


Professional Bereavement Photography in the Setting of Perinatal Loss: A Qualitative Analysis

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Abstract

Perinatal loss, including fetal and infant death, is a devastating experience for parents, resulting in long-term adverse physical and psychosocial outcomes. However, little is known about what services might best support grieving parents. We aimed to understand the role of professional bereavement photography in assisting the grieving process of parents who have lost a fetus or infant, by examining the perspectives of bereaved parents, professional photographers, and health care professionals. Twenty semistructured interviews were conducted, and interview transcripts were analyzed using modified grounded theory. Twenty-three individuals participated, including 6 bereaved parents, 8 photographers, and 9 health care professionals. Analyses generated 5 major themes describing ways in which the photographs were valuable to parents: validation of the experience, permission to share, creation of a permanent and tangible legacy, creation of positive memories, and moving forward after the loss. Hospitals should consider incorporation of professional bereavement photography services into palliative care and bereavement programs.

Keywords

bereavement, grief, qualitative research, perinatal loss, photography

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Introduction

Perinatal loss, which encompasses fetal, neonatal, and infant death, is a devastating and traumatic experience for parents, resulting in increased risk for long-term adverse physical and psychosocial outcomes.^{1–5} The death of a fetus or infant is a loss unlike any other,⁶ and its social, emotional, and spiritual burden has been greatly underestimated.⁷ Parents also suffer from the social stigma and culture of silence that surrounds perinatal loss.^{7–10} Despite these negative outcomes, little is known about what services might best support grieving parents.

Perinatal palliative care programs have gained prominence in the past decade to address the unique needs of families caring for fetuses and infants who may die.¹¹ Although bereavement care is considered essential to palliative care, large variations exist among the types of services offered by providers and hospitals.^{6,11,12} Previous studies addressing perinatal bereavement interventions have found that the majority of bereaved parents endorse photography of their child and family.^{13–15} However, very

few studies have examined the specific ways in which bereavement photography, whether occurring while the child is still alive or after death, may be beneficial to parents in the grieving process.^{16–18} Existing data suggest that photography can aid in memory-making, memorialization, and validation; however, these are primarily survey-based studies of mothers.^{16–18}

Thus, our objective was to understand the role of professional bereavement photography in assisting the grieving process of parents who have lost a fetus or infant. These findings are essential to informing the

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development of comprehensive, family-centered programs to support parental bereavement.

Methods

This narrative qualitative study recruited participants in 3 categories: bereaved parents, professional photographers, and health care professionals. All participants were recruited using a nonprobability purposive sampling strategy. Contact was made with a photographer well-known in the Seattle pediatric palliative care community. She was approached about individuals whom she thought would be willing to participate, and she obtained their permission prior to sharing their contact information. Participants were then approached by telephone and given background information about the study, according to a preapproved telephone contact protocol.

Inclusion criteria for bereaved parents included having experienced a third trimester fetal demise or loss of an infant within the first year of life and having received professional bereavement photography services while the child was alive or at the time of the loss. Photographers were recruited from 1 of 2 organizations that provide free, professional photographs to families with children facing life-threatening conditions: Soulumination and Now I Lay Me Down to Sleep (NILMDTS). Health care professionals were recruited from local organizations with the goal of achieving a heterogeneous representation of professionals involved in pediatric, neonatal, and palliative care. Inclusion criteria for health care professionals included clinical or professional experience, in any of the health care-related professions, caring for families who had lost a fetus or infant within the first year of life. Health care professional participants were not necessarily the providers of parent participants. Participants with limited English proficiency were excluded.

In-depth semistructured interviews were conducted in person by the primary investigator (FDR). All parent participants were queried regarding preferences to participate in interviews alone or with their coparent. Based on parental preference, some interviews were conducted with both parents together, while others were conducted with individual parents. Standard interview guides were used for each category of participant (Supplementary Table 1, available online). Questions were open-ended with prompts when necessary. Questions were nondirective and allowed for positive, negative, or neutral responses. For example, participants were not asked about why photographs were beneficial but rather were asked about whether they perceived the photographs helped parents with the grieving process. Parents were

asked to describe their experience of loss in as much detail as they felt comfortable. They were then asked questions about the experience of the photography shoot; the meaning, uses, and importance of the photographs; and whether they found the photographs beneficial in the grieving process. Questions for photographers focused on their experiences with parents and the content of the photographs. Interviews with health care professionals focused on their perspectives about whether these photographs were beneficial to families, and about their experiences with professional photography services at their respective institutions. Interviews lasted 45 to 90 minutes and were digitally audio-recorded and transcribed verbatim.

