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Bereavement and Autism: A Universal Experience with Unique Challenges

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Bereavement and grief are universal experiences in all of our lives. The prevalence of autism is rising; those on the spectrum and neurotypicals will be interacting with each other more. Schools are gradually becoming familiar with how to support these students. There will be more families with members on the spectrum and every family will experience bereavement. Recovering from grief is a process that is unique to each individual and is all are affected differently. For individuals on the autism spectrum, however, other factors may affect their grief recovery process. Individuals with autism often have challenges with theory of mind and empathy, abstract thinking, executive functioning, and perseveration.

In December 2004, my mom died at the age of 54 from melanoma when I was 15 years old; a few years later I was diagnosed with Asperger Syndrome. Looking at my life now, I made it through the grief recovery process. I have majored in psychology with a minor in counseling, and will be graduating this month from the College Program for Students with Asperger Syndrome at Marshall University in Huntington, West Virginia. During my academic years, I have dealt with grief by taking "Sociology of Death and Dying" and "Death and Grief Counseling." My volunteer experience in the field has been with Hospice of Huntington in Huntington, West Virginia and with the Wendt Center for Loss and Healing in my hometown the District of Columbia.



I have been to 17 funerals and 4 weddings. I hope to eventually pursue my Ph.D. in psychology and specialize in bereavement. Combining my personal experiences and academic knowledge, I have had the unique experience and challenge that many individuals on the spectrum may have when dealing with bereavement. I will first give an introduction of bereavement, and then I will discuss the unique challenges.

There are many equally important events in our lives that our parents and teachers help us prepare for. However, does everyone attend college? Does everyone know when they will have a wedding or if they will marry? Are all of us 100% certain that we will raise children with our future significant others? No. However, we can be absolutely certain of one thing in our lives, besides taxes, and that is loss. At some point in our lives someone close to us will die, if not already.

The terms grief and bereavement are often used interchangeably. However, there is a difference. My favorite definition of grief is “the normal and natural reaction to loss of any kind” and “the conflicting feelings caused by the end of or change in a familiar pattern of behavior” (James & Friedman, 2009, p. 3). Grief does not always have to involve a death. Sometimes an individual has grief from a loss that others may not recognize as a loss to be grieved; this type of grief has been coined as disenfranchised grief by Kenneth Doka (Doka, 2008). Bereavement is the death of a loved one. In psychotherapy grief appears as themes in the lives of clients regularly and is often overlooked; the issue of grief appears far more often in therapy as an underlying cause or contributing factor to their troubles, rather than the presenting issue (Humphrey, 2009).



Brian and his mom at the Liberty Bell in 2003

A support system is vital to grieving individuals.

While the availability of a support network may not always be an issue, the quality of the support network is most important. It is not uncommon for members in the support network to invalidate the griever's feelings (James & Friedman, 2009; Pomeroy & Garcia, 2009). At funerals, I have heard people say things such as, "She is no longer in pain," "She is home with God," or, "She wouldn't want to see you cry." It often takes a month or two for reality to sink in. That is usually when grievers tend to reach out for support. James & Friedman (2009) point out: "It is only natural and quite healthy for people who are caught in a grieving situation to seek solace from those around them. However sometimes, it becomes abundantly clear to the griever that friends and associates just cannot help. Even though they are well meaning, they often say things that can seem inappropriate (p.39). The support system is vital to maintain through significant dates such as anniversaries, birthdays, holidays, etc. One common challenge I have seen in my experience is that the support network is available shortly around the time leading up to the death or funeral, but not available in the future when the reality of the loss becomes clearer.

Grievers often go through a grief recovery process. There are different models for the grief process. My favorite model is the Task and Mediator Model by Worden (2009); what affects a griever's journey through the Tasks are the Mediators of Mourning. There are four Tasks of Mourning (Worden, 2009, pp. 35-54) and seven Mediators of Mourning which I will share below:

TASKS OF MOURNING

1. Accept the Reality of the Loss. Even if the death was anticipated, shortly after the death there is usually a feeling that the death has not happened. In my personal experience, people are usually able to go through this first task with no difficulty; they soon notify the funeral home, family, friends, and others of the death. However, there are rare times when a loved one will deny the actual death. There is also the denial of the meaning of the loss; an individual may react to the death by saying that the person who died was not important to her or him in some way. Sometimes the feeling of numbness is mistaken for denial (James & Friedman, 2009).

