Families of Children with Traumatic Brain Injuries:
Stressors and needs in the South African context

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ABSTRACT

When a child sustains a traumatic brain injury (TBI) the effects can be devastating, not only for that child but also for his or her family. The literature shows that a TBI's can negatively affect a child cognitively, emotionally, and behaviourally. In developing countries such as South Africa these negative effects are often compounded by the impact of other health crises such as HIV/AIDS, as well as relatively few economic resources and a lack of neuropsychological rehabilitation services. Injury-related consequences, further compounded by developing world contexts, seem to suggest that families of children with TBI have many stresses and strains that need to be addressed. This study aimed to explore the experiences and needs of South African families who care for children with TBI. A quantitative analysis using three questionnaires assessed 18 families' stressors and needs arising following the child's injury. The results show that South African families seem to display more stress and have more needs than similar samples in first world countries. In addition, these stresses stem mainly from (a) changes in the child, and (b) the family not having adequate support to deal with those changes.

Keywords: traumatic brain injury, acquired brain injury, pediatric TBI, cross-cultural TBI, families, stress.

Head injuries are one of the main contributors to childhood mortality and morbidity in South Africa (Lalloo & van As, 2004). Eighty percent of individuals hospitalised for traumatic brain injuries (TBI) in South Africa are severely injured (Nell & Brown, 1990). Severe TBI usually leads to a number of long-term impairments, including cognitive dysfunction and emotional and behavioural difficulties (Vanderploeg, 2000, as cited in Mokhosi & Grieve, 2004). Individuals who sustain a mild or moderate brain injury may also, but to a lesser degree, experience cognitive, emotional, and/or behavioural impairments (Hartlage, Durant-Wilson, & Patch, 2000, as cited in Mokhosi & Grieve, 2004).

TBI-related cognitive, emotional, and behavioural impairments affect not only the injured individual, but also their families. The latter have to deal with a number of resulting issues from the injury, such as caring for the child, changes in family roles, financial and time pressure, and uncertainty about the course of the child's recovery (Watanabe Shiel, McLellan, Kurihara, & Hayashi, 2001). Long-term rehabilitation services in First World countries usually involve physical, speech, and occupational therapy, neurological monitoring, and psychological counselling (Martin, 1988). Watanabe et al. (2000) showed that families of children who have sustained a TBI have a need for professional services and support in order to cope with the situation; not having these services places an enormous amount of strain on them.

Even despite these well-described consequences of TBI for the affected child and his/her family, and the similarly clear need for professional services in helping families to cope, dedicated paediatric rehabilitation units in South Africa are scarce (Levin, 2004). Placed especially within the context of a country affected by a poor socio-economic situation, such a lack of services would seemingly add negatively to the stresses and strains of caring for a child with TBI.

RATIONALE FOR STUDY

The proposed study aims to explore families' experiences of having a child with TBI, framed within the unique context of South Africa. The sudden occurrence of brain injuries and the often uncertain associated effects and course of the injury puts families in an unfamiliar situation. Therefore, as discussed above and as evidenced by experiences in First World countries, high-quality health services (including neuropsychological rehabilitative) are necessary to support affected children and their families.

It is important to note, however, that although the experience of TBI in a developing country like South Africa may be similar to the experience of TBI in developed countries (from which most of the literature emanates), the degree of stress and the amount of need within these experiences may be vastly different. This is because developing countries, by definition, have fewer economic resources than developed countries, and consequently (a) frequently place their children at higher risk for diseases such as HIV/AIDS and malaria, in addition to their TBI, and (b) have health services that do not provide the full range of services needed by children with TBI and their families. Therefore, rehabilitation services (especially neuropsychological services) require an understanding of the local context, as this is likely to have an impact on the effectiveness of these services. To date, there is little South African research on the experiences of families and family systems of children with TBI, creating a need for the kind of research carried out in the current study. This study finds its relevance not only in the additional understanding it can provide of families' experiences of having children with TBI, but more broadly it can be used valuably in the upsurge of brain research in South Africa, which hopefully has as one of its major goals the establishment of a larger number of dedicated neuropsychological rehabilitation services.

LITERATURE REVIEW

A number of the studies that were used in this literature review were based on results from First World countries. Nevertheless, studies have shown that the effects and impact of TBI on children with TBI and their families is fairly similar across cultures (Al-Adawi et al., 2004; Simpson, Mohr, & Redman, 2000). Owing to its unique context and the dearth of research in this area, the current study was specifically aimed at exploring whether the experiences of families in South Africa who have children with TBI is in fact similar to those reported by families/caregivers in developed countries.

The prevalence of traumatic brain injury (TBI) in South Africa is higher than most other countries in the world, with an estimated 316 people per 100 000 locally versus an average of 200 (range: 150 – 375) per 100 000 people worldwide sustaining TBI (Nell & Brown, 1990). The vast majority of TBI cases in South Africa are due to motor vehicle accidents, falls, and violence (Hawley, Ward, Long, Owen, & Magnay, 2003; Levin, 2004). Children are often the victims of these incidents, and although no statistics on the prevalence of TBI amongst children in South Africa are available, a large number are quite likely to incur brain injuries in their lifetime

(Levin, 2004). Determining the prevalence of paediatric TBI is important as for many of these brain-injured children, their cognitive, emotional, and behavioural functions are negatively affected (Martin, 1988).

The stress associated with having a child that has been affected by TBI is enormous and therefore help from health professionals (including psychologists), is greatly needed in order to help alleviate this stress (Watanabe et al., 2000). However, in South Africa, although there are important efforts being made by groups of clinicians, generally there is very little help available, especially once the most acute stages of the injury have been stabilised (Levin, 2004). This literature review will focus on the psychosocial, as well as physical, effects of TBI on affected children and their families, with the aim of demonstrating the essential need for various rehabilitation services (including neuropsychological rehabilitation) and support services for children and their families in South Africa.

Paediatric traumatic brain injury

Internationally, it is estimated that of those who sustain a TBI, 80% present with mild head injuries, 10% with moderate head injuries, and 10% with severe head injuries (Bruns & Hauser, 2003; see Appendix A for how severity of injury is measured). This means that although most children do not sustain severe traumatic brain injuries, a reasonable number of children do; those individuals will therefore be permanently and quite acutely affected by their injuries. TBI can be debilitating on a number of levels for affected children, as it has the ability to not just affect their cognitive functioning, but also their personality and psychosocial functioning. The child's personality and behaviour may change and become quite troublesome, with increasing susceptibility to mood swings, aggressiveness, poor self-control, and inappropriate behaviour in social situations (Martin, 1988). A child may even regress developmentally and behave in age-inappropriate ways. Although these deficits may only be temporary, they are frequently not, and the child may need years of rehabilitation in order to make progress in overcoming these functioning difficulties.

