



Grandparents' pregnancy and neonatal loss network: Designing a website for grandparents bereaved by the perinatal loss of a grandchild

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ABSTRACT

Objectives: When a child dies during the perinatal period, grandparents lack the resources to navigate their loss. We applied principles of co-creation and consumer-informed design to seek grandparents' expertise in determining (1) whether an internet-based resource would be suitable/beneficial for grandparents, (2) if so, what design features and content should be included and, (3) any barriers to utilising an internet-based resource.

Method: In Stage One, 152 grandparents responded to a survey regarding health and eHealth literacy and website design and content. In Stage Two, a draft website was developed, with 21 grandparents providing feedback about the website's design, content and navigability.

Results: Health and eHealth literacy measures indicated that >60% of participants had adequate literacy, and over 70% considered an internet-based resource useful. Grandparents provided design and content preferences, valuing diversity and peer support, and offered recommendations to optimise the website. Directing grandparents to public internet facilities would reduce barriers to access.

Conclusion: A website is a suitable resource for grandparents seeking information and support following the loss of a grandchild in the perinatal period.

Innovation: Grandparents see benefits in internet-based resources and can contribute to co-design. Further work could explore cultural differences.

1. Introduction

Grandparents report the loss of a grandchild during the perinatal period as a distressing experience that can disrupt family systems and lead to longer-term adverse health and family outcomes [1-4]. Grandparents in previous research [1-4] described the impacts of perinatal loss encompassing their whole family, disrupting relationships and requiring the reorganisation of family communication, norms and practices. Previous research has also shown that there is a lack of knowledge about perinatal loss among grandparents, as well as a lack of grandparent-specific supports, and that these factors make it particularly difficult for grandparents to cope with the loss of their grandchild [1-6]. Furthermore, the disenfranchisement of their grief as grandparents due to ongoing relative silence around perinatal loss made sharing their experiences with others challenging [1-3,7].

The impacts of perinatal loss upon parents include depression, anxiety, post-traumatic stress disorder (PTSD), sleep disturbances, complicated or prolonged grief disorders and chronic illnesses (e.g., diabetes, hypertension, cancer) [1-3,7,30]. Grandparents in previous research [1-

4] identified similar impacts, including anxiety, sleep disturbances, prolonged grief, and exacerbation of chronic illnesses such as hypertension. In some instances, participants also attributed the development of illnesses such as Alzheimer's Disease and Multiple Sclerosis to the long-term stress on their families [4]. The need for relevant, tailored information and supports has been repeatedly expressed by grandmothers and grandfathers following perinatal loss [1-4]. As such, this research aimed to explore the utility of an internet resource for grandparents who have experienced the perinatal loss of a grandchild.

In the current study, perinatal loss includes miscarriage, ectopic pregnancy, termination of pregnancy, stillbirth, and neonatal death because research suggests grandparents are affected by all these forms of loss [3,4,6]. Past research [1-4] has identified that when experiencing perinatal loss, grandparents typically sought information about how to support their child/ren first, followed by supports for themselves. However, most reported finding no grandparent-specific information resources [1-4]. Additionally, even when resources were available for grandparents, they were often hard-copy resources given to parents to give to grandparents and thus were not accessible directly to

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grandparents [2,4]. In terms of internet resources, grandparents in previous research have indicated that very little exists, particularly in terms of information about their grief and loss as grandparents following perinatal loss [1-4]; the same is true of support groups. This lack of information and available support highlights a large gap in knowledge (e.g., evidence-based supports) and practice.

In terms of support for grandparents, previous research indicates that many grandparents desire peer support [2-4]; however, developing such supports requires funding, suitably qualified person/s to facilitate interactions, co-ordination with relevant support organisations, and considerable time. Given that many grandparents seek information online and to serve urban and rural grandparents, a dedicated online resource offers a potential way to provide desired information and support. There are few examples to draw upon to determine whether an online resource is suitable for grandparents. However, Wilson and colleagues [8], in a scoping review of 14 studies, found that e-health could be an effective method by which to deliver timely care to older persons. They recommended engaging the end users in resource design and delivery, enhancing user self-efficacy and ensuring user privacy [8]. While Wilson et al. [8] specifically reviewed the delivery of healthcare programs, their findings suggest that an internet-based resource for information and support may be valuable for grandparents.

In terms of creating an appropriate internet-based resource, more research is needed to guide development, with the methodology used in previous research on website creation varying significantly [9-12]. Therefore, the evidence base for any particular methodology is limited [13,14]. However, previous research points to some key principles. In particular, co-creation has been utilised in health service design and is an increasingly accepted approach to aligning research with service development. As such, increasing attention is being given to the six-stage Experience Based Co-Design (EBCD) methodology, utilised in diverse settings and services, predominantly service improvement [15]. EBCD is an appealing method for translating research to practice and focuses on collaboration, user-centred design and narrative-based approaches to change [10,11,13-18].

