Exploring How a Palliative Care Team Impacts the Grieving Process for Families After the Death Of a Child

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Abstract

Background: For parents, there is nothing more devastating than the death of their child. The initial support families receive after the death comes in all forms, such as, family, social network, clergy/church, professional counseling and support groups. For many, these support systems are sufficient in providing the support they need during their journey of grief. However, for others these systems are not in place or they find the support received by others is either lacking or not in line with their values and needs.

Purpose: The purpose of this study was to explore how a pediatric palliative care team can affect the grieving process for families after the death of their child.

Methods: The research design was an interpretive phenomenological qualitative study involving parents of children who had died while undergoing palliative care treatment at a Mid-western academic pediatric hospital. Parents were interviewed and all audiotapes transcribed and analyzed for prevalent themes.

Results: Five major themes emerged after thematic analysis including: (a) fear of their child being forgotten (b) loss of purpose or meaning in life (c) loss of support after the first one to two years (d) lack of counseling resources (e) lack of sibling support.

Conclusions: Findings from this study demonstrated the need for additional support and resources for bereaved parents. Providing such support and resources would be an impactful way for pediatric palliative care teams to continue the work of supporting these families through the grieving process.

Introduction

For parents, there is nothing more devastating than losing a child. This enormous tragedy affects them intensely and causes significant disruption to the family unit. Many parents struggle with understanding and accepting this loss, which is out of the natural order of life. The impact of the death felt daily, and the devastating feelings may continue for several months to years. Often, parents receive support from their social network, i.e., family members, and friends. While others also receive support from their clergy/church, professional counseling, and support groups. However, there are many who lack support or find the support received was not helpful or in line with their needs. In addition, there are many who experience support from their community but often these members of the community withdraw after the initial few days to weeks following the funeral, resulting in a deep sense of isolation for the family[1].

At the study hospital, bereaved families are provided with support from the hospital wide bereavement program, which includes an initial telephone call from the bereavement program chaplain within the first two months expressing condolences. Mailings are then sent 1, 3, 6, 9, and 13 months after the death of the child. Each mailing includes information on expected feelings and resources for support, i.e., support

groups, professional clinicians, hospital sponsored bereavement camps, etc. In addition, a quarterly memorial service with a light lunch following is offered to all bereaved families who experienced the death of a child in the previous quarter.

The pediatric palliative care (PPC) team, known as the Pediatric Advanced Care Team (PACT), at the study hospital would like to explore the most effective way to provide bereavement follow-up to the families who received PACT services during their child's illness/injury. Currently, PACT sends a bereavement card within a month after the death of a child followed by their service personally signed by all members of the team. In addition, follow-up telephone calls are attempted when time allows in the workflow of the team. However, previous literature indicates this is lacking and a more comprehensive follow-up bereavement outreach is important for the families to feel supported during their bereavement journey[1]. The purpose of this study is to explore how a PPC team can positively impact the grieving process for families after the death of their child.

Study Aims
1. Describe the families' experiences of receiving current bereavement support provided by the study hospital PPPC team and house wide bereavement program
2. Determine what bereavement support facilitated the grieving process
3. Determine what bereavement support inhibited the grieving process
4. Describe what bereavement support would be most beneficial and impactful for families after the death of a child

Review of the Literature
Grief and Grieving
Dr. Elisabeth Kubler-Ross identified five stages of grief, which have become well respected and accepted, despite early misunderstandings, as the framework for navigating life after the loss of a loved one. Her initial intent was to identify the emotions experienced by actively dying terminally ill patients. She later generalized her framework to the broader stages of grief for the grieving community after the loss of a loved one. These stages are denial, anger, bargaining, depression and acceptance[2].

The five stages allow the grieving to heal through feelings experienced during each stage including denial, shock, anger, resistance, guilt, emptiness, depression, adjustment, and eventually, acceptance. There is no linear fashion or time limit in which those grieving travel through these stages. In fact, many will often find themselves going in and out of the stages, spending as little as minutes to as long as months or years in each stage as they grieve. Often, these stages are revisited in no particular order as life evolves and the grieving family learns to live without their loved one[2].

Self-identity for adults are often tied to the parental role. The death of a child calls into question this identity as it undermines the parent's role as protector and devalues the investment in caring for their child[3]. Often, the relationship they have with their other child(ren) is affected beginning with the care of their sick child and continuing post death. Mothers, in particular struggle with other relationships such as, work, friends, shared hobbies, and partners. The lack of these relationships can lead to negative perceptions of their social support, loss of purpose in life and potentially destructive thoughts and behaviors[3].