The impact of TBI on the child is not only related to the severity of the injury, but also to factors such as the child's pre-morbid mental ability, level of education, social circumstances, socio-economic resources, and pre-morbid personality and social adjustment (Lezak, 1989). A child who is not very aware of how much he/she has mentally regressed; who has good financial, health, and social support, especially from the primary caregiver; whose pre-morbid personality was not temperamental, and who was socially well-adjusted before the injury, is more likely to have a better recovery from the TBI than a child who has the opposite psycho-social circumstances.

Impact on the family

The occurrence of TBI, especially amongst loved ones, is usually quite a shock for families, and often involves feelings of guilt, disbelief, anger, and/or sorrow (Martin, 1988). Once the acute stages of TBI have been stabilised, families then have to deal with an enormous amount of stress due to the often long-term cognitive, emotional, and behavioural changes in the child (Watanabe et al., 2000). Demands placed on parents usually include providing constant care, attention, and guidance. Psychological stress can occur in caregivers of individuals with TBI. Marsh et al. (1998) found clinically significant levels of depression, anxiety, and impaired social adjustment in one -third of their sample of carers of people with severe TBI. Emotional strain and stress has been attributed to uncertainty over the child's recovery and adjustment and changes in the families' roles and routines (Wade, Taylor, Drotar, Stancin, & Yeates, 1996; Watanabe et al., 2000). Other demands include accepting and coming to terms with the situation; and financial burden due to medical bills, time taken off work, and adjustments being made to the home in order to accommodate the injured child. Furthermore, Watanabe et al. (2000) showed that family members have a need for professional services and support in order to cope with the situation.

The role of social support was one of the factors considered in a study carried out by Wade et al. (2004) on the interpersonal stressors and resources that predict parental adaptation following paediatric TBI. This study showed that social support is important for the psychological adjustment of caregivers of children with TBI. The impact of social support on the psychological adjustment of caregivers is influenced by both the quality of support (i.e., whether it is supportive or stressful), and the source of support (i.e., whether it is from friends, family or a spouse). Furthermore, Armstrong and Kerns (2002) also showed that two of the needs which parents most often rate as unmet include their needs for professional and community support. However, even with evidence to show the value of social support for those families of children with disabilities who do not have sufficient support structures, there are no dedicated support groups in South Africa for families of children with TBI (Levin, 2004).

TBI in the South African context

The incidence of traumatic brain injury in South Africa has its own unique context. This is because South Africa is a culturally diverse nation affected by HIV/AIDS, a poor economic situation, ill-equipped schools, many illiterate people, and health care services that are mostly not of the same standards as those in developed countries (Levin, 2004). This context creates a variety of stressors and unique consequences for children with TBI and their families.

However, the majority of the paediatric TBI literature is based on findings from developed first world countries, where children with TBI are not faced with the same socio-cultural circumstances. Therefore, as much literature as possible will be used that directly relates to South Africa, and even though some of the literature used does emanate from First World studies, this review aims to use such data with the South African context in mind.

As mentioned above, it is suggested that the major causes of traumatic brain injury (TBI) are motor vehicle accidents (MVA), falls and violence (Hawley, Ward, Long, Owen, & Magnay, 2003; Levin, 2004). With regard to MVAs, many South African children use minibus taxis that are often overloaded with passengers and whose drivers are notoriously unsafe. With regard to violence, this frequently occurs in the form of domestic abuse: South Africa has an enormous occurrence of child abuse, with over 20 000 child rape and attempted rapes being reported each year (Shilumani, 2004). Violence also occurs in the form of hijackings and gang-related activities, which sometimes result in children sustaining gunshot wounds to the head (Levin, 2004).

It seems that it is those South Africans with the lowest socioeconomic status (SES) who are also those who are most affected by TBI, as the abovementioned kinds of violence and forms of motor vehicle accidents mostly affect people of low SES in South Africa (Levin, 2004). In support of the notion that TBI might affect children who have a low SES in South Africa, in America, it has been shown that the estimated average number of annual injuries from 1985-1987 was highest for families that fell in the lowest income levels (Collins, 1990, as cited in Kraus & Lawrence, 2005)

South African children from low socioeconomic backgrounds are not just at a higher risk for head trauma than those from higher SES's. Low SES children are also at higher risk for contracting the HIV/AIDS virus, and of having family members who suffer from HIV/AIDS. This disease is debilitating in that it attacks one's immune system so that one cannot fight off illness. Jaffe, O'Neill, Vandergoot, Gordon, and Small (2000) studied the prevalence of TBI amongst an HIV-positive population. They found that of the 173 participants, 128 had a lifetime prevalence of a blow to the head. Furthermore, of those who merely reported a blow to the head, but did not self-identify as having been traumatically brain injured, a significant number were shown to have the 25 symptoms that are specific to mild TBI, as well as a high total number of symptoms. These data show that there is a high incidence of TBI amongst HIV/AIDS patients, and that even mild trauma to the head, has a highly negative effect on this population. Therefore it is the children who originate from a low SES, who seem to be most at risk for having TBI with the added strain of HIV/AIDS. This puts them at risk for worse symptoms and, consequently, the need for more care from their families and the health sector.

There are many South Africans who can be grouped in the low SES bracket. The reason for this high number is that in South Africa about 60% of individuals are unemployed, and 70-80% of black and coloured people are classified as living below the breadline (Department of Social Development, 2000, as cited in Levin, 2004). This means that the majority of South African families who have a child with TBI cannot afford the costs of caring for an injured child, let alone any possible long-term rehabilitation services (Levin, 2004).

In addition to many South Africans not having the financial resources to provide effective care for their injured children, many South Africans have varied understandings and perceptions of TBI due their level of education and cultural beliefs. It is estimated that approximately 70% of black South Africans are functionally illiterate (Nell, 1999), which has negative consequences for their understandings of TBI and their ability to independently learn more about it.