Co-creation approaches move service design away from expert-led design to enable users to be equal contributors [18] and are key to effective change in service provision [10,14,16,19,20]. However, co-creation is not without challenges, including costs, time commitment, complicated processes, logistical barriers to reaching participants, participant retention, and power imbalances resulting in program implementation difficulties [11,14,16,17]. However, Green and colleagues [14] highlight two key phases where user participation is essential; (i) the experience-gathering phase, involving gathering potential end users' experiences, and (ii) the co-design phase, involving the design and review of a resource in partnership with end users. Consumer involvement in these steps is considered significant in developing a credible and worthwhile program or resource. Additionally, Greenhalgh and colleagues [21] identify three key features that address local adaptation and reflexivity – (i) the framing of research as a creative enterprise oriented to design, (ii) with human experience at its core, and (iii) an emphasis on process, particularly power-sharing measures. These key features ensure that the research purpose is explicit and directed to design, that lived experience informs the design and that stakeholder power imbalances are minimised.

Health literacy, a person's ability to make decisions and take action to manage their healthcare in a way that is appropriate to the individual [22,23], is a further important consideration when developing an accessible and effective resource. In Australia, approximately 40% of the population are thought to have a health literacy level too low to adequately interpret and apply health information [22]. More than general literacy skills, adequate health literacy is essential to finding and accessing health care, communicating needs and making decisions for enhanced wellbeing. Furthermore, using information technology for health and wellbeing requires e-health literacy, where to make use of an internet-based resource, an individual must be able to read, use an

internet-accessible device, know how to search for information, understand and interpret what is read, and put this information into context for their specific situation [24]. Also, to engage in internet support, an individual needs to understand how to create and respond to posts in a group forum or connect to a communication platform that utilises video or audio technology. For our study, health literacy and e-health literacy measures will guide understanding of whether an online resource is suitable for grandparents whose families have experienced perinatal loss.

Given the limited existing research on support needs and lack of available resources for grandparents following perinatal loss, we applied principles of co-creation and consumer-informed design, to seek grandparents' views and expertise in determining the usefulness of an internet-based resource for bereaved grandparents. Specifically, we aimed to determine (1) whether an internet-based resource would be suitable and beneficial for grandparents, (2) if so, what design features and content should be included and, (3) what barriers to utilising an internet-based resource might exist.

2. Methods and materials

The [removed for blind review] approved this study. We developed an online resource - a perinatal loss website for grandparents - in two stages: Stage One involved determining the suitability and features of an online resource, and Stage Two sought feedback on the proposed design derived from Stage One.

2.1. Participants

2.1.1. Stage one

One hundred and fifty-two Australian grandparents (146 females, 6 males) participated in Stage One; females were aged 41–82 years ($M = 59.91$, $SD = 7.53$), while males were aged 60–72 years ($M = 64.60$, $SD = 3.98$). Most participants (62%) described themselves as Australian/Oceanic. The remaining participants were from British and European backgrounds (22%), with a small number from the rest of the world (16%). Most grandparents (71%) had completed at least Year 12 education.

Participants had experienced a total of 296 perinatal deaths of their grandchildren, with some grandparents experiencing multiple forms of loss; individually grandparents had experienced the perinatal death of 1–12 grandchildren ($M = 2$). Perinatal loss types experienced included ectopic pregnancy ($n = 4$ grandparents), miscarriage ($n = 60$ grandparents), termination for medical reasons ($n = 20$ grandparents), stillbirth ($n = 68$ grandparents); loss type was unknown for two children. Seventy-six participants provided an email address for Stage Two of the research, the follow-up survey.

2.1.2. Stage two

Thirty grandparents (29 females, 1 male) commenced Stage Two, but nine ceased responding after the tenth question; the reasons for discontinuation are unknown. No significant differences were found between completers and non-completers for demographics or number of perinatal losses. The non-completers were excluded from the analysis of website feedback.

Female participants were aged 42–78 years ($M = 58.92$, $SD = 9.25$), while the male participant did not provide an age. Most participants (86%) described themselves as Australian/Oceanic; the remainder indicated British ethnicity (14%). Most participants (86%) had at least Year 12 education. Participants experienced the perinatal loss of one to six grandchildren ($M = 1.8$). Two participants commented in their responses that they had difficulty accessing the website; it is unknown if this difficulty was device- or link-related.

2.2. Measures

2.2.1. Stage one

A 70-item study-specific survey was hosted online via Qualtrics. Topics included demographics, health literacy, perceived usefulness of a website for grandparents following perinatal loss, preferred website design features, and perceived barriers to using such a website.

