Stillbirth, still life: A qualitative patient-led study on parents' unsilenced stories of stillbirth

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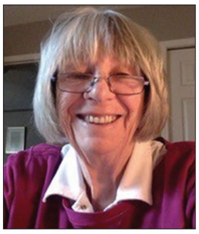

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Abstract: Our objective was to explore parents' experiences of stillbirth using a patient-led qualitative approach, in the Canadian context. Parents who had experienced stillbirth in the previous five years were recruited through posters and snowball sampling. We conducted a co-design focus group to set the direction of our research, narrative interviews, and a reflect focus group to engage parents in finalizing the analysis and findings. Data was analysed iteratively using a participatory approach with grounded theory principles. Our findings highlight that stillbirth is a story of death, but it is also a story of life. Parents (n=11) require the space to experience both the birth and death elements of the story; yet, one or both elements are often silenced. *Stillbirth, still life* was the core concept that emerged from parents' stories of their stillborn babies. Parents' narratives are driven by the need to honour their babies' lives. They are learning to be unsilenced.

Keywords: maternal health, perinatal loss, fetal death, fetal loss, patient-oriented research, patient and public involvement

DOI: 10.1080/02682621.2020.1828724

Introduction

Stillbirth is defined in Canada as a fetal death with a birth weight ≥ 500 g and/or a gestational age ≥ 20 weeks (StatisticsCanada, 2014). In 2014, there were approximately 8.3 stillborn babies delivered in Canada for every 1000 births (StatisticsCanada, 2014). To put this statistic into perspective, a similar number of babies die during their first year of life and stillbirth causes more than 10 times as many deaths as the number that occur from Sudden Infant Death Syndrome (SIDS) (Centers for Disease Control & Prevention, 2017). Stillbirth is often referred to as a 'silent' occurrence, and thus the bereavement associated with this type of death remains underrepresented and not well understood.

In recognition that 'we can no longer remain silent about stillbirth' *The Lancet* produced a call to action series on stillbirth in the years 2011 (Froen et al., 2011) and 2016 (Froen et al., 2016). Several researchers have also described the profoundly distressing silent loss of stillborn babies by mothers (Murphy, 2012), fathers (Cacciatore et al., 2013), parents (Lisy et al., 2016), and families (Murphy & Cacciatore, 2017) all over the world (Chen et al., 2015). The plethora of qualitative research on stillbirth is largely aimed at providing insight into this unimaginable experience for the purpose of improving care for bereaved families. Collectively, the findings reveal stillbirth is emotionally complex, characterized by enduring grief, psychological pain, struggles to find meaning, and, often, for mothers, a crisis of their identify as a 'moral mother' (Cacciatore at al.,, 2013; Chen et al., 2015; Murphy, 2012). The care provided to families during this time leaves an indelible mark. Meaningful care is considered to be compassionate, personalized, and validates individualized experiences as well as the status of parenthood (Cacciatore et al., 2013; Lisy et al., 2016).

Our primary research objective is not unlike that of the other researchers: we aimed to explore and understand parents' experiences of stillbirth for the purpose of improving care. Yet our approach differed in several compelling ways. First, patient-researchers and academics worked in partnership at the highest level of patient engagement; according to the IAP2 (International Association for Public Participation) framework, which is often used to illustrate the spectrum of possible patient engagement in research, the highest level of patient engagement is a partnership where patients are viewed as experts and lead research efforts (Amirav et al., 2017). We are a research group comprised of academics and trained patient-researchers. Some of the patient-researchers in our group have personal experience with unexpected birth outcomes, including stillbirth. The patient-researchers on our team conducted the interviews and facilitated the focus groups using a narrative peer-to-peer method that permitted a natural space, whereby participants could feel comfortable sharing the depths of their experience through normalized conversation with their peers (Berger, 2015). We employed the Patient and Community Engagement Research (PaCER) participatory methodology (Marlett et al., 2015; Shklarov et al., 2017), which allowed patient-participant priorities to drive every step of the research process. As patients, with patients, and for patients, we present a narrative theory of stillbirth.

