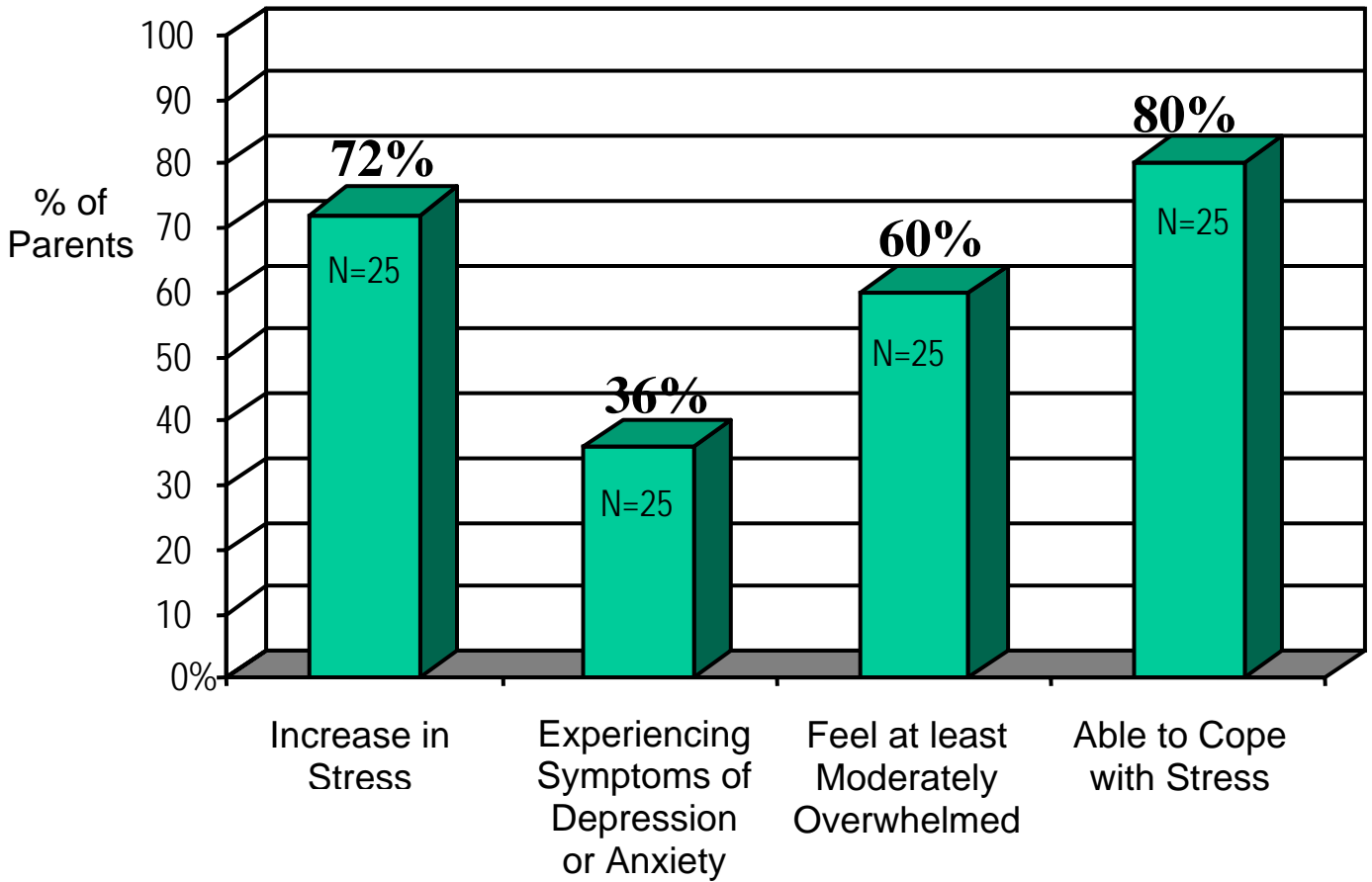


Figure 4

MOST SALIENT STRESSOR ASSOCIATED WITH CARING FOR A CHILD WITH EPILEPSY