2. Process the Pain of Grief. Often this second task can be hindered by family and friends by distracting the griever from their emotions. This can influence the griever's belief that they should not grieve or express their emotions. Sometimes people can invalidate a griever's feelings; this can also impact a normal grieving process. At times there are those who believe that everyone should receive counseling or therapy. However, intervention can make the situation worse. According to Bonanno (2009), the one-size fits all approach to grief counseling

has proven to be “notoriously ineffective but sometimes even harmful” and “psychological interventions do sometimes actually make people worse, and this usually happens when the intervention is unwarranted and interferes with a natural recovery process” (p. 105).

3. Adjust to a World Without the Deceased.

Adjusting to the loss includes restructuring daily routines which can be described as an external adjustment. Other adjustments involve our perceptions and thoughts of life and reality as a result of the loss which can be described as an internal adjustment. For the first two months after my mom’s death, when I walked home from school I would shout, “Hello, mom!” I was not in denial of her death; it was out of habit. Establishing a new norm will come gradually. I also questioned why God would let my mom die.

4. Find an Enduring Connection with the Deceased in the Midst of Embarking on a New Life.

This task is often the most challenging; many confuse this task with letting go or giving up the relationship. The goal of this task is to emotionally relocate the deceased in life. Those who knew the deceased, as a group, grieve the person who died. Each individual will grieve the unique relationship they had. There are mediators that will affect how we individually will grieve a loss. Regardless of how well two people knew the deceased person, their unique relationship and their individual differences will affect their grief recovery process as they go through the Tasks of Mourning.

MEDIATORS OF MOURNING

1. Who is the Person that died? The connection to the deceased person will affect how one grieves. For example, the death of a parent will be grieved differently than the death of a spouse. The death of a professor will be grieved differently between the faculty and the student body.

2. The Nature of the Attachment. What was the quality of the relationship to the deceased? Were there any unresolved conflicts with the deceased or regrets? The attachment style is also important. Unresolved issues with the deceased can rob the griever of having a chance at resolving the issue or repairing the relationship.

3. How the Person Died. Whether the death was anticipated or not can impact the griever. In cases of expected death, such as illness, there may be the opportunity of gradually adapting and resolving unfinished business. Often in this situation, the family of the loved one will experience anticipatory grief, the grief over losses brought upon by the illness as well as losses that will continue to occur (Pomeroy & Garcia, 2009). In my experience the question of whether anticipatory grief helps with post-loss grief should be determined by the individual griever. If the deceased died suddenly or violently, it can preoccupy the griever with thoughts of whether the death could have been prevented. Sometimes the death can be violent to the extent that the body could not be recovered or was damaged beyond recognition. Even if the griever knows their loved one died, their sense of reality of the death can

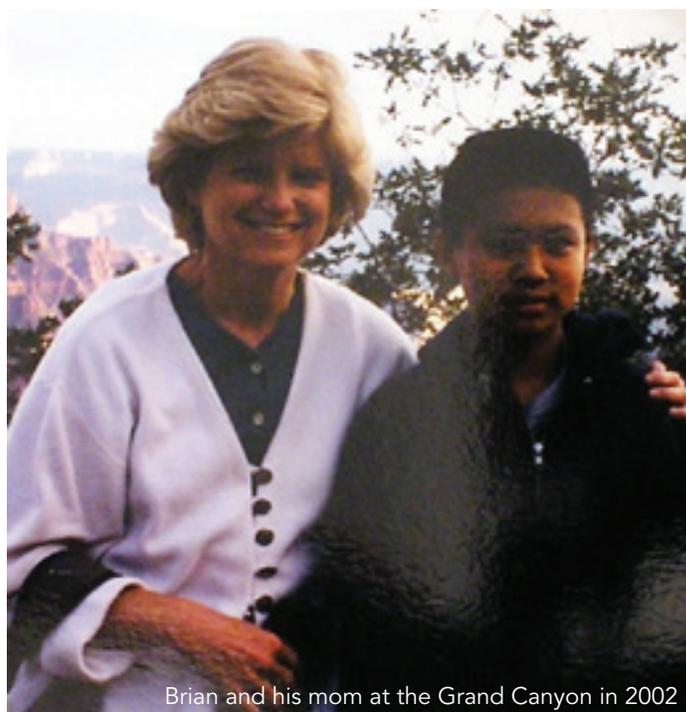
be affected in circumstances which the body was not able to be viewed; this can affect the griever's ability to accomplish the first task of mourning and accepting the reality of the loss. Another factor is the stigma attached to the cause of death; death by suicide and AIDS are examples of deaths that can be stigmatized.

4. Historical Antecedents. Previous losses are important. Sometimes previous losses have not been adequately grieved and the current loss provides an opportunity for the griever to finish grieving the previous loss. When my maternal grandparents from Minnesota died in their 80's, it was not a shock, due to their age. It was emotionally difficult given my mom's death two to three years earlier; I was still in the early phases of grief. Knowing about previous losses can be helpful in supporting individuals in their grief process.

