



4-12-2021

## Exploring the Lived Experience of Adolescent Caregivers

Abbigale Laurentius

Western Michigan University, [abbilaurentius@yahoo.com](mailto:abbilaurentius@yahoo.com)

Follow this and additional works at: [https://scholarworks.wmich.edu/honors\\_theses](https://scholarworks.wmich.edu/honors_theses)



Part of the Critical Care Nursing Commons, Family Practice Nursing Commons, Geriatric Nursing Commons, Other Nursing Commons, and the Palliative Nursing Commons

---

### Recommended Citation

Laurentius, Abbigale, "Exploring the Lived Experience of Adolescent Caregivers" (2021). *Honors Theses*. 3376.

[https://scholarworks.wmich.edu/honors\\_theses/3376](https://scholarworks.wmich.edu/honors_theses/3376)

This Honors Thesis-Open Access is brought to you for free and open access by the Lee Honors College at ScholarWorks at WMU. It has been accepted for inclusion in Honors Theses by an authorized administrator of ScholarWorks at WMU. For more information, please contact [wmu-scholarworks@wmich.edu](mailto:wmu-scholarworks@wmich.edu).



Exploring the Lived Experience of Adolescent Caregivers

Abbigale R. Laurentius

Western Michigan University

Bronson School of Nursing

### Abstract

In today's society, the population is aging, and any member of the family could find themselves in the role as an informal caregiver. Adolescents between the ages of 12 and 18 years old may have these caregiving responsibilities, and it is imperative that healthcare professionals recognize and support this change of roles. A literature review revealed a general lack of research from within the last five years regarding adolescent caregivers. Those studies that were analyzed in the review presented themes of depression, anxiety, lack of education, and insufficient social supports for the adolescent. An unfolding case study was then designed to fill the gap within recent literature, to address these themes, and to provide education to healthcare professionals on the topic.

*Keywords:* adolescent, youth, caregiving, young caregivers' experience, and young carers

### Exploring the Lived Experience of Adolescent Caregivers

As the average life span of an American citizen continues to increase due to medical and technological advancements, more and more individuals are finding themselves in the informal caregiver role for aging adults. Numerous studies have documented that there is a link between caring for aging adults and the potential for burden (Shim, Kang, Kim, & Kim, 2016; Mosley, Moodie, & Dissanayaka, 2017). An informal caregiver faces increased stress in their dynamic role of being involved in the health and quality of life aspects of the individual receiving care (Mello et al., 2017). Despite the vast knowledge on caregiving, there is one population of individuals who take on the caregiving role and may have a completely different experience. Adolescents between the ages of 12 to 18 years old are sometimes referred to as “young carers” when they take on new responsibilities and caregiving activities, much like the adult of the family, during vulnerable situations (Charles, Stainton, & Marshall, 2009). These adolescents have the potential to endure caregiver burden that is unlike the trials of a caregiver over the age of 19 years old. The purpose of this paper is to conduct a literature review regarding the adolescent caregiving experience and to provide rationale for the development of an unfolding case study to raise awareness of this phenomenon in nursing students.

#### **Review of the Literature**

Research databases utilized for gathering this literature include Western Michigan University’s online library, ResearchGate, PubMed, and Elsevier. Keywords like adolescent, caregiving, youth, young caregivers’ experiences, and young carers guided this literature search. Different search methods, such as the ancestry approach, were employed to track down additional relevant research that was not identified through the key words. The search was limited to adolescents aged 12 to 18 years old, but the diagnosis of the individual receiving care

was not a limiting search factor. These techniques resulted in a majority of qualitative studies based on the interviews of adolescents and a handful of quantitative studies. While gathering evidence, it became clear that there was a lack of research between 2016 and the present time that is specific to adolescent caregiving. As previously stated, a substantial amount of research is dedicated to gaining insight to the adult caregiver that is 19 years or older, and research of adolescent caregivers is disproportionately low. Although it was tedious to find applicable content, those studies that pertain to the adolescent caregiving experience are analyzed in the proceeding portion of this literature review.

### **Effects on the Adolescent Caregiver**

To gain insight on the adolescent caregiving experience, recent research was gathered on acute and long-term effects of the journey on the adolescent carer. Literature from the past five years on this topic is scant creating a gap that needs to be explored. Although some of the studies in this review of the literature are from outside the five-year time frame, they are still included to establish a well-rounded picture of the experience.

