Coping with Caring: Identifying Negative Effects of Caregiving and needed Actions of Self-Care, Support and Supervision

Abstract

Previous research has indicated that providing care to trauma survivors has both positive and negative effects on caregivers. However, negative side effects are more persistent, especially in caregivers who do not have adequate coping skills and methods of self-care, training and supervision, and a positive support system. Negative effects that caregiving may have include: experiencing symptoms of vicarious trauma (VT), compassion fatigue (CF), secondary traumatic stress (STS), or burn out. In contrast, positive effects may include experiencing CF, posttraumatic growth (PTG), or vicarious resilience (VR). This article explores research conducted with various caregivers including clinical caregivers, mental health providers, familial and nonfamilial caregivers, interpreters, nurses, and informal caregivers, to understand the totality of the effect of caregiving and self-care, supervision, and support.

Discussion

Previous research studies have indicated both positive and negative effects among caregivers who provide care to survivors of trauma [1-5]. Caregiver of trauma survivors is defined as anyone providing care to a survivor of trauma in any capacity. This may include mental health or medical professionals, social workers, and significant others to include spouse or life partner, parents, grandparents, foster parents, and other relatives, as well as nannies, in-home aid, and other nonfamilial parties. Although both positive and negative effects may occur, research has indicated that positive effects of caregiving only occur if the caregiver has been equipped with adequate stress release or coping skills, training, and a positive support system [4]. If caregivers are not equipped with the proper support, providing care to trauma survivors can take a detrimental toll on their overall quality of life (QoL). When determining what type of coping skills, training, and support systems are needed among global caregivers it is important to understand the social constructs that contribute to an individual’s QoL in a global context, rather than assuming that all cultures retain the same values [6,7]. Thus, in determining what coping skills can be implemented to reduce the negative effects of caregiving, literature from various international researchers, covering various types of trauma care providers will be explored. Providing care to survivors of trauma can take a toll on the physical and emotional state of formal and informal caregivers, and in many cases, it can lead to psychological distress [2-11]. The philosophy that prolonged exposure to traumatic narratives can lead to psychological strain in some individuals has been around since the 1970s [12,13]. Williams et al. [14] suggested that the intensity of the trauma narratives and the length of time caregivers are exposed to these traumatic narratives affect the extent of the effects on caregivers. Research conducted by Ullman [11] concurs with Williams et al. [14]. Ullman [11] states distress is very common among caregivers of trauma survivors; more so if the caregiver is of close relation or share similarities with the victim. Cohen & Collens [1] found that caregivers reported an array of emotional responses when exposed to traumatic narratives including sadness, anger, fear, frustration, helplessness, powerlessness, despair, and shock [14]. Cohen & Collens [1] further reported that the effect of trauma stretches beyond simply an emotional affect. In fact, some caregivers also reported experiencing somatic responses, including numbness, nausea, tiredness, or craving sweets, and they also engaged in existential meaning-making processes, questioning themselves, their lives, and their identities [1-16]. Caregivers have previously reported feeling overwhelmed and detached from the survivors, and having difficulty performing their duties [1]. Studies conducted with mental health professionals, interpreters, child welfare workers, and informal caregivers have indicated that up to 50% of advocates and caregivers reported symptoms of anger, fear, helplessness, and lack of control [2-17]. Further, Catanese [8] suggested because caregivers connect emotionally with survivors of trauma, symptoms of Vicarious Trauma (VT), Secondary Traumatic Stress (STS), Compassion Fatigue, and burnout will ultimately occur.

