Stressors of Caregivers of School-Age Children With Epilepsy and Use of Community Resources

Gladys Saburi

ABSTRACT

Childhood epilepsy causes multiple stressors, difficulty in adjustment, and disruptions in family relations. This study sought to identify stressors of caregivers of school-age children and to assess whether use of community resources alleviates or contributes to caregiver stress. Stressors refer to concern about the child, communication with healthcare providers, changes in family relationships, interaction with school, and support within the community. A caregiver refers to the person who had looked after the child for the past 6–12 months. Support groups, religious or worship groups, counseling services, and traditional and spiritual faith healers were the community resources that were addressed. Face-to-face interviews were conducted on a convenience sample of 46 caregivers. A three-part structured interview schedule was used to describe demographic data, stressors of caregivers, and use of community resources. The top 6 stressors were the inability to get antiepileptic drugs, the deep pain or sadness caused by the child’s seizures, caregiving (which was predominantly by mothers), limited help from the extended family, inadequate information on side effects of drugs, and inadequate information on seizures. The most commonly used community resource was religious or worship groups, with epilepsy support groups being least used. To alleviate caregiver stress, it is important that healthcare providers routinely assess the effect of seizures on caregivers and refer those requiring counseling, advocate for more male and extended family involvement in caregiving and provide adequate information on side effects of drugs and on seizures as standard practice. Nurses in developed countries should incorporate religious activities among complementary and alternative medicine interventions to reduce caregiver stress. Spiritual faith healers should be encouraged to refer clients with epilepsy for drug therapy and counseling.

Parents of children with disabilities face special child care demands that cause significant stress and disruptions in family relationships (Floyd & Gallagher, 1997). Epilepsy differs from other chronic conditions because of the stigma surrounding it (Pal, 2003). Eighty percent of 30 million children with epilepsy live in developing countries such as Zimbabwe, and most of the children go untreated because of the lack of affordable, accessible, and available healthcare (Pal, Nandy, & Sander, 1999; World Health Organization [WHO], 2004). Beliefs in traditional treatment of epilepsy further contribute to the underutilization of modern medical health services, resulting in greater disability and mortality in Africa than elsewhere (WHO, 2004).

Zimbabwe is a Southern African country with an estimated population of 11.6 million according to the last census of 2002. The prevalence rate of epilepsy at the time of the study in 2008 was unknown.

Primary care services for patients with epilepsy are provided by rural health centers and clinics through a referral system to the district, provincial, and tertiary hospitals for specialist care. The exodus of skilled health and social workers to the developed countries and inadequate diagnostic facilities have seriously undermined the delivery of healthcare by both public and private sectors.

Specifically, the channeling of scarce resources to HIV and AIDS and maternal and child health interventions has left neurological diseases with little attention in terms of healthcare (Mielke, Sebit, & Adamolekun, 2000). Difficulties with using public transport were cited by a third of those who attended an epilepsy clinic in Harare, presumably because of financial hardships (Mielke et al., 2000). Furthermore, the study was conducted during a severe economic crisis with hyperinflation, exorbitant clinic or hospital fees, and lack of drugs or supplies. Yet, the ability to access appropriate support services to cope with the child’s needs has been identified as key to successful adaptation (Floyd & Gallagher, 1997).

Recommendation of Buelow, McNelis, Shore, and Austin (2006) for the need to assess family stressors provided an impetus for this study in order to improve caregivers’ adjustment to the child’s
epilepsy, thereby improving the lives of the children. Little has been done to identify stressors of caregivers of school-age children with epilepsy in Zimbabwe. Specifically, anecdotal evidence from a mother of a school-age child with epilepsy prompted the investigator when the mother recounted her family’s lived experience at the launch of the 2006 epilepsy awareness campaign.

Social support from the community might help parents to meet the demands of caring for their child and decrease parental stress (Buelow et al., 2006). Community resources addressed in this study were religious or worship groups, counseling services, and support groups. Traditional and spiritual faith healers were included to accommodate some sociocultural aspects. The purpose of this descriptive study was to identify stressors of caregivers of school-age children with epilepsy and assess whether use of community resources alleviates or contributes to caregiver stress. Findings from the study may help identify areas in which caregivers are most in need of support and information that might be useful during counseling, so that they are better placed to meet the emotional needs of their children (Austin, Dunn, Johnson, & Perkins, 2004).

**Literature Review**

**Stressors of Caregivers**

Cross-cultural studies have lent support to the burden imposed on caregivers of children with epilepsy. In the United States, epilepsy and the burden it causes directly affect parent-child relationships and contributes to child behavior problems (Austin et al., 2004; Pianta & Lothman, 1994). In developing countries, childhood epilepsy has far reaching consequences for parents because of multiple stressors, difficulty in adjustment, and societal beliefs about hereditary transmission (Pal, 2003).

