

Support for family members who are caregivers to relatives with acquired brain injury

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ABSTRACT



Objectives. Family members caring for a patient with acquired brain injury (ABI) are coping with inordinate levels of stress partially due to their lack of understanding of the neuropsychological effects of acquired brain injury in the patient. The objective of this research is to show that as the caregivers' stress levels increase, there is an increase in suicidal ideation. This highlights the causal relationship between unhealthy stress and reduced psychological well-being in these caregivers. In addition, qualitative research evidence regarding the caregivers' views of their main sources of stress are presented. **Methods.** The participants were a random sample of 80 family caregivers of patients with acquired brain injury, out of whom 72.5% (58) are primary caregivers and 27.5% (22) are secondary caregivers. A mixed methodology was utilized. It comprised cross-sectional descriptive and phenomenological approaches. Quantitative data were obtained from two standardized measures: The Stress Symptom Checklist (SSCL) and item 9 of the Beck Depression Inventory. The qualitative data were derived from self-report procedures that were part of a structured questionnaire administered individually during the interviews. **Results.** The Kruskal-Wallis test with a significance level of $p = .05$ was used to compare the stress and suicidal ideation scores, which revealed that increasing levels of stress led to increased suicidality. The analysis of the qualitative data revealed five themes which were identified as the triggers of the caregivers' profound stress. Most caregivers felt that it was predominantly the patient's neuropsychological deficits, such as emotions and/or moods, cognitive ability, behavior and personality, executive function, and social factors that caused them profound stress. **Conclusions.** Support and education are needed to help family caregivers understand the neuropsychological impact of acquired brain injury on the patient. Once caregivers have an improved understanding and receive better support from healthcare providers, they should experience less stress and be better prepared to provide the appropriate support to patients with acquired brain injury.

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Introduction

Family members who care for a relative with acquired brain injury (ABI) may experience chronic stress that could result in an increased risk to their well-being following their prolonged responsibility as a caregiver [1-6]. Because the focus is often on the patient with ABI, such stress-related problems in family caregivers may not be diagnosed and treated in a timely manner by healthcare professionals involved in the management of the patient with ABI [4, 7].

Psychosocial well-being and physical health can impact each other either positively or negatively [8-10]. In general, some degree of stress is unavoidable as an essential part of life, may be positively harnessed (referred to as eustress), and may promote improved coping and

resilience [10, 11]. However, chronic stress has a negative impact on human mental and physical health and reduces coping skills when the stress response involves various neuro-physiological and psychological mechanisms [9, 11-13]. Although the interrelationship between these variables is complex, stress-related health problems may arise at any stage in family members who care for a relative with ABI.

Notably, when the patient with ABI is discharged from the hospital, healthcare professionals tend to concentrate on preparing the family to care for the patient's activities of daily living (ADL), such as bathing, eating and mobility, sometimes with less emphasis on the accompanying neuropsychological deficits that are usually present in the patient with ABI. It is well-documented that the varied neuropsychological deficits experienced by patients with ABI can undermine their ability to function effectively in

accordance with the daily demands of life. These may include changes and/or vicissitudes in psychological, social, cognitive, and personality/behavioral functioning [1,2,14]. These impairments can cause pronounced stress and burden in family caregivers, as they repeatedly attempt and fail to adapt to or cope effectively with the ensuing patient demands [1,2,15-17]. In many instances, the expected physical impairment in patients with ABI appears to be less distressful for family caregivers [16]. The World Health Organization (WHO) refers to health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” [18]. In light of this conceptualization, timely assessment of the caregiver’s physical, mental, and social well-being may help to prevent the development of serious psychopathological and other health-related complications in them. In the present study, the biopsychosocial (BPS) model was utilized as the theoretical framework underlying our approach, as it provides a holistic means of describing and treating patients in terms of physical, psychological, and social variables [8,19-21].

Apart from establishing the severity of the stress levels and its relationship with the suicidal ideation in family members who care for patients with ABI, the primary aims of this study were to investigate the following: whether the family caregivers of patients with ABI felt that the healthcare professionals adequately prepared them to deal with the potential neuropsychological deficits during the acute and sub-acute treatment of the patients; which neuropsychological and physical deficits in the patients with ABI were perceived by the family caregivers as causing the most stress; and whether the family caregivers felt that relevant psychosocial support and education with regard to ABI helped them to better manage their stress. Based on our current and related earlier findings on caregiver burden [4,7] that constitute part of a larger project on this exposition, guidelines are recommended that can assist healthcare professionals to better manage the psychological distress experienced by family members who care for a relative with ABI and to promote the development of resilience in these family members.