In an attempt to restore a personal sense of meaning after their child has died, many bereaved parents will assign meaning to the death allowing them to identify the extent of distress they experience. By doing so, this allows them to envision a meaningful life leading to a better adjustment on the tragic death of their child[4]. Parents who are unsuccessful in this will continue to have distress with ongoing attempts to find a sense of meaning in their life which may lead to complicated grief.

The very deep grief that develops from the death of a child is often difficult for some parents to surmount over time resulting in a high prevalence of posttraumatic stress, substance abuse and psychopathological disturbances[5]. This requires an additional demand on health professionals to comfort and support these parents through the mourning process with the intent of providing them a foundation for developing a healthy grief process.

Despite the importance of being supported through each of the stages of grief and education in recognizing signs of complicated grief, the development of posttraumatic stress, potential substance abuse, and psychopathological disturbances, there has been minimal research in identifying ways to support parents and families in the months and years following the loss of a child. Once appropriate support is identified for these families, the hope is the impact will be profound. However, until further research is conducted to identify effective and sufficient support with grieving families, there appears to be a missing piece in how a palliative care team can fully support a family after the death of their child.

The Role of the PACT
The role of PACT begins prior to the death of the child. Ideally, it is best if this relationship begins at diagnosis, however, in many instances the initial consult request occurs when the medical team has identified no other medical treatments to offer. Regardless of when PACT becomes involved, their role is to provide an added layer of support for the patient/family while they navigate the difficult journey. This support often includes emotional, psychological, spiritual and pain/symptom management.

After the death of a child, continuing this extra layer of support could be instrumental in assisting these families during the grieving process. What does that support look like and what is the best way to provide that support? It is our team's belief this support should be defined by parents and families who have experienced the loss of a child. By doing so, it will eliminate any risk of erroneous assumptions made on behalf of these individuals by someone who has never shared their experience in grieving the loss of a child.

Hospital Bereavement Support
An intense relationship between the family and staff caring for their child frequently develops over the period of a child receiving care until their death[1]. This relationship was intensified and appreciated more if the staff regarded their child as an individual that is worthy of dignity and respect before and after death, thereby recognizing them as human and with social worth[4]. With the death of the child, this relationship is suddenly disrupted and future contact between care givers and family comes to a halt causing a secondary loss for the family[6]. For many par-

ents, their grief journey is adversely affected with this additional loss of contact from the medical staff who cared for their child. The connection families make with the members of the medical team who care for their child often becomes one of significance in their coping abilities. When that relationship is severed, and they receive little or no bereavement follow-up, parents will often report a feeling of abandonment resulting in a deep sense of isolation, betrayal and anguish[7,8]. Families often report when hospital staff contact them after the death of their child, they feel less abandoned and believe their child mattered to those who cared for them[6].

Bereavement support from hospital staff varies from center to center. Typically, there are two goals of bereavement care for families after the death of their child. First, to facilitate adaptation so the bereaved parents and family can heal and process the death in a way that allows them to continue living meaningful lives. Secondly, identifying persons at risk of experiencing difficult bereavement reactions to provide early intervention[9].

Hospital wide bereavement support often involves providing information regarding the nature of grief and expectations for the parents/family in the following initial weeks, months to first two years. This may include, but not limited to, condolence letters/cards; expected feelings; support group contact information; memorial events; bereavement seminars; and, signs of complicated grief process indicating a need to seek professional help. This information and education resources may be provided through telephone calls, in person, and/or mailings. Parents report contact from staff, i.e., yearly memorial services, and receiving information on the grief process is appreciated[6]. Survey research was conducted previously to evaluate one such bereavement program through questionnaires via mailings[1]. Overall, the parents surveyed appreciated the mementos and the mailings but felt sibling support and bereavement services closer to home were lacking. In this survey, demographics on disease state and whether the death was sudden versus a lengthy illness were not collected and may have affected the results. In addition, an initial phone call was initiated to seek interest in the survey research and the investigators found that many of these calls were quite lengthy suggesting the need for bereaved parents to talk about their experiences.

