

**Special Article**

## **Family Caregivers for Older Adults with a Tracheostomy during Hospitalization: Psychological Impacts and Support**

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### **Abstract**

The proportion of older adults with a tracheostomy is dramatically increasing in hospitals. Although care for older adults would be supervised by physicians and nurses, they also need to be supported by their family members during hospitalization. Family caregivers often provide care for their older adults. Consequently, this has an impact on the caregiver such as inadequate sleep, fatigue, reduction of social interaction, and insufficient income. Meanwhile, psychological impacts also occur as a result of the caregiving burden. These are mainly negative impacts expressed in terms of stress, depression, and a feeling of abandonment by other family members. Nonetheless, caregiving can also be viewed as a positive experience as well such as a sense of giving back to older family members who have cared for them, improved ability involving tracheostomy care, building a good relationship, and enhancing capability of expressing empathy. However, family caregivers who have negative psychological impacts of caregiving should be supported by healthcare professionals regarding tracheostomy care. This could reduce stress and prevent depression along with enhancing the quality of life among family caregivers of older adults with a tracheostomy.

**Keywords:** caregivers, family, older adults, psychological impact, support, tracheostomy

### **Introduction**

The number of tracheotomies performed among older adults is dramatically increasing in the hospitals. A study of Liu et al. (2017a) indicated that 76.2% of patients who underwent tracheostomy in respiratory care wards were mainly older adults with an average age being 63-74 years. This is attributed to indications of tracheostomies such as prolonged mechanical ventilation, respiratory distress, and airway protection (Bergeron and Audet, 2016, Vargas et al., 2015). Furthermore, a tracheostomy tube can impact the ability to communicate. This makes older adults feel frustrated due to inability to communicate and feeling of helplessness (Sherlock et al., 2009). This affects self-esteem and quality of life of older adults with a tracheostomy (Freeman-Sanderson et al., 2018).

In addition, older adults need care while having a tracheostomy tube, assistance in performing daily activities, and observation of the symptoms related to the tracheostomy tube as well. Therefore, family caregivers have to care and extremely support them together with physicians, nurses, and another healthcare professional during hospitalization. Family caregivers are often involved in care for older adults with a tracheostomy in hospital. They are mainly involved in tasks including communicating with doctors and nurses, cleaning and dressing the patient, feeding the patient, procuring medication and other supplies, administering oral medications, changing position, back care, intra-facility transportation of the patients for investigations, collecting reports, and providing physiotherapy (Bhalla et al., 2014).

However, such tasks can change the roles and responsibility of family caregivers. Changed responsibilities are evident in daily routines, emotions, and social relations of those who assume caregiving roles (Van Pelt et al., 2007). This is attributed to the significantly higher physical burden levels. This is evident in form of insufficient sleep, physical exhaustion, and back pain (Liu et al., 2017b). In addition, family caregivers have an elevated and persistent risk of depression, disruption in lifestyle, and loss of employment (Van Pelt et al., 2007).

Noteworthy, previous research has indicated that negative psychological impacts of caregiving are commonly experienced by family caregivers during a patient's admission (Van Beusekom et al., 2016, Choi et al., 2016). Depression, anxiety, and post-traumatic stress disorder are the most prevalent (Choi et al., 2016). Psychological impacts have been identified among family caregivers of older adults with more severe diseases. Anxiety and depression are the commonest psychological disorders reported (Fumis et al., 2015). Meanwhile, family caregiver strain has also been reported as a psychological impact of tracheostomy on the caregivers of older adults who have undergone tracheostomies (Rossi Ferrario et al., 2001).

On the other hand, family caregivers have also reported that providing care for their loved one is prideful as they became closer to the patient during the period that they were providing care. Positive values of caregiving are higher among family caregivers when they are motivated by a strong personal bond with their family members. In so doing, they often have a higher preference for providing care (Broese van Groenou et al., 2013).