Materials and Methods

Study design

A random sample of 80 family caregivers of patients with ABI was enrolled in this study between June 2018 and October 2019. They were recruited from the Hyde Park and Soweto branches of a registered non-profit organization known as Headway Gauteng, located in Johannesburg, South Africa. Headway Gauteng provides various support programmes to adults living with ABI, their family members and caregivers. Research participants were either primary caregivers (72.5%) who are the family members

that deal with most of the responsibilities of caring for the patient with ABI, or secondary caregivers (27.5%), whose role is to provide support to the primary caregivers. Their baseline age range was 18 to 75 years ($\bar{X} = 49.6$), with 75% (60) female and 25% (20) male participants.

Data collection (done by the principal author JW) involved a mixed methodology that comprised a cross-sectional descriptive and phenomenological approach. Quantitative data were obtained by collating the responses to two previously administered standardized measures (4, 7): The Stress Symptom Checklist (SSCL) [22,23] and item 9 of the Beck Depression Inventory (BDI) [24]. Qualitative data were derived from self-report procedures that formed part of a structured questionnaire based on individual interviews of approximately 2-3 hours duration each and which formed the essence of the present study’s specific focus.

Ethical considerations

The study was granted ethical approval by the Biomedical Research and Ethics Committee, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa. Research participants received explanations regarding the study both verbally and in writing as part of a study information document. This explanation outlined their rights, and that participation was entirely voluntary, confidential and pertained to their experience of caring for a relative with ABI. Headway Gauteng organized appropriate professional follow-ups and interventions as needed for individual study participants.

Data analyses

Since the quantitative results included stress and suicidal ideation scores that were abnormally distributed, nonparametric statistical tests were used. They included the Kruskal-Wallis test with a significance level of 0.05. Percentiles were also reported. The SSCL provided a total stress score and sub-scale scores of the physical, psychological and behavioral symptoms of stress, whereas the BDI provided an indication of suicidality based on responses to item 9 of the inventory. Expanding our earlier research on this topic [4,7], the SSCL global and sub-category scores were compared with scores on item 9 of the BDI to determine if there is a relationship between high levels of stress and suicidality in the sample studied. Item 9 on the BDI relating to suicidal ideation, which is the dependent variable, was used as a categorical variable with 4 discreet levels, as follows: 0 = I don’t have any thoughts of killing myself; 1 = I have thoughts of killing myself, but I would not carry them out; 2 = I would like to kill myself, or 3 = I would kill myself if I had the chance. A score of 1 to 3 indicated suicidal ideation.

Some of the qualitative data gathered during the in-depth interviews required research participants to make

written notes during the interview in response to the items covered in the questionnaire. This included investigating the study participants' lived experiences as caregivers and the factors which they identified as being contributory to their high level of stress. Their written notes and the information transcribed by the interviewer were analyzed and common themes were identified, highlighted, and categorized. This process revealed five main themes which are described in the Results section.

Results

Figure 1 provides graphic representation of the severity of the stress levels of the participants (N=80) in terms of their total stress scores compared to their BDI item 9 scores, which indicated the presence of suicidal ideation. This shows a linear trend with BDI item 9 scores increasing as stress symptoms increased, reflecting a positive association between the two sets of scores, i.e. increasing levels of stress led to increased suicidality.

Table 1 provides further support for the findings presented in Figure 1 and an explanation of the summary statistics of the participants' (N=80) scores on the SSCL and the BDI item 9. The latter scores that ranged from 0 to 3 were compared to the SSCL total and sub-category scores

(physical, psychological and behavioral stress-related symptoms), indicating significant differences and that over one third (31; 38.8%) of the participants were so highly stressed that they felt suicidal.

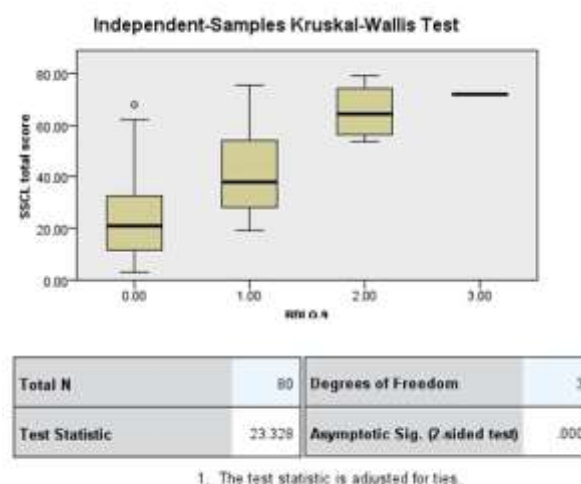


Figure 1. The association between increasing stress and BDI item 9 scores

Table 1. Summary statistics of SSCL categories by BDI item 9 scores

		BDI item 9				
		0.00	1.00	2.00	3.00	Total
		Total SSCL scores				
	Valid N	49	26	4	1	80
	Percentile 25	11.5	28.0	56.5	72.0	16.5
	Percentile 75	32.5	54.0	74.3	72.0	49.3
		Physical sub-category				
	Percentile 25	2.0	6.0	10.8	16.5	3.3
	Percentile 75	8.0	12.5	16.8	16.5	11.3
		Psychological sub-category				
	Percentile 25	2.5	8.5	20.3	23.5	4.0
	Percentile 75	11.0	18.0	24.8	23.5	16.0
		Behavioural sub-category				
	Percentile 25	5.5	11.0	24.3	32.0	7.0
	Percentile 75	15.5	25.0	34.0	32.0	22.8

The results of the following question were captured in Figure 2.

