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Adolescent grief: The nurse's role in promoting healthy coping mechanisms and preventing future hospitalizations

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Adolescent Grief: The Nurse's Role in Promoting Healthy Coping Mechanisms and Preventing
Future Hospitalizations

A Literature Review

An Honors Program Project Presented to
the Faculty of the Undergraduate
College of Health and Behavioral Sciences
James Madison University

by Erica Catherine Reighard

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Accepted by the faculty of the Department of Nursing, James Madison University, in partial fulfillment of the requirements for the Honors Program.

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PUBLIC PRESENTATION

This work is accepted for presentation, in part or in full, at Nursing Departmental Symposium on 5-5-2016.

Dedication

This project is dedicated to my grandpa, Dr. Gary Reighard, whose unwavering love and support motivated me to join the JMU Honors Program after his passing in the spring of 2013. As a college educator he was known as “Dr. R” to many students, but always just “Gramps” to me. I am forever thankful for a grandpa who photocopied every single one of my report cards since kindergarten because he was “so proud.” This is for you, Gramps.



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Acknowledgements

I would like to thank the James Madison University School of Nursing and the Honors Program for giving me the flexibility and support I needed to finish my senior thesis. I never realized how hard it would be to complete a senior honors project as a nursing major, and I am incredibly thankful for my honors advisor, Dr. Erika Metzler-Sawin for her continued support and encouragement. I would also like to thank my committee members, Prof. Arlene Kelley, Dr. Julie Strunk, and Dr. Debbie Gleason for their guidance and support. I am very thankful for everything they have taught me throughout the entire nursing program.

I would like to recognize my parents, Scott and Mindy Reighard, for encouraging me to finish what I started. Above all, I am forever grateful to them for the opportunity to attend my dream school and the subsequent dream job that has followed.

Finally, I would like to thank my boyfriend, Ryan Maglio, for his support throughout the entire nursing program. Thank you for constantly reminding me that I am not actually going to fail and helping me through some of the most stressful times of my life.

Preface

In the spring of 2016, I was enrolled at James Madison University and majoring in nursing. I was focused on trying to maintain excellent grades before applying to the very competitive program the following year. Although I came to JMU knowing not a single person, I had a strong support system at home in Lancaster, Pennsylvania and was truly excelling at JMU both socially and academically. I felt incredibly lucky to be able to build so many new friendships while remaining close with my family and friends in Lancaster.

My grandpa, who I often referred to as “my person,” had a timeshare at the nearby Massanutten Resort and visited me frequently at JMU. He was a former college educator with a doctorate degree and had always expressed a great deal of interest in my academic accomplishments. He was the first person I called when I got into my dream school, and was someone I admired deeply. In February of spring 2013, he and my grandma visited for a long weekend and took me out to eat several times. I spent most of the weekend studying for my anatomy exam and after they left, I called him, just as I always did, to tell him that I got an A on my exam. That day he sat down and wrote me a letter, which said, “Congratulations, Erica! We are so proud it is hard to put into words. Keep up the great work. You can be my nurse anytime. Love you.” I did not get the letter until a week later when I came home for his funeral. Just a few days after that last call my grandpa had a massive stroke and subsequently passed away. He was 78 years old and traveled the world, but he was “my person,” and I was overwhelmed with grief while trying to still maintain my grades so that I could be accepted into nursing school and make him proud.

I did my best to focus on my grades and enjoy the school that I loved. I went to a small high school and had a solid group of girlfriends that I still talked to every single day. We had all

gone off to different colleges but we remained close and made an effort to visit each other. When my grandpa passed away, my best friend Ali sent me a Dominos pizza with a side of ranch and a Coke. She figured I would enjoy a pizza more than flowers and I laughed at her thoughtfulness. Ali was funny, generous, and was liked by everyone. Her personality (and her bleached blonde hair) lit up every room she walked into. I had invited her and another friend from home to visit JMU for the highly anticipated spring concert and looked forward to seeing her. After finally arriving for the concert, we got ready and Ali proceeded to put on bright red lipstick while commenting on how much her mom hated that look. We had a great time at the concert and talked about how we would see each other in just a few short weeks as our freshman years were ending. Just a few days after visiting me, Ali went to visit her boyfriend for Temple University's "Spring Fling." She was at a rooftop party when she backed up to take a picture and accidentally fell four stories to her death. Several news outlets used a picture taken of Ali (with her red lipstick) that was posted on social media the night of the concert to announce the tragic accident.

