

**STRESS, DEPRESSION AND SUICIDAL IDEATION AMONGST FAMILY  
MEMBERS CARING FOR A PATIENT WITH ACQUIRED BRAIN INJURY**

By

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DATE OF SUBMISSION: 3<sup>RD</sup> MAY 2021

## DECLARATION

I, Janet Walker, declare that:

- (i) The research reported in this dissertation, except where otherwise indicated, is my original work.
- (ii) This dissertation has not been submitted for any degree or examination at any other university.
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Date:

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## **DEDICATION**

For my mother, Sally Walker, with love and gratitude.

## **ACKNOWLEDGEMENTS**

Heartfelt gratitude to my husband, Lee, and my mother, Sally, for their support throughout all the stages of the development of this master's research dissertation.

Profound gratitude to Professor Lourens Schlebusch for helping me to grow and develop as a researcher and counsellor. I would not have been able to complete this research project without his experienced input and guidance. I also thank Professor Bernhard Gaede for his assistance and his kind words of encouragement along the way.

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Walker, J., Schlebusch, L., & Gaede, B. (2020). The impact of stress on depression, ill health and coping in family members caring for patients with acquired brain injury. *South African Family Practice*, 62(1), 1-6.

Walker, J., Schlebusch, L., & Gaede, B. (2021). Support for family members who are caregivers to relatives with acquired brain injury. *Journal of Mind and Medical Sciences*, 8(1), 76-85.

### CONTRIBUTIONS

The researcher designed and developed all phases of the research protocol, performed all literature searches, sought and obtained ethical permissions, personally undertook the implementation of the research protocols, performed data capturing, made major contributions to the aforementioned journal publications and prepared the final manuscripts for publication. This is confirmed and supported in the supervisors' report.

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## LIST OF KEY TERMS AND DEFINITIONS

**Acquired brain injury (ABI)** is defined as neurological damage that occurs after birth due to a traumatic brain injury (TBI), such as a blow to the head, fall, motor vehicle collision or sports-related injury; or a non-traumatic event, such as brain tumour, meningitis, encephalitis, oxygen deprivation (hypoxia) and stroke. However, congenital disorders and degenerative diseases, such as Alzheimer's, Multiple Sclerosis or Parkinson's Disease do not fall under the category of ABI (Lezak, Howieson, Bigler, & Tranel, 2012; Ontario Brain Injury Association, 2019). ABI is an umbrella term which incorporates both TBI and non-traumatic brain injury as part of its definition, therefore, the terms ABI and TBI are sometimes used interchangeably.

**Neuropsychological sequelae or symptoms** are defined as the psychological, cognitive and behavioural deficits of an ABI (Lezak et al., 2012).

**Stress** is defined as the outcome of an interaction between a person and his or her environment and is brought about by a stressor(s), which could include any internal or external event or situation, that is appraised as threatening by the individual and results in a demand being placed upon an individual causing mental, emotional and physiological strain and tension (Schlebusch, 2000, 2004).

**The stress response** is defined as the biological, psychological and behavioural responses when encountering a threat that is appraised as being unmanageable (Schlebusch, 2000, 2004).

**Suicidal ideation** is defined as having thoughts about suicide, and the intention and desire to commit suicide with or without making plans or attempting to do so (Schlebusch, 2005; Wasserman & Wasserman, 2009).

**Hopelessness** is defined as feeling that neither internal resources nor external efforts can change a bleak and unresponsive environment and includes a feeling of despair, pessimism and negative expectancies of the future (Abramson, Alloy, & Metalsky, 1990; Beck, Weissman, Lester, & Trexler, 1974).

**Depression** is defined as low mood presenting with psychological, cognitive and behavioural symptoms (American Psychiatric Association, 2013; Beck, Rush, Shaw, & Emery, 1979; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961).

**Caregiver burden** is defined as involving multiple factors and demands associated with being a caregiver, such as physical, emotional and socioeconomic adverse implications (Buhse, 2008; Schlebusch & Walker, 2020).

## **ABSTRACT**

### **Background**

This study investigated the relationship between stress, depression, ill health and suicidal ideation in family members caring for a patient with acquired brain injury. The sample consisted of 80 family caregivers who are members of Headway Gauteng (the brain injury association) located in Johannesburg and Soweto, South Africa. Most were primary caregivers (72.5%) with secondary caregivers making up a smaller percentage (27.5%), their role being to assist and support the primary caregiver.

### **Method and materials**

The study involved a mixed methodology that incorporated a cross-sectional descriptive and phenomenological approach. This included self-report procedures (structured questionnaires and interviews), post-interview content analyses and three individually administered standardized measures (The Stress Symptom Checklist, The Beck Depression Inventory and Beck's Hopelessness Scale). Scores were non-normally distributed. Therefore, nonparametric statistical tests were used, including the Kruskal-Wallis, Mann Whitney and Chi-Square Tests with a significance level of  $p = 0.05$ .

### **Results**

The results revealed significant levels of stress, depression, ill health and suicidal ideation in the research participants. Suicidal ideation increased with elevating stress levels and 62.5% (50) of the sample had received a medical and/or psychological diagnosis after they became a caregiver. Five themes were identified as causing the caregivers' profound stress that highlighted a lack of caregiver support, preparation, referral and education regarding their relative's acquired brain injury and the stress they experience due to caregiver burden. Most participants (78.7%) did not feel adequately prepared by healthcare professionals (during the acute and sub-acute hospital treatment) for the neuropsychological deficits caused by the acquired brain injury, resulting in reduced coping and family conflict once the patient started receiving home-based care. Predominantly the family caregivers identified the patients' neuropsychological deficits, such as affect, cognitive ability, behaviour, personality, executive function, and social factors as causing them profound stress.



## **Conclusions**

This study underscored a significant prevalence of depression, ill health and stress-related suicidal ideation in family members caring for patients with acquired brain injury. Early identification of these problems and referral for appropriate treatment are recommended, along with the need to alert professional healthcare workers to the value of psychological screening for elevated stress and poor coping in family caregivers. Additionally, a collaborative effort between medical and psychological healthcare practitioners is recommended.

**Keywords:** acquired brain injury; caregiver burden; depression; neuropsychological sequelae/symptoms; stress; suicidal ideation; ill health.

## **CHAPTER 1**

### **INTRODUCTION**

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This chapter provides an overview of, and rationale for the study.

#### **1. BACKGROUND AND PROBLEM STATEMENT**

Globally one of the more common causes of death and disability is brain injury (Hux, Schram, & Goeken, 2006; Pretorius & Broodryk, 2013). Road traffic accident injuries in South Africa are estimated to be double the global number (Norman, Matzopoulos, Groenewald, & Bradshaw, 2007), and the resulting elevated prevalence of traumatic brain injury (TBI) is cause for concern (Naidoo, 2013), prompting some to refer to TBI as a hidden pandemic (Webster, Taylor, & Balchin, 2015). Because of progress in healthcare and better resuscitation methods, as well as limited facilities available to patients recovering from and living with the long-term effects of acquired brain injury (ABI), there is a growing population of people with ABI who are being cared for by family members (Diedler et al., 2009; Webster et al., 2015). Additionally, there is an increasing number of children and young adults surviving TBI with neuropsychological deficits (Lezak et al., 2012). In South Africa, approximately 89 000 new patients with TBI are reported per annum (National Institute for Occupational Health, 2019), and this figure excludes other disorders resulting in ABI, such as stroke and dementia, and highlights the fact that ABI is a serious public health concern in South Africa.

ABI can result in varied psychological, cognitive, social and physical changes in the patient (Lezak et al., 2012). Studies investigating the psychological effects of managing and coping with the neuropsychological and physical changes in the patient tend to report on caregiver burden (Allen, Linn, Gutierrez, & Willer, 1994; Camplair, Butler, & Lezak, 2003; Manskow et al., 2017). Symptoms in patients with ABI that appear to increase caregiver burden are associated with changes and/or vicissitudes in psychological, social, cognitive and personality functioning (Allen et al., 1994; Anderson, Parmenter, & Mok, 2002; Ashman, Gordon, Cantor, & Hibbard, 2006), that is the neuropsychological sequelae. The physical impairment in these patients appear to be of a lesser distressful nature for family caregivers (Allen et al., 1994). This is important because currently when a patient is discharged from hospital healthcare professionals tend to focus on preparing the family to care for the patient's physical well-being and their activities of daily living (ADL), such as bathing, mobility and eating, with little emphasis on the neuropsychological sequelae of ABI. Assisting family members and the patients with ABI to develop more effective coping mechanisms may substantially ease caregiver burden (Benedict et al., 2000; Lezak et al., 2012; Smith & Godfrey, 1995).

## 1.1 STRESS, COPING AND HEALTH

The relationship between stress and reduced coping has been established (Everly Jr & Lating, 2019; Folkman, 2013; Schlebusch, 2000, 2012a; Verhaeghe, Defloor, & Grypdonck, 2005). The human stress response has been described as expressing through two pathways, one being physiological and the other psychological (Everly Jr & Lating, 2019; Schlebusch, 2000, 2004, 2012b; Selye, 1956). Untreated, unhealthy stress can lead to psychological and/or physiological symptoms and disorders (Everly Jr & Lating, 2019; Horowitz, 1997; Logan & Barksdale, 2008; McEwen, 2017; Schlebusch, 2000, 2012a; Thoits, 2010), and result in reduced psychological resilience in family members caring for patients with ABI, who may experience depression, suicidal ideation and ill health. Given the above, the conditional probability is high that if stress experienced by these family members is not adequately managed, it may develop into pathological stress. In this regard, the study's objectives are listed under the title AIMS.

## 1.2 SUICIDE, DEPRESSION AND HOPELESSNESS

The World Health Organization (WHO) (2018) reported several years ago that worldwide nearly one million people commit suicide every year, and it was suggested that this may increase to 1.53 million by 2020 (Bertolote & Fleischmann, 2009). In Southern Africa suicide statistics are also very high and must be viewed with caution as many attempted and completed suicides are not reported nor recorded due to inadequate data collection and other reasons, such as cultural and religious reservations (Bantjes & Kagee, 2013; Engelbrecht, Blumenthal, Morris, & Saayman, 2017; Govender & Schlebusch, 2012; Mars, Burrows, Hjelmeland, & Gunnell, 2014; Schlebusch, 2011, 2020; World Health Organisation, 2018). Both chronic and acute stress have been found to be critical co-morbid causes of suicidal behaviour in South Africa (Schlebusch, 2000, 2005, 2012a). The psychological distress experienced by patients with ABI, as well as their suicide risk, have been well-documented in neuropsychological and psychological literature (Berman & Pompili, 2011; Cerri, Perin, Cornaggia, & Beghi, 2020; Chan, Parmenter, & Stancliffe, 2009; Lezak et al., 2012; Mainio et al., 2007; Meroni et al., 2013; Schlebusch, 1990; Wasserman & Wasserman, 2009), but there is a comparatively marked paucity of research regarding suicidal ideation and behaviour in family members caring for patients with ABI, particularly in South Africa. Whereas elsewhere depression and feelings of hopelessness experienced by caregivers of patients with ABI have been well-examined (Calvete & de Arroyabe, 2012; Harris, Godfrey, Partridge, & Knight, 2001; Kreutzer, Gervasio, & Camplair, 1994; Kreutzer et al., 2009; Marsh, Kersel, Havill, & Sleight, 1998). However, in South Africa the potential for suicide in other high-risk groups has been well-established, such

as people diagnosed with HIV (Schlebusch & Govender, 2012) and breast cancer patients (van Oers & Schlebusch, 2016, 2021).

### **1.3 THE ROLE OF THE HEALTHCARE PROFESSIONAL**

ABI and its effects on the patients' functioning are often misunderstood by the family members and others (Hux et al., 2006; Lezak et al., 2012; Pretorius & Broodryk, 2013). The role of healthcare professionals who treat patients with ABI and their family members is important, particularly in terms of preparing the family for the potential neuropsychological sequelae in the patient and, in many cases, could prevent an exacerbation of stress. The healthcare professionals' role should also involve educating the family about the neurological and the psychological factors involved and to refer them to appropriate sources for relevant treatment where necessary.

## **2. THEORETICAL FRAMEWORK**

The theoretical framework underpinning this research was based on an integrated biopsychosocial model described by Schlebusch (1990, 2000, 2004, 2012b). This approach is grounded in general systems theory (von Bertalanffy, 1968) and views human health holistically involving biological, psychological and social factors (Engel, 1977; Schlebusch, 1990). The stress-diathesis and stress-vulnerability models of health (Everly Jr & Lating, 2019; Mann, 2003; Mann, Waternaux, Haas, & Malone, 1999; Schlebusch, 2012b; Wasserman, 2001) were also drawn on to highlight the fact that prolonged stress can be detrimental in individuals with specific vulnerabilities. Chronic stress can undermine the physiological process of allostasis, causing an allostatic overload thereby undermining health and well-being (Logan & Barksdale, 2008; McEwen, 2000, 2017). This is considered as a contributing factor to the very high percentage of medical diagnoses reported by the family members after becoming caregivers to patients with ABI.

