



World Scientific News

An International Scientific Journal

WSN 140 (2020) 156-171

EISSN 2392-2192

The relationship between stress and suicidal ideation in family members caring for a patient with acquired brain injury

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ABSTRACT

The aim of this study was to investigate the relationship between stress and suicidal ideation in family members who care for a patient with acquired brain injury (ABI). The sample consisted of 80 family carers who are members of Headway Gauteng (the brain injury association) located in Johannesburg, South Africa. Most of the research participants were primary caregivers (72.5%) with secondary caregivers making up a smaller percentage (27.5%). Secondary caregivers tend to perform the role of assisting and supporting the primary caregiver. Stress levels were measured, and a global stress score was obtained for each research participant. This global stress score included individual scores for physical, psychological and behavioural symptoms of stress for each participant. Both global and individual stress scores were correlated with answers to Question nine of the Beck's depression inventory. The correlation between stress and suicidal ideation was significant, with data showing that suicidal ideation directly increased with increasing levels of stress.

Keywords: stress, suicidal ideation, caregivers, acquired brain injury

1. INTRODUCTION

Suicidal behaviour is a complex phenomenon that occurs in different forms and degrees of severity that can range from someone wishing to be dead to actually committing suicide. It remains a significant health care concern in developed and developing countries and risk factors are multifactorial, multidimensional and varied, which can also include stress and certain medical conditions [1-14]. The World Health Organization (WHO) [15] has reported that globally nearly a million people commit suicide every year (although this figure may be higher because of unrecorded data) and based on current trends this is likely to increase to 1.53 million by 2020 [16]. According to a recent WHO report [15] just under one-third of these are young people, based on 2016 global age-standardized suicide rates.

In South Africa suicide statistics are equally alarming although, as elsewhere, figures must be viewed with caution as many attempted and completed suicides go unreported and/or are not recorded due to various factors, including limitations with data collection [4, 6, 10, 11, 17-21]. As a result, suicide rates in South Africa may, as in the case of global figures, be higher than generally mentioned in studies which have reported suicide rates ranging from 11 per 100, 000 to 25 per 100, 000 of the population [11]. According to some studies, this accounts for about 9.5% of non-natural deaths in young people and 11% in adults and about 9.6% to 12% in all age groups [9, 21]. One study estimated suicide rates within South Africa to be higher than the international average, particularly in males aged 15-29 years [22].

Similarly, inordinate stress levels and suicidal ideation are of major concern and both chronic and acute stress have been found to be critical co-morbid variables in suicidal behaviour [4,8,14,23-25]. As part of the larger WHO multisite intervention study on suicidal behaviour (SUPRE-MISS), a WHO community survey [26, 27] conducted over eight international sites (including South Africa) found that suicide attempts, plans and ideation varied across sites, that the ratios between attempts, plans, and thoughts of suicide differed widely and that medical attention following a suicide attempt ranged between 22% and 88%.

The study concluded that the concept of the suicidal process as a progressive, smooth evolution from thoughts to plans to suicide attempts needs further research because it appears to be influenced by the cultural setting as well as the fact that the prevalence of undetected suicide attempts is high in different cultures. Consequently, there is a need for an improved health care awareness of how to identify and assist such people in a better understanding of the strong cultural underpinnings behind suicidal behaviour [27]. Likewise, studies on suicidal ideation in South Africa have produced diverse results, including in medical conditions and community samples which have ranged from 4% in young primary school children to 24% or higher in high school students and adolescents or higher in adults [4, 6, 21, 28-33]. One of the sites of the WHO community SUPRE-MISS survey [26] was in the port city of Durban, situated on the eastern seaboard of the country in the province of KwaZulu-Natal where suicidal ideation was found to be as high as 25.4%.