A more recent study by Snarmanet.al.,conducted at a pediatric cancer treatment center, employed a qualitative design to conduct focus groups for bereaved parents after the death of a child from cancer[8]. The overall goal of the research was to explore the role of the healthcare team in the grief journeys both before and after the death of their child. Bereaved parents identified integral aspects of their grief journey to be on-going support from the health care professionals (HCPs) and the institution. There were four prevailing concepts, which emerged from their analysis:
1) The importance of strong and ongoing relationships between HCPs and bereaved families; 2) The importance of high-quality communication between HCPs and families; 3) The effect of negative experiences between HCPs and families on parental grief; and 4) The importance of the institution's role in the grief journeys of bereaved parents. In particular, the parents felt the hospital was a "sacred place" and on-site memorials of their child was important regardless if the child died in the hospital or the home. In addition, grief was a continuum and that bereavement services should be made available beyond the first year after the death as each parent grieves differently and at different times along a continuum.

Research Gap

There has been a fair amount of research performed to identify the risk factors for prolonged grief disorder (formerly known as complicated grief), as well as, potential greater psychological distress during the bereavement period[10]. However, limited research has examined the needed support from a PPC team after the death of a child from the parent's perspective. Through an extensive review of literature, a dedicated qualitative descriptive study approach utilizing individual interviews with bereaved parents has not been completed. In order to identify meaningful support for future bereaved parents, it is paramount to allow current bereaved parents to voice their thoughts through their experiences what follow-up support would have been impactful during their grieving process.

Methods

Design
An interpretive phenomenological qualitative descriptive study approach was employed. A convenience sample of eligible participants were recruited from the list of parents who loss a child in 2014, 2015 and 2016 who received support from PACT during their child's illness at the study hospital.

Sample & Setting
The purposive sample targeted participants or parent dyads who lost a child in 2014, 2015 or 2016 and received support from PACT during their child's illness. Participants included the direct caretakers of the child at the time of death. Consented participants were invited to complete an interview with a research team coordinator during pre-arranged gatherings at a private room in a public library.

Inclusion and exclusion criteria
Participant eligibility criteria included: (a) Child death in 2014, 2015 or 2016; (b) Received support from PACT during child's illness; (c) Able to speak and understand English; (d) Able to verbally participate in a face-to-face interview; and, (e) Able to provide informed consent.

Participant exclusion criteria included: (a) Unable to speak and understand English; (b) Child in Child Protective Services custody or known parental custody issues at time of death; and/or (c) Significant social issues affecting the relationship between child and parents at time of death.

Data-Collection Procedures
Approval by the University Institutional Review Boards (IRBs) was obtained prior to initiation of this study and informed consent was sought from each participant. After completing study-activation training procedures by the Principal Investigator (PI), identification and screening of eligible participants to enroll in this study was initiated by study team members. Through mailings to eligible participants, they were provided with the purpose

of the study and given the opportunity to receive more information. Participants were directed to call one of the study team members to obtain further information about the study and the participation in an interview including discussion of the risks, benefits, and alternatives to participation. Interviews were audio-taped utilizing the previously prepared interview question guide. The interviews were transcribed by a professional transcription service. Written consent was obtained the same day as the focus group immediately prior to the session.

Table 1: Interview Guide

After the loss of your son/daughter, (insert name), what type of information/resources did you receive on a regular basis from the hospital?
Can you tell us what was most helpful?
Can you tell us what was least helpful?
Can you describe your feelings each time you received any information from the hospital?
Can you think back and identify anything that would have been helpful to you that you did not receive?
Tell me how you would have felt, and/or if it would have been helpful to you, to have received items to recognize special days, such as, holidays, birthday, anniversary of (child's name) death, mother's day, father's day, etc.?
(If there are siblings only) Tell me what would have been helpful for you to receive to assist (child's name) brother(s)/sister(s) mourn the loss of (child's name). Examples may be, books, coloring books, grief activity books, etc.

Participant Interview Procedure
Duration of the participants' interviews included two hours of discussion driven by a prepared script of questions. Two qualitative nurse researchers and a social worker were present for each interview. After all interviews had been completed and the data analyzed, study team members sent all participants a letter of appreciation through the e-mail for their participation in the study. The letter included a summary of the study findings and gave participants the option to provide feedback about the study findings to the principal investigator (PI). When identified during the interview process and permission granted by the participant(s), social work follow-up was performed through telephone call or email to provide additional grief and/or counseling resources. No further follow-up or contact was made with participants unless requested by the participant.

Data Analysis
Demographic data were analyzed with descriptive statistics. Demographic data for each participant was obtained which included participant relationship to child, age, race, education level, marital status, age of child at time of death, child diagnosis, and time in months since death of the child. Qualitative data from the interview was coded and analyzed for content analysis[11]. This form of qualitative content analysis is aimed toward summarizing the informational contents of the data and is not abstract or interpretive, but rather a straight forward description of phenomena. The benefit of using this approach is that it is more likely to result in a consensus among researchers[11]. This data analysis process is also aimed at summarizing the information obtained in the data and generating data codes that are derived from the data itself. These codes can then be organized by identifying the most common themes.