The sources of stress identified by Buelow et al. (2006) provided a modified framework for this study, namely, concern about the child, communication with healthcare providers, changes in family relationships, interactions with school, and support within the community. According to Pal (2003), alleviating parental stress and helping them to cope with the child’s diagnosis is a critical component of intervention in developing countries.

**Concern About the Child**

Austin et al. (2004) found that, in the United States, worries about the child’s future and fears about the child’s seizures were among four key parental needs at 65.2% and 66.7%, respectively. Lack of skills to live independently and worry about the potential consequences of seizures were stressors for all 20 primary caregivers of children with epilepsy and intellectual disability (Buelow et al., 2006). Caregivers in developing countries tended to be overprotective and restrictive of the child’s activities (Butau & Piachaud, 1993; Pal, 2003), increasing the caregiver burden. Among the Chinese, epilepsy caused sadness and depression among family members who emphasized their own adversity as being equal to or even greater than the patient’s experience (Kleinman et al., 1995).

**Communication With Healthcare Providers**

Austin et al. (2004) reported parents’ greater need for information or support as being positively associated with anxiety and depression in the children ($p < .0311$) and that receiving encouragement and support from others was one of four key parental needs. The preoccupation of clinicians with the drug management of epilepsy and disinterest in side effects of drugs, school problems, child socialization, relations in the nuclear family, and the future course of the condition, which is consistently documented in developed countries (Buelow et al., 2006; Schneider & Conrad, 1981; Suurmeijer, Reuvekamp, & Aldenkamp, 2001) can contribute to caregiver stress. Moreover, nurses were cited as being unhelpful and lacked time to provide information (Hartshorn & Byers, 1994).

Equivalent studies in developing countries show mixed findings. Doctors in Oman, a developing Arab country, were sympathetic to people with epilepsy (Al-Adawi et al., 2002). The authors attributed this finding to chronic illness receiving sympathetic acceptance in traditional communities, alleviating stress. In contrast, in a rural setting in Kenya, Kendal-Taylor, Kathomi, Rimbah, and Newton (2009) found doctor–patient interaction limited, communication frequently strained, and patients guarded in sharing their information. Healthcare that is provided on incomplete information can be erroneous, compounding stress.

**Changes in Family Relationships**

Epilepsy can impact negatively on many aspects of the child and family (Camfield, Breau, & Camfield,
2001). In the United States, Buelow et al. (2006) identified sources of stress as poor marital communication; sibling anger toward the ill sibling; grandparents, aunts, and uncles who were not comfortable with giving care to the child with epilepsy; and leisure time activities, which were affected. Across cultures, the burden of caregiving falls predominantly on mothers, and female caregivers may be subjected to more stress (Austin et al., 2004; Mrabet, Mrabet, Zouari, & Ghachem, 2004; Pianta & Lothman, 1994) as they also bear the greater share of child rearing responsibilities (Sriram, 1993). Moreover, in some developing societies, mothers are frequently blamed for the birth of a child with disability (Singhi, Goyal, Pershad, Singhi, & Walia, 1990), and being blamed can be stressful.

**Interaction With School**

In the United States, Buelow et al. (2006) cited poor communication with school as a source of parental stress, whereas Butau and Piachaud (1993) reported that parents in Zimbabwe avoided talking to the schoolteacher about the child’s epilepsy with a mean score of 1.8 of 5. Failure to address caregiver concerns can be a source of stress. Furthermore, Buelow et al. found that only 15% of the parents were happy with the way their children were being educated and cared for and that most parents were discouraged that the children were not equipped with relevant transition skills such as how money and time work and how to balance a checkbook. This deprives the children of the ability to live independently as adults, increasing the caregiver burden. Another area of concern was lack of acceptability of the child by peers, which impacts negatively on the child’s self-esteem and may prevent the child from reaching his or her full potential, increasing parental stress.

In India, education was reported as the first casualty by Pal (2003), as one third of children attending urban clinics had been expelled or withdrawn from school because of their seizures. Similarly, Butau and Piachaud (1993) reported that 32% of children with epilepsy in Zimbabwe were out of school because of the seizures at the instigation of parents and school authorities, which also contributes to dependence. Whereas less than half of secondary school students in Tanzania would allow their sibling to play with a child with epilepsy because of fear of contagion (Matuja & Rwiza, 1994), Mielke, Adamolekun, Ball, and Mundanda (1997) found that 82% of teachers in Zimbabwe would allow their own children to play with a child with epilepsy, which minimizes parental stress.