Interview transcripts were analyzed using the constant comparative method within modified grounded theory, in which narratives were repeatedly read in order to identify themes.^{19,20} The transcripts were first read multiple times to identify statements of interest and were then read more closely to identify emerging themes using an open-coding approach. Transcripts were hand-coded and reread several times after an initial coding scheme was developed. This iterative process was repeated until the coding scheme was fully developed. Saturation, or the point at which additional interviews no longer generate meaningful new themes, was used to guide the sample size and was felt to have been achieved after interviews with 23 participants (6 bereaved parents, 8 photographers, and 9 health care professionals). Codes were organized into major themes and subthemes. Coding was led by the primary investigator (FDR) with critical review of the final coding scheme by senior investigators LMY and JFB. All participants who were approached agreed to participate. No incentives to participate were offered; and all participants, especially parents, expressed gratitude for the opportunity to share their stories.

Ethical Approval and Informed Consent

Ethical approval was obtained from the University of Washington Human Subjects Review Committee (Institutional Review Board Number 41765). All participants provided written informed consent.

Results

A total of 23 individuals participated, including 6 bereaved parents, 8 photographers, and 9 health care professionals. Of the parents, 1 experienced a fetal loss and 5 experienced neonatal or infant losses (Table 1). Only one parent was able to take her child home for his last days of life and photographs were taken at that time;

Table 1. Study Participants: Parents.

	Cause and Timing of Child's Death ^a	Location and Timing of Photographs	Time Between Child's Death and Interview
Mother 1 and father 1	Twin-to-twin transfusion syndrome and severe intrauterine growth restriction (7 months postnatal)	Hospital, 1 month before death (6 months postnatal)	6 years
Mother 2 and father 2	Aneuploidy and congenital diaphragmatic hernia (carried to term and lived 10 minutes)	Hospital, at time of delivery	2 years
Mother 3	Traumatic neurologic birth injury (2 weeks postnatal)	Home, several days before death	9 years
Mother 4	Congenital cytomegalovirus infection (6 days before due date)	Hospital, at time of delivery (stillbirth)	2 months

^aCauses of death are parent-reported and not corroborated with medical records.

all others had photographs taken at the hospital. At the time of the interview, none of the families had experienced a previous or subsequent fetal, infant, or child loss. The number of years from the death to the time of interview ranged from 2 months to 9 years. The category of health care professionals included 3 nurses, 2 social workers, 1 chaplain, 1 child life specialist, 1 grief support consultant, and 1 pediatrician. The photographers included 2 from NILMDTS and 6 from Soulumination, and several photographers had personal or family experiences with photography in the setting of perinatal loss.

Qualitative analyses generated 5 major themes: validation of the experience, permission to share, creation of a permanent and tangible legacy, creation of positive memories, and moving forward after the loss. Although the perspectives of parents were considered most central to the findings, all themes, and nearly all subthemes, were echoed in the perspectives of photographers and health care professionals.

Validation of the Experience

Parents consistently identified the photographs as an essential means of validating their experience, including validation of their baby's existence, their identity as parents, and their child's place in the family unit (Table 2):

It's a validation of being a parent . . . that this person was here on this planet, and that he lived. He was here very briefly, he had a huge impact on our lives, and that presence is recognized and celebrated in the pictures. (Mother)

The photographs may have been the only means available to parents to authenticate the reality of their baby's existence:

He was here, and the pictures celebrate that, you can't take that away. Even though he's not here you can't take that

away, that he was here, and he was part of our family, and a beautiful looking kid. (Mother)

Parents found this was particularly important, as all had experienced either fetal death or only a short period of their child's life, and few family members and friends had the opportunity to meet their child:

I think in part because when a baby dies, it might be the immediate family, there might be other siblings, but, you know, nobody knows this person . . . but this person is obviously an incredibly important part of your life, and having the pictures lets everybody know, lets you realize and remember that yes, this is a real person, this is your baby, this is your family. (Mother)

In addition, the photographs confirmed parental identity and validated the child's place in the family unit through the language of inheritance and family resemblance:

All those pictures that are at certain angles where the both of them are facing the same . . . they look exactly alike. You can tell in all of them that they're related. (Mother)

Permission to Share

Families and health care professionals felt that the photographs provided permission to share, as they facilitated difficult conversations, enabled the creation of narratives, and helped siblings understand the loss (Table 3). As aesthetically pleasing and professionally created images, the photographs provided parents opportunities to share their child and initiate conversations with others:

That's one way to introduce the subject, because it's always a little like, "When do we tell them we have a dead child?" Because it's not the easiest thing to bring up, yet it's really important for us because he's still so much of our family. (Mother)

Table 2. Validation of the Experience: Subthemes and Illustrative Quotations.