During your family member's treatment in the hospital, did you feel adequately prepared by the healthcare professionals for the changes in your family member's psychological status, behavior, cognition, and personality? Circle Yes or No: Please elaborate.

This question was designed to ascertain whether during the acute and sub-acute treatment of their relative with ABI, the family caregivers felt adequately prepared for the potential neuropsychological deficits in the patient with ABI. This question pertains to the family caregivers' experience before joining Headway Gauteng. A lack of understanding and preparation for these deficits in the patient was identified as an indicator of reduced coping and adaptation to home-based care. Family caregivers who did not feel prepared described experiencing problems, such as family conflicts once the patient had returned home. They also reported that their lack of understanding and preparation meant that they often did not respond appropriately to the patient's behavior resulting in feelings of guilt and shame on their behalf. In addition, not feeling prepared for the neuropsychological consequences of the ABI in their relatives was identified as a significant initial contributor to their prolonged experience of unhealthy stress.

Figure 2 indicates that most research participants (78.7%) did not feel prepared for the neuropsychological consequences of ABI in their relatives. A much smaller percentage (16.3%) felt that the healthcare professionals had prepared them for the potential changes in their relative's functioning. A small number (5%) were not present during the patient's treatment in the hospital and were unable to give an opinion.

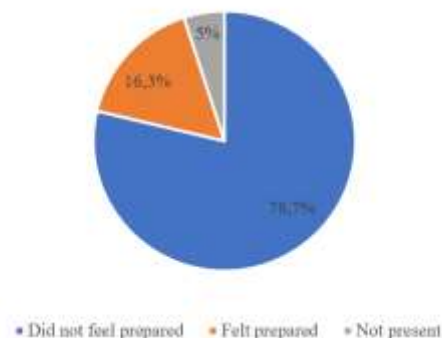


Figure 2. Preparation of family members

Figure 3 indicates the responses to the following question:

Which changes in your family member with ABI cause you most stress? Using the rating scale provided, please rate the categories listed in the box below according to the level of stress each one causes.

Figure 3 shows the percentage of the research participants who rated a particular neuropsychological deficit in the patient with ABI as causing them profound stress. Most caregivers felt that deficits involving emotions and/or moods (83.8%), cognitive ability (78.8%), behavior and personality (75.0%), executive and organizational ability (70.0%), and social factors (65.0%) caused them profound stress. Less than 60% of the participants felt that the patient's deficits in speech and communication, physical function and movement, and sexual behavior caused them stress. Comparatively, the results show that a large percentage of the research participants were experiencing profound stress as a result of having to cope with the neuropsychological deficits in their relative with ABI.

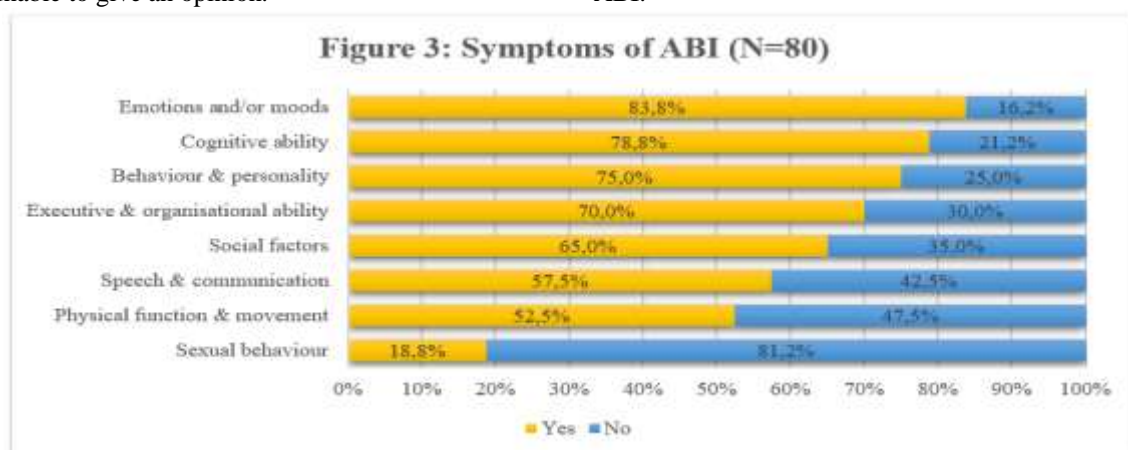


Figure 3. Research participants rate the impact of their relatives neuropsychological deficits on their stress levels

Five main themes were identified in the research participants' written and verbal feedback in response to the two questions posed above. The feedback, which has been adjusted to maintain confidentiality, reveals the experiences of the research participants.

