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Knowing how to help: Grandmothers' experiences of providing and receiving support following their child's pregnancy loss

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ABSTRACT

Problem: Pregnancy loss is a distressing experience for parents, however no research has addressed grandmothers' experiences of grief and support following a child's pregnancy loss.
Background: No research has specifically addressed grandmothers' experiences of support and bereavement care following pregnancy loss.
Aim: This study seeks to understand three key areas: (1) the support grandmothers provide to their child; (2) the support they received themselves following pregnancy loss, and; (3) supports desired by grandmothers. The study aims to contribute insights into actions midwives could take to support grandmothers following pregnancy loss.
Methods: Semi-structured interviews were conducted with 14 grandmothers to understand their support experiences. Interviews were analysed using Braun and Clarke's approach to thematic analysis.
Findings: Themes related directly to the three research questions: one: providing support, comprising two themes — being strong, protecting their family and the challenges of knowing how to help. Two, receiving support, also comprised two themes — lack of professional support offered to grandmothers and informal support and self-support strategies. Three, desired support, comprised three themes — I had no idea: increasing knowledge of pregnancy loss, peer support helps: they know how it feels, and honouring our grandchildren, making meaning.
Discussion: Grandmothers may give extensive support to their child following pregnancy loss but lack confidence and face challenges in doing so. Few formal supports are available to grandmothers themselves, with grandmothers relying on their social networks for their own support.
Conclusions: Grandmothers need early access to information and guidance from midwives and hospital bereavement services, as well as ongoing peer support with flexible delivery options.

Statement of significance

Problem
Lack of understanding of the support grandmothers provide and their support needs following a child's pregnancy loss.

What is already known on this subject?
No research pertaining to grandmothers' support experiences following their child's pregnancy loss exists.

What does this new study add?
- Provides knowledge of grandmothers' experiences of providing and receiving support following a child's pregnancy loss.
- Grandmothers may provide extensive support, but face challenges in knowing how to best help their child.
- Few formal supports are available to grandmothers, leaving them reliant on family and friends for support.
- Grandmothers request that hospital staff provide guidance to education and information.
- Grandmothers need ongoing peer support, with flexible delivery options for isolated grandmothers.

1. Introduction

Pregnancy loss, including miscarriage, medically indicated termination of pregnancy and stillbirth, remains a frequent occurrence for families around the world. Research has increasingly recognised the potential psychological distress that parents can experience following all forms of pregnancy loss [1–3]. The

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consequent informal and formal support needs of parents who have experienced pregnancy loss have also been well-recognised [2,4–7]. No research exploring the support needs of grandparents following their child's pregnancy loss has been identified. This gap is significant given that grandparents may experience overwhelming grief following pregnancy loss [8] and may also be called upon to support their child. As such, this research aims to explore the support needs of grandparents when their child experiences pregnancy loss.

2. Background and previous literature

Most research exploring pregnancy loss has only incidentally considered grandparents within the context of family-based research [9,10]. Our recent research [8] explored grandmothers' experiences of grief and loss following their child's pregnancy loss, finding that grandparents experience disenfranchised and compounded grief. In our study, grandmothers described significant grief for both their grandchild and their child, leaving them feeling overwhelmed and isolated. Moreover, grief often affected family relationships negatively, causing tension and further distress [8]. Both our research and that of others has identified that grandparents are frequently among the first to be informed of their child's miscarriage or stillbirth and may provide varying forms and amounts of support to their child [8,10,11]. As such, it is likely that grandparents may also need support following their child's pregnancy loss.

In terms of support provided following pregnancy loss, much research has focussed on informal supports [4–6,12,13]. Support is often sought, and provided, by family members [4,10,14] and while the extent of grandparent involvement is likely to vary within each family [14,15] it is likely that grandparents will be involved to some extent in supporting their families. Despite this, no research has considered the role informal supports may play in supporting grandparents who are adversely affected by their child's pregnancy loss.

With regards to formal support provided following pregnancy loss, there are a range of guidelines for perinatal health care providers to ensure the provision of respectful and supportive bereavement care to parents [2,16,17]. However, despite often having the dual role of managing their grief *and* supporting their child, no specific support guidelines exist for grandparents, who often remain unrecognised as bereaved in their own right [8,18]. Therefore, grandparents may face challenges receiving the support needed for their wellbeing following their child's pregnancy loss [11,14,18].