Subtheme	Illustrative Quotations
Provide undeniable proof of the baby's existence	<p>What was so helpful is that at his funeral, I just made a collage of all of the pictures she had taken, to show everybody, "Here he is, here he was! He was a really normal looking, beautiful baby." (Mother)</p> <p>She made the validation of his presence stronger, that's for sure. . . . She captured his humanity even though he was essentially brain-dead . . . so in that sense, that was acknowledgment and validation that there's this little person. (Mother)</p> <p>It's validation that the baby existed, it's validation of their love for the baby, rather than things getting all murky in their memory. (Photographer)</p> <p>It validates, it validates that little life, that it really did exist, and they have honored this baby. . . . It's validation of that life, and they can show it and share it, and they can feel it again and again themselves. (Photographer)</p>
Confirm parental identity	<p>The parent is going to have a relationship. Much of your life is defined as being a mother, and if that isn't available for you because your child has died, to be able to have that, that photo to recall that in a very real way. (Health care professional)</p> <p>I think that's why she occasionally brings up the experience, or posts a picture, it's again that further validation that it happened, "I survived it, and I am a mom, I will always be her mom." (Photographer)</p>
Authenticate the baby's place in the family unit	<p>It really signifies that child's place in the family. This child really had a place in our family, there's no denying that, even though it wasn't a lot of time. (Health care professional)</p> <p>"We could not be sadder, but we are a family, we love each other, we've gathered in support, and we are acknowledging that we had a baby, we always will have the baby, the baby just was not able to live and stay with us that way." And I think that's very healing, very healing. (Photographer)</p>

Table 3. Permission to Share: Subthemes and Illustrative Quotations.

Subtheme	Illustrative Quotations
Facilitate difficult conversations	<p>I think in the long run emotionally you're just damaging yourself more . . . by holding everything in and not sharing your stories. With all those pictures, it is a way to share my story without blatantly saying, "Hey my baby died and here's the story." . . . So just by posting up those pictures, it was like people knew it without me telling them. It wasn't something that I have to talk about, but everybody still knows . . . because of those pictures. It's easier to just start like, "Oh that picture was really cute," than starting with nothing and wondering what to say. (Mother)</p> <p>It gives them permission, I think, to share, where, it's easier to talk around a picture, than just telling somebody. (Health care professional)</p> <p>The conversation is difficult. Being able to show somebody those little things, "But look at how cute her little feet were!" And it's a pleasing image, it doesn't look like a baby that is, you know. . . . It looks like a photo of anybody's baby. So I think there's some freedom in that for the family as well . . . that you can say, "Oh, look at her little hand, look how perfect her little nose was." (Photographer)</p> <p>It's another thing that they can show people, that is beautifully done, and the photos are beautiful, and you can easily show it to someone. . . . So it opens that channel, I think in some ways, it's more visually acceptable. (Photographer)</p>
Enable the creation of narratives	<p>The [photographs] are still very much part of our telling of our story for [him], so like pages in a book . . . they are our pictures in his book. (Mother)</p> <p>We have said, by example, "Here's one way to describe your brother by showing a picture and sharing it and explaining who he is." (Mother)</p>
Help siblings understand the loss	<p>For the siblings in the future, those are very significant because they might not have a memory, but the picture allows for them to create that memory. (Health care professional)</p> <p>Even talking about it with [our youngest son] . . . it's just been awesome, like it's totally opened the door for us to talk about death and what happens. (Photographer, who personally experienced the death of her second child at birth)</p> <p>I know from my perspective as his sister, it meant that I got to meet my brother. . . . So it was really a chance for myself, my sister, and our 2 brothers, there are 4 of us, to kind of know this other brother. I can't imagine not being able to have some pictures of what he looked like, that he looked similar to some of us, different from others. . . . So it's a way that they've been able to introduce him to us, been able to keep him in the family. (Photographer, whose parents had professional photographs taken of his older brother who died at age 3 months)</p>

Photographs facilitated desired opportunities to share stories and memories, and enabled the creation of narratives:

It's constructing a narrative about it, sharing stories. . . . And it's hugely, hugely healing. We see those families cope better, later, and these are the ones . . . that are more happy, years later, than the families who try to forget, shove things in drawers. (Health care professional)

In addition, parents were able to share their child with family members who were not present, including siblings who were born later or were too young to remember. Parents greatly valued this function of the photographs, which enabled them to talk about the loss and the meaning of the child's death with their other children:

