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Professional bereavement photography for perinatal loss: A mixed-methods study

Kitty Vivekananda, Chiara McDowell, Kayleigh Knipe, Charlotte McMaster, Fatima Rahimi, Mia Richards, and Sarah Salvini

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ABSTRACT

This study addresses research gaps regarding the impact of professional bereavement photography for perinatal loss. Utilizing a mixed-methods research design, 504 parents completed an online survey measuring their attitudes toward bereavement photography and its impact. Thirty-one parents participated in semi-structured interviews. The results indicate a high level of acceptability and satisfaction for professional bereavement photography by parents (including those from more diverse backgrounds). Data triangulation confirmed that photos are valuable in enfranchising grief, validating parental and babies' identities and facilitating connections with others. Significant correlations were found for sharing of photos with both positive attitudes toward photography and for continuing bonds. The expression of continuing bonds in public social media spaces suggests increased social acceptance and validation for grieving perinatal losses. The findings from this study further inform practice guidelines for supporting perinatal loss.

Over the past decade, bereavement photography as a memory-making activity has been encouraged as part of perinatal bereavement support (Perinatal Society of Australia & New Zealand, 2018). However, research specifically into the impact of professional perinatal bereavement photography is scarce.

Earlier systematic reviews investigating perinatal loss and bereavement support by Gold (2007) and Harvey et al. (2008) found no studies focused specifically on bereavement photography. In studies where photography was mentioned, parent participants (almost always well-educated white women) reported that photographs of their babies were enormously valuable and important to them. Being offered photographs was associated with high parent satisfaction and those who did not receive photographs expressed regret about lacking such mementos.

A more recent scoping review conducted by Thornton et al. (2019) identified only three studies by Alexander (2001), Blood and Cacciatore (2014), and Martel and Ives-Baine (2014) that specifically examined bereavement photography. Though not focused specifically on perinatal loss, a more recent review by

Kochen et al. (2020) identified only one study by Michelson et al. (2013) related to bereavement photography taken by carers and nurses. Both reviews concluded that memory-making interventions, including bereavement photography, were important for affirming parenthood and babies' existences and legitimized losses.

Research focusing on bereavement photography is scant, with qualitative studies with small sample sizes reported. However, an influential study by Blood and Cacciatore (2014) reported the largest sample (N = 93) of North American, almost exclusively white mothers, using bereavement photography with children of varying ages ranging from stillbirth to adulthood. Photos were taken by families themselves, by nurses or by professional photographers. Results showed overwhelming support for bereavement photography, and those who were initially resistant subsequently expressed gratitude for receiving bereavement photography. Qualitative thematic analysis revealed that photography created a social identity for babies, validated perinatal losses and grieving and provided parents with something tangible when mourning their child.

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These themes were also reported in qualitative interviews with nineteen parents (Cacciatore & Flint, 2012) and in a sample of 10 parents (Martel & Ives-Baine, 2014). Triangulating the perspectives of six bereaved parents, eight photographers and nine healthcare professionals, Ramirez et al. (2019) reported perinatal bereavement photography validated parents' experiences and their babies' existence, gave permission to share their loss, provided positive memories and a permanent and tangible legacy.

While literature from primarily qualitative studies provides a rich understanding of parents' experiences of bereavement photography and demonstrates that most parents highly value their photographs, there needs to be more mixed-methods research investigating the effects and outcomes of bereavement photography with larger, more diverse samples. Studies published so far have taken place largely in North America and the United Kingdom, with no studies focusing specifically on bereavement photography in Australia or New Zealand. Further, research is warranted as participants from nonwestern or Indigenous backgrounds need to be included. Bereavement photography is often studied with various memory-making interventions, and almost none have focused on parents' experiences of using professional bereavement photographers.

Professional bereavement photography

Earlier research in bereavement photography focused on photos taken by nursing and other carers; however, access to professional photography (including volunteers) may increase parents' satisfaction and outcomes (Alexander, 2001; Blood & Cacciatore, 2014; Ramirez et al., 2019) due to the high-quality photographs provided to parents (Blood & Cacciatore, 2014). However, introducing a professional photographer who is a stranger into a situation of acute grief and distress is potentially intrusive if not done sensitively (Thornton et al., 2019). Further research is needed into using professional bereavement photography and whether professional photographers provide families with additional grief support. Such research could inform the training of bereavement photographers and clinical practice guidelines in bereavement photography.

Continuing bonds and perinatal loss

Thematic analysis from past qualitative data provides evidence that bereavement photography helps maintain connections with the deceased baby through

memory-making activities and may be an important facilitator in continuing bonds (Blood & Cacciatore, 2014, 2014; Ramirez et al., 2019). Continuing bonds, which include keeping mementos, linking objects, or continuing conversations about the deceased (Scholtes & Browne, 2015), may help parents legitimize their loss as the connection between themselves and their children is recognized (Bobo et al., 2017). However, very few studies have explored continuing bonds in perinatal loss (Jones, 2020). In addition, research has yet to be conducted into professional bereavement photography and how it impacts the creation of continuing bonds and supports grieving.