As such, this paper reports on findings from an exploratory qualitative study which sought to understand three key areas: (1) support grandparents provide to their child, (2) the support they receive following their child's pregnancy loss, and; (3) the supports desired by grandparents. Findings from this research may contribute preliminary insights into actions that perinatal healthcare providers and community-based pregnancy loss support services could take to support grandparents.

3. Method

This paper forms part of a larger project concerning grandparents and pregnancy loss, with the aims of the overall project to explore both psychological outcomes (e.g., grief and loss) as well as the support needs that grandparents identify. We have previously published a paper outlining the first aim of the project — grief and loss experiences of grandparents [8]. As part of this overall project, the methodology and the participants that formed the basis of the data presented in this paper are identical to those of our previous paper [8]. However, in reporting on the support needs of grandparents, this paper presents findings concerning a unique and important element of pregnancy loss in a significantly under-researched population. In presenting findings concerning support needs specifically, this paper aims to inform health researchers and professionals about the distinct support needs of this previously unstudied population.

4. Participants

While we sought to explore the experiences of grandmothers and grandfathers, recruitment of grandfathers proved unsuccessful resulting in a sample of grandmothers only. Therefore, for the remainder of this article, we use the term 'grandmother'. Participants were 14 Australian grandmothers whose son or

Table 1
Modified from Lockton et al. [8].

Summary of participant characteristics								
Pseudonym	Age	Cult. background	No. of children	Own pregnancy loss	D/S	Type of loss	Time since loss	No. of G/children living (expected)
Betty	70	Aust	2	Nil	D	MC × 2, 9 and 11 wks	19 mths, 3 yrs	2
Cathy	N/A	Aust	3	Nil	S	SB term	6.5 mths	0
Donna	57	Aust	3	1 MC, <20 weeks	D	1 twin SB, 1 died at birth 37 wks	15 mths	6
Fiona	64	Aust	4	Nil	D	SB 30 wks	3 yrs	6
Gina	52	Maltese/Aust	2	Nil	S	SB 27 wks, 2 × MC, 10 & 17 wks	16 mths	7
Helen	59	Aust	2	Nil	D	SB term	4 yrs	3
Iris	56	English	6	Nil	S	SB 33 wks	3 yrs	4
Julie	59	Aust	2	1 MC, <20 weeks	S	2 × MITOP post 22 wks	4.5 yrs, 6 mths	2
Karen	63	Aust	3	Nil	S	SB term	3.5 yrs	6
Lisa	61	Aust	2	1 MC, 14 weeks	D	SB 37 wks	6 mths	1 (2)
Mary	55	Aust	2	2 MC, 9 weeks and 11 weeks	D	SB 23 wks	13 mths	0
Nat	56	Aust	3	1 MC	S	SB term	12 mths	4 (2)
Rose	60	Aust	2	1MC, 14 weeks, 1 SB, 22 weeks	D × 2	MC × 3	17 mths, 3 yrs	4
Sally	62	Aust	2	Nil	D	SB 22 wks	3 yrs	3

Note: MC = miscarriage, MITOP = medically indicated termination of pregnancy, SB = stillbirth, D = daughter, S = son, wks = weeks, mths = months, yrs = years, Aust = Australia.

daughter had experienced a pregnancy loss between six months and five years prior. This time span was chosen to minimise distress to participants, while capturing experiences within current support practices. Eight were the mothers of daughters, and six were the mothers of sons. Any grandparent was eligible to participate, whether maternal or paternal, biological or non-biological. The nature of the pregnancy loss varied; 11 grandmothers had children who had experienced a stillbirth, five experienced one or more miscarriages, and one experienced a medically indicated termination at more than 20 weeks' gestation. Four grandmothers had experienced more than one type of loss. Gestational age at the time of loss ranged from nine to forty weeks ($M = 27.1$, $SD = 10.8$), while time since loss ranged between six months and four and a half years ($M = 25.5$ months, $SD = 15.2$). Grandmothers were aged between 52 and 70 years ($M = 59.5$, $SD = 4.6$). All participants were fluent in English. Participant characteristics are summarised in Table 1.