Worldwide one of the more common causes of death and disability is brain injury [34, 35]. In South Africa, injuries from road traffic accidents have been indicated to be double the global number [22]. The consequent high incidence of traumatic brain injury (TBI) points to a profound problem [36], prompting some [37] to refer to TBI as a hidden pandemic. Furthermore, because there are limited facilities available to patients recovering from and living with the long-term effects of acquired brain injury (ABI), caring for these patients often tends to become the responsibility of the patients' family members [37]. Also progress in healthcare

and better resuscitation methods have resulted in a steadily growing population of people with ABI being dependent on family members [38]. Moreover, there is an increasing number of children and young adults surviving TBI with impaired brain function and resulting cognitive deficits [39]. According to the National Institute for Occupational Health [40] in South Africa approximately 89 000 new patients with TBI are reported per annum. This figure does not include those people living with non-traumatic ABI, and further highlights the fact that ABI is a serious public health concern in South Africa.

There has been robust research into the psychological distress experienced by patients with neurocognitive disorders, TBI and ABI and their suicide risk [1, 14, 39, 41-44], although according to recent research post-traumatic stress disorder is still underestimated in these patients [44]. Consistent with international findings, in South Africa the potential for depression and suicide where there may be high-risk groups associated with specific medical conditions has been well established, such as, for example, in people diagnosed with analgesic nephropathy, uraemic encephalopathy, end-stage renal disease, HIV-AIDS, cancer and in those who seek elective cosmetic surgery [4, 5, 7, 21, 28-30, 33, 45-51]. Nevertheless, there is a lack of South African research data in respect of suicide risk in patients with ABI and their close family members. Determinants of family members' psychosocial-related caregiver burden regarding TBI have been extensively documented [39]. Comparatively, however, there is a paucity of research on suicidal ideation in relation to such burden, particularly in South Africa. Therefore, as part of an ongoing research project on suicidal behaviour, this study aimed to investigate the prevalence of stress-related suicidal ideation in close family members who care for patients with ABI.

2. MATERIALS AND METHODS

2. 1. Definitions of core concepts

For the purpose of this study, the following definitions apply. ABI is defined as neurological damage that occurs after birth due to a traumatic incident, such as a blow to the head, fall, motor vehicle collision or sports-related injury; or a non-traumatic incident, such as brain tumour, meningitis, encephalitis, oxygen deprivation (hypoxia) and stroke, while aetiological considerations such as congenital disorders and degenerative diseases are excluded [39, 52]. It is important to note that the terms ABI and TBI are sometimes used interchangeably. ABI is an umbrella term which incorporates both TBI and non-traumatic brain injury as part of its definition. For the purpose of this study, the term ABI is used.

Stress is defined as the outcome of an interaction between a person and his or her environment brought about by a stressor(s) that may include any internal condition such as anxiety or low mood, or external event or situation like a traumatic life event or ongoing daily hassles, which are appraised and perceived to be threatening by the individual thereby resulting in demands being placed upon that individual's coping and adaptive processes and skills. When the individual encountering a threat appraises and perceives it as being beyond his or her ability to cope with, it may lead to a stress response that involves biological/physical, psychological and behavioural reactions [53, 54].

Suicidal ideation is defined as a discreet and complex phenomenon including thoughts about suicide but is not restricted to just thinking about committing suicide. It can also include

a person writing or talking about suicide or having the intention and desire to commit suicide with or without making plans or attempting to do so [3, 4, 14].

Caregiver burden is defined as multifaceted stressors caused by the caregiving experience and may include physical, psychological, social, and financial demands [55]. Individuals experiencing caregiver burden are at higher risk for depression and reduced quality of life [55].

2. 2. Sample

The sample recruited (N = 80) consisted of close family members who care for a patient with ABI and who are members of Headway Gauteng (the brain injury association) in Johannesburg, South Africa. The recruitment was conducted from June 2018 to October 2019. Each interview was extensive and took approximately two to three hours and included the administration of the various assessments described below under measures as part of a mixed research design.

Of the sample, 72.5% were primary caregivers, that is, the family members who are first in line to provide care to the patient with ABI. The secondary caregivers made up 25.5% and include family members who assisted and supported the primary caregiver(s). The patients with ABI, that the family members care for, all attend Headway Gauteng where they were neuropsychologically screened after being referred by healthcare practitioners. The age range of the sample of caregivers at baseline was 18 to 75 years ($\bar{X} = 49.6$). Of these 20 (25%) were males and 60 (75%) females.