Sharing photos

Social taboos around sharing perinatal loss persist (Fernández-Basanta et al., 2020) where bereaved parents may have their loss invalidated, disenfranchized, "marginalized and minimized" (Blood & Cacciatore, 2014, p. 2). Given the reported social stigma surrounding perinatal loss, limited research is available on whether or not parents share their photos, if so, how they share them, and the impact of such sharing.

Current study

The literature review highlights the importance of research with a more diverse sample using robust mixed methods research. This study aims to investigate parents' experiences of bereavement photography following a perinatal loss. The research questions are:

- 1. How do diverse parent groups assess the impact of and satisfaction with professional bereavement photography?
- What is the relationship between attitudes toward bereavement photography, sharing photos and continuing bonds?
- 3. What do parents do with photos of their baby, to what extent do they share photos, and what is the impact?

Method

Study design

The current study is part of a larger research project involving a larger sample of older babies with different research questions. A mixed-method exploratory research design, consisting of an online survey with open and closed-ended questions and semistructured interviews, was employed to address the research questions.

Recruitment

Purposive sampling was used to recruit participants who had received professional perinatal bereavement photography in Australia and New Zealand through Heartfelt (the only volunteer-led organization that provides this service). A survey link was published on Heartfelt's public Facebook page, and 500 emails were sent to potential participants. The online survey was completed by a sample of 655 (a response rate of 6.55%). Individuals were excluded from the survey analysis if they had not completed a significant proportion of questions or if their baby's age exceeded 28 days, as this did not constitute a perinatal loss. Of the 655 respondents, 151 were excluded, leaving 504 surveys to be analyzed. On completing the survey, 121 participants indicated they wished to participate in semi-structured interviews, with 31 self-registering during the four-week interview period.

Participants

The following information was collected from those who responded to the demographic questions. The majority, 441, lived in Australia and 62 in New Zealand; 469 (93.1%) were female, and 31 (6.2%) were male. The age of the parents ranged between 20 and 59 years (M = 35.68, SD = 6.04). Forty-five (9%) were either single/separated/divorced/widowed, and 455 (90.3%) were married or in a de facto relationship. Four hundred and fifty-two (89.95%) were still together with their baby's other parent. Eighty-six (17.1%) had a high school education, 284 (56.3%) had tertiary education, and 118 (23.4%) had postgraduate qualifications. The mean age of the baby at birth in gestational weeks was 30.29 (Min. = 20, Max. = 43, SD = 7.01). The mean age of the baby at death in days was 1.97 (Min. = 0, Max. = 28, SD = 5.24), with '0' indicating stillborn. The number of perinatal losses experienced by participants ranged between 1 and 22 (M=1.52, SD=1.5), with the mean time since loss being 50 months (SD = 32.7 months; range 0-156 months). In terms of ethnicity, 385 (76.4%) were non-Indigenous Australian, 55 (10.9%) were New Zealander, 13 (2.6%) were Australian Aboriginal or New Zealand Maori, 21 (4.4%) were British, European, or North American, and 15 (3%) came from non-western backgrounds (Asia, Middle East, Africa, and South America).

Materials

Survey

An anonymous, 20-min online survey was designed with a mix of closed and open-ended questions. Questions related to 12 demographic variables of participants and their babies; two 5-point Likert scale questions ranging from 1 (strongly agree) to 5 (strongly disagree) to measure whether participants identified with organized religion and/or with spiritual beliefs; one 5-point Likert scale question measured individualist or collectivist cultural orientation.

Attitudes toward photography. The researchers developed 10 questions using a four-point Likert Scale ranging from strongly agree to disagree to measure overall attitudes toward bereavement photography strongly. Four of these questions were negatively worded, such as feeling forced by family or hospital staff to take photos. The value for Cronbach's Alpha for the scale in the current sample was $\alpha = 0.79$, indicating good internal consistency.

Continuing bonds. Eight Continuing Bonds questions were adapted from Jones (2020) to measure the impact of photography on bereaved parents' continuing bonds with their children. Participants are asked to rate themselves on a scale from 1 (strongly disagree) to 7 (strongly agree), with higher scores indicating stronger continued bonds. A factor analysis was conducted, and all component items loading onto the scale. The value for Cronbach's Alpha for the scale in the current sample was $\alpha = 0.92$, indicating strong internal consistency.

Attitudes toward sharing photos. Sixteen questions were modified by Jones (2020) to measure participants' attitudes toward photos taken, their comfort in sharing them, and how others responded. Items were rated on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). Four items were negatively worded, for example, "I avoid sharing photos of my baby", and were reverse-coded for the final analysis. Two questions examined whether participants shared their photographs online/social media and participants' perceived support for doing this. Cronbach's alpha value for the scale was $\alpha = .88$, indicating strong internal consistency (Gliem & Gliem, 2003). Factor analysis also demonstrated that the scale items loaded onto the same scale, indicating a cohesiveness of the items.

The perinatal grief intensity scale (PGIS). The PGIS was designed to measure grief intensity following perinatal loss. Hutti et al. (2017) reported a Cronbach's

alpha of the PGIS full scale of 0.75, indicating high reliability. Factor analyses identified all factors loaded together into a single factor accounting for 66.94% of the total variance (Hutti et al., 2017). Total PGIS scores of 3.53 or higher indicate high grief intensity. The value for Cronbach's Alpha for the scale in the current sample was $\alpha = 0.68$, which is a little lower than previous research has found.