**Support Within the Community**

Social support from the community might help parents meet the demands of caring for their child and decrease parental stress (Buelow et al., 2006). The authors reported that many mothers in the United States were stressed by needing to leave work to pick up the child at school and were frequently absent from work because of the child’s condition. Similarly, Kleinman et al. (1995) noted that, in China, time spent in caregiving hinders one from generating income and limited reserves are used up, creating or deepening debt, and this often means the difference between receiving treatment and not, contributing to stress. Few parents in the United States felt family counseling would have been useful to save their marriage and to help the siblings (Buelow et al., 2006), yet counseling has been identified as an essential intervention for dysfunctional family relationships (Hartshom & Byers, 1994). These parents deprived themselves of the benefits of counseling because of lack of insight, although lack of resources for counseling people with epilepsy and their caregivers in developing countries (Al-Adawi et al., 2002; Mbuba & Newton, 2009) may be contributory.

**Use of Community Resources**

Cross-culturally, secrecy has been identified as one of the negative strategies used by families to manage epilepsy (Raty, Hamrin, & Soderfeldt, 1999; Saburi, Mapanga, & Mapanga, 2006; Scambler & Hopkins, 1990) and limits the use of social support. A supportive environment is considered a second major determinant (after the disease process itself) of the psychosocial status of the patient (Suurmeijer et al., 2001). Anecdotal evidence from the mother at the epilepsy awareness campaign launch pointed to isolation of the family by friends and neighbors because of the child’s epilepsy, which can be a source of stress.

Austin et al. (2004) reported that, in the United States, support groups with other parents provide opportunities to discuss concerns about their children’s future, thereby alleviating stress. Similarly, they help to break down fears mothers in developing countries have about their children’s abilities and vulnerabilities (Pal, 2003). Locally, community support groups initiated by the Epilepsy Support Foundation (ESF) enable people with epilepsy and their caregivers to find emotional and practical assistance in the form of medical care and income-generating projects (Mielke et al., 2000).

Herbs and supplements are used in addition to conventional treatment of epilepsy in the United States, but nondisclosure is common (Kennedy,
Wang, & Wu, 2007) and may lead to adverse drug interactions. Liow et al. (2007) found that prayer or spirituality was the most commonly used form of complementary and alternative medicine (CAM) in epilepsy in the midwestern United States, followed by “mega” vitamins, chiropractic care, and stress management. The authors acknowledged that this pattern of CAM use may be slightly different than in other regions of the United States and elsewhere.

The positive role religion plays in health is acknowledged cross-culturally. According to Ignatavicius, Workman, and Mishler (1999), a strong faith in God, prayer, increased religious activity, and an acceptance of God’s will may generally help reduce the perception of stress. Specifically, recent research in some African countries has highlighted how submission to God’s will makes clients with epilepsy more accepting of the illness (Mrabet et al., 2004; Saburi et al., 2006), thereby alleviating stress.

In Zimbabwe, therapy from traditional healers usually involves the family and is culturally acceptable, minimizing conflict. Traditional healers are usually consulted first before seeking pharmacological treatment (Butau & Piachaud, 1993) to counteract the witchcraft, which families believe to be the cause of the condition (Kleinman et al., 1995). Seeking of pharmacological treatment may be delayed with a consequent worsening of the prognosis (Butau & Piachaud, 1993), increasing caregiver stress. Banerjee and Banerjee (1995) reported that most of those who chose indigenous healers as their first contact treatment facility did so on the decision of the family, which can be a source of stress.

Faith healers have strong social and religious connections but may play a negative role (Aziz, 2007). They largely believe prayer can cure all ailments and reportedly misled some clients into prematurely stopping their ARVs (Ochai, 2008). They could similarly influence lack of adherence to antiepileptic drugs (AEDs), worsening the prognosis. Butau and Piachaud (1993) found that traditional healers were sought first for treatment, with the least sought being faith healers. Identifying stressors of caregivers and evaluating use of and reasons for joining the community resources may yield information that may help caregivers meet the demands of caring for their children, thereby decreasing stress.

Methods
This descriptive cross-sectional study sought to identify stressors of caregivers of school-age children with epilepsy and to evaluate use of community resources. Participants were recruited from the ESF clinic at the George Nicholas Rehabilitation Center and from Parirenyatwa Central Hospital in Harare.

Sample
A convenience sample of 46 caregivers was interviewed. To be included in the study, the caregiver must have looked after a school-age child for the past year; Shona speaking; and not on anxiolytics, antidepressants, or antipsychotics. The child was aged from 6 to 17 years, diagnosed with epilepsy for more than a year, and on AEDs.

Procedure
The study was approved by the social worker in charge at ESF, the Joint Parirenyatwa Hospital and College of Health Sciences Research Ethics Committee, and the Medical Research Council of Zimbabwe. A three-part interview schedule was developed by the author to elicit demographic data, identify stressors of caregivers, and assess use of community resources. Demographic data addressed caregivers’ relationship to child, gender, age, religion, marital status, occupation, place of residence, monthly family income, educational level, and ESF membership. The child’s demographic data was elicited from the caregiver and encompassed the child’s age, gender, age at onset of epilepsy, age at diagnosis, school grade or form, class type, duration of epilepsy, seizure type, medications taken, number of seizures in past 3 months, and type of injuries sustained in the last 12 months.

