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Experience of hope: An exploratory research with bereaved mothers following perinatal death

Willyane de Andrade Alvarenga[a], Francine deMontigny[a,*], Sabrina Zeghiche[a], Chantal Verdon[c], Lucila Castanheira Nascimento[b]

[a] Département des sciences infirmières, Université du Québec en Outaouais, Gatineau, QC, Canada
[b] Department of Maternal-Infant and Public Health Nursing, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, SP, Brazil
[c] Département des sciences infirmières, Université du Québec en Outaouais, St-Jérôme, QC, Canada

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ABSTRACT

Problem: The negative implications of perinatal death on mothers' mental health are documented, however little is known about their experience of hope.
Background: Within the broader literature, hope has contributed to better mental health and bereavement adjustment and often bereaved mothers report the importance of hope for the grieving process.
Aim: This study aims to explore bereaved mothers' experience of hope following perinatal death.
Methods: Individual interviews were conducted with 33 mothers having experienced the death of an infant in the perinatal period. Data from the interviews were analysed using thematic analysis.
Findings: The mothers' experience of hope following perinatal loss is organized into three themes: *Hope disrupted by perinatal loss*; *Transformed hope: a new pregnancy challenged by the sense of foreboding of another loss;* and *Ways to restore and foster hope in life.*
Discussion: Although hope has been a motivating force for mothers to reconnect with their life plan and move on after a loss, it is also negatively affected by the experience of perinatal bereavement, social support, and health professionals' clinical practice.
Conclusion: Bereaved mothers have reported a disruption in their experience of hope. While some experience a loss of hope or a sense of hopelessness, others experience a transformation and restoration of hope, which is reinvested in the grieving process. Mothers' experience of hope highlights the need for the support of a healthcare professional and may contribute to enhanced clinical practice through the promotion of bereavement care, considering the aspects that instil, maintain, and interfere with hope.

Statement of significance

Problem or issue
Although we know the negative implications of perinatal death on mothers' mental health, little is known about bereaved mothers' experience of hope following a perinatal death.
What is already known
Perinatal loss is a devastating experience with negative implications for the mental health of mothers. Hope is important for the grieving process of mothers after the death of an older child.

What this paper adds
Although hope has been a motivating force for mothers to reconnect with their life plan and move on after a loss, it is also negatively affected by the experience of perinatal bereavement, social support, and health professionals' clinical practice.

1. Introduction

Perinatal death, that is the loss of an infant through death by miscarriage, stillbirth, neonatal loss, or elective termination for fetal anomalies [1], is a devastating experience with lifelong impacts, affecting more than 5 million women worldwide [2,3]. Although bereaved mothers are susceptible to anxiety, depression, post-traumatic stress disorder, suicidal thoughts, anger, fear, social

* Corresponding author at: Université du Québec en Outaouais, 283 Taché Boul., P. O. Box 1250, Postal Station Hull, Gatineau, Québec J8X 3X7, Canada.
E-mail address: francine.demontigny@uqo.ca (F. deMontigny).

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isolation, and guilt after perinatal loss and in subsequent pregnancies [4–6], their grief is disenfranchised [4]. Also, complicated grief reactions [7], conjugal and financial difficulties [4], and spiritual distress have been consequences following perinatal death [8].

Within the broader literature, hope as a valuable human response has been an important resource during times of suffering [9] and a key factor for recovery when facing trauma such as the death of a loved one [10,11]. Hope can also act as a resilience factor that buffers the impact of hopelessness, which is related to an increased risk of suicide [10], depression [12], and complicated grief [13]. Despite the negative implications of perinatal death for mothers' mental health and the importance of hope for bereavement adjustment, little research on bereaved mothers' experience of hope following perinatal has been carried out.

Prior research on perinatal bereavement stressed that pregnancy represents the hope of a new life, as a mother of the expected child, hope which was interrupted by a perinatal death. [14,15] Bereaved mothers often report the importance of hope and the struggle between hope and despair in the grieving process that persists in subsequent pregnancies [16,17]. Thus, hope is featured in the perinatal bereavement experience, but how mothers maintain hope and positive feelings about the future after perinatal loss is still insufficiently understood.

There are multiple definitions and ways of conceptualizing hope. Hope is a multi-dimensional, dynamic, and individualized phenomenon related to temporality and future, to staying positive and to moving ahead in life [9,18,19]. Hope also is described as a positive future [20] and it has both cognitive and emotional aspects, involving three components: goals, pathways thinking, and agency thinking. Agency thinking refers to one's motivations to use pathways to reach important goals, whereas pathways thinking involves one's perceived abilities to find and use routes to achieve those goals [21]. Thus, hope is one's expectations and ability to attain important goals [21] and to anticipate possibilities while awaiting new discoveries [11].

Considering hope in maternal bereavement care may contribute to improving mental health and bereavement adjustment for women experiencing perinatal loss. However, protecting, fostering, and even instilling hope in a bereaved mother may be challenging to health professionals who need to ensure the presence of factors likely to promote hope in the grieving process. Since addressing the gap in the literature and improving access and quality of healthcare services around perinatal death is a global challenge [22], a qualitative analysis was proposed to explore bereaved mothers' experience of hope following a perinatal death. The specific research questions were as follows: What is the mothers' experience of hope following a perinatal loss?; What is the focus of that hope?; and What are the aspects that instill, maintain, and interfere with their hope?