Semi-structured interviews

Semi-structured interviews were conducted to gather indepth accounts of parents' experiences. Provisional psychologists from Monash University undertook the telephone interviews. Interviews were semi-structured and open-ended, providing participants with an open space to discuss their experiences. Interviews typically lasted for 45 min and were recorded and transcribed following the interview process. The questions explicitly focused on parents' experience with Heartfelt, receiving the photos, and their possible impact on grieving.

Data analysis

Both quantitative and qualitative analyses were conducted in this study. The participants' responses were collected as raw data, transferred into Excel, and then entered into IBM Statistical Package for Social Science (SPSS) version 27. A missing values analysis was conducted. No variable had more than 5% missing values, so the expectation maximization method was determined to be appropriate to replace missing values. Values were only replaced if participants had mostly completed a scale. Any participant missing more than a third of a scale was recorded as not completing that scale, and values for that scale were not replaced.

Qualitative responses from semi-structured interviews were transcribed through machine transcription

Table 1. Descriptive statistics for attitudes to photography, continuing bonds, and sharing photos.

Scale	Mean (SD)	Range
Attitudes toward photography	38.6 (3.7)	16–50
Sharing photos	75.3 (14.6)	19–96
Continuing bonds	45.5 (4.9)	4-49
Grief intensity	2.9 (0.3)	2.26-3.60

called Otter. The student research team checked transcripts with recordings and made appropriate corrections for any inaccuracies. Thematic analysis was used to construct themes (Braun & Clarke, 2006, 2019) by first getting acquainted with the data by reading over the interviews. Next, the data were coded, with key quotes and ideas highlighted and grouped into their corresponding theme. This process was revised and cross-validated by two additional researchers, reducing the potential influence of bias from the research team. These constructed themes are thought to represent both participants' semantic and latent thoughts (Braun & Clarke, 2019). Further, the themes are contextually constructed from the researchers' reflections (Braun & Clarke, 2019).

Data triangulation was applied to increase the credibility and validity of the research (Noble & Heale, 2019). Information was combined and integrated from the literature review and quantitative and qualitative findings to ensure the results' trustworthiness.

Ethics

This research was amended and approved by the Monash University Human Research Ethics Committee on February 2021 (MUHREC Reference #23165). As the topic of perinatal bereavement is highly sensitive and distressing, protocols were initiated to alleviate potential harm and mitigate risks for participants and the student research team.

Results

Descriptive statistics

Descriptive statistics were calculated for each variable. The majority of participants had positive attitudes toward photography and photo sharing. Table 1 provides means, standard deviations, and ranges for Attitudes Toward Photography, Continuing Bonds, Grief Intensity and Photo Sharing.

Attitudes toward bereavement photography

Table 2 shows percentage ratings for levels of satisfaction with bereavement photography.

Table 2. Attitudes toward bereavement photography.

Scale items	Strongly agree	Agree	Disagree	Strongly disagree
Bereavement photography was a positive experience	96.3%	5.0%	0.8%	0.6%
I would recommend bereavement photography	98.8%	0.8%	0.2%	0.2%
Bereavement photography could improve	2.7%	8.9%	23.5%	64.9%
I felt forced to take photos by family	1.2%	3.1%	4.1%	91.6%
I felt forced to take photos by hospital staff	0.2%	1.5%	3.1%	95.2%
I was happy with the photos taken	90.9%	7.9%	0.6%	0.6%

Continuing bonds

Most participants reported that photos helped the development of a strong continued bond, with 89.8% (n = 486) scoring total scores above 47 and 60% (n = 300) scoring the maximum score of 56. Only 10.2% (n = 14) scored 47 or below. Table 3 presents percentages for participants' ratings on Continuing Bonds items.

Photo sharing

Table 4 shows percentages for measuring attitudes toward sharing photos. Nearly all (97.98%) participants agreed they could look at photos of their babies, the majority being able to share photos with their partner, other family members and friends who displayed positive social attitudes toward photos. A fifth of the sample disagreed that society more broadly understands and supports bereavement photography, while 75% said they would like to talk more freely about their photos. Regarding negative impacts on grieving, 5.2% felt photos stopped them from moving on with their life, with similar levels of partners and family members holding negative views. Over half felt comfortable sharing photos via social media, whereas more than three-quarters felt comfortable sharing face-to-face and being able to display their photos.

Spearman's correlation

Spearman's correlations were conducted due to a strong negative skew in the Continued Bonds data. As seen in Table 5, Attitudes Toward Sharing were positively correlated with Continued Bonds and Attitudes Toward Photography. On the other hand, attitudes Toward Sharing had a small negative correlation with

Table 3. Continuing bonds.

Scale items	Strongly agree	Agree	Slightly agree	Neither agree/disagree	Slightly disagree	Disagree	Strongly disagree
Photos help me feel connected to my baby	83.8%	11.6%	3.0%	1.4%	0	0	0.2%
Photos bring me comfort	87.4%	9.2%	2.2%	1.0%	0	0	0.2%
Photos help maintain relationship with my baby	76.2%	14.6%	5.2%	3.0%	0.6%	0.2%	0.2%
Photos help me through my bereavement	82.0%	10.4%	4.6%	2.0%	0.7%	0.3%	0
Photos help me to remember my baby	89.0%	6.9%	1.9%	1.9%	0	0.3%	0
Photos remind baby is part of everyday life	73.9%	14.4%	5.8%	4.2%	0.9%	0.4%	0.4%
Photos remind baby is part of the family	80.6%	10.4%	3.4%	4.2%	0.6%	0.6%	0.2%
Photos affirm me as a parent to my baby	76.4%	12.6%	3.8%	5.4%	0.8%	0.8%	0.2%

Table 4. Attitudes toward sharing photos.