We developed the survey questions guided by the findings of past work [1-4] and literature concerning health and e-health literacy, co-design and person-centred design principles [23,25,26]. We included the eight-item eHEALS measure and three health literacy screening questions identified as effective in identifying inadequate health literacy [24,27]. Item response options included multiple choice and short response, with opportunities to provide additional information if desired. We also asked participants if they wished to be involved in reviewing and providing feedback for a draft of the proposed website (Stage Two). The survey can be found in Appendix A.

2.2.2. Stage two

The follow-up survey comprised 24 questions, including demographics and feedback regarding website design, images, content and navigability. Participants could choose not to answer any question/s in both stages. The survey can be found in Appendix B.

2.3. Procedure

2.3.1. Stage one

We utilised multiple methods to recruit grandparents. Perinatal loss support organisations in Australia promoted the research via social media and newsletter posts, which included a link to the survey. Grandparents who had participated in our previous qualitative research and indicated a desire to be contacted about participating in future related research were also emailed about the survey. Passive snowball sampling through sharing of the survey link was also used. Grandparents without internet access were advised in study information to email the researchers if they required alternate means to access the survey. These recruitment methods were chosen to distribute the survey to as many grandparents as possible. Due to the broad geographic distribution of the Australian population, and the lack of grandparent supports available, our previous work identified that perinatal loss support organisations were the most effective method of reaching grandparents who had experienced the perinatal loss of a grandchild [1-4]. Upon accessing the survey link, potential participants viewed information describing the study and consent questions as part of the survey preamble. Only people who consented could proceed to the survey questions; those who did not consent were directed to an exit page. Participants progressed through the Stage One survey, and if they wished to be involved in reviewing and providing feedback for a draft of the proposed website (Stage Two), they provided an email address (stored securely and separately from their data) to enable future contact. Participants were provided with a list of support organisations at the commencement and completion of the survey.

2.3.2. Stage two

We attempted to accommodate all participants' preferences in the draft website. Where there were differences in design preferences and, in some cases, opposite preferences (e.g., "no pink or blue" and "pinks and blues"), we chose the design feature identified by more participants. Where possible, we discreetly incorporated the opposite preference on the website. In addition, we made some adjustments to colour schemes to enhance readability. In terms of imagery, we excluded any images that participants expressed they did not want included (e.g., images of deceased babies). Furthermore, grandparents requested representation of cultural and family diversity and images of "real" grandparents. At this stage of development, photographs could only be sourced from stock sites and therefore we were reliant on finding suitable images of

adequate clarity. We also attempted to address any life stage barriers to access (i.e., using larger font sizes, offering information in multiple formats). Finally, we were responsive to the topics grandparents wished to see covered on the website. Examples of topics requested include guidance about how to support their child, how to support their wider family, differences in grieving styles, memory-making activities, where to find support for themselves, links to pregnancy loss support organisations, and connection to other grandparents who had experienced the perinatal loss of a grandchild. Additionally, they requested information about what to expect in the future and information regarding subsequent pregnancies.

Following the development of the draft website, we sent participants who had provided an email address at Stage One a link to the website and Stage Two survey. Participants were invited to review the draft website and respond via the survey with their opinions and suggestions about the website's design, images, content and navigability. Participants were able to make suggestions for improvements via open response questions, and three participants also left feedback directly on the website. It is unknown whether these participants also completed the survey; however, their feedback was noted in revising the website. While no explicit suggestions were made to improve navigation, we reflected on feedback and made headings and pathways as clear as possible until further information is available upon activation of the site.

2.4. Data analysis

Data were analysed using Stata version 15.0. We calculated descriptive statistics for participants' demographic characteristics, health literacy, perceived usefulness of a website for grandparents following perinatal loss, preferred website design features, and perceived barriers to using such a website. We also conducted content analysis of short-answer responses to identify common preferences to inform design decisions.

3. Results

3.1. Stage one

Most grandparents did not receive the information (82%) or support (93%) they desired after their loss. Most grandparents (78%) agreed or somewhat agreed that they can typically find health resources they want online, indicating that this cohort uses the internet. While 64% sought general health information through their General Practitioner, 71% indicated that they might, probably or definitely would seek health-related information online. Indeed, 60% of grandparents reported searching online for information following their child's loss. Grandparents saw value in a dedicated website; 76% indicated that a website with information about perinatal loss would be extremely or very useful to them, and 70% indicated that a website with information about support resources would be extremely or very helpful to them.

Results of the e-health literacy questions indicated that participants could use internet-based resources, with 78% of grandparents strongly or somewhat agreeing that they knew how to find helpful resources on the internet. Grandparents provided information regarding their preferences for the website design and content (Table 1). We incorporated these preferences and responses to the remaining questions about website design and content into the draft website.

