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The Effect of Support Groups on the Psychological Well-being of Traumatic Brain Injury Caregivers

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Across the United States traumatic brain injury is among the highest in reported injuries (Rates of TBI, 2014). These brain injuries debilitate a patient, leaving them with psychological, cognitive, and physical ailments. While the patient is overcoming these hardships they require a caregiver to help them get through their daily life. During the rehabilitation process there are many means of support for the patient but they are few and far between for caregivers. The deficit of support for caregivers leaves them with high stress levels, anxiety and low well-being. In this study I will examine how implementing a support group for caregivers will help raise their well-being, and lower other negative psychological symptoms.

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During my own experience as a patient with a traumatic brain injury, I found myself relying on others for almost everything. My main caregiver was my mother, whom is also a nurse. She was the one who was with me night and day for the six weeks I needed round-the-clock care. While the injury was taxing on me as the patient, the experience also negatively affected my mother's life. Throughout the course of my injury, I had a steady and strong support system. My mother on the other hand, had little help and support aside from my dad, aunt and grandmother. I could see the responsibilities taking a toll on her. She was worried, scared and rundown from taking care of me as well as going to work. While there are many opportunities for support and rehabilitation for patients, there is little help for the people who provide care for the patients. In this paper, I will be looking at how traumatic brain injury affects the well-being of the caregiver and what can be done to improve their wellbeing during and after the injury.

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Traumatic brain injury, (TBI) affects millions of people in the United States alone (Rates of TBI, 2014). With so many people being affected, it is one of the biggest public health problems in the United States (Rates of TBI, 2014).

In 2010 there were 2.5 million injuries reported that were related to TBI. This included Emergency Room visits, hospitalizations, and deaths. Out of the 2.5 million injuries 91.7 per 100,000 of them were severe enough to require hospitalization and round the clock care (Rates of TBI, 2014).

Traumatic brain injury is by definition an injury caused by damaging of the head that inhibits normal functioning of the brain (Rates of TBI, 2014). In 2010 a total of 720.3 per 100,000 women and 932.1 per 100,000 men were affected by a brain injury that needed either an emergency room visit, hospital stay or resulted in death. From 2009-2010 the largest number of people affected by TBI were people 65+ years old with a total of 294 per 100,000 people; secondly, people 15-24 years old with 81.2 per 100,000 (Rates of TBI, 2014). All of these people required someone to care for them for some length of time.



There are two major types of TBI, penetrating injury and closed head injury. Penetrating injury occurs when a foreign object enters the head such as a bullet (American Speech-Language-Hearing Association, 2014). Closed head injury is caused by a blow to the head such as what occurs during a car accident (American Speech-Language-Hearing Association, 2014). Within the two types of TBIs, there is a secondary classification subset; primary and secondary (American Speech-Language-Hearing Association, 2014). Primary brain injury is something such as a skull fracture, contusion, blood clot, or nerve damage (American Speech-Language-Hearing Association, 2014). Secondary brain injury occurs after the primary injury (American Speech-Language-Hearing Association, 2014). Such as brain swelling, epilepsy, fever, infection, lung and cardiac changes to name a few (American Speech-Language-Hearing Association, 2014).

Effects for TBI patients can be long lasting and can be physical, cognitive and psychological. Physical effects can range from being in a vegetative state, to reduced strength and coordination (Anderson, Parmeter & Mok, 2002). The cognitive effects can range from losing speech and language abilities to memory loss. Psychologically patients can become depressed or have major mood swings due to the stress they are under. Short term or less damaging effects can range from dizziness, nausea, decreased smell or taste to mild headaches (Anderson, Parmeter & Mok, 2002). Damaging effects to cognitive functions include abilities such as memory, conversation skills, goal setting and starting tasks (Anderson, Parmeter & Mok, 2002).