South Africa is a culturally diverse nation, and therefore different cultural beliefs will also have implications for people's understandings of the phenomenon of TBI. Mokhosi and Grieve (2004) showed that many African families attribute TBI to an external source, including God, their ancestors, and/or sorcery. These attributions often imply that TBI is a misfortune caused by the anger of an external spiritual power. Not all of these beliefs about the causes of TBI were negative, however, as some found comfort in attributing the TBI to an external power, such as due to “the will of God”. Within the African culture, TBI also does not just affect Westernised notions of the immediate family, but also communities, as African societies include all relatives, including cousins and grandparents, as close family members (Mokhosi & Grieve, 2004). Having a child with a TBI often shatters hopes, and traditional expectations of chores to be carried out by the child. The child also sometimes brings embarrassment to the family, when the care responsibilities exclude the family or tradition excludes the injured child from attending traditional ceremonies. As can be seen above, cultural beliefs can have an impact on individual’s understandings of the causes of TBI and an influence on the impact of TBI on the child and the family.

These South African socio-cultural variables also influence the provision of care for those affected by TBI because many people are not in close proximity to specialised medical care. It is estimated that 50% of South Africans live in rural areas (Atmore, 1998). Most specialised medical services are found in urban areas, and therefore people who live in rural areas do not have access to specialized medical care (Levin, 2004). There are also very limited special schools in rural areas, in addition to the vast majority of mainstream schools not having teachers with training for children with special needs. For those that do attend special schools for the disabled, whether rural or urban, these schools do not usually educate children according to their specific disorders (Bubb, 2003, as cited in Levin, 2004).

Even for those children whose families can afford the best possible medical care, health care services, as mentioned above, are relatively lacking in South Africa (Levin, 2004). Developed countries are far more advanced in many health care areas, particularly with regard to TBI. Furthermore, many hospitals, especially government hospitals, do not have adequate facilities or staff with the required education to provide dedicated long-term neuropsychological rehabilitation services for TBI patients. There are also very few paediatric rehabilitation services for children with TBI in South Africa.

SPECIFIC AIMS AND HYPOTHESES

The study’s broad aim was to investigate whether the experiences of South African families containing a child with TBI are consistent with those of First-World families containing a child with TBI. These experiences include that their stress is due to a variety of factors including burden of care, financial and time strains, emotional stressors, change in family roles, and uncertainty about the future recovery of the affected child. Two more specific aims are these: First, I aim to investigate whether broad social concerns within the South African context contribute negatively to these stressors. The majority of patients who use the hospital in which the study will take place are from disadvantaged communities and it is therefore expected that stressors, mostly to do with finances, will be more severe for this low socioeconomic (SES) sample than it would be for a high SES sample. Second, I aim to investigate the effect of injury severity (is it the case that the more severe the child's injuries, the more stressors will be incurred by the family?).

DESIGN AND METHODOLOGY

Research design

This research study is part of a larger PhD study that is examining rehabilitation strategies for children with TBI. The research setting was the Red Cross War Memorial Children's Hospital (RXH) in Cape Town, South Africa and the University of Cape Town. The research design was quantitative. Data was collected using three questionnaires that relate to participants' experiences of having children with TBI. These questionnaires cover a variety of topics, including the types and degrees of stresses and strains experienced by participants due associated with having a child with an injury. Additionally participants own and their child's needs are assessed.

Participants

Children who had sustained a TBI at least 1 year previously and who had been admitted to RXH as a result of the injury were identified using hospital records. The parents, guardians, or caregivers of those children identified as most suitable were contacted telephonically. Information about the study was briefly given to them. For those who expressed interest in participating in the study, a meeting was scheduled for a date within 2 weeks of the initial contact.

The final sample consisted of 18 mothers or female caregivers of children who had sustained TBIs. Seventeen of the participants were Coloured and one was White. Twelve of the participants were English speaking and 6 were Afrikaans speaking. A language inclusion criterion, specifying that we would recruit only English- or Afrikaans-speaking participants, was imposed due to resource constraints.

The Red Cross War Memorial Children's Hospital services a community consisting of mostly disadvantaged patients. It is therefore assumed, as the sample consisted of mothers or caregivers of children who were admitted to RXH, that the majority of the sample came from low to low-average socio-economic backgrounds. This is reflected in the fact that 50% of the sample lives in the 'Cape Flats' (Mitchell's Plain) or surrounding areas. The majority of people living in Mitchell's Plain and the surrounding areas are of low SES.

The traumatically brain injured children of the mothers or caregivers included in the sample ranged in age from 3 to 12 years old. All of the children had sustained a TBI of varying severity. Nine of the children had acquired a mild TBI, one had acquired a moderate TBI, and eight had acquired a severe TBI. All of the children had been admitted to RXH at least 1 year earlier. Children with a pre-morbid history of neurological or developmental disorders, or of any pre-morbid psychiatric conditions, were excluded from the study. This exclusion criterion was put in place so that the affected child's pre-existing disorders did not influence the responses of his/her family member on the questionnaires, thereby affecting the validity of the data.

Materials

The questionnaires used were the Parenting Stress Index, 3rd edition (PSI; Abidin, 1995), the Family Burden of Injury Interview (Short Form) (FBII/SF; Taylor et al., 1995; see Appendix B), and the Family Needs Questionnaire (FNQ; Kreutzer, Complair, & Waaland, 1988; see Appendix C).

The *PSI* has 120 items and is designed to evaluate the amount of stress occurring in the parent-child relationship, so as to assess whether (a) parenting and family characteristics are failing to support normal development and functioning in children; (b) children have behavioural and/or emotional problems; and (c) parents might become dysfunctional in their parenting practices (FRIENDS National Resource Centre, 2006). There are six subscales relating to the child, including, for example, measurements of characteristics such as distractibility and adaptability. There are seven subscales relating to the parent, including, for example, measurements of characteristics such as competence and attachment. An overall child domain score, parent domain score, total stress score, and life stress score can be derived from this measure.

The PSI has been empirically validated as predicting both parenting and child behaviour, as well the child's emotional adjustment (FRIENDS National Resource Centre, 2006). Based on studies in a variety of American and international (including Chinese, Portuguese, and Italian) populations, this validation has been confirmed (Forgays, 1993, as cited in Abidin, 1995; Pearson & Chan, 1993, as cited in Abidin, 1995; Santos, 1992, as cited in Abidin, 1995).

The *FBII/SF* is designed to assess the burdens and challenges of families specifically relating to paediatric TBI (Drotar, 1996, as cited in Wade et al., 1996). It consists of 26 questions, each relating to a particular concern. Participants rate the level of stress caused by each concern on a 5-point scale (Burgess et al., 1999). The instrument generates five subscales relating to changes in routine, work, and school schedules; concerns with the child's adjustment and recovery; reactions of friends and family; the spouse's reactions; and sibling's reactions (Wade et al., 1996). Burgess et al. (1999, p. 400) describe the FBII as a "promising tool", and showed that it has a high internal consistency and is a reliable measure of participants' perceptions of family stress due to the injuries of the child.