Conclusively, family caregivers of older adults with a tracheostomy are faced with psychological implications of caregiving. This is mainly attributed to the caregiving roles and responsibilities assumed. Indeed, the psychological consequences of caregiving assert potential harm to family caregivers. Meanwhile, most studies have focused on the negative impact aspect of caregiving. This article describes both positive and negative psychological aspects of caregiving among family caregivers of older adults with a tracheostomy. It further provides evidence on how to support family caregivers when faced with psychological consequences of caregiving.

## **Psychological impacts of caregiving**

Family caregivers have various experiences while providing care for their older family members. Nonetheless, they experience both positive and negative aspects of caregiving.

### **Positive aspects**

The positive aspects of caregiving include a family caregiver's perception are influenced by coping, a good relationship between healthcare providers and family members, and the feeling to be appreciated as a family caregiver (Balducci et al., 2008, Vellone et al., 2011). However, many studies mainly focused on the negative impacts of older adult caregiving, as expressed in terms of stress and burden, but caregiving can also be viewed as a positive experience as well (Broese van Groenou et al., 2013). For instance, the following positive aspects have been attributed to family caregiving:

- 1) A sense of giving back to older family members who have cared for them, children tend to support and assist their older parents during times of illness and disability. Indeed, the National Opinion Research Center (2014) reported that family caregivers found positive experiences from caregiving, including a sense of giving back to someone who has cared for them as well as the satisfaction that accompanies knowing that their loved one is getting excellent care. One study by Meisner and Binnington (2017) highlighted that family caregivers felt privileged, lucky, and grateful for the opportunity to provide care to their family members.

- 2) Caregiving is also associated with improved abilities and skills gained from experiences of providing care for their family members. That is, family caregivers improve their abilities to assist and support an older adult with a tracheostomy in the hospital and after discharge to home (Meisner and Binnington, 2017).

- 3) Furthermore, caregiving fosters building a good relationship between family members. This follows the opportunity to provide care to their older family members with a tracheostomy. Consequently, a good relationship develops between the family caregivers with their care recipients through caregiving (Meisner and Binnington, 2017, Balducci et al., 2008).

4) Caregiving also allows for expression of empathy, empathy is an effective response that encompasses acknowledgment of suffering and attempts to understand an individual's suffering through emotional resonance (Sinclair et al., 2017). Family caregivers' responsibilities in providing care for older adults with a tracheostomy can enhance the capabilities of expressing empathy with care recipients and other caregivers (Meisner and Binnington, 2017).

### **Negative Aspects**

Family caregivers always report that they experience negative psychological consequences of providing care to older adults with a tracheostomy. Stress, depression, and abandonment are described and discussed in this article.

1) Family caregiver stress: family caregivers are responsible for providing care for older people with a tracheostomy. They often feel stressed to play multiple roles at the same time (Scott and Arslanian-Engoren, 2002). Indeed, the study of McPeake et al. (2016) reported that poor quality of life in the patient was significantly associated with higher caregiver stress.

2) A certain study showed that up to 56% of family caregivers experienced depression (McPeake et al., 2016). Specifically, it has been highlighted family caregivers for older people with a tracheostomy feel depressed due to lack of independence in their lives (Scott and Arslanian-Engoren, 2002, Van Pelt et al., 2007). Similarly, McAdam et al. (2012) indicated that family members of patients in intensive care units are at an increased risk for psychological symptoms such as depression scores.

3) Furthermore, a feeling of abandonment is another negative psychological impact that is associated with caring for older adults with a tracheostomy, especially among family caregivers who assume responsibilities for providing care to their older adults with a tracheostomy in the hospital for a long time (Scott and Arslanian-Engoren, 2002).

