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Seminal ethical considerations associated with elevated stress, depression, suicidal and ill-health challenges family carers experience during home-based care of patients with traumatic brain injury

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ABSTRACT

An increasing number of people are living with the consequences of Traumatic Brain Injury (TBI). Because of limited facilities and mental health resources, family members often have to care for them at home where they may experience the adverse sequelae of elevated stress and related ineffectual family carer support. As part of an extension of our research, the objective of this article is to present a cognate and coalescent rationale where we address relevant issues pertaining to seminal ethical considerations. The research incorporated a cross-sectional descriptive and phenomenological mixed methodology, structured questionnaires, post-interview content analyses and two individually administered standardized measures, a Stress Symptom Checklist and The Beck Depression Inventory. Scores were non-normally distributed, therefore nonparametric statistical tests were used for the statistical analyses with a significance level of $p = 0.05$. The sample recruited ($N = 80$) consisted of close family members who care for a patient with TBI with an age range of 18 to 75 years ($\bar{x} = 49.6$), of whom 25% were males and 75% females. Their participation in the study was voluntary. The majority of the caregivers suffered from moderate, severe or profound stress. Those with higher stress levels had correspondingly increasing levels of depression, suicidal ideation and ill-health, while carers who were coping expressed concern in respect of their future well-being. Most maintained that they were not adequately prepared by healthcare professionals in respect of support, follow-up, education and preparation concerning the demands of homebased care. The present study emphasizes seminal ethical considerations as part of a synergistic and collaborative approach that could assist in enhancing family

caregivers' coping skills to help them adapt more effectively in their management of the TBI patients they care for at home.

Keywords: ethical considerations, family carers, stress, depression, suicidality, ill-health, brain injury

1. INTRODUCTION

An increasing number of people are living with the consequences of Traumatic Brain Injury (TBI), sometimes also referred to as acquired brain injury, that may result in a variety of long-term adverse sequelae. These can be widely divergent and can include neuropsychological, motor, psychological, psychiatric, personality, behavioural problems and ancillary medical complications. Because of limited facilities and mental health resources available to TBI patients who have to live with these long term discordant effects upon discharge from hospital, family members often have to face failed public health expectations and accept the responsibility to care for them with the propensity to cause elevated family stress, reduced resilience and carer coping abilities [1-18]. This raises further issues, such as ethical considerations related to effectual family carer support [17, 19].

Ethical considerations frequently tend to involve biomedical, neuropsychological and attendant matters in respect of the treatment of TBI patients [8, 20, 21]. However, emblematic of being inclined to be the poorer cousin, research has been underexplored in developing and developmental countries, including in South Africa within the context of any ensuing ethical concerns in respect of reducing elevated stress, depression, suicidal challenges and ill-health family carers experience during the process of family and community re-integration of TBI patients being cared for at home. To the best of our knowledge there are no specific guidelines in this regard. Given such lack of clarity, as part of one component of an extension of our current and published research [13-17, 22], this article presents a cognate and coalescent rationale based on a review of expedient aspects of the literature, our own experience and some of our salient findings where we address relevant issues pertaining to seminal ethical considerations.

2. MATERIALS AND METHOD

The research [13, 14, 16, 17, 22] incorporated a cross-sectional descriptive and phenomenological mixed methodology. This included self-report procedures, post-interview content analyses and two individually administered standardized measures, a Stress Symptom Checklist (SSCL) [14, 23, 24] and The Beck Depression Inventory (BDI) [25]. The SSCL provides a total stress score and three sub-categories of stress scores viz.: physical, psychological and behavioural symptoms. Responses to Question 9 (Q9) of the BDI were also used to assess suicide risk if present. It has a choice of one of four options: 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. Forth right questions have been used before in the study of suicidal behaviour in, amongst others, large surveys across different community sites, such as the global suicide prevention programme of the World Health Organization's. Multi-site Intervention Study on Suicidal Behaviours (SUPRE-MISS) with Durban as its Africa research site [26-28].