Scale items	Strongly agree	Agree	Slightly agree	Neither agree/disagree	Slightly disagree	Disagree	Strongly disagree
I am able to look at photos of my baby	83.5%	12.7%	1.8%	0.4%	1%	0.2%	0.4%
I am able to share photos of my baby with partner	76.9%	11.6%	3.4%	3.2%	2.3%	1%	1.6%
I am able to share photos of my baby with family	61%	15.5%	11%	1.7%	4.6%	3.7%	2.5%
I am able to share photos of my baby with friends	45%	18.8%	16.6%	5.0%	5.6%	5.4%	3.6%
My partner thinks photography is positive	66.7%	17.3%	4.5%	7.3%	1.6%	1.2%	1.4%
My family thinks photography is positive	59.9%	19.9%	6.2%	10.8%	0.9%	0.9%	1.4%
My friends think photography is positive	52%	22.3%	7.1%	16.2%	0.4%	1.1%	0.8%
I feel photos stop me moving on with my life	2%	1.1%	2.2%	6.7%	4.4%	21.2%	62.4%
My partner feels photos stop us moving on with our lives	2.5%	1.4%	4.9%	12.1%	4.1%	22.7%	52.3%
My family feel photos stop us moving on with our lives	1.8%	1.4%	3.5%	19%	6.1%	22.1%	46.1%
I avoid sharing photos with others	11%	20.6%	23.8%	5.9%	4%	11.1%	23.6%
I feel comfortable sharing photos in person	37%	28.7%	13%	6.7%	6.5%	5.1%	3%
I feel comfortable sharing photos on social media	23.2%	13%	15%	7.2%	10.6%	15.5%	15.5%
I feel comfortable displaying photos of my baby	43.8%	23.4%	10.3%	5.9%	6.1%	6.1%	4.4%
I would like to talk about photography more freely	36.9%	26.8%	11.8%	17.6%	1.8%	4.1%	1%
I feel society understands and supports photography	19.2%	25.4%	20.6%	14.5%	12.1%	5.2%	3%

Table 5. Correlations for sharing, continuing bonds, grief intensity, photography attitudes.

	1.	2.	3.	4.
1. Sharing	_			
2. Continuing bonds	0.36 (<.001*)	_		
3. Grief intensity	-0.16 (<.001*)	−0.06 (.22)	-	
4. Attitudes toward photography	0.46 (<.001*)	0.52 (<.001*)	-0.09 (.063)	_

^{*}p < .05.

Table 6. t-tests for continuing bonds, attitudes toward photography and sharing photos.

Demographic Variables	Continuing bonds <i>t</i> (<i>p</i> value)	Photography t (p value)	Sharing t (p value)
Organized religion	1.97 (.049) ^a	0.38 (.70)	0.02 (.98)
Spirituality	1.72 (.086) ^a	0.50 (.61)	1.09 (.28)
Cultural orientation	0.74 (.46)	0.93 (.35)	1.01 (.32)
No. of losses	1.01 (.31)	1.78 (.076)	1.39 (.17) ^a

^aWelch correction used due to violated homogeneity of variance.

Grief Intensity. Attitudes Toward Photography was also positively correlated with Continued Bonds.

As the Age at Death and Time Since Death were positively skewed, a Spearman's rank-order correlation was run to investigate the relationships between the Age of the Baby at Death, Age of the Baby at Birth, Time Since Death and Continued Bonds. Preliminary analyses showed the relationship between variables to be monotonic, as assessed by visual inspection of the scatterplots. All variables had weak but non-significant correlations. The correlation between the Age of the Baby at Birth and Continued Bonds was rho = 0.03, p = .55. The correlation between the Age of the Baby at Death and Continued Bonds was rho = -0.04, p = .37.

Demographic diversity variables

Table 6 presents t-tests conducted for demographic variables (gender, number of losses experienced, cultural orientations, organized religion, and spirituality). Cultural orientations, organized religion, and spirituality were measured on a 5-point Likert scale. Scores were not normally distributed, so responses were grouped. Those who responded with Strongly Disagree or Disagree were combined, as were those who responded with Strongly Agree or Agree. Those who responded neutrally were not included in the analysis.

Largely, no significant differences were found for Continued Bonds and Attitudes Toward Photos and Sharing. Only one significant difference was found for those belonging to organized religion who gave slightly higher ratings for the Continued Bonds score (mean difference = 1.05, t(293.96) = 1.97, p = .049). Welch's correction was used due to a violation of the assumption of homogeneity of variance. However, this difference is small; Cohen's d = 0.22.

Qualitative analysis

Qualitative analysis of semi-structured interviews examined how participants initially engaged with photos and whether this changed over time. Five themes were constructed: Tangible Memories, Enfranchising Grief, Identity and Ongoing Bonds, Facilitate Connection, and Social Stigma and Denial.