2. Methods

2.1. Design

Qualitative secondary analysis (QSA) was conducted using data sets collected through interviews with mothers for a study about the experience of perinatal death, the grief trajectories over time, and the health services surrounding that experience. This initial study was a multiple case study, conducted in the province of Quebec, Canada from 2015 to 2017. [23] During primary analysis, the hope experience, which emerged spontaneously in speech, was recognized as a significant area which raised new questions to be answered through secondary analysis. The secondary analysis, performed in 2019, is a retrospective analysis of the whole or part of the data from a new perspective in order to examine concepts that were not central to the primary analysis [24]. QSA is beneficial for maximizing the use of existing data, mainly on vulnerable groups and sensitive topics, such as the experience of bereaved women in perinatal death research [25,26]. Thus, an analytic expansion was conducted from a secondary interpretation from a database [27] to deepen the understanding of the mothers' experience of hope following perinatal bereavement.

2.2. Primary data sources

The final sample for the secondary data analysis consisted of semi-structured interviews with 33 mothers having experienced the death of an infant in the perinatal period, that is to say during pregnancy and up to a few hours of life. These women were recruited by key informants (nurses, midwives, doctors) as part of a study taking place at three sites representing seven regions of Quebec (Canada). These regions were chosen to represent diversity in terms of urban, semi-urban, metropolitan, and rural regions. To be eligible to participate in the study, these women had to have experienced a perinatal death in the ten months preceding the interview, to have received services from one of the participating establishments (hospitals, birthing centres, community organizations), and be able to understand and speak French. Women wishing to participate in an interview lasting approximately 90 min were met at their home or in a room reserved for the university, based on their preference. The interviews were conducted in French, transcribed verbatim, and have been reviewed for accuracy by bilingual authors (English and French).

The interview guide had the following questions: How did you decide to become pregnant? What was your initial reaction when you found out you were pregnant? What did your pregnancy change in your life at the start? How did the death unfold? How did you find out that the pregnancy was over, or that it was about to end? How were the events? Who was with you at the time? How did you react to this? How did you feel at the time of the loss? What helped you to cope with your grief?

2.3. Research ethics

The [redacted for blinded review] Human Research Ethics Committee that approved the primary research has been approached to approve the data to undergo a secondary analysis. Thus, this study was approved on the 17/08/2014 (Protocol number #1799). All participants gave freely informed consent and signed the informed consent form prior to interviews. Contractual arrangements detailing access to data and authorship were established for investigators of the QSA who were not part of the primary study team.

2.4. Procedure of the secondary data analysis

Thematic analysis was employed to identify themes from original interview transcripts [28], which involved careful examination of the common elements and experiences of participants related to hope. NVivo qualitative data analysis software (Version 12 for Mac) was used to manage the coding and analysis. First, we ensured that the epistemological orientation, objectives, and methods across primary and secondary studies were aligned. Secondly, we determined whether the existing data answered the research questions of the QSA by the repeated reading of the data; this step was overlapped with a phase that involved familiarization with the primary data sets [25]. Finally, we initiated the processes of line-by-line inductive coding, and a list of the different codes was collated. Higher order codes were organized into themes that were refined hierarchically and ordered to best reflect the data. Direct quotations from the

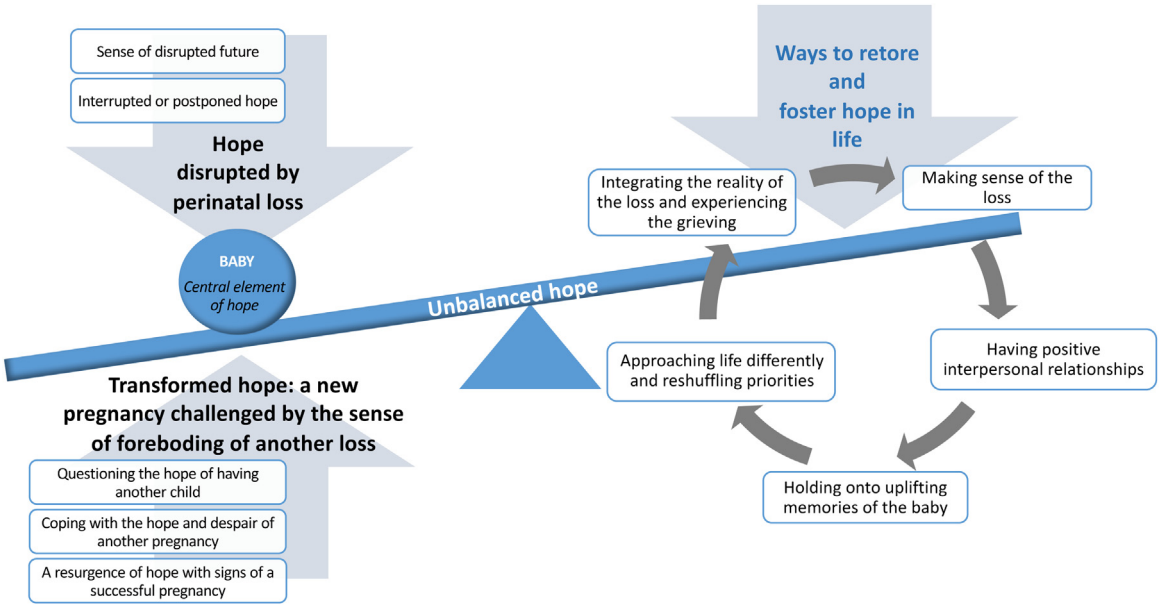

Fig. 1. Mothers' experience of hope following perinatal death.

transcripts and a figure to summarize selected themes are provided to illustrate the participants' hope experience (Fig. 1).