5. Ethics and procedure

The study was approved by the University of Adelaide Human Research Ethics Committee. Information sheets and flyers were submitted to organisations where Australian grandparents might seek information and support, including Stillbirth and Neonatal Death Support (SANDS), the Stillbirth Foundation, and Perinatal Anxiety and Depression Australia. Community groups such as the Rotary Club, local councils, and church-based groups were also contacted. Potential participants were invited to contact the researchers to express interest and gain information. Informed consent was obtained from all participants before interview.

Interviews were semi-structured, with a series of open-ended questions created based upon previous studies concerning support following pregnancy loss [3] and existing pregnancy loss support guidelines [16,19,20]. Adhering to Braun and Clarke's [21,22] guidelines for qualitative research practice, a pilot interview was conducted to assess the pertinence and thoroughness of the interview questions. Consequently, minor adjustments were made to the question content and order. Following each interview, and reflection on the information disclosed by participants, adjustments were considered, and added to the interview guide where relevant. No adjustments were required after interview four. Example questions included: 'What are your experiences of providing support for your daughter/son?', 'Can you tell me about the support/s you received at the time of the loss of your grandchild, if any?', and 'What other types of supports do you think would have been useful to you during that time/would you like to have received?' Interviews were recorded for transcription purposes.

Due to geographical distance, ten interviews were conducted via telephone, with the remainder conducted in person. Interviews ranged from 27 to 82 min ($M = 56$). No differences were noted between telephone and face-to-face interviews regarding interview length and data quality or richness. While data saturation [23] was achieved by the tenth interview, interviewing continued until all grandmothers who had expressed interest in participation were interviewed, to enable grandmothers to speak of their experience. No specific time limit to participation was stated in recruitment materials; however, no further expressions of interest were received beyond two months of the commencement of recruitment. Following each interview, grandmothers were offered support resources, including the option of support from a health professional. Interviews were transcribed verbatim using an orthographic approach [22]. Tracy's [24] "Big-Tent" criteria for excellence in qualitative research were followed to enhance methodological rigour. Each participant was given a pseudonym, and all identifying features were removed from the transcripts. All participants were provided with a copy of their interview transcript, allowing for 'member reflections' [24]. No changes relevant to support were requested from participants. At this time offers of professional support were re-iterated, however no participant required assistance.

Self-reflexivity is an essential part of conducting qualitative research [22,24], and was conducted throughout the research. The first author, who conducted the interviews, is a middle-aged female, with three children and experience of pregnancy loss. The second author, a practicing Clinical and Health Psychologist working in fertility and reproductive health has two children but has not experienced pregnancy loss, while the third author has three children and experience of pregnancy loss. Therefore, all authors may have been oriented to particular experiences of motherhood, caring or loss. For the purpose of reflecting on her thoughts and feelings, and to maintain consistency in the approach to all interviews, the interviewer also kept a diary of her experiences of hearing participants' stories. The interviewer also engaged in self-care by spacing interviews to minimise distress, debriefing with co-authors, one of whom is a practicing psychologist, and had access to professional support.

6. Data analysis

The analysis followed the principles of grounded theory to conduct a qualitative exploratory inductive thematic analysis from a realist ontological position [25]. This position assumes that reality is independent from human knowledge and corresponds with exactly what is present. Therefore, data was analysed as a reflection of participants' lived experience [26]. Analysis was performed using Braun and Clarke's [22] approach to thematic analysis. This is a flexible systematic process, involving six major steps. To ensure the trustworthiness of the results, in addition to member checking, codes and themes were reviewed by all authors to ensure that the analysis was robust and reasoned. Illustrative extracts were identified to support the themes. Finally, an audit trail was kept throughout the analysis process to facilitate confirmation of the findings.

7. Findings

Results were divided into three areas in line with the research questions: Providing support, comprising two themes, Receiving support, comprising two themes, and Desired support, comprising three themes.

8. Research question 1: providing support

Two themes about grandmothers providing support for their child were identified: "Being strong, protecting their family" and "The challenges of knowing how to help".

