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Grief and Loss Across the Lifespan

A BIOPSYCHOSOCIAL PERSPECTIVE



Judith L. M. McCoyd
Jeanne M. Koller
Carolyn Ambler Walter

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Klass (2005) describes the importance of the social world sharing in the parents' grief and acknowledging the parents' loss, yet this is precisely what is often limited, particularly when the infant is quite young. This seems to mirror a myth that the connection a parent feels is dependent on the length of the child's life. This myth may comfort those who remain uninformed and distant from the bereaved parents, but the reality is that parents grieve deeply and intensely regardless of the child's age (Rando, 1993). Klass found that bereaved parents moved through periods he called into their grief, well along in their grief, and resolved as much as it will be. This last term does not imply (as words like closure and acceptance do) that parents will "move on" and forget or accept what has happened, neither of which is possible. Often, grieving is itself a comfort for parents as it aids their continued connection to their deceased child. Parents wonder if continuing with their own lives as usual is disloyal to the memory of their child (Klass, 2005). Parents often maintain the bond by memorializing the deceased child through participation in groups like Compassionate Friends or by promoting legislation related to the child's death (e.g., Megan's Law for Megan Kanka) or starting a charity in the child's name (Alex's Lemonade for Alexandra [Alex] Scott). Parents find many ways to keep the bond active (Klass et al., 1996).

Sometimes, children die in accidents that result from tragic oversights. Infants and toddlers occasionally die as a result of being left in car seats in hot cars; toddlers are run over by the family car or die in an accident in the home. Parents feel intense guilt and have trouble with meaning-making when their child of any age dies from disease, accident, and other uncontrollable events (Lichtenthal et al., 2013). In our experience, when death results from something that can be imagined as preventable, parents will have an even more difficult time finding a way to make meaning and to mourn.

INTERVENTIONS

McKissock and others strongly recommend that bereavement support be available to all children, if only for a "grief checkup" (2017, p. 48). This would entail a meeting during which caregivers receive psychoeducation about normal regressive and somatic responses of preschoolers along with guidance and role-modeling of how to answer the child's questions in a direct, developmentally appropriate and nurturing manner. The key is providing support to the caregiver/s of the child so they can help the child redevelop a sense of security and predictability. McKissock emphasizes that preschool-age children need to be given truthful, developmentally appropriate information in a safe space where they can comfortably ask their questions. They need to hear that they will be valued, safe, and cared for despite changes due to their loss.

READINGS

Latrice's Story **COLLEEN MARTINEZ**

Colleen Martinez is a registered play therapist-supervisor and New Jersey licensed clinical social worker. She is a clinical social work associate at Ramapo College of New Jersey and also teaches MSW students at Rutgers University. She has been treating children and families for over 20 years. In her private practice, she provides supervision and consultation to mental health professionals

who serve children and families. You can find her as Colleen The Play Therapist on Instagram and Facebook.

Latrice's Referral for Services

Latrice is a 4-year-old African American girl enrolled in a preschool program in an urban public school district in the northeastern United States. Although only 4, she is described at school as a "bully." According to staff and teachers, she frequently pushes and kicks her classmates. She is also described as difficult to teach. She does not respond verbally and frequently does not follow direction. She uses only one- or two-word utterances when she wants something but does not respond verbally to attempts at conversation from her teachers or peers. She was evaluated by the child study team due to her apparent speech delays and behavioral challenges.

At the child study team interview, Latrice's mother, Ginelle, reported that Latrice is an only child who has always lived with Ginelle and Ginelle's mother. Ginelle and Latrice's father were never married, and he has not been involved in Latrice's life for the past couple of years. Ginelle reported that Latrice "was never a noisy child"; she didn't cry much and generally is quieter than other children in the extended family. Ginelle had previously not been concerned about Latrice's lack of speech as she, too, is quiet and did not speak much until she was kindergarten age. While she does not see the aggressive behaviors seen at school, she is concerned that Latrice does not seem happy.