3.2. Stage two

Most participants indicated that the website was definitely or possibly useful (95%), helpful (90%), easy to navigate (86%) and find key topics (81%), and that the information was easy to understand (86%) and relevant to their needs (86%; See Table 2).

Short-answer responses were largely favourable; however, participants recommended some revisions. For example, participants

Table 1
Summary of responses to eHealth literacy questions.

Question	Likert Response Anchors				
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)
<i>N</i> = 152					
I know how to find helpful health resources on the internet.	94 (61.8)	24 (15.8)	3 (1.9)	13 (8.6)	1 (0.6)
I know how to use the internet to answer my health questions.	66 (43.4)	46 (30.2)	4 (2.6)	13 (8.6)	2 (1.3)
I know what health resources are available on the internet.	48 (31.5)	62 (40.7)	20 (13.1)	3 (2)	2 (1.3)
I know where to find helpful resources on the internet.	55 (36.1)	58 (38.1)	11 (7.2)	5 (3.3)	22 (14.5)
I know how to use health information I find on the internet to help me.	56 (36.8)	58 (38.2)	15 (9.9)	3 (2)	3 (2)
I have the skills I need to evaluate the health information I find on the internet.	52 (34.2)	49 (32.2)	17 (11.2)	7 (4.6)	4 (2.6)
I can tell high quality from low quality health resources on the internet.	54 (35.5)	43 (28.3)	23 (15.1)	9 (5.9)	5 (3.3)
I feel confident in using information from the internet to make health decisions.	33 (21.7)	44 (29)	37 (24.3)	13 (8.6)	8 (5.2)
Is the Internet somewhere you typically look for health information?	35 (23)	38 (25)	35 (23)	19 (12.5)	5 (3.2)
Would an Internet website providing information for grandparents about pregnancy loss be useful to you?	76 (50)	33 (21.7)	16 (10.5)	6 (3.9)	2 (1.3)
Would an Internet website providing information about support resources for grandparents after the loss of a grandchild/grandchildren be useful to you?	73 (48)	34 (22.4)	18 (11.8)	7 (4.6)	1 (0.6)

Likert response anchors are presented from most affirming (1) to least affirming (5).

suggested that the images of grandparents should show diversity in age and relationships status (i.e., represent younger and older ages, and single and partnered people). For example:

The pictures, I'm a younger grandmother & would love pictures that represent all varying types of grandparents. The pictures represent a very stereotypical grandparent. Would help to feel more invited to the forum.

Nineteen grandparents were satisfied with the design theme used. One grandparent disliked the background image, assumed to be the front-page image, and one grandparent disliked like the 'colour', assumed to be the main theme colours of navy blue and yellow. Nine grandparents specifically stated that the website was easy to navigate. One grandparent advised:

The only thing that I didn't like was the 'About' link. I think it is too heavily worded for a person new to the experience, and this being one of the first things they will see/read.

One grandparent was uncomfortable using the word 'Death' in the website title. While no other grandparents commented either favourably or unfavourably on the title, as including the word 'Death' in the title was potentially distressing, it was removed and replaced with the word 'Loss'. Further recommendations were that any research papers included in the website be summarised/annotated to make current research more accessible for those unfamiliar with academic writing and regularly refreshing the content.

Table 2
Summary of responses accessibility and usefulness of the website draft.

Question	Likert Response Anchors				
	1 (%)	2 (%)	3 (%)	4 (%)	5 (%)
<i>N</i> = 21					
Do you think this website would be a useful resource following a child's pregnancy loss?	17 (80.9)	3 (14.2)	1 (4.7)	0 (0)	0 (0)
How helpful do you think this website would be?	16 (76)	3 (14.2)	2 (9.5)	0 (0)	0 (0)
Was the site easy to navigate?	15 (71.4)	3 (14.2)	0 (0)	1 (4.7)	2 (9.5)
How easily could you find the topics you were searching for?	15 (71.4)	10 (47.6)	0 (0)	1 (4.7)	2 (9.5)
How easy to understand was the information provided?	16 (76.2)	2 (9.5)	0 (0)	1 (4.7)	2 (9.5)
How relevant is the information provided?	16 (76.2)	2 (9.5)	2 (9.5)	0 (0)	1 (4.7)

Further information that may be useful					
Stage One – summary of losses					
Type of loss	Miscarriage	Stillbirth	TFMR	Ectopic pregnancy	Unknown
No. of G/children lost. <i>N</i> = 148	60	68	20	4	2
Min no. losses	1	12	296	2	
Max no. losses			20	4	
Total known losses			296	2	
Average no. losses				2	

Likert response anchors are presented from most affirming (1) to least affirming (5).

TFMR = termination for medical reasons; G/children = grandchildren.