Ethical approval for the study was obtained from the Biomedical Research and Ethics Committee, College of Health Sciences, University of KwaZulu-Natal, Durban, South Africa. Participants were provided with an information sheet that explained the research study and their rights clearly. This included the reassurances that their participation in the study was entirely voluntary and confidential, and that the assessment procedures pertained specifically to their involvement with caring for a relative with ABI. Appropriate professional follow-up and treatment, where necessary, were arranged by Headway Gauteng.

2. 3. Measures

There are various well-described stress-related [56-58], suicide risk assessment and suicidal ideation measures [3, 4, 12, 14]. Some have been designed for general use and others for people with specific medical conditions [59]. Short scales with clinical utility tend to be the most useful, as for example, used in the SUPRE-MISS community study [27].

In addition to utilising a research-designed questionnaire to record socio-demographic data, the study incorporated the use of the following two individually administered measures that have been extensively used in research and clinical practice. The Stress Symptom Checklist (SSCL) [53, 54, 60] was used to measure the research participants' stress levels and symptoms of stress. The SSCL is a reliable, valid and clinically useful dichotomous-scaled, 87-item checklist of the general signs and symptoms of unhealthy stress. Reliability coefficients ranged from 0.8 to 0.9 which are consistent with a significant number of existing psychological measures [54]. Validity included content validity based on a discriminating item selection, criterion and construct validity, as well as convergent and discriminant validity. Validity coefficients range from 4 to 5 [54]. There are three main sub-scales into which the items are categorised: physical symptoms (18 items); psychological symptoms (27 items); and behavioural symptoms (42 items). The highest total score is 87, with scoring categories being:

low stress = 8 and below; mild stress = 9 to 15; moderate stress = 16 to 30; severe stress = 31 to 45; and profound stress = 46 and above [54]. In using the SSCL, reactions to stress are measured by how often they occur, either weekly or at least monthly. A high score signifies a high level of stress. Scores higher than three on any sub-scale indicate symptoms of unhealthy stress for that sub-scale (physical, psychological or behavioural). A total score of nine or higher across all three sub-scales indicates the onset of dysfunctional stress for that person. Thus, the SSCL was additionally useful because it provided a total stress score, and it indicates whether research participants experienced primarily physical, psychological or behavioural reactions and/or symptoms of stress.

Item 9 of the Beck Depression Inventory (BDI) [61] was used to measure suicidal ideation. The BDI is a 21-item multiple-choice self-report inventory which measures the severity of depression. Item 9 of the BDI specifically addresses thoughts about suicide (i.e. suicidal ideation). Research participants were asked to choose from 4 options from Item 9, viz.: 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. For the purpose of this research study, a score of 1 to 3 denoted suicidal ideation.

2. 4. Data Analyses

Scores obtained on the SSCL were compared with those obtained on Item 9 of the BDI in order to identify if there is a relationship between elevated stress and suicidality in the sample studied. The SSCL scores were non normally distributed, thus it was decided to use nonparametric statistical tests (including the Kruskal-Wallis, Mann Whitney and Chi-Square Tests with a significance level of $p = .05$) and to report medians and interquartile ranges for these variables. The dependent variable (Item 9 on the BDI) was treated as a categorical variable with 4 independent levels.

3. RESULTS

Table 1. Total stress scores of the SSCL.

	Frequency	%	Cumulative %
Low	7	8.8	8.8
Mild	11	13.8	22.5
Moderate	25	31.3	53.8
Severe	14	17.5	71.3
Profound	23	28.7	100.0
Total	80	100.0	
N = 80			

The results show that participants with higher levels of stress had correspondingly higher levels of suicidal ideation. Table 1 displays a descriptive analysis of the total SSCL scores of all the subjects. The majority (77.5%; 62) suffered from moderate, severe or profound stress.

Table 2 shows the summary statistics of all the participants' scores for the SSCL, as well as Item 9 of the BDI. In terms of sub-category scores on the SSCL, most participants scored higher on the behavioural than the physical and psychological sub-scales.