Ginelle reported no problems during pregnancy, delivery, or in feeding Latrice as an infant. Ginelle described Latrice as an easy child. Latrice never really demands much attention at home. She seems to be content watching television or playing by herself. Latrice has always been easy to separate from her mother for babysitting, day care, and school, and Latrice never showed a strong preference for her mother when she was a baby. Ginelle remembers that Latrice was "fine" as a baby being held by her mother, a babysitter, or even a stranger. If she is very upset or hurt, Latrice will cry loudly and seek out her mother or grandmother, but this is an infrequent occurrence.

Ginelle reported no history of substance or mental health issues in her own, or Latrice's father's, family but acknowledged that she is probably depressed herself. Due to her busy work schedule and Latrice's issues at school, treating her depression is not a priority for her at this time. She agrees that after Latrice is more settled in school, it might be good to talk to a professional about her own depression. Ginelle does not see any medical providers regularly, but she does take Latrice for pediatric visits and vaccination appointments at the local hospital pediatric clinic. Ginelle denies any trauma or abuse in her, or Latrice's, history.

Latrice's Child-Centered Play Therapy Experience

Latrice was eligible for special education services. She was placed in an inclusion classroom and referred for speech and play therapy. I observed Latrice in her classroom in my role as her play therapist. She is the tallest child in the room. She engaged in pretend play with her classmates in the play kitchen area and grabbed a toy food item from her classmate's hand. At transition time, she was the last child to leave the play area and only joined the rest of the class for circle time when the teacher took her hand and led her to the circle.

My playroom is a typical one designed for child-centered play therapy (CCPT), with a variety of toys and play materials. CCPT is nondirective, so all sessions are child directed, and child-centered play therapists (CCPTtherapists) set limits only when necessary (Van Fleet et al., 2010). In our first session, I told Latrice that I help children with their problems and worries through play and that she could play with whatever she liked in my playroom. Latrice was silent in our first session and for many subsequent sessions. She occasionally glanced tentatively at me but rarely maintained eye contact. In the first session, she engaged with the dollhouse and dolls, and she continued to do so for many sessions that followed.

CCPTherapists follow the child's play, looking for patterns and themes in children's play (Van Fleet et al., 2010). For each weekly session, Latrice separated easily from her classroom, becoming more enthusiastic about going to the playroom. Each week, she focused on the dollhouse, playing with the adult and child female dolls. Over time, she became more enthusiastic to see me and eventually greeted me by name. She was consistently eager to go to the play therapy room, and the only time she ever required therapeutic limit setting was when she did not want to leave when our session was over. This is not an uncommon response (Van Fleet et al., 2010), and eventually Latrice did not test limits about ending sessions.

Week after week, Latrice consistently played with the same materials. She would bring a number of female figures to the dollhouse and move them around, over time increasingly making positive sounds and utterances, such as "Hmm," "Hi," and "Wow." She did not attempt to engage me in her play, so I used empathic listening and tracking (reflecting her actions) to demonstrate my attention and acceptance. CCPTherapists do not rush the process (Van Fleet et al., 2010). After nine sessions of this repetitive play, Latrice introduced a male figure to the gathering in the dollhouse. Up to and including this change, Latrice was calm, with an affect that was neutral to positive. At times in her play, she seemed to be saying pleasant things that I could not understand. She would smile at the figures and seemed to engage them in talking with each other. During this period of her treatment, Latrice interacted more with me, by verbally greeting me, looking and smiling at me, and initiating closer proximity by bringing the toys closer to sit by me while she played.

During the 11th session, there was a significant change in Latrice's play. After the female figures gathered in the dollhouse and the male figure joined them, another male figure was introduced to the house. When this male figure entered, her demeanor changed. She frowned and furrowed her brow, and she moved the male figures around the house abruptly. She grumbled loudly and stamped her feet. Later in the same session, she yelled for the first time in her sessions "No," more loudly than I knew her voice was capable of.