The research participants felt that the psychosocial support and education regarding brain injury received at Headway Gauteng had particularly assisted them to better manage their stress and the effects of the ABI in their relative.

Theme 1: Lack of availability of the healthcare professionals during the acute phase of the hospital treatment.

The caregivers felt that healthcare professionals were not readily available and that there was a lack of clear communication regarding the patient's injury and well-being. This may be partly the reason that family members draw inaccurate conclusions about the patient's health and functionality.

Feedback 1: The doctors were generally unavailable. When we did get to see them, there was a lack of clear communication. Little information was available, and the doctors seemed to make sure their rounds took place when you were not there. The nurses also avoided providing any explanation. We felt isolated and incredibly stressed all the time.

Feedback 2: There was no information about the severity of our daughter's ABI, there was limited assistance and feedback on the long-term treatment and prognosis. We were told to expect some changes, but we never thought that she would be so aggressive with extreme moods. We were never told what to expect, except that she would be physically disabled. Everything I know about brain injury I got from the internet, Headway Gauteng and reading books as the medical staff treats you as if you were standing in their way.

Theme 2: Lack of psychological referral, support and follow-up.

The family caregivers felt that they did not receive the appropriate psychological support and follow-up after the patients were discharged from the hospital. Moreover, they described a lack of appropriate referrals to organizations and/or healthcare professionals. Many of the family caregivers noticed that some of the healthcare professionals they were referred to did not seem to understand the implications of brain injury on the patients' psychological functioning and how this may be impacting the family caregivers.

Feedback 1: It took 36 months to find out that my husband has a traumatic brain injury and what this means. Headway Gauteng is where I am getting counselling and understanding. We feel let down by the doctors and the hospital. Why did no one explain the potential difficulties caused by ABI?

Feedback 2: We as a family had no idea how to cope with the problem and we did not know that an organization such as Headway Gauteng even existed. Follow-up from the hospital was non-existent. We are all traumatized because we feel that we have made so many mistakes in terms of our relative's health and care. We feel that we have failed him. We were not

given any real support. When we did end up in a sub-acute rehabilitation facility, they helped a lot with information and advice. It made all the difference.

Theme 3: Lack of education and preparation for home-based care.

Family caregivers reported that they had not been prepared for the home-based care of the patient. Many of the research participants said that the healthcare professionals provided some information on the patient's physical mobility, eating, and bathing, that is, the activities of daily living. However, minimal education and preparation were provided to the family caregivers regarding the patient's mood, personality and behavior changes. Figure 3 shows that a significant number of the family caregivers experienced the patients' changes in mood, personality and behavior (neuropsychological deficits) as a profound source of stress.

Feedback 1: We were not informed of the extent of the injury and how severely it would impact our lives once he was back home. We were given some information about his physical disability. We were only told that he would not function normally, and any improvement would only occur in the first 2 years. I feel that we should have been informed or educated about the severe impact of ABI on his personality and how to handle this. They have never contacted me to provide the family with trauma support. No one told me what to expect. The main problem was that he was sent home extremely aggressive and he physically abused both myself and my daughters. It was extremely traumatic as he had not been an aggressive person before the brain injury.

Feedback 2: When my wife was discharged from the hospital, we were told that she was stable and ready to go home. We thought everything would be fine and that she would go back to work and live a normal life. We discovered that she had lost her memory and she would never be able to work again. The whole family wishes that we had been warned. We all went through a lot of pain and difficulty before figuring out what was going on with her. The children were confused by her erratic behavior. For a long time, they were angry with her and they did not want to have anything to do with their mother. I feel that this could have been avoided if we had had a better understanding of the brain injury.

Theme 4: Lack of education and information regarding ABI and its varied effects in the patient, such as extreme moods and aggression.

Many of the family caregivers reported that they had blamed and resented the patient because they did not understand that the inappropriate behavior that they witnessed was due to neurological and other changes

caused by brain injury. They described feeling very confused and angry with the patient because of the ABI-related neuropsychological symptoms/deficits. Deficits, such as loss of memory, erratic moods, aggression, lack of organizational skills, amongst others, were interpreted by the family caregivers as non-cooperative and obstructive behavior by the patient. Complications in family relationships due to the patient's difficulty with impulse control, self-awareness and insight served as cardinal sources of stress in family caregivers who described aggressive and sometimes physically violent interactions between themselves and the patient which they felt could have been avoided if they had had a better understanding of the patient's limitations due to the brain injury. The family caregivers reported that they started feeling impatient, which resulted in an escalation of the conflict within the family constellation. Most of the caregivers reported that they gained an understanding of brain injury and its effects at Headway Gauteng and that it helped them view the patients' behavior differently. As a result, they were able to improve their coping skills and resilience and manage the patient more effectively, thus lowering their levels of stress to a certain degree.

Feedback 1: There was no indication that my husband might be different. He has lost his fantastic sense of humor, lost his sharp intellect, lost his good sense of direction. I feel as if I were married to someone else, who is now in my husband's body.