I totally think it helped [our oldest son], just like it helped us, no question about it. He was really young but I think it definitely helped him to know, "Hey, I have this brother," who he talks about to this day. . . . We'll bring him up here and there, or say how he's watching us doing something, so we definitely still talk about him as a family. But we're sure it helped [him] to kind of understand what happened, and that he died so he's not here with us but he's still with us in spirit. (Photographer, who personally experienced the death of her second child at birth)

Sharing photographs, and the memories that accompany them, allowed other children in the family to understand and talk comfortably about their deceased sibling. This, in turn, helped them develop and maintain a sense of individual and family identity that incorporated the memory of their sibling:

At his last daycare, I went in and helped share pictures with him to his classmates so that he could have that voice about it, because for him it's a different dynamic. It's not only his brother, but it's his twin brother. And for us it's really important for him to have the opportunity to incorporate the twin identity, you know, we always say, "You're a twin, you're a twin, you're a twin," but that he can say when he's comfortable, "Yeah, that's part of who I am, I am a twin, and even though my brother died that doesn't change anything." So we use it as a way to allow him to verbalize it. (Mother)

Creation of a Permanent and Tangible Legacy

Participants highlighted the ways in which the photographs created a permanent and tangible record, captured irreplaceable moments and small details, relieved the fear of forgetting, and created a family legacy (Table 4). The permanency of photographs provided parents

assurance that the memory of their child would exist well beyond their child's brief existence:

This was the only way, we don't have any other option. . . . It was either this, or rely on our memory, and I think we both felt that we wanted something more permanent than just our memory of him. (Father)

The photographs were among the only tangible things parents had once their baby died:

They can still love this child and remember the child in a more tangible way, by looking at those images, by seeing their hands holding the baby. (Photographer)

For one father, the photographs were the "most precious thing." Because parents left the hospital without a child, the photographs took on an increased importance, often becoming their most valuable and irreplaceable possessions:

I just know that when they take those photos [home], it's like they're actually taking a part of their child that they otherwise would not have. (Health care professional)

Moreover, parents valued the photographs for their ability to capture irreplaceable moments that would never be possible again:

Knowing that this is my only chance to ever take a picture with him. . . . I would never get that second chance again . . . it's a guarantee . . . (Mother)

Parents also highlighted the importance of the photographs in capturing small details about their child's appearance that were often difficult to remember, because they only spent a few moments with their baby, or were sleep-deprived and/or clouded by medications:

We look at his nose, and he's got the same nose as the other kids, his hair. . . . And if it was just in my memory I wouldn't have that, because I don't, I can't remember much about that day. If it wasn't for the photos, I don't know what I would remember, really. . . . It's a comfort to us. (Father)

As such, photographs provided reassurance and comfort to parents, and relieved their fear of forgetting:

I can see his whole body in some of them, I can see his fingers, and toes, and face. And I just know that he totally existed and that I don't have to hold him so tightly in my mind and remember every little ounce of him. I can just relax because I know I have those photos. (Mother)

Table 4. Creation of a Permanent and Tangible Legacy: Subthemes and Illustrative Quotations.