Methods

This qualitative patient-led research study was carried out by Patient and Community Engagement Researchers (PaCERs) (Marlett et al., 2015; Shklarov et al., 2017). PaCERs are patients who have been trained to conduct experiential qualitative research using participatory grounded theory; the training program is based at the University of Calgary, Cumming School of Medicine. Participatory grounded theory merges participatory research with some principles of grounded theory (Simmons & Gregory, 2005; Teram et al., 2005). The PaCER methodology of *Set, Collect, Reflect* (Figure 1) engages patient-participants through every step of the research process for the purpose of developing relevant patient-informed theories (Gill et al., 2016; Gillis et al., 2017). Note that we have used the term 'patient' as an all-encompassing term to describe people who had received health care services.

Ethics approval was obtained from the Conjoint Research Ethics Board, the University of Calgary. Participants met inclusion criteria if they self-identified as a parent who had experienced the delivery (vaginally or through caesarian section) of a stillborn baby within the last five years, were more than 18 years of age, and spoke English well enough to participate in a focus group or interview. Recruitment was conducted through posters and snowball sampling. The posters were provided to the Caring Beyond and Pregnancy and Infant Loss groups, the Elbow River Healing Lodge, and to Stillbirth Doulas in Calgary. Interested participants contacted a PaCER researcher who provided the study details and obtained informed consent. Recruitment continued until data saturation was reached (Hennink et al., 2017).

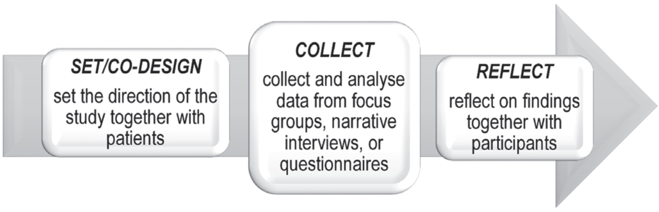

Figure 1: The PaCER (Patient and Community Engagement Research) method of *Set, Collect, Reflect* engages patient-participants as partners throughout the research process.

Set/co-design focus group

The *Set* stage is the initial co-design phase of the PaCER methodology and was conducted to better understand patient priorities and refine the study proposal, including the identification of research topics that are relevant to those who have experienced a stillbirth, development of patient-informed interview questions, and recruitment considerations. A five-hour focus group was held in a private space within the university, with four co-design participant-advisors (n=1 mother, n=1 heterosexual couple, 1=grandmother) to better understand families' experiences of stillbirth and set the direction of our research. The focus group was facilitated, audio recorded, and transcribed by the PaCER researchers.

The question posed to the *Set* focus group participants was: '*Can you tell us about your experience of having a stillbirth?'* Discussion among the participant-advisors was encouraged with a series of prompts used by PaCER researchers to deepen and elaborate the information provided. Participant responses were recorded on flipchart paper and mounted during the group session, so that participants could highlight the points that resonated as a top priority.

The topics and top priorities that emerged were: 1. Help acute and community health providers give better, more consistent and compassionate care; 2. The need for a comprehensive resource which will prepare families for delivering and caring for their stillborn in hospital and for the return home; 3. The impact on relationships (partners and external); 4. How we talk about stillbirth needs to change; 5. The need for better and longer follow-up care and support including programs designed specifically for families grieving a stillborn (different than a miscarriage); 6. The impact of stillbirth on subsequent pregnancies and how subsequent prenatal care needs to change; 7. The desire to honour stillborn babies. These initial ideas guided our research direction and were used to formulate subsequent guiding interview questions for the data collection phase. Based on the findings from this focus group we narrowed our study population to the recruitment of parents only and shifted our original research aim from exploring the experience of families to exploring the experience of parents only.

Data collection/analysis cycles

Data collection and analysis were conducted by drawing on principles of grounded theory practice (Glaser & Strauss, 1967), with small groups of interviews analysed in an iterative process by PaCER researchers to ensure interrogation of the data and emerging categories, as well as to guide the direction of recruitment and data collection strategies.

Narrative interviews encouraged participants to 'tell their story' using prompts sparingly to elicit greater depth. Once participants had told the story of their stillbirth experience, open-ended questions were posed to test emerging categories. Data collection/analysis cycles continued until data saturation was achieved and all PaCER researchers as well as academics agreed on a core construct that organised the working theory and emerging categories. All interviews were audiotaped and transcribed. All PaCER researchers kept a research diary to memo and be reflexive.