Instead of allowing myself to grieve, I threw myself into my studies. I studied over 100 hours for my anatomy final and subsequently only missed one question. It was easier for me to obsessively memorize all aspects of the human body than to accept that two of my favorite people were gone. I spent my very first day at home speaking in front of over 800 people at Ali's memorial. I had to have someone drive me because I was extremely sick and felt like a truck had hit me. The next day I scheduled a doctor's appointment because I was convinced I needed to be tested for mononucleosis. It was not until the doctors asked, "Well, are you currently stressed about anything?" that I realized the affect that their deaths had on my mind and body. I spent the entire rest of the summer barely able to get out of bed and I canceled several plans because I did not have the energy to act happy for extended periods. I started school at JMU with six people

saved in my phone as “favorites,” and with two of them gone, I truly was not sure if I would ever feel happy again.

I came back to JMU the following fall and answered the typical question “how was your summer?” by smiling and saying it was great. Despite the heartbreak I experienced, I thought a lot, about how I spoke of my grandpa and Ali at their memorial services and I wondered what I would want someone to say about me someday. I decided to join the JMU Honors Program that semester in honor of my grandpa and his passion for education. Later, I decided to honor Ali by combining my personal experiences with grief and my nursing background to educate nurses on how to support grieving adolescents and prevent negative coping habits. While this project is a small thank you for the impact they had on my life, I hope to continue my professional career as a nurse who is compassionate, generous, and ambitious, just like they were.

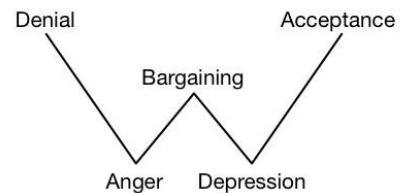
Introduction

Nursing as a profession is based largely off a single definition. In addition to patient care, the American Nurses Association's definition of nursing emphasizes "advocacy in the care of individuals, families, groups, communities, and populations" ("What is Nursing," 2016). While many people see the nurse's job as caring for patients, nurses are constantly reminded that their job also includes providing care to the patient's family, friends, co-workers, and community. Unfortunately, not all patients can be saved and nurses working in critical care settings frequently experience the death of a patient. The most important time for a nurse to serve as an advocate for the patient's family and community is when a death occurs. Although the patient's pain and suffering has ended, their loved one's pain is just beginning.

Age and developmental stage directly influence the grieving individual's ability to understand and process death. Adolescents are especially vulnerable to developing negative coping skills such as substance abuse, self-destructive behaviors, and eating disorders, among others (Doka, 2014). While there is a lot of information in a variety of disciplines on grief and loss, there is a lack of information on how nurses can provide bereavement interventions to adolescents who have suffered the loss of a loved one (Waller, 2016; Herberman, 2013). Research shows that "approximately 3.5% of young adults have lost a parent prior to age 18," meaning there is a significant population that could benefit from intervention (Herberman, 2013, p. 1203). Sadly, it is reported that between 10,000 and 15,000 children lost one or both parents in the September 11 terrorist attacks alone and the need for nurses to understand the grief process has only continued to rise since then (Kirwin, 2005). By intervening soon after an adolescent experiences a loss, nurses may help to prevent negative coping habits and decrease future hospitalizations related to ineffective coping skills.

Background

Death and grief are unavoidable. Death affects all humans regardless of their age, race, genetics, health habits, or culture. Despite death being a universal experience, the grief that follows the loss of a loved one is unique to the individual. While people handle loss differently, “most bereaved people will experience normal, uncomplicated grief reactions and will recover from their loss within a reasonable time period” (Waller, 2016, p. 33). In order to help health professionals better understand the concept of normal, uncomplicated grief; the Kubler-Ross theory was developed (McAlearney, 2015). McAlearney lists the stages as denial, anger, bargaining, depression, and acceptance (McAlearney 2015). As the person experiences grief, he or she moves through the five different stages, although not necessarily in a linear progression.