A study designed by Rainville, Dumont, Simard, and Savard (2012) and revealed that adolescents between the ages of 15- and 18-years old living with a parent suffering from cancer experienced more psychological distress compared to the same age group of the general population. Another study by Buchwald, Demar, and Schantz-Laursen (2011) details a child's perspective of death in his or her own words. The population under study ranged from 11 to 17 years old. The results assert that the visible death of a parent creates many insecurities, anxieties, and worries in the adolescent child's life. The study also highlights the difference between the child experiencing a death close to them and the idea of knowing everyone will die one day, further perpetuating the child's fears and insecurities. A similar study by Grenklo et al. (2013)

also compared adolescents who experienced the death of a parent with the general population of the same age, but in the context of self-harm. The results display that bereaved adolescents were twice as likely to participate in self-harm activities when compared to nonbereaved youth (Grenklo et al., 2013). Although all of these studies do not directly pertain to the caregiving experience, they are important to include to understand that simply the exposure to a seriously ill person, such as one that would require constant caregiving needs, can impact the life and development of adolescents.

The most recent study regarding the effects of the caregiving experience was developed by Muhammad et al. (2018) with the purpose of determining the frequency of anxiety and depression symptoms in adolescent caregivers aged 11 to 21 years old. The researchers also examined the correlation between the symptoms and role, gender, and socio-economic status. Through a series of questionnaires and statistical analyses, Muhammad et al. (2018) determined that there is a higher percentage of anxiety symptoms in this group of adolescents. Specifically, 95% of these adolescent caregivers had positive scores for anxiety symptoms, while 9.4% suffered with depressive symptoms. Muhammad et al. (2018) also found that females were more likely than males to experience these symptoms and that there is a lower frequency of anxiety and depression symptoms in adolescents from a higher socioeconomic status. When analyzing the correlation to age, it was found that the frequency of anxiety or depression symptoms declined as the age of the caregiver increased. This contradicts the results of Rainville et al. (2012) and deserves further study. The results of this study certainly contribute to the greater understanding of adolescent caregivers, but the generalization of them should be done cautiously because of the limited sampling methods from one hospital department in Lahore, Pakistan (Muhammad et al., 2018). There is a need for continued for study in this area using a larger and

more diverse sample to further contribute to the understanding of the adolescent caregiving experience and to identify more sources of support.

### **Intervening for the Adolescent Caregiver**

The next area of the literature review is dedicated to studies that assess the needs of adolescent caregiving and the development appropriate interventions to foster support for the adolescents and decrease stress. This appears to be a much more widely studied area within the last five years because there is increased accessibility of research. The study by Mayo et al. (2016) addresses this area with the purpose of identifying the types of interactions that occur between the hospice health care team and adolescents living with a dying parent. The sample included 18 daughters and 12 sons from 25 different families within the one hospice program. A series of interviews were conducted with the adolescents followed by content analysis and coding of the participant's narrative. Mayo et al. (2016) divided the interactions into four types: no interactions, in-passing interactions, engaged interactions, and formal interactions. The results of content analysis reveal that a majority of the interactions between the adolescent and hospice team fell into the categories of no interaction or in passing interaction. After identifying this lack of interaction, Mayo et al. (2016) expand on the need and opportunities for improvement. The need for improvement stems from the results that those adolescents with engaged and active interactions with the hospice team perceived more social support during the time of caregiving. Mayo et al. (2016) suggest that the hospice team find a common ground with the adolescent, schedule meetings or care tasks when the adolescent is more likely to be home if it is appropriate for the patient or provide other means of communication such as video calling or texting. All of these interventions can establish nurse relationships with the adolescents. This provides additional social support for the adolescent, improving the caregiving experience.