### **How to support family caregivers with psychological consequences of caregiving**

Family caregivers are an integral part of the care process for older adults with a tracheostomy. A better understanding of both the positive and negative aspects of caregiving may provide

additional areas of intervention with the goal to improve outcomes and quality care for both older adults and their family caregivers (Kross, 2015). To assist and support family caregivers with the psychological impacts of caregiving, nurses and healthcare professionals can play certain roles to assist and support family caregivers. These are highlighted below:

1) The family caregiver should be initially assessed for stress. Such an assessment could include the following: (a) Healthcare professional should assess all the life changes, hardships, situational demands, and strains affecting the family. (b) Evaluating family stressors: this could include the origin of the stressor, the impact of a stressor on all family members, the degree of severity of stressor, length of time needed for adjustment, and ability to cope and solve the stressor. (c) Family resources: these are means through which the family to meets the demands of stressful events and for resisting crisis. They include family members' personal resources, family system characteristics, and social support. (d) Typology: this refers to the set of basic family patterns of behavior that explain how the family normally functions. (e) Family's perception of their situation or their definition of the stressor. (f) Family coping should be evaluated: actions are taken to reduce the number and intensity of demands, acquisition of additional resources, managing the tension associated with ongoing stressors, strategies for making the situation more constructive, manageable, and acceptable. (g) Family adaptation: a well-functioning adaptive family is a flexible one that is able to shift roles, levels of responsibilities, and patterns of interaction as it passes through various levels of stress and change (Robinson, 1997). To promote family health or the health of family caregivers, healthcare professional should know and assess their family system, family stress, family problem coping, and family adaptation before assisting family caregivers and their families (Tomlinson, 1986). Instruments that can be used to assess family are shown in table 1.

Screening for depression: the healthcare profession should screen a family caregiver to prevent psychological issues such as depression among family caregivers for older adults with a tracheostomy. The Hospital Depression Scale (HDS) has been regularly used as an instrument for depression screening (Fumis et al., 2015,

Vellone et al., 2011). In addition, we can also observe family caregivers' facial expressions as it might be related to depression. Such facial expression include: happy, surprise, disgust, sadness, fear, and angry (Wu et al., 2012).

2) The strategies to manage stress among family caregivers who are experiencing psychological consequences of caregiving comprise of:

2.1) Providing concrete care information along with emotional support can help family caregivers of older adults to better manage their caregiving roles (Reinhard et al., 2008). Therefore, the use of effective communication; listen to the family's concerns, feelings, and questions is needed at all times. That way, healthcare professionals have to answer all questions or assist the family in finding the answers (Kaakinen et al., 2014).

2.2) Support family coping mechanisms: healthcare professionals should recognize the uniqueness of each family to grasp and offer assistance based on family background (Kaakinen et al., 2014). At the same time, family caregivers should engage in social support groups. These could help them to learn about and obtain positive coping strategies used by other family caregivers who have similar psychological experiences regarding caregiving (Azman et al., 2017). Therefore, healthcare professionals should play an important role in clarifying information and sharing resources regarding support groups with family caregivers (Kaakinen et al., 2014).

2.3) Assist family in decision making by providing information about options. Healthcare professionals alongside family caregivers need to be involved in the decision about advance tracheostomy care planning while focusing on specific life-sustaining treatments (Hirschman et al., 2010). In addition, healthcare professionals should permit the family to make decisions about patient care at an appropriate time (Kaakinen et al., 2014).

2.4) Provide adequate time to visit privately: it has been indicated that if family caregivers are unable to look after their older adults more often due to limited time for visiting patients during hospitalization, they might be worried and stressed about older adults' illness (Scott and Arslanian-Engoren, 2002). Therefore, nurses and other healthcare professionals may provide family caregivers adequate time to privately visit

older adults with a tracheostomy provided it does not interrupt the treatment plan (Kaakinen et al., 2014).

2.5) Healthcare professionals such as nurses, physicians, and physical therapists should facilitate family conferences to allow open sharing of family feelings and foster positive nurse-family relationships through all phases of caregiving (Kaakinen et al., 2014).

2.6) Techniques to help reduce stress in the short- and long-term consisted of taking a break from the stressor, exercise, laughs or smiles. These can help in relieving some stress, lobby for social support such as a call to a friend, meditation, and mindful prayers. These help the mind and body to relax (American Psychological Association, 2018).

3) Some ways that can be used to battle depression are as follows (Agingcare, 2018, Family Caregiver Alliance, 2018);

3.1) Positive thinking can replace the negative thinking that is a part of depression.