The *FNQ* is a 40-item questionnaire that assesses the perceived needs of family members following the brain injury of a relative (Armstrong & Kerns, 2002). The FNQ measures the degree to which needs are perceived by the participant to be important, and how well those needs have been met. A factor analysis study of the FNQ revealed six scales: health information, emotional support, instrumental support, professional support, community support network, and involvement with care (Serio, Kreutzer, & Witol, 1997, as cited in Armstrong & Kerns, 2002). Waaland and Kreutzer (1988, as cited in Armstrong & Kerns, 2002) adapted the FNQ for caregivers of children with TBI, in which developmental issues are dealt with. The adapted questionnaire was used in this study.

Each of the above-mentioned questionnaires was translated into Afrikaans for the Afrikaans-speaking participants. These translations were linguistically validated through both forward and back translations, and the two English versions were compared in order to validate the Afrikaans translation.

Procedure

When parents/caregivers arrived at the testing site, they were given a detailed verbal account of the study. They were also asked to read and sign an informed consent form and an information sheet. They were then given the PSI, FBII/SF, and FNQ to complete. For each participant, someone who was fluent in that participant's home language was made available for describing the study, for reading the questionnaire (if needed), and for any questions that the participant might have had. Each session lasted between 60 and 90 minutes. At the end of the session, participants were fully debriefed and financially compensated for their travelling expenses.

Data Analysis

Descriptive statistics were calculated in order to show the means and standard deviations amongst the caregivers' scores. A multiple regression was used on the subscales and domains from the PSI, and a comparison was made between the scores of the mild and severe group using their scores on the PSI. A one-way ANOVA and Tukey's post-hoc analysis was also used to observe significant differences on subscales ratings on the FNQ. Some questionnaires were too incomplete to use, and therefore some of the analyses were not based on all of the participants' responses. There was also missing data (e.g., a rating not given for a particular item) on a number of the questionnaires. This was dealt with, for all of the measures, using the methodology given in Abidin (1995) on dealing with missing data when scoring answer sheets on the PSI. So long as not more than 1 item per subscale and 5 items altogether was missing, the average score for the completed items within the subscale were calculated and rounded to the nearest whole number. This whole number was then added to the scores of the completed items to get the required scores or score averages.

RESULTS

Parental Stress

The PSI measured stress amongst caregivers. Mean percentage scores and standard deviations for all 14 subscales and the Child Domain, Parent Domain, and Total Stress indexes are shown in Table 1. Also shown is the percentile rank corresponding to each mean score. Those scores that fall into the critical (or clinically significant) percentile range (≥ 85) are highlighted.

The percentile score of Total Stress shows that, on average, this group of caregivers are critically stressed. Additionally, the majority of this stress comes from the child's behaviour and emotions: All of the subscales within the Child Domain (viz., Distractibility/Hyperactivity, Adaptability, Reinforces Parent, Demandingness, Mood, and Acceptability) fall into the critical percentile range. Within the Parent Domain, only the Depression and Competence subscales indicated clinically significant stress for caregivers. It is also important to note that these caregivers had an abnormally high mean score for Life Stress (≥ 90). Within this domain the death of a close family friend (53%) and going deeply into debt (41%) during the previous 12 months were the two most often selected life stressors.

A regression analysis was used to determine which subscales accounted for the greatest amount of variance within their respective domains. The results of this analysis supported initial impressions from Table 1: The subscales of Demandingness ($\beta = 0,311$), Adaptability ($\beta = 0.249$), and Acceptability ($\beta = 0.219$) explain most of the variance the Child Domain. The subscales Depression ($\beta = 0.239$) and Competence ($\beta = 0.221$) explain the most variance in the Parent Domain.

Parental Stress: TBI Severity Group Differences

Table 2 shows that caregivers of children with severe TBI are more stressed, with higher scores in the Child Domain, Parent Domain, and Total Stress domain. Surprisingly, the table shows that Life Stress is higher in the Mild TBI group, even though their Total Stress is lower. With specific regard to the Total Stress domain, 67% of all caregivers fell into the critical percentile range of scores; this number included 56% of parents of the mild TBI children, the 1 moderate caregiver, and 88% of the parents of severe TBI children.

Injury-related Stress

Findings from the FBII/SF (shown in Table 3) suggest that caregivers' biggest injury-related concerns lie with the TBI child and his/her behaviour since, and reactions to, the injury. Although a one-way ANOVA did not detect statistically significant differences between mean ratings on the various scales, $F(5, 21) = 0.437$, $p = 0.780412$, this piece of data nonetheless supports findings from the PSI that some of caregivers’ biggest stressors are associated with their TBI children.

Family Needs

The results obtained on the FNQ were analysed using the methodology of Armstrong (2000, as cited in Murray, Maslany, & Jeffery, 2006). A response on the FNQ was categorised as important if the caregiver rated an item as either ‘important’ or ‘very important’. For each of the 40 items, the mean importance rating was calculated. The items were then ranked according to these importance ratings. On average, parents/caregivers in this study rated 37 out of the 40 questions on the questionnaire as either ‘important’ or ‘very important’.

The six most important needs/items are shown in Table 4. Of these six needs, four were from the Health Information subscale, one was from the Emotional Support subscale, and the other was from the Professional Support subscale.

The 5 least important needs/items, as rated by this sample of caregivers, are shown in Table 5. The three least important needs were from the Instrumental Support subscale, while the other two were from the Emotional Support subscale.

Table 6 shows the needs most frequently rated as ‘met’ by participants. This endorsement was given as a percentage. All of the needs that were rated by participants as having been ‘met’ were added up and this number was divided by the total number of items (40) on the FNQ, in order to get a percentage for each item of those who endorsed it. On average, 49 % of the sample’s needs were rated as having been ‘met’. The top 3 items rated as ‘met’ were from the Health Information subscale, while the other items came from the Professional Support and Instrumental Support subscales.

Needs that were rated as either ‘unmet’ or ‘partly met’ were categorised as ‘unmet’ for this analysis, and these results are shown in Table 7. Most of the items rated as ‘unmet’ were from the Professional Support subscale. Items from the Emotional Support and the Instrumental Support subscales were also present.

The mean number of needs under each subscale that was rated as ‘met’ was calculated. Table 8 shows that the highest number of ‘met’ needs come from the Health Information subscale and the least number of needs met come from the Emotional Support subscale. Although a one-way ANOVA did not detect statistically significant differences between mean ratings on the various scales, $F(5, 33) = 1.7507$, $p = 0.150582$, the trend here supports findings from the FNQ that some of caregivers’ biggest needs are associated with Health Information.