Stage 1: 71% had education level of year 12 or higher.

Stage 2: 86% had education level of year 12 or higher.

Grandparents suggested adding further topics, such as information about arranging funerals:

The website doesn't include a link to (general) information around autopsies and funerals for babies. This was something I had to do for my grieving daughter and her partner and I didn't know where to start. I had to ring around which was distressing.

Other suggestions included how to support other grandchildren, the deceased baby's aunts and uncles, and family members when a family experiences multiple losses. Podcasts and videos on website topics were also of interest. All grandparents were otherwise satisfied with the included topics. However, one grandparent asked whether termination of pregnancy more generally could be included.

All grandparents commented favourably on the need for a website and were very keen to see the 'Chat Forum' option enabled. Others commented that a website would provide recognition and a voice for grandparents experiencing perinatal loss.

4. Discussion and conclusion

4.1. Discussion

Our study involved employing co-creation principles to develop a website for grandparents who had experienced the perinatal loss of a grandchild/ren. We aimed to determine (1) whether an internet-based resource would be suitable and beneficial, (2) if so, what design features and content should be included, and (3) what barriers to utilising an internet-based resource might exist.

Our findings indicate that a website would be beneficial, with most grandparents surveyed indicating that a website with tailored resources and support would address their desire for information and provide a way to connect with other bereaved grandparents. Our results also indicated that health and e-health literacy were sufficient for most

participants to access and navigate an internet-based resource. However, as approximately 40% of the Australian population is estimated to have a health literacy level too low to adequately interpret and apply health information [22], we factored this into the website design, taking steps to aid in the readability and understanding of the information. Actions taken included setting the reading level of the text at approximately Year 7 level as recommended [22], performing readability assessments to confirm this and being responsive to participants' feedback regarding this issue. Moreover, on the website, grandparents are encouraged to discuss concerns with a health professional who can assist them in receiving information and support in the most suitable format for their needs. In addition, where barriers to digital access may currently exist, as adults become more familiar with digital technology, there is improved accessibility in broader geographical areas [28,29], and its use becomes increasingly common, the scope of such a resource will only increase. In the meantime, we also recommend the continued use of current pamphlets or brochures for grandparents who have experienced the perinatal loss of a grandchild; ideally, provided directly to grandparents through hospitals or primary health care services.

Results from Stage Two of our study indicate that grandparents were particularly interested in a chat forum, which the website can facilitate. While a website cannot replace all the benefits of face-to-face peer support programs [30-34], an online resource confers some advantages. For example, in the absence of other forms of grandparent-specific support, a website could provide such support given grandparents can access it from anywhere that a device and internet service are available. Furthermore, the forum provides opportunities to share knowledge and benefit from distributed health literacy, where grandparents may be both distributors or recipients of information and knowledge [35].

The value of including grandparents with experiences of perinatal loss in the website design is seen throughout the site, including design, images, content and navigation. Key preferences included images of "real" grandparents, information about how to help their child and other family members, diverse images, links to pregnancy loss organisations and the ability to connect with other grandparents. In designing a website, we expected differences in grandparents' preferences and made every effort to accommodate suggestions. In some cases, this required reflecting on the reasons that might underlie certain suggestions and, therefore, the design choice most likely acceptable to most participants was selected.

Feedback in Stage Two provided further opportunities to reflect on our decisions and adjust the design accordingly. For example, a small number of grandparents did not like the word 'death' in the website's title. While few participants expressed this opinion, given the potential for the use of this term to cause distress, we felt that this was an important revision. A further example, where feedback suggested that the 'About' page was too "wordy", the content was reduced, the language simplified and information that could be placed in other parts of the website was relocated. Furthermore, where a small number of grandparents commented that they were unsure where to find certain topics, additional information was added to link names to guide easier navigation. Such revisions addressed participants' feedback while also hopefully improving the user experience. Moreover, a further benefit of a website-based resource is that it can be revised and modified in response to users' needs in future and as information and support options change.

Grandparents indicated few barriers to using an internet resource. However, to participate in our study, participants required access to the internet and a suitable device. Without these resources, grandparents would rely on public facilities, and access may be impossible for those remotely located. Most grandparents indicated that they use the internet to seek information and support and had adequate e-health literacy [24,27]. However, 20% of grandparents indicated that they did not know where to find helpful resources on the internet. Therefore, continuing to provide brief information pamphlets and brochures currently available at hospitals and some primary care providers would

be useful, and additional information about the website could be added to these documents. Additionally, once launched, it will be essential to actively promote the website to health professionals and families via social media, perinatal loss support organisations and posters in community organisations and health services waiting rooms. Design features enhancing readability and navigation were valued, and content written in plain language would further facilitate accessibility and comprehension [36]. Furthermore, participants suggested that videos contain subtitles and that translation be available for non-English speaking users.