Because various scores were non-normally distributed, nonparametric statistical tests were used for the statistical analyses with a significance level of $p = 0.05$, including the Kruskal-Wallis, Mann Whitney and Chi-Square Tests.

3. SAMPLE AND RESULTS

The sample recruited ($N = 80$) consisted of close family members who care for a patient with TBI and who are members of Headway Gauteng (a brain injury association) in Johannesburg, South Africa [13, 14, 16, 17, 22]. The age range of the sample of caregivers at baseline was 18 to 75 years ($\bar{x} = 49.6$). Of these 25% were males and 75% females. Their participation in the study was voluntary. According to the SSCL total scores only 22.5% of the research participants fell into the low to mild stress categories. Because of their caregiver responsibilities, most (77.5%) suffered from moderate, severe or profound stress (Figure 1).

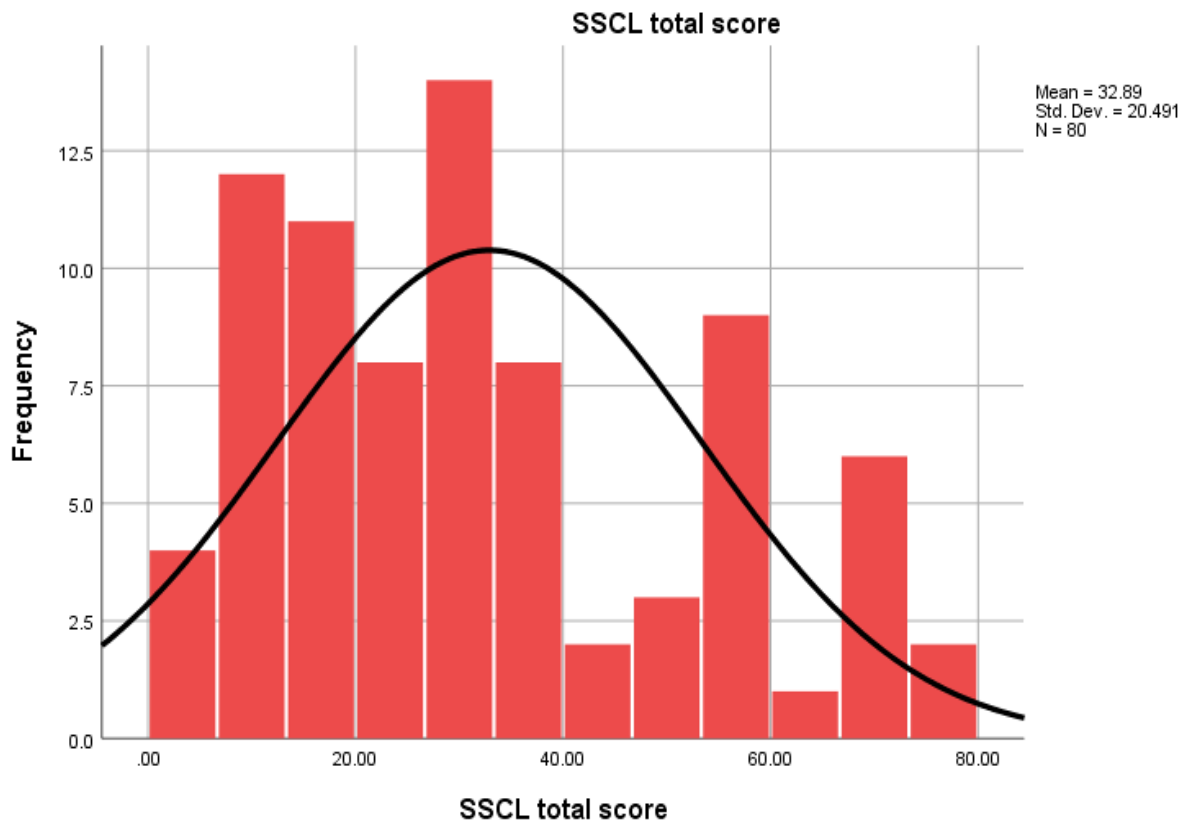


Figure 1. The total non-normally distributed elevated stress scores.