Well-being of TBI patients is greatly altered during the scary and long road to recovery and maintaining a positive outlook is very important to rehabilitation. Doering et al., (2011) found that negative self-evaluations seem to negatively impact well-being of the patient, suggesting that having a positive self-concept is important for patients. Patients have support groups, facilities, psychological and physical rehabilitation centers to help them cope with the injury and their emotions. Evans (2011) emphasizes the fact that positive psychology impacts the rehabilitation period for patients with TBI. He quotes from Seligman "Building what's stronger rather than fixing what's wrong" is what is important and helpful. Setting goals and accepting what has happened is a very crucial step towards getting better. The patients need to go from a negative way of thinking to a more

positive and optimistic outlook on their situation in order to overcome their situation (Evans, 2011).

During the time of rehabilitation for a TBI patient a caregiver is needed to help the patient go through the motions of everyday life. A caregiver in a hospital or rehabilitation facility is typically a nurse, but when the patient is brought home a family member becomes the caregiver. If it is necessary the family can hire a nurse to go to the house every day to take care of the patient (Anderson, Parmeter & Mok, 2002). Due to the great responsibility the caregiver has while taking care of patients, the caregiver becomes emotionally and physically drained and stressed (Anderson, Parmeter & Mok, 2002). The caregiver provides: personal care, daily activity care, psychological support, safety, and organization. The more disabling the injury the more effort and time the caregiver has to invest. If for example if one spouse is taking care of the other, the home environment becomes completely different. Now what was once their home, a place for relaxation, becomes a place for labor and caregiving. Behavioral changes, communication issues and social problem are experienced by both the spouses in this situation (Anderson, Parmeter & Mok, 2002). The patient and caregiver can be affected by the same stressors which then causes their well-being to diminish (Anderson, Parmeter & Mok, 2002).

Just as negative feelings can affect the patient and caregiver at the same time, positive feelings can as well. Having a positive outlook is important for patients as well as caregivers. A study conducted by Simpson and Jones (2013) found that higher ratings of resilience among family caregivers were significantly correlated with increased levels of positive affect and decreased levels of both negative affect and caregiver burden. Although having a positive attitude is important it is not the remedy for negative well-being. The majority of caregivers indicated at least mild negative life change following the brain injury of a family member (Wallace et al, 1998). When something this devastating happens it is difficult to have a positive attitude and the pressures of being a caregiver can be intense. This negative life change is something that needs to be addressed, and currently there is little relief in the community to help combat the negative life changes. There are long term alterations to a caregiver's life that affect their well-being. TBI caregivers reported substantially lower mental health scores across indices of depression, satisfaction with life, anxiety, and self-esteem, as well as lower appraisal- and belonging-type social support (Perrin et al., 2013).



Statistically, 51% and 69% of caregivers reported anxiety and depression, respectively, as well as significantly impaired quality-of-life compared to normal reference populations. (Norup et al., 2012). For caregivers, there is little refuge to help combat the negative life changes.

While there are websites and blogs as support there are little professional facilities. Support groups have been shown to be a good tool to help people overcome adverse times in their lives by allowing them to regain confidence and happiness (Farris-Kurtz, 1997). A support group allows effected people, such as alcoholics, parents with disabled children or cancer patients, to go and talk about their stories and struggles in a safe, confidential environment (Farris-Kurtz, 1997). It is not known why support groups allow for personal growth while in a large group of people, but going to places where there are people who are affected with the same issues helps to overcome the problems in peoples' lives. Studies show support groups are a useful tool to help overcome challenging situations (Farris-Kurtz, 1997). An increasing number of Americans attempt to change their physical behaviors or change their thinking through self-help in combination with professional programs (Davison, Pennebaker & Dickerson, 2000). People that migrate together to form these groups often have powerful effects on each other's mental and physical health (Davison, Pennebaker & Dickerson, 2000). Alcoholics Anonymous (AA) for example is an organization that is wide spread through the country, which has been a support structure for alcoholics trying to regain control in their lives. For alcoholics, a support group such as AA is important for recovery and helps to maximize the potential benefits of treatment (Tonigan et al., 2003). Support groups are also used for parents who have children that are disabled. For parents with children with autism, there are support groups to help them deal with stress and enhance their well-being (Wolf et al., 1989). Cancer patients can also benefit from support groups by reducing psychological distress (Cain et al., 2006). According to Ergh et al., (2003) social support appears to buffer the detrimental effects of certain injury-related characteristics on caregiver well-being. Social support has a powerful beneficial influence on combatting the effects of caring for someone with TBI (Ergh et al., 2003).