The mean rating of needs under each subscale was calculated. Table 9 shows that the highest mean rating comes from the Health Information subscale, and the lowest mean rating of needs comes from the Instrumental Support subscale. A one-way ANOVA was used to observe whether there were any significant differences between these six subscale means. The results showed that the omnibus test statistic was significant, $F\ (5, 33) = 14.04$, $p \leq 0.001$. Thus, Tukey’s post-hoc analysis was used. The results showed that there was a significant difference between the mean ratings of Health Information and Emotional Support ($p \leq 0.05$). There was also a significant difference between Instrumental Support and all five other subscales: Health Information ($p = 0.000136$), Professional Support ($p = 0.000136$), Community Network Support ($p = 0.000881$), Emotional Support ($p = 0.001521$), and Involvement with Care ($p = 0.024205$).

DISCUSSION

The present study provides evidence for the fact that, in accordance with international literature, families of children with TBI do have a number of injury-related stressors and needs. However, this South African sample shows an even greater amount of stress, and more needs rated as important, than samples from developed countries. This conclusion is evidenced from the fact that the South African sample studied here had a mean Total Stress score on the PSI that falls in the ≥ 90 percentile (i.e., clinically significant) range. In contrast, families from America with members who have serious illnesses such as Down’s Syndrome and cerebral palsy had mean Total Stress score percentile rankings of ≥ 70 and ≥80 respectively (Abidin, 1995). An average of 27 FNQ items were rated by a Canadian sample ($N = 66$) as being important (Murray et al., 2006). In the current study, however, the average number of FNQ items rated as important was 37 out of 40 items, showing the likely greater amount of needs displayed in South African families.

Parental Stress

As evidenced by both the PSI and the FBII, most of the caregivers' stress was the result of the child's behaviour or characteristics, rather than the parent's own characteristics or behaviour, or the reactions of the caregiver's spouse, other children, or other family and friends in relation to the child's injury. The area that caused the most stress for these caregivers in the PSI Child Domain was Acceptability. High scores in this subscale imply that the caregiver did not feel that his/her child possessed the physical, intellectual, and/or emotional characteristics that the caregiver had expected for the child (Abidin, 1995). The other two very stressful areas were Adaptability and Demandingness. High scores in the Adaptability area indicate that the child displays an inability to adjust to changes in his or her social or physical environment (Bendall, Culbertson, Shelton, & Carter, 1986; Breen & Barkley, 1988; Chavkin, 1986; Johnson, Floyd, & Isleib, 1984; Mash & Johnston, 1983a, 1983b, 1983c, as cited in Abidin, 1995). Examples in this area include that the child might possibly overreact to changes in sensory stimulation and to changes in routine (Abidin, 1995). High scores in the Demandingness area indicate that the child places a number of demands on the parent, including crying, often asking for help, and/or frequently engaging in minor problem behaviours (Beebe, Casey, & Pinto-Martin, 1993; Bendell et al., 1986; Hanson & Hanline, 1990; Pokorni & Perry, 1988; Russ, 1988; as cited in Abidin, 1995).

Within the PSI Parent Domain, Depression and Competence caused the most stress for caregivers. High scores on the Depression subscale suggest the possible presence of clinically significant depression in the caregiver (Webster-Stratton, 1988, as cited in Abidin, 1995). This result is in line with previous research, such as that mentioned in the literature review above in which Marsh et al. (1998) found clinically significant levels of depression, amongst other psychological sequelae, in one-third of their sample of caregivers of people with severe TBI. However, some responses to items on this subscale may just be related to a general dissatisfaction with oneself and life circumstances, rather than clinically significant depression. When caregivers' scores are high in this area, it is suggested that these caregivers have difficulty mustering the physical and psychological energy needed to provide adequate parenting for their children (Dumas, Gibson, & Albin, 1989, as cited in Abidin, 1995). They also tend to show an incapacity to act assertively or authoritatively with their child (Perez, 1989; Webster-Stratton, 1990a, 1990b, Webster-Stratton & Hammond, 1988, as cited in Abidin, 1995). High scores in the Competence subscale indicate that caregivers may either not have practical knowledge or child management skills to deal with their children. They also may not have found parenting to be as reinforcing as they had expected (Abidin & Wilfong, 1989; Mash & Johnston, 1983a, 1983c; Mouton & Tuma, 1988; Sommer, Whitman, Borkwowski, Schellenbach, & Maxwell, 1993; Stoiber & Houghton, 1993; Webster-Stratton & Hammond, 1988; as cited in Abidin, 1995).

It is also important to note that these caregivers had an abnormally high mean score for Life Stress. Within this domain the death of a close family friend and going deeply into debt during the previous 12 months were the two most often selected life stressors. Although the participants did not provide reasons for the causes of these life stressors, it is suggested that the South African context of high rates of unemployment, crime, and HIV/AIDS may have contributed to these endorsements.

Caring for a Child with Severe versus Mild TBI

As shown in previous literature, caregivers of children with severe injuries resulting from the TBI have more stressors than caregivers of children with mild TBI. This higher result is shown in both the PSI Child and Parent domain, suggesting that not only does the severe TBI child’s behaviour result in more stressed relations with their parent than does that of a mild TBI child, but his/her parent also have less personal and/or parental capacity to cope effectively with these changes.

Caregiver Needs

The needs rated as important most often by participants fell into the areas of Health Information and Professional Support. This finding suggests that caregivers have a need for honest and understandable injury and recovery-related explanations from professionals (Armstrong & Kerns, 2002). They also need to have professionals available for advice both during acute and long-term phases in the child’s recovery. However, while significant differences were found between the mean ratings of needs on some of the FNQ subscales, all except one subscale (Instrumental Support), had a mean rating that was lower than 3.53. Considering that the highest score one can give an item is ‘4’, this suggests that while Health Information and Professional Support have the highest ratings, Community Network Support, Involvement with Care, and Emotional Support are also greatly needed. Therefore, support, such as in the form of TBI support groups and counselling services should also be made available for family members of the injured child (Murray et. al, 2006). Instrumental Support may have a significantly lower rating than the other the subscales because family and friends can be used for such things as helping keep the house. While needs seem to be being adequately met within the Health Information domain, the Emotional Support and Professional Support domain had the lowest rating of needs met. This suggests a need for more adequate provision of services in these areas.