Stressors of Caregivers
Stressors of caregivers were measured on the basis of the five categories of Buelow et al. (2006), which were adapted, and additional items from literature that were added. Concern about the child comprised of four items. Items 1, 3, and 4 were open-ended such as follows: What are your worries about the child’s future? In what ways do your child’s seizures affect you? What do you fear most that can happen to your child because of seizures? Item 2 was closed-ended, requiring a ‘yes’ or ‘no’ response to “Do you think your child will always have to live with you?” A follow-up question was “What makes you think like that?”

Communication with healthcare providers comprised four closed-ended items such as follows: Do doctors and nurses show interest in your family relationships, child’s school achievements, and child’s problems (Buelow et al., 2006; Scambler & Hopkins, 1990)? Which of the following information have you been given about the drugs which control seizures: how to take drugs, how the drugs work, and how often to take them? Have you been told about the side effects that can occur because of these drugs? Do you think you have been given enough information about the child’s seizures? All items required
yes’ or ‘no’ responses. Caregivers needed to state the side effects they were told for a positive response to item 3 and further information they required for a negative response to item 4. There were six closed-ended items on changes in family relationships such as follows: Do you think the child’s seizures affect your relationship with your spouse or partner? Do you think the child’s seizures affect the child’s relationship with the brothers and sisters? Does your family attend social events like parties, weddings, church, or family gatherings? Do you talk openly about your child’s seizures to members of the extended family? Do you think the child’s seizures affect your relationships with the extended family? Does the extended family help you in caring for the child? All items required ‘yes’ or ‘no’ responses. Explanations were required for either positive or negative responses to items 1, 3, 5, and 6 and for a positive response to item 2.

Interactions with the school comprised four closed-ended items such as follows: Do you feel schoolteachers and other school personnel address your concerns about the child adequately? Do you talk openly about your child’s seizures (Saburi et al., 2006; Scambler & Hopkins, 1990) to schoolteachers and other school personnel? Do you feel your child’s learning needs are being met? Is your child able to make friends? All items required ‘yes’ or ‘no’ responses. Explanations were required for either positive or negative responses to items 1, 3, and 4. There were five items on support within the community. Items 1, 3, 4, and 5 were closed-ended such as follows: Are you employed away from home? Are you able to get drugs for treating the seizures easily? Does your family feel accepted by friends and neighbors? Do you talk openly about the child’s seizures to your friends and neighbors? The four items required ‘yes’ or ‘no’ responses. Explanations were required for either positive or negative responses to items 1 and 5 and for a negative response to item 3. Item 2 was open-ended such as “What effect have the child’s seizures had on your family finances?” with a follow-up question of “If you experience problems with money, what do you do?”

**Use of Community Resources**

Use of community resources comprised five closed-ended items. In items 1 and 2, caregivers were asked, “Do you belong to an epilepsy support group?” (Austin et al., 2004; Mielke et al., 2000) and “Do you belong to any religious or worship group?” (Mrabet et al., 2004; Saburi et al., 2006), respectively. For positive responses, caregivers had to indicate what made them join such a group and in what way belonging to such a group helped them to deal with the child’s seizures. In item 3, caregivers responded to “Have you ever received counseling because of the child’s seizures?” (Buelow et al., 2006). For a positive response, caregivers had to indicate where the services were offered, the reason for the counseling, in what way counseling helped them deal with the child’s seizures, and whether their spouse or partner was present during counseling. In items 4 and 5, caregivers were asked, “Has your family consulted traditional and spiritual faith healers for the child’s seizures?” (Butau & Piachaud, 1993; Kleinman et al., 1995). For positive responses, caregivers needed to indicate whose decision it was to consult the healers (Banerjee & Banerjee, 1995) and in what way consulting them helped them deal with the child’s seizures.

The interview schedule was translated from English to Shona and was back-translated by the social worker in charge at the ESF to ensure the accuracy of the translated version. Pretesting was done to assess the reliability and validity of the instrument and to evaluate its clarity and cultural relevance. During the face-to-face interviews, questions were further prompted to clarify information that was not clear.

After consulting the social worker in charge, 26 caregivers were selected from the register at the ESF clinic. The center provides medication, information and literature, advocacy, computer training skills, and counseling; assists with work placements in companies; and coordinates the support groups. A list of the caregivers with children who fitted the inclusion criteria was compiled. After obtaining informed consent, participants were interviewed as they reported for services to reduce transport costs.