Denial – The affected person cannot begin to fathom that a loss occurred and refuses to acknowledge that their loved one has passed away

Anger – The individual becomes angry about the situation or events leading up to the death and looks to people or events to place blame

Bargaining – The grieving person tries to bargain with a higher power by making promises in exchange for their loved one’s presence

Depression – The individual acknowledges that their loved one has passed away and begins to feel the affects of life without them

Acceptance – The affected person begins to accept that their loved has passed away and begins to find happiness despite loss

While the Kubler Ross Model is useful in defining the grief process, nurses must remember that grief is unique to the individual and their developmental stage. Factors such as age, type of loss, and support system can affect how a person processes grief (Herberman, 2013). Children ages 12-19 are especially vulnerable to experiencing complicated grief due to the spiritual questioning and identity searching that encompasses adolescence. (Herberman, 2013). An article that explores adolescent grief, states, “At a time when adolescents face numerous social and emotional challenges in a highly-charged developmental period, it is essential to realize that they may exhibit grief differently than young children or adults” (Doka, 2014, p. 1). When adolescents experience the death of a peer, it is likely the death was unexpected given that unintentional injuries, suicides, and homicides are the leading causes of death among adolescents (Doka, 2014; Herberman, 2013). Adolescents grieving after an untimely death may be at a higher risk for negative coping behaviors and require special attention. (Herberman, 2013). Even deaths caused by natural reasons can feel unexpected. (Doka, 2014).

During adolescence, separation from the family, and the need to become more independent occurs. Although adolescents most likely rely on their parents financially, they may be less comfortable seeking support from their parents during a time of grief. Adolescents want to prove that like many things, they can handle loss on their own. While independence is a sign of growth, isolation during a time of grief can lead to adolescents seeking attention through risky behaviors, substance abuse, and eating disorders (Doka, 2014). In addition to avoiding support from parents, adolescents may also isolate themselves from their peers. Children ages 12-19 place a great emphasis on fitting in with their friends. The concept of being ‘normal’ is important

for adolescents and they do not want to be labeled as “the kid whose father died.” (Doka, 2014). After a death occurs, nurses can use their role as a caregiver who is neither a parent nor a peer to provide adolescents with an opportunity to express their grief. In fact, research shows that the adolescent’s ability to express emotions related to grief is the most significant predictor of effective coping (Reed, 2008). In addition to offering support, nurses can educate grieving adolescents on the differences between positive and negative coping skills and therefore reduce the number of future hospitalizations. As difficulties with mental illness become more prevalent in the United States, it is imperative that professionals from all disciplines play a role in prevention.

Discussion

Although adolescents may have an adult understanding of death, they may have fewer coping skills. As a result, grieving adolescents experience more intense and prolonged grief, a greater need for medical intervention due to physical and emotional problems, and substance abuse after loss (Herberman, 2013). Moreover, research suggests that up to 7% of individuals grieving a loss will develop complicated grief (Zisook, 2014). Nurses need to identify adolescents currently experiencing grief or at risk for complicated grief in order to prevent negative coping skills and the subsequent decline in wellbeing. Adolescents who have experienced an untimely death, loss of a close family member, peer, or multiple losses are at an increased risk for experiencing complicated grief. In addition, the adolescent's type of support system may also play a role in how they cope with loss. It was noted that some parents may not have the knowledge or time to help children process grief (Kirkwin, 2005). Adolescents living with busy or absent parents may not get the attention or care needed to overcome a significant loss. In addition, a loss that affects the whole family, like the death of a sibling, may disrupt the child's support system. Studies show that the disruption of the family following a loss is the main determinant of the development of adult psychiatric disorders, rather than the loss itself (Bradach, 1995). Those with a lower socioeconomic status may also be at an increased risk due to a lack of access to appropriate care, or an acceptable role model. Adolescents who grow up in households where drugs or alcohol are abused may be more likely to turn to substances in order to cope with their loss (Waller, 2016). Adolescents who already use substances inappropriately are more likely to develop problems with substance abuse in the year following the death of a loved one (Zisook, 2014, Herberman, 2013).