2.5. Rigour of QSA

Strategies were used to enhance the trustworthiness and validity of the QSA [28,29]. Most researchers of the QSA were members of the primary study team and had been involved in data collection and primary data analysis. We assessed the nature, completeness, quality, and appropriateness of existing data to answer new research questions in the QSA by the direct access to the primary data set and study team [29]. The influence of the findings of the primary study on the secondary study was decreased by an independent coder, who has an interpretivist research position and was not a member of the primary study team, to conduct the QSA. The field notes and direct team access contributed to the sensitivity of the independent coder to the context of the primary study. To achieve credibility, we invested in prolonged engagement with the data. To address the issues of dependability and confirmability of findings, the team of researchers who had bereavement perinatal and hope expertise, and knew the context in which the data was originally produced, reviewed the coded data extracts for each theme of the secondary analysis. Finally, team consensus on themes was reached (Table 1) [28].

3. Results

First, a profile of the participants was developed. Then, mothers' experience of hope following perinatal death was organized into three themes: Hope disrupted by perinatal loss; Transformed hope: a new pregnancy challenged by a sense of foreboding of another loss; and Ways to restore and foster hope (Fig. 1).

3.1. Participant profiles

The mothers in this sample had an average age of 30 years (25–38 years) and were all born in Canada. They had been living with the child's father for an average of seven years (ranging from two to 14 years), the majority were married (39%, n = 13) or in a common-law relationship (61%, n = 20). Ten women (30%) had experienced an early pregnancy loss (less than 19 weeks pregnancy), 18 had experienced a late pregnancy loss (54%, from 20 weeks to term) and 5 had experienced the death of the baby at birth or in the early neonatal period (15%). Thirteen women (39%) had no prior experience of a perinatal death, while fifteen women had previously had one or more miscarriages (45%), one had lived a neonatal death and five (15%) had had a termination of pregnancy in previous pregnancies. Ten women had no other living children (30%), while 12 had one (36%). Eleven women had between two and five children (33%). The majority worked full-time (66%, n = 22), 18% worked part-time (n = 6), four were stay-at-home mothers (n = 12%), and one was a student. As a result, almost half of the sample (49%, n = 16) had a household income of more than $100,000 Canadian dollars, while 9% of mothers had a low household income (n = 3) of less than $49,999.

3.2. Hope disrupted by perinatal loss

Hope disrupted by perinatal loss due to frustrated dreams and plans, resulting in a sense of a disrupted future and a sense of interrupted or postponed hope.

Table 1
Identified themes and subthemes related to bereaved mothers' experience of hope.

Theme	Subtheme
Hope disrupted by perinatal loss	Sense of disrupted future Interrupted or postponed hope
Transformed hope: a new pregnancy challenged by a sense of foreboding of another loss	Questioning the hope of having another child Coping with the hope and despair of another pregnancy A resurgence of hope with signs of a successful pregnancy
Ways to restore and foster hope in life	Integrating the reality of the loss and experiencing the grieving Making sense of the loss Having positive interpersonal relationships Holding onto uplifting memories with the baby Approaching life differently and reshuffling priorities

3.2.1. Sense of disrupted future

Perinatal loss was considered as a failure in mothers' life, regardless of the time and type of loss. Hope is jeopardized by perinatal death, leading to a decrease/decline in hope and a sense of helplessness, as the future is uncertain and bleak without the baby. There was a sense of disruption of the future. Mothers experienced grieving for both the deceased baby and the loss of their expectations and dreams, assuming that *"to lose a baby is to grieve all the imagined future with the child"* (Joanna, one stillbirth).

> *"It was like a failure in my life, the end of a dream really. I didn't get what I wanted; I didn't succeed in this part of my life that is having children"* (Anya, one termination of pregnancy for fetal anomaly).

> *"It's like a rejection, a failure, you know . . . like I'm grieving for motherhood"* (Claire, one stillbirth, one miscarriage).
> *"We bought a house here. So, we had planned to put the baby's room here, we had bought furniture, we had decided, we had bought the paint, so, all those things fell through. I thought I was going to die. Totally. My life was ruined"* (Rose, one stillbirth).

3.2.2. Interrupted or postponed hope

Pregnancy had a valuable meaning for mothers; it was the hope of their life's journey. The baby was the central element of hope to achieve this planned family project even before the pregnancy. Some mothers maintained the hope that their family project had been postponed to a future pregnancy while others saw their hope interrupted with perinatal loss.

