Bereavement Services in the Hospital Setting: A Focus on How Children and Families Cope with the Loss of a Loved One

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> *"Play is often talked about as if it were a relief from serious learning. But for children, play is serious learning. Play is really the work of children."*
>
> --Fred Rogers

Going to the hospital can be a traumatic event for a child; whether the child is the patient or whether their parent, sibling or other family member is the patient. The field of Child Life focuses on developmentally appropriate coping skills for children in the hospital and other medical settings. Making sure that a child has no misconceptions over what is happening and what is going to happen is critical in the overall health of a child. A Child Life Specialist focuses on normalization for children that are in the hospital for long periods of time. This includes providing opportunities for children to play, express and continue a normal routine. Normalization also involves making sure that a child stays "up-to-date" with the rest of their peers as well as making sure the child continues to hit developmentally appropriate stages and milestones.

Along with normalization, Child Life provides intervention for children before and during procedures. They make sure that the child understands what is happening to them and around them in a way that they developmentally are capable of. They also provide interventions to encourage appropriate coping skills among the children in a hospital or medical setting.

Child Life is vital in maintaining a child's ability to cope and play in the hospital and other medical settings. Like Fred Roger's said, play is the work of children. A child uses play to express emotions and explore the world. It is how they learn to interact and how they fit in the world around them. Making sure that a child maintains that ability under less than ideal situations is vitally important to a child's physical, mental and emotional development.

As amazing as doctors are and with all the incredible advancements that have been made, the hospital is still a place where many families will lose a loved one. This can be a very traumatic experience for everyone involved. Bereavement services and programs can be hard for doctors and nurses to implement along with their other duties and responsibilities. Child Life can be a great provider of these services for families when children are involved. Whether a family loses their child or whether a child is the one losing a family member, Child Life Specialists and other professionals can provide intervention to allow appropriate grieving and coping with the loss. This paper will review theory involved with loss and grief, interventions for the grieving child, interventions for the grieving family and a review of hospital bereavement programs.

Literature Review

Theory

In the field of psychology and social sciences, there are many theories that guide our practices and our thinking towards the people we work with. In the case of Child Life, it is vital that we know the developmental theories and how children develop their physical, cognitive and emotional existence.

One of the most widely talked about theories of development in children is Piaget's theory of cognitive development (Wadsworth, 1979). In this theory, Piaget describes 4 stages. These stages are: (1) Sensori-Motor Intelligence – This stage starts at birth and goes until a child is around 2 years old. At this time, most of the child's development is of the motor skills. (2) Preoperational Thought – This stage starts at 2 years old and continues until about 7 years. This is the stage where children learn language and begin conceptual development. This is also when we see "magical thinking" in children. (3) Concrete Operations – This stage begins at 7 years of age and ends at age 11. A child's ability to think logically develops greatly during this time. This is when a child begins to understand concrete concepts. (4) Formal Operations – This final stage of cognitive development is where a child is able to apply the concepts that they have mastered to various areas of life. This stage goes from age 11 into the adolescent years to around 15 years of age.

(Wadsworth, 1979)

Along with knowing the cognitive development of a child, it is important to know the implications of this theory. For example, what does the developmental stage of a child mean for their concept of death, ability to mourn and cope with a traumatic event such as the loss of a parent or sibling?

John Bowlby's (date***) theory of attachment is important to consider when discussing bereavement and planning services, because there can be no grief if there is no attachment to the deceased person. Therefore, knowing how attachment and separation anxiety manifests is crucial in providing effective bereavement services to family members who have lost a loved one.

Bowlby's theory primarily revolves around the formation of bonds, between a mother and child, or father and child. It also focuses on the maintenance of the attachment. When a death occurs between a bonded relationship, whether expected or not, it causes a disruption in the attachment, resulting in separation anxiety. There are 3 steps of separation anxiety: protest, despair, and detachment (Garcia & Pomeroy, 2011). Protest is when a child screams and cries what separated from their caregiver. Despair is when the child experiences anguish upon continued separation from the attached person and the final stage is detachment, where a child becomes emotionally detached from the separated caregiver and can struggle attaching to new people (Garcia & Pomeroy, 2011).

