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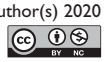
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The "Lactation After Infant Death (AID) Framework": A Guide for Online Health Information Provision About Lactation After Stillbirth and Infant Death

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Keywords

breastfeeding, health services research, lactation education, maternal health, policy analysis

Background

Most parents who give birth to a stillborn infant, or who give birth then endure the death of their young infant, will encounter the onset of lactation (McGuinness et al., 2014). For breastfeeding parents who experience the death of their older infant, many will have established lactation or frozen stores of expressed human milk ([EHM] McGuinness et al., 2014). Despite this, lactation and EHM are rarely discussed with bereaved parents in healthcare settings (Britz & Henry, 2013; Carroll, Lenne, McEgan et al., 2014; Redshaw et al., 2014). As a result, many bereaved parents who have recently given birth are unprepared when they begin to lactate, and few are aware of the range of suppression, expression, or donation options that may be available to them (Carroll & Lenne, 2019; McGuinness et al., 2014; Welborn, 2012b). The lack of anticipatory guidance regarding lactation after infant death can be a significant source of distress for parents, exacerbating the emotional pain of their child's death (Carroll & Lenne, 2019; McGuinness et al., 2014; Welborn, 2012b). This lack may also inadvertently compound the invisibility and ambiguity of parenthood experienced by many bereaved parents (Cacciatore et al., 2008; Layne, 2003; Oreg, 2019). Furthermore, parents bereaved as a result of giving birth to a stillborn infant or enduring their infant's death are likely to experience breast engorgement, pain, and milk leakage (McGuinness et al., 2014) and, in the absence of reliable information, they may follow lactation management methods that prove ineffective or lead to mastitis or abscess. To prevent adverse outcomes, bereaved parents require anticipatory guidance or lactation support from qualified health professionals.

Discussing or making decisions about the suppression, expression, or donation of human milk with bereaved parents in the midst of grief can be a confronting and difficult task for both health professionals and families (PATH, 2019). In addition to the general taboo that surrounds infant death and lactation in our society, health professionals may have limited knowledge, or lack the confidence to initiate or manage these conversations (Carroll & Lenne, 2019; Layne, 2003; Oreg,

Key Messages

- There is a dearth of targeted online lactation health information provided to bereaved parents after stillbirth and infant death.
- We collated and critically reviewed international evidence-based lactation and bereavement information to devise a comprehensive framework on the diverse options for lactation management after stillbirth and infant death.
- We outline the development of the 25-point evidence-based Lactation AID Framework intended for use by health organizations that provide written online lactation health information to bereaved parents.

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2019). Moreover, hospital staff are presented with the practical challenges of engaging in sensitive and timely lactation conversations with bereaved parents who may leave hospital after giving birth, but before lactogenesis II or changes to their lactation practices have occurred (Cole, 2012; McGuinness et al., 2014; Redshaw et al., 2014). In these circumstances, having ready access to quality evidenced-based written information that specifies lactation management and care options is vital (McGuinness et al., 2014).

Written information may be the most effective and sensitive way to convey the various lactation options—including suppression, sustained expression, or donation—available to bereaved parents (Welborn, 2012b). Written information can be consulted frequently and over time, and is particularly helpful for parents who may have difficulty understanding and retaining information whilst in a state of shock or grief (Flenady, Oats et al., 2018). Following their discharge from hospital, bereaved parents may be reluctant to seek lactation help from healthcare providers and they may turn to online health information ([OHI] Lariviere-Bastien et al., 2019; Sweeney et al., 2020). If it is reliable and evidenced-based, OHI can act to supplement the care received from health professionals (Gleeson et al., 2019; Iacovetto & Allen, 2015).

To date, there has been little exploration or consideration of the OHI available to bereaved parents about lactation after infant death. To address this gap, a study was conducted in 2019 to review the lactation information presented on the websites of 21 targeted Australian health organizations (Sweeney et al., 2020). To evaluate website content, the research team devised an evidenced-based tool that succinctly incorporates information required by bereaved parents to promote effective management of, and informed decision-making about, lactation after infant death. The development of this tool provided a timely opportunity to critically review the growing international research and available best-practice resources within the milk banking, bereavement, and lactation/breastfeeding sectors. In this article we outline the development of this tool, the Lactation After Infant Death (AID) Framework, and provide a description and justification for each of the Framework's 25 information criterion. The Framework's limitations and potential adoption by health organizations is also considered.