Similarly, after seeking permission from the consultant in charge of the epilepsy clinic at Parirenyatwa Central Hospital, 20 caregivers were interviewed as they reported for services. The hospital offers specialist services, and the epilepsy clinic is conducted in the outpatient department twice a month. Clients of all age groups and from different settings are reviewed in the clinic upon referral. Interviews lasted approximately 40 minutes and were conducted privately before the patient’s consultation. All information from the study was confidential and only available to the investigator. Original data were stored in a locked cabinet for safekeeping.

**Data Analysis**

The first research question “What are the stressors of caregivers of school-age children with epilepsy?” and the second research question “What is the extent of use of community resources by caregivers of school-age children with epilepsy?” were analyzed using descriptive statistics to identify types of
stressors and frequency of use of community resources. Closed-ended questions were categorized, for example, as 1 for male gender and 2 for female gender. Similarly, responses to dichotomous questions were categorized as 1 for yes and 2 for no. Open-ended questions and “please explain” or “give the reason” option elicited qualitative data. The responses were transferred from words into numerical symbols that were computerized. Numbers assigned to each question were recorded in a codebook to document the location and value of every variable entered in the computer files. The Statistical Package for Social Sciences (SPSS Inc., Chicago, IL) was used for the analyses.

Findings
Demographic Characteristics
The sample of the caregivers (N = 46) was predominantly mothers, married, Harare urban residents, self-employed, and members of the Apostolic sects and the ESF. Children (N = 46) had a mean duration of 13 months from onset of seizures to diagnosis of epilepsy. All children were in school, and 35 were in regular classes. Most children were either on phenobarbitone or carbamazepine. Thirty-five children had not experienced any epilepsy-related injuries in the past 12 months. The seizure type was unknown by 35 caregivers.

Stressors of Caregivers
Stressors are presented in rank order for each category, with the most distressful to the least distressful. Responses to “please explain” or “give reasons” are not shown in the tables.

| TABLE 1. Stressors of Caregivers: Concerns About the Child (N = 46) |
|-----------------|------|------|
| Factor          | n    | %    |
| Effect of seizures on caregiver |      |      |
| Deeply pained   | 33   | 71.7 |
| Living with caregivers forever |      |      |
| Yes             | 27   | 58.7 |
| Most feared consequences of seizures |      |      |
| Road traffic accidents, drowning or burns | 22   | 47.9 |
| Child’s future  |      |      |
| Ability to fend for self | 15   | 32.6 |

Concern About the Child
The child’s seizures caused deep pain and sadness for 33 caregivers (Table 1). Twenty-seven caregivers feared that the child would live with them forever because of worry about seizures occurring in their absence. Twenty-two cited road traffic accidents, drowning, or burns as the most feared consequences of seizures, whereas the rest cited physical disability from falls, death, cognitive impairment, sexual abuse, and dependency. Fifteen caregivers worried about the child’s ability to fend for self in their absence or death, whereas the rest worried about possibilities of a good education, marriage prospects, and whether the condition was curable.

Communication With Healthcare Providers
Table 2 shows that only 27 caregivers were given adequate information on side effects of drugs and seizures. Twenty-eight healthcare providers showed interest in family relationships, and 31 showed interest in child’s school achievements and problems. Thirty-three caregivers received information on how drugs work, and 44 had information on how to take drugs and the frequency of taking drugs. The rest were keen to know whether the child would ever stop taking tablets; whether epilepsy is curable; the types, causes, and prevention of seizures; and diet and exercises. One caregiver even thought that temporal lobe epilepsy meant that epilepsy was temporary in nature.

Changes in Family Relationships
Twenty-six caregivers received help from the extended family (Table 2) in the form of money for drugs, hospital fees, transport and groceries, emotional support, looking after the child in their absence, and visiting the child. This finding implies limited support, and the prevailing hyperinflationary environment could have contributed. Thirty-three caregivers indicated that relationships with the extended family were not affected because they had accepted the child’s condition. Reasons given by those with strained relationships included fear of contagion to children, seizures being attributed to the maternal side, and accusations of sourcing seizures from traditional healers in exchange for supernatural powers.

Thirty caregivers reported that sibling relationships were not affected as siblings were brought together by the child’s seizures and supported the child when taking drugs. On the negative side, some siblings regarded the child as a “fool” who could not carry out routine chores, whereas others were overprotective. Twenty-eight caregivers indicated that relationships with spouse or partner were not
Affected. Caregivers in affected relationships cited fathers who lacked patience with the child, abandoned the family at birth of a disabled child, hated the child, and blamed the seizures on the maternal side. One mother moved from the marital bed to sleep with the child before AEDs controlled the seizures. Forty-five caregivers reported that they disclosed the child’s seizures to the extended family and all caregivers attended social events, with church attendance being predominant.