This suggests a denial and/or lack of acceptance of the impact of the physical and psychological stress-related symptoms on them. There was, in fact, a profound psychological and physical impact on the research participants as the following findings indicate: 62.5% (50) of the sample had received a medical and/or psychological diagnosis from a healthcare professional after becoming a caregiver.

Of this number, 30% (15) were diagnosed with a medical disorder and 36% (18) had been diagnosed with a psychological problem, and 34% (17) had been diagnosed with both a medical and psychological condition. Of the total sample, 23.8% (19) reported experiencing intense feelings of depression, anxiety and stress which they had not sought treatment for. 6.3% (5) reported having been diagnosed with medical and psychological conditions before becoming a caregiver, and all of these participants expressed that their health had worsened after becoming a caregiver. Out of the entire sample, only 7.5% (6) expressed having no psychological or medical concerns.

These findings highlight the value of looking at the different sub-categories of stress as done by the SSCL, since investigating the physical, psychological and behavioural stress symptoms, in addition to a total stress score for each caregiver, provided a useful means of identifying denial by them. A high score in any one of these sub-categories combined with lower scores in the others suggests that the patient may not be fully cognisant of the global impact of their stress and/or may not want to admit to not coping with their caregiver burden.

Table 2. Summary of the SSCL (total and sub-categories) and Item 9 of the BDI.

	SSCL Scores							BDI Item 9
	Total	Physiological	%	Psychological	%	Behavioural	%	Suicidality
Mean	32.9	7.7	42.6	10.5	38.8	14.8	35.2	.5
Std Dev.	20.5	5.1	28.1	7.4	27.4	9.9	23.7	.7
N = 80								

There were very significant differences across the 4 options of BDI Item 9 for each of the individual stress scores as well as the total stress score on the SSCL (Table 3). Multiple comparison tests were done to assess which of the 4 options of the BDI Item 9 were significantly different from each other and it was found in each of the scores that only options 0 and 1, and 0 and 2 were significantly different from each other. The other options had too few participants to be statistically significantly different from each other.

However, it did show a clear linear trend with the scores on the SSCL increasing as the BDI Item 9 option scores increased, which added further evidence of a positive association between increased stress levels as measured and the BDI Item 9 options (i.e. for all 3 components of the stress response on the SSCL as well as overall).

Table 3. SSCL and BDI Item 9 Options Scores.

		BDI Item 9 options				Total
		0	1	2	3	
SSCL total scores	Valid N	49	26	4	1	80
	Median	21.0	37.8	64.5	72.0	29.8
physical symptoms	Valid N	49	26	4	1	80
	Median	6.0	9.0	15.5	16.5	7.3
psychological symptoms	Valid N	49	26	4	1	80
	Median	5.0	12.8	22.0	23.5	9.0
behavioural symptoms	Valid N	49	26	4	1	80
	Median	8.0	15.5	26.8	32.0	11.8
%	Valid N	49	26	4	1	80
	Median	19.0	36.9	63.7	76.2	28.0

The total stress scores were then cross tabulated with the BDI Item 9 options using the categorical data rather than the raw scores (Table 4). Results show that 61.3% (49) of the research participants indicated that they had no suicidal thoughts. However, 32.5% (26) indicated that they were experiencing suicidal thoughts. A further 5% (4) of the sample indicated that they would like to commit suicide and 1.3% (1) said that they would commit suicide if they got the chance. Of the 38.8% (31) of participants reporting suicidal ideation and intention, 25.8% (8) reported moderate stress, 29% (9) reported severe stress and 45.2% (14) reported profound stress levels.

The same trend as the previous numerical data was found, that is, as the SSCL scores increased, so did the scores on Item 9 of the BDI. Interestingly, if one compares these results with those from Table 1, it can be seen that of the 31.3% (25) participants with moderate levels of stress, 32% (8) experienced suicidal ideation.

Of the 17.5% (14) of the sample with severe stress levels, 64.3% (9) experienced suicidal ideation. Of the 28.7% (23) of the sample with profound stress levels, 39.1% (9) experienced suicidal ideation and 21.7% (5) also reported suicidal intent. In summary, our findings indicated a positive relationship between high stress levels and suicidal ideation as measured in the sample studied.