Subtheme	Illustrative Quotations
Create a permanent record	<p>We talked a little bit about the permanency of the images, and you know, life is not permanent, but the artifacts that we leave behind can be. (Father)</p> <p>They solidify his memory and hold it more firm, whereas if you didn't have those [photographs], they would have a tendency to fade more. (Mother)</p> <p>Even when I have my next baby, I still want people to know that I still had him and lost him. I wouldn't want to just forget about him. . . . And now I can't, it's impossible to. With pictures, now I'll never forget him. (Mother)</p> <p>To have those moments captured forever . . . it's truly priceless, like it's the most important thing. (Photographer)</p>
Create a tangible record	<p>I think they're helpful in that they're concrete reminders—not that I need a reminder—that he was here, and that he shone so beautifully. (Mother)</p> <p>Pictures are amazing for our patients. . . . They're the only concrete visual things. (Health care professional)</p> <p>She needed that reality of those images, the realness, because she probably wasn't getting any realness anywhere else. (Photographer)</p>
Capture irreplaceable moments	<p>You can always go back and open it up in private, and you know it's always in the drawer. You don't have to look at it but you can. And that's the thing about it, the regret that people have when they didn't. . . . Why wouldn't you want that? Because you can't get it back. (Father)</p> <p>Those photos are the only photos that they have of this child with the sibling, and so that was huge for them, to be able to have them both in the same space and capture that moment. (Health care professional)</p> <p>I tell everybody this, when I'm in that room, and I'm taking photos, I feel more like a photographer than any other time I hold my camera . . . because it is this moment, that can never, ever, ever come again. . . . This is actually something that can't come again, it's a moment in time. (Photographer)</p>
Capture small details	<p>I can remember exactly what every part of him looks like, his hands and feet and everything, because of [our photographer]. I wouldn't remember from our [phone] pictures. . . . Because she took such close-ups, so distinct . . . so I remember everything about him. (Mother)</p> <p>This is the way that tells them she did have mom's little finger, and look, her nose is just like dad's. . . . It's really, I think, a really crucial part of the healing process for them. (Photographer)</p> <p>For all those people who lose, especially babies, there is this way of remembering. You forget the details. I have to look at pictures to remember what my kids looked like as babies. If that child isn't here, it's unfathomable to me not to have that to remember the color of their eyes, eyelashes, nose, shape of their mouth, all of that, all of those wonderful details. And the time after you give birth too is such a blur for parents, you're not sleeping. . . . If you're dealing with an illness, your head is in such a fog that I think you need someone to document it for you. (Photographer)</p>
Relieve the fear of forgetting	<p>That's something that even though we don't look at the pictures or the CD or DVDs or everything, I think we don't feel like we have to look at it all the time, it's just knowing that it's there . . . (Father)</p> <p>It's a way to not have to struggle to remember. (Photographer)</p> <p>For a lot of the women, that have been heavily medicated, heavily drugged, and then the emotional impact of the day. . . . To go home and not really remember very clearly everything that went on in that room. . . . For many of them, they get those images and they see themselves, all snuggled up with their baby, and that is a huge relief, because they may not have that really strong memory in their head of that moment, that they were really snuggled with that baby. That can be so helpful for them to realize, "Ok, I did, I got to, I was there, I was present. I may not remember it, but I really was there." (Photographer)</p>
Create a family legacy	<p>For all these parents who lost their kid, they only really want one thing. They just want their kid to be remembered. Generally, the parents have to be the holders of that torch, to help make sure that other people remember. So those artifacts that we have around the house help transcend that and initiate conversations. (Father)</p> <p>You think about somebody's life and you look back at old photos and you have those memories, and that's what we're putting into somebody's box of photos or albums . . . 50 years from now, or 100 years from now, somebody's digging through the old photos and there's going to be these pictures of these babies, that had names, and that were loved. (Photographer)</p> <p>These become heirlooms, in a way, which is why I am willing to spend as much time as it takes. (Photographer)</p>

Finally, as permanent and concrete artifacts, the photographs contributed to the creation of a family legacy:

[If] the child died while they were [in the hospital], in that case, the photographs are a hugely important part of their legacy. (Health care professional)

Creation of Positive Memories

The experience of taking the photographs also created positive memories, by providing a special occasion for the family, a sense of normalcy, opportunities to hold the baby, and time spent together as a family, even for parents who had experienced a fetal loss (Table 5):

We look at [the photographs] and it was a good day. . . . The sadness never goes away, so the photographs can never erase that. It can diminish it, lessen it. . . . But for us, we look at them and smile. (Mother)

The experience represented a special occasion for the family that often brought more joyful emotions:

They are choosing at that moment to grieve and to celebrate, and to honor that life, so there can be more smiles in the room than tears. (Photographer)

The opportunity to have photographs taken also fostered a sense of normalcy for parents, who felt that family portraits are things that “normal” families do:

[Our photographer] had the knack of transporting us into an environment of normalcy, where we were just living hospital, hospital, hospital, but when she came in it was like, oh this is what normal people do, that’s right, you have photographs of your children taken whether it’s at Sears or JC Penney, you know. . . . There was a gift in that moment of just creating a very normal moment for us. (Mother)

In addition, participants consistently emphasized how important it was for parents to have the opportunity and be encouraged to hold their baby, especially if parents were initially hesitant:

She wanted me to hold him, and I was really afraid. . . . I thought he was so fragile he could die if we were to move him very much. . . . And she convinced me to hold him, which I’m glad she did. (Mother)

Parents greatly cherished the time spent together as a family while the photographs were being taken:

It was also one of the few times that we had all 5 of us together, because we had 2 young kids still at home. . . . So it was a very rare and special moment . . . it was this time

for our entire family to be together. . . . I think at the moment, it was very cherished, and even looking back . . . that was a good day for us. (Mother)

Moving Forward After the Loss

Finally, the photographs helped parents move forward after the loss through a variety of mechanisms, including keeping the memory of the child alive, acting as anchors to continuing relationships, providing the freedom to grieve, allowing movement between stages of grief, and facilitating acceptance (Table 6). The presence of this theme did not seem to differ based on time since the death.