In Children and Loss, Elizabeth Pomeroy and Renée Bradford Garcia (2011) discuss how along with his theory of attachment, Bowlby came up with 4 phases that people go through after the death of a loved one. The first phase of grief, according to Bowlby, is the stage of denial and numbness. The second stage is yearning for the deceased person. People will tend to see signs from their loved one during this phase. The third phase is disorganization and desolation and the fourth stage is acceptance and reorganization.

Bowlby is not the only psychologist that has developed a model of stages of grief. Garcia and Pomeroy (2011) talk about Kübler Ross's stages of grief, Worden's task-oriented framework of mourning, the Freudian theory of loss, Eric Lindemann's crisis theory, and Rando's theoretical framework of the grief process. They also discuss frameworks of grief such as a strengths-based focus and a constructivist framework. Each of these models walks a grieving person through denial, anger,

and some sort of adaption. Each model focuses on a different viewpoint of grief. Some models such as J. William Worden's, are task-oriented, meaning there are specific things that a person must complete in order to process grief. This includes acceptance of the loss, working through the pain, adapting to a new life and to "emotionally relocate" the deceased person and move forward with life. Some models are free-flowing and allow the notion that grieving individuals are able to go back and forth from stage to stage; that it is not necessarily a one-after-another process.

There are many concepts that are universally accepted about death. Herman Feifel (1990) discusses some of these perceptions that he found in the research that has been done on death, grief and bereavement. For example, the notion that death can affect anyone at any time is a universally accepted statement. Other perceptions such as the fact that grief does not signify weakness and that there are many ways that people grieve and cope are also strongly prevalent in our society. Different types of personalities are guaranteed to grieve in different ways. Amelia Pohl (2000) talks about how social people will grieve much differently than an introverted person. Pohl says the introverted person tends to cope better by internal reflection and meditation where as an extroverted person will cope better in going to a support group and sharing stories with people who have similar experiences.

When looking at bereavement programs and services, it is important to understand these theories and the fact that because each person is different and that each child is at a different stage of cognitive development, they will all cope

with grief in a different way. As a professional providing bereavement services, whether as a counselor, social worker or Child Life Specialist, there are ways of assessing people to know how they will be impacted by grief. Samar M. Aoun, et al. (2015) conducted a study from which they developed a 3-tiered risk assessment tool. The three levels are high risk, moderate level, and low level. The study was focused on recognition of Prolonged Grief Disorder (PGD).

Aoun, et al. (2015) discusses the criteria for each of the risk categories. They also discuss the types of support that are needed for each risk category. People were placed in the low-level risk category if they met 1-2 of the PGD criteria. An example of a person in this category would be someone who was mourning the death of a parent. This grieving person needs support from family and friends; from people that are close to them and know them best. This is a very personal and informal form of support. The moderate-level risk category contained individuals who showed 3-4 of the PGD criteria. A person in this category could be grieving after losing a spouse. Someone classified in this category needs more structured support, such as a support group or other community supports. The high-risk level needs the most support. These people have 5 or more criteria for PGD and need the support from a counselor or some sort of mental health professional. A person in this category will have lost someone significantly close to them such as a child or a spouse.

The coping process is different for each family, each person and definitely each child. G. Gordon Williamson and Shirley Zeitlin (1994) discuss the coping process and contributors and influences on how people cope, focusing mostly on

children. They start by defining coping and stress; coping as how a person adapts to their needs and to the environment around them and stress being the tension when the environment is seen as a threat to a person's well being.

Williamson and Zeitlin (1994) say there are four main steps in the coping process. These steps are to determine the meaning behind the event, create a plan of action, implementing that plan for themselves, and evaluating the effectiveness of their way of coping. Most of the time, these steps are not in the forefront of people's minds when they are trying to cope through grief. We have talked before about how there are many factors that affect how a person grieves. Cultural customs, beliefs and values, knowledge, family connections, environmental supports and physical capabilities all impact how a person grieves. These factors can also act as resources for a person dealing with the loss of a loved one. For example, a person grieving the loss of their mother can turn to the comfort of their religious beliefs and know she is in a better place and will see her again someday. They can provide comfort and support to allow the person to adapt to the life without their loved one.