Developing the Lactation AID Framework

Numerous tools exist to guide the development, implementation, and evaluation of health policy or practice guidelines (Selva et al., 2017; Schünemann et al., 2014). Arguably, the most comprehensive and well regarded of these is the GIN-McMaster Guideline Development Checklist ([GDC] Morgan et al., 2018; Schünemann et al., 2014). Developed by Schünemann et al. (2014), the GDC is organized into 146 elements that span 18 topics, from guideline planning to implementation and evaluation (Morgan et al., 2018). The GDC and associated resources offered valuable guidance to ensure our development process was systematic, rigorous, and evidence-based. As our Framework was not intended for health policy or clinical practice, we followed Schünemann et al. (2014) advice and used only the GDC items that were relevant to the intended focus and purpose of our Framework.

In accordance with the initial steps outlined in the GDC (Schünemann et al., 2014), the research team spent preliminary time planning and organizing roles, priorities, budget, and timelines for the Framework development. The GDC's Steps 3–6 (Schünemann et al., 2014) recommends support from a Stakeholder Advisory Group (SAG) to critically advise on Framework development. Researchers selected SAG members with expertise and/or extensive experience interfacing with bereaved parents who may experience lactation after infant death. The SAG included: IBCLCs, Neonatologists, Human Milk Bank Managers, an Infant Death Bereavement Educator, and an Infant Death Bereavement Counsellor. One member also had personal experience of infant bereavement. The SAG members were selected from three different Australian states and represented universities, neonatal intensive care units, human milk banks, and not-for-profit community organizations. The variety of professions and organizations represented assisted the research team to assess and address conflict of interest considerations (Step 7 of the GDC) and any bias that may be evident in member perspectives. SAG members provided advice at different stages of development, with early discussions confirming the lack of succinct guides or information currently at their disposal to assist organizations to develop appropriate lactation after infant death information materials.

Literature Search and Review

With initial planning conducted and a clear research aim established and agreed to by the SAG, the next steps of the GDC informed the need to search for, identify, and assess current best-practice guidelines. The research team consulted international best-practice guidelines governing: (a) stillbirth or infant bereavement care (including, Flenady, King et al., 2009, 2018; National bereavement care pathway for pregnancy and baby loss, 2018a, 2018b, 2018c, 2018d, 2018e; National Institute for Health and Care Excellence, 2019; Sands Stillbirth & Neonatal Death Charity [Sands], 2016); (b) bereaved donor milk donation (including National Institute for Health and Care Excellence, 2018; PATH, 2019; Welborn, 2012b); and (c) lactation management (including publications from the World Health Organization, 2019; Academy of Breastfeeding Medicine Protocols, 2019; and the Australian Breastfeeding Association, 2019). Although some exemplar documents were uncovered from within the milk banking policy and practice sector (see PATH, 2019; Welborn, 2012b), the search confirmed the need to develop a tool that could succinctly guide the presentation of OHI across the bereavement, milk banking, and lactation or breastfeeding sectors.

To ensure the tool reflected internationally emergent knowledge from this rapidly growing area of interest, it was necessary for the research team to also review scholarly and grey literature available on the topic. This ensured the proposed Framework encompassed evidenced-based health policy and practice information whilst also representing bereaved parents' experiences of lactation after infant death. Key search terms used within databases and search engines included: "lactation after loss;" "lactation after infant death;" "milk production after death;" "milk production after loss;" and a combination of "infant death" (and synonyms: "bereavement;" "loss;" "baby loss;" "pregnancy loss;" "miscarriage;" "stillbirth;" "still birth;" "neonatal death;" "neonatal loss;" "infant loss;" "loss of baby;" "death of baby") with "lactation;" "breastmilk;" "milk donation;" or "milk bank". This search uncovered a growing body of research that often incorporated bereaved parents' perspectives, and advocated for the need to improve lactation care and guidance for bereaved parents (e.g., Britz & Henry, 2013; Carroll & Lenne, 2019; Carroll, Lenne, McEgan et al., 2014; Cole, 2012; Ellis et al., 2016; Fry & Henner, 2016; Spatz, 2016).