The photographs helped parents keep their child “alive” through the conversations, stories, and memories they evoked:

I think it’s keeping them alive, too. I mean so much of their personality is captured by these photographs, but I think it’s a way to . . . keep them alive and legitimize the parent doing that when they show it to someone who wasn’t involved, years down the line. (Health care professional)

They enabled parents to maintain connections with their child, and acted as anchors to continuing relationships, allowing the bond between parent and child, or sibling and child, to continue:

I think it’s overall helped our whole process of grieving. It’s been easier for us to talk about and to help our kids. And also understand, because that’s a continuing process of understanding and evolving perspective on what it means to have a dead sibling, or a dead twin, or a dead child. (Mother)

In addition, parents found the meanings of the photographs, and the way they related to them, evolved over time, as a manifestation of whichever stage of grief they were currently experiencing:

What are the stages of grief . . . it’s not linear, they skip around, it’s circular. . . . I think acceptance is the last one, but I occasionally get angry again, and then I’ll have a weird dream where you’re in that disbelief part, and you’re like wait, did this really happen? And you wake up and you’re like, oh yeah it did . . . these pictures are helpful in going through those stages, whatever they may be. (Mother)

The photographs also gave parents the permission to grieve—to feel and express all the different emotions of sadness, anger, resentment, joy, and pride. Many parents found that expressing these emotions, facilitated by the photographs, enabled them to move forward following the loss:

Table 5. Creation of Positive Memories: Subthemes and Illustrative Quotations.

Subtheme	Illustrative Quotations
Create a special occasion for the family	<p>I remember one kid in the NICU whose mom and dad had the kids over from eastern Washington, which was not an easy thing to do, and they're little kids, and there were a lot of them. They're energetic, and this is the neonatal ICU, not really a playground, but they were dressed up in their special clothes, and came into the room and did their thing. . . . It was a big deal for them. (Health care professional)</p> <p>I know for many it's been a highlight of the day, of the week, or weeks they've been going through it. . . . It's a chance to, I mean it's so weird for me to speak from the parents' perspective, but from what I've heard, it's a highlight. (Photographer)</p>
Foster a sense of normalcy	<p>You want to smile, but you have a very sick child at the same time that you're holding, and that's where I think [our photographer] created that ability to let go of, oh I have a sick child, and just be in the moment. (Mother)</p> <p>So there's a totally abnormal, totally non-normal situation going on in the room, but if you can stop for a minute and hold your child like you would hold your child on any other day, then for a minute it is a little more normal. (Photographer)</p>
Provide opportunities to hold baby	<p>The whole time that I'm getting my pictures taken by her, it's more time that I'm spending with the baby instead of me sitting there taking pictures. (Mother)</p> <p>She doesn't get to hold her baby very often, and so it's this rare opportunity for her to be able to be with the baby, and it's just the coolest thing. Honestly, even if I got no good pictures of that shoot I would walk away so grateful, because I usually always leave with the baby still in the mom's arms. It's an opportunity that she's barely had, and so just for me to have been there to suggest, to make that suggestion, so that they get to do that is huge. . . . Yeah, so that is fantastic. (Photographer)</p> <p>If somebody wasn't doing that, putting that baby in her arms. . . . Because she might hold the baby for a minute after it's born, and then they wrap it up and put it in the bassinet. . . . And then the nurses are going about their nursing duties, they have a lot to do, and there's still a placenta to deal with, so that baby can end up staying over there and nobody is picking that baby up until we get there. . . . A lot of times when I leave, I say "Do you want me to put the baby back in the bassinet?" "Nooo. . . ." So getting them connected with that baby, which I think is really important. . . . Because they've already bonded, they bonded for a long time, and so you can't, just by removing the baby from the room, you're not going to break that bond, that doesn't make it go away. So why not acknowledge it, if that's what they want, if that's what they need? (Photographer)</p> <p>I've never had a parent that regretted not introducing their infant, even if they were dead, to their sibling. Many parents have told us that they cherish those photos of the sibling holding the baby. (Health care professional)</p>
Create family time	<p>For those few minutes we were feeling connected . . . even for that minute, that you had that time, even if the baby was not alive, but still, for that time, being connected as a family. (Photographer)</p> <p>I was just so moved by this one family . . . there was great joy, there were smiles, there was that wonderful warmth. It was so easy to tell how they loved each other, and all of that support from family that was around them, you can sense that. (Photographer)</p> <p>I think if the photo shoot wouldn't have happened and we would've defaulted to the traditional thing, maybe he wouldn't have been in that room to be able to have our daughter come in and see him, the family come in, [his grandmother] hold him, you know that kind of stuff. . . . Maybe that wouldn't ever have happened. . . . So I think beyond just the small hour or hour and a half that we actually took the photos, I think it extended into the next couple of days our time as a family. (Father)</p> <p>This photo session . . . was a ritual of creating time to be together as a family and to capture some images that [they] will have forever. (Health care professional)</p> <p>[The photographers] create that experience of family time, almost maybe disappearing behind the lens so that the family can have their time and know that it was captured. (Health care professional)</p>