“Complicated grief has been considered for inclusion in the DSM-V as a distinct mental disorder” and is described as the debilitating and painful emotions that prevent people from resuming their lives after suffering a loss (Herberman, 2013, p. 1202). Complicated grief is characterized as a “prolonged and intensified response” rather than the immediate reaction to a loss (Herberman, 2013, p. 1203). Indications of complicated grief may include: preoccupation with the death, intense yearning and longing for the deceased, trouble accepting the loss, anger surrounding the circumstances of the death, avoidance of issues associated with the loss, and suicidal ideations (Herberman, 2013). While symptoms may be evident in the first few days after the adolescent experiences a loss, it is essential to note that positive coping skills may not be immediately present. Adolescents who experience a tremendous loss, like the loss of a parent, may be emotionally distressed in the days following the loss, given that the interpersonal quality of the relationship plays a role in the grief response (Herberman, 2013). On the other hand, adolescents who delay grief, or show no emotion to a significant loss, should also be evaluated for ineffective coping (Perrin, 2012). It is important for nurses to be able to distinguish between positive and negative coping skills that may indicate a need for further education or support.

Table 1 shows examples of positive and negative coping skills

Positive Coping Skills	Negative Coping Skills
<ul style="list-style-type: none"> • Acknowledges the death • Does not feel extremely lonely or empty after the death • Feels emotionally connect to others • Believes life still has meaning • Retains a sense of self-efficacy 	<ul style="list-style-type: none"> • Has trouble acknowledging the death • Feels extremely lonely and empty • Emotionally isolated from others • Suicidal thoughts • Preoccupied with worthlessness • Enduring sleep disturbances

While negative coping skills may be easy to identify immediately following a loss, they can be harder to distinguish after a significant amount of time has passed. For example, behaviors such as being absent to school, abusing drugs or alcohol, or engaging in risky behaviors may be seen as part of the teenage desire to test boundaries, when in fact it may stem from a recent loss. Inappropriate behaviors and actions are often a disguised cry for help from adolescents who are suffering from complicated grief. By recognizing the signs and symptoms of ineffective coping skills, adolescents can be given the support they need to overcome a significant loss. Recognition of complicated grief might start with a comprehensive assessment. As with any assessment, adolescents should be asked open-ended questions about any current stress they might be experiencing. Questions such as “I imagine these days after losing your mother have been very difficult for you?” Or more broadly, “Is there anything that has been troubling you lately?” Because the questions cannot be answered with a simple yes or no, adolescents may be willing to open up about how they are overcoming a loss.

Many health professionals are unaware of the reality surrounding adolescent grief and the affect that ineffective coping can have on their adult lives (Kirwin, 2005; Mortlock 2005). Contrary to popular belief, adolescents do not recover quickly from loss. While children are often described as being resilient, adolescents require support in order to overcome grief through positive coping mechanisms. Interventions cannot be constructed based on a “one size fits all” mindset. Nurses are taught to assess first, they must draw on this training when providing support to children at risk for complicated grief. Adolescents who have experienced a loss should be questioned about the type of loss (sudden or expected) and the impact that the death has had on their life. Adolescents who have lost someone who was a part of their everyday lives will have a harder time adjusting to life without their loved one (Herberman, 2013). It is important to

assess what role that person played in their life and how the loss is affecting them. For example, adolescents who lose a mother may need help with cooking, doing laundry, and other activities. The increased responsibility that comes after the death of a parent may increase the child's responsibilities and take away the ability to grieve. Studies suggest that adolescents who have family members, friends, and teachers that are willing to assume the roles of the deceased may be protected from the stress associated with the loss (Marwit, 1998).

After identifying adolescents at risk for complicated grief, nurses can provide adolescents with guidance and resources. While there are an abundance of online resources and hotlines for adolescents experiencing grief, teens may be reluctant to seek help without guidance. They simply might not know where to look. Nurses can use their role as a caregiver and advocate to guide adolescents in the right direction before behaviors of complicated grief become evident. As always, interventions should be tailored to each individual patient and may differ based on gender. Teenage girls tend to react to loss by crying and expressing their emotions through talking about the loss. On the other hand, boys may be noticeably quiet (Mortlock, 2005).