Data Analysis

The completed literature review enabled the research team to identify information critical to bereaved parents' lactation care, and the Framework was drafted. SAG members provided feedback to review and refine the draft Framework, raising important points about the balance of information provided and ensuring it was appropriate to the current Australian healthcare context and climate. Further research team meetings were then held to review and finalize each of the Framework's criterion and to attend to the overall tone and language used. These reflective discussions considered the GDC's (Schünemann et al., 2014) recommendation to interrogate the values, equity, feasibility, and (un)intended consequences of the proposed Framework. The literature relating to the development and assessment of quality OHI was also helpful at this time, ensuring we considered whether the Framework would meet the imperatives of providing up-to-date, relevant, evidence-based, accurate, coherent, respectful, and sensitive information to the intended users (Beaunoyer et al., 2017).

In accordance with the final stages of the GDC (Schünemann et al., 2014), the research team and SAG will continually review, evaluate, and adapt the Framework to ensure its enduring applicability to health organizations and the bereaved parents that they aim to inform and support. The publication of this article is an important component of this stage, providing an opportunity for the necessary reporting and peer review of the Lactation AID Framework.

The Lactation AID Framework

Our review confirmed that bereaved parents experiencing stillbirth or infant death would benefit from access to written information that: (a) provides anticipatory guidance regarding the production or presence of human milk after loss (Welborn, 2012a); (b) acknowledges the varied emotional responses and meanings that may be attached to this experience (Welborn, 2012b); (c) addresses and reduces the chances of ill-health associated with mismanaged lactation (McGuinness et al., 2014); and (d) provides sufficient information in regard to the full spectrum of possible lactation responses to ensure parents can make informed decisions about what to do with their milk (PATH, 2019; Welborn, 2012b).

To meet these needs the Lactation AID Framework (outlined in Table 1) consists of 25 criteria, cohered into seven overarching categories. To provide transparency and education to users of Table 1, a justification for the inclusion of each criteria and an overview of key supporting evidence is presented in Table 2. In this way, Table 2 acts as an audit trail by providing the evidence base for each of the Framework's 25 criteria. We now provide further transparency by highlighting how we responded to limitations or contradictions evident within the extant literature, and provide further guidance on the language and framing required for each criterion, particularly for those criteria that are novel, contentious, or complex.

Category A: Acknowledgement of Human Milk and Lactation after Infant Death

Our review confirmed that it remains commonplace for clinical standards or guidelines for perinatal bereavement care to neglect, or offer limited attention to lactation. Advice regarding if, and when, to expect lactation after infant death varies significantly across current guidelines, with advice often being directed to parents experiencing miscarriage or stillbirth, rather than to parents who experience an older infant death (for example, see variance in the National bereavement care pathway for pregnancy and baby loss, 2018a, 2018b, 2018c, 2018d, 2018e). Guidelines usually offered little specificity regarding the gestational period most likely to elicit lactation. Scholars suggest people at 16 weeks gestation may expect to produce and leak milk after loss (McGuinness et al., 2014). However, due to the inevitable variability in the onset of lactogenesis, our Framework advises that information be framed in general terms to simply acknowledge milk production can occur after early or late miscarriage, stillbirth, neonatal death, or infant death, thereby ensuring that no people are excluded from receiving information they may require.

The literature reviewed indicated that, when discussing lactation, the adoption of open and non-judgmental language is essential. Currently, lactation is often portrayed as being a physically and emotionally painful experience (Sweeney et al., 2020). Thus, human milk is rarely included as a suitable object for meaning or memory-making to

Table 1. Lactation AID Framework for Online Heath Information.