> *"When we heard the little heart beat at ten weeks, the first ultrasound at twelve weeks, that was it. Both of us were in fact completely overjoyed. It had been a really hard process and something that we had been waiting for a long time"* (Melissa, two miscarriages, one termination of pregnancy for fetal anomaly).
> *"It's the dream, part of our life plan, and a hope that this pregnancy carries. The baby carries a lot of hope. The hope we put into our future. The "baby" part has been postponed. It was like: I still have to wait to have that much-desired baby!"* (Claire, one stillbirth, one miscarriage).

3.3. Transformed hope: a new pregnancy challenged by the sense of foreboding of another loss

Following a perinatal loss, mothers questioned whether to suspend or postpone the hope of having another child. Some mothers embraced the hope of a subsequent pregnancy and planned for it, while dealing with the challenge of a sense of foreboding of another loss. Hope flourished during pregnancy when there were signs that the pregnancy was going well and that the baby was thriving.

3.3.1. Questioning the hope of having another child

Mothers reviewed their family planning following loss and questioned themselves and their partner if they should suspend or postpone the hope of having another child. Although mothers did not seek to erase the memory of or replace the deceased child with another child, the thought of a subsequent pregnancy nourished their hope to achieve their life plan and to move on after the loss. In this process, they questioned whether they wanted another child and would be physiologically and emotionally able to go through a subsequent pregnancy. Mothers needed some degree of certainty that their goal of having another baby could be achieved in order to be able to embrace the hope of a new pregnancy. In order to feel confident that the goal of having another baby could be achieved, mothers did a realistic initial assessment reviewing both the reason for the perinatal death and their ability to cope with grief. Moving in the grieving process and being emotionally prepared were important to take a new step towards a subsequent pregnancy.

> *"The second pregnancy cannot erase everything that has happened, but it can improve the situation a bit because you say: there is another hope of a baby who is there! I say all the time, the arrival of another baby comes to beautify life. He will never replace the first"* (Anya, one termination of pregnancy for fetal anomaly).
> *"We wondered for a long time whether we wanted another child. So, this questioned our marriage, our family life. It put many things into question. We wondered where we were going with this. We wondered why this happened to us and I did a lot of blood tests to see if there was a specific cause. So we had to say to each other: 'we want to try to have another child anyway'"* (Daniela, one miscarriage, one stillbirth).

3.3.2. Coping with the hope and despair of another pregnancy

Some mothers following perinatal death restored hope to achieve their planned family project with a new pregnancy. They focused their energies on the subsequent pregnancy. They thus planned, made changes in their lives, and overall attempted to control risk factors associated with the demise of their baby to achieve their goal of a successful pregnancy. However, the efforts made to persevere in achieving this pregnancy were accompanied by hopelessness, pessimism, anxiety, fear, and hypervigilance. These were exacerbated when the causes of the previous perinatal death remained unknown, there were delays in becoming pregnant again, and mothers experienced multiple losses and grief as they aged. These factors were hindrances to mothers' hope towards a successful pregnancy and jeopardized their life plan of having another child.

> *"I knew it was going to be even worse because the grief was building up. It was the second time and we had been waiting six years. It's an in vitro treatment. So that makes it even more difficult because you still can't realize this plan, this dream of having a child. So, is that ever going to happen? My hope is diminishing very much. I'm starting to visualize that this may not happen, may never happen. We're getting older, we're getting closer to* 40" (Fanny, one miscarriage, one stillbirth).
> *"The fact that we're postponing the plan to have another child, well, due to my age too, and the fact that we've already been in the process of trying to start a family for four years now, has caused me a lot of anxiety. I find it difficult because I had started again and I was having panic attacks when I saw that the plan was being postponed and that it wasn't going to happen right away"* (Audrey, one miscarriage, one neonatal death).

Some mothers experienced a disruption in their hope of a subsequent pregnancy due to the onset of infertility or to a discordance in plans between partners in regards to the desire for another child. There were difficulties in dealing with these circumstances that enhanced the grieving for their family planning.

> *"I realized that my life is incomplete without a second child. It's like grief: I'm just going to have one child. I want another one, but it's a joint decision. I have to respect his decision. He doesn't want to anymore. He finished that chapter and wants to move on"* (Esther, three miscarriages, one stillbirth).

3.3.3. A resurgence of hope with signs of a successful pregnancy

Mothers dreamed of another child, but felt unable to reproduce the feelings of innocence and joyful contentment during the

subsequent pregnancy due to the unsettling foreboding of new loss. Although most mothers got pregnant again, they tried to control hope during pregnancy. This hope grew when they reached some milestones, such as hearing the baby's heartbeat, not experiencing risk factors, abnormalities or signs which had brought about the previous pregnancy loss. In order to cope with the uncertainty and fear of another loss, mothers continuously evaluated pregnancy-related signs that reinforced and sustained the hope and optimism of having their baby. After the arrival of the dreamed and desired baby, mothers felt hope, happiness, and a sense of purpose.

"I was happy, but I did not want to give myself false hope. My baby is there, but she can pass away. I was afraid all the time that something would happen, but I said: She was doing well! We heard her little heart; we saw both arms, both legs and fingers" (Heloise, one miscarriage).