## **3. AIMS**

- i. To identify the presence, effects and degree of stress in family members caring for a patient with ABI.
- ii. To identify the family members' ability to cope with caring for the patient with ABI.
- iii. To identify levels of depression, hopelessness and/or suicidal ideation in the family members caring for the patient with ABI.
- iv. To identify the extent to which family members felt prepared by healthcare professionals for the neuropsychological sequelae in the patient with ABI, and whether they

were referred to appropriate organisations and/or healthcare professionals for psychosocial support, education and treatment as necessary.

v. To identify which neuropsychological changes in the patient with ABI present the greatest stress for the family members.

vi. To identify the extent to which education and psychosocial support helps to ameliorate the negative effects of stress in the close family members of a person with ABI.

vii. To utilize the results to formulate guidelines to assist healthcare professionals in managing the psychological distress in patients with ABI and their close family members.

#### **4. OBJECTIVES**

The study's objectives were to ascertain the impact of elevated stress on family members caring for a patient with ABI; to investigate the presence of depression, hopelessness and suicidal ideation; and the extent to which the various neuropsychological deficits/symptoms in the patients with ABI caused psychological distress for the family members, who reported ill health after they started caring for the patient with ABI which was significant as part of their stress response. Since the stress, depression and suicidal ideation levels of the participants were inordinate it obviated the need to specifically report on the results of the hopelessness scale (Beck et al., 1974) as they were statistically not significant. The reason for this, as reported by the participants, was the support that they receive from Headway Gauteng which mitigated feelings of hopelessness. The study results were utilized to formulate guidelines to assist healthcare professionals in managing the psychological distress in the family members caring for patients with ABI. The intention being to improve long-term quality of life for both the patient with ABI and their family caregivers.

#### **5. METHODOLOGY**

The study sample consisted of 80 family members caring for a relative with ABI and who were members of Headway Gauteng (the brain injury association), Hyde Park and Soweto branches, South Africa. The study involved a mixed methodology that incorporated a cross-sectional descriptive and phenomenological approach. Self-report procedures (structured questionnaires and interviews), post-interview content analyses and three individually administered standardized measures, that is, the Stress Symptom Checklist (Schlebusch, 2004), the Beck Depression Inventory (Beck et al., 1961) and the Beck's Hopelessness Scale (Beck et al., 1974) were utilised. Information obtained comprised descriptive, observational, analytical and correlational elements. Scores were non-normally distributed. Therefore, nonparametric

statistical tests were used (including the Kruskal-Wallis, Mann Whitney and Chi-Square Tests with a significance level of  $p = 0.05$ ).

Research participants were volunteers drawn from the family members who attend a support group or who are members of Headway Gauteng, South Africa. Predominantly, the study population consisted of a chain-referral criterion group and snowball sampling was utilized, which is a non-probability, non-random sampling method. Snowball sampling was particularly useful with the family members of the Headway Soweto group. It involved approaching families who attend the Headway Friendship Circle (HFC) in Soweto and informing them about the study. The family members were requested to recruit other family members from the extended Headway membership. The sampling procedure at the Headway Hyde Park branch involved approaching family members who are on the Headway Hyde Park database, via cell phone and email. Headway Hyde Park family members were also approached at HFC where the study and its objectives were explained. Family members who met the inclusion criteria were selected from the group of volunteers from the Soweto and Hyde Park branches. All family members, who met the inclusion criteria, were free to choose to participate in the study or not. The inclusion criteria were the following: family members caring for a patient with ABI and who are members of Headway Gauteng, between the ages of 18 and 75, and English literate. The research participants' education levels were variable, and the requirement was that they were able to understand the study and give written informed consent on the appropriate form, prior to being included in the study. All the research participants had been caring for their relative with ABI for a minimum of 12 months.

Headway Gauteng is a registered non-profit organisation dedicated to offering various support programmes to adult survivors of ABI, their family members and caregivers. Headway family members have either a son, a daughter, a partner, a parent or a friend who has sustained a brain injury (BI). Most of the members with ABI have sustained a traumatic brain injury (TBI) as a result of motor vehicle, pedestrian vehicle or motorcycle accidents, physical assaults, falls or sporting injuries, or non-traumatic injury, such as stroke. All of the members with ABI led active lives until sustaining a brain injury, which has caused permanent changes to their physical, cognitive, emotional and behavioural processes. Headway Gauteng offers various programmes, information, practical advice and better understanding about what this will mean for the future and how the family can make a meaningful contribution to the recovery of the injured individual. Before the COVID-19 pandemic the support programmes involved conducting daily groups from 09h00 to 16h00, which included psychology, occupational

therapy, speech and language, biokinetics, physiotherapy and art groups. Each group consisted of approximately 5 to 20 individuals with ABI.

## **6. DELINEATION OF THIS STUDY**

**Chapter 1** includes an introduction and background which outlines the rationale for the broader study.

**Chapter 2** includes published article one which is titled *The relationship between stress and suicidal ideation in family members caring for a patient with acquired brain injury* (Schlebusch & Walker, 2020). The correlation between stress and suicidal ideation was significant, with data showing that suicidal ideation directly increased with increasing levels of stress. This article addressed the objectives of aims i and iii as listed under AIMS.

**Chapter 3** includes published article two which is titled *The impact of stress on depression, ill health and coping in family members caring for patients with acquired brain injury* (Walker, Schlebusch, & Gaede, 2020). This article reports on the impact of stress on levels of depression and ill health as an indication of psychological coping. The majority of the research participants experienced high levels of stress along with an inordinate negative physiological and mental health impact indicating that they were not able to cope with the ongoing chronic stress of caregiving. This article addressed the objectives of aims ii and iii as listed under AIMS.

**Chapter 4** includes published article three which is titled *Support for family members who are caregivers to relatives with acquired brain injury* (Walker, Schlebusch, & Gaede, 2021). Most of the caregivers felt that it was predominantly the patients' neuropsychological deficits that caused them to experience profound stress. They reported that they did not feel adequately prepared by healthcare professionals for the neuropsychological deficits caused by the ABI in their relatives during the acute and sub-acute hospital treatment, and that this resulted in family conflict once the patient started receiving home-based care. Education and support as provided by Headway Gauteng were described as highly beneficial and enhanced their ability to cope with and manage the patient. This article addressed the objectives of aims iv, v, vi and vii as listed under AIMS.

**Chapter 5** includes a synthesis of the articles key research findings, their practical applications and the study limitations and recommendations for future research.

## **7. 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 profoundly stressful for them. The present study emphasizes the need to optimize quality of life for patients with ABI and their caregiver family members, to assist them to effectively adapt and cope after the patient has been discharged from hospital, thereby ameliorating psychological distress in both the patient and the caregivers. It should become standard procedure amongst healthcare professionals in South Africa to refer family members of patients with ABI for appropriate education and psychological intervention in order to develop their resilience and coping skills. Stress-symptom screening is a quick and effective method of detecting any early onset of the symptoms brought on by chronic stress in these family members and assists in identifying how an individual's stress is manifesting, thus facilitating applicable referrals for preventative treatment and interventions.



## **CHAPTER 2**

### **INTRODUCTION**

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#### **THE RELATIONSHIP BETWEEN STRESS AND SUICIDAL IDEATION AMONGST FAMILY MEMBERS CARING FOR A PATIENT WITH ACQUIRED BRAIN INJURY.**

This chapter introduces the first article and includes a scanned copy of the peer-reviewed published journal article. The article addresses the objectives of aim (i) (to identify the presence, effects and degree of stress in family members caring for a patient with ABI) and part of aim (iii) (to identify levels of depression, hopelessness and/or suicidal ideation in the family members caring for a patient with ABI) as listed in Chapter One under AIMS.

As part of an ongoing research project on suicidal behaviour, the aim of this article was to investigate the relationship between stress and suicidal ideation in family members who care for a patient with ABI. Three factors influenced the choice of the subject in article one. Firstly, the marked levels of suicidal ideation identified in the research participants. Secondly, data revealed that suicidal ideation and behaviour directly increased with increasing levels of stress. Thirdly, the death by suicide of one of the family caregivers (briefly discussed in chapter five) which highlighted the importance of assessing levels of suicidal ideation and behaviour in these caregivers. The article also provides statistical evidence and information about the type and severity of stress and the physical, psychological and behavioural symptoms of stress. The article emphasizes that elevated levels of stress can cause the caregivers of patients with ABI to develop suicidal ideation as they start feeling that they are not coping with the demands associated with caregiving, which is often unrecognised by both the caregiver and the healthcare professionals that they see for medical and psychological treatment. This is clinically relevant and early identification of such problems and referral for appropriate help is recommended along with the need to alert professional healthcare workers to this.



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## 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

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## 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 27.5% 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**

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 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   |           |       |              |

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    |       |
| <b>SSCL total scores</b>      | Valid N | 49                 | 26   | 4    | 1    | 80    |
|                               | Median  | 21.0               | 37.8 | 64.5 | 72.0 | 29.8  |
| <b>physical symptoms</b>      | Valid N | 49                 | 26   | 4    | 1    | 80    |
|                               | Median  | 6.0                | 9.0  | 15.5 | 16.5 | 7.3   |
| <b>psychological symptoms</b> | Valid N | 49                 | 26   | 4    | 1    | 80    |
|                               | Median  | 5.0                | 12.8 | 22.0 | 23.5 | 9.0   |
| <b>behavioural symptoms</b>   | Valid N | 49                 | 26   | 4    | 1    | 80    |
|                               | Median  | 8.0                | 15.5 | 26.8 | 32.0 | 11.8  |
| <b>%</b>                      | 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<br>Category<br>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% |

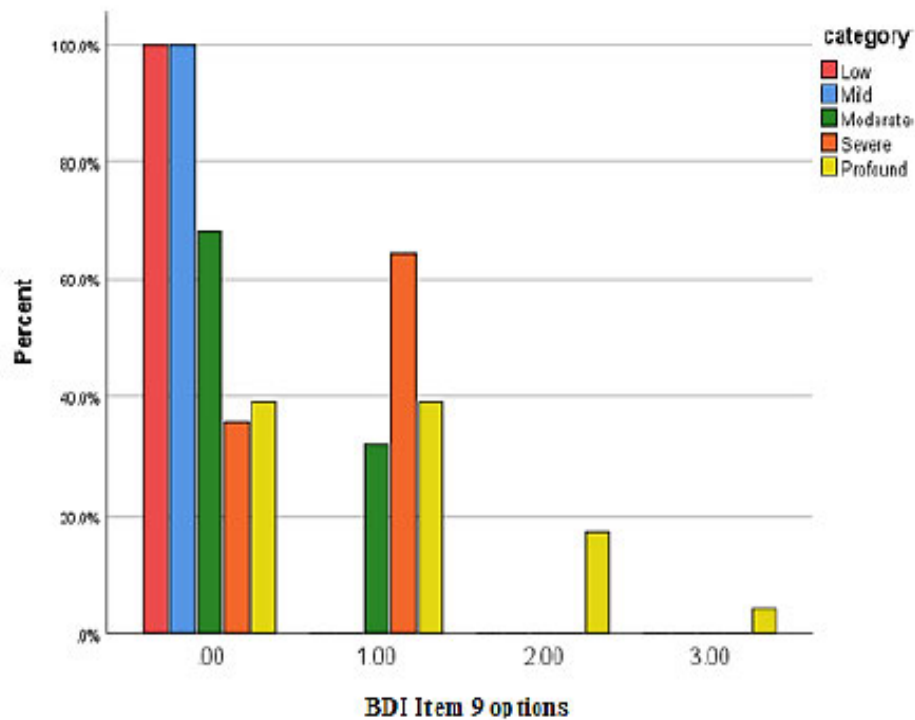


Figure 1. Total SSCL and BDI Item 9 scores.

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.

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## **CHAPTER 3**

### **INTRODUCTION**

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#### **THE IMPACT OF STRESS ON DEPRESSION, ILL HEALTH AND COPING IN FAMILY MEMBERS CARING FOR PATIENTS WITH ACQUIRED BRAIN INJURY.**

This chapter introduces the second article along with a scanned copy of the peer-reviewed published journal article. The article addresses the objectives of aim (i) (to identify the presence, effects and degree of stress in family members caring for a patient with ABI); aim (ii) (to identify the family members' ability to cope with caring for the patient with ABI) and part of aim (iii) (to identify levels of depression, hopelessness and/or suicidal ideation in the family members caring for the patient with ABI) as listed under AIMS in Chapter One.

Article two further expands on the findings reported in article one by describing the impact of stress on levels of depression and ill health as an indication of psychological coping in these family members caring for a patient with ABI. The results, both qualitative and quantitative, show high levels of stress, depression and ill health amongst the family caregivers. In addition, research participants had marked physical and psychological symptoms of stress which indicated that they were not coping with the ensuing burden of being caregivers. Many of the caregivers had received medical and/or psychological diagnoses after becoming caregivers further indicating that they were not coping with the chronic stress associated with being a caregiver. The article also describes how stress can result in the dysregulation of allostasis which results in allostatic overload that may be responsible for the elevated number of psychological and/or physiological diagnoses found in the research participants. The importance of psychological screening for elevated stress and poor coping in these family members is emphasised and it is recommended that medical and psychological healthcare practitioners collaborate in order to ensure a holistic and inclusive approach towards treatment procedures and interventions to improve coping skills and resilience in these family members who care for patients with ABI.