8.1. Being strong, protecting their family

In their discussions of supporting their child, all grandmothers oriented particularly to the need for them to "be strong for you and strong for them" (Cathy) — regardless of any grief, they may be feeling. In doing so, grandmothers reported that they attempted to hide the extent of their grief from their child. Importantly, however, others commented that sharing their grief with their child was a fundamental way to offer support and build connection and understanding between them and their child:

> "I think he saw how much (grandson) mattered to everyone, and so it was appropriate to grieve the loss, you know it was, I mean we tried to minimise, to minimise the impact on him as much as we could but he needed to know that we were sharing

this grief and this journey with him. I think that's important. But no, I think cos I guess for him it acknowledged for him that (grandson) was there that we, you know, we were missing him and that we missed him, that he existed and he was important and enough a part of our life to grieve for." (Karen)

However, regardless of whether grandmothers felt that the best support strategy was to hide or to share their grief, their priority appeared to be providing support for their child, with their child's needs taking priority over their own. As such, many grandmothers described there was little time to care for themselves in the weeks following the death of their grandchild. However, time out to care for themselves, away from their child and others, became necessary and vital for long-term wellbeing:

"I've decided to give myself the day before, the day we found out the news that she wouldn't be born alive. I've given that to myself as my stay at home, eat pizza and do nothing day, don't get out of bed if that's what I want to do you know . . . so I'm just going to be taking the day off every year, that's just going to be my day to remember her and be a bit miserable. And then next day it's her birthday and then I can be on top of it for the kids, you know, they need me, I'll be ready." (Gina)

Overall, most grandmothers commented that the best way to help their child was to 'be present', although grandmothers also felt that there were specific actions they could take to support their child further. In particular, grandmothers indicated that it was important that their child knew that their support was ongoing and that their grandchild would always be remembered and loved:

"You just want that feeling of love and caring and nurturing to go on, and its going on, you don't have to worry about it, ((laughs)) its going on. But you don't want (grandson) to be forgotten as a grandmother, but you want (daughter and son in law) to always be remembered, you know." (Fiona)

Another key area of support was protecting their child from added stress, particularly that which came from interactions with other people. For example, Helen said:

"I thought I just wanted to bundle them up and protect them from everything so they didn't have to face anybody or see anybody or, it was probably wrong because that didn't happen do you know what I mean, they saw people and they still had to function." (Helen)

Following this desire to shield children from added stress, some grandmothers spoke of protecting their child specifically from the perceived insensitivity of others, and to allow their child's grief to be recognised. As explained by Sally:

"Then someone else said to (daughter) people always try to have sayings, you know, there will be a silver lining you know. There's always all these platitudes that because people can't understand, they put a positive spin on it, and that's just, there are a whole, there is a whole list of things people could say that are crap ((laughs)) but people will do it you know, because that's just human nature that, they try to put a positive spin on everything that's negative."

Overall, then, all grandmothers highlighted that their priority following their child's pregnancy loss was to support their child. To an extent, variations in support strategies reflected the fact that grandmothers sometimes found it hard to know how to help their child, as seen in the second theme below.

8.2. The challenges of knowing how to help

While grandmothers attempted to protect their child, all expressed distress being unable to control the situation or make things better. In this regard, grandmothers typically appeared to feel helpless and limited in the support they could offer. With a lack of formal guidance regarding how to help their child, grandmothers relied on instinct to inform their support. Almost all grandmothers indicated that they lacked confidence regarding how to best support their child, as noted by Nat:

"I think the hardest thing you know is when your kids are hurt, you just don't know what to do in that situation you know it's totally out of your control you know I mean, you know I had no idea how to deal with that you know . . . "

" . . . .maybe for grandparents perhaps that need a bit of guidance you know um what to say and what to do, and how to be how to think I mean some people just don't know and they stay away."

Grandmothers who could not be with their child physically (e.g., due to distance) were particularly likely to struggle with how to support their child in a meaningful way. In addition, feelings of helplessness and disconnection appeared to be more pronounced for mothers of sons and for in-laws, who found communication more challenging from a distance, and therefore had less direction regarding how to support their child:

"Yeah at the time, exactly, that's right, so and when it's something you haven't come across before, and you no experience in um, you know and you're not really getting a lot of communication about what you should be doing from the person involved, for me, I just thought well if I don't want to go and be in the way well, and well maybe I could have been more help but I don't know how?" (Iris)

Overall, the analysis indicated that having someone to talk to – particularly in the initial period following the loss – is likely to benefit both parents and grandparents.