Complete Information
Category A: Acknowledgement of human milk and lactation after infant death
1. Acknowledges milk production can occur after early or late miscarriage, stillbirth, neonatal death, or infant death
2. Acknowledges emotional responses or changes may be associated with milk production after pregnancy loss, stillbirth, or infant death
3. Acknowledges that frozen or stored human milk may exist at the time of infant death: Can be discarded, kept as memento, or potentially donated
Category B: Breast changes commonly associated with milk production
1. Mentions breast engorgement
2. Mentions milk leakage
Category C: Advice on alleviation of symptoms: Discomfort, engorgement, leakage, and infection
1. Describes non-pharmacological means for symptom relief
2. Describes pharmacological pain relief options
3. Describes signs of infection and mastitis
Category D: Description of full range of suppression options, including:
1. Advice and techniques for milk suppression
2. That some people have found lactation suppression beneficial after infant death
3. What to do with milk from suppression process: Can be discarded, kept as memento, frozen
4. Advises pharmaceutical suppression only in consultation with a health professional
Category E: Description of sustained expression option, including:
1. Advice and techniques for milk expression
2. Sustained expression without donation
3. That some people have found this option beneficial after infant death
4. What to do with milk from expression process: Can be discarded, kept as memento, frozen
Category F: Description of milk donation option, including:
1. Donation from sustained expression
2. That some people have found this option beneficial after infant death
3. Describes what milk banks do with human milk
4. Describes donation process, including screening and eligibility requirements
5. Provides list of milk banks in your specified region.
6. What to do with milk: can be frozen before donation
7. Acknowledging informal milk sharing and associated risks
Category G: Recognition that additional bereavement and/or lactation support may be necessary
1. Provides links to other relevant websites or resources
2. Advises seeking advice of relevant healthcare professionals

Note. Adapted from "Lactation After Infant Death: An Analysis of Australian Health Care Agencies Online Health Information," by L. Sweeney, K. Carroll, D. Noble-Carr, & Waldby, C. 2020. *Health Sociology Review, 29*(1), 45–61. https://doi.org/10.1080/14461242.2019.1708206 Copyright 2020 by Taylor & Francis Ltd.

assist bereaved families' grieving (Sweeney et al., 2020). The omission of variable responses to lactation and human milk after loss is concerning, as it potentially reinforces the presumption that a bereaved parent should or would want nothing to do with their milk (Welborn, 2012b).

Category B: Information on Breast Changes Commonly Associated With Milk Production

Information about breast changes commonly associated with milk production are often minimally presented within the context of other physiological changes that can result from miscarriage or stillbirth (Sweeney et al., 2020). As a result, many parents who have miscarried or given birth to a stillborn infant can be surprised, unprepared, and distressed when they experience breast sensitivity, engorgement, leakage of milk, discomfort, and pain (McGuinness et al., 2014; Welborn, 2012b). Through our Framework we suggest that all bereaved new parents should be advised of the full range of potential breast changes they can expect.

Category C: Advice on Alleviation of Symptoms: Discomfort, Engorgement, Leakage, and Infection

It is important that bereaved parents are presented with options for the alleviation of symptoms or complications that may result from lactation. Various methods of pain control are outlined in currently available information. However, conclusive evidence on the effectiveness of both pharmacologic and nonpharmacologic treatment options remains elusive (Berens & Brodribb, 2016; Welborn, 2012b). Rather than simply providing parents with a long list of potential strategies, we advise that, where possible, the strength of evidence for each strategy or treatment be carefully considered and conveyed. Parents must also be informed that some measures currently promoted to address engorgement or leakage, for example binding or bandaging breasts that may be more present in particular cultures, may increase the risk of infection (Cole, 2012; Welborn, 2012b).

Table 2. Lactation AID Framework for Online Heath Information: An Overview of Supporting Evidence.