# The impact of stress on depression, ill health and coping in family members caring for patients with acquired brain injury



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**Background:** This study investigated the impact of stress on levels of depression and ill health as an indication of psychological coping. The research sample consisted of 80 family caregivers (who are members of Headway Gauteng, located in Johannesburg, South Africa) of patients with acquired brain injury.

**Methods:** A mixed method design of data collection was utilised that included self-report procedures (structured questionnaires and interviews) and post-interview content analyses. In addition, two individually administered measures that have been widely used in clinical practice and research were administered (a stress symptom checklist and the Beck Depression Inventory).

**Results:** The majority of the research participants experienced high levels of stress along with an inordinate physical and mental health impact indicating that they were not able to cope with the ongoing chronic stress of caregiving.

**Conclusion:** Findings provide compelling evidence of the value of psychological screening for elevated stress and poor coping in family members caring for a patient with acquired brain injury in a resource-limited healthcare society. We recommend a collaborative effort between medical and psychological health practitioners in order to ensure a holistic and inclusive approach towards treatment procedures and interventions to improve coping skills in family members caring for a patient with acquired brain injury.

**Keywords:** acquired brain injury; stress; depression; ill health; caregiver burden; coping.

## Introduction

A leading cause of disability, globally and in South Africa, is brain injury and because of often-limited availability of rehabilitation and support resources, these patients can become a family member's responsibility.<sup>1,2,3,4,5</sup> Both patients with acquired brain injury (ABI) and the family members who care for them can experience very high levels of stress which can undermine their psychological and physiological well-being and thereby reduce the family members' ability to cope with the demands associated with being an effective caregiver. This is because chronic stress can lead to serious physiological and psychological<sup>6,7,8,9,10</sup> health complications and can reduce psychological resilience and adaptation.<sup>7</sup> Allostasis is the body's way of adapting to the stress response. Prolonged and unmanaged stress can disrupt this neurobiological process by producing harmful allostatic load or overload (AL).<sup>7,8,11</sup> This AL can, over time, result in the breakdown of allostasis through the cumulative erosion of neurophysiological mechanisms, potentially undermining mood, cognition, organ, neuroendocrine, autonomic, immune, metabolic and other functions.<sup>7,8,12</sup> Because of multiple demands made on family members caring for a patient with ABI they may be particularly susceptible to AL, which may result in adverse psychophysiological complications. For example, a study of individuals who have a gene variant involved in moderating the neurotransmitter serotonin showed that those who experienced several stressful events had a markedly higher risk of developing major depression.<sup>13</sup> Furthermore, stress and the resultant AL has been suggested to be a significant contributor to the development of cardiovascular disease.<sup>7</sup>

The neuropsychological and other ramifications in patients with ABI often require the family caregivers to accommodate within the family system a person displaying changes in personality, behaviour and cognitive ability, amongst others.<sup>4</sup> This could further increase their exposure to severe stress as they attempt to adapt to what has been referred to as the caregiver burden.<sup>14</sup>



Caregiver burden is a cause of significant difficulty for the family carer of a patient with ABI.<sup>15,16,17</sup> The resultant depression, feelings of hopelessness and reduced quality of life experienced by family caregivers have been well documented.<sup>17,18,19,20,21,22</sup> A recent study also found that many of the family members who care for a patient with ABI and who suffer from high levels of stress can have marked suicidal ideation.<sup>14</sup>

Furthermore, research has identified a significant correlation between stress and reduced coping.<sup>8,23,24,25,26</sup> Although a degree of stress in life is inevitable and can be positive (referred to as eustress), prolonged negative stress as experienced by family members who care for a patient with ABI can reduce their ability to cope, which may negatively impact on the well-being of the patient with ABI. When considering the influence of chronic stress on the psychological and physiological well-being in these family members, it becomes evident that identifying ways to ameliorating its effect is imperative in order to help them to cope with the caregiver demands in the long-term. The use of a theoretical framework is elaborated on in more detail in the discussion section.

Despite these facts, there is a paucity of research in South Africa regarding the impact of stress on psychological and physiological health and coping skills of family members caring for a patient with ABI. Therefore, the objective of this study was to investigate the impact of stress on levels of depression, ill health and coping amongst family members and to highlight the profoundly negative impact of stress on the family caregivers' health and their well-being, so that when healthcare professionals see these families in their practices, they will be more likely to enquire about the family caregivers' experience of stress, and treat and refer as necessary. This study forms part of a larger investigation of caregiver burden or stress in family members who care for a patient with ABI.<sup>14</sup>

## Methodology

### Definitions of core terminology

For the purpose of this study, the following definitions apply.

'Stress' is defined as a person's psychological, behavioural and physiological response to an event or set of circumstances that the individual interprets as being beyond his or her capacity to cope with, resulting in a sustained stress response to their stressor(s), and which can be measured, amongst others, through psychological screening.<sup>28,29</sup>

'Acquired brain injury' is a blanket term which is defined as neurological damage that occurs after birth either due to a traumatic event such as an injury to the head or a fall, motor vehicle collision or sports-related injury, or a non-traumatic incident, such as a brain tumour, meningitis, encephalitis, hypoxia and cerebrovascular accident (CVA).<sup>1,30</sup>

'Coping' is defined as a conscious effort towards solving problems and managing difficult emotions in order to master or minimise the impact of unhealthy stress. This involves developing coping strategies and skills which are adaptive and not maladaptive. Many different coping strategies have been identified. Typically, people use a mixture of these. From a psychological perspective, emotion-focused and problem-focused coping are, amongst others, important strategies.<sup>30</sup> For our purposes, we have concentrated on problem-focused coping skills.

'Depression' incorporates the experience of feeling low, irritable and meaningless along with physiological and cognitive effects that profoundly undermine the person's ability to cope with life.<sup>30</sup> This includes Beck's cognitive model (utilised in this study as mentioned in the discussion section) described the development of depression as comprising a triad of three fundamental components that include negative thought patterns about the self, environment and the future.<sup>30</sup>

'Caregiver burden' is defined as involving multiple factors and demands associated with being a caregiver, such as physical, emotional and socioeconomic adverse implications.<sup>14,38</sup>

### Study design

The research involved a cross-sectional descriptive study of family members who are caring for a patient with ABI. A mixed method design of data collection was used which included the administration of two standardized inventories to measure stress and depression, as well as self-report procedures (structured questionnaires and interviews).

### Sample

The research sample consisted of 80 family caregivers who are members of Headway Gauteng, located in Johannesburg, South Africa. Headway Gauteng is a registered non-profit organisation that offers a variety of support programmes to adults living with ABI, their families and caregivers. The study sample consisted of primary caregivers (72.5%) who are the foremost family members providing care for the patients with moderate to severe ABI, and secondary caregivers (27.5%) who are the family members who assist and support the primary caregivers. The patients with ABI that the family members care for, all attend Headway Gauteng where they were neuropsychologically screened. The age range at baseline of the sample of caregivers was 18 to 75 years ( $\bar{X}$  = 49.6), with 75% (60) being females and 25% (20) being males.

### Data collection and analyses

The interviews (conducted between June 2018 and October 2019) with the family caregivers were in-depth and took approximately 2 hours to 3 hours each. They consisted of one-on-one discussion and included the research participants completing a questionnaire and two psychological measures as discussed later in the article. The principal author



conducted the interviews individually at the Headway Hyde Park and Soweto branches in Johannesburg. The responses to the questionnaires were both verbal and written. Extensive notes were made and collated. For the purpose of this study, information gained from the following question was used as part of the questionnaire where the study participants were asked to answer yes or no to the question: 'Do you believe that your current health status has been affected by your family member's ABI? Yes/No, please elaborate'. Each participant gave further verbal and written information about how their caregiver burden was undermining their well-being and reducing their ability to cope. The research participants were also asked to write down the medical and psychological diagnoses that they have received since becoming a caregiver.

A stress symptom checklist (SSCL)<sup>35,37,38</sup> was used to measure the research participants' stress levels. The SSCL is a reliable, valid and clinically effective dichotomous-scaled 87-item checklist of the typical indicators and symptoms of negative stress.<sup>37</sup> Rounded-off reliability coefficients range from 0.8 to 0.9, and validity (correlation) coefficients range from 0.5 to 0.6.<sup>37</sup> Validity included content validity based on a discriminating item selection, criterion and construct validity, as well as convergent and discriminant validity. Items are categorised into three main subscales: 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.<sup>37</sup> A total score of nine or higher across all three subscales indicates the onset of unhealthy stress for that research participant. The Beck Depression Inventory (BDI)<sup>39</sup> was used to measure levels of depression. It is a 21-item multiple-choice self-report inventory which measures severity of depression. Individual scale items are scored on a 4-point continuum (0 = least, 3 = most), with a total score range of 0-63. We used the standard cut-off scores (0-9 = minimal depression, 10-18 = mild depression, 19-29 = moderate depression and 30-63 = severe depression).

The SSCL scores were non-normally distributed and, as a result, nonparametric statistical tests (including the Mann-Whitney) were used with a significance level of  $p = 0.05$ . Data were categorised on several dimensions. Scores obtained on the psychological and physiological subscales of the SSCL were calculated separately and the total scores were compared with the total scores obtained from the BDI in order to identify a relationship between elevated stress and depression that could have resulted in poor coping in the sample studied. As the focus was on the psychological and physiological stress symptoms, the behavioural subscale of the SSCL was excluded as its relevance was previously reported, and it reflected a significant correlation between high stress levels and behavioural stress symptoms and suicidal ideation in the participants.<sup>14</sup> Interview and questionnaire responses combined with the scores on the SSCL and the BDI were analysed to determine whether the

participants were coping and implementing effective coping skills. Research participants whose total SSCL stress scores fell in the moderate to severe categories, together with their BDI scores that indicated mild to severe depression taken with their self-reported physical and/or psychological diagnoses revealed that they were not coping with their caregiver burden. This was further supported by the qualitative analyses of the written information revealing their personal experience of high stress and caregiver burden which also indicated that they were not coping.

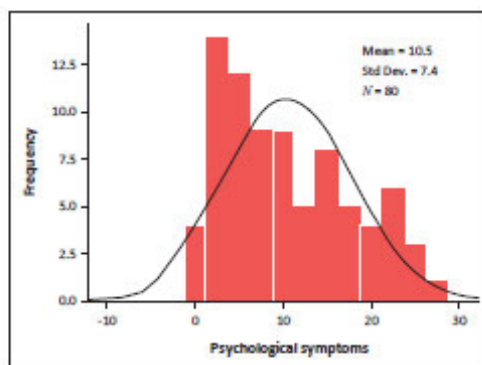
## Ethical consideration

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 which explained that their participation in the study was entirely voluntary and confidential. In addition, they understood that the information provided and the assessment procedures completed pertained specifically to their personal experience of caring for a relative with acquired brain injury.

## Results

Results are reflected as a graphical representation in histograms of the psychological and physical symptoms recorded on the SSCL showing their non-normal distribution. From this, a significant psychological (Figure 1) and physical (Figure 2) health impact on the research participants can be seen. The scores on the psychological subcategory of the SSCL (Figure 1) were more elevated than the scores on the physical subcategory of the SSCL (Figure 2), although scores on both subcategories were indicative of inordinate stress and ill health-related consequences.

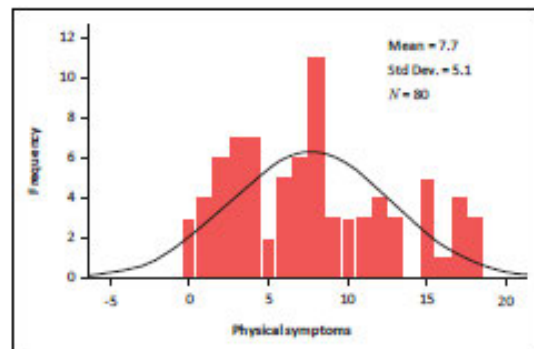
Self-report questionnaires and interview data (based on the qualitative results) corroborated the findings of the psychological and physical stress symptom scores on the SSCL. Overall, 62.5% (50) of the sample had received a medical and/or psychological diagnosis after they became



Std Dev., standard deviation.

FIGURE 1: Psychological symptoms of stress.





Std Dev., standard deviation.

FIGURE 2: Physical symptoms of stress.

a caregiver. Qualitative analyses of the participants' questionnaire responses revealed that they reported marked variability in health effects. For example, some (18.75%) of the participants developed only physical ill health and there was also variability in this, such as hypertension, cancer, stroke and autoimmune conditions. Others (22.5%) developed only psychological disorders, such as depression and anxiety, whereas a significant percentage (21.25%) developed both physical and psychological disorders. The verbal and written feedback from the research participants included insightful information about how they believed that caregiver stress was impacting their health. For example, a young woman caring for her sister said the following:

'Since my sister's ABI, I have had to seek psychiatric treatment for my stress disorder and I am now taking a handful of medications everyday just to cope, but before her injury, I occasionally took a headache tablet and nothing else and this sums up how my life has changed.' (Female, sister, caregiver)

#### A husband caring for his wife reported:

'I have been ignoring my own health since my wife's ABI and recently I was diagnosed with spinal ependymoma, which I believe is directly due to the extreme strain of the past few years.' (Male, husband, caregiver)

#### Another caring for her daughter reported:

'I can't cope without my medication for depression and anxiety' (Female, caregiver) and 'since being the primary caregiver my previously controlled hypertension has now become uncontrollable despite taking the medication' (Female, mother, caregiver).