3.4. Ways to restore and foster hope in life

Bereaved mothers were continuously seeking hope to regain their life projects and to move forward after the loss. They listed ways to restore, support and increase hope such as integrating the reality of the loss and experiencing the grieving; making sense of the loss; having positive personal relationships; holding uplifting memories of the baby; approaching life differently and reshuffling priorities.

3.4.1. Integrating the reality of the loss and experiencing the grieving

At the time of the infant's death, some mothers were reluctant to accept the reality of their baby's death and maintained the hope of their baby's survival. They also hoped that the diagnosis was incorrect, hope that was sometimes fed by the lack of clarity or ability to understand the information shared by health professionals.

"I told myself that I knew this, but at the same time, you somehow hope that they are wrong. I think you just do not want to believe" (Georgia, one stillbirth).

"I was not going to start waiting two days for the ultrasound and then keep hoping. So two days later, we left, but we still had hope. We said to each other, 'Sometimes they're wrong . . . '" (Lynn, two miscarriages, one stillbirth).

Integrating the reality of the perinatal loss and expressing their grief were important before mothers could move on to find a new meaning of life, to recognize the need to seek social support, and to restore hope, for example by deciding to have a subsequent pregnancy. Information and the passage of time were significant in these processes. Receiving the diagnosis of perinatal death or fetal anomalies and being informed of the cause of the demise and the risk factors in an empathetic, clear, and informed manner promoted hope by reducing uncertainties. Mothers stated that with the passage of time, they felt relief from intense grief, and were able to better recognize their needs and emotions related to the grieving process, thus, transforming hope.

"Do not deny this; do not minimize it. It's really living the pain of your grief, then asking questions to gain access to the most varied possible resources" (Daniela, one miscarriage, one stillbirth).

"You have to give it some time. It's the only thing that can really help; it's the passing of time. Then, just live, then go to the depth of grieving and let time make things better" (Ivana, one miscarriage, one neonatal death).

3.4.2. Making sense of the loss

Finding meaning for the loss instilled hope and made mothers reconstruct their understanding of the loss, integrate the reality of their baby's death, and live the grieving process more positively. Mothers sought explanations for the loss ("Why my baby;" "Why me again?") and directed their energy toward making sense, engaging in pathways of an existential quest for meaning or a medical explanation. They interacted with their spouse, peers, health professionals, and family in order to build an explanation for the loss that made sense for them and to draw positive aspects of the experience, thus directing their actions toward hope.

"I think I moved on because I know the cause of death, the reason for death. So I cannot even imagine women who do not know the cause. I would not be where I am today, how I am today or functioning as I do. This brings guilt, even if it's not women's fault. So at least I had answers" (Esther, three miscarriages, one stillbirth).

Inability to find an explanation for the loss, regarding the nature of life as unfair, holding grudges and being angry about life, deepened hopelessness, and resulted in increased suffering, self-guilt, and ruminant thinking. Mothers then made persistent efforts to revisit the past in order to find out what could have been done to avoid the loss. Some mothers focused on actions toward hope and produced alternative routes such as deciding to stop looking for the reasons for the loss and finding unsuspected benefits while making sense of the loss.

"I was trying to find the 'why' then I said: looking for 'why' doesn't lead anywhere. I have to stop looking for the reasons for the loss because he went away. So I guess maybe it's better because I would not want to have a sick or disabled baby. I would have thought it was a pity for the baby" (Heloise, one miscarriage).

3.4.3. Having positive interpersonal relationships

Family, a partner, friends, other bereaved parents, and health professionals enhanced hope by making mothers feel they were being supported in their grieving process and encouraged keeping hope. Love, support, and comforting words promoting positive thoughts from loved ones and the connection between the couple were important for engendering hope and optimism. In this way, mothers embraced new meanings for loss, other goals in life, and future pregnancy. Some mothers also emphasized that the support of health professionals enhanced their hope through empathy, grief counselling, and bereavement follow-up. Psychotherapy was also important in the process of nourishing hope and moving on. In contrast, non-recognition and non-validation of the loss by health professionals and loved ones discouraged hope. Some mothers moved away from these people in order not to lose hope.

"There is nothing that could have helped me more than my loved ones. My family and my friends helped me get through all this. Also, my husband was always positive. Every time I thought negatively, he brought a positive point to the issue. My gynecologist, who was attentive, who listened to me, who advised me and who told me: 'That doesn't mean you won't have other kids, your next pregnancy will turn out to be the right one" (Heloise, one miscarriage).

"When people say, 'I'm sending you energy, I'm thinking about you.' Well, I'm very spiritual too, and I believe a lot in all things related to energy, but when you're experiencing it, it's amazing the energy that you get. It feels really good" (Tina, one neonatal death).

Resources such as books, as well as online and in-person support groups of parents experiencing the perinatal loss, inspire hope. Mothers search for hope within the group and encourage hope among the other members of the group by sharing experiences, offering support, and exchanging advice. They support hope among each other by being encouraged to move on, validated in their experience of grief, recognized by each other, and by reconstructing their meaning of loss.

"Reading on the internet and in books about other mothers who have lived through this and going to the 'Etoiles filantes' group was very good. Talking to people who have already lived it, I felt even more understood and then it seems easier to move on. Then I said to myself: 'It's normal for me to act like this.' Seeing them gave me hope. There's a life after that. They moved on" (Anya, one termination of pregnancy for fetal anomaly).