4.2. Innovation

Our study indicates that grandparents can be valuable co-designers of health and wellbeing internet-based resources. Furthermore, the methodology used suggests that including design input and review via online surveys enables a broad range of participants across geographical areas to contribute to resource development that addresses a gap in service provision. Additionally, an online resource can offer another means of peer support.

The website's content provides some information similar to that provided for parents on pregnancy loss support organisation websites. Similarities include, for example, information about causes of pregnancy loss, grief reactions and differences in grieving styles, memory-making activities, and what to expect in subsequent pregnancies. While some pregnancy loss support organisations offer a website section or printed brochure for grandparents, our co-designed website provides a larger offering of information specifically requested by grandparents and a grandparent-specific perspective about the information and support needs of grandparents following the perinatal loss of a grandchild. Our website also provides additional topics that related to grandparents' desire to know how to support their children and families, grandparent self-care and where to seek support for themselves, and a space to seek grandparent-specific peer support. Our website is unique in its offering and its grandparent-informed design.

A grandparent-specific website could be hosted alone or by pregnancy loss support organisations as an adjunct to their current offerings, with their public profile potentially increasing the likelihood of grandparents and families locating the resource and aiding in perceptions of trustworthiness. However, if the website were standalone, links are provided to support organisations in Australia and internationally, linking grandparents to general perinatal loss information in their proximity. Given the importance of the website remaining up-to-date and responsive to users' needs, the site would require an administrator knowledgeable about grandparents' needs following the perinatal loss of a grandchild. The site also encourages users to provide feedback and suggest updates or recommendations for the site. The site administrator will monitor and implement appropriate suggestions, mindful of possible user sensitivities. Ongoing analysis would also review the site's usage, and the impact of the resource on grandparent coping and wellbeing. Potential analytical methods could include analysis of feedback, brief entry survey instruments for users who create an account, and periodic brief surveys developed using validated instruments once the site is activated.

Furthermore, grandparents' life stages varied significantly in our study; participants were aged from mid 40's to mid 80's. Some grandparents were employed and may have had additional caring responsibilities for younger and older family members. On the other hand, some grandparents were retired with a range of time and responsibility pressures. Such differences in life stage may impact where grandparents seek information and support and what they can readily access. In a broader population sample, age diversity may also impact access to and usefulness of an online resource, where familiarity and confidence in using digital technology may vary widely. This diversity means that any current information sources should remain available. Given that grandparents indicated that they seek health-related information from

health services, information such as pamphlets or brochures remain beneficial; however, ideally, these would be available directly to grandparents rather than through their child, either through hospitals or primary health care services.

Finally, our study points to the need for resources – internet-based or otherwise – to support grandparents who have experienced perinatal loss. While supports are increasing for parents following perinatal loss, in Australia and around the world [37,38], grandparents remain overlooked in much of the available supports and related research. In designing a study that explores grandparents' needs following perinatal loss, and the possibility of internet resources to meet those needs, this study reinforces previous research [1-4] showing that grandparents are often significantly affected by perinatal loss and lack support options.

We attempted to depict family diversity in the images we used; however, only stock images could be used for the draft website, limiting the available options. The images can be revised for diversity and to include images of "real" grandparents once the website is active (as requested by participants in Stage One; once the website is enabled, we can source images of grandparents who have experienced perinatal loss and consented to the use of their images). Such an approach would better represent grandparents' diversity (i.e., age, culture and circumstances). One further limitation is the cultural diversity of our participants. Participants preferred the website to show diversity and cater to a range of languages and communication needs; however, the needs of grandparents with diverse belief systems concerning perinatal death were not captured. Previous work [1-4] has also encountered this challenge; we recommend further research with culturally diverse groups exploring website utility and enhanced co-creation of culturally-appropriate resources.

Considerably more grandmothers participated in the surveys than grandfathers, which may have impacted the findings. We observed no substantive differences between grandfathers' and grandmothers' responses, and therefore the design was based on the preferences of the complete participant group. Grandparents were not directed how to complete the survey (i.e., only one grandparent per family, separately or as a couple). Therefore, it is possible that grandparents contributed to survey responses together but completed them with the grandmothers' demographic details. However, our previous research with grandfathers [3] found that men may be even more disenfranchised in their grief and more hesitant to express their needs following the perinatal loss of a grandchild. Grandfathers described an inclination towards more action-based support for their child [3,4]. Grandfathers' lower survey participation may reflect a view that these surveys may not be a means to action-based outcomes rather than a lack of interest in a website. Grandfathers identified the internet as a place they sought information about perinatal loss and how to support their child [3]. Therefore, a grandparent-specific website may be a useful resource for grandfathers. Monitoring of website usage is likely to provide further guidance in this regard.