Reflect

Interested participants from the interview and co-design phases were invited to a five-hour focus group to *Reflect* on the study findings and offer feedback. To facilitate meaningful contribution by patient-participants, the focus group opened the team's analytical interpretations for discussion and input by participants.

Trustworthiness & reflexivity

The manuscript was written by Chelsia Gillis, a PhD candidate and PaCER-trained researcher, in collaboration with PaCER patient-researchers Venesa Wheatley, Ashley Jones, and Brenda Roland. Some of the patient-researchers in our group have personal experience with unexpected birth outcomes, including stillbirth. VW created Table 2. Oversight and direction were provided by senior PaCER patient-researcher Marlyn Gill and academic qualitative researchers Svetlana Shklarov and Nancy Marlett.

We aimed to enhance the credibility of our findings through employing two methods of data collection (focus groups and interviews), and emphasizing team-based analysis, in which team members' individual interpretations and possible biases were carefully compared and analyzed. We aimed for investigator triangulation by discussing emerging scripts, memos, and findings with our team of patient-researchers, patient-researchers with stillbirth experience, and academics. Disagreements among researchers were discussed before coming to a consensus. In addition, our participatory method engaged patient research participants in data analysis beyond the conventional member checking. The *Reflect* stage tested the credibility of our findings with those who have experienced stillbirth.

Results

Participants

A total of 11 participants from Alberta, Canada were enrolled in our study from October 2016 to May 2017. Our sample included eight women and three men, aged 23 to 39 years, all of whom experienced one stillbirth two-and-a-half months to five years before study enrollment. Some participants were engaged in more than one data collection event. In total, four family members with stillbirth experience participated in our *Set* focus group (one heterosexual couple, one grandmother, one mother), nine parents participated in narrative interviews (two heterosexual couples, five mothers) and seven parents (one heterosexual couple, five mothers) participated in our *Reflect* focus group. None of the participants withdrew from the study.

Core concept: Stillbirth, still life

'It's like no one seems to know how to deal with a stillbirth.' Some examples of such helpless confusion include mothers who internalize feelings of guilt and blame, parents who are debilitated by trauma, friends and family who are unprepared to offer successful support, a health care system designed to serve only acute events, and our society that silences stillbirth.

Stillbirth is a story of death, but it is also a story of life. Understanding this paradoxical, yet explanatory, concept may help alleviate the confusion of '*not knowing how to deal with stillbirth*'. Parents experience their child's entire lifestory over a matter of hours or days and require the space to experience both the birth and death elements of the story. Yet often parents are given the space to experience only one element or neither elements of the story. *Stillbirth, still life* was the core concept that emerged from parents' stories of their stillborn babies. Stillborn babies, including Kate, Henry, Caleb, Charlotte, Rio, Maddox, Emilina, Everly and Annalee, need space to exist in our society.

Parents' experiences took the form of two narratives: clinical and personal (see Figure 2 and Appendix (online supplementary material)).

The two narratives stood alone, but also influenced one another. At the helm was the *Historical silent discourse*, which appeared to impact both the clinical and personal narratives. The clinical experience, *Abandoned in silence*, was sub-divided into three categories: 1. Lead me through the decision with one sub-category: Recognize that I am having a birth and death experience; 2. I need specialized care now; and 3. I need specialized care later. The personal experience, *Shrouded in silence*, was sub-divided into three categories: 1. I survived the space between; 2. I am learning to forge a new path; and 3. My daughter's name is Charlotte. These narratives were driven by the need and desire to shift the silent discourse: *Still, and always, a part of our lives* and to honour every baby's life. The analysis revealed the current change of attitudes: parents are learning to be unsilenced; their individual stories are paving the way for a changing discourse, and their collective narrative is a blueprint for real change. Parents' narratives suggested that by *Losing the secret and sharing in the memory,* we would all be better equipped to 'deal with a stillbirth' and honour every still life. The following section describes the identified categories and sub-categories in detail.