3.4.4. Holding onto uplifting memories of the baby

Mothers reflect on memories and mementos of the pregnancy and their baby. Recalling good memories of the moments preceding and following the baby's death and their love for the baby fosters hope. Seeing, touching, and holding their baby, having photographs and keepsakes, holding a funeral, and other rituals of mourning are elements which honour and keep the bond with baby, generating feelings of love, joy, comfort, and gratitude. On the other hand, remembering events such as the abrupt way in which the news of perinatal death was announced by the health team, the disrespectful care of the baby's body or her mourning, and the impossibility of performing funeral rituals to honour the baby declined the mothers' hope.

"When I saw and held my baby, I'll remember it all my life. It is the feeling of maternal love, even if the baby was not alive. It was so strong! So I thought it was beautiful, the most beautiful moment of my life and, at the same time, the most difficult. Beautiful moments!" (Katia, two miscarriages, one stillbirth).

"We have nothing . . . We didn't take a bracelet, we didn't take fingerprints, we got nothing. [silence] Actually at some point, I mean, you don't need all that stuff to remember anyway" (Livia, one miscarriage, one termination of pregnancy for fetal anomalies).

3.4.5. Approaching life differently and reshuffling priorities

Mothers changed their view of the future following perinatal death, which led them to approach life differently and reshuffle priorities. They dealt concurrently with difficulties returning to their everyday activities and feelings of vulnerability, anxiety, and fear of the future. They struggled against hopelessness when dealing with the intensity of their grief, their frustrated expectations, and the sense of insecurity, fragility, and lack of control over life. Changing their attitudes towards life such as living in the present, focusing on what is important, and being more tolerant, positive, and determined to maintain optimism and hope were ways to foster hope in the grieving process. Bereaved mothers reshuffled priorities to focus their time and energy on what was valuable and meaningful to them like engaging in grieving and going with the flow, being with their family, doing what they liked, and engaging in new family planning such as a subsequent pregnancy.

"Stay positive, keep hope, have plans, no matter what, for trips, houses, to find things that you have an interest in. Because it keeps you alive, it keeps you busy while waiting for life to do its work (. . .). Since it happened, because of the experience, I see the other side of the coin, life is hanging by a thread. I enjoy every day to the fullest, every day I am with my daughter, my partner, my family" (Kelly, three miscarriages).

Mothers sought to alter negative thoughts and to remain hopeful towards a positive future of healing, a successful subsequent pregnancy, or even a childless future. Being grateful for pregnancy, appreciating their experience despite the loss, and comparing themselves to other mothers who had a successful subsequent pregnancy after multiple losses increased hope.

"Each pregnancy has allowed me to move forward a little bit. Maybe I'll finally get a baby. I'm glad I got pregnant and had those moments. I know it will pass because I'm lucky. I'm going to be able to overcome this" (Fanny, one miscarriage, one stillbirth).

4. Discussion

This study explored mothers' experience of hope following a perinatal death. The bereaved mothers' hope had multiple expressions during the grieving process, including a decreased in feelings of hope possibly leading to hopelessness, the hope of their baby's survival or incorrect diagnosis, and a restored and transformed hope. Because the deceased baby is the central element of mothers' hope to achieve a family plan that was interrupted or postponed due to perinatal death, mothers' hope is disrupted and tends toward decline and hopelessness. Consequently, they seek hope in their grieving trajectory to regain their life plan and to move forward after the death in various ways. These multiple facets of hopes are consistent with the multidimensionality and dynamism of the concept of hope [9,18,19]. Also, these results confirm previous studies [6,16,17] and offer new insights on mothers' search for hope and their struggle between hope and hopelessness in the grieving process and subsequent pregnancy.

Bereaved mothers had hopes and expectations of family planning that is consistent with another study [15]. As a consequence of the death, there is a sense of a disrupted and bleak future without their baby along with mothers' frustrated expectations, which disrupts their hope and tends toward decline and hopelessness. The loss of hope has also been found in another study with bereaved persons [9], as well as thoughts of self-harm and a sense of wanting to die after the baby's death [14].

Hope and hopelessness are distinct future-oriented expectations which may coexist in the individual. [10] Hopelessness involves negative expectations, feelings, and thoughts concerning oneself and one's future life [30] that may be exacerbated in the presence of low hope [10].

Hope and hopelessness were also present in the subsequent pregnancy following perinatal death. Despite getting pregnant again and hope having been a motivational resource to the subsequent pregnancy, their hope was transformed as a consequence of the previous perinatal death. The impact of a previous perinatal death on subsequent pregnancies has been reported in previous studies, [4–6] as well as the negative expectations and fear of another death that plagues the mothers [15,16]. In our study, mothers tried to control their hope toward subsequent pregnancy in the presence of hopelessness in such a way that hope and optimism flourished with mothers' belief in the likelihood of achieving a successful pregnancy. In addition, they continuously assessed signs during pregnancy to reinforce their hope. These findings were also found in another study [16].