As identified in the literature [10,11,13-18], power imbalances between participants in the design process were a challenging consideration. Ultimately, we made design decisions based on participants' preferences. In cases of conflicting preferences, we had the final decision on each design feature. While using a survey to aid co-design was useful, it also meant there was no opportunity for groups to meet and discuss the rationale for choices. However, one factor ameliorating this concern is that a website can be modified easily, unlike other health information and services. Providing we and the website host remain responsive to feedback, the website can evolve to meet users' needs.

4.3. Conclusion

Grandparents who have experienced the loss of a grandchild/ren in the perinatal period desire information and support. We demonstrated that by applying key principles of co-design and consumer-informed design, grandparents can participate in the creation of a useful online

resource that addresses their needs. Furthermore, ongoing user feedback can be incorporated easily to accommodate changing needs. Further work could focus on overcoming possible barriers to access and the needs of culturally diverse grandparents.

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Declaration of Competing Interest

The authors have no conflicts to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.pecinn.2023.100228>.

References

- [1] Removed for blind review.
- [2] Removed for blind review.
- [3] Removed for blind review.
- [4] Removed for blind review.
- [5] Bennett N, Chichester M. Ripples in the pond: caring for extended family members after a perinatal loss. *BMC Pregnancy Childbirth* 2015;15(1):A17. <https://doi.org/10.1186/1471-2393-15-S1-A17>.
- [6] O'Leary J, Warland J, Parker L. Bereaved parents' perception of the grandparents' reactions to perinatal loss and the pregnancy that follows. *J Fam Nurs* 2011;17(3): 330–56. <https://doi.org/10.1177/1074840711414908>.
- [7] Doka KJ. Disenfranchised grief in historical and cultural perspective. In: *Handbook of bereavement research and practice: Advances in theory and intervention*; 2008. p. 223–40. <https://doi.org/10.1037/14498-011>.
- [8] Wilson J, Heinsch M, Betts D, et al. Barriers and facilitators to the use of e-health by older adults: a scoping review. *BMC Public Health* 2021;21:1556. <https://doi.org/10.1186/s12889-021-11623-w>.
- [9] Leap Step by step step-by-step.pdf Leap Step by step an introductory guide to the Leap Framework Second Edition by Alan Barr and Jane Dailly - [PDF document] [Internet]. vdocuments.net. Available from, <https://vdocuments.net/leap-step-by-step-by-step-pdf-leap-step-by-step-an-introductory-guide-to-the.html>; 2022 Nov 28.
- [10] Cooper K, Gillmore C, Hogg L. Experience-based co-design in an adult psychological therapies service. *J Ment Health* 2015;25(1):36–40. <https://doi.org/10.3109/09638237.2015.1101423>.
- [11] Dimopoulos-Bick T, Dawda P, Verma R, Palmer V. Experience-based co-design: tackling common challenges. *J Health Design* 2018;3(1):86–93. <https://doi.org/10.21853/JHD.2018.46>.
- [12] Murtagh MJ, Minion JT, Turner A, Wilson RC, Blell M, Ochieng C, et al. The ECOUTER methodology for stakeholder engagement in translational research. *BMC Med Ethics* 2017;18(1):24. <https://doi.org/10.1186/s12910-017-0167-z>.
- [13] Archibald M, Ambagtsheer R, Lawless MT, Thompson MO, Shultz T, Chehade MJ, et al. Co-designing evidence-based videos in health care: a case exemplar of developing creative knowledge translation "evidence-experience" resources. *Int J Qual Methods* 2021;20(20):1–10. <https://doi.org/10.1177/16094069211019623>.
- [14] Green T, Bonner A, Teleni L, Bradford N, Purtell L, Douglas C, et al. Use and reporting of experience-based codesign studies in the healthcare setting: a systematic review. *BMJ Qual Saf* 2019;29(1):64–76. <https://doi.org/10.1136/bmjqs-2019-009570>.
- [15] Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *BMJ Qual Saf* 2006;15:307–10. <https://doi.org/10.1136/qshc.2005.016527>.
- [16] Donetto S, Pierri P, Tsianakas V, Robert G. Experience-based co-design and healthcare improvement: realizing participatory design in the public sector. *Design J* 2015;18(2):227–48. <https://doi.org/10.2752/175630615X14212498964312>.
- [17] Larkin M, Boden ZV, Newton E. On the brink of genuinely collaborative care. *Qual Health Res* 2015;25(11):1463–76. <https://doi.org/10.1177/1049732315576494>.
- [18] Robert G. Participatory action research: Using experience-based co-design to improve the quality of healthcare services. In: Ziebland S, et al., editors.