9. Receiving support

Two themes concerning the support offered to grandmothers were identified: "Lack of formal support offered to grandparents" and "Informal support and self-support strategies".

9.1. Lack of professional support offered to grandparents

Some grandmothers said that they experienced unhelpful encounters with hospital staff before their child's pregnancy loss and a lack of support during and following the birth (where relevant). Other grandmothers found hospital staff to be kind. However, only one grandmother felt directly supported by hospital staff. In all other cases, no support was offered, and no information or education was provided. Furthermore, very few grandmothers sought any form of formal support themselves and did not know where to source such support if it was desired. For example, in response to a question about what support she had received, Karen said:

"None ((pause)) none. Other than some friends, but even then you know they would call I mean there was no professional support available, not even at the hospital like there was no um ((pause)) no there was no support available. The only thing that we found was, as I said, I googled other people's stories and got some solace from that [. . . .] Yeah so there wasn't any support other than what we looked for ourselves, none offered, it was just a matter of deal with it as best you can."

Other grandmothers reported feeling that their emotions were minimised by those who typically provide formal support. For example, when asked if she had received support from her primary health care provider, Rose said:

"No, not really, I think I went in there not, I think I went in there for support and maybe I didn't ask the right questions or

whether I didn't um ((pause)) say it in the right way but no he just sort of said to me um 'oh well he said, you'll be there for them, that daughter, you know, you been through it, you'll be right, you'll be right', and I thought ok but I do remember thinking I would have liked to talk about it. I've been through it but I haven't been through my daughters' loss."

This comment also implies that having experienced pregnancy loss themselves does not protect grandmothers from the effects of this loss, or equip them with all the skills needed to support their child through a similar experience.

9.2. Informal support and self-support strategies

As seen in the previous theme, while few grandmothers received formal support, some were able to draw upon relatives or friends involved in the healthcare system for support or advice. As indicated by Nat, this was found to be helpful:

"My sister being a palliative care nurse knew a lot of little things that, you know, and she just took over, and um, yes ((sigh)) um helped me out with things like that. Um you know you've got to do this and you've got to do that, and just guided me really so that I was fortunate to have that." (Nat)

Indeed, grandmothers stated that common sources of support were extended family, friends, and church communities, demonstrating the benefit of community networks. Almost all grandmothers indicated that they valued strong social support and opportunities to talk about their loss. Donna commented that:

"My husband comes from a massive family his mother was one of sixteen, they all live here, um they've all got, so he's got something like seventy first cousins of which fifty live locally [...] so you know and this was the first set of twins in that family so there was a lot of people our age looking forward to them being born so it was the first set of twins in both sides . . . like we got bombarded with people consoling us, I was amazed, actually I was pretty floored I was pretty humbled. But up there we didn't know anybody so it was a different situation, it was a different situation there to here."

Those grandmothers that did not have such a strong social support network reported feeling further isolated, in an already isolating experience:

"What I think was the biggest thing as a grandparent was the isolation, because the monumental grief that your children are going through you feel all of that but you're not really part of it . . . It's very isolating." (Gina)

For those participants who were employed, work was noted to be helpful. For example, most of the grandmothers in paid employment at the time of the loss found their employers and fellow staff to be supportive, and this was highly valued:

"Oh they [work colleagues] were wonderful, they were absolutely wonderful. I was with, I worked in a library in a [. . .] girls school just up the road from where I'm living, and, um, I couldn't have asked for any more from anybody." (Fiona)

10. Desired support

Three themes were identified in relation to grandmothers desiring additional information or specific supports to be better positioned to support their child or to feel supported: "I had no idea: increasing knowledge of pregnancy loss", "Peer support helps: they know how it feels", and "Honouring our grandchildren, making meaning."