Feedback 2: We were never informed about his injury and as a result, a lot of time was wasted. He had lived with the injury for a couple of years before he could be treated. A lot of healthcare professionals do not know about brain injury. Advocacy is needed around brain injury from healthcare professionals. Also, counselling family is essential. My husband can run and move around just as easily as he used to, but he has a lack of emotions, such as love and kindness. He is impatient, needs instant gratification and is excessively selfish and sometimes very aggressive. At the Headway Friendship Circle, I have met other wives with similar experiences, which has helped me a lot. I feel less alone.

Theme 5: Lack of treatment and education regarding the effects of stress on the psychological and physiological health in the family caregivers.

The caregivers all stated that being able to register the patient for the group support programme at Headway Gauteng provided them with relief from the many varied demands of being a caregiver. The importance of this respite for caregivers became more evident in that, those families who had access to private sub-acute care reported that they experienced less stress and felt more prepared for future home-based care. However, the majority of the

patients with ABI were not able to access the sub-acute rehabilitation treatment. These families experienced noticeably higher degrees of stress with poorer outcomes for the patient with ABI.

Feedback 1: Caring for my wife since she had a brain injury has been my priority. It is a lonely job, but I do it willingly. Before her injury, she had cared for me for many years. Unfortunately, I smoke and drink more than I ever have before. It is hard not to be able to have a proper conversation with my wife. Lately, I have been feeling low. I have also had a mini-stroke (trans ischemic attack) and I have been told that my heart is not as good as it should be. I have been neglecting my health and I am now suffering the consequences. I can see that the stress of being my wife's primary carer has gotten on top of me. At Headway Gauteng, they have explained that I need to start taking care of myself too and I am going to start doing that. I do not want my wife to end up alone. My wife will be attending the group support programme two days per week. I am looking forward to the time out.

Discussion

The results highlight the severity of the impact of stress on family members caring for a relative with ABI, with many family members experiencing suicidal ideation, which is consistent with our earlier findings [4, 7]. In this regard, postvention deals with the aftermath in survivors of suicidal ideation and/or behavior, which should be considered a form of preventing further psychological complications in these family members [25,26]. Of additional interest is the importance of the themes that were identified in the verbal and written feedback described by the family caregivers as major contributors to the stress that they experienced. All five themes can be summed up as family members expressing their need for caregiver support and improved preparation and education with regard to their relative's brain injury and the burden they experience due to being caregivers. Generally, there are at least three important stages in the treatment of a patient who has experienced brain injury, that is, the acute phase (in-patient hospitalization), sub-acute phase (in-patient rehabilitation) and home-based care which may include out-patient rehabilitation treatment. The healthcare professionals' efforts to provide adequate support, preparation and education of the family caregivers during these phases of the patient's treatment are essential to ensure more holistic management of both the family and the patient.

One of the predominant themes in their feedback was the expressed need for clearer communication from the healthcare professionals involved during the in-patient treatment phase. The acute phase of the patient's treatment

in the hospital may take days, weeks or months depending on the severity of the patient's brain injury and the required time for any recovery. The family members spend an extensive period visiting the patient in the hospital during this phase. Addressing the family caregivers' need for ongoing support, preparation and education should start during this initial acute phase of the patients' treatment. Family caregivers are more likely to develop effective coping skills if they have some understanding of the potential impact of the ABI on the patient both physically and neuropsychologically. They reported that sometimes they experienced healthcare professionals as vague in their communication, especially regarding the patient's prognosis. Explaining the reasons why it might be difficult to make a prognosis regarding the recovery from ABI would benefit the family's understanding. It is useful to advise the primary family caregiver to be accompanied by another family member to enhance understanding and remembering what the healthcare provider explains about the ABI, since the primary caregiver is often so overwhelmed that he/she may not register and remember accurately what they are told. Each ABI is unique and can result in different outcomes and consequences and comorbid psychological disorders in patients [2,27,28]. Family members do not always understand this and the fact that healthcare professionals may have time constraints and large patient loads. This does not always allow for the time required to help them during a possible prolonged process of understanding the varied potential effects of ABI during the acute phase. This may cause family members to become confused and angry when they fail to obtain a clear indication of an outcome and/or prognosis for the patient. An effective way to mitigate this difficulty is to provide the family with brain injury resources. Resources, such as verbal information, written material, and informative online and/or video material could help them process the new information that they have to understand. As part of the preparation of the family caregiver, the potential neuropsychological effects could be discussed with them, guided by the type and location of the ABI experienced by the patient. Psychologists, counsellors and/or social workers with training in cognitive neuroscience and/or neuropsychology would be able to assist them.