Abbreviation: NICU, neonatal intensive care unit.

At first they did make me cry a lot . . . but I think that is a part of grieving. If I didn't cry. . . . I would probably . . . still be feeling like I didn't get it all out. So they made me cry more in the beginning, which I think is good because it helped me to cry less later on. (Mother)

Although participants acknowledged that "acceptance" was never truly reached, to many families, acceptance represented a delicately balanced state where they were able to integrate the loss of their child into their life and move forward in a healthy way—both acknowledging the

Table 6. Moving Forward After the Loss: Subthemes and Illustrative Quotations.

Subtheme	Illustrative Quotations
Keep the child alive	<p>We don't want him to be forgotten, that's why we agreed to do the news story and even this [interview], because in a way he still lives. (Father)</p> <p>I also truly believe that healing happens because we are able to keep that child, that person who has died, alive within our hearts. And that happens through memory. So the storytelling is essential, and the memories they had . . . (Health care professional)</p> <p>In an email, one mother wrote me, she said: "My baby only lives in images." (Photographer)</p>
Act as anchors to continuing relationships	<p>What I've learned about families' grief is that the relationship with the deceased continues and just changes over time. I would imagine . . . that the photos could be an anchor for that, but that the experience would be changing as the living change. (Health care professional)</p> <p>You always hear parents who will appreciate that person who risked and said, "Tell me about your child . . ." "Yes, I'd love to tell you about my child!" For them, it's a way of continuing that relationship. (Health care professional)</p> <p>This kind of photography, keeps you tethered, and connected, to your grief. When everyone around you tells you that you need to move on, need to get over it, what you need to do is stay tethered to something, because it fills the space. What fills the space when your baby is taken from you? It isn't, there's nothing, there's not another baby that comes along that fills that space, so the only thing that fills that space is your grief, is that connection to your child. And it isn't always this heavy, dragging this big chain behind you kind of grief. There's a lot of joy, it can be a joyful grief, peaceful grief, but it's yours. If you take that away from people, what do they have that connects them back to their child? Nothing. So this is what, I think, those images do. It keeps you tethered to that grief, and that grief is the connection you have back to your child. I think it's a really healthy grief in that sense. (Photographer)</p>
Provide the freedom to grieve	<p>It's nice to know they're always there, if we need to . . . and sometimes you do want to feel sad, and so sometimes, looking at the images is a good way to let yourself have the permission . . . to feel sad right now. (Mother)</p> <p>It makes people cry, which I think is very good, especially people who don't necessarily want to show their emotions. I think it's very good that it gets in there and it makes them feel emotions. (Photographer)</p>
Enable movement between stages of grief	<p>I look at them now and I feel blessed. Before it was just . . . nothing but sadness, and now you start to feel like things are going to be okay. . . . Before it was just hopelessness, and now I look at them and think how beautiful my next baby is going to be because that one was so beautiful, or how much alike they'll look I wonder. . . . And now I have all these good pictures, and when my next baby is here, it will be so easy to just look at those and see how alike they are. (Mother)</p> <p>Sometimes I was very angry, I'd stare at them and I'd be very angry, thankful that [the photographer] took them but still very, very angry. . . . I don't feel that way now, but I am still very sad. (Mother)</p> <p>You look at that picture, and you cry, and you get those things out, and you breathe over it. . . . And eventually you're able to put the picture away . . . but you never put it away here [pointing to her heart]. (Photographer)</p>
Facilitate acceptance	<p>[The photographer] shows the baby in such a very delicate beautiful way. Even if there are tubes or horrible illnesses, she does a really wonderful job of portraying them with their family beautifully, and I think that helps you grieve and come to acceptance at some point. (Mother)</p> <p>I mean it was huge . . . honestly it is the thing that got me through losing [him]. (Photographer, who personally experienced the death of her second child at birth)</p> <p>I also think that it's a fantastic way for families to. . . . I don't really like the word acceptance, but there's an aspect of that. It takes a long time to come to this point where you can wholeheartedly acknowledge that your child is dead—is not physically here—but that you are still completely able to celebrate their life. And those photographs are a kind of pinnacle moment where this negotiation, didn't start there, but it was irrevocable. It shows this moment in time where the parents just remember all of it, and there's this quality of celebration in those photographs in the presence of all that limitation. (Health care professional)</p> <p>I think our work is more conducive to a positive reflection, and a way to honor the past and also probably move forward in a healthy way. (Photographer)</p> <p>I think the belief really is on my part, and my experience seems to support it, is that this remembrance photography really is a means, another tool, for helping a family overcome the grief of their loss, their devastating loss. (Photographer)</p>