10.1. I had no idea: increasing knowledge of pregnancy loss

Many grandmothers indicated that they were shocked when they learned of the rates of pregnancy loss in Australia shortly after the loss of their grandchild. Many, particularly those whose children had experienced stillbirth rather than miscarriage, said they were unaware of the incidence rates and felt they would have been better prepared to support their child had they been more aware of the possibility of such a loss. Grandmothers indicated that this general lack of awareness highlighted a broader lack of understanding and education in the wider community:

"Um I've had kids, I've had six kids, I've never had a problem with pregnancy and I was, I never once heard anyone mention anything about still birth. I think it's something I thought that was something back in the dark ages and the midwife couldn't get there in time you know and I was actually, so I was actually shocked that um that how common it is, you know." (Iris)

Some participants felt that raising awareness would also increase community understanding of pregnancy loss, resulting in increased support opportunities:

"We put in our church newsletter and people like who might have been 60 or 70 came up to us and said 'I had a stillbirth and nothing was, nothing, it was we didn't even see the baby it was just taken away', so I guess um that surprised, the extent of it surprised me, the numbers just blew me away and that its been happening for 60–70 years and people still didn't talk. We had close friends, like close friends and the conversations never come up {mm} and so I guess we were trying to be more open because we thought no this is a conversation that needs to be had, um you know and I think some people, you know it was, yeah I think that's what surprised me most, the extent of stillbirths in Australia {yes} um and the fact that we don't seem to have improved that situation in that time." (Karen)

Additionally, while all grandmothers indicated that they preferred the focus of support to be on their children when such a loss occurs, they expressed frustration at the lack of information made available to them at the time of the loss, resulting in more difficulty supporting both their child and themselves:

"These people that help the kids are just, they're wonderful, wonderful people, you know. But there should be something just for grandparents, you know. Just to say help me help my child." (Fiona)

Hospital staff providing brochures to grandparents directly or via their child was seen as a simple and easy means to provide resources, which could also be available in doctors' surgeries and community areas such as libraries:

"You know have leaflet stands and even those sorts of things, um, can be left in libraries and places like that as well. But probably um, doctors' offices, but I think if it can be, there needs to be some sort of, I don't know whether there is or not, a pack given to people when they go through it, even if they go through it later, and 'oh here's a brochure I can give to mum', cos they don't consider at the time" (Julie)

10.2. Peer support helps: they know how it feels

Many grandmothers indicated that talking to other people who had been through a similar experience and therefore knew how they felt would be the most helpful support avenue. In particular, these grandmothers wished there was someone who could advise them on how to help their child:

"Um, and I wish there was places out there where you could talk to people, just to grandparents, and say 'oh my god, what did

you do?' and 'what did you do when you found your daughter in the foetal position on the bottom of the shower {oh}, and couldn't get her out?'. Or 'what did you do when you felt that their marriage was suffering so badly that you didn't think they were going to survive?', 'How did you help your son or your daughter, what should have I done, what could I have done?', 'what can you do down the track'." (Fiona)

This peer support could be in small groups or one-on-one. Of importance was that this support be provided separately to supports for parents:

"I thought it's a shame that there's not an opportunity for even those same groups of people to have um a grandparents group linked to that in some way. Not meet with them you know like people are very private [. . .], I don't um want to go with my children and see go through what they go through but I think a separate group um for grandparents where they can talk to another grandparent has experienced the same thing, um that that would be so beneficial." (Helen)

Online or telephone peer support for geographically isolated people could also fill this need.

Online forums were not widely used by participants, however some grandmothers felt that such support methods could be helpful if participation was encouraged:

"Maybe we're all as bad as each other, maybe we're waiting for somebody to say, 'ok how's everyone going, how's everyone's day today' and start a conversation. Maybe I should just do that. [. . .] I don't think, I don't think there's a great deal of members on there, there not a lot of people in it, but maybe that's what it takes, just someone to say 'hey how's your day been, I've had a shit day' or something." (Mary)

Many grandmothers also spoke of their willingness to share their experiences and reach out to help others they knew or met who had more recently experienced the loss of their grandchild. Donna spoke of a recently bereaved friend:

"I met her not so long ago, and [...] I said everybody's journey is different, the outcome is the same but the journeys different, I just said allow yourself some time to grieve as well because you've lost as well."

and Karen noted:

"I would I would suggest that they find or create a group of people who have been through the same situation as grandparents, um to look after themselves"