Table 4. SSCL categorical data and BDI Item 9 options cross-tabulation.

			BDI Item 9 Options				Total
			0	1	2	3	
SSCL Category Scores	Low	Count	7	0	0	0	7
		Category %	100.0%	0.0%	0.0%	0.0%	100.0%
	Mild	Count	11	0	0	0	11
		Category %	100.0%	0.0%	0.0%	0.0%	100.0%
	Moderate	Count	17	8	0	0	25
		Category %	68.0%	32.0%	0.0%	0.0%	100.0%
	Severe	Count	5	9	0	0	14
		Category %	35.7%	64.3%	0.0%	0.0%	100.0%
	Profound	Count	9	9	4	1	23
		Category %	39.1%	39.1%	17.4%	4.3%	100.0%
Total	Count	49	26	4	1	80	
	Category %	61.3%	32.5%	5.0%	1.3%	100.0%	

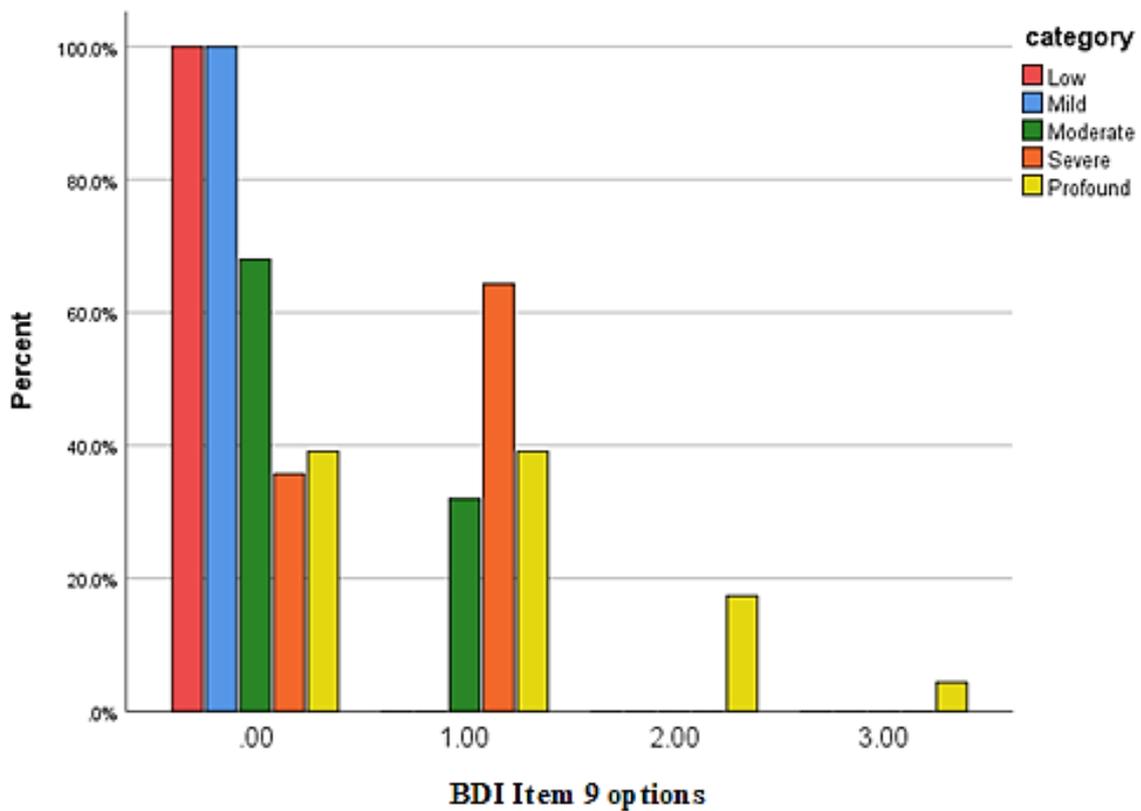


Figure 1. Total SSCL and BDI Item 9 scores.