Economic Burden

No specific subscale addressed the broader social concern of not having adequate economic resources while caring for a child with a TBI, and also the economic burden of caring for a child with a TBI. However, this problem was raised by the participants in the fact that while having enough resources for oneself and one's family was one of the needs given high importance, having enough resources for oneself and one's family, and having enough resources for the injured child, both fell into the 'needs most frequently unmet' category. In addition, one of the highest-scoring Life Stress items was 'went deeply into debt' in the last 12 months. This finding suggests that both the broader economic context and the costs involved in caring for a child with a TBI has contributed to this sample having many stressors and needs that should be addressed through services that deal with both the costs of caring for the injured child and providing resources for those from a low SES background. It is also suggested that the burden of care that looking after an injured child creates can negatively contribute to the state of the South African economy because caregivers often have to take time off work, or even stop working, in order to care for their child, and that this in turn affects both their family and the broader economy.

RECOMMENDATIONS

With the above findings in mind, it is suggested that a number of additional services are provided for family members, especially primary caregivers, of children with TBIs. These should include education and training for parents in the areas of disciplining their child, child management skills, and practical child development knowledge. These educational services could be delivered in the form of workshops and educational materials. In addition, their emotional needs can be met through the provision of self-esteem enhancing therapy as well as dedicated support groups for family members of children with TBI (Abidin, 1995). Professionals also need to make themselves available for discussion of concerns with caregivers (Murray et al., 2006) and referrals to other professionals and services, for example, disability grants. In addition, these evidenced needs have broader implications for policies regarding the range of services that are made available for families and children with TBIs.

LIMITATIONS

Due to limited time available for data collection and problems with recruiting possible participants, the sample used in this study was small, and therefore these results should be interpreted with caution. However, this study will continue and will assess a bigger sample; therefore, more valid conclusions will later be made available. Owing to the fact that one questionnaire per measure was not used, and the fact that data was missing on some of the questionnaires, there may be calls for additional cautious interpretation of the suggested results from this study. As the study continues, though, this problem will be avoided through the researcher completing each questionnaire with the participant, and not leaving the participant to fill the questionnaire in by his/herself. This will ensure that all (or at least more) of the questions are completed.

CONCLUSION

This study has discussed the fact that TBI is a debilitating disease not only for injured children, but also for their families. Injury-related consequences are compounded by a poorly resourced South Africa (in terms of finances, educational and health services) and a context in which many people are illiterate and an array of cultural beliefs, which influences understandings of TBI, abounds (Levin, 2004, Mokhosi & Grieve, 2004). It was suggested that in this context, South African families should be experiencing similar, if not greater, injury-related stressors and needs as samples from First World countries As evidenced in the results, the hypothesis was confirmed in that the sample did not merely have a similar, but rather a larger, amount of stressors and needs than evidenced in First World samples. Much of this stress had to do with the child’s behaviour and ways of relating to their caregiver. Some of this stress had to do with the caregivers’ self-described incompetency and potential depressive states. In addition, this sample had a high number of needs that need to be addressed, including Health Information, Community Network Support, Involvement with Care, and Emotional Support. The needs that the sample rated as being the least ‘met’ included the Emotional Support and Professional Support subscales, suggesting a need for these areas in particular to be addressed. The biggest change agents needed in addressing the stressors and needs of those families who care for children with TBIs are policy makers who take note of the requirements of affected families and set into motion a sequence of services that more adequately aid both the child and the family.

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Appendix A

Measures of Severity of Injury

Hawley, Ward, Magnay, and Long, (2003) determined severity of participants brain injuries using the Glasgow Coma Scale (GCS) and length of unconsciousness caused by TBI. They classified a severe head injury as being an injury that caused unconsciousness for longer than 6 hours, and a GCS of 3-8; a moderate head injury as being an injury causing unconsciousness for more than 15 minutes, and a GCS of 9-12; and a mild head injury as being an injury causing unconsciousness for less than 15 minutes and a GCS of 13-15.

Appendix B

Family Burden of Injury Interview – Short Form

Date: ____________

Family Burden of Injury Self-report Questionnaire

What is your relationship to the child? (circle 1)

Mother Father Grandmother Guardian Other
Explain: ______________

Please rate how much stress each of the following issues has caused for you since the child's injury using the following scale.

0	1	2	3	4	NA
NOT AT ALL STRESSFUL	A BIT STRESSFUL	FAIRLY STRESSFUL	QUITE STRESSFUL	EXTREMELY STRESSFUL	Not Applicable

Statement	**Stress Rating**					
1. Concerns about how your child reacts or relates to you or your spouse/partner Are these concerns related to the injury? Y N	0	1	2	3	4	NA
2. Disciplining or managing your child's behavior Are these concerns related to the injury? Y N	0	1	2	3	4	NA
3. The behavior of your other children Are these concerns related to the injury? Y N	0	1	2	3	4	NA
4. Disciplining or managing your other children's behavior Are these concerns related to the injury? Y N	0	1	2	3	4	NA
5. Concerns about how your other children are reacting to or accepting __________'s injury or any consequences of the injury	0	1	2	3	4	NA
6. Concerns about your child's recovery from the injury, or about any possible problems related to the injury in the future	0	1	2	3	4	NA
7. Consequences of the injury affecting the day to day life in your family	0	1	2	3	4	NA
8. You or your spouse missing work or other commitments because of the injury or any consequences of the injury	0	1	2	3	4	NA

Please continue to rate how much stress each of the following issues has caused for you since the injury using the following scale:

0 NOT AT ALL STRESSFUL	1 A BIT STRESSFUL	2 FAIRLY STRESSFUL	3 QUITE STRESSFUL	4 EXTREMELY STRESSFUL	NA Not Applicable

Statement	**Stress Rating**					
9. Taking care of your other children Are these concerns related to the injury? Y N	0	1	2	3	4	NA
10. Taking care of daily chores, such as shopping or household tasks Are these concerns related to the injury? Y N	0	1	2	3	4	NA
11. Difficulties handling or accepting feelings about the injury	0	1	2	3	4	NA
12. Achieving your long-term goals Are these concerns related to the injury? Y N	0	1	2	3	4	NA
13. Achieving your spouse's long-term goals Are these concerns related to the injury? Y N	0	1	2	3	4	NA
14. Achieving your injured child's long-term goals Are these concerns related to the injury? Y N	0	1	2	3	4	NA
15. Achieving your other children's long-term goals Are these concerns related to the injury? Y N	0	1	2	3	4	NA
16. Concerns about how your injured child is accepted by his/her peers Are these concerns related to the injury? Y N	0	1	2	3	4	NA
17. Concerns about your spouse's/partner's reaction to your child's injury or any consequences of the injury	0	1	2	3	4	NA
18. Disagreements between you and your spouse/ partner about how to take care of family problems Are these concerns related to the injury? Y N	0	1	2	3	4	NA