Family carers with higher stress levels had correspondingly increasing levels of psychological problems, including depression and suicidal ideation compared to those who scored in the low and mild stress categories on the SSCL and according to their BDI scores, 75% of the family caregivers suffered from mild, moderate to severe depression [13, 14, 16].

As the severity of their stress scores on the SSCL increased, so did their suicidal ideation and intent scores as measured by the BDI Q9, confirming our hypothesis that according to the research protocol the more profound the stress levels were in family members caring for a patient with TBI because of compromised resilience and coping, the higher the risk for suicidal ideation and behaviour got [13, 17] (Figure 2).

Hypothesis Test Summary

	Null Hypothesis	Test	Sig.	Decision
1	The distribution of SSCL total score is the same across categories of BDI Q.9.	Independent-Samples Kruskal-Wallis Test	.000	Reject the null hypothesis.
2	The distribution of physical symptoms is the same across categories of BDI Q.9.	Independent-Samples Kruskal-Wallis Test	.002	Reject the null hypothesis.
3	The distribution of % is the same across categories of BDI Q.9.	Independent-Samples Kruskal-Wallis Test	.002	Reject the null hypothesis.
4	The distribution of psychological symptoms is the same across categories of BDI Q.9.	Independent-Samples Kruskal-Wallis Test	.000	Reject the null hypothesis.
5	The distribution of % is the same across categories of BDI Q.9.	Independent-Samples Kruskal-Wallis Test	.000	Reject the null hypothesis.
6	The distribution of behavioural symptoms is the same across categories of BDI Q.9.	Independent-Samples Kruskal-Wallis Test	.000	Reject the null hypothesis.
7	The distribution of % is the same across categories of BDI Q.9.	Independent-Samples Kruskal-Wallis Test	.000	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

Figure 2. A summary of the hypothesis testing of the SSCL and Q9 of the BDI responses.

We found that most participants scored higher on the behavioural than the physical and psychological sub-categories of the SSCL [14]. This was observed as indicative of denial and/or aversive acceptance that correlated with the deleterious effects of the physical and psychological stress-related symptoms and cognitive function. A notable number (62.5%) of the family caregivers had received a professional medical and/or psychological diagnosis after becoming a caregiver, whereas those with pre-existing medical and/or psychological conditions reported that their health had worsened since becoming a family caregiver, and 67.5% felt that they were not coping well with being a caregiver, while the 32.5% who said that they were coping expressed concern in respect of their future well-being [13, 14, 16].

Overall 78.7% maintained that they were not adequately prepared by healthcare professionals in respect of the neuropsychological sequelae and associated changes in the patient which intensified family conflict and their stress levels [17]. Compared to deficiencies in speech and communication, physical function, movement and sexual behaviour family carers felt that most of their stress was caused by the neuropsychological deficits in their relatives with TBI that involved: emotions and/or moods (83.3%), cognitive ability (78.8%), behaviour and personality (75.0%), executive and organisational functioning (70.0%), and social factors (65.0%) [17]. Additionally, the qualitative data obtained identified five themes as major triggers of the caregivers' stress. These included a lack of: availability of healthcare professionals during the acute phase of the hospital treatment of the patients with TBI; appropriate psychological referrals, support and follow-up; education and preparation concerning the demands homebased care could entail; information about TBI and its varied effects on the patients; and adequate treatment of the impact of stress on the psychological and physical health of the family caregivers [17].

4. DISCUSSION

Our current and previous findings [13, 14, 16, 17, 22] support the fact that family carers of TBI patients often have to deal with unmet short and long-term needs [3, 8, 19, 29, 30]. It also underscores the need to alert healthcare professionals to the high levels of stress experienced by family caregivers and the resulting increased risk for depression, suicidal ideation/behaviour and potential ill health. This implies understanding the importance of considering ethical decision making in attempts to avoid and/or manage these problems and to assist with improvement of parity between any physical and mental health issues within the context and significance of the relationship between stress, lifestyle and suicidal behaviour [23, 31]. A stress cycle can manifest in variable ways including in physical, psychological and behavioural symptoms [14, 23, 24] whereby it can release stress hormones that can require increased micronutrient intake which, if neglected, can further lower resistance to stress and compromise physical well-being, cognitive function, and reduce resilience and coping [14, 17, 32, 33]. A low score on any of the sub-categories that we measured [14] indicated that the family caregivers may not have fully understood the differential impact of their stress levels on their health and/or may not have wanted to admit to their caregiver burden difficulties in the relevant area.