Results

A total number of 8 caregivers were interviewed with 2 being mother/father dyads. Of the participants, 62% were mothers and all participants were Caucasian. All but one participant had higher than a college education and 75% were still married to the same partner (child's parents). Care giver age ranged from 36-62 years and the age of the child at time of death ranged from 2.5-28 years. An average of 43 months had lapsed among the participants since the time of the child's death. All the children of the participants were non-verbal with a chronic life-limiting disease. After reviewing and compiling the results from the six focus groups performed, there were five overarching themes identified: 1. Fear of their child being forgotten; 2. Loss of purpose or meaning in life; 3. Loss of support after the first one to two years; 4. Lack of counseling resources; and, 5. Lack of sibling support.

Table 2: Major Themes Identified from Analysis of Interviews

Theme
1. Fear of their child being forgotten
2. Loss of purpose or meaning in life
3. Loss of support after the first one to two years
4. Lack of counseling resources
5. Lack of sibling support

Fear of the Child Being Forgotten
The fear of their child being forgotten was an overarching theme identified by all the participants. One parent worried no one "remembers their child", while another parent confirmed this by stating ". . . the biggest fear, and I don't know if you've heard this, and (I) still live with this, is the fear of your child being forgotten", "It's just remembering her."

Parents felt that remembrance of their child could be accomplished through many means. Telephone calls can be effective in sending the message their child is still thought of according to one parent, "just want to see how you're doing . . . (this) sends a message to them that they haven't forgotten, they still care." Another parent confirmed that even though they may not have appreciated it at the time, ". . . a phone call would've been kind of nice, now that I think about it, I don't know if I would've felt that way right at the time". There was a consensus the timing of these telephone calls was critical. Generally, all participants agree the telephone call would be more impactful after the first month or two after their child died as they felt they would be in a healthier state of mind to process the call. Anything less than that may not be appreciated or as impactful, "two weeks seems like a really short notice to do that", "at that point if they say how are you doing, you're still probably going to say not too good."; "I can't imagine how it is for everyone but for me, the first couple of weeks there was usually somebody there . . ."; "I wouldn't have answered it."; ". . . you're just kind of exhausted from life at that time." "I would say no sooner than a month. I would say that would be the earliest, maybe even 2-3 months."; when you've had some time to sit on things a little bit, and then it starts to sink in exactly what happened." Receiv-

ing these telephone calls from a familiar member on the team is more meaningful according to one parent, ". . . means more if it were someone that you had that relationship with", ". . . somebody that you knew was with you through that experience, because you feel probably a little more comfortable talking about it or sharing a memory". For one parent, leaving a voicemail if no one answers can be just as meaningful, ". . . saying we just wanted to say hello and see how you're doing, I think that carries a lot of weight with some people".

Another way of remembering their children can be through cards acknowledging special days during that first year. "I think it would've been nice. Just kind of a reminder."; ". . . a reminder of how much support they had through that process", ". . . a reminder of that relationship that was built over the course of some really stressful days and weeks and months"; "I think it's good, just because the more time goes by the less people acknowledge it, and it's still a very real thing"; "Special words, cards, acknowledgement . . . all of those things could turn the tide, . . . to get that card in the mail, or just to show that somebody remembered, because not all the time everybody does."; ". . . I remember her first birthday being really, really hard . . . I definitely think that would be helpful, because that's just about her." For one family, receiving cards may not have been helpful, ". . . that first year, you're the walking dead. What you do, where you go, I mean if anybody else says that they remember, I applaud them." Another family cautioned on having awareness on the cascade of dates as it may be overwhelming to receive multiple cards in a short period of time. In a situation where this occurs, they suggested receiving only one card acknowledging this, ". . . a card just saying we know you have some difficult days coming up, just wanted to let you know we're think about you", ". . . all this stuff happened boom, boom, boom, but they took a second out of their day to reach out to me. That's important."

Receiving something tangible was, or would be, seen as impactful by all the participants. Receiving a book with powerful and beneficial information on grief can provide validation of feelings and anticipation of what to expect in the first year. ". . . something that's like it's normal to feel this way . . . I mean everybody's had some kind of death in their family, but there's something about a husband, a child, a wife. I mean it's even different than your parents dying."; ". . . every day (I) would search why do I feel like this. I just was constantly trying to find some sort of answers as to why I would wake up every day and just . . ."; ". . . something I can absorb on my own time, my own feelings"; ". . . to have those right at my fingertips to start reading and not to have to, it's so hard to function, so to even get yourself to a bookstore, get yourself to look online to order something . . . it would've been better to have things I think given to me."