Whether an adolescent is grieving a sudden or unexpected loss, nurses can encourage adolescents to focus on the positive characteristics of the deceased (Perrin, 2012). For instance, acknowledging the bond that the child and their parent shared, rather than the circumstances of the death. In addition, nurses can recommend books that are tailored to grieving adolescents (Perrin, 2012). Grief is specific to the child's developmental process, and books that are personalized for adolescent's needs may help them to overcome grief while remaining independent (Kirkwin, 2005). Adolescents who enjoy being active may benefit more from involvement in summer camps for children who have experienced a loss. Summer camps, such as Camp Dragonfly (Harrisonburg, VA), emphasize the need for children to not be isolated in

their grief. The camp offers an environment for teens to gather and share their personal experience(s) with loss. As social media continues to be a popular means for expression among adolescents, teens may feel more comfortable looking online for resources to help them cope. It is important for nurses to provide adolescents with good resources, while reminding teens that information found online may not be accurate. In addition, expressing oneself on social media may lead to unintended consequences such as painful or harsh comments (Doka, 2014). Websites such as hospicenet.org provide adolescents with a list of excellent resources that are specific to their geographic location. In addition, monitored websites like hellogrief.org allow adolescents to safely express themselves. Children who are aged 12-19 years spend a great deal of their time in school, and should be given information about accessing counseling support in the school setting. If adolescents do not feel comfortable talking to a parent or school guidance counselor, nurses should encourage adolescents to find an adult they are comfortable with (Kirkwin, 2005). In order to best support adolescents experiencing grief, formal and informal supports should be accessible to adolescents within school, health, and social settings in order to prevent future hospitalizations and negative coping behaviors.

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Author & Date	Purpose	Sample Size/ Description	Interventions	Measurements	Results	Conclusions
Bradach et al., (1995) LOE 3	Examines the direct and indirect effects of traumatic loss on young adults	N=181 late adolescents and young adults ages 17-28	Subjects divided up into 3 groups based on the types of losses they experienced (traumatic, non-traumatic, experienced during own lifetime)	6 types of self reported questionnaires completed by the participants	Participants who experienced a traumatic loss during their own lifetimes reported increased levels of psychological distress compared to the control group (non-traumatic)	The nature of the death, traumatic vs. non-traumatic, plays a significant role in future psychological distress
Herberman et al., (2013) LOE 3	Examines the effect of the relationship (sibling or close friend) and relationship quality with complicated grief	N=107 young adults aged 17-29 (73 bereaved and 34 had never experienced a loss)	None reported	Questionnaires completed by the participants which assessed current and past thoughts, feelings, behaviors, and physical symptoms	19% of participants met criteria for complicated grief and those who lost a sibling reported significantly higher levels of grief	Sibling loss significantly increases the risk for complicated grief in young adults
Kirwin et al., (2005) LOE 2	To determine major factors that influence a child's response to the death of a parent	Relevant literature from child psychiatry, child psychology, and nursing	No interventions/ metanalysis of data	Not applicable	Not applicable	The death of a parent is a major event for children and can cause psychological distress, especially to children with a lack of support system

Marwit et al., (1998) LOE 3	To examine the perceived helpfulness of support-intended statements to people who have experienced a parental divorce or death	N=15 m and 15 w who experienced a parental death in adolescence, and 15 m and 15 w who experienced parental divorce in adolescence (ages 13 to 20)	None reported	42 item inventory which participants were asked to rate each support-intended statement on a 7-point Likert scale. They were then instructed to identify which statements they personally experienced	Providing opportunity to ventilate feelings, expressing concern, and reaffirming a supportive presence were regarded as “most helpful” support-intended statements	Few differences found between adults who experienced a death or divorce in adolescence
McAlearney et al., (2015) LOE 3	To increase understanding of HER system implementations regarding grief intervention	N=47 physician and 35 administrative key informants from six US health care organizations who demonstrated success with EHR implementation	35 in person or telephone interviews which consisted of a series of open-ended questions and lasted 30-60 minutes. Six focus groups were held which lasted 60-90 minutes.	Transcripts from interviews and focus groups were analyzed using the constant comparative method	HER adoption of Kubler-Ross’s five stages of grief model may help organizations to effectively implement interventions related to grief and loss	Comprehensive EHR systems which assess grief after loss may help healthcare professionals to intervene
Waller et al., (2016) LOE 2	Examines the need for support by health professionals after a loss through grief counseling and interventions	N=126 data based papers on grief counseling	Metanalysis of papers found on MEDLINE, Embase, Cochrane Library and PsycINFO	Studies categorized as descriptive, measurement, commentary, reviews or intervention	Study quality was poor and majority of interventions showed bias	Grief counseling interventions need to be evidenced-based and require a strong rationale for design