All these research participants reported that their health-related conditions began after the onset of their inordinate stress associated with being a caregiver of a patient with ABI. Additionally, total scores on the SSCL and BDI indicated elevated levels of both stress and depression respectively. As can be seen in Figure 3, 77.5% (62) of the research participants' scores fell in either the moderate, severe or profound stress categories.

When compared with the elevated stress scores, 75% (60) of the sample were also found to have either mild, moderate or severe depression as measured on the BDI (Figure 4).

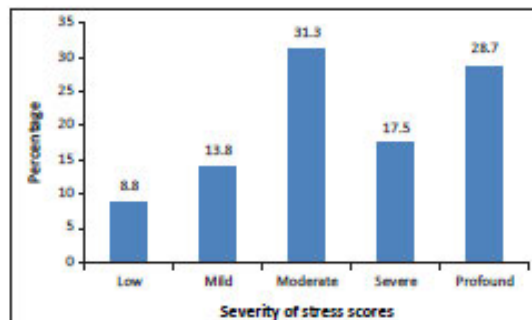


FIGURE 3: Total stress symptom checklist scores (N = 80).

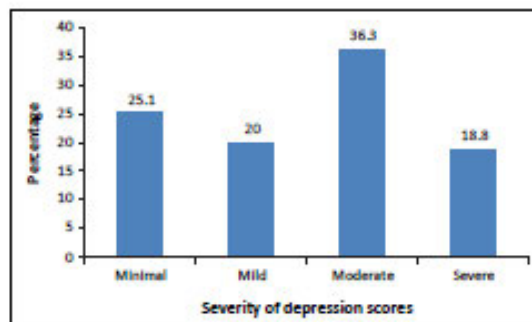


FIGURE 4: Total Beck Depression Inventory scores (N = 80).

confirming a positive link between stress, depression and poor coping skills in the sample studied.

Taking all of this information into consideration, the research participants were determined to be either coping or not coping. From the total sample, 67.5% (54) were found to be not coping and 32.5% (26) were found to be coping, but these participants also had areas of concern with respect to their health risks and future well-being.

## Discussion

The results of this study (both qualitative and quantitative) highlighted the psychological and physiological toll on family members caring for a patient with ABI and the difficulty in coping with their caregiver demands. These findings were identified despite the research participants all having substantial support from well-trained therapists at Headway Gauteng. However, in our experience many caregivers do not receive or have access to such support. On a societal level, there are likely many families experiencing serious physiological and psychological negative health effects as a result of the ongoing stress of caring for a patient with ABI. This increases the risk of additional strain on limited access to resources for patients with ABI especially when having to deal with many related diverse problems including psychiatric disorders and the underestimation of stress-related conditions, such as post-traumatic stress disorder.<sup>2,14,33,34</sup>



The theoretical framework underpinning this research is based, in part, on an integrated biopsychosocial (BPS) model of health described by Schlebusch.<sup>9,24,25,27</sup> This model has at its basis the general systems theory,<sup>28</sup> which contributed to the refinement of the medical model of health and involved a movement away from a reductionistic view of health to a more holistic perspective.<sup>26</sup> The BPS model emphasises that both health and ill health involve an interaction between biological, psychological and social factors as, for example incorporated in the SSCL.<sup>9,24,25,27,28,29</sup> This approach has been particularly useful in appreciating the negative impact of acute and chronic stress on physiological and psychological well-being in this study's participants. The high percentage of psychological and physical stress-related symptoms, in addition to the total stress scores associated with depression and ill health as found in the research participants, highlighted the systemic impact of stress on them.

People's predispositions to the development of physical and/or psychological disorders are understood to be highly variable,<sup>9,25,27,28,29</sup> as also found in this study. When coping skills are adaptive and allostasis occurs, the individual under stress should be better placed to maintain good health. However, pathophysiology can occur when stress reduces coping skills which may become maladaptive, causing disruptions to the process of allostasis and resulting in AL.<sup>8</sup> This helped improve our understanding of why this study's participants reported high levels of ill health. Because of this, the BPS model was further complemented by the utilization of the cognitive model in terms of the psychological impact of stress<sup>34,40</sup> which describes individuals who are not coping with stress as being unable to process or rationalise the stressor(s). The effect is distress along with a feeling of being unable to cope, influence or control the stressor(s).<sup>35</sup> As part of this, the psychological stress response begins with the individual's perception and interpretation of their stressor(s). Many of this study's participants, who had a diagnosis of depression and/or ill health, reported feeling overwhelmed by and trapped in their role as caregiver. This feeling of helplessness was described by many of the research participants during interviews. It has the potential to produce a markedly dysfunctional psychological state in a person who was previously healthy. The small number of family caregivers who had minimal signs of stress, depression or ill health before or after becoming a caregiver all described finding meaning in the caregiver experience which helped them to develop more adaptive coping skills. For example, a mother caring for her daughter said that her daughter's ABI had 'brought her back to her' as before the injury their relationship had been distant. Another carer described finding great joy in being able to comfort and alleviate the suffering of her partner with ABI. In addition, some of the family members who were coping believed that their caregiver duties had a spiritual significance for themselves and the patient. They had developed effective coping responses which acted as mitigating or interceding factors between stressors and their stress response.

If coping skills remain maladaptive, the risk for psychological and physiological health complications may increase

significantly as borne out in the case of most of our research participants. These findings have implications for the family members' ability to cope over time with the demands of being a caregiver. There is a need for appropriate support and education for people providing care to patients with ABI. Family members would benefit from education regarding their stress response and how it can affect them. Effective assessment and stress prevention require a comprehensive approach in order to identify the extent to which these factors negatively interact and place family members who care for patients with ABI at higher risk for problematic health outcomes. Our findings underscore the importance of medical and mental health professionals working together in order to prevent and/or manage the negative physical and psychological health effects of inordinate stress in the sample that we studied and which may be applicable to other high-risk family members caring for patients with debilitating conditions. When considering the influence of chronic stress on the psychological and physiological well-being in these family members, it becomes evident that identifying ways of ameliorating its effect is imperative in order to help them to cope with the caregiver demands in the long term. In this regard, protective factors such as developing effective coping strategies can help to mitigate the negative effects of inordinate stress and potentially contribute to improved resilience, adaptation and coping.

The limitations of this study include the fact that the research participants were all drawn from a single organisation, Headway Gauteng, which operates in Johannesburg, Hyde Park and Soweto. The study participants all have access to psychological support services which implies that the findings may be different in a population of family caregivers who do not have access to such support. In addition, the study consisted of a small sample size ( $N = 80$ ) and therefore the findings cannot necessarily be generalised.

## Conclusion

The relationship between elevated stress, depression, ill health and reduced coping skills in family members who care for patients with ABI has, in the past, not been extensively researched, especially in developing countries including South Africa. The high percentage of stress, depression and ill health amongst our sample suggests that they are not coping as well as they could with their self-perceived burden of being a family caregiver of a patient with ABI. Given the above, the conditional probability is high that if stress experienced by these family members is not adequately managed, it may exacerbate any physical and psychological health complications. This provides compelling evidence of the value of psychological screening for elevated stress and poor coping in family members caring for a patient with ABI. In this regard, we recommend a collaborative effort between medical and psychological health practitioners which could help to ensure a more holistic and inclusive approach to treatment procedures and interventions to improve coping skills in these individuals.



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## Competing interests

The authors have declared that no competing interests exist.

## Authors' contributions

All authors contributed equally to this work.

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## Data availability statement

Data is available upon request from the corresponding author.

## Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.

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## **CHAPTER 4**

### **INTRODUCTION**

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#### **SUPPORT FOR FAMILY MEMBERS WHO ARE CAREGIVERS TO RELATIVES WITH ACQUIRED BRAIN INJURY.**

This chapter introduces and presents the third article along with a scanned copy of the peer-reviewed published journal article.

The article establishes the severity of the stress levels and its causal relationship to suicidal ideation in family members who care for patients with ABI. Thereafter, the article reports on information gained from qualitative procedures that were designed to identify the caregivers' opinions of what causes them profound stress and caregiver burden. The article quotes feedback from some of the caregivers in order to provide a sense of their lived experience. In this regard, the primary aims of this article are to indicate the following: whether the family caregivers felt that the healthcare professionals adequately prepared them to deal with the potential neuropsychological deficits in the patients with ABI during the acute and sub-acute treatment of the patients (aim iv); which neuropsychological and physical deficits in the patients with ABI are perceived by the family caregivers as causing them the most stress (aim v); and whether the family caregivers feel that relevant psychosocial support and education with regard to ABI helped them to better manage their stress (aim vi). Based on the current and related earlier findings on caregiver burden, guidelines are recommended (in the discussion section of this article) that can assist healthcare professionals to better manage the psychological distress experienced by family members who care for a patient with ABI and to promote the development of coping and resilience in these family members (aim vii). The article highlights the role of healthcare professionals in terms of preparing the family members who care for patients with ABI to develop their resilience and coping skills. This requires a shared understanding between family members and healthcare professionals that could prevent an exacerbation of the caregiver's stress.

## 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



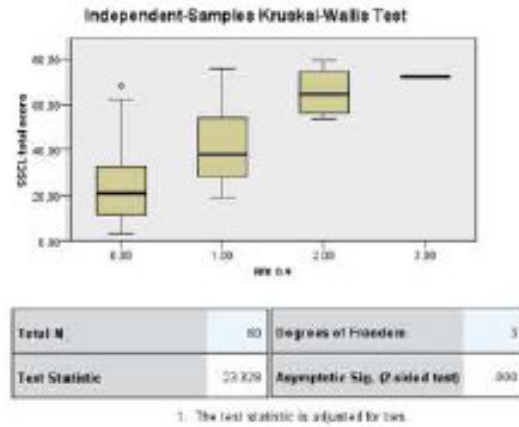
written notes during the interview in response to the items covered in the questionnaire. This included investigating the study participants' lived experiences as caregivers and the factors which they identified as being contributory to their high level of stress. Their written notes and the information 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.

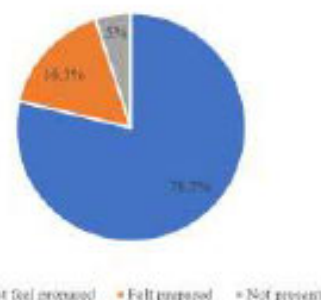


Figure 2. Preparation of family members

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 (83.3%), cognitive ability (76.8%), 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.

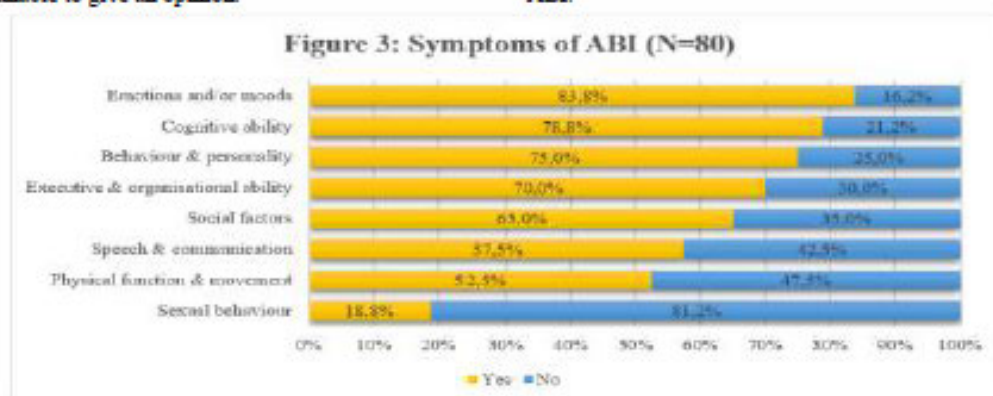


Figure 3. Research participants rate the impact of their relatives neuropsychological deficits on their stress levels

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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## **CHAPTER 5**

### **SYNTHESIS**

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#### **5.1 INTRODUCTION**

This chapter includes a synthesis and summary of the three published articles' key findings and the practical applications thereof. Additionally, it outlines the study limitations and recommends further research.

#### **5.2 SYNTHESIS**

##### **5.2.1. SYNTHESIS OF ARTICLES**

Article one forms the foundation for article two and three which further expand on the findings discussed in the first article. Article one addresses the relationship between stress and suicidal ideation in the research participants. The correlation between stress and suicidal ideation was significant, with data showing that suicidal ideation increased with increasing levels of stress. Article one also describes how most of the participants scored higher on the behavioural than the physical and psychological sub-categories of the SSCL. This suggests a denial and/or lack of acceptance of the impact of their physical and psychological stress-related symptoms. The marked number of medical and psychological diagnoses reported by the research participants after they became caregivers to the patients with ABI was further evidence of the pronounced effect of caregiver stress on their psychological and physical well-being.