The Grieving Child

Child Life, though focused mainly on the sick child, also works with the children of adult patients. Most of the research on bereaved children discusses developmental theory, attachment theory and the development of a child's concept of death. When a loved one dies, it is important to know where a child is cognitively because that will tell you how a child is able to grieve.

There are many things that influence how a child will respond to a loss. Cultural factors, circumstances of the death, age and developmental stage that he

child is at impact how a child grieves (Krupnick & Solomon, 1987). This section is going to walk us through the cognitive development of a child and how that impacts their understanding of death and their coping with the loss.

Development of the Concept of Death

Sherry Johnson (1987) lays out a three-step process to the development of a child's concept of death. She says that from 3-5 years of age, a child struggles with the idea that death means a person is gone for good. This finality is not understood at this stage. The second step to death concept development is when the child understands that death will happen to everyone, eventually; however, the idea of death still occurs "outside of me". This stage occurs between the ages of 5 and 9 years old. The third stage is from 10 years of age and beyond. At this point, it is understood that death happens to everyone; including oneself and that it is completely permanent.

This three-step process to the development of a child's concept of death cannot be understood without first understanding the implications of Piaget's model of cognitive development. A concept of death cannot be developed without other concepts formed first.

Birth-Two Years Old. In this stage, a child is in the sensori-motor intelligence stage according to Piaget (Wadsworth, 1979). This stage focuses on motor skill development. Shirley Johnson (1987) discusses this age in detail. This stage is where learning is very much a stimulus-reaction exchange. The author refers to the popular game for babies and toddlers of peek-a-boo. Peek-a-boo does many things for the cognitive development of children at this age. It helps a child

learn awareness of others as well as object permanence. This is also the time in a child's development when separation anxiety is prevalent. Johnson argues that a child at this age does not grieve but experiences separation anxiety, alone.

Two-Seven Years Old. The two to seven year age range is the stage of Preoperational development and when children start really experimenting with their environment for the first time (Johnson, 1987). This is the time when we see "rapid conceptual development" in children (Wadsworth, 1979). Children in this stage of development will have "magical thinking." Magical thinking is when a child's imagination and cognitive development allows the child to perceive occurrences and situations as different than they actually are.

Johnson (1987) talks about how at this age, a child understands that people die and that when people die, they are no longer here. Even though this is true, they do not understand that the deceased person will not come back. This is due to the magical thinking. Cartoons and TV shows that a child sees may help to support this type of thinking in a child. Many cartoons, such as Looney Tunes, will show a character fall of a cliff and they are still alive. They see videos games where their characters "die" but come back to life when they start a new round. Children will see an actor or actress die in a movie or TV show, but might see them in a different movie the next day. This magical thinking can cause a child to have misconceptions about death. This may cause a child to ask when they can go see their grandma again or when their dad will come back home. Children at this age also tend to feel a lot of guilt when a person they love passes. Children may think that they did something to cause the passing of their loved one.

Seven-Eleven Years Old. A child who is in this age range is considered to be in Piaget's concrete operations stage of cognitive development. This is the stage where logic and reasoning controls the child's thinking (Wadsworth, 1979). Johnson (1990) talks about how this is the age where children start to fear death. Children are able to see factual reasons for a death, such as cancer or a heart attack, however they struggle when a death does not fit into their previous abstract thinking about the world. The example that Johnson gives is the concept that bad things happen to bad people and good things happen to good people. A child can experience anxiety when a person they perceive as being good dies, especially if the death is a tragic accident or sudden.

Adolescents. In the formal operations stage of development, adolescents become able to apply their logic and develop the ability to problem solve (Wadsworth, 1979). Teenagers are on a journey to self-discovery, trying to determine who they are separately from their surroundings. Children at this age are battling the need to be independent from their family, yet knowing they should spend time with the person who is sick or dying (Jones & Tesh, 2011).

Adolescents live largely in the moment and the concept of dying can be a distant possibility. This can cause an adolescent to fantasize about death (Johnson, 1987). Johnson (1987) also says that personal beliefs and social influences play strongly on how the adolescent views the world. This can impact how a child views the death and how they cope with the passing of their loved one.

The initial reaction of adolescents can be much different that the reaction of other age groups. An adolescent who is grieving the loss of a loved one may, at first, may

wish to continue on as if nothing happened. They also may respond with feelings of helplessness or fear of death (Raphael, 1983).