Despite the differences in terminology utilized throughout literature, research continuously reflects that caregivers are continuously at risk for developing equal symptoms and sometimes greater distress then the actual victims of the trauma [9]. Although these symptoms of distress do not prevent the caregiver from providing support to the survivors, it may hinder the caregivers ability to provide adequate treatment over time and hinder the development of successful personal and professional relationships [11-14]. Thus the need for adequate coping mechanism is imperative to the overall adjustment of the caregiver. Ullman [11] stated that non-clinical caregivers may...
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need additional information and emotional support in order to effectively provide care for the survivor and respond to the ongoing results of his or her trauma. This additional support will assist in the caregiver’s ability to take care of the victim and deal with his or her own reactions to the experiences of the survivor. According to Ilesanmi & Ebioyihe [18], Ullman [11], West [4] and Williams et al. [14] assumptions about safety and the goodness of self and the world may be threatened or altered when caregivers are exposed to narratives and the ongoing physical and psychological effects of trauma survivors. This may result in feelings of distress or symptoms of vicarious trauma (VT), secondary traumatic stress (STS), compassion fatigue (CF), or burnout [11-18]. Clinical caregivers are particularly vulnerable to CF as a result of their empathic engagement with trauma survivors and exposure to their traumatic narratives [19]. Therefore, it is essential that caregivers obtain the proper training, supervision, and support from work, family, and the community [20]. Incorporating training, supervision and support will assist the caregivers in becoming aware of their own vulnerabilities, attending to their self-care needs, and establishing a personal and professional support system [20]. According to Pearman & Saalvite [21], VT affects the cognitive schemas, personal identity and worldview of caregivers exposed to trauma, causing them to shift on a continuum from natural to dysfunctional, eventually leading to their cognitive schemas, personal identity, and worldview becoming uncontrollable [14-18]. This shift in cognitive schemas may occur in five different areas, including: individuals’ beliefs about their personal safety, their self-esteem and feelings of safety regarding themselves and others, their ability to control self, trusting themselves and others, and intimate relationships with others [14,15]. In a study conducted by Williams et al. [14], caregivers who reported a history of childhood trauma indicated higher scores in areas of cognitive distortions which potentially may result in a tremendous negative effect on caregivers’ relationships at work, home, and in the community, causing them to change the way they view their life and the world in general [14-18]. Further, research suggest that caregivers may experience prolonged feelings of grief, anxiety, depression, hopelessness, hyper-vigilance, irritability, emotional numbness, cynicism, isolation, mood swings, disrupted psychological functioning, loss of energy, paranoia, mistrust, disrupted frame of reference, dissociation or depersonalization, and avoidance of duties or clients [1-23]. Catanese [8] suggested that VT has caused some caregivers to second guess their spirituality, humanity, and sense of self. Harrison & Westwood [16], and Cohen & Collins [1] indicated themes reported by trauma caregivers suggest that having a spiritual connection reduces symptoms of VT because it counters isolation and despair, inspires them to keep going despite difficult challenges of their work, and provides them with the belief that they are a part of something larger, meaningful and good, that they are not alone in their efforts, and that their efforts are not futile. However, if these symptoms remain unaddressed, cynicism and loss of purpose tend to occur [8-18]. In addition, physical symptoms may also occur, including rashes or hives, fatigue, headaches or migraines, feeling unsympathetic, heartburn, general unresponsiveness to others, ulcers, and even more serious symptoms, such as heart attack or stroke [8-11]. Caregivers in a study conducted by Goldblatt et al. [15], reported that trauma work intensified personal and work-related problems and difficulties. Additionally, research conducted by Ben-Porat & Itzhaky [25], and Pistorius et al. [23] indicated that clinical caregivers reported having difficulties in family life, feelings of being less attentive and emotionally available, more protective of children, more distant from friends, and more hyper-vigilant. Similarly, in a qualitative study conducted on Israeli trauma nurses, Goldblatt et al. [15] found that nurses who also reported having similar prolonged distressing feelings had difficulty in separating between work life and home life. Trauma nurses further indicated block the effect of their trauma work from invading their private life, but they were often unsuccessful [15]. Likewise, in a qualitative study conducted on informal Nonfamilial caregivers of childhood sexual abuse survivors, West [4] found that over half of the participants reporting negative effects on their relationships, home lives, work, and the community in general. Eighty percent of the participants reported symptoms of anger, resulting in outbursts including use of profanity, throwing or breaking items, and making violent threats; and 66% of the population indicated experiencing sadness, depression, frustration, helplessness, shock, anxiety, and flashbacks. Yet another qualitative study conducted by Pereira & Rebelo Botelho [22] on 14 informal caregivers in Portugal, four themes that correlate with this information were discovered; including feelings of “losing control over time,” “loneliness,” “failing expectations,” and “taking care of someone else’s life.” The participants in the study reported feeling as if time had been stolen from them, like they had little control over their lives, feelings of abandonment and solitude, and as if they were losing their world and personal lives as a result of their work. As a result, personal, family, and other needs were neglected and participants felt as if their lives were confusing and full of chaos, which led to feelings of anxiety, anger, isolation, guilt, resentment, sadness, worry, and ambivalence [1-25]. According to Catanese [8], Goldblatt et al. [15], West [4], and Williams et al. [14], caregivers may also experience symptoms of paranoia or a mistrust of other people, which can significantly affect their relationships at work, home, and in their communities. For example, caregivers may begin to avoid intimacy with their spouse due to feelings of disgust brought upon being exposed to narratives of sexual abuse; or they could become overprotective of their children. West [4] reported caregivers having high rates or divorce, displaced relationships with biological children and extended family members, and severed relationships with community relationships and neighbors as a result of caregiving. Some researchers reported that negative effects of trauma work were more persistent if clinical caregivers had a lack of family and professional support, had difficulty with changes and adjustments in roles and responsibilities, or financial concerns [1-24]. Family and peer support, along with adequate supervision and financial stability, are crucial to reducing stressors and improving QoL [1-26]. Bride et al. [27] indicated that conducting trauma work has a clear effect on the caregivers. His research indicated that 70.2% of participants had experienced at least one symptom of STS within the week prior to his conducting his study. Fifty-five percent met the criteria for at least one of the core symptom clusters of STS, and 15.2% met the core criteria for a diagnosis of PTSD [27]. A study conducted by Shah et al. [28] also indicated that 100% (N = 76) of humanitarian aid workers interviewed in their study reported CF as a negative consequence of their work as well; and
in a study conducted by Adams et al. [29], indicated that increased exposure to trauma survivors among 236 social workers in New York City increased the likelihood of contracting symptoms of CF. These numerous research studies insist that despite the role of the caregiver, proving care for vulnerable populations, such as trauma survivors, have an intense negative impact on the physical and mental health of caregivers. Although positive aspects were also reported, they were only a result of proper self-care, adequate education, training, supervision, and a positive support system of friends, family, and co-workers.