finality of the loss and celebrating their child's life. Several participants discussed the role of the photographs in helping parents move toward this equilibrium:

I feel like her pictures are like, positive ones . . . they make me feel like I can accept that he's gone . . . (Mother)

Discussion

A central goal of perinatal palliative care is to provide support to families in circumstances where a fetus or infant is expected to die. Bereavement photography has been used as a way to support families in these circumstances, although little evidence exists to guide this practice. Among our study sample, parents who experienced a perinatal loss valued professional photographs for a number of unique reasons, including validation of the experience, permission to share, creation of a legacy, creation of positive memories, and moving forward. The families, health care professionals, and photographers interviewed in our study held similar supportive beliefs about the role of bereavement photography.

Social theory has identified several problems unique to fetal and infant loss, including parents' fear of losing the few memories they have of their child, as well as societal pressures to forget and move on.²¹ Parents also suffer from the ambiguities surrounding perinatal loss, including ambiguities about what has been lost, about one's identity as a parent, and about societal and family membership of the baby.^{7,9,22-24} Many parents feel disenfranchised in their grieving process, as they feel their grief is not socially recognized or legitimized by health care providers and society.^{7,9,10,24} Our findings mirror and expand on results of prior limited survey literature, suggesting the various functions of bereavement photographs may help address these challenges, and are also consistent with previous studies that found that bereavement photography can support parents in memory-making, memorialization, and validation.^{16,18}

Our findings are highly relevant in the context of contemporary grief theories, which emphasize the importance of continuing bonds between the living and the deceased.²⁵⁻²⁷ As vehicles of memory, photographs help parents keep memories alive and maintain relationships with their child.^{28,29} Moreover, current bereavement theory highlights the importance of talking about traumatic experiences and constructing narratives related to the loss as a way to contextualize, find meaning, integrate the experience, and move beyond it.^{26,30-32} Photographs, and the conversations, memories, and narratives associated with them, may

help bereaved parents and their other children come to terms with the loss.²⁸

This study addressed bereavement photography from multiple perspectives. It uniquely included parents who had photographs taken when their child was still alive, in contrast to previous studies, which have focused on postmortem photography.¹⁶⁻¹⁸ The use of rigorous qualitative analyses provides a more comprehensive understanding of the different functions of bereavement photography compared with prior survey studies. We also incorporated perspectives of fathers, as well as photographers and health care professionals, who have worked with hundreds of families who have experienced perinatal loss. We identified nearly identical themes and subthemes in all interviews, suggesting our findings may have external validity.

There are limitations of this study, notably a small sample of parents, which may limit the socioeconomic, racial/ethnic, and cultural diversity of the perspectives presented herein. We acknowledge the potential for selection bias as we used a volunteer, nonprobability sampling strategy, as was necessary for the nature of the research question. Parents who agreed to be interviewed likely had positive perspectives regarding the photographs. We cannot assume photographs benefit all families; for example, some cultures do not allow postmortem photography, and some families may not be comfortable with this practice. The bereavement needs of individual families vary tremendously and should be supported in a personalized and family-centered manner.

In conclusion, among our study sample, parents who experienced a perinatal loss valued bereavement photography in coming to terms with their loss. Previous research has identified key components of perinatal bereavement interventions, including validating the baby's existence, facilitating parents' expression of grief, providing a framework for social support, and assisting in memory-making.^{11,13} Our findings suggest that bereavement photography can support parents across all of these categories, providing compelling evidence that supports further research and consideration for the widespread incorporation of professional bereavement photography services into palliative care and hospital programs.

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Author Contributions

FDR conceptualized and designed the study, collected data, carried out the initial analyses, drafted the initial manuscript, and reviewed and revised the manuscript. JFB and LMY supervised analyses and interpretation of data, and substantially reviewed and revised the manuscript.

MK contributed to study design, collected data, and critically reviewed the manuscript for important intellectual content. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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Supplemental Material

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