Interventions

Russell McIntire (1990) talks about 3 tasks that children must accomplish to process their grief. These are: understanding that the person who passed is no longer there, feeling their feelings about that fact and then reinvesting in their life. When helping children through a loss, it is important to understand where they are cognitively and developmentally as to not have unrealistic expectations for the child's understanding of the situation.

If a child does not cope through their grief, extreme changes in behavior can occur. McIntire (1990) talks about this in his article on the Dougy Center in Portland Oregon, and how grief can manifest in children when their emotions are not expressed. Children can experience lack of sleep, nightmares, and regression in development. This regression can be seen in habits like thumb sucking or in more extreme ways such as a major decline in school productivity and grades.

McIntire (1990) and the staff at the Dougy Center believe that play is the best way for children to process and work through their grief. Along with this, one of the most important things you can do for a child in any form of traumatic situation is to give them a sense of control over themselves and their environment (Jones & Tesh, 2011). This sense of control can be given to a child by allowing them to ask questions, answering honestly to what they ask (Johnson, 1987). Honesty is very important when dealing with grieving children. Children are very aware of when people are hiding something. This can cause anxiety for a child (Pearson, 2009).

Another way of empowering a child to have a sense of control is to allow them to give them the freedom to decide if they wish to attend the funeral, see the body, etc. Allowing them to write letters to their loved one, draw pictures and other creative outlets, allows a child to express their love for the deceased person (Jones & Tesh, 2011).

Jones and Tesh (2011) say for adolescents, interventions to assist in coping can, at times, be similar to interventions for a younger child. Talking to their loved one can be a helpful way to express their feelings and talking to a peer in a similar situation can help with any fears or concerns that the teen has. Talking to other people who have experienced loss can diminish the adolescent's feeling of isolation.

The Grieving Family

For this paper, we are going to focus on Raphael's (1983) sections of sudden infant death, death in the childhood years, and death of the adolescent.

Infant Death

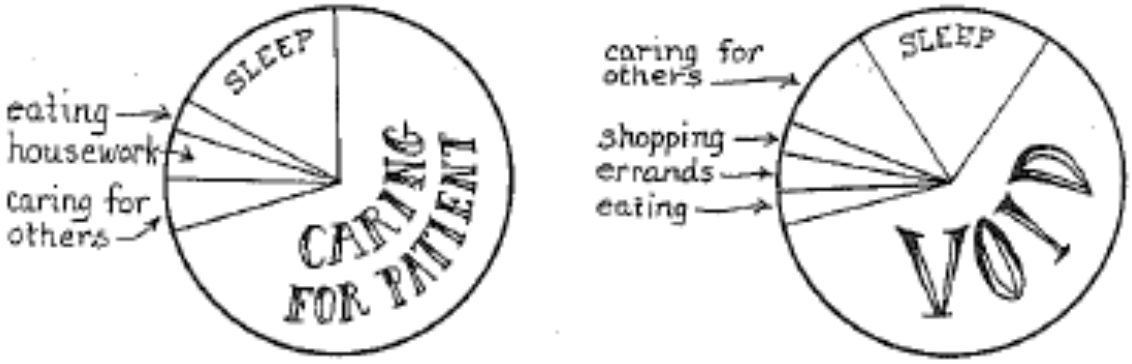
Doctors are still not sure what the cause is for sudden infant death syndrome (SIDS), but they know that it is one of the most common reasons that infants die in their first year of living (Raphael, 1983). This is just one of the complications that newborn babies may experience. From prematurity to heart problems and other congenial conditions, the health of a baby can be jeopardized.

When dealing with a loss of a child at this stage of development, it is important to understand the degree that the parents have been able to attach and bond with the baby (Raphael, 1983). When it comes to parental grieving, mothers are more likely to blame themselves for the death of their newborn child. The

feeling of separation that the mother feels when she loses a baby can cause extreme distress.

Death in the Childhood Years

When an older child dies, it can be harder for a family, because a preexisting relationship has occurred that is not there with a newborn. This child is known by the family as an individual person who has likes, dislikes, a sense of humor and a personality of their own (Raphael, 1983). A child at this age is completely dependent on his or her parents and the parents spend a majority of their time caring for the child. When it comes to the cause of the child's death, it can effect the grieving of the family. A family will grieve differently if the death is sudden than if the child has been sick for a long time (Johnson, 1987).