Since our research found that extremely high caregiver stress levels can increase the risk for depression, suicidal behaviour and ill-health in some caregivers, stress-symptom screening to reduce such potential risks should be considered for family caregivers of patients with TBI to detect early onset of unhealthy stress, psychopathology and suicidal ideation in order to facilitate applicable intervention and referrals for requisite treatment where necessary [14]. Suicidal behaviour in South Africa is disturbingly high [34-43] with, amongst others, prevalent physical [38, 44-49] and mental health implications [38, 50, 51].

Local conceptual organizational systems for managing and preventing suicidal behaviour [35, 38, 51, 52] as well as national suicide prevention strategies for the country [53, 54] have been proposed as imperative. The effectiveness of suicide prevention strategies have been comprehensively explored from both an international and South African perspective and although ethical issues in this field can be complex, multitudinous and can vary worldwide

depending on community practices and available resources, some universal principles do apply [26, 35, 38, 55-58]. Given this and regarding the present study, a joint effort with similarities to the concept of postvention can be useful to improve coping skills and resilience in family carers of TBI patients [17]. In essence, postvention involves providing support to the survivors of suicidal behaviour [59-61]. Within a broader framework a comparable situation may prevail in the case of family members who care for patients with TBI, though there could be different scenarios to deal with because of diverse circumstances. Regardless, one should always be conscious of the possibility of depression (or other psychopathology) in family caregivers, where a first option for help might have to be their family physician who can play a critical role in suicide prevention in the absence of established support programmes [51].

Caregiver resilience may be augmented by social support, but in some instances, support programmes have to be designed within a resource-limited milieu and a shortage of adequately trained mental healthcare professionals where family care needs are insufficiently attended to [14, 17]. One way to overcome this is to rely on community-based efforts backed up by trained volunteers who should have acquired adequate knowledge to educate family carers of TBI patients with particular attention given to the importance of early detection and referral for treatment of psychiatric/psychological ramifications within primary health care settings [38, 51]. In being mindful of this, the need for follow-up help for family carers both immediately upon the TBI patient's discharge from hospital as well as on a long-term basis is pivotal [3, 17, 29]. Akin to going through different stages of adaption [17] that collectively bears down heavily on them, family carers frequently report that the initial compassion and support they are offered from others tend to decrease as they try to re-focus on a sense of getting on with their lives and long-term adjustment. As is the case in postvention [60] follow-up help should also take this into consideration as well as the reality that, although there can be an overlap of stress-related risk factors between children and adults that need to be managed, vulnerable youngsters may manifest different reactions to those of a parent or another adult family carer of a patient with a TBI.

The provision of quality information can be of meaningful benefit to family carers during their initial experiences, i.e. from the beginning stages of recovery from TBI [3]. Therefore, any negative influences of social media should be counteracted, where the truth about TBI and its repercussions can emerge incongruously and when there is little support and a lack of pertinent education [17] that can lead to alternate complications such as family carers having to grapple with second-guessing on how to deal with the consequences of the TBI and possibly go through secondary traumatisation. The adverse interpersonal effects of secondary traumatisation can resemble symptoms of Posttraumatic Stress Disorder [62]. This in turn, may have a significant impact on family members' adjustment experience, which requires understanding and social support to help them to deal with their subsequent varying emotions. Carers not only require quality information and inter-professional education but also support and engagement of the carer [11].