Article two amplifies article one's findings by reporting on the impact of stress on levels of depression and ill health as an indication of psychological coping. It provides an explanation for the high percentage of physical and psychological diagnoses reported by the research participants after becoming caregivers, providing evidence that they were not coping given their inordinate stress and depression levels. These findings provide compelling evidence of the value of psychological screening for elevated stress and poor coping in family members caring for a patient with ABI.

Article three elaborates on article one's findings with the focus being the qualitative research information gained from the analyses of the questionnaire and self-report procedures. This revealed five themes, listed in the key findings, which were identified as major triggers of the caregivers' profound stress. They reported that they were not adequately prepared by healthcare professionals during the patients' treatment in hospital for the neuropsychological sequelae in the patient with ABI and that the lack of preparation resulted in family conflict and the

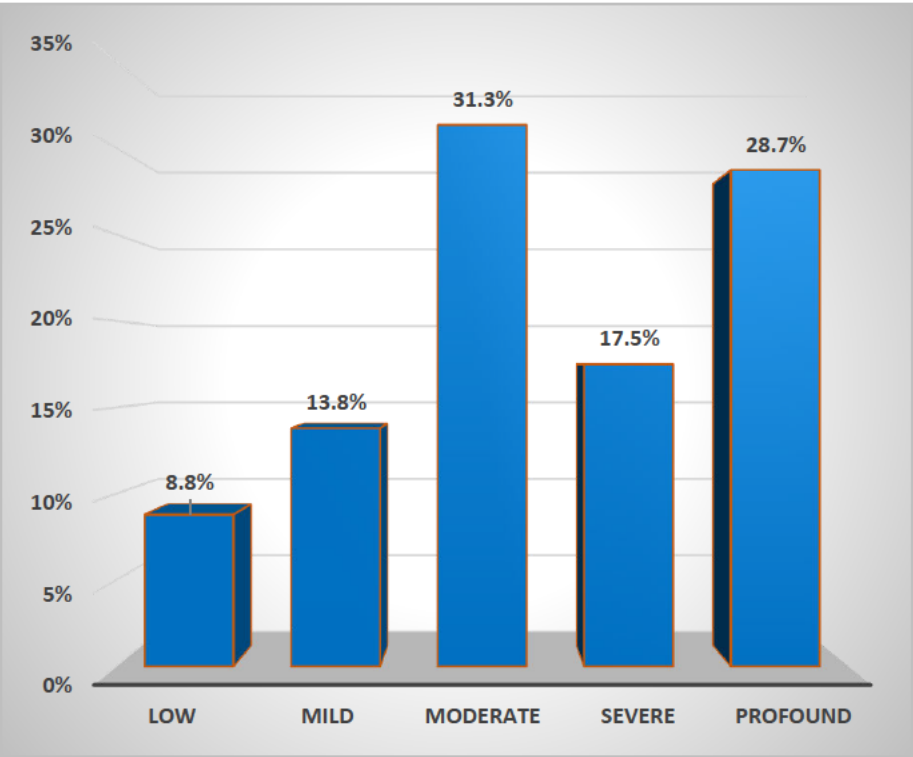
problems found by the present research. The article emphasises the role of the healthcare professionals in assisting these caregivers to cope and provides guidelines and recommendations as part of the discussion.

5.2.2. KEY FINDINGS

The key findings discussed in all three articles are listed here using bar graphs and pie charts for clarification.

5.2.2.1. Stress Levels

Most of the research participants (77.5%; 62) suffered from moderate, severe or profound stress (Figure 1). Only 22.6% (18) fell into the low to mild stress categories. This finding showed that the research participants were experiencing extreme stress effects and symptoms due to their caregiver responsibilities.



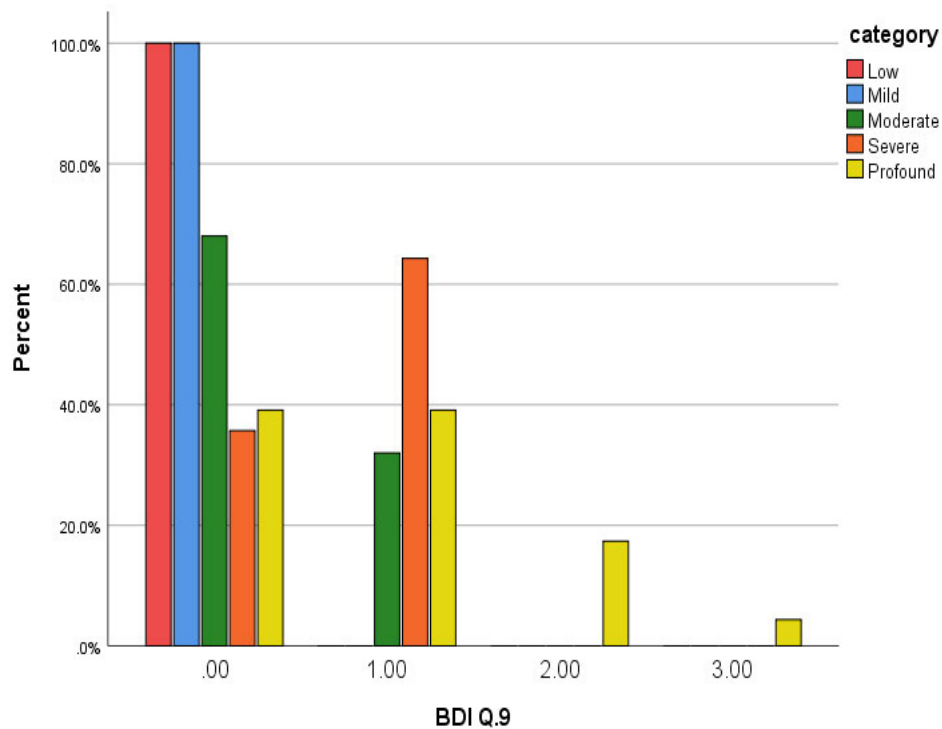
**Figure 1:** Results of the SSCL.

5.2.2.2. The Relationship Between Stress and Suicidal Ideation

Participants with higher levels of stress had correspondingly higher levels of suicidal ideation. Data showed that 100% of the low and mild stress scorers on the SSCL fell in the BDI Item 9 option of 0 (no suicidal ideation). As the BDI Item 9 options increased, so did the severity of the



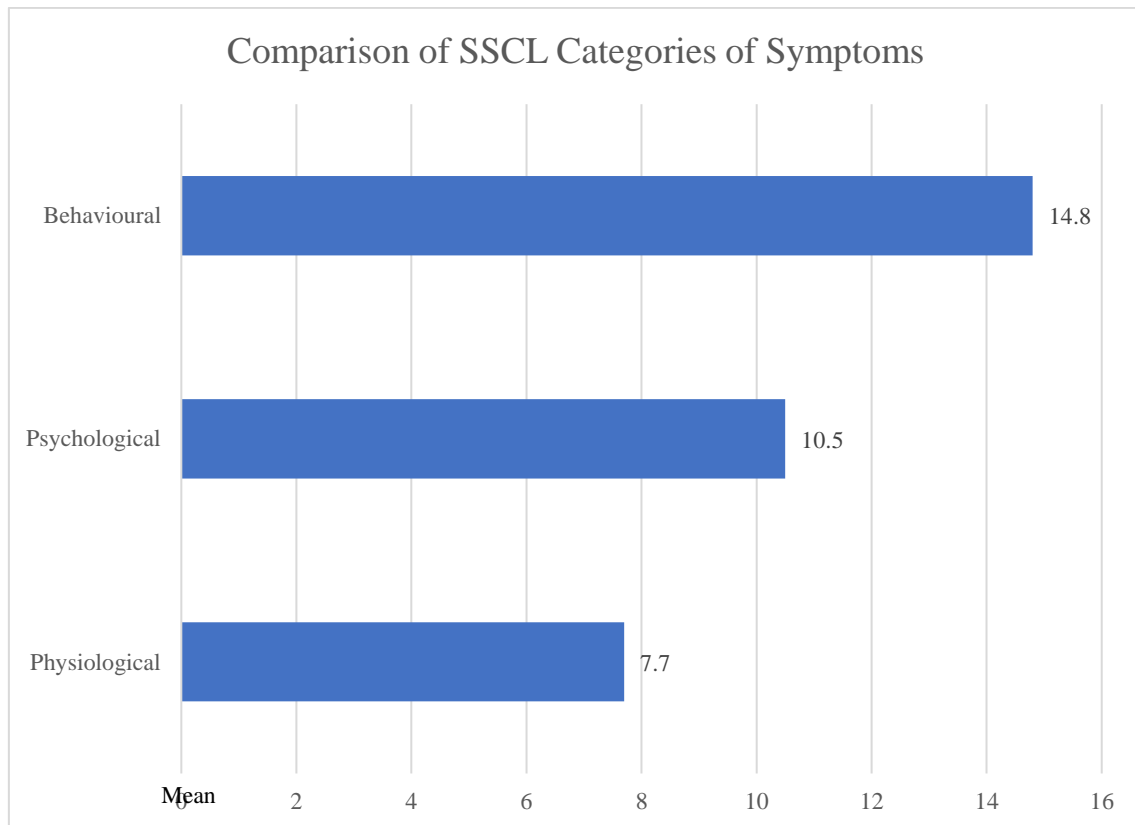
stress scores on the SSCL. On the BDI Item 9 options 2 and 3 (suicidal ideation and intent) profound stress levels were noted. The conclusion is that profound stress increases risk for suicidal ideation and behaviour in family members caring for a patient with ABI.



**Figure 2.** Total SSCL and BDI Item 9 scores.

#### 5.2.2.3. Evidence of Denial

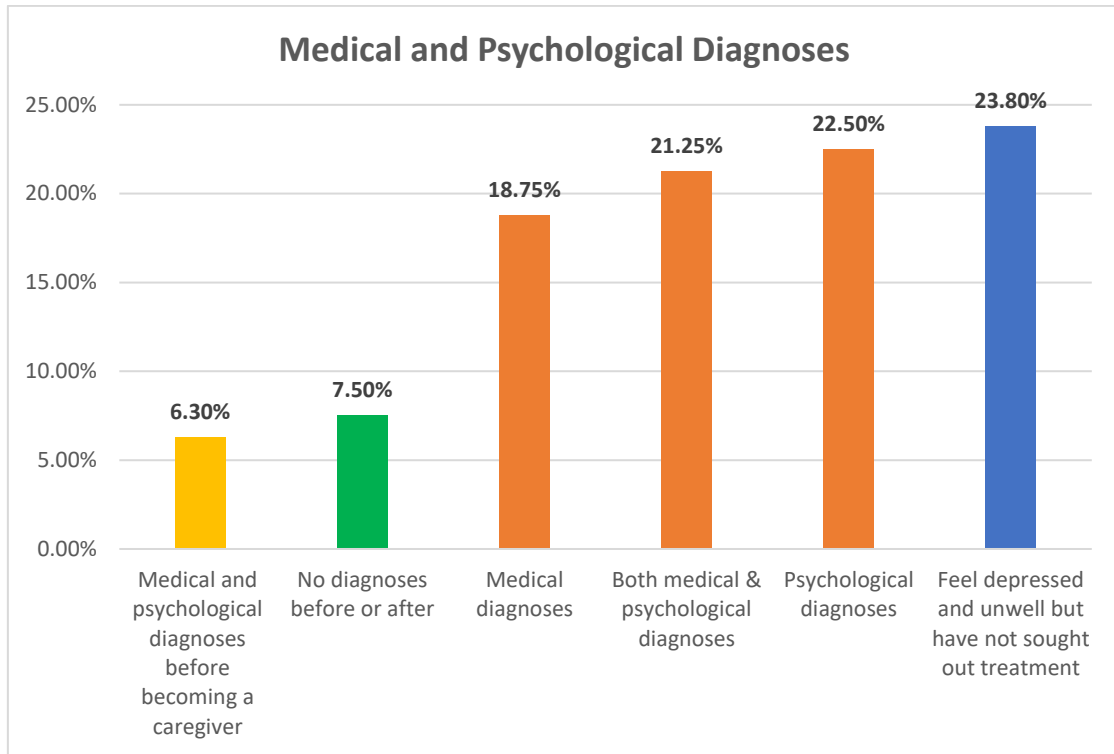
In terms of sub-category scores on the SSCL, most participants scored higher on the behavioural than the physical and psychological sub-scales as shown in Figure 3. This suggests a denial and/or lack of acceptance of the impact of the physical and psychological stress-related symptoms on them. These findings highlight the value of looking at the different sub-categories of stress as measured by the SSCL and not only a total stress score for each caregiver. A high score in any one of the sub-categories combined with lower scores in the others suggests that the patient may not be fully cognisant of the differential impact of their stress and/or may not want to admit to not coping with their caregiver burden.