The adolescent's need for social support during the time of caregiving was identified in two recent studies. Newman, Brookey-Bassett, Wang, and Wang (2019) set out to determine the needs and experiences of adolescent caregivers through a set of retrospective interviews. The analysis of these interviews revealed themes of the need for support and education, accessing available resources, perceived impact of the progression of dementia, changes in understanding of dementia, and responding to changes in roles and relationships. The study participants expressed many of the changes they experienced like the various feelings of loss, as well as the positive value that social supports had on coping with these feelings. However, participants detailed the barriers to accessing those supports and resources such as the lack of education (Newman, Brookey-Bassett, Wang, & Wang, 2019). Similarly, Pankenham and Cox (2018) identified social support and benefit finding as interventions for preventing adverse effects of caregiving, like anxiety and depression discussed before, in adolescent carers. Analysis of the quantitative measurements of this study reveal a positive relationship between benefit finding, social supports, and adjustment to the caregiving process. Both of these studies highlight the importance of social supports for adolescent carers. Additionally, they both call for continued research on appropriate interventions to help adolescent caregivers build or find support systems and education on caregiving responsibilities or disease processes because these areas lack research.

Adolescent carers have expressed the need for more education, such as those participants did in the study by Newman et al. (2019), and Kavanaugh, Howard, and Banker-Horner (2018) sought to fill this need. Kavanaugh et al. (2018) directly studied the feasibility of implementing a training program for adolescent caregivers to improve education and to foster supports. The training program designed use a multidisciplinary approach including physical therapy,

occupational therapy, social work, and speech therapy. The study participants went through one day of the training as a trial run for the design with evaluations before and after the training (Kavanaugh, Howard, & Banker-Horner, 2018). The outline for the day included teachings on basic care like transferring and toileting, the safe use of assistive devices, and speech and communications strategies like cueing and feeding. At the end of the day, the results highlighted that it is possible, and almost necessary, to provide this type of training for adolescent caregivers. The group training design also helped the participants to develop relationships with other adolescents in similar situations to them, thus expanding their social support systems. Kavanaugh et al. (2018) also found that the “teach back” method of training was the most effective and beneficial for the adolescents, because it grants them opportunities to watch, practice, and ask questions. The hope of this education was that the adolescent would incorporate these PT, OT, and Speech therapy techniques into their everyday care because the licensed therapist may only visit the home a few times a week. This research is fundamental for the development and implementation of caregiving training for adolescents, and it can serve as encouragement for nurses to involve the adolescent in education and skill training when it is appropriate.

### **Summary of the Findings**

All in all, there is a disproportionate amount of research from within the last five years pertaining to the adolescent caregiving experience. Of the studies gathered, the results reveal themes like stress, anxiety, fear, lack of preparedness and education, and isolation. These themes are displayed through a majority of qualitative research rather than quantitative. One major positive coming out of the literature review is the possibility of successful training programs for these adolescents that also foster a sense of community. After final analysis, there is a great need for more studies to be conducted in this area including a much larger and diverse sample.

### **Case Study Development**

After analyzing the current literature available, the gaps in knowledge regarding the adolescent's caregiving experience became apparent. Many of the research studies called for further study in the area as well as greater education for patients, families, and members of the healthcare team. In order to fill this need, a case study was developed with the purpose of expanding educational resources. The objectives guiding the case study are based on the Quality and Safety Education for Nurses (QSEN) standards to ensure the consistency and accuracy of the teaching. Of the six QSEN competencies, the objectives and directive of this case study targets patient-centered care. The objectives include the following:

1. The student nurse will recognize his or her (the student nurse's) personal attitudes and values about the adolescent caregiving process (Attitudes).
2. The student nurse will articulate that the adolescent has unique needs and perspectives when in the caregiving role (Attitudes, Knowledge).
3. The student nurse will utilize (demonstrate) therapeutic techniques to assess the adolescent's needs according to patient preference (Knowledge, Skills, and Attitudes).

These objectives will be accomplished through the three sections of the developing case study, with each section being dedicated to one objective. The sections will be composed of a multimedia form of storytelling followed by a series of questions using a holistic approach and self-reflection. The use of storytelling is an effective teaching method and is beneficial with many age groups. A publication by Robin (2016) details the varying types of storytelling and explains how it is a useful teaching method that has been employed for many years. The study also encompasses guidelines for using storytelling that were considered during the creation of this developing case study.