Category	Criteria and Evidence-Based Rationale for Inclusion
A. Acknowledgement of human milk and lactation after infant death	1. Acknowledges milk production can occur after early or late miscarriage, still birth, neonatal death, or infant death. It is important to physical health and emotional wellbeing that parents are aware that lactation can occur after late miscarriage, later-term abortions, stillbirth, and infant death, and are provided with lactation management information and are supported to make decisions about their human milk (Busta Moore & Catlin, 2003). Bereaved parents require this information at the time that their baby dies (Britz & Henry, 2013; Welborn, 2012a). 2. Acknowledges emotional responses or changes may be associated with milk production after pregnancy loss, still birth, or infant death. Information should not presuppose any particular emotional response to the presence of human milk or lactation. There are variable meanings and emotional responses that bereaved parents may attach to lactation or the presence of human milk after infant death (Welborn, 2012a) that vary across individuals, families, religions, or cultures. 3. Acknowledges that frozen or stored human milk may exist at the time of infant death: Can be discarded, kept as memento, or potentially donated. Where possible, parents should be presented with options to keep their milk, have it discarded, or be considered for donation (PATH, 2019; Stillbirth & Charity, 2016). Inclusion of human milk in memory making should also be considered (Stillbirth & Charity, 2016).
B. Breast changes commonly associated with milk production	1. Mentions breast engorgement: Bereaved parents who lactate may experience breast sensitivity, engorgement, and leakage of milk. Discomfort and pain with lactation, and even mastitis or abscess may result if these symptoms are left unattended (McGuinness et al., 2014; Oladapo & Fawole, 2012). 2. Mentions milk leakage: Parents should receive information about why lactation may commence or continue after perinatal or infant death (Welborn, 2012b). Bereaved parents should be advised that it is normal for milk to be present for days, weeks, or even months after stopping breastfeeding or expressing (Neifert, 2009 cited in Welborn, 2012b).
C. Advice on alleviation of symptoms, discomfort, engorgement, leakage, and infection	1. Describes non-pharmacological means for symptom relief: A range of nonpharmacological measures to alleviate discomfort and avoid engorgement are routinely advocated (Hernández-Aguilar et al., 2018), most commonly described as the gradual removal of enough milk from the breast in order to reduce pressure in the breasts, but not too much so as to stimulate milk production (Welborn, 2012b). 2. Describes pharmacological pain relief options: Painful engorgement should not be experienced by bereaved parents, and analgesia can be taken for engorgement-related pain (McGuinness et al., 2014) including over-the-counter anti-inflammatory medications (PATH, 2019). 3. Describes signs of infection and mastitis: It is critical that bereaved parents receive information and advice about signs of mastitis and its prevention (Stillbirth & Charity, 2016).

(Continued)

Table 2. Continued

Category	Criteria and Evidence-Based Rationale for Inclusion
D. Description of a full range of suppression options	1. Advice and techniques for milk suppression: There is currently no universal guideline on the most appropriate approach for suppressing lactation (Marcellin & Chantry, 2015; Oladapo & Fawole, 2012). Parents should be given information about the range of options to suppress their milk, and the advantages and disadvantages of each (Stillbirth & Charity, 2016). The full range of non-pharmacological options should be provided to alleviate discomfort and avoid engorgement, including coherent instructions and indicators for their use and efficacy (Cole, 2012; Hernández-Aguilar et al., 2018; Oladapo & Fawole, 2012; Royal College of Obstetricians & Gynecologists, 2010; Stillbirth & Charity, 2016). 2. That some people have found lactation suppression beneficial after infant death. Many parents who experience lactation as a painful reminder of their loss will want to promptly suppress lactation (Carroll & Lenne, 2019; Cole, 2012; Welborn, 2012b). 3. What to do with milk from suppression process: Can be discarded, kept as memento, frozen. The timeline and process for involution will be different for every person (Welborn, 2012a). Parents should be advised that even if they choose to suppress their lactation, milk may be produced and they can make decisions to either discard this milk, keep it as a memento, or freeze it until they feel more ready to make a decision. 4. Advises pharmaceutical suppression only in consultation with a health professional. There is a risk of rebound lactation and increased risks of thromboembolism, cerebral accident, and myocardial infarction reported with the use of pharmaceutical oestrogens and bromocriptine (Oladapo & Fawole, 2012). However, the Royal College of Obstetricians & Gynecologists (2010) suggest pharmacological lactation suppression—and, in particular, dopamine agonists—are effective and well-tolerated by many. Where pharmaceutical suppression is advised, it must always be accompanied by the requirement to consult with an appropriate health professional to explain risks and side effects (PATH, 2019).
E. Description of sustained expression options	1. Advice and techniques for milk expression: To facilitate sustained expression, information must instruct on how to express milk effectively either by hand or pump, and how to access an appropriate breast pump (Evans et al., 2014; Hernández-Aguilar et al., 2018, PATH, 2019; Welborn, 2012b, 2012b). 2. Sustained expression without donation: Sustaining lactation is a viable lactation management option and potential grief alleviation strategy for bereaved parents (Cole, 2012; Oreg, 2019; Welborn, 2012a). 3. Some people have found this option beneficial after infant death: "Continuing to lactate may be important for some women who may feel that lactation is a tangible link to their baby, be interested in the health benefits of lactation or wish to delay stopping lactation for other reasons" (Stillbirth & Charity, 2016, p. 238). For some parents pumping milk is a way to maintain a close connection to the baby and to develop a relationship with the deceased infant (Welborn, 2012a). Expressing milk may enable a bereaved parent to identify and validate their parenthood or act as a form of ritual to assist in the grieving process (Carroll & Lenne, 2019; Welborn, 2012a). 4. What to do with milk from the expression process: Can be discarded, kept as memento, frozen. Parents should be reminded that they have the choice of discarding expressed milk, keeping it as a memento, or freezing it until they are ready to make decisions about its potential use or disposal. For bereaved parents who want to continue to express their human milk, the option to donate should be made accessible (Busta Moore & Catlin, 2003; Welborn, 2012b).