**Interaction With School**

Table 2 showed that 29 caregivers were satisfied that the children’s learning needs were being met. The rest were unhappy because the children were unable to read or write their names and were left to learn vernacular language; to draw; and to do drama, singing, and sports. Thirty-one caregivers felt that their concerns were addressed adequately, that the children were treated like other children, attended to after a seizure, and had their problems listened to. However, some school personnel paid little attention to children with epilepsy in normal classes and ridiculed them, and one child was even accused of faking the seizures.

Thirty-six caregivers reported that the children were able to make friends. Some friends assisted during a seizure and knew the warning signs. Caregivers of children who played alone reported that the children were laughed at by other children and were isolated because of the inability to speak and that some children were dissuaded by their parents because of fear of contagion. Thirty-nine caregivers disclosed the child’s seizures to school staff.

**Support Within the Community**

Table 3 showed that 34 caregivers were unable to get drugs because these were scarce in hospitals or clinics and more expensive in pharmacies. Only 12 caregivers were able to get AEDs for free from ESF.
Half of the caregivers borrowed when experiencing money problems. Some either missed the appointment, walked long distances to the clinic, bought inadequate supplies, got assistance from the social worker, or waited until they got money to buy drugs. Twenty-six caregivers reported that the cost of tablets drained the scarce family finances and cost more than their salaries.

Thirty-three caregivers were not employed far from home, therefore easily reachable. Forty-two caregivers disclosed the child’s seizures to friends and neighbors to enable them to know what to do in their absence and the cause of the falls and to prevent them from saying hurtful things. Four who did not disclose feared stigmatization and wanted to protect the child from physical and emotional hurt. All caregivers reported that their family was accepted by friends and neighbors.

**Use of Community Resources**

Use of community resources is presented from the most commonly used to the least used (Table 4). All caregivers belonged to religious or worship groups, and 30 had either been members since birth or grown up in the church. Religious or worship groups helped to enlighten the caregiver burden; accept the illness as God’s will; and get encouragement, advice, money, emotional support, holy water, and the ability to fend off evil spirits.

Thirty-two caregivers consulted spiritual faith healers on the basis of decisions made mostly by the nuclear family and the rest by grandparents and caregiver’s siblings. Eleven of those who consulted spiritual faith healers reported that the healers attributed the seizures to witchcraft from relatives and neighbors, inciting hatred. Four were told that the child had evil or ancestral spirits, which needed appeasement through slaughter of livestock, increasing expenses and debt. Three were told that the children would die, increasing fear. Two felt they were told lies, which caused them more pain. Only seven caregivers reported that spiritual faith healers helped them to accept the child’s condition.

Twenty-six caregivers used counseling services. Sixteen caregivers were counseled at the ESF, whereas the rest were counseled at hospitals or clinics and in support groups. Fourteen caregivers sought counseling to get more information about epilepsy and how to look after the child. The rest were counseled routinely at follow-up clinics or because they were depressed, not eating, or deeply troubled by the seizures. Caregivers were encouraged not to worry too much about the seizures, to increase adherence to AEDs, to ensure child safety, and to know that the child was not the only one affected and not bewitched. Only eight spouses were present at the counseling session because most spouses either felt it was a woman’s responsibility, were at work, had remained at home looking after the other children, or lacked money for transport.

Twenty-two caregivers consulted traditional healers on the basis of decisions made mostly by the nuclear family and the rest by grandparents and caregiver’s siblings and older children. Fourteen of those who consulted traditional healers were disenchanted because the child’s condition did not change, and traditional healers blamed the seizures on relatives and neighbors. One lost livestock as payment for services.

Only seven caregivers belonged to epilepsy support groups. Reasons given for joining included the need to interact with other caregivers and to lessen the burden. Belonging to a support group helped caregivers to accept the condition, get information and free drugs, and advise each other about epilepsy.

**TABLE 3. Stressors of Caregivers: Support Within the Community (N = 46)**

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<thead>
<tr>
<th>Factor</th>
<th>n</th>
<th>%</th>
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<tbody>
<tr>
<td>Ability to get AEDs easily</td>
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<td></td>
</tr>
<tr>
<td>Yes</td>
<td>12</td>
<td>20.1</td>
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<tr>
<td>No</td>
<td>34</td>
<td>73.9</td>
</tr>
<tr>
<td>Borrow when experiencing money problems</td>
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<td></td>
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<td>23</td>
<td>50.0</td>
<td></td>
</tr>
<tr>
<td>Cost of tablets draining resources</td>
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<td></td>
</tr>
<tr>
<td>26</td>
<td>56.5</td>
<td></td>
</tr>
<tr>
<td>Not employed away from home</td>
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<tr>
<td>33</td>
<td>71.7</td>
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<td>Disclosing to friends and neighbors</td>
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<tr>
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<td>42</td>
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<td>Family accepted by friends and neighbors</td>
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<td>Yes</td>
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**TABLE 4. Use of Community Resources (N = 46)**