10.3. Honouring our grandchildren, making meaning

Finally, bringing these concepts together, most grandmothers found that participating in activities to raise awareness was helpful to themselves, and was a way of honouring their grandchild and ensuring that their life mattered. Raising awareness was a meaningful way that grandmothers could support their family, and was also an important means of offering support to others experiencing this form of loss:

"Yes, well the walk seems to help me, and even just talking to you seems to help me. Just to, um, just to do, I don't know, just go out and do fundraising and volunteering and just um, celebrate their life and not forget their life, you know. Cos he was on the planet for a brief time, so, um, yeah just um, and, and remember when he was born. Well we all lit candles, cos there was ah, it was a day where it was world support for stillborn babies so at a certain time we all lit a candle. Lighting a candle helps and doing all these positive things and not forgetting about him. Just remembering that he was here, so yeah. If that sort of makes sense?" (Cathy)

Grandmothers provided this type of support in various ways, including fundraising, participating in research, reaching out to others, and marking national and international awareness days. The choice of method gave them some control in an otherwise uncontrollable situation:

"I was more interested, you know, if there was an awareness group or a fund raising, um, and I guess I was angry as well thinking why didn't I know about this ((cough)). And that's why now you know I do what I can and have stalls at fetes and I will talk to people, and the number of people who have come up to me and shared their stories that they haven't been able to share with anyone else." (Iris)

Grandmothers hoped that by using their experience to support others and raise awareness, other grandparents would feel less isolated.

11. Discussion

This study explored grandmothers' experiences of giving and receiving support when their child has experienced a pregnancy loss, as well as additional support desired by grandmothers at such a time. Three broad research questions were considered: providing support, receiving support, and desired support. The themes identified within each of these research questions are addressed below, together with implications for further research and practice.

The study indicated that grandmothers provide support to their child in a variety of ways following pregnancy loss, with support being mostly unidirectional, from parent to child. White et al. [10] argue that listening and being present is as important as 'doing' during times of loss, and the current study similarly found that grandmothers described 'being there' as critical to their support of their child. However, the lack of individual and community awareness regarding the frequency of pregnancy loss, together with the lack of information provided to grandparents, and the subsequent changes in family interactions brought about by loss and grief, meant grandmothers needed to rely on their parental instincts and life experiences to help their family. Furthermore, five grandmothers had experienced miscarriages themselves, one of whom also experienced a stillbirth. While this may have informed their understanding of their child's loss, these losses did not equip them with all the skills they needed to support their child. Therefore, even when grandmothers have experienced loss themselves, it should not be assumed that grandmothers will know what is required of them. Participants reported that this necessity to rely on instincts and life experience was stressful and at times, exacerbating their distress. This finding is consistent with research exploring the loss of a grandchild at other stages of childhood, where grandparents indicated that timely information and support would reduce their feelings of helplessness, and help them to better support their families [27,28].

Grandmothers frequently commented that there was a lack of support provided to them at the time of birth (where relevant). While grandmothers were anxious to reinforce that the focus of support should remain on the parents, and acknowledged that medical and support staff were very busy, many felt that including grandparents in information and education given by midwives and other hospital support staff would have provided helpful guidance regarding how to help their child, as well as validation of their grief. Applying principles of sensitive, genuine and respectful communication, as well as recognition of their role and effective support strategies, is likely to be beneficial for grandparents [17,20,29]. Furthermore, with parent consent, and where appropriate for individual families, including grandparents in established memory-making activities may also have a lasting impact upon

grandparents' wellbeing and is likely to give the baby a 'real' presence. Such approaches may then offer a pathway for further discussion about the child within the family [8,30]. With some minor, achievable changes in approaches to care, midwives can have a considerable impact on grandparents and in turn, families.

An additional key finding of the current study was that available formal supports for grandparents were inadequate. Grandmothers who received grief counselling and support informally through social networks found this beneficial. As grandmothers received the most support from their social network, those without strong networks found themselves isolated in their grief, and therefore possibly in greater need of support services. This finding suggests that formal grief support services may be of value in some cases, particularly for those without strong existing support networks. Midwives may be able to assist access to such support, ideally by providing grandparents who are present at the hospital with written information (e.g., SANDS brochure), or including this in the resources given to parents to be passed on to grandparents.