**Figure 3:** Presentation of mean scores for SSCL sub-categories.

#### 5.2.2.4. Physical and Psychological Diagnoses

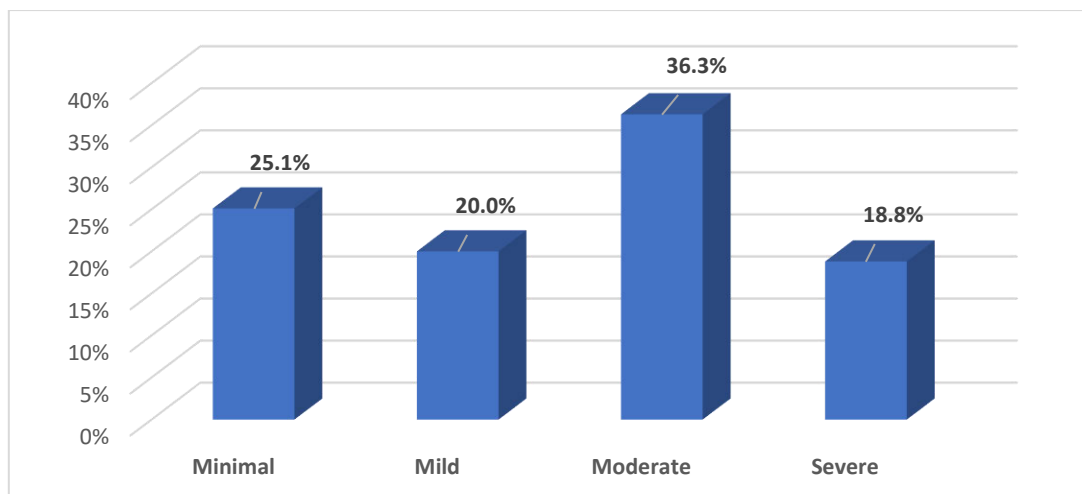
A profound psychological and physical impact on the research participants was identified as the following findings indicate: 62.5% (50) of the sample had received a medical and/or psychological diagnosis from a healthcare professional after becoming a caregiver. Of this number, 30% (15) were diagnosed 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. Only 6.3% (5) reported having been diagnosed with medical and/or psychological conditions before becoming a caregiver, and all these participants reported 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 before or after becoming a caregiver.



**Figure 4:** Medical and psychological diagnoses received after becoming a caregiver.

#### 5.2.2.5 Depression

The research participants were found to have markedly high levels of depression. Results from the BDI are presented in figure 5 which indicates the percentage of research participants who had minimal depression (25.1%), mild depression (20%), moderate depression (36.3%), and severe depression (18.8%). A total percentage of 75.1% of the research participants had mild to severe depression.

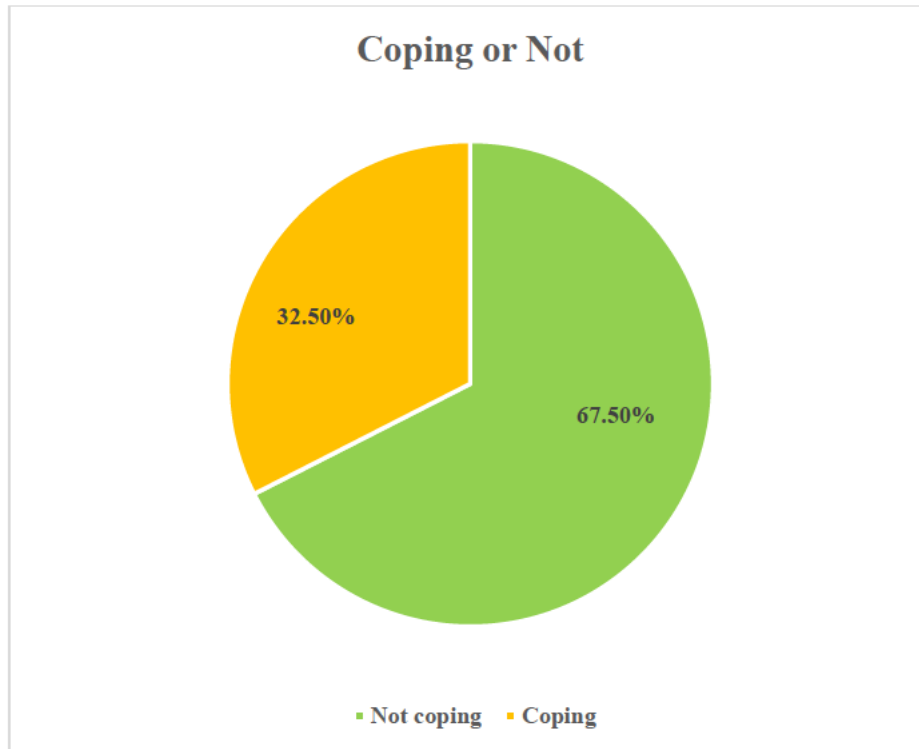


**Figure 5:** Results from the BDI.



#### 5.2.2.6 Psychological Coping

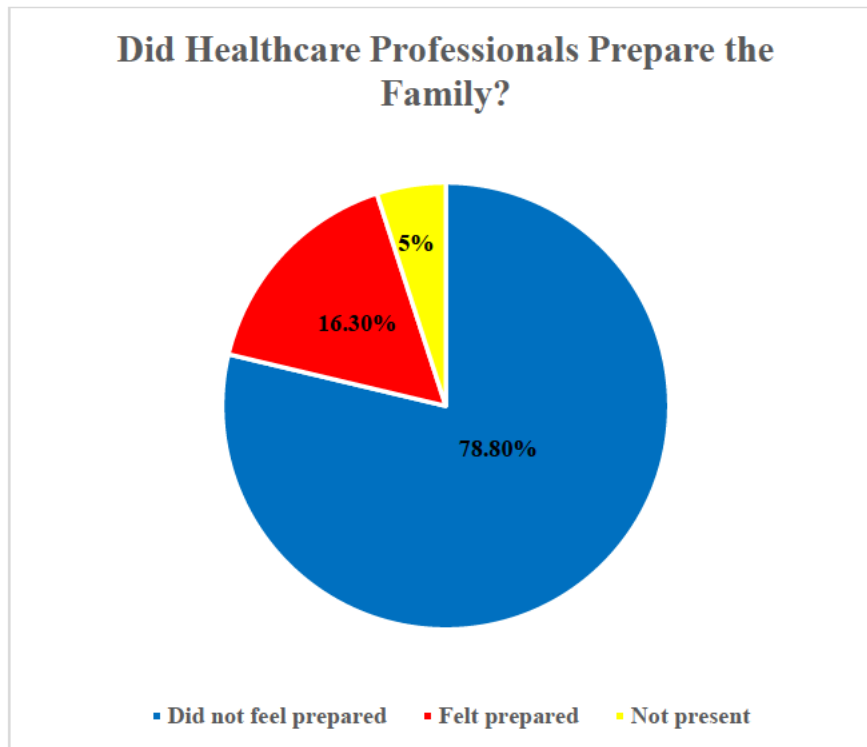
Scores on the SSCL, BDI and qualitative information were analysed, and each research participant was assessed to be either coping or not coping with their caregiver stress. Overall, 67.5% (54) were not coping and 32.5% (26) were coping but these participants had areas of concern in respect of their future well-being.



**Figure 6:** Coping or not coping with caregiver stress.

#### 5.2.2.7 The Families Hospital Experience

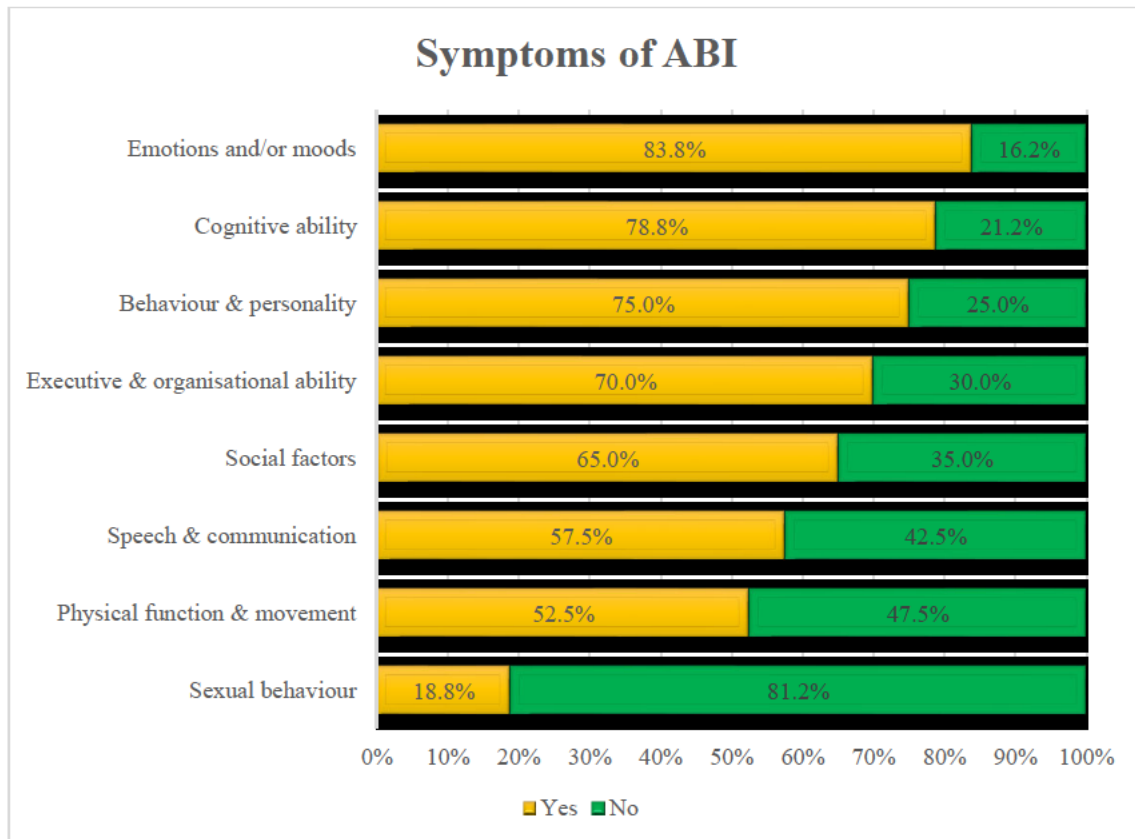
The research participants were asked if they felt prepared for the neuropsychological sequelae in the patients with ABI during the acute stage of hospital treatment. The results (figure 7) showed that 78.8% did not feel that they were adequately prepared for the changes in the patient. And only 16.3% did feel that they were adequately prepared and were able to anticipate the patient's changed behaviour and 5% of the sample said they were not present during the acute phase of treatment.



**Figure 7:** Preparation of family members (percentage of caregivers who felt adequately prepared for the neuropsychological deficits in the patient)

#### 5.2.2.8 Neuropsychological Deficits

Figure 8 indicates the percentage of the research participants who rated a particular neuropsychological or physical symptom in the patient with ABI as causing them profound stress. Most caregivers felt that deficits involving emotions and/or moods (83.3%), cognitive ability (78.8%), behaviour 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 behaviour caused them stress. The results show that a large percentage of the research participants were experiencing profound stress because of having to cope with the neuropsychological deficits in their relative with ABI.



**Figure 8:** Neuropsychological deficits rated by caregivers as the cause of profound stress.

#### 5.2.2.9 Qualitative Report - Five Themes

The analyses of the qualitative data revealed five themes which were identified as major triggers of the caregivers' profound stress.

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

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

**Theme 3:** Lack of education and preparation for homebased care.

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

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

### 5.3 PRACTICAL APPLICATIONS

The findings of the present study should alert healthcare professionals to the very high levels of stress experienced by caregivers of patients with ABI and the resulting increased risk for



suicidal ideation/behaviour, depression and ill health. This awareness should result in more holistic and effective psychological and medical treatment of these patients. Healthcare professionals who read the published articles will be better informed and more able to ask relevant questions and identify potential health problems allowing for a preventative approach to the treatment of these caregivers. The study's findings highlight the need for support, education and preparation of these caregivers regarding the neuropsychological sequelae in the patient which should significantly reduce family conflict and caregiver stress.

Stress-symptom screening is recommended for caregivers of patients with ABI to detect any early onset of unhealthy stress. This is an effective, quick and practical means of identifying behavioural, psychological and physiological risks in them and, thereby, facilitates applicable referrals for preventative treatment and interventions. In this regard a collaborative effort between medical and psychological healthcare practitioners is recommended to ensure a holistic and inclusive approach towards treatment procedures and interventions to improve coping skills and resilience in these family members.

The research findings emphasise that extremely high levels of stress in caregivers significantly increases risk for suicide and ill health. During the data collection phase of this study one of the research participants, who scored extremely high on both the SSCL and the BDI question 9, did choose to die by suicide. This death could have been avoided and it highlights the danger of denial in caregivers and their families, and the importance of identifying risk for suicide in family caregivers by healthcare professionals.

#### **5.4 STUDY LIMITATIONS AND RECOMMENDATIONS**

The limitations of this study include the fact that the sample size was small (N=80) and all the research participants were drawn from a single organisation, Headway Gauteng (Hyde Park and Soweto branches), which limits the generalizability of the findings. Further research is recommended which should be undertaken with a larger sample to identify a history of possible pre-morbid and other risk 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. The study participants all had access to psychological support services and education which implies that the findings may be different in a population of family caregivers who do not have access to such support. Although all the research participants in this study were caregivers for a minimum of 12 months, it would be

useful to establish what difference the time period of being a caregiver would make in terms of their coping skills and stress levels.