The bar graph (Fig. 1) shows the results in visual format: 100% of the low and 100% of the mild stress scorers on the SSCL fell in the BDI Item 9 option of 0 (i.e. no suicidal ideation). As the BDI Item 9 options increased, so did the severity of the stress scores on the SSCL. On the BDI Item 9 options 2 and 3 (i.e. suicidal ideation and intent) profound stress levels were noted.

4. DISCUSSION

Both chronic and acute stress have been found to be comorbid aetiological considerations in suicidal behaviour as well as in somatic disease/medical conditions [2-4, 8, 14, 23-25, 53]. Generally, less emphasis has been placed on the relationship between carers' exposure to high stress levels and subsequent suicidal ideation when looking after loved ones with medical conditions. Our research has, in fact, focused on this aspect in respect of ABI and showed that the higher the carer burden stress-related levels in the research participants, the more likely they were at risk for suicidal ideation.

This research population is unique in the sense that both the patients with ABI and family carers have access to psycho-social services as members of Headway Gauteng, Johannesburg where the study was done. These services include the provision of counselling (telephonic and face to face) and an appropriate referral system for psychiatric and/or psychological treatment and other support services where deemed necessary. They can also attend the Headway Friendship Circle (HFC) which is an information and psychological support group for family members caring for a patient with ABI. The group has a social component and family members can connect and form friendships with others going through similar challenges. Many of the families assist each other in coping with ongoing caregiving demands. Headway Gauteng also offers weekly activity days for people with ABI. Patients with ABI can spend a few days per week in an environment that is safe and provides a stimulating programme made up of various group activities facilitated by highly trained therapists.

This allows family members to get respite from their caregiving duties. However, despite having access to such support, the results of this study show that a significant number of family members caring for a patient with ABI who fell into the moderate, severe and profound stress categories experienced suicidal ideation. None of the participants who expressed low and mild levels of stress reported any suicidal ideation. It is only when participants were found to have moderate, severe or profound stress that there were corresponding findings of suicidal ideation and/or intent. In this group, caregivers who expressed overwhelming feelings of being trapped and who experienced profound caregiver burden were more likely to have thoughts about suicide as a way out of their situation. In addition, it was observed that many participants, both those who reported suicidal ideation and those who did not, seemed to have a reduced concern for their own health and psychological well-being. Many of the family caregivers reported that they neglected these aspects and that their priority was the patient with ABI.

The theoretical framework underpinning the present research was based, in part, on an integrated biopsychosocial model as described by Schlebusch [54, 62]. This approach is grounded in systems theory [63]. From this perspective human health is viewed holistically, involving the interaction of biological, psychological and social factors. The stress-vulnerability [25] and stress-diathesis [64, 65] models were also drawn on. A vulnerability or predisposition towards a specific disorder is referred to as a diathesis where high stress levels

in a person who has a diathesis can be conducive to the disorder emerging [8]. We used this to highlight the stress effects on individuals in our sample with specific vulnerabilities, that is the family members who reported that they had experienced a sequence of traumatic events collectively linked to their high stress scores in their roles as caregivers.

These traumatic events included: being informed that the relevant family member had suffered a serious brain injury; fears that their relative may not survive and/or could have permanent life-changing effects; difficulty in getting clear information about the relative's prognosis; unrealistic expectations of the potential chances of recovery of the patient with ABI; realisation that the expected recovery may not occur and difficulty coming to terms with this; demands made during the time the patient with ABI is in a rehabilitation facility; adjusting to another set of altered circumstances once the patient with ABI is home; doubting individual carer coping resources; difficulty coping with the physical, psychological, behavioural and personality changes in the patient with ABI; and the carer ultimately having to face the reality of the situation and deal with a personal sense of reduced social interaction and quality of life. The inordinate stress experienced by the family members results in the expression of individual diatheses, as our findings indicate.

The consequences of compassion fatigue (sometimes also referred to as burnout) in health care professionals generally and those who are involved in providing postvention services following suicidal behaviour are well described [66, 67]. This is less so in terms of stress-related suicidal ideation as a result of carer burden in close family members who look after patients with ABI, where the potential toll that it can take on the respective family members can be severe. Allostatic load (AL) is the accumulated physical wear and tear on an individual's body as he or she repeatedly attempts to adapt to acute and/or chronic stressors over time [68, 69]. Exposure to inordinate levels of ongoing stress can lead to marked AL, potentially resulting in significant physiological and psychological complications.