It is important to note that during the sub-acute phase of the in-patient rehabilitation, the burden of caregiving is often even more problematic in developing countries [29]. Various factors prevent many patients with ABI from having access to sub-acute rehabilitation, such as financial constraints and lack of private medical cover, amongst others. In these situations, family caregivers are required to start home-based care immediately after the patient is discharged from the acute stage of treatment. They may not be adequately prepared for this, since ABI and its effects

on the patient's level of functioning are often misunderstood by the family members and others [1,30]. Our feedback from the family caregivers revealed that the families who had immediate access to the sub-acute rehabilitation of the patient had a better understanding of the implications of ABI. They had also received more psychological support and information about ABI and, as a result, they were far better prepared and equipped to cope with the social, cognitive and psychological changes in the patient. Several of these families were also able to employ a caregiver to support them in their caregiving role. The families who did not have access to sub-acute rehabilitation had less favorable outcomes.

Notably, the physical changes in mobility were reported to be less distressful by many participants. These results support research [16] indicating that it is primarily the neuropsychological symptoms of ABI that cause the caregivers' elevated stress. According to the research participants' feedback, healthcare professionals were more focused on the patients' physical well-being and ADLs, whereas the research participants expressed the need for more information and support about coping with the neuropsychological deficits of ABI in their relative. These findings highlight that family caregivers may need more support and education with regard to the emotional, cognitive, behavioral, personality, executive function and social changes that may occur in the patient because of the ABI.

The transition from the hospital or rehabilitation facility to home-based care is an extremely pivotal period and if problems occur which are not managed, this may result in the family caregivers being exposed to even more elevated stress and other accompanying problems. In some instances, the effects of brain injury that can result in impairment have been referred to as the invisible or hidden disability [31]. Some patients with brain injury appear outwardly the same, which can give the impression that the patient has made a complete recovery, especially where physical recovery is relatively rapid but cognitive, behavioral and personality functioning is reduced and less definitive. Despite their poor insight, low tolerance levels, mood changes and the many hidden effects of brain injury, these patients may be asked by family caregivers to manage or to do things that they are not ready or able to execute. This disconnection between the patient and the family caregivers appears to be a significant contributor to the family conflict that we found. The opposite can also occur, where family caregivers overcompensate for the patients' difficulties and, as a result, the patients may fail to make any adequate progress. In both cases, the family caregivers may unknowingly and unintentionally inhibit the patient's progress and increase their own stress levels. We found that family caregivers also experience a range of

behavioral, psychological and physical effects of stress for extended periods before the onset of their own ill-health. It has been reported elsewhere [32] that post-ABI changes in personality functioning tend to have the main impact on the quality of life in the patient affecting the family members. In our study, it was only once family caregivers also started to attend support and education groups at Headway Gauteng that they realized how the patient's psychological, cognitive, personality and behavioral problems were due to the effects of the ABI. This was achieved by the provision of carer educational programmes, group, family, couple and individual counselling. Unfortunately, very often this only happens years after the patient has been discharged from the hospital and family carers have lived with other increasing personal problems such as strains on finances, social relationships, leisure pursuits, work-related and independence issues that can contribute to potential impediments when engaging with their extended family and friends.

Research supports the idea that appropriate stress interventions, such as mindfulness-based stress management and cognitive behavioral therapy amongst others, can improve the negative health effects of chronic stress [9,33,34]. According to our findings, healthcare professionals can help to foster resilience, which for the purpose of this study was defined as the ability to adapt, cope and maintain health when confronted with caregiver stress. In this regard, cognizance should be taken that resilience is a complicated construct which can be influenced by multiple factors, within the individual's personal and cultural context [35-37]. Generally, people who have high levels of self-mastery, self-esteem and social support tend to have improved physical and psychological health [38]. Therefore, assisting family members to develop more effective coping mechanisms can substantially ease the caregiver's burden/stress [1,39]. This could further result in better long-term health for both the caregivers and the patients with ABI.

The healthcare professionals involved could benefit family caregivers by exploring their long-term needs and implementing a method to identify the early signs and symptoms of stress. This could be done by including, in careful history taking, any premorbid factors such as personal and social circumstances and coping style. It is also recommended to adopt a quick and simple method of assessing caregivers' negative stress with its risks of attendant mental and physical health complications. In this regard, it could be worthwhile to request family members to fill in a stress symptom checklist that is easily scored. This could be emailed to the family or completed in the waiting area before their consultation. The results could provide an immediate indication of where problems may be occurring so that the family caregivers who need it can be referred for appropriate treatment. Such interventions

could prevent possible stress-related ill-health in the long-term and assist caregivers with coping skills and promote resilience in them.

Study limitations

The generalizability of the research results is limited by the small sample size (N=80) and the fact that the research participants were all selected from a single organization, Headway Gauteng. Additionally, all the research participants received and continued to have access to psychological and educational support services. The results could vary in a sample of family caregivers who do not receive such support.