(Continued)

Table 2. Continued

Category	Criteria and Evidence-Based Rationale for Inclusion
F. Description of milk donation options	1. Donation from sustained expression: Bereaved parents should be informed of all possible options for providing milk to a milk bank (PATH, 2019; Welborn, 2012b). This may include donating existing stores of expressed human milk obtained during the infant's life, expressed human milk obtained after infant death while working toward lactation suppression, expressed human milk obtained after infant death due to sustaining lactation, and human milk expressed for donation as a result of lactation also intended for a living infant (Carroll, Lenne, McEgan et al., 2014). 2. That some people have found this option beneficial after infant death. Many bereaved parents experience milk donation as healing, comforting, positive, productive, agency-enhancing, and meaningful (Carroll & Lenne, 2019; Welborn, 2012a). 3. Describes what milk banks do with human milk. Parents should also be informed as to how donor milk is used and why human milk is essential to infants in Neonatal Intensive Care Units (Welborn, 2012b). 4. Describes donation process, including screening and eligibility requirements: Careful and sensitive guidance is required, as not all bereaved parents will be eligible or able to donate milk (Britz & Henry, 2013). When considering donation, comprehensive information about eligibility criteria, the requirements for milk expression and storage, and the availability of emotional or practical support is essential (National Institute for Health and Care Excellence [NICE], 2018). If bereaved donors do not meet eligibility criteria, they should be advised if they can donate their milk for research (Stillbirth & Charity, 2016; Welborn, 2012b). 5. Provides list of milk banks in your specified region. When considering donation, comprehensive information about where and how to donate is essential (National Institute for Health and Care Excellence, 2018). 6. What to do with milk: Can be frozen before donation. When considering donation, comprehensive information about the requirements for milk expression and storage and the availability of emotional or practical support available is essential (National Institute for Health and Care Excellence, 2018). 7. Acknowledging informal milk sharing and associated risks: Given the prevalence of informal milk sharing and its prominence in online spaces health authorities should acknowledge peer-to-peer milk sharing and provide tailored practical support to ensure it is rendered as safe as possible (Akre et al., 2011).
G. Recognition that additional bereavement and/or lactation support may be necessary	1. Provides links to other relevant websites or resources: Parents should know where and how they can access additional bereavement or lactation support that is suited to their own needs and preferences (Bakhbakhi et al., 2017). Parents should be provided with these contact details for additional support (PATH, 2019). 2. Advises seeking advice of relevant healthcare professionals: Some parents may require follow up care from specialist care providers including IBCLCs who can answer questions concerning human milk or lactation (Cole, 2012; Welborn, 2012a). Many parents also find the practical and emotional support provided by bereavement counsellors or social workers of benefit (Cole, 2012; Welborn, 2012a, 2012b).