A historical silent discourse; still, and always, a part of our lives; a changing discourse: losing the secret, sharing in the memory

'I'll never forget the silence.' Stillborn babies come into our world silent and our culture seemingly consigns them to silence thereafter. Parents described their story as one that does not fit with what society wants it to be (i.e. return to life as usual); as a result, their grief is socially constrained, and their story is often silenced. Parents described needing the space to talk about their experience and their children in a socially permissive fashion – '*I felt like a weight lifted off my shoulders … to be able to tell my story.*' Yet, parents expressed that, '*No one knows what to say*' and because of this they often faced platitudes, endured a lack of validation, or received no or little acknowledgment of their child's life and the profound impact of this unique loss on their family. Despite these barriers, all participants were actively sharing their stories publicly (when perceived

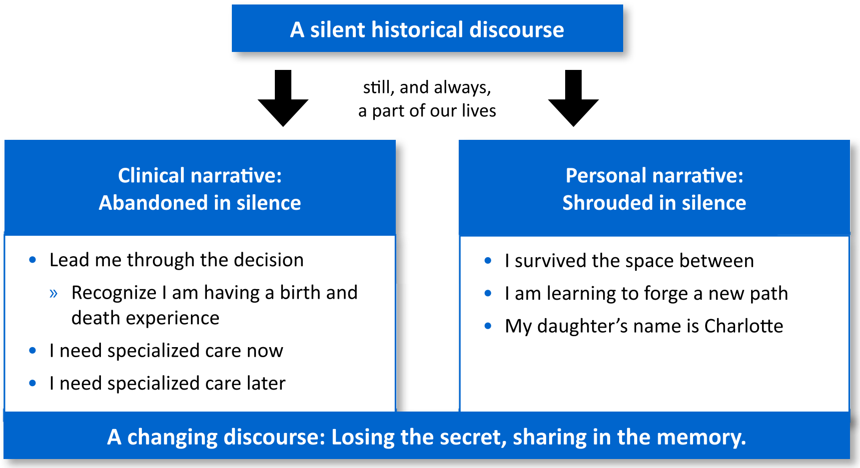

Figure 2: A patient-driven narrative theory of the experience of stillbirth.

appropriate) and seeking both cultural and medical change for families of stillbirth: '*It starts with us I think … people that have experienced loss … coming forward … you know being brave*' because '*Talking about it doesn't mean I am stuck there … .and it doesn't mean I haven't moved on, whatever the heck that means.*'

Clinical experience: Abandoned in silence

The clinical narrative focused on how future care for families experiencing stillbirth can be improved. Several parents described a stigma surrounding stillbirth – '*I felt shameful that there was a dead baby inside of me*' – that governed or clouded their decision-making in hospital. Personal shame – '*my body can't do what it is supposed to do*' – and the generalized silence of stillbirth left parents uncertain as to how to behave 'acceptably' in the acute clinical period – '*I didn't know that I could spend as much time with him as I wanted. I felt like it was morbid to ask.*' Parents also perceived that silence clouded the healthcare providers' clinical judgements as well as the acute and long-term care that they received from their providers. Marooned in silence, some parents did not fully engage with their children post-delivery; a decision that was deeply regretted.

Lead me through the decision

Parents had mixed clinical experiences, but the best experiences were had by those whose healthcare providers lead them through their decision-making: '*They really guided us through the process. 'Cuz we would have been lost and floundering had we not had that direction.*' The silence of stillbirth meant that most parents were completely unprepared for this outcome, and this resulted in heavy and crucial reliance on healthcare providers to help them make decisions. Parents asked that healthcare providers not only present all options, but also explain the potential consequences of these options and provide them with time to process the information. Parents stressed that they needed to make timely decisions that they could live with, and if providers led them through the decisions it would prevent missed opportunities and needless regret.

Recognize I am having a birth and death experience

Parents need to be supported through both a birth and death experience at the same time. In fact, most parents described wanting their birth experience to be normalized as much as possible (often only the death experience is acknowledged and stressed). '*We want you to treat it as though we were having a normal delivery. We don't know what we are having [boy or girl], so announce it, like you would announce it if it were a living baby.*' Parents also needed the space and privacy to grieve, and, at an appropriate time, to be walked through the practical post-mortem details. Healthcare providers that capacitated parents to have both a birth and a death experience provided care with a lasting positive impact on these families.

I need specialized care now

'Ok, this person is having a stillborn … unleash the program … ' Parents unanimously agreed that stillbirth care should be specialized. Every participant described disappointing healthcare treatment at some point and felt that this poor treatment stemmed from inexperienced or unprepared healthcare providers. Employment of a consistent bereavement team that includes specialized professionals, chaplaincy, and peer supporters would be ideal. Parents also require a specialized dedicated ward that is removed from unnecessary personnel, expectant mothers, and pictures of healthy babies plastered on the walls. Our participants recognized several additional areas for improvement (see Table 1), which largely arose from the need for the healthcare team and for them, personally, to have been better prepared.