According to one parent, a personal note inside a book would have been very meaningful, ". . . if it came with that personal note from somebody that they worked with. Just thinking of you, I thought this might help". Books written by a parent who had a child die or books relied on by the staff were mentioned by two parents. As with the cards, waiting at least 1-2 months after the death would be most appreciated, ". . . everyone is so anxious to give you stuff right when it happens, right after, and you're not really absorbing anything, or you're thinking I'm doing okay, you know, I'm really, really sad but I'm doing okay.

It's just as time goes on."

Other impactful tangible items received included a candle with their child's picture on it, wind chimes ". . . I hear it and I just know", and an inscribed heart, "That was kind of like the happiest thing, . . . it is a significant thing.", ". . . it just hit, like right at the right time.". A suggestion by a pair of parents was to have a memory wall or statue as a way to stay connected to the hospital, ". . . some sort of something that when parents come back with other children that will make them want to choose that hospital.", ". . . it keeps his memory there, that he was a real person, he was really alive at some point in time. . . ", ". . . it's something to look at, it's a reminder that their kid was real and was here and those experiences matter."

Finally, an impactful way to convey remembrance and value of life to these parents, was by attending their child's funeral, "They came down from St. Louis to my daughter's funeral when 90% of our relationship was over the phone I think, that they would make that effort. I mean that's huge."; ". . . all of the, or most that we worked with came to either the visitation or the funeral".

Loss of Purpose or Meaning in Life

Loss of purpose or meaning of life for the surviving parent(s) continues to be a struggle for several of these families. As one parent shared, ". . . we haven't found that passion for anything yet or that, that makes our heart filled." "It's like your kind of going through stuff you like doing it, but there's something missing." Another parent described it as being unable to move through the grief process, "group of parents, grieving parents . . . weren't moving on". While another parent described it as not having a clear pathway, ". . . after the funeral is over, after everything else is said and done, then you have to figure out how to be a human again, and how to get back into life, when everybody else sees you differently." Providing validation for these families would be instrumental as they heal from their loss, find new ways to make meaning, and find new purposes in their lives.

Loss of Support after the First One to Two Years

These parents described a sense of strong support from family and friends in the first year after the death of their child. This support was crucial to many in helping them navigate through an extremely difficult time. ". . . when it does finally sink in and you finally realize this is my reality now, . . . is when those supports become really important."Some also found support through other families who had suffered the same loss of a child dying. One parent described his experience attending a park service specifically for bereaved families whose child died which provided him with validation he was not alone in this journey. "you look and you see all these kiddos being honored, and then you see the families, and it helps you recognize that you're not the only person that's going through that . . .", "it does help you realize I'm not in this by myself, there are other people that are dealing with the same set of circumstances, the same set of challenges."; what would've helped me is being able to go to a parent group . . . (and) sit down with these parents . . . and be like this is normal . . . ".

However, after the first year, and especially after the second year, this support began to fade away for these families leaving them feeling isolated in their grief, ". . . everybody just

wanted me to be, obviously they wanted me to be okay, but I wasn't okay, and then one by one they just stopped talking to me . . ."; "People have a different time line . . . they expect you to be moving on really rapidly and others understand it takes longer, but probably after that first year I doubt if people think about it very much at all".; ". . .people are really good for the first two years and now it's not really. . .". Encouraging families to foster connections may help enhance their coping in the years following their child's death.

Lack of Counseling Resources

Regarding counseling for the parents, each parent had thoughts on the benefit of counseling and how to best meet their needs through counseling. Most families thought counseling would be helpful but found barriers in obtaining such counseling. These barriers included lack of local resources in the area in which they lived (several did not live in the St. Louis area), personal resistance to counseling based on previous experience, and lack of understanding by counselors in regards to the grief experience of losing a child.