The risk of mastitis was highlighted by our SAG panel as requiring explicit attention in the Framework. Mastitis is a common condition affecting lactating parents (Amir, 2014). Mastitis and breast abscesses are largely preventable if early signs of engorgement or blocked ducts are treated promptly (World Health Organization, 2000). Given the risk of pain and complications, including infection, and that many parents may be unsure of how to respond to their lactation even after initial guidance (Chen et al., 2015), we advise health organizations to adopt proactive language. This may appear to be a conscious departure from the PATH (2019) resource that suggests "all mothers should be given the option to *do nothing* [emphasis added] about their milk supply, to suppress their milk supply, or to express their milk" (pp. 111–112). Although we support an approach that enables people to have choice over their own bodies and healthcare decisions, that necessarily includes to "*do nothing*," we believe people must be actively informed of the potential harms and risk associated with this approach.

Category D: Description of Full Range of Suppression Options

There is currently no universal guideline on the most appropriate approach for suppressing postpartum lactation (Marcellin & Chantry, 2015; Oladapo & Fawole, 2012). Despite this, information on the full range of suppression options is rarely provided to bereaved parents (Chen et al., 2015). Cole (2012, p. 95) states that non-pharmacological measures which allow discomfort and engorgement to be minimized whilst people gently suppress their milk have become "the norm". In contrast to this approach, the Royal College of Obstetricians & Gynecologists (2010) suggest that pharmacological methods of lactation suppression—and, in particular, dopamine agonists—are effective and well-tolerated by many. They further suggest that "women should be advised that almost one-third of those that choose non-pharmacological measures are troubled by excessive discomfort" (Royal College of Obstetricians & Gynecologists, 2010, p. 17). In light of this evidence and findings of qualitative studies with bereaved parents (Chen et al., 2015) we advocate in the Framework that all suppression options be fully presented to parents, along with coherent instructions and indicators for their use and efficacy, and referral to appropriate health professionals for further information or prescription.

We would also caution against brief ambiguous statements that can sometimes accompany information endorsing gentle suppression. Specificity in how to gently suppress milk supply, without making more milk, (see for example: PATH, 2019, p. 16.) is likely to be required by parents who may have little lactation experience and may not know how to confidently express for the purpose of suppression (Welborn, 2012a). In addition, parents should always be presented with information about what they may like to do with human milk produced as a result of suppression techniques. It should not be assumed that parents who want to suppress as quickly as possible will not want to keep or donate their milk (Welborn, 2012a).

Category E: Description of Sustained Expression Option

There is currently very limited attention given to sustained expression after infant death in the extant literature directed to health professionals and bereaved parents (Sweeney et al., 2020). Lactation management options, including deliberately sustaining lactation for a period of time after infant death, can assist the transition to bereaved parenthood (Carroll & Lenne, 2019; Oreg, 2019; Welborn, 2012a). To enact this strategy, lactating parents will need guidance on how to express their milk. Academy of Breastfeeding Medicine Clinical Protocols prescribe that every mother receive instruction on the technique of expressing milk by hand and, if necessary, on how to use a breast pump in order to alleviate engorgement, increase or maintain milk supply, and obtain milk (Evans et al., 2014; Hernández-Aguilar et al., 2018). Bereaved parents may be forgotten as a category of people who may require this information. Bereaved parents would particularly benefit from tailored information that provides sufficient instruction on "how to express" that does not presume the presence of a living infant.

Category F: Description of Milk Donation Option

Milk donation is recognized as a viable option requiring better integration into the range of options presented to bereaved parents (Britz & Henry, 2013; Carroll, Lenne, McEgan et al., 2014; Spatz, 2016). Donation is facilitated if human milk banks provide services that can address the unique circumstances of bereaved parents (Carroll, Lenne, McEgan et al., 2014). Bereaved donors are currently excluded from donor profiles advertised on Australian milk banks' online information (Sweeney et al., 2020). However, international resources, including PATH (2019) and Welborn (2012b), offer comprehensive guidance on how to present the option of donation to bereaved parents.

Whilst bereaved donation to human milk banks receives cursory attention in current discourse (Carroll, Lenne, McEgan et al., 2014; Oreg, 2019), informal milk sharing receives even less. Many health organizations appear reticent to acknowledge or present information on informal milk sharing that is often cast as a risky undertaking (Akre et al., 2011; Reyes-Foster & Carter, 2018). Whilst donation to a human milk bank is considered to be the safest method of milk donation, some parents are interested in exploring the possibility of donating or sharing their

human milk with known friends or family or through the use of internet and social networking sites (Akre et al., 2011; Cole, 2012).