Theme 1: tangible memories

Participants described photos as a "tactile memory...you can hold onto forever" (P11) and "tangible things that you can look and... hold in your hand when you need to" (P12) and "validates how real and tangible they [baby] were that we could cradle in our arms" (P23). This aligns with P5 stating, "I can't really go in my own memory bank and access memories of him [or] how he looked; the only way I can access a memory is [through] the photos."

Participants also reported the value of photos strengthened over time, as evident in P3's comment that photographs were "more precious than what they were when [we] first got them because they're part of the memory of your child" and became "more important [as] there is a reminder of that time with my son" (P27). This was reinforced by P20,"after she had passed, they held a lot more significance... Because our time was so limited that we don't have a lot of stories to share about her... And you look back at them and talk about moments in time."

Several participants, like P5, appreciated the quality of professional photographs: "We've obviously taken photos ourselves on the phone... they're nowhere near the same...just to be able to have a beautiful image of [baby] to share ... for people to appreciate how beautiful she was."

Theme 2: enfranchising grief

For many, initial responses to the photographs provoked raw and painful reality of grief, as stated by P26: "In the initial stages ... it was a bit of a shock (and) confronting". P3 described feeling "that bit of pain there" when initially viewing photographs of their baby. Similarly, P20 stated: "I just cry, which I think is appropriate. It's very emotional. It reminds you of an event that's quite difficult ... it is hard to look at them [photos], but I appreciate having them." Others like P20 reported photos as "assisting me with my grieving ... made the process easier in some ways as I have less regrets."

Initially, some participants stated they needed to view photographs "constantly", as P6 reported, as they were "terrified at the beginning that I was going to forget her [baby]". Similarly, P17 felt " ... a lot of guilt if [I] didn't look at her photos everyday... [in] the first year..." With the passing of time, participants reported this "need" (P6) and "that pull to look at them [photos] constantly" (P17) dissipated.



Photographs evoked contradictory feelings for participants as P21 explained:

They remind me although her death was very sad, the time we spent with her was really beautiful [...] I look at the [photos] and feel happy and calm.

Whereas, for P1, her emotions

ebb and flow [...] sometimes it's really cathartic to go back and look, and other times all it does is tease me.

Participants reflected on how their engagement with the photographs had changed and evolved with time with more integrated grief responses emerging. P27 and P22, respectively, did not have "the same overwhelming sense of grief" and "I don't get upset like I used to" when viewing the photographs. Others, like P18, described changes "as time pass[es], grief is less raw" allowing for "more fondness [when] look[ing] at photos and feeling[s] of love for her." P10 concurs, "as time goes on, time does heal" where they can now "flick through the photo album, and feel a sense of gratitude", while P22 reported "find[ing] them ... quite comforting,"

Participants varied between sharing and not sharing the photos through their grieving. For P1, sharing on social media "helps me move forwards" as did P17 who felt "sharing [photos] and talking ... helped me work through my grief." In contrast, P17 stated they coped with their grief more privately: "I understand why some people [share] but personally that's not my way of dealing with things".

Theme 3: identity and ongoing bonds

Photos are also important for establishing babies' identities "to acknowledge [baby's] existence, acknowledge her personhood and her as an individual" (P28). Many participants described how photos provided a vehicle for the ongoing expression of love and conversations with their babies:

... We could ... show that we loved and wanted that little baby in our lives. And we say goodnight to [baby's] picture as we go to bed ... We have changed the way we interact with the photos ... it's almost like him developing as a person in as much as you can, it makes the babies more real in people's minds. (P18)

Theme 4: facilitate connections

Photographs helped participants to facilitate ongoing connections with their partners, family, friends and the wider community too. Some participants felt photos "helped us in being able to share with our kids" (P2) and gave siblings a chance "to see her photo, and ... have that physical acknowledgement of his sister" (P26) thereby, fostering "connection and understanding" (P19). P2 explained they were looking "forward to the day that I have another child, and I can have [these] photos, and we can see [the] similarities in them, I think that'll be really helpful for creating a connection down the line". Photos enabled conversations with others too as P18 explained: "I need to talk about him [baby] and photos allowed us to do that." Photos enabled relatives overseas to be involved according to P24: "For us that was very beneficial to email photos so that family and friends overseas could see [baby] and see that he existed." Photographs facilitated ongoing connections with partners as P2 explained: "My husband and I have many times looked at the photographs and spoken about the different features of [babies] ... and it's been a good conversation." P3 found additional support from sharing with their faith community: "Our church has been very supportive ... sometimes people ... don't want to make you upset. But... not talking about [baby] makes me upset, because it feels like people have forgotten" (P3).

Theme 5: social stigma and denial

This theme explores negative responses from others and social stigma related to bereavement photography with a few participants commenting on negative intergenerational attitudes "....my husband's biological father ... said, 'Why are you posting a dead baby on Facebook?' So, it was very hard" (P8). Similarly, P12 noted denial of loss: "I showed my grandma... it was a huge shock to her. And obviously, things have changed since when she was younger..." Participants also commented on the disenfranchisement of their grief because "people get very uncomfortable with death in general" (P5) and "friends who kept a distance" (P18). P2 expresses her disappointment: "I get really taken aback by other people's responses. And that's like wow... you don't really care do you? ... It's easy to just dismiss things or turn a blind eye because it's too hard."