Because hope requires beliefs of possibility and positive expectation needs beliefs of certainty [31], mothers are highly defensive about subsequent pregnancy and consequently less hopeful and more realistic in their goal-setting [32]. These results show how past events and future expectations influence the mothers' hope, corroborating other studies on hope [11,19].

When fear and hope coexist, the conflict between them entails anxiety and hybervigilance [31], which have also been reported including negative psychological symptoms in subsequent pregnancies [4–6,16]. When mothers experience heightened anxiety, their perceptions of the probability of achieving their goal lessens, while achieving their goal becomes even more important [32]. Hope and pessimism can also be present in events that are less likely to happen [33]. Notably, greater uncertainties, particularly when mothers did not know the cause of perinatal death, delayed getting pregnant again, had multiple losses, and were at an

advanced in age, diminished mothers' hopes and exacerbated anxiety and pessimism in our study. Multiple losses also were hindrances to hope as reported in other studies [9,34].

The possibility of achieving an outcome is necessary for hope [11]. Thus, the impossibility of a subsequent pregnancy led mothers to experience a disrupted hope, due to infertility news or discordant plans between partners about the desire to have another child. As a consequence, mothers reported a grieving for their life plan corroborated with findings in another study [15]. Our data suggest that mothers' wishes were still present, but devoid of any positive expectancies to achieve it. Giving up any positive perspective and associated hope and embracing a negative certainty can lead to hopelessness and depression [31]. A study found that psychopathology is associated with lower estimates of the perceived probability of attaining a goal [32].

Our findings showed that hope can be both affected by perinatal death and a significant resource in dealing with the loss. Some mothers were hopeful for the baby's survival or for an incorrect diagnosis. This finding corroborates a recent literature review that found conflicting expressions of hope and lack of hope in parents after a stillbirth [8]. Reaction linked to the refusal of facts or sense of rebellion may occur in a violated positive expectation and disappointed hope from loss [31]. Likewise, unclear information from staff may sustain hope based on the patient's misinterpretation about the diagnosis [17]. Other studies showed bereaved parents felt they were not adequately informed by healthcare professionals at the time of their loss [6,35]. When the child is dying, it is important for healthcare professionals to explore how much parents understand the medical situation and what are their hopes for the child [36].

In our study, information related to the risk factors and cause of loss were notable for mothers in restoring hope, accepting the reality of baby's death, and reducing uncertainties. In addition, mothers sought an explanation for the loss and directed energy toward making sense, results that were consistent with another study [15]. In contrast, the inability to find an explanation for the loss resulted in increased suffering [8] and decreased hope in the course of grieving [9]. Expanding view of the reality from the meaning of an experience integrates hope [11].

The passage of time linked to the course of grief was another key aspect in restoring mothers' hope in our study. Another study found the bereaved women's hope was defined as a gradual process requiring time for new hope [9]. Hope also was positively related to grief resolution in a study with older widows or widowers [34]. Although perinatal bereavement has no prescribed timeframe [1], a study showed the progressive decline in grief intensity over the two years after the loss, particularly in scores of despair, which represented feelings of worthlessness and hopelessness [13]. Thus, mothers' hope may benefit by the passage of time and the experience of grief as grief suppression may lead to psychological consequences [6,14].

Corroborating other studies, hope was found to be a sense of connection with self and the environment to live their life as planned, despite limitations [9,11]. Staying positive, being grateful, keeping the focus of hope on oneself, family, and future, as well as finding new meanings and purpose of life, were important elements for hope [9,19]. Finding the positive in loss and the transformation resulting from the identity of bereaved parent was also evidenced in another study [37].

Our results also highlighted the positive interpersonal relationships and reaffirmed the role of social support to deal with the death of the baby [4,7,14]. The 'supporter' role of man to their female partner [35,38], peer support from bereaved parents groups [16,35], as well as family and community's advice to mothers on coping with infant death [15], were relevant in bereavement adjustment and promotion of hope.

In contrast, non-recognition and non-validation of the death by healthcare professionals and loved ones diminished hope for mothers. Some mothers withdrew from these people in order not to lose hope. Bereaved parents commonly report that their loss is unacknowledged or minimized by their families, health professionals, and community [4,14,35]. The lack of social recognition of grief and parenthood may lead to a disconnection from the outside world and a sense of loneliness [8] complicating the grieving process [6]. Inadequate support and isolation also were hindrances to hope reported in other studies [9,19,39].

The relational aspect of hope was also evidenced by the relationship with the deceased baby. Recalling good memories of moments preceding and following the baby's death was significant to foster mothers' hope. Memory making and memorialization are important for validating the meaning of parenthood, facilitating legacy, and creating positive memories, which foster a sense of normalcy for parents and help them move forward after loss [17,40,41]. Memories are also related to the continuous bond with the baby [8] and the construction of narratives in grieving [42]. However, traumatic memories such as the abrupt way in which the news of perinatal death was announced and the disrespectful care of the baby's body or their mourning declined the mothers' hope in this study. The health professional has a significant role in reducing the impacts of perinatal death, for instance supporting uplifting memory-making both before and after birth [41], as a strategy for fostering hope [39].