I need specialized care later

'I had a great experience with the nurses and stuff helping me through my loss and giving birth, but it was just afterwards where I felt like it kinda failed … I felt really lost.' Parents felt that specialized care should extend beyond the acute trauma and perceived a lack of care continuity. Parents described a feeling of being pelted with leaflets and bombarded by counsellors early on, which was unfitting for their acute state of trauma, and how this attention was later abandoned when they could have used it: '*I needed time … I think … to determine what I would need to talk to a counselor about.*' Parents asked that healthcare providers inquire about their wellbeing, recognize *both* parents' struggles, acknowledge anxieties, and provide awareness and reassurance at *all* medical appointments going forward (*especially* with subsequent pregnancies). Parents felt that if care continuity were achieved it would reduce insensitive questioning, such as 'is this your first?' or 'how many pregnancies have you had?' at future appointments.

Personal experience: Shrouded in silence

The personal narrative largely focused on enduring social silence, stigma, and beliefs stemming from culturally misguided recognition of stillbirth, which often had an isolating effect that impacted relationships and, in some cases, made full social participation difficult: '*You have*

Table 1. Practical recommendations to enhance bereavement care by parents in our study who experienced stillbirth:

1. Parents who are sent home prior to the delivery of their stillborn babies need information packets and someone to review the information with them. This period was considered a missed opportunity for parents to consider how they would deliver their baby, whether they would have an autopsy, if or how they could create memories with their baby, if they would invite family, and to be prepared to answer questions related to the funeral.
2. Most parents would like a dedicated space for stillborn deliveries, where parents don't have to witness other pregnant women and/or hear newborn babies.
3. Employ a peer-to-peer or family-to-family support program: Patients with practical stillbirth experience to help guide parents through the birth and the grief process.
4. Create perinatal loss nurse champions who have the desire and dedication to improve stillbirth experience department wide.
5. Inpatient healthcare providers (HCP) need a checklist of discussion points for parents while they are in hospital. Parents need to be walked through the birthing process step-by-step as well as the choices they might consider with respect to their babies (i.e., dressing or bathing baby, changing baby's diaper, taking photographs, baptising baby, etc.). Parents need to be presented with all options and be given the potential pros and cons of each option. Parents need the perspective of experienced HCP to offer insight into understanding the impact of their choices. Parents also need to have the option to revisit their decisions and change their minds. Finally, the checklist needs to be used in a patient-centred way, where HCP recognise the individual wants and needs of their patients.
6. Focus on the importance of documentation and memory making; parents want and need tangible items to confirm and honour their babies' existence. These are the only things they will have of their babies' lives.
7. HCP need to remember that everything that is said, smelt, experienced etc., is engrained in the minds of their patients forever. As an example, a patient said to her nurse, '*I am so sorry that this [loss] is your workday. It must be terrible.*' The nurse responded, '*No. I am one of the few people who get to meet your baby. I am privileged.*' Words matter.
8. Many parents spoke of the ineffectiveness of social workers as resources during their hospital stay. Social workers need specialized training to care for grieving parents.
9. Consider adopting/developing specialized care for dads.
10. Our findings support the continuing bonds bereavement theory (Root & Exline, 2014), and we advocate for its use in guiding care for stillbirth.
11. Develop a follow-up system and a plan to enhance continuity of care at subsequent hospital visits and in the community.
12. Establish evaluation criteria for care programs to ensure parents are finding value in the resources and supports offered.
13. Develop a dedicated program to support parents with subsequent pregnancies. Evaluate/consider specialized treatment for subsequent pregnancies (e.g., new minimum standards of ultrasounds, etc.).
14. Standardize stillbirth treatment at all hospitals. Review the capacity of low-risk or rural clinics/hospitals to deal with stillbirth. Parents tended to have worse (even traumatizing) experiences at these hospitals, possibly because these institutions were ill-equipped and inexperienced to '*deal with stillbirth.*'
15. Include the risk of stillbirth in the antenatal medical literature and in prenatal classes. Parents spoke of not having any awareness of stillbirth as a potential outcome. While careful consideration would have to be given to handle this tastefully and not in a fear-mongering way, parents should be aware of and prepared for an outcome of stillbirth by highlighting monitoring measures (e.g., Kick Counts), similarly to SIDS.

this secret … you kinda feel … shame … that you have this secret.' Parents often found it easier to present the dimension of self that is socially pleasing, but this self is incomplete and, ultimately, unfulfilling. Yet, when the profound impact of stillbirth was socially recognized (even through social media) parents were supported in healing and in restructuring their lives.