Grandmothers indicated that peer support would be beneficial, with peers perceived to be better able to relate to the feelings experienced than formal support providers. This finding regarding peer support is reinforced by grief and support theorists who advocate for the valuable benefits provided by such support [31–33]. Peer support provides the opportunity for connection and sharing experiences while avoiding the risk of burdening family members. Furthermore, it is effective because it provides an opportunity to connect with people who have a similar, credible experience, provides validation, and reduces isolation [30,34,35]. Moreover, peer support provides a safe environment that is free of judgement, and can also improve coping skills, promote healthy recovery, provide a social identity, and a way to establish trusting connections [32,33,36]. While recognising that grievers will vary in their needs and desires, it is suggested that peer support be made available as an option for grandparents as soon as possible [32]. This support could be provided one-to-one or as a small group and could be delivered face-to-face or via telephone and internet-based meeting sites, thereby providing effective support [37] that caters to diverse needs and allows access for geographically isolated grandparents.

The current study also identified the need to raise individual and community awareness regarding the incidence of pregnancy loss, and the need to acknowledge and to give voice to those experiencing such losses. Increased knowledge could be achieved by making information brochures available in health facilities such as doctors' surgeries, and community areas such as libraries, increasing the accessibility of these resources. Moreover, many grandmothers described a sense of purpose gained from participating in activities such as fundraising and awareness days. As well as educating and raising community knowledge and understanding, this gave opportunities to provide peer support to other families, with this endeavour helping to create a positive legacy that gave meaning to their loss, and the life of their grandchild.

Some limitations must be considered when applying these findings to the broader population. The most significant of these is the lack of grandfather involvement. This under-representation of grandfathers may reflect issues such as the types of roles that grandfathers perceive they have in supporting their families, and societal or self-disenfranchisement of their loss [3,35,38]. Further research that explores the experiences of grandfathers would help identify any differences in experiences and support needs, and provide an opportunity to reflect on how support is offered and received. For example, Riley et al. [35] suggest that men may not benefit from peer support in the same ways as women. Therefore, any support strategies, including peer support, may require a different format for grandfathers.

The lack of cultural diversity among participants may reflect the English language competency required and has implications for generalising the findings to people from other cultural backgrounds. Future research is required to explore this issue in more detail. The same is true for exploration of support following different types of loss (e.g., miscarriage as compared to stillbirth or medically-indicated termination) as the current study was not able to draw such distinctions.

While the current study has identified that grandmothers would like access to peer support, the exact way in which they would like this delivered has not been ascertained. Research that determines the components that grandparents would like included within peer support offerings has the potential to inform the development of suitable programs which are, in turn, more likely to engage grandparents. Further research that explores varying peer support models, and identifies strengths and limitations of any grandparent models being utilised elsewhere in the world may provide an evidence basis for such a program to be modelled upon, and customised if desired.

Of further value would be an investigation of the longer-term impact of pregnancy loss on grandparents and their families. Identifying impacts on family relationships, facilitators and barriers to healing, and any consequent health issues would provide additional guidance regarding the development of support strategies.

12. Conclusions

This research confirmed grandparents' need for support following the overwhelming and isolating experience of the loss of a grandchild during pregnancy. The lack of support available for grandparents, together with a simultaneous desire to support their child, leaves many grandmothers lacking confidence in knowing how to support their child, and struggling to access support for their grief. Extending pregnancy loss support programs will benefit grandparents and their families. Midwives have a vital role to play by acknowledging that a loved grandchild has died, and guiding grandparents to much-needed information and desired support.

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Conflict of interest

The authors of this research have no financial or other conflict of interest, in the product or the distributor of the product.

Ethics approval

The research upon which this paper is based was approved by the University of Adelaide's Human Research Ethics Committee, approval number H-2018-070, on the 17th April 2018. All ethical requirements in the recruitment of participants, consent, gathering of data, usage of date and storage of data as per the approval have been followed.

CRediT authorship contribution statement

Jane Lockton: Conceptualization, Methodology, Formal analysis, Investigation, Data curation, Writing - original draft, Visualization, Project administration. **Melissa Oxlad:** Conceptualization, Methodology, Writing - review & editing, Supervision, Project administration. **Clemence Due:** Conceptualization, Methodology, Writing - review & editing, Supervision, Project administration.

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