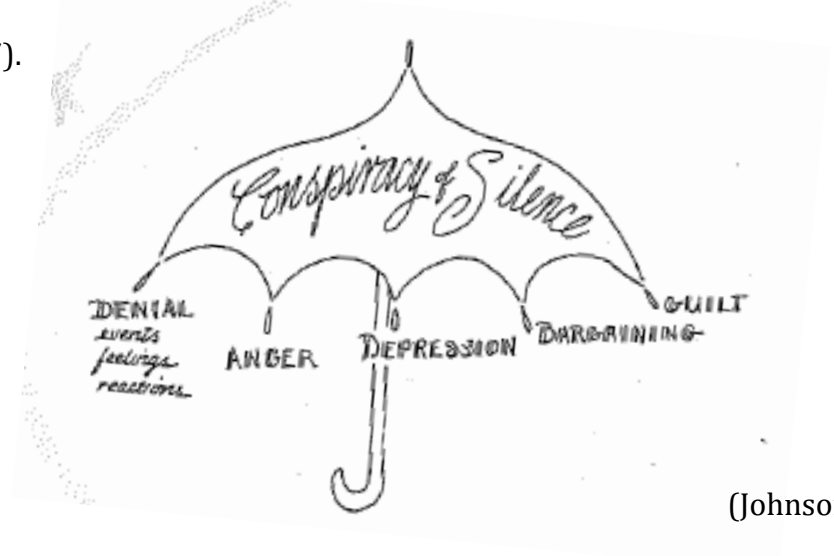
(Johnson, 1987)

Family Themes in Grieving

When a family is dealing with a loss, there can be many unhealthy patterns that they can develop to deal with, or to avoid dealing with, their grief. One of these patterns is scapegoating. Scapegoating is when the blame is placed on one or two people and they carry that burden with the (Johnson, 1987). This can be a

dangerous habit for surviving family member after the loss of a loved one. Johnson gives examples of siblings who we used as the scapegoat for their family member's death and it ends up being psychologically damaging to the person.

Johnson (1987) also talks about the conspiracy of silence. The conspiracy of silence is a pattern that is validated by not just the grieving family, but the family and friends of the family dealing with a loss. This pattern is when people are afraid to talk to a family about their loss and perpetuate the pattern of avoidance with the family. They will refuse to talk about their loss and thus will never deal with the loss. If the death of a child is sudden or unexpected, it may be hard for the family to explain to other people what happen (Green, Osterweis, & Solomon1984). There can be so many questions that people may want to ask, but will not because they do not want to make anyone upset. This pattern of avoidance leads to the development of other negative habits of grief such as the previously mentioned scapegoating (Johnson, 1987).



(Johnson, 1987)

When there are surviving siblings involved, it can be hard for parents to deal with their own grief, let alone ensure that a child understands what is happening. We talked earlier about how the way a child understands death largely depends on

their stage of cognitive development (Krupnick & Solomon, 1987). Because of these differences in development, a child may not respond to the death of their sibling in the way that the parents believe they should. For example, a 7 year-old sibling who is in the concrete operational stage may not understand what you say when you say that their sibling has passed on. They may ask, "Passed on to what?" These abstract and religious views that comfort us as adults can confuse a child in their understanding of what happened (McIntire, 1990). Similar to misconceptions about death, children tend to mirror adults' behavior & anxieties following the death of a family member.

Because the way that children cope with grief and anxiety is so different than that of adults, it is important to allow a variety of ways that a child can express the feelings and emotions that they are experiencing (Pearson, 2009). Teens will cope with a loss much differently than children of a younger age.

A Review of Bereavement Programs & Services

> *"Although grief is not an illness, health professional and health care institutions have important roles to play in caring for the bereaved, both before and after the death of a patient."*
>
> (Green, Osterweis, & Solomon, 1984)

Programs for Family

Many of the articles that gathered were a review of a new or preexisting bereavement program in a medical setting. The following will review each program discussed, as well as talk about what the roles of health care professionals should be in the grieving process. In a review of studies on bereavement services provided

after the death of a child by Cohn, R., Donovan, L., Russell, V., & Wakefield, C. (2015), they discuss how one qualitative study showed that bereavement services benefitted families cared for. These services were mostly geared toward providing education and support for families such as support groups, phone calls, as well as remembrance programs helped the families feel less isolated after the loss of their child.