I survived the space between

'*It sorta felt like … I didn't understand the world.*' The personal story tended to follow the clinical experience and often started with an initial feeling of living in a boundless impenetrable space; although residence within this space was often transient, it was not necessarily linear, and some participants still felt: '*I live in that space.*' The space between pertains to the indescribable, incomprehensible period of returning home from the hospital – '*We had to hide the car seat in the back of the truck … and go home to the bedroom*' – and coping with multidimensional loss (loss of child, loss of dreams, loss of parenthood).

I am learning to forge a new path

'*From that one stillborn baby, it affected everything.*' Parents described a continuum-type journey that changed who they are. Parents not only perceived a change within themselves, they also felt as though they were different from other people – '*We do parent differently*' – which was not necessarily considered to be a bad thing. Parents had learned, or were learning, to cope with adversity and this positively impacted their lives – '*… holy smokes! I am tough.*'

My daughter's name is Charlotte

'*There's something important about being able to say your child's name even if they aren't here anymore.*' Parents want their stillborn babies acknowledged: not just through death, but life. Parents stressed that not all conversations have to be sad: '*Caleb brought hope. He taught me more about life in his short life than anyone ever could.*'

Discussion

In 1968 Bourne surveyed physicians with medical experience of stillbirth and concluded that, '…a woman experiencing a stillbirth is liable to be bereft of medical help owing to the unconscious alienation of her doctor's interest from her and her family or because the doctor-patient relationship breaks down.' Bourne reasoned that the problem was related to the perceived 'non-event' of stillbirth with no physical illness to treat or tangible experience of a living human to mourn. Approximately ten years later Smith and Lewis published their narrative reviews, *The abhorrence of stillbirth* (Smith, 1977) and *Management of stillbirth: Coping with an unreality* (Lewis, 1976), to urge the medical community to shift this 'well-meaning conspiracy of silence' after stillbirth by helping families create tangible memories to mourn. In 1979 Cooper interviewed couples with experience of stillbirth, and her findings were notably similar to ours. More recently, two systematic reviews of 52 (Ellis et al., 2016) and 114 (Burden et al., 2016) qualitative, quantitative, and mixed methods studies also produced similar findings to that of ours, suggesting that the social and medical 'non-event' culture and silence surrounding stillbirth persists.

A 2010 global report (Sather et al., 2010) on stillbirth provided some insight into this pervasive phenomenon. Interviews with key stakeholders and knowledge users (n=41 from 14 countries) on the current knowledge, attitudes, and commitments toward stillbirth revealed several perceived challenges to advocacy, including lack of knowledge about the magnitude and impact of stillbirth, lack of awareness and understanding, and lack of cost effective and scalable interventions. These perceived challenges resonate with the stories of our parents who often encountered social ignorance that functioned to preserve the silence. Indeed, a general lack of public knowledge on stillbirth, its risk factors and causes (some of which could be perceived as stigmatizing), were recently reported in an Irish population survey (Nuzum et al., 2018). These findings correspond with our study, and together these views also correlate with the theory of disenfranchised grief (Doka, 1989), which explains the negative or ignorant social attitudes to grief associated with a loss that cannot be openly discussed or socially supported. As a result of disenfranchising, the bereaved parents are often deprived of longstanding empathy and support from their family, friends and care providers (Degroot & Vik, 2017), their grief being minimised or silenced with shame and embarrassment (Doka, 1999). Public health campaigns illustrating the significance and reality of stillbirth, similar to that observed with SIDS (Young 2018), may be appropriate to shift the cultural and personal perceptions of stillbirth.