The fear of social disapproval also made some participants hesitant about sharing, as P11 explained: "I think I was just so worried about what everyone else would think. If people get offended, and ... unfriend me. I was in such a vulnerable state ... I just didn't want any extra criticism." In addition, P22 felt there was an increased stigma associated with sharing losses if it has resulted from a "medical termination" due to their baby's genetic abnormality, while P31 believed photos of their baby's considerable physical deformities might be "too confronting" for others to view.

Discussion

This study aimed to address gaps in the literature regarding professional bereavement photography for perinatal loss. The results indicate a high level of acceptability for professional bereavement photography, where photos were valued, treasured and cherished by parents. Most appreciated the sensitive and caring approaches taken by photographers and reported feeling supported and validated by the process. This is supported by a recent study on bereavement photographers whose own experiences with loss provided compassion and increased empathy for bereaved parents (Vivekananda et al., 2023). Nearly all (99%) were happy with the photos taken to support the benefits of providing parents with high-quality photos by professional photographers proposed by Blood & Cacciatore (2014), and this may facilitate the high levels of displaying and sharing photos found in our study. The results of this mixed methods research validated several recurrent themes from previous qualitative studies where photos affirmed parenthood and babies' existences, creating and sustaining memories over time (Blood & Cacciatore, 2014; Martel & Ives-Baine, 2014; Ramirez et al., 2019). In addition, photos held significant meaning for parents and maintained ongoing connections to their babies (Blood & Cacciatore, 2014, 2014).

Several new findings on bereavement photography emerged from this study. Our results found the vast majority of participants perceived photography as assisting them through their bereavement and were helpful enfranchising largely in their grief. Quantitative findings of a moderate negative correlation suggest that sharing photos is associated with reduced grief intensity. The thematic analysis illustrated that photos played a role in assisting parents in navigating their journey through grief. However, in the minority of cases (2.8%), participants reported photos were unhelpful in the grieving process, while 5.3% felt photos stopped them from moving on with their life, and 8.8% reported their partners held this view. These are relatively low levels of potentially complicated grief reactions in the sample, as 25-30% of women are estimated to suffer from prolonged, intense, complicated grief reactions following a perinatal loss (Hutti et al., 2017).

Participants in this study scored at the very high range for Continued Bonds, with 60% of participants scoring the maximum score. Our study found significant moderate correlations between sharing of photos and continued bonds, as well as between sharing of photos and satisfaction with photography. While

previous research is equivocal on outcomes for continuing bonds (Jones, 2020), this is a meaningful finding where photographs are perceived as facilitating not only strong continued bonds between parents and their baby but often within the wider family and friendship networks. Participants reported strong endorsement that photos helped them to maintain a relationship with their baby and to feel that their baby was part of their family.

The concept of 'transitional objects' has been applied to bereavement photography for perinatal loss, as the object - the photo - allows for the creation of lasting memories (LeDuff et al., 2017). Our finding supports previous qualitative results that transitional objects such as photographs facilitate healthy grieving and allow for meaningful and tangible memories to be created. In addition, triangulation with the qualitative responses gives insight into why participants scored so highly, providing subjective perspectives on continued bonds and expressions of love over time. For participants, the photographs became an avenue for creating an identity and developing a narrative for their baby, which could be shared with others, thus facilitating connections with family, friends, and community. Connections could also be built with subsequent children, strengthening continuing bonds over time and photos focused on expressing love for babies. Further, our findings show that these continued bonds persisted over time as time since death was not a significant variable for continued bonds.

The large sample size enabled the comparison of the number of losses, cultural, religious and spiritual beliefs, as well as variables related to the babies' death that may be related to bereavement photography. Largely, no differences were found for these diversity factors and their relationships with continued bonds and attitudes toward photos and sharing variables. However, those who belonged to an organized religion reported slightly higher significant Continued Bonds scores. In addition, no significant correlations existed between continued bonds and the baby's age at both birth and death and time passed since the death of babies. These results differ from those (Scholtes & Browne, 2015) who found weaker effects of continued bonds for younger children, type of death and time since death. Nevertheless, these findings are very encouraging regarding the positive impact of bereavement photography on groups with diverse views, values, and orientations.

This is the first study on bereavement photography to report these findings, as previous studies used smaller, more homogenous samples. Although some cultures (particularly indigenous and non-western) and religions may hold taboos around photographing the deceased, these were not widely reported in our study, as our results were skewed in the positive direction. The relatively high levels of education in the sample, with nearly 80% holding post-secondary and postgraduate educational qualifications, may explain this finding where more highly educated groups may have higher death literacy (Noonan et al., 2016) for acknowledging, supporting and discussing perinatal