One article by C. Cox et al. (2014), talks about the family-centered children's palliative care program that was implemented at one hospital and the knowledge that they gained in working with these families. While palliative care is different than end of life care and bereavement services, it is still important and impacts the families coping with the situation. The program focused largely on the fact that there are social influences on a family's grief. This entails understanding that the way a family perceives the event and what their values as a family are, impact how they will cope. In this program, they reflected on their experiences with the families to bring focus to less on what is feasible and more on what the family needs.

Breslin et al. (2013) discussed various views on a whole-hospital approach to bereavement services. This article pointed out the importance of the whole hospital being committed to seeing through the care of their families, however it also focused on making sure the program was flexible to fit the needs of the various units. Some units, such as an oncology unit, may need more palliative or end of life care services, where as units like the emergency department will need other supports for families.

Dory Hottensen (2013) writes about caring for loved ones after a patient dies and in her article, she mentions a five-step program that the New York-Presbyterian

Hospital follows when providing bereavement services to family and friends of a deceased patient. These 5 steps are as follows: (1) Define what or where the biggest need lies. Does the biggest need lie in helping a family explain what is happening to a younger sibling? This is important because providing services for an area that is irrelevant to a family or is unneeded, can be a bigger burden to a family in their time of loss than intended. (2) Identify the people that can carry out the services and the resources available to do so. Will the nurses be providing the services? Or would the use of Child Life Specialists or volunteers be more effective? This is a very reasonable step of making sure that a hospital has the means to provide such services. (3) Provide the proper training to implement services. It is important that the nurses, volunteers or other professionals know the protocol for the services and how they are to be delivered in order to provide a consistent and supportive service to a grieving family. (4) Make a plan and implement the program. This is where to decide what specific services will be provided and when. Examples of this are a balloon basket being delivered after the death or a sympathy card being sent on the anniversary of the patients passing. (5) And finally, evaluating the success and effectiveness of the program.