Please continue to rate how much stress each of the following issues has caused for you since the injury using the following scale:

0 NOT AT ALL STRESSFUL	1 A BIT STRESSFUL	2 FAIRLY STRESSFUL	3 QUITE STRESSFUL	4 EXTREMELY STRESSFUL	NA Not Applicable

19. Talking about your child's injury with your spouse/partner	0	1	2	3	4	NA
20. The reactions of others (outside your family) to your child's injury	0	1	2	3	4	NA
21. Disagreements with others about how to best care for your family Are these concerns related to the injury? Y N	0	1	2	3	4	NA
22. Disagreements with others about how to discipline your children, or the kinds of things you allow them to do/not do Are these concerns related to the injury? Y N	0	1	2	3	4	NA
23. Talking about your child's injury with others	0	1	2	3	4	NA
24. Finding time for your own activities Are these concerns related to the injury? Y N	0	1	2	3	4	NA
25. Finding time to be with your spouse/partner and to do things together Are these concerns related to the injury? Y N	0	1	2	3	4	NA
26. Finding time to do things with your other children Are these concerns related to the injury? Y N	0	1	2	3	4	NA

Appendix C

Family Needs Questionnaire

Your Name: Date:

INTRODUCTION: Family and/or friends of persons who have had a traumatic injury often find they have their own special needs. These needs may or may not have been taken care of during the patient's rehabilitation. Often, these needs change over time. We are interested in seeing how important some of these needs are to you and whether or not those needs have been met. The information you provide will help us to understand the needs of your family as well as other families of persons with serious injuries.

DIRECTIONS: For each of the following 40 questions please use the scales described below to tell us about your needs. *Each question contains two parts*.

PART I

For each statement, use the scale below to show how important you feel these needs are by placing a circle around the number which best describes your answer. After rating each statement as 1, 2, 3, 4, use the second scale (right) to relate whether each need is being met.

1	2	3	4
Not Important	Slightly Important	Important	Very Important

PART II

Use the next scale to tell us whether a need has been met. Circle Y (Yes) if the need has been met, circle P (Partly) if the need has only partly been met, and circle N (NO) if the need has not been met at all.

Y	P	N
Yes	Partly	No

EXAMPLES:

This person rated the need as "Important"

The need was rated as being "Partly Met"

1. I need to get enough rest or sleep 1 2 3 4 Y P N

N/A	1	2	3	4	Y	P	N
Not Applicable	Not Important	Slightly Important	Important	Very Important	Yes	Partly	No

I NEED………	**PART I** How important is this need?	**PART II** Has this need been met?
1. to be shown that medical, educational or rehabilitation staff respect the patient’s needs or wishes.	1 2 3 4	Y P N
2. to be told daily what is being done with or for the patient.	1 2 3 4	Y P N
3. to give my opinions daily to others involved in the patient’s care, rehabilitation, or education.	1 2 3 4	Y P N
4. to be told about all changes in the patient’s medical status.	1 2 3 4	Y P N
5. to be assured that the best possible medical care is being given to the patient.	1 2 3 4	Y P N
6. to have explanations from professionals given in terms I can understand.	1 2 3 4	Y P N
7. to have my questions answered honestly.	1 2 3 4	Y P N
8. to be shown that my opinions are used in planning the patient’s treatment, rehabilitation, or education.	1 2 3 4	Y P N
9. to have a professional to turn to for advice or services when the patient needs help.	1 2 3 4	Y P N
10. to have different professionals agree on the best way to help the patient.	1 2 3 4	Y P N
11. to have complete information on the <u>medical care</u> of traumatic injuries (e.g. medications, injections, or surgery).	1 2 3 4	Y P N

N/A	1	2	3	4	Y	P	N
Not Applicable	Not Important	Slightly Important	Important	Very Important	Yes	Partly	No

I NEED………	**PART I** How important is this need?	**PART II** Has this need been met?
12. to have complete information on the patient's patient's <u>physical problems</u>(e.g. weakness, headaches, dizziness problems with vision or walking)	1 2 3 4	Y P N
13. to have complete information on the patient's problems in <u>thinking</u> (e.g. confusion, memory, or communication).	1 2 3 4	Y P N
14. to have complete information on drug or alcohol problems and treatment.	1 2 3 4	Y P N
15. to be told why the patient acts different, difficult or strange	1 2 3 4	Y P N
16. to be told how long each of the patient's problems is expected to last .	1 2 3 4	Y P N
17. to be shown what to do when the patient is upset or acting strange.	1 2 3 4	Y P N
18. to have information on the patient's rehabilitative or educational progress.	1 2 3 4	Y P N
19. to have help in deciding how much to let the patient do by himself/herself.	1 2 3 4	Y P N
20. to have enough resources for the patient (e.g. rehabilitation programs, physical therapy, counselling)	1 2 3 4	Y P N
21. to have enough resources for myself or the family (e.g. financial or legal counselling, respite care, counselling, nursing or day care)	1 2 3 4	Y P N
22. to have help keeping the house (e.g. shopping, cooking, cleaning, etc.)	1 2 3 4	Y P N

N/A	1	2	3	4	Y	P	N
Not Applicable	Not Important	Slightly Important	Important	Very Important	Yes	Partly	No

I NEED………	**PART I** How important is this need?	**PART II** Has this need been met?
23. to have help from other members of the family in taking care of the patient.	1 2 3 4	Y P N
24. to get enough rest or sleep.	1 2 3 4	Y P N
25. to get a break from my problems and responsibilities.	1 2 3 4	Y P N
26. to spend time with my friends.	1 2 3 4	Y P N
27. to pay attention to my own needs, job or interests.	1 2 3 4	Y P N
28. to be told if I am making the best possible decisions about the patient.	1 2 3 4	Y P N
29. to have my significant other understand how difficult it is for me.	1 2 3 4	Y P N
30. to have my partner or friends understand how difficult it is for me.	1 2 3 4	Y P N
31. to have other family members understand the patient's problems	1 2 3 4	Y P N
32. to have the patient's friends understand his/her problems	1 2 3 4	Y P N
33. to have the patient's teachers understand his/her problems.	1 2 3 4	Y P N
34. to discuss my feeling about the patient with someone who has gone through the same experience.	1 2 3 4	Y P N
35. to discuss my feelings about the patient with other friends or family.	1 2 3 4	Y P N
36. to be reassured that it is usual to have strong	1 2 3 4	Y P N

negative feelings about the patient.