Our quantitative results show that relatively high levels of acceptance for bereavement photography were reported not only by parents but found in their wider social networks. However, some social stigma and taboos persist, with 12.3% of partners, 14.3% of family members, and 19.8% of friends being perceived as holding negative views on bereavement photography and confirmed by a small number of qualitative responses related to taboos and stigma. Higher rates of social disapproval for sharing photos are reported by Jones (2020), who reported that 38% of the sample had received negative reactions from others regarding photos, and participants avoided sharing with others for fear of causing offense or negative reactions. The age of the baby at death, physical deterioration or discoloration of the baby's body, and any deformities were all factors that parents considered when sharing photos. Interestingly, three-quarters of the sample reported wanting to talk more freely about photos indicating stigma persists with perinatal loss in Western cultures (Markin & Zilcha-Mano, 2018). To be able to share, parents need to have the appropriate social environment and culture that allows for emotional disclosure without fear of judgment (Tedeschi & Blevins, 2017). Wanting to share memories more freely and societal pressure to move on are identified as risk factors for mental health distress (Jones, 2023). While taboos may inhibit sharing, some parents saw photography as an opportunity to break the social silence surrounding perinatal loss. However, very few participants (1.16%) in our sample reported using avoidance coping (Fernández-Basanta et al., 2020), with almost all our participants being able to view photos and the majority being able to display them.

The positive attitudes toward sharing photos on social media about perinatal loss is also a new finding. Parents frequently reported using social media as a platform to raise awareness and open the conversation surrounding perinatal loss. Although earlier studies (Murphy & Thomas, 2013) reported that continued bonds were more likely to be expressed privately, our findings represent a cultural and social change in attitudes over the last decade about sharing losses on social media. This new form of mourning represents shifting continued bonds from a private space to expressing it in a new, more widely shared, public space within online communities (Irwin, 2017).

Data triangulation from the study confirmed that photos were not only valuable in enfranchising grief and validating parental and babies' identities and that bereavement photography offers more than just a visual memory but importantly supports continued bonds for parents throughout their lives.

Strengths

Overall, this study adds to the limited research available on professional bereavement photography for perinatal loss. To date, this is the largest study on the use of professional bereavement photographers for perinatal losses, making this a worthwhile investigation. The mixed-method design is a key strength, enabling data triangulation of both quantitative and qualitative data. In addition, the large data set allowed for new data analysis related to cultural and religious diversity and baby-related variables.

Limitations and future research

There are a few limitations that may impact the quality of the study and the generalizability of the results. Firstly, the sample only consisted of parents who had received bereavement photography, potentially skewing the results in the overly positive direction, as there is no comparison group of parents who rejected or did not receive photos. Using convenience sampling and recruitment through the only existing bereavement photography organization in Australia and New Zealand may have added a positive bias to the results. Participants who have negative experiences may discontinue engagement with the organization's online community. The cross-sectional survey design is also a limitation of the methodology used, and the skew toward strong continued bonds limited the analysis of correlations. Future studies should include parents who did not receive bereavement photography.

Implications

Findings from this study may have important implications for the application of perinatal bereavement support guidelines and further inform the practice of bereavement photography in hospitals. The research suggests that bereavement photography has a positive impact in enfranchising parental grief, though additional ongoing grief support is required for those who continue to suffer from prolonged grief.

Participants advised other parents in the same situation to have photos taken, even if reluctant, through a process of informed consent. The service should be offered several times to account for the initial shock parents face when losing their babies. The need for education is essential for the broader community and health professionals on perinatal loss and the importance of memory making. Ongoing training and professional development for volunteer photographers are also necessary to undertake this delicate work with sensitivity, compassion, and respect for diverse parental needs and attitudes.

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References

- Alexander, K. V. (2001). The one thing you can never take away": Perinatal bereavement photographs. MCN American Journal of Maternal Child Nursing, 26(3), 23-127. https:// doi.org/10.1097/00005721-200105000-00004.
- Blood, C., & Cacciatore, J. (2014). Parental grief and memento mori photography: Narrative, meaning, culture, and context. Death Studies, 38(1-5), 224-233. https://doi. org/10.1080/07481187.2013.788584
- Blood, C., & Cacciatore, J. (2014). Best practice in bereavement photography after perinatal death: qualitative analysis with 104 parents. BMC Psychology, 2(1), 15. https:// doi.org/10.1186/2050-7283-2-15
- Bobo, H. P., Lau, C., Fong, H. C., & Chan, C. H. Y. (2017). Reaching the unspoken grief. In D. Klass, & E. M. Steffen (Eds.), Continuing bonds in bereavement: New directions for research and practice (pp. 150-160). Taylor & Francis
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77-101. https://doi.org/10.1191/1478088706qp063oa
- Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health, 11(4), 589-597. https://doi.org/10.1080/2159676X. 2019.1628806
- Cacciatore, J., & Flint, M. (2012). Mediating grief: Postmortem ritualization after child death. Journal of Loss and Trauma, 17(2), 158-172. https://doi.org/10.1080/ 15325024.2011.595299