The theoretical models that we utilized [25, 54, 62, 64, 65] were useful in explaining how this happened in the participants in our study in terms of their suicidal ideation because they offer practical, explanatory and predictive methods to detect stress-related suicidal risk. In addition, since people are biologically unique and have had their own set of life experiences, individuals who experience high stress levels tend to express different symptoms as also found in our study.

Some may have a tendency towards physiological symptoms and others may experience more psychological or behavioural ones, while others may experience a combination of symptoms. In the present study population, although elevated stress was found over all three SSCL sub-categories and a combination of these, a high percentage reported more behavioural stress-related symptoms compared to physical and psychological ones.

To some extent, this is similar to other findings that show that the caregiver burden associated with looking after TBI patients includes social isolation because of low levels of socializing/social interaction, dissatisfaction and reduced quality of life, amongst others [39].

However, in our sample, it also indicated denial and/or a struggle to effectively deal with and recognise the physical and psychological manifestations of their high stress levels.

Finally, it has been pointed out by authorities [23] that in clinical settings, the adverse sequelae of exposure to traumatic stress is frequently unrecognized or neglected when the presenting symptomatology resulting in stress-related suicidology in the non-index patient is not detected. Suicide prevention programmes can be comprehensive and varied [2, 3, 9, 14]. In essence, though, it includes any self-injury prevention or health-promotion strategy that is

generally or specifically aimed at reducing the incidence and prevalence of suicidal behaviour and/or ideation.

This involves early recognition and assessment of suicidal risk; immediate response to such risk; resource referrals and follow-up management and treatment strategies. Hence, given our findings when considering various mediating mechanisms we also recommend that, because of the seminal emotional residue following the consequences of prolonged exposure to stress, family members who are caring for a patient with ABI should undergo regular stress assessments and be referred for appropriate professional help where applicable.

In addition, as part of holistic management and suicide prevention, treatment strategies should incorporate increasing professional health care workers' awareness and knowledge of stress and suicidal ideation in close family members who care for patients with ABI. The limitations of this study include the fact that the sample size was small which limits the generalizability of the findings. As a result, despite the study finding a significant correlation between elevated stress levels and suicidal ideation in close family members who care for patients with ABI, the results cannot be axiomatically generalised.

Further research should be undertaken with a larger sample to identify a history of possible pre-morbid and other variables. These include which neuropsychological, physical and social changes in the patients with ABI cause the family carers the most stress, whether there are gender and/or age-related differences in them and if there is a correlation between the severity level of ABI and the caregivers' suicidality.

5. CONCLUSIONS

There has been extensive research of caregiver burden in caregivers of patients with ABI and the fact that they experience an inordinate amount of stress due to the ongoing demands and stressors associated with being a caregiver. However, less research has paid attention to stress-related suicidal ideation in close family members who care for patients with ABI.

Inordinate stress levels and suicidal ideation are of significant concern and both chronic and acute stress have been found to be critical co-morbid variables in suicidal behaviour. As part of an ongoing research project on suicidal behaviour, this study investigated the prevalence of stress-related suicidal ideation in close family members who care for patients with ABI.

The study showed that elevated levels of stress can cause these caregivers to develop suicidal ideation as they start feeling that they are not coping with the demands associated with caregiving, which is often unrecognised.

This is clinically relevant and early identification of such problems and referral for appropriate help is recommended along with the need to alert professional health care workers to this.

Acknowledgements

The authors would like to extend their gratitude to Headway Gauteng, Johannesburg, South Africa (the brain injury association), Bianca Burger (General Manager), Christine Buchanan (Counselling and Support Manager), the staff at Headway and to all the Headway research participants. Gratitude is also extended to Tonya Esterhuizen for her biostatistical assistance and to Sally Walker, Prenisha Pillay and Anricia Padayachee for administrative support.

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