- Understanding and Using Health Experiences; Improving patient care. Oxford Academic; 2013. p. 138–49. <https://doi.org/10.1093/acprof:oso/9780199665372.003.0014>.
- [19] Trischler J, Dietrich T, Rundie-Thiele S. Co-design: from expert- to user-driven ideas in public service design. *Public Manag Rev* 2019;21(11):1595–619. <https://doi.org/10.1080/14719037.2019.1619810>.
- [20] Bird M, McGillion M, Chambers EM, Dix J, Fajardo CJ, Gilmour M, et al. A generative co-design framework for healthcare innovation: development and application of an end-user engagement framework. *Res Involv Engagem* 2021;7(1). <https://doi.org/10.1186/s40900-021-00252-7>.
- [21] Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. *Health Expect* 2019;22(4):785–801. <https://doi.org/10.1111/hex.12888>.
- [22] Health literacy [Internet]. Australian Institute of Health and Welfare. Available from, <https://www.aihw.gov.au/reports/australias-health/health-literacy>; 2022 Nov 28.
- [23] Lee HY, Jin SW, Henning-Smith C, Lee J, Lee J. Role of health literacy in health-related information-seeking behavior online: cross-sectional study. *J Med Internet Res* 2021;23(1):e14088. <https://doi.org/10.2196/14088>.
- [24] Norman CD, Skinner HA. eHEALS: the eHealth literacy scale. *J Med Internet Res* 2006;8(4):e27. <https://doi.org/10.2196/jmir.8.4.e27>.
- [25] Champlin S, Mackert M, Glowacki EM, Donovan EE. Toward a better understanding of patient health literacy: a focus on the skills patients need to find health information. *Qual Health Res* 2016;27(8):1160–76. <https://doi.org/10.1177/1049732316646355>.
- [26] Collins SA, Currie LM, Bakken S, Vawdrey DK, Stone PW. Health literacy screening instruments for eHealth applications: a systematic review. *J Biomed Inform* 2012; 45(3):598–607. <https://doi.org/10.1016/j.jbi.2012.04.001>.
- [27] Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med* 2004;36(8):588–94 [PMID:15343421].
- [28] Thomas J, Barraket J, Wilson CK, Holcombe-James I, Kennedy J, Rennie E, et al. Measuring Australia's digital divide: The Australian digital inclusion index 2020 [internet]. RMIT University, Centre for Social Impact, Telstra; 2020 [cited 2022Nov28]. Available from: <https://apo.org.au/node/308474>.
- [29] Faverio M. Share of those 65 and older who are tech users has grown in the past decade [internet]. Pew Research Center. Pew Research Center; 2022 [cited 2022Nov28]. Available from: <https://www.pewresearch.org/fact-tank/2022/01/13/share-of-those-65-and-older-who-are-tech-users-has-grown-in-the-past-decade/>.
- [30] Ambler-Walter C, McCoy J. *Grief and loss across the lifespan: a biopsychosocial perspective*. 2nd ed. New York, NY: Springer Publishing Company; 2015. p. 368.
- [31] Bartone P, Bartone J, Gileno Z, Violante J. Exploration into best practices in peer support for bereaved survivors. *Death Stud* 2018;42(9):555–68. <https://doi.org/10.1080/07481187.2017.1414087>.
- [32] Livingston W, Thompson N. Critical explorations of marginalized grief. *Illn Crisis Loss* 2019;27(1):3–5. <https://doi.org/10.1177/1054137318780569>.
- [33] Normann-Vigil I. Conceptualizing and articulating pregnancy loss through embodiment in peer interaction. *Lang Commun* 2015;45:70–2. <https://doi.org/10.1016/j.langcom.2015.10.002>.
- [34] Riley S, Pettus K, Abel J. The buddy group - peer support for the bereaved. *London J Prim Care* 2018;10(3):68–70. <https://doi.org/10.1080/17571472.2018.1455021>.
- [35] Edwards M, Wood F, Davies M, Edwards A. 'Distributed health literacy': longitudinal qualitative analysis of the roles of health literacy mediators and social networks of people living with a long-term health condition. *Health Expect* 2013; 18(5):1180–93. <https://doi.org/10.1111/hex.12093>.
- [36] The NSQHS standards [Internet]. The NSQHS Standards | Australian Commission on Safety and Quality in Health Care. Available from, <https://www.safetyandquality.gov.au/standards/nsqhs-standards>; 2022 Nov 28.
- [37] Flenady V, Oats J, Gardener G, Masson V, McCowan L, Kent A, et al. For the PSANZ care around the time of stillbirth and neonatal death guidelines group. In: *Clinical practice guideline for care around stillbirth and neonatal death*. Version 3.4. Brisbane, Australia: NHMRC Centre of Research Excellence in Stillbirth; January 2020.
- [38] Removed for blind review.