## **5.5 CONCLUSIONS**

Inordinate stress levels amongst caregivers of relatives with ABI are of significant concern and both chronic and acute stress have been found to be critical co-morbid variables in suicidal behaviour and ill health. The present research showed that elevated levels of stress can cause caregivers of patients with ABI to develop suicidal ideation, depression and ill health as they start feeling that they are not coping with the demands associated with caregiving. This is clinically relevant and early identification of such problems and referral for appropriate help is recommended along with the need to alert healthcare professionals to this. Given the above, the conditional probability is high that if stress experienced by these family members is not adequately treated, it may exacerbate physical and psychological stress-related diatheses. Hence the value of stress-symptom screening cannot be overemphasized, along with support and education regarding the potential neuropsychological deficits in the patients with ABI, and the effects of the caregivers' unmanaged stress on their physical and psychological well-being so that they are better able to manage their stress and cope as a caregiver.

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# ANNEXURE ONE

| SOCIODEMOGRAPHIC QUESTIONNAIRE   |  |  |  | Computer generated number: |  |
|--|--|--|--|----------------------------|--|
| Age:   |  |  |  |                            |  |
| Male:  |  |  |  |                            |  |
| Female:  |  |  |  |                            |  |
| Job title:   |  |  |  |                            |  |
| What is your relationship to your family member with brain injury? (mother, father, sister, brother etc) |  |  |  |                            |  |
| Educational qualifications:  |  | Primary school                                   |  |                            |  |
| (tick the highest qualification, where applicable)   |  | Grade 8  |  |                            |  |
|  |  | Grade 9  |  |                            |  |
|  |  | Grade 10   |  |                            |  |
|  |  | Grade 11   |  |                            |  |
|  |  | Grade 12   |  |                            |  |
|  |  | Diploma (teaching/engineering etc)               |  |                            |  |
|  |  | Degree (BA/BSc/Bcomm etc)                        |  |                            |  |
|  |  | Other qualifications, please specify             |  |                            |  |
|  |  | None   |  |                            |  |
| Occupation:  |  | Unemployed, but qualified as                     |  |                            |  |
| (please tick more than one box if applicable)  |  | Learner/Student                                  |  |                            |  |
|  |  | Unskilled (gardener/painter), please specify     |  |                            |  |
|  |  | Skilled (technical/diploma), please specify      |  |                            |  |
|  |  | Professional (university degree), please specify |  |                            |  |
|  |  | Pensioner/retired, please specify                |  |                            |  |
|  |  | Business owner, please specify                   |  |                            |  |
|  |  | Other, please specify                            |  |                            |  |
| Marital status:  |  | Married  |  |                            |  |
|  |  | Single   |  |                            |  |
|  |  | Divorced   |  |                            |  |
|  |  | Living together with partner                     |  |                            |  |
|  |  | Other, please specify                            |  |                            |  |
| Ethnic group:  |  | Black  |  |                            |  |
|  |  | Coloured   |  |                            |  |
|  |  | Indian   |  |                            |  |
|  |  | White  |  |                            |  |
|  |  | Other, please specify                            |  |                            |  |
| Religious group:   |  | Hindu  |  |                            |  |
|  |  | Muslim   |  |                            |  |
|  |  | Jewish   |  |                            |  |
|  |  | Christian  |  |                            |  |
|  |  | Other, please specify                            |  |                            |  |



## ANNEXURE TWO

### NEUROPSYCHOLOGICAL-RELATED QUESTIONNAIRE

RESEARCHER: MRS JANET WALKER (JANN)

1. Type of injury sustained by the person with acquired brain injury (ABI):

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2. Cause of the ABI:

---

3. Date of the ABI:

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4. Do you attend the Headway Friendship Circle? Circle yes or no below:

Yes / No

Or have you attended HFC in the past? Circle yes or no below:

Yes/No

5. Does your family member with ABI attend the Headway activity programme or has s/he attended in the past?

Yes / No

If yes, how often and for how long? (for e.g., once a week for 2 years)

---

---

6. Where is your family member with ABI living? Place a ☒ tick next to the relevant option below:

|                        |                          |
|------------------------|--------------------------|
| Assisted care facility | <input type="checkbox"/> |
| Living at home         | <input type="checkbox"/> |
| Living independently   | <input type="checkbox"/> |
| Elsewhere              | <input type="checkbox"/> |

If your family member with ABI is living elsewhere, please specify:

---

---

---

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

|   |
|---|
| <b>Rating scale – my stress levels are:</b> |
| <b>1 – Mild</b>                             |
| <b>2 – Moderate</b>                         |
| <b>3 – Severe</b>                           |
| <b>4 – Not applicable</b>                   |

| <b>Changes in family member with ABI</b>  | <b>Rating</b> |
|---|---------------|
| Emotions and/or mood<br>(for e.g., depression, anxiety, anger, etc)   |               |
| Sexual behaviour<br>(for e.g., inappropriate sexual behaviour, increased/decreased sex drive, etc)                            |               |
| Cognitive or intellectual ability<br>(for e.g., memory, comprehension, etc)   |               |
| Physical functionality and movement<br>(for e.g., use of a wheelchair, loss of movement, etc)                                 |               |
| Speech & communication<br>(for e.g., loss of speech, lack of clarity or comprehension in speech, etc)                         |               |
| Behaviour/personality changes<br>(for e.g., impulsivity, lack of spontaneity, aggressiveness, irritability, selfishness, etc) |               |
| Executive skills or general organisational skills<br>(for e.g., timekeeping, organisation, planning, etc)                     |               |
| Social factors<br>(for e.g., inappropriate social behaviour)  |               |

Please specify and provide further information where applicable:

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8. During your family member's treatment in hospital, did you feel adequately prepared by medical staff and/or healthcare professionals for the changes in your family member's psychological status, behaviour, cognition and personality? Circle yes or no below:

Yes / No

Please elaborate:

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---

9. Since your family member's ABI, have you been diagnosed with a medical or psychological health concern or condition? Circle yes or no below:

Yes / No

Please elaborate:

---

---

---

10. Which healthcare professionals, if any, have you consulted for assistance with your personal difficulties and health concerns since your family member sustained an ABI. Please indicate with a tick ✓ below:

|                        |  |
|------------------------|--|
| Medical doctor         |  |
| Psychiatrist           |  |
| Psychologist           |  |
| Counsellor             |  |
| Physiotherapist        |  |
| Other (please specify) |  |

11. Are you currently taking medication for a psychological and/or psychiatric condition, such as depression, anxiety or any other psychological concern? Circle yes or no below:

Yes / No

If yes, please elaborate:

---

---

---

12. If you have been diagnosed with a psychological and/or psychiatric condition, please indicate if your diagnosis occurred before or after your family member sustained an ABI by ticking ✓ the appropriate box below:

|  |  |
|--|--|
| <b>Before</b> your family member's ABI |  |
| <b>After</b> your family member's ABI  |  |

13. Do you believe that your current well-being and health status has been affected by your family member's ABI? Circle yes or no below:

Yes / No

If yes, please elaborate:

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## **ANNEXURE THREE**

### **BECK'S DEPRESSION INVENTORY**

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the one statement in each group that best describes the way you have been feeling during the past two weeks, including today. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

**1. SADNESS**

- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

**2. PESSIMISM**

- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

**3. PAST FAILURE**

- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

**4. LOSS OF PLEASURE**

- 0 I get as much pleasure as I ever did from the things I enjoy.
- 1 I don't enjoy things as much as I used to.
- 2 I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

**5. GUILTY FEELINGS**

- 0 I don't feel particularly guilty.
- 1 I feel guilty over many things I have done or should have done.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

**6. PUNISHMENT FEELINGS**

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

**7. SELF-DISLIKE**

- 0 I feel the same about myself as ever.
- 1 I feel I may be punished.
- 2 I am disappointed in myself.

- 3 I dislike myself.
- 8. SELF-CRITICALNESS**
  - 0 I don't criticize or blame myself more than usual.
  - 1 I am more critical of myself than I used to be.
  - 2 I criticize myself for all of my faults.
  - 3 I blame myself for everything bad that happens.
- 9. SUICIDAL THOUGHTS OR WISHES**
  - 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.
  - 3 I would kill myself if I had the chance.
- 10. CRYING**
  - 0 I don't cry any more than I used to.
  - 1 I cry more than I used to.
  - 2 I cry over every little thing.
  - 3 I feel like crying, but I can't.
- 11. AGITATION**
  - 0 I am no more restless or wound up than usual.
  - 1 I feel more restless or wound up than usual.
  - 2 I am so restless or agitated that it's hard to stay still.
  - 3 I am so restless or agitated that I have to keep moving or doing something.
- 12. LOSS OF INTEREST**
  - 0 I have not lost interest in other people or activities.
  - 1 I am less interested in other people or things than before.
  - 2 I have lost most of my interest in other people or things.
  - 3 It's hard to get interested in anything.
- 13. INDECISIVENESS**
  - 0 I make decisions about as well as ever.
  - 1 I find it more difficult to make decision than usual.
  - 2 I have much greater difficulty in making decision than I used to.
  - 3 I have trouble making any decisions.
- 14. WORTHLESSNESS**
  - 0 I do not feel that I am worthless.
  - 1 I don't consider myself as worthwhile and useful as I used to.
  - 2 I feel more worthless as compared to other people.
  - 3 I feel utterly worthless.
- 15. LOSS OF ENERGY**
  - 0 I have as much energy as ever.
  - 1 I have less energy than I used to have.
  - 2 I don't have enough energy to do very much.
  - 3 I don't have enough energy to do anything.
- 16. CHANGES IN SLEEPING PATTERN**
  - 0 I have not experienced any change in my sleeping pattern.
  - 1a I sleep somewhat more than usual.

- 1b I sleep somewhat less than usual.
- 2a I sleep a lot more than usual.
- 2b I sleep a lot less than usual.
- 3a I sleep most of the day.
- 3b I wake up 1-2 hours early and can't get back to sleep.

**17. IRRITABILITY**

- 0 I am no more irritable than usual.
- 1 I am more irritable than usual.
- 2 I am much more irritable than usual.
- 3 I am irritable all the time.

**18. CHANGES IN APPETITE**

- 0 I have not experienced any change in my appetite.
- 1a My appetite is somewhat less than usual.
- 1b My appetite is somewhat greater than usual.
- 2a MY appetite is much less than before.
- 2b My appetite is much greater than usual.
- 3a I have no appetite at all.
- 3b I crave food all the time.

**19. CONCENTRATION DIFFICULTY**

- 0 I can concentrate as well as ever.
- 1 I can't concentrate as well as usual.
- 2 It's hard to keep my mind on anything for very long.
- 3 I find I can't concentrate on anything.

**20. TIREDNESS OR FATIGUE**

- 0 I am no more tired or fatigued than usual.
- 1 I get more tired or fatigued more easily than usual.
- 2 I am too tired or fatigued to do a lot of the things I used to do.
- 3 I am too tired or fatigued to do most of the things I used to do.

**21. LOSS OF INTEREST IN SEX**

- 0 I have not noticed any recent changes in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I am much less interested in sex now.
- 3 I have lost interest in sex completely.

| <b>SCORING</b> |                     |
|----------------|---------------------|
| 0 to 9:        | MINIMAL DEPRESSION  |
| 10 to 16:      | MILD DEPRESSION     |
| 17 to 29:      | MODERATE DEPRESSION |
| 30 to 63:      | SEVERE DEPRESSION   |



## ANNEXURE FOUR

### BECK'S HOPELESS SCALE

Read the following statements about you and your feelings today. Make a cross in the TRUE block if the statement indicates how you felt in the past week (including today), and a cross in the FALSE block if you did not feel like that in the past week.

|   | true | false |
|---|------|-------|
| 1. I look forward to the future and feel enthusiastic about it.                                       |      |       |
| 2. I may as well give up because I cannot improve my condition.                                       |      |       |
| 3. If things go badly, I feel better in the knowledge that things will not always be bad              |      |       |
| 4. I can't think what my life will be like in ten years times.  |      |       |
| 5. I have enough time to achieve that which I really want to achieve.                                 |      |       |
| 6. I think that I will be successful in the future in those things that are important to me.          |      |       |
| 7. My future looks dark.  |      |       |
| 8. I expect to get more good things out of life than the average person.                              |      |       |
| 9. Everything is going wrong with me and there is no reason to have faith in the future.              |      |       |
| 10. My past has prepared me well for the future.  |      |       |
| 11. My future looks strewn with unhappiness rather than happiness.                                    |      |       |
| 12. I do not expect to get those things that I want so badly.   |      |       |
| 13. If I look into the future, I hope that I will be happier than I am now.                           |      |       |
| 14. Things are just not going to happen as I would like them to.                                      |      |       |
| 15. I believe in the future.  |      |       |
| 16. I never get what I want, therefore it is stupid to expect anything.                               |      |       |
| 17. It is unlikely that things will be really better in the future.                                   |      |       |
| 18. The future looks vague and uncertain.   |      |       |
| 19. I look forward to better rather than worse times.   |      |       |
| 20. It is not worthwhile looking forward to something, seeing that it probably will not happen to me. |      |       |

## ANNEXURE FIVE

### THE STRESS SYMPTOM CHECKLIST

Make a tick ✓ if you experience the symptoms *often* (at least once a week or more), and an X if you experience it *sometimes* (less than weekly, but at least monthly).