The target population for this teaching will be second year nursing students within the University of Western Michigan's Bronson's School of Nursing. This population was chosen because the students will be enrolled in the Nursing care of Children and Families course where they will encounter and care for a variety of adolescents. Although advanced education on the adolescent caregiver's experience is important for many populations, the hope is to present the information now to nursing students, so that they can continue on in their practice to educate the patients and families on the topic over the course of their career. All in all, the goal of this developing case is to begin to fill the gap in the literature and expand awareness of the experiences of adolescent carers.

### **Conclusion**

As times continue to change, the role of the adolescent within the family is changing along with it. It is imperative that healthcare professionals become educated on these changes and work to understand the individual experiences these adolescents face and the unique needs that they have. The purpose of this paper was to review recent literature on adolescent caregivers and identify the gaps in what is currently known or not known. The second portion of the paper details the development of a case study as one part of the solution to that literature gap. Hopefully this literature review and education contributes to the improvement of patient centered care of the adolescent caregiver.

## References

- Buchwald, D., Delmar, C., & Schantz-Laursen, B. (2011). How children handle life when their mother or father is seriously ill and dying. *Scandinavian Journal of Caring Sciences*, 26(2), 228-235. doi:10.1111/j.1471-6712.2011.00922.x
- Charles, G., Stainton, T., & Marshall, S. (2009). Young carers: Mature before their time. *Reclaiming Children and Youth*, 18(2), 37-41.
- Grenklo, T. B., Kreicbergs, U., Hauksdóttir, A., Valdimarsdóttir, U. A., Nyberg, T., Steineck, G., & Fürst, C. J. (2013). Self-injury in teenagers who lost a parent to cancer. *JAMA Pediatrics*, 167(2), 133. doi:10.1001/jamapediatrics.2013.430
- Kavanaugh, M. S., Howard, M., & Banker-Horner, L. (2018). Feasibility of a multidisciplinary caregiving training protocol for young caregivers in families with ALS. *Social work in health care*, 57(1), 1-12.
- Mayo, M. M., Sheehan, D. K., Hansen, D., Stephenson, P., Christ, G. H., Heim, K., . . . Draucker, C. B. (2016). An examination of interactions between hospice health care providers and adolescents with a parent in hospice. *Journal of Hospice & Palliative Nursing*, 18(4), 302-309. doi:10.1097/njh.0000000000000247
- Mello, J. D. A., Macq, J., Van Durme, T., Cès, S., Spruytte, N., Van Audenhove, C., & Declercq, A. (2017). The determinants of informal caregivers' burden in the care of frail older persons: a dynamic and role-related perspective. *Aging & mental health*, 21(8), 838-843.
- Mosley, P. E., Moodie, R., & Dissanayaka, N. (2017). Caregiver Burden in Parkinson Disease: A Critical Review of Recent Literature. *Journal of Geriatric Psychiatry and Neurology*, 30(5), 235-252. doi:10.1177/0891988717720302

- Muhammad, H. M., Muhammad, A. K., Abid, M., Raza, A., Muhammad, N. Q., Ali, A. A., & Ahmed, W. (2018). Frequency and correlates of symptoms of anxiety and depression among young caregivers of cancer patients: A pilot study. *BMC Research Notes*, *11*doi:<http://dx.doi.org.libproxy.library.wmich.edu/10.1186/s13104-018-3740-8>
- Newman, K., Bookey-Bassett, S., Wang, A., & Wang, A. (2019). Carers need care too: Recalling the experience of being a young female carer for a relative living with dementia. *Perspectives*, *40*(3), 6-16.
- Pakenham, K. I., & Cox, S. (2018). Effects of benefit finding, social support and caregiving on youth adjustment in a parental illness context. *Journal of Child and Family Studies*, *27*(8), 2491-2506.
- Rainville, F., Dumont, S., Simard, S., & Savard, M. (2012). Psychological Distress Among Adolescents Living with a Parent with Advanced Cancer. *Journal of Psychosocial Oncology*, *30*(5), 519-534. doi:10.1080/07347332.2012.703765
- Robin, B. R. (2016). The power of digital storytelling to support teaching and learning. *Digital Education Review*, (30), 17-29.
- Shim, S. H., Kang, H. S., Kim, J. H., & Kim, D. K. (2016). Factors Associated with Caregiver Burden in Dementia: 1-Year Follow-Up Study. *Psychiatry Investigation*, *13*(1), 43. doi:10.4306/pi.2016.13.1.43