37. help getting over my doubts and fears about the future. 1 2 3 4 Y P N

38. help in remaining hopeful about the patient’s future. 1 2 3 4 Y P N

39. Help preparing for the worst. 1 2 3 4 Y P N

40. to be encouraged to ask others to help out. 1 2 3 4 Y P N

Table 1.

Parental Stress measured by the Parenting Stress Index (PSI)

Index/Subscale	Percentile Rank	Score (%)
Child Domain	≥ **95**	59.73 (12.52)
Distractibility/ Hyperactivity	≥ **85**	63.75 (11.12)
Adaptability	≥ **95**	64.43 (12.93)
Reinforces Parent	≥ **90**	48.96 (16.41)
Demandingness	≥ **95**	57.36 (20.39)
Mood	≥ **90**	53.0 (9.41)
Acceptability	≥ **99**	64.29 (18.31)
Parent Domain	≥ **85**	55.97 (12.99)
Competence	≥ **85**	56.25 (11.92)
Isolation	≥ 80	54.58 (16.59)
Attachment	≥ 75	42.32 (12.39)
Health	≥ 80	60.0 (17.22)
Role Restriction	≥ 70	62.32 (19.74)
Depression	≥ **90**	60.83 (18.61)
Spouse	≥ 70	54.82 (19.94)
Total Stress	≥ **90**	57.97 (11.13)
Life Stress	≥ **90**	24.21 (17.28)

Note. Mean percentage scores are presented with standard deviations in parentheses. Bold numbers indicate a clinically significant percentile rank.

Table 2.

Comparison of Mild and Severe Mean Percentage Scores

	Mild TBI	Percentile Rank	Severe TBI	Percentile Rank
Child Domain	52.5 (11.47)	**≥ 90**	65.37 (8.46)	**≥ 99**
Parent Domain	56.71 (16.14)	**≥ 90**	56.67 (10.71)	**≥ 90**
Life Stress	27.22 (15.87)	**≥ 95**	24.22 (19.73)	**≥ 90**
Total Stress	54.75 (13.09)	**≥ 90**	60.72 (8.69)	**≥ 95**

Note. Mean percentage scores are presented with standard deviations in parentheses.

Bold numbers indicate a clinically significant percentile rank.

Table 3.

Injury-related concerns measured by the Family Burden of Injury Interview (FBII/SF)

Subscale	Score
Concern for child	2.32 (1.42)
Spouse’s reactions	2.1 (1.45)
Other’s reactions	1.59 (1.46)
Siblings reactions	1.82 (1.47)
Family Routines and Planning	1.9 (1.53)
Total Score	1.95 (1.48)

Note. Mean scores are presented with standard deviations in parentheses.

Table 4.

Needs with the highest importance ratings as measured by the Family Needs Questionnaire

I need…	Score	Subscale
Help preparing for the worst	3.8825 (0.33)	Emotional Support
To have complete information on the medical care of traumatic injuries (e.g. medications, injections, or surgery	3.88235 (0.33)	Health Information
To have complete information on the patient’s physical problems (e.g. weakness, headaches, dizziness, problems with vision)	3.88235 (0.33)	Health Information
To have complete information on the patient’s problems in thinking (e.g. confusion, memory, or communication	3.88235 (0.33)	Health Information
To have information on the patient’s rehabilitative or educational progress	3.88235 (0.33)	Health Information
To have enough resources for myself or the family (e.g. financial or legal counselling, respite care, counselling, nursing or day care	3.88235 (0.44)	Professional Support

Note. Mean scores are presented with standard deviations in parentheses

Table 5.

Needs with the Lowest Importance Ratings

I need…	Score	Subscale
To spend time with my friends	2.70588 (1.05)	Instrumental Support
To have help keeping the house (e.g. shopping, keeping the house, cleaning etc	2.82353 (1.13)	Instrumental Support
To have help from other members of the family in taking care of the patient	3.05882 (1.03)	Instrumental Support
To be reassured that it is usual to have strong negative feelings about the patient	3.187 (1.17)	Emotional Support
To be encouraged to ask others to help out	3.25 (1)	Emotional Support

Note. Mean scores are presented with standard deviations in parentheses

Table 6.

Family Needs Most Frequently Rated as 'Met'
Note. Percentage of endorsement is presented with standard deviations in parentheses

I need…	Endorsement	Subscale
To have complete information on the medical care of traumatic injuries (e.g. medications, injections, or surgery)	71 %	Health Information
To be shown that medical, educational, or rehabilitation staff respect the patient's needs or wishes	65%	Health Information
To be assured that the best possible medical care is being given to the patient	65%	Health Information
To have different professionals agree on the best way to help the patient	65%	Professional Support
To get enough rest or sleep	65%	Instrumental Support

Table 7.

Family needs most frequently rated as 'unmet' or 'partly met'

Note. Percentage of endorsement is presented with standard deviations in parentheses

I need…	Endorsement	Subscale
To have my partner or friends understand how hard it is for me	71%	Emotional Support
To be shown what to do when the patient is upset or acting strange	71%	Professional Support
To get a break from my problems and responsibilities	71%	Instrumental Support
To have help in deciding how much to let the patient do by himself/herself	65%	Professional Support
To have enough resources for the patient (e.g. rehabilitation programs, physical therapy counselling)	65%	Professional Support
To have enough resources for myself or the family (e.g. financial or legal counselling, respite care, counselling, nursing or day care	65%	Professional Support
To have help keeping the house (e.g. shopping, keeping the house, cleaning etc)	65%	Professional Support
Help getting over my doubts and fears about the future	65%	Emotional Support

Table 8.

Mean Number of Needs Rated as 'Met' According to Subscale

Note. Mean scores are presented with standard deviations in parentheses

Subscale	Score
Health Information	9.3 (1.89)
Emotional Support	6.88 (1.46)
Instrumental Support	7.33 (2.5)
Professional Support	7 (2)
Community Network Support	8.6 (1.14)
Involvement with Care	8 (1)

Table 9.

Mean Rating of Needs According to Subscale

Note. Mean scores are presented with standard deviations in parenthes

Subscale	Score
Health Information	3.83 (0.05)
Emotional Support	3.53 (0.26)
Instrumental Support	3.09 (0.28)
Professional Support	3.79 (0.05)
Community Network Support	3.61 (0.16)
Involvement with Care	3.53 (0.2)