<table>
<thead>
<tr>
<th>Factor</th>
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<tr>
<td>Religious or worship group</td>
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<td>Spiritual faith healers</td>
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<td>Counseling services</td>
<td>26</td>
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<tr>
<td>Traditional healers</td>
<td>22</td>
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<tr>
<td>Support groups</td>
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</tbody>
</table>
Discussion

Stressors of Caregivers

The framework of Buelow et al. (2006) helped to identify the top 6 stressors of caregivers of school-age children such as inability to get AEDs, deep pain or sadness caused by the child’s seizures, caregiving falling predominantly on mothers, limited help from the extended family, inadequate information on side effects of drugs, and inadequate information on seizures. The most commonly used community resource was religious or worship groups, with epilepsy support groups being least used. Hypotheses could be formulated to further test the framework.

Study findings confirm earlier findings that epilepsy causes increased economic burdens to families in developing countries (Kleinman et al., 1995). Most caregivers were unable to get AEDs easily, and half of them borrowed when they experienced money problems, confirming the assertion of Pal et al. (1999) that most children in developing countries go untreated because of lack of finances, increasing parental stress if seizures are uncontrolled. The deep pain and sadness caused by the child’s seizures echoes the finding of Kleinman et al. (1995) but was not reflected in the study of Buelow et al. (2006), probably because of adequate and accessible psychological services for coping with epilepsy in developed as opposed to developing countries (Al-Adawi et al., 2002; Mbuba & Newton, 2009). Provision of counseling services should therefore be prioritized to enable caregivers to adjust to the condition, thereby alleviating stress. In line with earlier studies, this study showed that caregiving fell predominantly on mothers (Austin et al., 2004; Mrabet et al., 2004; Pianta & Lothman, 1994) and is true of the patriarchal society of Zimbabwe. This finding underscores the need for more male involvement in caregiving to reduce stress on women who also bear the greater share of child rearing responsibilities (Sriram, 1993).

Contrary to studies in developed countries that have reported lack of interest by clinicians in wider aspects of epilepsy care (Buelow et al., 2006; Hartshorn & Byers, 1994; Schneider & Conrad, 1981) and to a recent study in Kenya that reported strained communication between doctors and patients (Kendall-Taylor et al., 2009), a positive finding from the current study was that, locally, healthcare providers may be providing sympathetic acceptance that Al-Adawi et al. (2002) reported to be present among traditional communities, alleviating stress. However, consistent with the findings of Buelow et al., least information was given on side effects of drugs and on seizures, which contributes to caregiver stress. Whereas above half of the caregivers in this study received some help from the extended family in caring for the child in their absence, the opposite was true in the study of Buelow et al. (2006). This finding affirms the supportive extended family concept in African countries (Mrabet et al., 2004; Saburi et al., 2006), which may be an important source of stress reduction for caregivers.

A more collaborative relationship with the school was shown, in contrast to Buelow et al. (2006) who cited poor communication as a source of parental stress for many in their study. The difference might be explained on the dual diagnosis of epilepsy and intellectual disability in the latter study. Failure to address relevant transition skills was a shared concern in this study as in that of Buelow et al., depriving the children of the ability to live independently. Educational authorities should prioritize equipping children with epilepsy with skills to live a productive and self-sustaining life to decrease the caregiver burden. Education was not the first casualty as reported by Pal (2003) and contradicts earlier findings in Zimbabwe (Butau & Piachaud, 1993). Most of the caregivers reported that their children were accepted and assisted by peers, reflecting tolerant attitudes reported by Mielke et al. (1997), alleviating caregiver stress.

Another positive finding in light of previous research suggesting secrecy as a strategy used by families to manage epilepsy (Raty et al., 1999; Saburi et al., 2006; Scambler & Hopkins, 1990) was that nearly all caregivers were able to disclose to outsiders about the child’s seizures, increasing use of social support systems. This finding implies that the nationwide epilepsy awareness campaigns may be yielding positive results.

Use of Community Resources

Important findings were how religion helps to alleviate stress and how spiritual faith healers contribute to caregiver stress. In line with previous studies in some African countries (Mrabet et al., 2004; Saburi et al., 2006), religious or worship groups were the most commonly used community resource, which helped to enlighten the caregiver burden. Similarly, in the United States, prayer or spirituality was the most commonly used form of CAM in epilepsy, but with its use limited to some regions (Liow, et al., 2007).

Contrary to the assertion of Banerjee and Banerjee (1995) that indigenous healers were sought first on the decision of the family, this study showed that the nuclear family, rather than the extended family, made the decisions to consult the healers. There may be a shifting focus from the extended to nuclear family
in this largely urban sample. The nuclear family may experience increased stress from decreased social support, while also experiencing less pressure from the extended family on decision making. In contrast to the finding of Butau and Piachaud (1993), more spiritual faith than traditional healers were consulted. This is a worrying development, as spiritual faith healers incited hatred; predicted death of children with epilepsy; and increased caregiver pain, expenses, and debt.