3.2) Participate in activities that may make family caregivers feel better, such as going to see a movie, gardening, exercise, attending church or temple, going to join the social event, talking with friends, and support groups have demonstrated positive results with respect to quality of life, depression, as well as strain (Dam et al., 2016).

3.3) Exercises have also been reported to reduce the effects of depression. Walking three times a week for 30 to 45 minutes has been linked to reducing symptoms of depression.

3.4) Implementing mind-body techniques into a family caregiver routines may help alleviate depression. Even 5 to 10 minutes of any of these techniques may be beneficial such as meditation, prayer, taking deep breath, massage, and listening to music.

4) Feeling of abandonment by other family members also has a tremendous influence on the caregiving process among family members. Thus, healthcare professionals may intervene through contacting other family members. This is based on the fact that visitations by other family members, relatives, and friends give courage to family caregivers hence reducing the feeling of abandonment. Meanwhile, it is important to develop ways to manage abandonment feelings such as going for a walk, sports, reading

interesting books, watching a television show, and spending time with a friend or loved one (Szmerling, 2013). The systematic review of Dam et al. (2016) described that family support and social network interventions for caregivers can prevent a feeling of abandonment as well as caregiver's depression or anxiety symptoms.

Furthermore, there are other programs that can assist healthcare professionals to support family caregivers experiencing psychological impacts of caregiving, for instance; the psychoeducational intervention for caregivers of the older adults in the hospital before going back home that was developed by Zabalegui et al. (2016). This program was designed to provide information for improving the caregiver's knowledge, training for developing practical skills of caring for older persons, and emotional support. The program consisted of weekly 90 minutes sessions that took place 8 weeks. The aims of each week comprised of program introduction along with describing the age-related changes, caregivers' self-care, nutrition for the elderly, general hygiene recommendations and problems related to elimination, mobility for dependent elderly, developing of effective communication techniques, how to deal with difficult situations, and how to manage with the family's concerns.

The study showed that caregivers of older people had less burden and emotional distress following such an intervention. Additionally, psychotherapeutic counseling can be helpful for family caregivers to cope with stressful emotions and problematic situations (Wilz and Pfeiffer, 2017).

### Conclusion

Providing care for older adults with a tracheostomy affects psychological aspects of family caregivers. The psychological impacts of caregiving can either be negative or positive. Therefore, it is essential that family caregivers are supported by physicians, nurses, and psychologist. The support could consist of screening one's symptoms regarding stress and depression, information support as a family concern, stress and depression management interventions such as meditation, prayer, massage, listening to music, and group support as well as consulting a psychiatrist or psychiatric nurse when need be. Meanwhile, strategies for providing such support should be developed, and healthcare professionals should approach family caregivers with awareness and respect for their problems by assessing their concerns and guiding them through the unfamiliar experiences of caregiving.

**Table 1.** The instruments for family assessment

The purpose of assessment	Instruments
To provide insight into the life events of the family and family strain.	- The Family Inventory of Life Events and Changes (FILE) - Caregiver Strain Index (CSI)
To identify family strengths and capabilities.	The Family Inventory of Resources for Management (FIRM) American Family Strength Inventory (AFSI) The Australian Family Strengths Nursing Assessment (AFSNA)
To assess for the family's established patterns of functioning and family type.	- The Family Hardiness Index (FHI). - The Family Adaptation and Cohesion Evaluation Scales (FACES).
To assess the family's problem solving and coping.	- The Family Problem-Solving Communication Index (FPSC) - The Coping Health Inventory for Parents (CHIP) - The Family Crisis-Oriented Coping Evaluation Scales (FCOCES)

To assess the degree to which the family has adapted to the crisis situation.	<ul style="list-style-type: none"> <li>- The Family's Sense of Coherence Index (FSOC)</li> <li>- Family Satisfaction (FS)</li> <li>- The Family Index of Resiliency and Adaptation (FIRA-G)</li> </ul>
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