Along with self-help and family support groups psycho-education [3, 13, 17] can be potent and inexpensive ways to enable this. However, it is especially helpful when conducted if they are assisted by experienced counsellors who are skilled in augmenting information programmes about coping with TBI and to destigmatise the reasons for it. Such intervention should be instituted sooner than later, be offered as long as needed, not be time-limited and not be prescriptive but endeavour to psychologically re-empower family carers so that they can rebuild their lives within a knowledgeable framework of caring for their loved ones with TBI.

To promote their well-being, a continuity of services is needed [9, 29]. Similar to its beneficial worth in suicide prevention, the adaptation of a Buddy intervention support programme could be useful in this process where a “buddy” or a friend is empowered to provide support, basic counselling and referral where needed [35]. Likewise, family support has also been shown to contribute to a good outcome for TBI patients [10].

Ethical considerations tend to overlap, but they essentially embody decisions about what is befitting and relative to particular family caregivers and how to achieve the appropriate results for them and their relatives living with TBI they care for. Because the sequelae of TBI can be significantly heterogeneous [10], posing wide ranging challenges the potential accompanying ethical dilemmas and concomitant complexities of being both a caregiver and a family member can contribute to a myriad of problems that can be intensely trying. Apart from what has been mentioned thus far, complications which often go unheeded and leave family carers unprepared, include future concerns about what will happen to their loved ones with TBI when they can no longer care for them [29].

This can be because of ageing, financial and other constraints about who should assume the responsibility of caring for the TBI patient when the initial index family carer is no longer able to. As part of a comprehensive process that pertains to these substantial unfulfilled needs and requirements there should be a focus on any supplementary undertakings to successfully traverse an improved healthcare format, the level of trust in it and the development of multidisciplinary caregiver intervention programmes [2, 6, 8, 14, 17, 19, 63-65].

The intention is to aspire towards an inclusive, holistic and preventative approach towards enabling family caregivers who need support, education and preparation to better cope with and manage the sequelae of the patients living with TBI that they care for.

This should help to reduce family conflict, caregiver stress and suicidality and discourage a potential disconnect between the various role players, including in terms of community expectations of health care professionals and the manner in which interaction between them occurs. Furthermore, although extensive data exists on both individual, national and international research levels, refinement of information about reporting on and preventing suicide could be improved, allowing for more of a focus on specific groups [27, 36, 38, 40-43, 53, 55, 56, 58, 66, 67].

There is growing evidence of suicide risks in family carers [13, 14, 22, 68, 69]. Space does not permit for an in-depth discussion here, but some of the principles that have been examined elsewhere are also applicable in this instance regarding ethical considerations associated with family carers of TBI patients, such as, for example, religious traditions [70], the effectiveness of brief intervention and contact in suicide prevention [71], the management of TBI in sport injuries where the development of trust between the treatment team and the patient is critical [72], appropriate mental health support [73], carer beliefs about difficult behaviour [74], the changing meanings and patterns of suicide [75], screening for suicide risk in medical conditions like HIV-infection [76] to assist high risk suicidal carers when necessary, as well as ethical and legal issues [77].

5. CONCLUSIONS

In conclusion, the present study emphasizes seminal ethical considerations as part of a synergistic and collaborative approach that could assist in enhancing family caregivers’ coping

skills to help them adapt more effectively in their management of the TBI patients they care for at home. This includes appropriate education, support and treatment intervention in order to amplify their resilience and to encourage healthcare professionals to consider such issues as accepted procedure. The ultimate objective is to help ameliorate stress, depression, suicidal, ill-health and allied challenges they experience. Although there is compelling evidence of the value of this, further research is recommended in other areas in this field that remain to be studied, including large scale surveys, the potential effect of the aetiology of the TBI and age differences in them on the carers, and identifying any possible pre-morbid and other risk variables in the carers that may have potential ethical implications. Embracing the veracity of these narratives should allow avoiding the pitfalls encountered by family carers not knowing and feeling unprepared for the challenges they face, but create preferences that do not detract from ultimately improving their quality of life and those of the patients living with TBI that they care for. What it implies, after all, is diligence in optimizing functioning of family systems for both who need a home where they feel safe, accepted, understood and loved.

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