This study found that caregivers sought counseling services mainly to get information about epilepsy and how to look after the child, rather than for the deep pain they felt, or to discuss family or marital problems (Buelow et al., 2006; Hartshorn & Byers, 1994). The latter finding might be explained on some local customs that discourage discussing family problems with outsiders, contributing to caregiver stress.

The fact that therapy from traditional healers is culturally acceptable may explain why caregivers in this study disclosed about consulting them, as opposed to the nondisclosure of CAM in an American sample (Kennedy et al., 2007). Thus, caregivers may be less prone to stress related to drug interactions. As with spiritual faith healers, consultation of traditional healers was based mostly on decisions made by the nuclear family to counteract witchcraft (Kleinman et al., 1995) but similarly incited hatred and increased caregiver debt. Therefore, dialogue with traditional healers is just as crucial.

Epilepsy support groups were the least used community resource. Caregivers deprive themselves of opportunities to discuss concerns (Austin et al., 2004) and to break down fears they have about their children’s abilities and vulnerabilities (Pal, 2003). In the Zimbabwean context, caregivers also deprive themselves of practical assistance and free drugs in support groups. Dissemination of information on support groups through local clinics and hospitals should be prioritized as access to appropriate support services has been identified as key to successful adaptation (Floyd & Gallagher, 1997).

Implications for Nursing Practice
Caregivers experienced deep pain and sadness, which may go unreported if not assessed. Including the effect of seizures on caregivers in the assessment guide of Buelow et al. (2006) for parental stressors could be a useful intervention. There should be more male and extended family involvement in caregiving to reduce stress in women and increase support levels for caregivers. The need for information and support was one of four key parental needs (Austin et al., 2004). Therefore, provision of complete information on drugs and on seizures should be standard practice to decrease stress in the caregivers and anxiety and depression in the children. Study findings confirmed that religion helps to alleviate stress. Nurses in developed countries should incorporate religious activities among CAM interventions to reduce the perception of stress (Ignatavicius et al., 1999). The increased use of spiritual faith healers and their negative influences needs to be curtailed through dialogue so that they refer clients for drug therapy and counseling. Similarly, enabling environments should be created to facilitate open discussion of CAM interventions and the assessment of use of herbs and supplements at each encounter to minimize adverse drug interactions. Caregivers did not seek counseling to alleviate their sadness nor to discuss marital problems, indicating lack of insight into the emotional benefits to be derived from counseling. Family relationships should, therefore, be assessed routinely, so that caregivers requiring counseling are identified and referred.

Recommendations
The conflicting findings on healthcare provider–patient interactions in developing countries need to be studied further to ascertain how widespread the strained communication reported by Kendall-Taylor et al. (2009) is, so that patients share their information freely. Research is needed to find out whether outsiders corroborate the new evidence that caregivers are less secretive about seizures. The extent to which education of children may be affected and who makes decisions to consult traditional or spiritual faith healers in rural communities should be studied. The views of spiritual faith healers can be investigated to assess whether there is variation with caregivers’ perceptions so that information that may be used during dialogue with them is obtained. Awareness about benefits or perceptions about counseling services warrants further investigation to obtain information that might be useful during counseling. Possible reasons why support groups were the least used resource need to be studied to provide information for recruiting more members. Further studies could be conducted to assess how prevalent sexual abuse may be in children with epilepsy, so that the capacity to identify such cases is enhanced and appropriate interventions are instituted.

Limitations
Study findings cannot be generalized to all caregivers of children with epilepsy because of the nonprobability sampling. The unknown seizure types may have an impact on stress and need to be included in future studies. Views of all caregivers were not
reflected, as those who were not Shona speaking were not represented and rural populations were under-represented. The interval from onset of epilepsy to diagnosis was based on caregivers’ self-report and may be misleading.

Summary
Findings confirm earlier research that epilepsy causes deep pain, that caregiving falls predominantly on mothers, that adequate information on side effects of drugs and on seizures is lacking, and that caregivers borrow because of the child’s seizures. The most commonly used community resource was religious or worship groups, which helped to alleviate stress, followed by spiritual faith healers, who contributed to caregiver stress. Epilepsy support groups were the least used. To alleviate caregiver stress, it is important that healthcare providers routinely assess the effect of seizures on caregivers, advocate for more male and extended family involvement in caregiving, and provide adequate information on side effects of drugs and on seizures. Nurses in developed countries could incorporate religious activities among CAM interventions to reduce caregiver stress. Spiritual faith healers should be encouraged to refer clients with epilepsy for drug therapy and counseling.

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