Conclusions

The various needs of caregivers of relatives with ABI are frequently not met and the complexities of being both a caregiver and family member can contribute to a myriad of problems and be very stressful for them. The role of healthcare professionals in terms of preparing the family members who care for a patient with ABI to develop their resilience and coping skills is extremely important. This requires a shared understanding between family members and healthcare professionals that could prevent an exacerbation of the caregiver's stress. The holistic treatment of these patients requires screening for these effects and providing appropriate preventative interventions. Stress-symptom screening is a quick and effective method of detecting any early onset of the symptoms brought on by chronic stress in families who care for ABI patients and assists in identifying how an individual's stress is manifesting, thus facilitating applicable referrals for preventative treatment and interventions.

Conflict of interest disclosure

There are no known conflicts of interest in the publication of this article. The manuscript was read and approved by all authors.

Compliance with ethical standards

Any aspect of the work covered in this manuscript has been conducted with the ethical approval of all relevant bodies and that such approvals are acknowledged within the manuscript.

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References

1. Lezak MD, Howieson DB, Bigler ED, Tranel D. Neuropsychological assessment. Oxford University Press. New York. 5th ed. 2012. ISBN: 9780195395525
2. Camplair PS, Butler RW, Lezak MD. Providing psychological services to families of brain injured adults and children in the present health-care environment. In: Prigatano GP, Pliskin NH, editors. Clinical neuropsychology and cost outcome research: A beginning. New York: Psychology Press; 2003. pp. 83-107.
3. Schlebusch L, Walker J. The relationship between stress and suicidal ideation in family members caring for a patient with acquired brain injury. *World Scientific News*. 2020;140:156-71.
4. Walker J, Schlebusch L, Gaede B. The impact of stress on depression, ill health and coping in family members caring for patients with acquired brain injury. *S Afr Fam Pract* (2004). 2020;62(1):e1-e6. doi: 10.4102/safp.v62i1.5149
5. Vitaliano PP, Young HM, Zhang J. Is caregiving a risk factor for illness? *Current Directions in Psychological Science*. 2004;13(1):13-6. doi: 10.1111/j.0963-7214.2004.01301004.x
6. Vitaliano PP, Scanlan JM, Zhang J, Savage MV, Hirsch IB, Siegler IC. A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosom Med*. 2002;64(3):418-35. doi: 10.1097/00006842-200205000-00006
7. Formica C, La Face A, Lo Buono V, Di Cara M, Micchià K, Bonanno L, Logiudice AL, Todaro A, Palmeri R, Bramanti P, Marino S, Corallo F. Factors related to cognitive reserve among caregivers of severe acquired brain injury. *J Clin Neurosci*. 2020;77:94-97. doi: 10.1016/j.jocn.2020.05.027
8. Zachariae R. Psychoneuroimmunology: a bio-psycho-social approach to health and disease. *Scand J Psychol*. 2009;50(6):645-51. doi: 10.1111/j.1467-9450.2009.00779.x
9. Howard L, Wibberley C, Crowe L, Body R. How events in emergency medicine impact doctors' psychological well-being. *Emerg Med J*. 2018;35(10):595-599. doi: 10.1136/emered-2017-207218
10. Kraemer KM, Luberto CM, O'Bryan EM, Mysinger E, Cotton S. Mind-Body Skills Training to Improve Distress Tolerance in Medical Students: A Pilot Study. *Teach Learn Med*. 2016;28(2):219-28. doi: 10.1080/10401334.2016.1146605
11. Logan JG, Barksdale DJ. Allostasis and allostatic load: expanding the discourse on stress and cardiovascular disease. *J Clin Nurs*. 2008;17(7B):201-8. doi: 10.1111/j.1365-2702.2008.02347.x
12. McEwen BS. Neurobiological and Systemic Effects of Chronic Stress. *Chronic Stress (Thousand Oaks)*. 2017;1:2470547017692328. doi: 10.1177/2470547017692328
13. Levy-Gigi E, Donner R, Bonanno GA. Free Your Mind: Emotional Expressive Flexibility Moderates the Effect of Stress on Post-Traumatic Stress Disorder Symptoms. *Int J Mol Sci*. 2020;21(15):5355. doi: 10.3390/ijms21155355
14. Ashman TA, Gordon WA, Cantor JB, Hibbard MR. Neurobehavioral consequences of traumatic brain injury. *Mt Sinai J Med*. 2006;73(7):999-1005.
15. Anderson MI, Parmenter TR, Mok M. The relationship between neurobehavioural problems of severe traumatic brain injury (TBI), family functioning and the psychological well-being of the spouse/caregiver: path model analysis. *Brain Inj*. 2002;16(9):743-57. doi: 10.1080/02699050210128906
16. Allen K, Linn RT, Gutierrez H, Willer BS. Family burden following traumatic brain injury. *Rehabilitation Psychology*. 1994;39(1):29-48. doi: 10.1037/h0080313
17. Manskow US, Friberg O, Røe C, Braine M, Damsgard E, Anke A. Patterns of change and stability in caregiver burden and life satisfaction from 1 to 2 years after severe traumatic brain injury: A Norwegian longitudinal study. *NeuroRehabilitation*. 2017;40(2):211-222. doi: 10.3233/NRE-161406
18. Mathers CD. History of global burden of disease assessment at the World Health Organization. *Arch Public Health*. 2020;78:77. doi: 10.1186/s13690-020-00458-3
19. Engel GL. The clinical application of the biopsychosocial model. *Am J Psychiatry*. 1980;137(5):535-44. doi: 10.1176/ajp.137.5.535
20. Schlebusch L. Health Psychology in South Africa: An Introduction. *South African Journal of Psychology*. 1996; 26(1):1-3. doi: 10.1177/008124639602600101
21. Mo Q, Ma Z, Wang G, Jia C, Niu L, Zhou L. The pattern of stressful life events prior to suicide among the older adults in rural China: a national case-control psychological autopsy study. *BMC Geriatr*. 2020; 20(1):473. doi: 10.1186/s12877-020-01874-4
22. Schlebusch L. The development of a stress symptom checklist. *South African Journal of Psychology*. 2004;34(3):327-49. doi: 10.1177/008124630403400301
23. Lo Castro AM, Schlebusch L. The measurement of stress in breast cancer patients. *South African Journal of Psychology*. 2006;36(4):762-79. doi: 10.1177/008124630603600407
24. Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. *Archives of General Psychiatry*. 1961;4:561-71.