Category G: Recognition That Additional Bereavement and/or Lactation Support May be Necessary

Although OHI has been lauded as empowering health consumers (Cotten, 2001; Lederman et al., 2014) there are potential dangers in relying too heavily on OHI (El Sherif et al., 2018; Iacovetto & Allen, 2015). Being mindful of this, and of the significant physiological and emotional challenges that lactation after infant death presents to parents (Chen et al., 2015; Cole, 2012), it was vital that information in our Framework advised that parents be offered information which enables them to seek out additional specialist lactation or bereavement support.

Discussion

The Lactation AID Framework for Online Heath Information (Table 1) was developed as an analytical tool to review the breadth and quality of Australia's health organizations' online content on the topic of lactation after stillbirth and infant death. It offers an evidenced-based set of 25 information criteria cohered into seven categories (see Table 2) that guide the provision of much needed OHI to assist bereaved parents with lactation care, management, and decision making. In developing the Framework, researchers have considered and addressed some of the gaps and inconsistencies evident in the extant literature, and have offered guidance on how health organizations can, through the use of OHI, work towards redefining dominant discourses (Sweeney et al., 2020). Above all, our aim for the Framework is to promote an evidenced-based, transparent, and sensitive approach to OHI and support, ensuring that bereaved families are presented with comprehensive information that enables them to make informed choices about the full spectrum of lactation management options.

Health organizations aiming to provide this online content will need to be cognizant of additional design elements and language that may influence how users interpret or engage with online information. Given the sensitive nature of the topic the language and images used must adopt a tone of sensitivity and non-judgement (Beaunoyer et al., 2017; Flenady, King et al., 2009). Whilst our Framework deals solely with the subject of lactation after infant death, health organizations should also be mindful that people may experience lactation after loss as a result of varied circumstances including abortion, child protection removal, surrogacy, or adoption (Cole, 2012). People in these circumstances may also be searching for information about lactation management, but some of their choices around suppression, expression, or donation may be constrained due to circumstances out of their control (Sweeney et al., 2020). Other equity issues, including the current lack of availability of human milk banks, must also be considered to ensure people are informed of the limitations of particular options applicable to their unique contexts and circumstances.

Public health guidance materials, including the Lactation AID Framework, are often limited by the extant body of evidence available on particular health problems, practices, or interventions (Payne et al., 2011), and the marginal input provided by the patients or service users (Selva et al., 2017). Despite drawing on international resources and research, the Lactation AID Framework was developed at a time when scholars have only recently recognized and begun to address the sensitive and somewhat vexed issue of lactation after infant death (Oreg, 2019). To date, there has been little research conducted on the issue. This Framework, developed within Australia, has been informed by predominantly Anglophone and western cultural resources and research, and thus exhibits a cultural bias in the fields of parenthood, lactation and milk donation, grief, and bereavement. In addition, there is a lack of evidence elicited directly from key potential users of the Framework (including health organizations and bereaved families) to help us understand what is required to best meet their needs and when, how, and by whom this information is best presented. The Framework necessarily needs adapting by stakeholders to suit local policy and custom and to reflect the diverse lactation, milk donation, and bereavement services and practices across the world.

In line with best practice standards that guide the development of health guidelines and OHI (Moult et al., 2004; Schünemann et al., 2014) further scholarly debate and discussion of the Lactation AID Framework is welcomed, particularly from outside western and Anglophone cultural practice. This will allow the Framework to be strengthened as the evidence base for lactation after infant death is advanced over time. Until this body of evidence is developed, the current Lactation AID Framework offers a useful and evidence-based guide for health organizations interested in providing OHI that meets the needs of bereaved parents.

Conclusion

Improving the quality of written information available to parents in anticipation of, and/or subsequent to, infant death is imperative (Carroll & Lenne, 2019). The Lactation AID Framework contributes to pursuing this goal by designating 25 OHI criteria to assist health organizations in providing comprehensive information to bereaved families so they can better understand and manage lactation and optimize their health and wellbeing. It is our sincere hope that this paper provokes further scholarly contributions from the international lactation and bereavement field, and

that relevant health organizations will give due consideration to the guidance provided by the Lactation AID Framework.

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