Cohen & Collens [1] further states that clinical caregivers reported positive and negative effects on their behaviors, beliefs and attitude about the world, when discussing changes to schemas post-caring. They also reported both positive and negative effects on their personal values and perceptions of self [1]. Clinical caregivers also reported as a result of their trauma work, they experienced personal growth, feelings of self-efficacy, and empowerment [11]. However, these positive responses were only reported by caregivers who had positive support systems, training, or supervision [4-17]. Further studies have revealed that caregivers who have a strong spiritual foundation and a relationship with God, self, and environment, and an ability to find meaning and purpose in life also have a more positive QoL [1-16]. Melvin [30] and Ullman [11] suggest caregivers are at risk for experiencing CF through exposure to trauma and not having adequate coping skills to regulate their exposure. Hence, Cohen & Collen [1] indicated that adequate self-care behaviors represented one of the major ways for caregivers to regulate their emotions and experiences and Williams et al. [14] noted that self-care and wellness activities reduced the onset of VT. Yet, West [4] found that caregiver in South Africa were not equipped with the skills and knowledge of proper self-care. In fact, eleven of the fifteen caregivers interviewed stated that they do not utilize coping skills and four participants stated that they cannot afford it [4]. Hernández et al. [20] further suggested that the negative effect of trauma work should be addressed in training and supervision in order to help caregivers become “aware of their own vulnerabilities, attend to self-care issues, and to establish a personal and organizational support system” (2010, p. 68).

The ability to address negative consequences of providing care to trauma survivors relies on caregivers being equipped with adequate methods of self-care, training and supervision, and having positive systems of support system within their family, community, and workplace. Unfortunately, not all caregivers have access to these resources. Many caregivers cannot afford the cost associated with obtaining training or supervision; while others do not have the resources to identify coping skills and methods of self-care. Thus, additional information and emotional support is needed in order to teach caregivers how to recognize symptoms of VT, CF, STS, and burnout. Furthermore, education and support will assist the caregivers with how to effectively provide care for trauma survivors and respond to the ongoing results of their trauma. It is essential that caregivers obtain the proper training, supervision, and support from work, family, and the community. It may be beneficial to identify ways educational courses or community-based training can be offered to caregivers free or low cost. These trainings may include how to effectively communicate coworkers, family and community members regarding the impacts of providing care in order to strengthen relationships, gain support, and even share parenting tips or ideas for self-care. It may also be beneficial to offer monthly meetings, support teams, or support groups made up of other community-based caregivers, to whom the caregivers feel they can relate and talk as well as community-based training on how to relieve stressors related to caregiving, as well as methods of self-care that are free or inexpensive, such as taking a walk, relaxing in a bath, listening to music, or meditation.

Conflict of Interest

None.

References