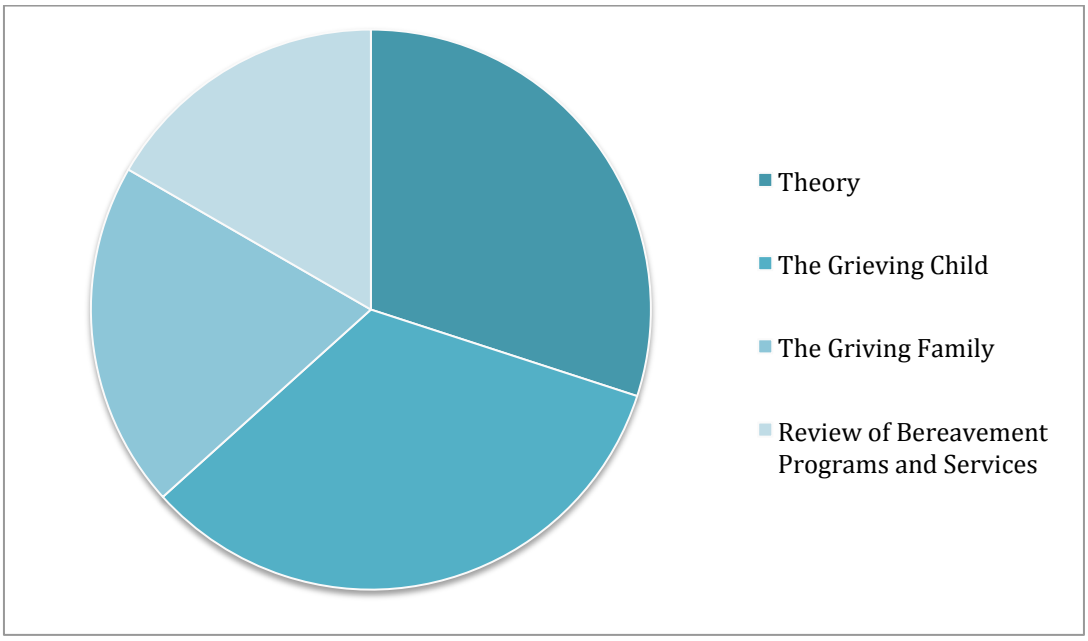
Programs for Professionals

Most of these programs can be directed to the families of the deceased person, yet some do focus on the grieving needs of the nurses, doctors and other staff that interact and build relationships with their dying patients. Katrina Fetter (2012) describes in one article, about the attempts of an inpatient oncology unit to provide bereavement services for the nurses and staff after a patient passed away.

This hospital understood the impacts of compassion fatigue and its affects on not only the health care professionals work, but also on their physical, mental and emotional health. These interventions included memorial lunches inviting the families of the deceased patients, remembrance trees and other ways for staff to work through their grief and cope with their own losses.

Discussion and Implications

This section will discuss the information reviewed above. The literature review was split into 4 sections with subsections underneath. The main sections are divided as below.



In the field of Child Life, it is the main focus to make sure children have no misconceptions about what is going on around them in a medical setting. This can be in the form of interventions to help a child prepare for a procedure so he or she experiences no surprises, working toward normalizing their routine and life in the hospital to continue proper mental and emotional health as well as social

development. When it comes to bereavement services, this is no different. Child Life Specialists are just that: professionals who specialize in the life and development of children.

Child Life students are able to complete a practicum with the Child Life department at Mercy Medical Center in Des Moines, Iowa. While there, the student spends each week focusing on a different Child Life aspect throughout the program. One of these weeks is focused on bereavement services for families. These services can include memory making, comfort and support for families, encouraging privacy and other interventions that upheld the dignity of the patient as well as the family.

Jones & Tesh (2011) mentioned how providing transitional objects can provide comfort for the family and give them something to remember their child. At Mercy, the Child Life Specialists will provide objects like this in the form of stuffed animals or blankets. When a patient was very ill and nearing the end, a quilt or blanket that was hand made and donated to the hospital would be given to the family. Many times the child would be covered with the blanket in his or her last days and the blanket would go home with the family.

In the case of a family that had other children, memory making becomes very important. Allowing siblings to draw pictures for the patient, make them crafts and other things to decorate the hospital room can be beneficial for many reasons. For one, it can make the environment feel less cold and foreign for the family, but also allows the children to build memories with the dying loved one.

Knowing how a surviving child understands the situation after the passing of a loved of, or even while their loved one is ill is important because it can make a

child feel helpless, scared or even guilty. Sherry Johnson (1987) talks about bereavement interventions. Using various forms of expression to help a child cope with their grief is important to the mental wellbeing of the child, as well as providing comfort to their parents and family that they are okay. These forms of expression can be done in storytelling or pictures, real or drawn for younger children or journaling and other reflective interventions for older children.

Earlier in this paper, there was a discussion of the importance of play to a child's development. Play is a great way for children to express anger, guilt, frustration and any other emotion that they are feeling in a natural way. An example of this is using puppets where one puppet is going through a similar situation to identify a child's thoughts about the situation. Something could be said such as, "This is Timmy. Timmy is sad because his mom was really sick and passed away. What do you think we could say to Timmy?" This can allow a professional to see the child's understanding of the situation. The child might say, "It's okay Timmy. Your mommy is in a better place." Or the child could say, "Maybe if you hadn't been bad at the store, mommy would come back." With an intervention like this, one can observe if a child has any misconceptions or if they are healthily coping with their grief.

Giving children books about kids in similar situations can help decrease children's feelings of isolation. These books are available for any age group and can help a child see that it is okay to cry as well as provide healthy demonstrations of coping skills.

Conclusion

Bereavement is a very important aspect of the care provided in a hospital or other medical setting. It is very important, when providing bereavement services to understand all of the things that go into the grieving process and influences that impact a family in this vulnerable time. Along with understanding family patterns and coping patterns, it is also important to understand where people, especially children are at in their cognitive development when providing such services. With the use of Child Life Specialists in situations where a child is the dying patient or the family member, these services can be provided in a way that best fits the family being cared for.

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