5. Personality Variables. The person's age and gender contributes significantly to the reaction to loss. Is the child at an age where they can comprehend death? Children cope with loss differently than adults. Children will often express their feelings through behavior and play (Walsh-Burke, 2006). It is not uncommon to see children playing with other children acting out the death. This is their way of comprehending and processing what happened. With gender, there are two styles of grieving (Humphrey, 2009; Pomeroy & Garcia, 2009). Men tend to cope by focusing on activities whereas women tend to focus on emotions and feelings which often times is intuitively natural for women. While these two grieving styles are dominant in men and women, respectively, there is usually a blending of the two in both.

6. Social Variables. Emotional and social support is beneficial to the griever. Not only is the availability of a support network important, so too is the quality and satisfaction. Grievers with a strong support network are likely to have a lower chance of becoming clinically depressed (Worden, 2009). Individuals who are involved in more than one social role are likely to adjust to the loss more easily than those who are not. Active involvement in some type of community also helps.

7. Concurrent Stresses. Often with a death there can be other life events that are stressful. When I was 14 years old, my paternal grandpa died in April 2004 in his 90's from injuries due to a fall. My mom was in the early phases of interferon treatment for her melanoma. Given my grandpa's age, his death was not a surprise, but seeing my mom go through cancer treatment added more stress to my life.



Brian and his mom at the Grand Canyon in 2002

Given the universality of bereavement and the rising prevalence of autism, **it is important to address the uniqueness of bereavement to individuals on the spectrum.** Bereavement can be a challenge for anyone. However for individuals on the spectrum, there may be additional challenges. I have found at least two peer-reviewed research articles that may help with additional challenges for individuals with autism. The authors are: Berthier (1995) and Marston & Clarke (1999).

Barbara Becker-Cottrill, Executive Director, West Virginia Autism Training Center at Marshall University (where I attend) and a member of Autism Society Panel of Professional Advisors says, "There is very little research in this area and there needs to be suggestions for helping individuals on the spectrum understand and cope with death." Also, Barbara mentions since all individuals with on the spectrum will face bereavement in their lives, this is an area that deserves more research attention, particularly focused on strategies and interventions.

Interacting with other bereft individuals may be a challenge. People mean well but tend to say things that are awkward and sometimes insensitive. However, given those on the spectrum may unintentionally come across as nonchalant and have challenges with Theory of Mind, this may be an area of concern; their intent may be the same but others may not see it the same. When talking with the family and others they may have difficulty understanding others are grieving differently. My advice before going to a funeral and talking with other mourners is to rehearse with the individual on

the spectrum what he or she might say when expressing condolences, either verbally or written, and to talk about how saying certain things to a grieving person may affect them.



Interpreting what people say literally and being right-to-the-point are common with individuals on the spectrum. At funerals metaphors are often used to avoid saying, "dead" or "death." The metaphor, "He is sleeping," is generally not wise to use with young minds. However an adolescent or an adult on the spectrum, depending on level of development, may interpret that metaphor literally and be afraid to sleep that night. Another issue is sometimes using the words "dead" or "death" may be too harsh. Sometimes the bereft family may prefer the cause of death not be mentioned, due to reasons such as cultural views and/or stigma surrounding the cause of death.

Dealing with death and grief involves abstract thinking. Understanding where the deceased person may have gone is one challenge. "The concept of heaven or an afterlife is difficult to comprehend for many of us," says Becker-Cottrill. "But for many people with ASD it is totally incomprehensible." This may be a challenge due to the fourth task of mourning, especially, if the body was not viewed. Being able to appropriately emotionally relocate the deceased individual in your life may be a challenge; this is definitely an abstract process. "Communicating abstract subjects such as feelings and fears is difficult," says Marc Ellison, Associate Director, West Virginia Autism Training Center at Marshall University. Ellison has supported individuals with autism in the face of bereavement as well as families grieving the loss of a child with autism. He states, "finding tangible ways to routinely and regularly communicate these feelings and thoughts would likely be helpful."



Another challenge is adapting new strategies.

Since individuals on the spectrum like routine and doing things the same way, this can be a challenge with the third task of mourning with externally adjusting to life without the deceased. New routines have to be established, especially if the deceased person was part of the individual's daily life. Adapting new strategies is linked to difficulty with executive functioning. Ellison says, "Challenges related to executive functioning may pose significant barriers to overcoming grief." In situations of anticipatory grief, Becker-Cottrill recommends adjusting early. "I would recommend that a consistent family member or person close to the family be selected to carry out the routines the terminally ill family member would typically do," she says. "Over time and the eventual death of the person, the child's routine has been reset which could avert behavior challenges."