During our 12th session, Latrice engaged with the female figures and the dollhouse with a pleasant demeanor, as she had for many sessions prior. She then brought a male figure to the dollhouse unremarkably. When the second male figure was introduced, she became louder and visibly angry. She yelled "No" and then took the first male figure to the toy kitchen, where she had not played previously. She placed the male figure in the toy oven, closed the door, and began to sob. Latrice stood next to the toy oven with tears streaming down her face for nearly 5 minutes. In line with CCPT, I tracked her behavior and reflected her feelings during this time. I said, "You're standing there and not moving. You're so sad." As had become typical, when I told Latrice that our session time was over, she easily left the room and returned to the classroom.

After this session, I felt compelled to call Ginelle to discuss Latrice's play. She was at work during school days, and while I had never met with her, she always made herself available to take phone calls from me. I told Ginelle that Latrice had been playing a story about females gathering pleasantly, that a male joined them, and that when a second male joined them the tone changed, there was yelling, and then a male was removed and Latrice cried. I told her that Latrice sobbed next to the toy oven, with the male figure inside. Ginelle, always quiet during our conversation, was nearly speechless. She eventually said, "I can't believe she's telling you that." I knew what she meant but clarified that Latrice had played it out rather than verbally telling me anything. Ginelle proceeded to tell me that she never told me or the other school staff about something that happened, because she did not think Latrice remembered. When Latrice was 2 years old, she and Ginelle were at a family party when Latrice's father arrived. It was a happy event, and there were no problems until a man showed up at the party to fight with Latrice's father. The man shot and killed Latrice's father in front of the women and children, including Latrice and her mother. Ginelle explained that while it was a horrible experience, the funeral was even worse. Latrice's father was a young man well loved in his community, and there were many people at his funeral who were despondent and inconsolable. Latrice saw many mourners cry and scream at her father's funeral.

Ginelle and I agreed that even though Latrice was very young at the time of her father's death, she was deeply affected by the trauma of her father's shooting and subsequent funeral. Ginelle was grateful that Latrice was getting an opportunity to "talk" about what happened and thought that she, too, would likely benefit from treatment to process her own trauma and loss.

Play therapy sessions with Latrice continued for the remainder of the school year. She played out the same story a number of times, with decreasing emotional intensity. The last time she placed the male figure into the oven she looked sad but did not cry. Playing out her experience many times may have given her a sense of mastery, and thus she may not have felt as overwhelmed. In subsequent sessions, Latrice began to explore other toys and materials in the room, and at the end of the year, she made pictures with the art materials similar to projects she was making in her classroom.

Within weeks of beginning play therapy, Latrice's aggressive behavior in the classroom became less frequent, and her verbalizations increased. Over time, Latrice became a relatively cooperative, well-liked, and well-integrated member of her preschool classroom. She no longer stood out from her typically developing peers. At her year-end reevaluation, she was found to no longer be in need of special education services due to improvements in her speech and behavior.

CCPT gave Latrice an opportunity to process her experiences of trauma and loss, of which I was completely unaware. Gaining mastery over the violence, grief, and loss that she experienced allowed her to move on to more developmentally appropriate tasks like speech and language development, and social and preacademic skills. Inspired by her daughter's progress, Latrice's mother agreed to seek therapy for herself.

Discussion

Because Latrice was so young when she witnessed her father's killing and funeral, her mother assumed that she did not "remember" what happened and therefore was not affected. This is an example of disenfranchised grief. As Crenshaw (2002) points out, a preschool-age child does not have the ability to conceptualize death and cannot process grief in the same way as adults, but they are surely impacted. Latrice's play clearly indicated that she needed to process her experiences. Future work with this family should include grief work for Ginelle and attention to her ability to comfort and reassure Latrice while she continues to process her own loss.