For those who did not live in the St. Louis area, finding a counselor trained in bereavement was difficult, and one trained in bereavement of a child was near impossible, "we didn't really have anybody local . . . we kept thinking that if we were closer there would be groups, because it was limited in our area."; "she was an extension of me and so it's like how am I supposed to relate and I know a loss is a loss but I feel like there's got to be somewhere, somebody to talk to and there's just not."And, driving to St. Louis for counseling was not an option for one parent, "I probably wouldn't have made the trip for that at that point". Most commonly, the parent(s) didn't feel just any counselor would understand the depth of their grief and would not be able to help them process through that grief or provide them with tools to navigate those waters. A counselor specializing in grief, especially that of the magnitude of losing a child, would be optimal, "you don't understand what it's like to lose a child until you lose your child . . . you're approaching it with a level of naivety, and ignorance"; "thought of how to move forward, but you don't know how to do it. How do I start where do I start! One parent felt a counselor specializing in grief would be able to provide her with the answers as to why she felt the way she did. Another parent wanted validation of "what's normal for grief" after losing a child.Even for the parents who lived in the St. Louis area, they also found it difficult to find an appropriately trained counselor, "there's nobody around St. Louis to really help with this. It's either private counseling or you figure it out yourself that's basically your options . . . people need to learn how to have skills to tackle grief."

Several parents had suggestions on how this counseling could be provided to bereaved parents. One parent felt counseling should be mandated as he was at a lost as to how to help his wife, much less himself, "I wish . . . it was almost mandated to work or talk to somebody . . . ", "we can't even sometimes seek support from each other because we're so dissimilar in the way that we handle that", "force the issue in a way that works for the person just to get them to talk about their feelings and deal with it more openly instead of kind of bottling it all up, . . . having to maybe deal with it later or it comes out and you self-medicate". Another parent agreed with the difficulty of supporting each oth-

er, "I thought we needed some kind of counseling of some sort, because I think even though we're both on the same page I really couldn't help him and he really couldn't help me." Ideally, this would be a free therapy/counseling service for an extended period of time.

Another suggestion was to provide counseling through a grieving parent group, "have other parents guide other parents who have already been through this that are far enough past." Ideally, these would be small groups developed by the hospital in coordination with a counselor to oversee the experience, "having people that work for your hospital that run these kind of things . . . with the overseer of a counselor . . . you have to put the right people in the right job to do it.", "People are going to look for the person who's lost a child to lead the grief". Several parents suggested utilizing social media in this day and age, such as a Facebook page that is well monitored. This would allow those who lived out of the St. Louis area to participate, as well as, those who were not comfortable in a group setting and those who need to go at their own pace, "focus group on social media that you could form as well, where if people can't necessarily drive to your hospital to have a meeting . . . there's some sort of social media group that they can be a part of through the hospital. They have moderators, or whatever they call them, like the rule keepers . . . "; "not one to sit down and share in a group setting", "you can say all the right things but until I'm ready . . . will it really be worth that time?"

Another parent spoke of how helpful and beneficial it was to find a counselor at the time of diagnosis to help validate your feelings afterwards, "a lot of what I have, I would say post her passing away is just guilt . . . you question could I have done something better?" This parent also spoke about the benefits of knowing what to expect and signs to be aware of, "Like I told you about my husband, like he was just in such an angry mood or the way he dealt with things for a long time after within the first year or so, . . . you don't pinpoint it to that until you can luckily make your way out of it, . . . knowing you may not see this right away, but these are signs and here's what you can do or here's a resource."

There were differing opinions with the mailings received by the hospital bereavement group. Three of the six participants did not remember receiving anything, even though one stated they probably did but couldn't "remember really of substance what all it was. I mean if it was an opportunity to partake or call about anything we didn't at that time." This same parent spoke of the importance of any material received "having a balance of telling you how you're going to feel, but yet knowing if you are feeling that that it's okay." For two of the parents, they did not find the mailing helpful stating "they're too generic", and manufactured "where you should be in three months this is where you should be in six . . . when it's more sincere . . . I think that would resonate with families." One parent did not find it helpful at the onset stating "when it first happens you're kind of in a haze . . . at least at the onset it wasn't as helpful because I don't think you're in the frame of mind where you're actively looking to engage in group meetings and support groups." Only one set of parents found the mailings helpful, "kind of nice to read a couple things that were in there . . . gave you ideas on things to try to help figure out as the days went on, like which way to turn or maybe some groups to get involved in. This same

parent appreciated "the fact that they didn't just cut you off, and like he's gone, we're moving on, when that's not so easy for the family." For one parent, they worried receiving anything from the hospital would have been a trigger for her since she does not even like driving by the hospital.