Do you experience:

| PHYSICAL REACTIONS  |  |   |  |  |  |
|---|--|---|--|--|--|
| - UNUSUAL TIREDNESS                                       |  | - HIGH BLOOD PRESSURE                           |  | - UNEXPLAINED NAUSEA                   |  |
| - APATHY/LACK OF ENTHUSIASM                               |  | - SEXUAL PROBLEMS                               |  | - FREQUENT INDIGESTION                 |  |
| - BREATHLESSNESS FOR NO REASON                            |  | - UNEXPLAINED HEADACHES/PAIN                    |  | - ERRATIC BOWEL FUNCTION               |  |
| - FEELINGS THAT YOUR APPEARANCE HAS ALTERED FOR THE WORSE |  | - FEELING FAINT OR UNUSUALLY WEAK FOR NO REASON |  | - EXCESSIVE PERSPIRATION FOR NO REASON |  |
| - DIFFICULTY IN RELAXING                                  |  | - MUSCLE TENSION                                |  | - DIZZY SPELLS FOR NO REASON           |  |
| - DISTURBING DREAMS OR NIGHTMARES                         |  | - FEELING PHYSICALLY UNWELL                     |  | - FEELING TIGHT-CHESTED FOR NO REASON  |  |

| PSYCHOLOGICAL REACTIONS                 |  |   |  |   |  |
|---|--|---|--|---|--|
| - FEELINGS OF HELPLESSNESS              |  | - FEELINGS OF DISLIKING YOURSELF                      |  | - FEELINGS THAT YOU ARE A FAILURE         |  |
| - FEELINGS OF DEPRESSION                |  | - BEING AFRAID OF DISEASE                             |  | - FEELING YOU CAN'T COPE                  |  |
| - FEELINGS THAT NO ONE UNDERSTANDS YOU  |  | - AN INCREASE IN COMPLAINTS ABOUT WHAT HAPPENS TO YOU |  | - FEELINGS THAT OTHER PEOPLE DISLIKE YOU  |  |
| - FEELINGS OF GENERAL ANXIOUSNESS       |  | - LOW SELF-ESTEEM/LOW OPINION OF YOURSELF             |  | - FEELINGS OF CONFUSION                   |  |
| - PHOBIAS (IRRATIONAL FEARS)            |  | - FEELINGS OF BEING GOSSIPED ABOUT                    |  | - FEELINGS OF CONCERN MAINLY FOR YOURSELF |  |
| - AWKWARD FEELINGS WHEN CLOSE TO OTHERS |  | - BEING OVER SELF-CRITICAL                            |  | - FEELINGS OF FREQUENT CRITICISM          |  |
| - FEELINGS THAT YOU HAVE FAILED IN      |  | - FEELINGS THAT NO ONE WANTS TO WORK WITH             |  | - FEELINGS THAT YOU HAVE BEEN             |  |

|  |  |                              |  |  |  |
|--|--|------------------------------|--|--|--|
| <b>YOUR ROLE AS A PARENT, SPOUSE, CHILD EMPLOYEE, EMPLOYER</b> |  | <b>YOU</b>                   |  | <b>NEGLECTED OR LET DOWN</b>                   |  |
| - PANICKY FEELINGS   |  | - FEELING TENSE AND KEYED-UP |  | - FEELINGS OF LONELINESS AND NO ONE TO TALK TO |  |
| - BEING UPSET BY DISEASE IN OTHERS                             |  | - PERSISTENT GUILT           |  | - A LACK OF SELF-CONFIDENCE                    |  |

| BEHAVIOURAL REACTIONS                         |  |  |  |  |  |
|---|--|--|--|--|--|
| - MEMORY LOSS/<br>FORGETFULNESS               |  | - DIFFICULTY IN MAKING<br>UP YOUR MIND                                     |  | - DISINTEREST IN<br>OTHER PEOPLE   |  |
| - POOR LONG-TERM<br>PLANNING                  |  | - DIFFICULTY IN<br>SHOWING/EXPRESSING<br>YOUR TRUE FEELINGS                |  | - SUPPRESSED OR<br>UNEXPRESSED<br>ANGER  |  |
| - POOR<br>CONCENTRATION                       |  | - WORRYING   |  | - FEARFULNESS  |  |
| - INCONSISTENCY                               |  | - SOCIAL WITHDRAWAL  |  | - POOR DECISION<br>MAKING  |  |
| - INABILITY TO MEET<br>DEADLINES              |  | - MAKING UNNECESSARY<br>MISTAKES   |  | - UNCO-OPERATIVE<br>RELATIONSHIPS  |  |
| - POOR TIME<br>MANAGEMENT                     |  | - THE NEED TO<br>REGULARLY WORK<br>LATE                                    |  | - FEELING<br>DISGRUNTLED/<br>MOODY/<br>IRRITABLE                               |  |
| - PROCRASTINATION                             |  | - POOR WORK QUALITY  |  | - EMOTIONAL<br>OUTBURSTS   |  |
| - THE NEED TO<br>CONSTANTLY TAKE<br>WORK HOME |  | - DIFFICULTY IN<br>COMPLETING ONE TASK<br>BEFORE RUSHING ON TO<br>THE NEXT |  | - GREATER USE OF<br>ALCOHOL,<br>CAFFEINE,<br>NICOTINE,<br>MEDICINES TO<br>COPE |  |
| - POOR PROBLEM-<br>SOLVING SKILLS             |  | - THE NEED TO CANCEL<br>LEAVE  |  | - FIDGETING/<br>RESTLESSNESS   |  |
| - ACCIDENT-<br>PRONENESS                      |  | - NAILBITING   |  | - UNPREDICT-<br>ABILITY  |  |
| - LOW INTEREST IN<br>WORK                     |  | - AN EXCESSIVE<br>APPETITE   |  | - A LOSS O F<br>APPETITE   |  |
| - A DROP IN<br>PERSONAL<br>STANDARDS          |  | - ENGAGING IN<br>FREQUENT CRITICISM<br>OF OTHERS                           |  | - THE NEED TO CRY<br>FOR NO REASON   |  |
| - INCREASED<br>AGGRESSIVENESS                 |  | - FRANTIC BURSTS OF<br>ENERGY  |  | - TICS/NERVOUS<br>HABITS   |  |
| - LACK OF INTEREST<br>IN LIFE                 |  | - LITTLE SENSE OF<br>HUMOUR  |  | - SLEEP<br>DISTURBANCES  |  |



Rate the **PRESENT INTENSITY** of your stress somewhere along the scale below.  
Choose any number between lowest intensity (1) to highest intensity (10). Circle  
only one number along the scale below:

|        |   |   |   |   |   |   |   |   |   |    |  |                   |
|--------|---|---|---|---|---|---|---|---|---|----|--|-------------------|
| No     |   |   |   |   |   |   |   |   |   |    |  | The most intense  |
| stress |   |   |   |   |   |   |   |   |   |    |  | stress imaginable |
|        | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |  |                   |

| SCORING                       |
|-------------------------------|
| 0 to 8: LOW STRESS            |
| 9 to 15: MILD STRESS          |
| 16 to 30: MODERATE STRESS     |
| 31 to 45: SEVERE STRESS       |
| 46 and above: PROFOUND STRESS |

## **ANNEXURE SIX**

### **STUDY INFORMATION SHEET**

**Study title: Stress, depression and suicidal ideation amongst family members of patients with acquired brain injury (ABI).**

Principal investigator: Janet (Jann) Walker

Cell phone number: 076 264 0044

Email address: jann@counselling-trauma.co.za

#### **Greetings Headway Members,**

This is an appeal to all the Headway members involved in caring for a relative with ABI. Please volunteer to become a part of this study. To help you understand what this research study is about here is some background information about myself and the study. As a registered counsellor I am involved in education and support of people living with ABI and their family members. As part of this work, I facilitate the Headway Friendship Circle (HFC) which is a group designed to provide emotional support and information to assist families. HFC also provides an outlet for people living with ABI so that they feel less isolated in coping with the struggles that come with ABI. In addition to this work I provide general education, life skills and psychological counselling to patients at my private practice in Rosebank, Johannesburg.

Consistently I have seen that the family members caring for a relative with ABI go through substantial pain and suffering. Very often this results in both physiological and psychological health effects. This research study is designed to identify levels of stress, depression, hopelessness and suicidal behaviours in family members caring for a relative with ABI. The primary purpose is to gain data and statistics that will assist in creating greater awareness of the psychological burden experienced by family members. With this information I will be able to draw up guidelines for medical and healthcare professionals so that greater emphasis is placed on providing family members with appropriate support.

At HFC family members often say that in the early days of their relative's illness or injury no-one explained that there could be ongoing personality and general functionality changes in their relative with ABI. Healthcare professionals do try to do this, however there is so much focus on the patient that very often the healthcare professional does not stop to assess and, thereby,

ensure that the family members are understanding what is happening to their relative's brain and potentially to their brain function. The education and support of the family members needs to begin in the hospital, and it should be undertaken in a systematic and sensitive manner by counsellors and/or psychologists with specialized training. This study intends to highlight this need.

If you choose to participate in this study, you will be required to take a battery of tests, which you will do under my guidance and supervision. This will take approximately 60 minutes and the interview can be done in a group setting.

This study has been ethically reviewed and approved by the UKZN Biomedical Research Ethics Committee (approval number: BE221/18).

### **YOUR PARTICIPATION IS VOLUNTARY**

Your participation is entirely voluntary. You can refuse to answer any questions that you find too embarrassing or personal. Please note that you are free to decline to participate or withdraw at any time from the study without suffering any disadvantage or prejudice.

### **CONFIDENTIALITY**

The information that you share with me is confidential and you will be identified in the research by a computer-generated number. No person will be able to link your name with this computer-generated number. However, those of you who are comfortable with providing contact details may do so. The informed consent and test forms will be locked away in a secure cupboard that will be accessible to myself only. Please note that all the information that you provide will be treated with complete confidentiality. At an appropriate time after the study has been completed all the test forms will be shredded and disposed of by myself. Once you understand the study and agree to participate, you will be asked to sign a consent form. You should not agree to take part unless you are completely happy with the study and have understood the information given to you.

### **RISKS AND DISCOMFORTS**

Sometimes filling out psychological tests such as these can cause distress, if you find that this is the case, please let me know and appropriate counselling will be made available to you. In addition, if you are embarrassed, worried or made to feel anxious by some of the questions, please remember that you can refuse to answer any questions that you wish to.



**BENEFITS**

The results of this study will be used to provide information and guidelines for medical and healthcare professionals who are involved in the care of patients with ABI and their family members. This will contribute to more appropriate counselling and education being made available to family members, so that they are better prepared and more able to cope with the challenges in caring for and supporting a person with ABI. The results of this study will also be published in scientific journals to achieve wider dissemination of the relevant data.

**COST OF THE STUDY**

There is no cost to you to take part in the study.

**COMPENSATION**

Neither you, nor the researcher (Jann), will receive any financial compensation for doing or taking part in this study.

**CONSENT**

You are required to sign a consent form if you agree to participate in this study.

**LANGUAGE**

Participants are required to be able to read and write in English.

**QUESTIONS**

In the event of any questions, problems or concerns you may contact me on my cell: 076 264 0044. Or you can contact the UKZN Biomedical Research Ethics Committee at:

**BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus

Govan Mbeki Building

University of KwaZulu-Natal

Private Bag X 54001, Durban, 4000

KwaZulu-Natal, SOUTH AFRICA

Tel: 27 31 2602486 - Fax: 27 31 2604609

Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

## **ANNEXURE SEVEN**

### **INFORMED CONSENT FORM**

I \_\_\_\_\_ have been informed about the study entitled: **stress, depression and suicidal ideation amongst family members of patients with acquired brain injury (ABI)**, by Jann Walker.

I have read the study information form and I understand the purpose and procedures of the study.

I have been given an opportunity to ask questions about the study and have had answers to my satisfaction.

I declare that my participation in this study is entirely voluntary and that I may withdraw at any time without affecting any of the benefits that I am usually entitled to.

I have been informed about available counselling if any harm or distress occurs to me as a result of study-related questions.

If I have any further questions or concerns related to the study, I understand that I may contact the researcher (Jann Walker) on her cell phone 076 264 0044.

If I have any questions or concerns about my rights as a study participant, or if I am concerned about an aspect of the study or the researcher then I may contact:

#### **BIOMEDICAL RESEARCH ETHICS ADMINISTRATION**

Research Office, Westville Campus  
Govan Mbeki Building  
University of KwaZulu-Natal  
Private Bag X 54001, Durban, 4000  
KwaZulu-Natal, SOUTH AFRICA  
Tel: 27 31 2602486 - Fax: 27 31 2604609  
Email: [BREC@ukzn.ac.za](mailto:BREC@ukzn.ac.za)

I understand what my involvement in the study means and I voluntarily agree to participate by completing the study tests and questionnaire.

---

**Signature of participant**

**Date**