Grievors often go through a phase of trying to make sense of the death or overcoming regrets of what should or should not have been done. With the tendency for those with ASD to perseverate on topics of their interest, matters surrounding the death can become their new interest. According to Attwood (2007), "the child or adult may collect information on a topic that is causing emotional distress or confusion, as a means of understanding a feeling or situation" and the interest could rise to an intense level that is "no longer pleasurable or of intellectual psychological value" (p. 190). Becker-Cottrill mentions this perseveration can be due to challenges with abstract thinking. "Death is something that they would perseverate on," she says. "Not

having any concrete or acceptable answers to why, what, and how this happened can be extremely difficult and difficult to let go of until a satisfactory answer comes into play." When my mom died, obituaries became my interest. I would go online and sign obituary guest books of people who died in a similar way as my mom. I was only a child and, for me, doing this helped me cope and feel less alone. If the new interest does not promote healing there is a chance that the griever could experience prolonged grief issues. My personal advice is to let the individual find his/her own way in connecting with the death. But it is just important to monitor how well they are coping.

A social support network is essential in grief recovery. However, for individuals on the spectrum this can be a challenge. "Developing a support system may be a challenge due to executive functioning difficulties and challenges with social communication," says Ellison. "With folks [on the spectrum] the expression of feelings associated with bereavement is difficult or, perhaps for some, even impossible. In those cases it's vital to find some means through which they may express their grief." Individuals with autism who are nonverbal may need to express their feelings through other means, such as art therapy or through online support groups. I found online support groups beneficial. Neurotypicals might not understand how to interact with individuals with autism. Ellison suggests that the individual on the spectrum may benefit from social skills and communication support and training to benefit the most from a bereavement support network. Another consideration with social

support networks is the age of the individuals. Since it is not uncommon for those with autism to have friends that are either older or younger, it may be a challenge to seek support from others of the same age who have experienced a similar loss. While it is beneficial to be in a support group within the same age range, it is best to develop a support network that meets the individual needs. I found support groups helpful, but I was not comfortable with talking about my feelings to strangers face-to-face at the time. I found reading books about grief and textbooks on grief counseling and therapy very helpful. The book that I highly recommend is *The Grief Recovery Handbook: The Action Program for Moving Beyond Death, Divorce, and Other Losses* by John W. James and Russell Friedman, who also wrote a book for parents to help children, it's called *When Children Grieve*.

I believe early discussion or exposure to bereavement in a concrete way could be beneficial and could assist the individual to use previously-learned knowledge when the time comes. The first funeral I went to was when I was 9 years old. My paternal grandma from Massachusetts died in December 1998 in a car accident while crossing the street. My parents told me what happened right after my dad received the phone call. They answered my questions in a concrete way. I went to the funeral and saw her body. The police didn't charge the driver; so my grandpa filed a wrongful death suit. My dad let me sit in on the meetings with the attorney during our monthly visits to grandpa. My dad did not tell me anything or give me any details with what was happening unless I asked. My dad

told me that when I would ask questions he would know I was ready to talk about it. This was a concrete way for me to understand the circumstances surrounding her death. Another concrete way to start a talk about loss is watching a bereavement themed movie that is age-appropriate. Regardless of how the topic of loss comes up, encourage questions but let the individual lead the discussion by the content and frequency of their questions. When young minds ask about death, it is usually a sign they are mature enough and ready to talk about it.

Bereavement and grief are inevitable and universal events in our lives. Each griever is just as unique as the relationship they had with the person who died. The goal of grief recovery is to establish a new norm and to emotionally relocate the deceased loved one; how an individual will go through the process will be affected by different mediators. How individuals on the spectrum will go through the tasks of grief will be also mediated by the individual's empathy skills interacting with other grievers, ability to think abstractly, comprehension of the situation, available support network, and how much they might perseverate over the death. With the different challenges those with ASD may face, it is important to be actively involved in their support before, during, months, or even years after a major loss. Death is universal no matter what your abilities are!

ABOUT THE AUTHOR



Brian Wong is a 2013 graduate of Marshall University in Huntington, West Virginia where he was a student in the College Program for Students with Asperger Syndrome. He majored

in psychology and minored in counseling. Brian has volunteered in the hospice setting and at a bereavement camp for children. Brian's area of interest is psychology with a specific focus on bereavement in individuals on the spectrum.

Brian has presented at many conferences, including, Marshall University's College of Liberal Arts Research and Creativity Conference and the 22nd Annual Tri-State Psychology Conference at the University of Charleston. He has also authored the book, *Helping a Grieving Friend*. He plans to work in the field of mental health and attend graduate school. His research on bereavement and grief can be read at <http://marshall.academia.edu/BrianWong>.



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