Lack of Sibling Support

The lack of sibling support resulted in additional stress for the four families who had other children. For the other two families, this was the only child for one family and the other family had adult children at the time of their child's death. While grieving the loss of their child, the parents with other children found it difficult to support the surviving children and to be the parent they needed during that grief process. This often led to a secondary loss for those children; the loss of the parent(s) who they could no longer turn to which resulted in poor choices and bad behavior. One parent described it as "the lost child" when she spoke about her daughter who eventually was diagnosed with depression and post-traumatic stress disorder (PTSD). "When you've got other kids at home and you're dealing with that grieving cycle as a parent, you're not really able to parent . . . when you leave that hospital after you child dies you are not the same person that you were when you went in"; ". . . (she) fell into the wrong crowd . . . it's been a mess. It has been hard. We can't get her to do anything."

Having a professional support system available to these parents would have provided them with the guidance they needed to support their other children while navigating their own grief. This support could come in the form of individual/family counseling, group support groups or books/reading material for the parent and children. Counseling could assist in guiding the parents and the child(ren) in recognizing the signs of sibling grief and provide them with suggestions for additional resources and tools, "wanting to know what would the signs be and knowing, because I think people think if the signs aren't there right when the death occurs or within a week or two after that then they're okay, but I think this stuff can come on."; ". . . tools to help the parents help the kids, that would be helpful too, you know, besides just here's an brochure (local bereavement center for grieving kids), go for that, because that really doesn't do too much. . .".

For one parent, however, her daughter was resistant to counseling, "She would say to me, mom, I do not want to talk to these people. They haven't been though what I've been through. How can they help me?" This parent described the frustration because she was being pressured by family and friends to "get her daughter under control." She was at a loss as to where to turn and how to help her daughter while she was struggling with her own grief. Having someone reach out to her to offer counseling services for herself would have been monumental for her at that time, "one particular person, like you did, reach out, follow up, what can I help you with? Do you need counseling services . . .?"

Additionally, group support with other children of similar age and/or experiences would benefit the siblings in validating their feelings and providing them with the assurance they are not alone in their grief at any age. ". . . we've got a teenager who is still grappling with it and we've got a 6-year-old who still doesn't really understand that he doesn't live in the sky . . . the problem was is that the grief was not all the same.", "I think

it would've been more helpful for her to go with kids who had almost the same issue with their sibling . . . ".

Books or reading material was mentioned as being a means of support and could even be more helpful if received prior to the death of the child. One parent specifically mentioned the book, "Heaven is Real", and spoke of having both the adult and child version. This parent would read this book to the sibling prior to the death of his sister and found it to be a useful tool to prepare him for what the future held, "we read that several times . . . at that point he could kind of relate it, what it meant a little bit more." She found this book and other age appropriate books not only cathartic for him, but for her as well, "If it doesn't help them, it sure helps the parents having those conversations if anything." Two additional requests outside of counseling and books that could be impactful according to our participants, was guidance on how to help siblings born after the death form a connection with the sibling they would never meet, because I want to keep her memory alive in some way and I don't know what that is . . . we're working on that journey . . . now it's just family pictures."; and, parent-child activity days, "not just a service or something, but maybe something that's a little more fun, but involves, like kind of forces that interaction and is involved."

Discussion

Findings from this study demonstrated the need for additional support and resources from the perspective of bereaved parents. This was evident in the five overarching themes identified: 1. Fear of their child being forgotten; 2. Loss of purpose or meaning in life; 3. Loss of support after the first one to two years; 4. Lack of counseling resources; and, 5. Lack of sibling support. In addressing these needs, the hope is there would be a decrease in complicated grief experienced by bereaved parents allowing them to travel through the grieving process in a supportive and healthy manner.

The findings from this research are similar to other studies in that the lack of sibling support and the need for ongoing bereavement services beyond the first year of life are identified themes[1,8]. In addition, the need for the on-site memorialization of their child within the hospital was similar to that experienced by parents of children suffering a long-term illness such as cancer[8]. However, this study was different than previous research in that it took into account the diagnosis and longevity of the child's illness versus sudden death that was incorporated into previous studies that evaluated palliative care programs[1].

Several new insights were gained through this research. By identifying impactful ways to remember their child, such as, sending a card on special dates, providing tangible items of remembrance and/or attending the funeral, the PPC team sends a strong message to the bereaved parents their child's life was meaningful, valued and not forgotten. This can also aide in helping bereaved parents find new purpose or meaning in life as a means to carry on their child's legacy and preserve their memory.

Additionally, a PPC team can encourage bereaved parents to foster connections they currently have as well as connections they make during the grieving process. These relationships may be instrumental in carrying them through the difficult period of time when they experience a sense of loss of support by others. By eliminating the sense of isolation that often develops

with this loss, enhancement of their coping skills may occur providing them with the tools to address future distress in the years following the death of their child.