At this time there is little offered to give support for TBI caregivers and either keep their well-being high or enhance negative well-being. The internet has websites and places to blog for

caregivers and these sites can be a place to gain information and release feelings but there is no intimate connection with anyone. There is a gap that does not allow for the caregivers to get a break in the action. This study proposes that attending support groups will give caregivers a safe place to talk about their problems, stressors and challenges, as well as give advice to others. Talking with other caregivers and learning about their experiences will advance coping strategies and result in higher well-being.

PROPOSED METHOD

Participants

Following the methodology used by Kreutzer, Gervasio and Camplair (2013), I will recruit 100 families of adult outpatients suffering from TBI. Family can be defined as people living together who care for each other. Traditional families, couples, legal guardians, step-families, and families who use adoption are all included. The TBI can range from mild to severe. The caregiver of the patient must be a family member who is living with the patient. The TBI patients will be taken from Albany Medical Center who have had a stay of at least one week and up to three months. Participants will be either male or female and range in age from 16-70.

Measures

Caregivers will be given the Brief Symptom Inventory (BSI), the Family Assessment Device (FAD) and the Satisfaction with Life Scale (SWLS) as measures. The BSI, a 53 item self-report questionnaire, will give information about many subscales of psychological disorders; the scales to be analyzed include depression, anxiety, hostility and somatization (Derogatis, & Melisaratos, 1983). The FAD, a 60 item self-report measure, will measure the caregivers' perception of family functioning. The measure includes subscales such as problem solving, communication, roles and involvement (Epstein, Baldwin, & Bishop, 1983). The SWLS measured global cognitive judgment of life satisfaction using only five items (Diener, Emmons, Larsen & Griffin, 1985).

Procedure

Participants will be split into two groups by random assignment. The caregivers in the first group will be sent to a support group during the first and

second months after patient release, the second group will be “wait listed” and sent to the support group only the second month of being released. Both groups will be given the measures mentioned above three times. First, they measures will be given the week of the patient being released. This be used as a baseline. Then, at the end of the first month of the patient’s release. This will be used to compare how attending a support group affects the caregiver as opposed to not attending a support group. Lastly, at end of the second month of release from the hospital to look at long term effects of the support group compared to shorter term.

The support groups will be organized by the author in a building close to the hospital, where patients initially received treatment. The sessions will be one hour long and available every evening. The leader of the meetings will be a long time caregiver who has experience with coping skills and overcoming the struggles of being a caregiver. The style of the support group will be conversation based. The caregivers will share their experiences and coping strategies to help one another. Due to the need of caregivers at home, the caregiver will have the option to have another caregiver provided for them for the time they are attending the support group. The caregiver will be asked to attend the support groups two times per week.

In summary this experimental study will be looking at how being in a support group affects a caregiver’s well-being relative to not being in a support group. Caregivers in both groups will have their psychological status measured by scores on the BSI, FAD and SWLS and will be compared between group one and two. The participants in this study will be given monetary compensation of 300 dollars and the study will last for about 3 months.

CONCLUDING REMARKS

Significance

Caregiving is a very important role in society today. The TBI rate in America is very high which also means the need for caregivers is very high. This study will help further the research that allows for caregivers to have greater well-being which could result in greater well-being for the patients as well. It will also allow for caregiver to be able to give care for a longer period of time and not become easily worn out. This study will help find out what caregivers need to increase their well-being.

Limitations

The sample of participants for this study is caregivers from only one hospital, making this study less generalizable. Since this study does not include caregivers other than family members it cannot be applied to other types of caregivers. This study will only have 100 participants, also lessening its generalizability. Lastly, the measures used in this study are all self-report measures which decreases the reliability of the study. In the future it is recommended that this be done in multiple cities and suburbs. Also including more types of caregivers to see if support groups are beneficial to a wider spectrum of people.

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