Attachment is a major factor that I consider when evaluating the complexities of Latrice's life and her presenting symptomology. Reportedly, Latrice rarely seeks comfort from her mother or other caregivers and never indicates a preference for proximity to her mother. These may be indicators that Latrice and her mother never formed a secure attachment. Not only does Ginelle appear to struggle with depression, which can lead to insecure attachment (Cicchetti et al., 1998), but both Latrice and Ginelle have been traumatized. Trauma can affect a dyad's attachment style (Lyons-Ruth & Block, 1996). A child who rarely seeks out interactive regulation (help with calming down) may have weakened her attachment with her mother. An insecure attachment style can lead to less competence in social relationships and more behavioral problems (Fearon et al., 2010). Future work with this family might include attachment-based therapies such as theraplay, or dyadic developmental psychotherapy (DDP). While it is optimal for parent and child to develop a secure attachment very early in life, theraplay and DDP may be effective in improving attachment between parents and older children (Rubin et al., 2009).

If we look at Latrice's life through the lens of Erikson's (1959/1980) stages, we might consider the impact of her experiences on developing a sense of trust versus mistrust. When a parent is unable to provide attuned caregiving, due to trauma, loss, depression, or other factors, the child may develop a sense of mistrust and have difficulties in developing trusting relationships with others (Siegel, 1999/2012). This may have contributed to Latrice's difficulties in relationships at

school. Hopefully, our work may contribute to Latrice's successful navigation of Erikson's stage of autonomy versus shame. When referred for services, Latrice was having difficulties with peer and adult relationships as well as preacademic achievement. Had she continued with these challenges, a long-standing sense of incompetence might remain. However, her first year of preschool ended with reports of significant improvement in social, language, and preacademic functioning, laying the foundation for a long-term sense of competence.

Hannah's Story

MAYA DOYLE AND CARRIE OSTREA

Maya Doyle, PhD, MSW, LCSW, is an assistant professor of social work at Quinnipiac University and a rare-disease researcher and advocate.

Carrie Ostrea, MBA, is a "rare mom" who now works as a coach, consultant, facilitator, and program development strategist specializing in rare-disease patient engagement, advocacy strategy, and non-profit growth and sustainability.

Carrie and her husband experienced several years of infertility and fertility treatments before adopting two children internationally and learning they were pregnant (Ostrea, 2003). Two days after their baby girl, Hannah, was born, she was admitted to the neonatal intensive care unit (NICU) with an enlarged spleen and extremely low platelets. By 5 months old, her liver became involved, and she was diagnosed with neuronopathic Gaucher's disease type 2 or type 3 (www.gaucher.org.uk), an extremely rare autosomal recessive lysosomal storage disorder. There are no more than 300 children in the world with Gaucher's at any one time, as most die before they are 2. The devastating (and ultimately incorrect) prognosis was that Hannah would survive only 9 months.

Rare disease creates unique challenges for caregivers (Pelentsov et al., 2015). In Hannah's case, very little was known about Gaucher's, limited research was in progress to improve knowledge, and there were few medical specialists for Gaucher's or similar diagnoses. Caregivers become financially stressed by treatment and have profound feelings of guilt and loss. Hannah's family sent cells to researchers in Canada, the United States, and Israel in hopes of finding life-prolonging treatment.

Even though the neurologic progression had started, charming Hannah persisted. She was able to cruise, crawl, play with toddler toys, eat pureed foods, cuddle, and chase her siblings in her walker when she was 20 months old. She was enrolled in physical therapy, occupational therapy, vision therapy, developmental therapy, and hydrotherapy to preserve her function and comfort.

Siblings of children with rare and life-limiting diseases often take on caregiving tasks and have considerable knowledge of an affected child's condition but may seek to protect parents from awareness of how much they know (Malcolm et al., 2014). At the same time, they must manage normative development tasks and relationships with peers, family members, and other adults. Additionally, siblings often struggle with the family's limited ability to focus attention on them while caring for a sick child. Hannah's parents relocated to be close to her dad's family. They worked to balance parenting Hannah with the needs of her young siblings, trying to give them a "normal" life. Grandparents and friends made sure the kids were able to join activities and events. Hannah received nursing services, gradually needing more hours per week. Her mother stayed up with her for the "night shift," because she required a tracheotomy and g-tube, four to seven syringes of medicine several times a day, and oxygen. The family had a vital window of