Finally, providing bereaved parents with resources for counseling and sibling support could alleviate stress by having these resources readily at their disposal. A common thread among these parents was reported lack of energy or drive to find counseling for themselves and/or for their other children. Additionally, they were often deficient in the knowledge on how to seek out the desired counseling resources in their area, nor were they aware of the importance of finding counselors who specialize in grief. This often resulted in unfavorable experiences with initial counseling visits. A PPC team could assist in providing the education necessary for these parents to increase the probability of successful counseling visits.

Limitations to this study are lack of diversity in race and socioeconomic status. All participants interviewed were Caucasian and all but one participant had a higher than college education. This is not unlike what has been previously reported in the literature[1,8]. A total of 69 letters were sent inviting bereaved parents who met the previously noted criteria to participate in the focus groups. Of those 69 contacts, 19 letters were recent to different address found on FindPeopleSearch.com and four contacts had moved out of the area to a different state. Follow-up telephone calls were made to last known telephone number located in the electronic medical record and voice messages were left with contact phone number to return the call when allowed. There were no return calls.

Future study with bereaved parents may include sibling trauma. Trauma of losing a sibling varies greatly dependent on age, family values, and relationship with said sibling. Identifying appropriate resources for siblings may aide in not only their grieving process, but that of their parents as well. As suggested by previous research, a needs assessment of the individual family would be an ideal intervention in order to anticipate the individual needs of the family and how best to individualize the care needed after the death of the child[1].

Conclusion

In conclusion, while this study was small in size, lacked diversity in race and socioeconomic status, it clearly identified bereaved parents would greatly benefit from ongoing bereavement support from a PPC team. Identifying a dedicated bereavement coordinator for a PPC team would be optimal to provide this much-needed support. However, there may be barriers to this including lack of financial support, available staff and resources.

Conflict of Interests: No conflict of interests are declared.

References

1. DeJong-Berg, M.A., Kane, L. Bereavement care for families part 2: Evaluation of a paediatric follow-up programme. (2006) Int J PalliatNurs12(10): 484-494.
   PubMed │ CrossRef │ Others

2. Grief.com. Five stages of grief. Accessed July 14, 2020.
   PubMed │ CrossRef │ Others

3. O'Connor, K., Barrera, M. Changes in parental self-identity following the death of a child to cancer. (2014) Death Stud38(6-10):404-411.
   PubMed │ CrossRef │ Others

4. Meert, K.L., Eggly, S., Kavanaugh, K., et al. Meaning making during parent-physician bereavement meetings after a child's death. (2015) Health Psychol34(4): 453-461.
   PubMed │ CrossRef │ Others

5. Vega, P., Rivera, M.S., Gonzalez, R. When grief turns Into Love: Understanding the experience of parents who have revived after losing a child due to cancer. (2014) Journal of Pediatric Oncology Nursing 31(3): 166-176.
   PubMed │ CrossRef │ Others

6. DeJong-Berg, M.A., DeVlaming, D. Bereavement care for families part 1: A review of a paediatric follow-up programme. (2005) Int J PalliatNurs11(10): 533-539.
   PubMed │ CrossRef │ Others

7. Lichtenthal, W.G., Sweeney, C.R., Roberts, K.E., et al. Bereavement follow-up after the death of a child as a standard of care in pediatric oncology. (2015)Pediatr Blood Cancer62(S5): S834-S869.
   PubMed │ CrossRef │ Others

8. Snaman, J.M., Kaye, E.C., Torres, C., et al. Helping parents live with the hole in their heart: The role of health care providers and institutions in the bereaved parents' grief journeys. (2016)Cancer 122(17): 2757-2765.
   PubMed │ CrossRef │ Others

9. Morris, S.E., Dole, O.R., Joselow, M., et al. The development of a hospital-wide bereavement program: Ensuring bereavement care for all families of pediatric patients. (2016) J Pediatr Health Care 31 (1): 88-95.
   PubMed │ CrossRef │ Others

10. Thomas, K., Hudson, P., Trauer, T., et al. Risk factors for developing prolonged grief during bereavement in family carers of cancer patients in palliative care: A longitudinal study. (2014) J Pain Symptom Manage47(3): 531-541.
    PubMed │ CrossRef │ Others

11. Sandelowski, M. Focus on research methods. Whatever happened to qualitative description? (2000)Res Nurs Health23(4): 334-340.
    PubMed │ CrossRef │ Others