25. Schlebusch L. South Africa - experiences of suicide survivors support. In: Andriessen K, Krysinska K, Grad OT, editors. *Postvention in action: the international handbook of suicide bereavement support*. Göttingen: Hogrefe 2017. p. 377-82.
26. Schlebusch L. Postvention in suicide survivor support: some ethical considerations. *Mental Health Matters*. 2020;7(4):12-3.
27. Auxéméry Y, Gayraud F. Post-concussion syndrome: Still forgotten? From the disappearance of the DSM-5 to a multidisciplinary consultation. *Encephale*. 2020; S0013-7006(20)30206-2. doi: 10.1016/j.encep.2020.06.017
28. de Vries PJ, Wilde L, de Vries MC, Moavero R, Pearson DA, Curatolo P. A clinical update on tuberous sclerosis complex-associated neuropsychiatric disorders (TAND). *Am J Med Genet C Semin Med Genet*. 2018;178(3):309-320. doi: 10.1002/ajmg.c.31637
29. Khondowe O, Rhoda A, Mpofu R. Perceived needs of caregivers of stroke patients' receiving out-patient physiotherapy treatment in Lusaka, Zambia. *South African Journal of Physiotherapy*. 2007;63(1):14-7. doi: 10.4102/sajp.v63i1.122
30. Hux K, Schram CD, Goeken T. Misconceptions about brain injury: a survey replication study. *Brain Inj*. 2006;20(5):547-53. doi: 10.1080/02699050600676784
31. Maunsell H, Tyerman A, Barton S, Bramley M. Ongoing support needs after brain injury, as reported by a long-term relatives' group. *The Neuropsychologist*. 2015(1):22-4.
32. Diaz AP, Schwarzbald ML, Thais ME, Hohl A, Bertotti MM, Schmoeller R, Nunes JC, Prediger R, Linhares MN, Guarnieri R, Walz R. Psychiatric disorders and health-related quality of life after severe traumatic brain injury: a prospective study. *J Neurotrauma*. 2012; 29(6):1029-37. doi: 10.1089/neu.2011.2089
33. Grossman P, Niemann L, Schmidt S, Walach H. Mindfulness-based stress reduction and health benefits. A meta-analysis. *J Psychosom Res*. 2004;57(1):35-43. doi: 10.1016/S0022-3999(03)00573-7
34. van der Klink JJ, Blonk RW, Schene AH, van Dijk FJ. The benefits of interventions for work-related stress. *Am J Public Health*. 2001;91(2):270-6. doi: 10.2105/ajph.91.2.270
35. Southwick SM, Bonanno GA, Masten AS, Panter-Brick C, Yehuda R. Resilience definitions, theory, and challenges: interdisciplinary perspectives. *Eur J Psychotraumatol*. 2014;5. doi: 10.3402/ejpt.v5.25338
36. Ungar M, Theron L, Murphy K, Jefferies P. Researching Multisystemic Resilience: A Sample Methodology. *Front Psychol*. 2021;11:607994. doi: 10.3389/fpsyg.2020.607994
37. Theron LC, Theron AM, Malindi MJ. Toward an African definition of resilience: A rural South African community's view of resilient Basotho youth. *Journal of Black Psychology*. 2013;39(1):63-87. doi: 10.1177/0095798412454675
38. Thoits PA. Stress and health: major findings and policy implications. *J Health Soc Behav*. 2010;51 Suppl:S41-53. doi: 10.1177/0022146510383499
39. Smith LM, Godfrey HPD. *Family support programs and rehabilitation: A cognitive-behavioural approach to traumatic brain injury*. Plenum Press. New York. 1995.