- Fernández-Basanta, S., Coronado, C., & Movilla-Fernández, M. J. (2020). Multicultural coping experiences of parents following perinatal loss: A meta-ethnographic synthesis. Journal of Advanced Nursing, 76(1), 9-21. https://doi.org/ 10.1111/jan.14211
- Gliem, J. A., & Gliem, R. R. (2003). Calculating, interpreting, and reporting Cronbach's alpha reliability coefficient for Likert-type scales [Paper presentation]. Midwest Researchto-Practice Conference in Adult, Continuing, and Community Education. http://hdl.handle.net/1805/344
- Gold, K. J. (2007). Navigating care after a baby dies: a systematic review of parent experiences with health providers. Journal of Perinatology, 27(4), 230-237. https:// doi.org/10.1038/sj.jp.7211676
- Harvey, S., Snowdon, C., & Elbourne, D. (2008). Effectiveness of bereavement interventions in neonatal intensive care: A review of the evidence. Seminars in Fetal & Neonatal Medicine, 13(5), 341-356. https://doi. org/10.1016/j.siny.2008.03.011
- Hutti, M. H., Myers, J., Hall, L. A., Polivka, B. J., White, S., Hill, J., Kloenne, E., Hayden, J., & Grisanti, M. M. (2017). Predicting grief intensity after recent perinatal loss. Journal of Psychosomatic Research, 101, 128-134. https://doi.org/10.1016/j.jpsychores.2017.07.016
- Irwin, M. D. (2017). Mourning 2.0 continuing bonds between the living and the dead on Facebook. In D. Klass, and E. M. Steffen (Eds.), Continued bonds in bereavement new directions for research and practice (pp.317-329). Taylor & Francis Group.
- Jones, E. E., Crawley, R., Brierley-Jones, L., & Kenny, C. (2023). Continuing bonds following stillbirth: Protective and risk factors associated with parental bereavement adaptation. Journal of Reproductive and Infant Psychology, 41(1), 93–109. https://doi.org/10.1080/02646838.2021.1972951
- Jones, E. E. (2020). Continuing bonds: Parent's experience of an ongoing relationship with their stillborn baby. [Doctoral dissertation]. University of Sunderland. http:// sure.sunderland.ac.uk/id/eprint/11544
- Kochen, E. M., Jenken, F., Boelen, P. A., Deben, L. M. A., Fahner, J. C., Van Den Hoogen, A., Teunissen, S., Geleijns, K., & Kars, M. C. (2020). When a child dies: a systematic review of well-defined parent-focused bereavement interventions and their alignment with grief- and loss theories. BMC Palliative Care, 19(1), 28. https://doi. org/10.1186/s12904-020-0529-z
- LeDuff, L. D., III, Bradshaw, W. T., & Blake, S. M. (2017). Transitional objects to facilitate grieving following perinatal loss. Advances in Neonatal Care, 17(5), 347-353. https://doi.org/10.1097/ANC.0000000000000429
- Markin, R. D., & Zilcha-Mano, S. (2018). Cultural processes in psychotherapy for perinatal loss: Breaking the cultural taboo against perinatal grief. Psychotherapy, 55(1), 20-26. https://doi.org/10.1037/pst0000122
- Martel, S. L., & Ives-Baine, L. (2014). "Most prized possessions": Photography as living relationships within the end-of-life care of newborns. Illness, Crisis & Loss, 22(4), 311-332. https://doi.org/10.2190/IL.22.4.d
- Michelson, K. N., Blehart, K., Hochberg, T., James, K., & Frader, J. (2013). Bereavement photography for children: Program development and health care professionals' response. Death Studies, 37(6), 513-528. https://doi.org/ 10.1080/07481187.2011.649942



- Murphy, S., & Thomas, H. (2013). Stillbirth and loss: Family practices and display. Sociological Research Online, 18(1), 27-37. https://doi.org/10.5153/sro.2889
- Noble, H., & Heale, R. (2019). Triangulation in research, with examples. Evidence-Based Nursing, 22(3), 67-68. https://doi.org/10.1136/ebnurs-2019-103145
- Noonan, K., Horsfall, K., Leonard, R., & Rosenberg, J. (2016). Developing death literacy. Progress in Palliative Care, 24(1), 31-35. https://doi.org/10.1080/09699260. 2015.1103498
- Perinatal Society of Australia & New Zealand. (2018). PSANZ. Clinical Practice Guideline for Care Around Stillbirth and Neonatal Death 3rd ed. https://sanda.psanz. com.au/clinical
- Ramirez, F. D., Bogetz, J. F., Kufeld, M., & Yee, L. M. (2019). Professional bereavement photography in the setting of perinatal loss: A qualitative analysis. Global Pediatric Health, 6, 2333794X19854941. https://doi.org/ 10.1177/2333794x19854941

- Scholtes, D., & Browne, M. (2015). Internalized and externalized continuing bonds in bereaved parents: Their relationship with grief intensity and personal growth. Death Studies, 39(2), 75-83. https://doi.org/10.1080/07481187. 2014.890680
- Tedeschi, R. G., & Blevins, C. L. (2017). Posttraumatic growth: A pathway to resilience. In U. Kumar (Ed.), The Routledge international handbook of psychosocial resilience (pp. 324-333). Routledge/Taylor & Francis Group. https://doi.org/10.1080/07481187.2014.890680
- Thornton, R., Nicholson, P., & Harms, L. (2019). Scoping review of memory making in bereavement care for parents after the death of a newborn. Journal of Obstetric, Gynecologic, and Neonatal Nursing, 48(3), 351-360. https://doi.org/10.1016/j.jogn.2019.02.001
- Vivekananda, K., Ong, U., Wurf, G., D'Souza, L., Giosserano, R., & Licqurish, S. (2023). Bereavement photography, volunteering, and posttraumatic growth: A mixed-methods investigation. Death Studies, 47(4), 371-380. https://doi.org/10.1080/07481187.2022.2067264