4.1. Clinical implications

This study has important implications for healthcare providers. Because hope influences mothers to reconnect with their life plan and to move forward after a loss, it is essential to consider hope with sensitive and empathetic care during maternal bereavement and subsequent pregnancy. The theme regarding "ways to restore and foster hope in life" suggest that midwives, nurses, and physicians can encourage hope and reduce experiences of hopelessness in bereaved mothers through meaningful actions. For instance, providing clear information regarding the risk factors and the causes of death, acknowledging grief, and offering grief counselling may instill hope by supporting maternal grieving and hope for the subsequent pregnancy. Other strategies lay in giving mothers the opportunity to express their feelings and thoughts, taking the time to investigate the hopelessness, reducing the impact of stressful events during hospitalization, and providing moments for uplifting memories and early resources, such as books or online and local support groups. Besides encouraging mothers' hope by the adoption of strategies to approach life differently, these health professionals can routinely assess mothers' decline in hope or feelings of hopelessness, especially with mothers who have experienced multiple losses, infertility, or a strong desire to become pregnant again. Health professionals need to be aware that experiencing a pregnancy after perinatal death may make a positive difference in the grief process and the psychological well-being, but it can also be a trigger for ambivalent feelings of fear, hope and hopelessness.

4.2. Strengths and limitations

Our results expand those of prior studies on the range of negative emotional and psychological symptoms around perinatal death and provide a profound vision for bereaved mothers' experience of hope during the grieving process. Also, it corroborates what is known about the impact of social support and health professionals' clinical practice in the grieving process, which can be helpful or detrimental to mothers' hope.

The authors used several strategies to enhance the trustworthiness and validity of this QSA. Although the passage of time may be a limitation for the QSA because the phenomenon of interest interacting with context and that context changes over time [29], we consider that primary data sets are current and the timing for the QSA is appropriate. The analysis has some limits in that the questions addressed in this study were not part of the primary research. Although hope was often expressed through experiences of suffering and grief, some aspects of the mothers' experience of hope might have been more fully described with specific questions addressing hope in the interview guide. As such, there needs to be further research to understand this concept, and to investigate how the religious beliefs and practices, the birth of a healthy baby, the infertility news, and the dyadic relationship influenced the experience of hope.

The present study has some limitations which need to be considered. Firstly, the sample only included French-language mothers in Quebec. Thus, the results of the present study may not be generalizable for other contexts because there are cultural differences in the way that societies address bereavement [1,4]. As a consequence, the experience of hope might also be influenced by the cultural environment. Secondly, it is not known whether the fathers' experience of hope is similar to that of mothers. Although in our study, the mothers' partner had a significant role in enhancing hope, future studies should investigate fathers' experience of hope around perinatal death. The effect of perinatal death on a father's mental health and aspirations for a future pregnancy has been documented [15,38]. Thus, their experiences of grief and hope should also be acknowledged and supported by health care providers.

Even though the primary study explored mothers' trajectories of bereavement, the data was collected in one single moment. Since the results suggest that hope was restored through the passage of time and the course of grief, the complexities of bereaved mothers' experience of hope could be further explored through longitudinal research, which could render the dynamic of hope during the grieving journey and the processes involved in change. More studies on the concept of hope are therefore required, as well as it is necessary to explore this concept as it pertains to fathers' experience, which might be different than that of mothers.

5. Conclusion

In this study, we have explored the bereaved mothers' experience of hope, using secondary qualitative data. Results have shown hope is both affected by the experience of perinatal death and considered a motivating force for mothers to reconnect to their life plan and move on after loss. Hope is disrupted and tends toward decline and feelings of hopelessness due to loss, transformed and restored throughout the grieving process. Although some mothers embraced the hope of a subsequent pregnancy, this hope was challenged by a sense of foreboding of another loss. Ways such as integrating the reality of the loss, experiencing the grieving, making sense of the loss, having positive interpersonal relationships, having uplifting memories of the baby, approaching life differently and reshuffling priorities functioned to instill and maintain the mothers' hope.

Understanding the experience of hope during the grieving process, and the aspects that instill, maintain, and interfere with hope is essential to support mothers through their experiences of perinatal death. Our results highlight the need for support from healthcare professionals and may contribute to enhancing clinical practice through the promotion of bereavement care that takes hope into consideration. Moreover, subsequent studies on the experience of hope with parents experiencing perinatal death can increase the understanding of risk factors related to declining hope and hopelessness, as well as its influence on the course and severity of grief.

Ethical statement

The authors declare that the research presented in the manuscript was approved on the 17/08/2014 by the Université du Québec en Outaouais Human Research Ethics Committee. Protocol number #1799.

Conflict of interest

The authors have declared no conflict of interest.

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CRediT authorship contribution statement

Willyane de Andrade Alvarenga: Conceptualization, Methodology, Formal analysis, Data curation, Writing - original draft, Funding acquisition. **Francine deMontigny:** Supervision, Conceptualization, Methodology, Investigation, Resources, Project administration, Writing - review & editing, Funding acquisition. **Sabrina Zeghiche:** Validation, Investigation, Data curation, Writing - review & editing. **Chantal Verdon:** Methodology, Validation, Investigation, Writing - review & editing. **Lucila Castanheira Nascimento:** Conceptualization, Methodology, Validation, Writing - review & editing.

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