A recent review of bereavement theory associated with perinatal loss (Price & El-Khoury, 2015) demonstrated that these silences have begun to lift in the past few decades, with many feminist-oriented theories of bereavement acknowledging the imposed sense of secrecy and shame, making it more acceptable for women to open up and process their experiences of grief following perinatal loss. In their review, Price and El-Khoury also described the strengths-based perspective on perinatal loss bereavement, where the traditional focus on the pathological aspects and negative symptoms is challenged by the emphasis on personal growth associated with perinatal bereavement. A literature review of bereavement theory by Rothaupt and Becker (2007) referred to studies addressing bereavement as a possible catalyst for increased coping skills and personal growth; one of the examples of reflecting such positive impact is the theory of continuing bonds (see also Root & Exline, 2014), in which the grief that involves maintaining an emotional connection with the deceased is viewed as a positive factor without the label of pathology.

Our findings suggest that parents are learning to be unsilenced; they are actively sharing their stories, thereby improving the visibility of stillbirths and contributing to a shift in the discourse. Similar findings were reported by Murphy (2012) after conducting in-depth interviews with 10 couples and 12 mothers of stillbirth: 'Far from being "passive victims of prejudice", some parents may be empowered to take action to improve local and, in some cases, national maternity services, as well as raising people's awareness of stillbirth and breaking the silence that surrounds it' (p. 98). These tendencies are also mentioned in Price & El-Khoury's review (2015). Social media may be playing a role in breaking the silence of stillbirth. In fact, an editorial by Kate Granger (Granger, 2014) in the *BMJ Supportive and Palliative Care,* described how social media can influence conversations related to death and dying to promote acceptance and openness.

The strength of our study is in deepening the knowledge of stillbirth parents' authentic insight into the impact of the silent discourse. As a novel contribution to previous research, our study demonstrates the power of supportive interaction between parents with similar experiences, as well as the parents' active position towards initiating change in social discourse. The statement of *Stillbirth, still life* originated from participants' stories and reflected the strength of their insight into the problem and its desirable solutions within social attitudes and clinical services.

Table 1, a summation of patient recommendations for clinicians who work in this area, highlights this point. Implementation of the practice recommendations presented in Table 1 has the potential to drastically improve the indelible care and traumatic experience of bereaved parents. In part, we owe this study's contribution to its method, in which a patient-researcher with stillbirth experience led the investigation and our patient-participants were engaged at each phase of the research design to ensure our findings truly represent parents' experiences and future expectations for stillbirth. The peer-to-peer nature of relationships between researchers and participants resulted in strong trust and depth of sharing. The data were not only collected, but also analyzed and interpreted by some patient-researchers on our team with relevant patient experience – a particularly beneficial feature of the method because the 'insider' knowledge sharpened the researchers' theoretical sensitivity. The combination of using principles of the grounded theory method with narrative analysis allowed for discovering the general meaning of parents' stories while also relying on their deeply personal relevance.

Given that our sample was small and relatively homogenous, our findings may not be representative of all parents experiencing stillbirth. Furthermore, our findings suggest that the needs and expectations of parents who were aware of their baby's death prior to delivery might differ from those who experienced death during their delivery. Future research should consider the unique needs of these two groups.

In conclusion, *Stillbirth, still life* is at the heart of parents' narratives of stillbirth. To truly hear this simple phrase would mean respect for the profound impact of stillbirth on the lives of families, no restrictions on grief timelines, recognition of the value of specialized care, and a true opportunity to share in the memory by losing the secret.

Acknowledgements

We would like to dedicate this work to Kate, Henry, Caleb, Charlotte, Rio, Maddox, Emilina, Everly and Annalee. We would like to thank Debbie McNeil RN PhD, Scientific Director, Maternal Newborn Child and Youth Strategic Clinical Network, Alberta Health Services, for her feedback on our research proposal and manuscript. We would like to thank Amanda Gillis RN, Foothills Medical Center, Department of Labour & Delivery, for her practical, clinical insights. We would also like to thank our participants for sharing their stories. ■

Conflict of interest

The authors declare that they have no conflict of interest.

Funding

This research was completed as part of the Patient and Community Engagement Research (PaCER) internship, in which patients are trained to conduct experiential qualitative research. The PaCER internship program is funded by a number of donations. The costs associated with this internship study drew from the donation received from the Strategic Clinical Networks, Alberta Health Services (AHS SCN™).

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