

Transnational Visual Activism For Women's Reproductive Rights: My Body, My Choice

Edited by Basia Sliwinska

First published 2025

ISBN: 978-1-032-53353-7 (hbk)

ISBN: 978-1-032-53356-8 (pbk)

ISBN: 978-1-003-41164-2 (ebk)

Chapter 2

Soft Advocacy: Using Textile Art to Enhance Lactation Care After Infant Loss

(CC-BY-NC-ND 4.0)

DOI: 10.4324/9781003411642-3

The funder for this chapter is Australian Research Council

2

SOFT ADVOCACY

Using Textile Art to Enhance Lactation Care After Infant Loss

*Rebecca Mayo, Lucy Irvine, Katherine Carroll,
and Debbie Noble-Carr*

Introduction

This chapter argues that care is a form of activism and a force for change. It traces how care ethics and practice were employed through the ideation, creation, and use of the *Lactation After Loss Commemorative Quilt* (hereafter ‘the quilt’) that mobilised findings from an Australian Research Council Study on Lactation After Infant Death.¹ The quilt was a collaboration between practitioner-sociologists and artist-researchers at the Australian National University. Designed to generate conversations with and between healthcare workers about reproductive healthcare, specifically lactation care following infant death, it presents mothers’ responses to experiencing lactation after loss, as recounted to researchers. The double-sided quilt is 110 × 144 cm. The mothers’ voices are mordant screenprinted onto silk, hemp, cotton, and linen pieces. Plant dye and breastmilk modify the colour and intensity of the text and its underlying fabric, creating a patchwork of colour and texture from soft apricots to pink, green, and brown hues. Discourse about lactation choices afforded to parents following the death of their baby has, until this research, been largely overlooked in Australia, and few health professionals or families are aware of the range of suppression, expression, or donation options that may be available following infant death (Noble-Carr et al. 2021). Using breastmilk² in the making of the quilt made visible the significance of breastmilk and lactation choices in bereaved parents’ care and meaning-making after stillbirth and infant death, generating tailored clinician-led practice and policy change in their institutions. Lactation decisions and practices play a crucial role in women’s reproductive autonomy during the fourth trimester, defined as the 3-month period following birth (Matambanadzo 2014: 117). This chapter’s discussion of our research and the decision to make a quilt is informed by Joan Tronto’s conceptualisation of care (2013: 22–23). The quilt embodies a care-based methodology that we understand as a ‘soft advocacy’ that is politically feminist and non-hierarchical. We also draw from Karen Barad’s approach to knowledge creation and meaning-making, where we follow ‘intra-actions’ between humans and matter in the quilt’s production and during workshops with healthcare professionals, to understand

how the quilt works. The term ‘intra-action’ is used by Barad to refer to the actions taking place between entities of matter. Rather than agency being held by one to be exercised over another, she sees agency as something produced dynamically and through relations. This is implicit in Barad’s diffractive methodology, which replaces hierarchical methods of pitching theories and ideas against each other with a dialogical approach where texts and traditions are read ‘through one another’ (Barad 2007: 30; Geerts and Tuin 2021: 173). Our collaboration, including writing this chapter, is infused with ‘intra-actions,’ where objects, apparatus, and operators cannot be objectively separated from the production of agency, and where diffraction takes place across matter and text. Furthermore, critical textile analysis of quilting, stitching, and dyeing expands how we examine the ‘soft advocacy’ of the quilt in terms of its powerful, emotive, and political effect by virtue of the materials and methodologies employed in its making.

Throughout our quilt-making we have endeavoured to work with and through an ethic of care, including how we collaborated as a group of women scholars, each of whom has significant caring responsibilities outside her academic position. As such, this careful approach, embedded in listening and slowing down to step in time with our thinking and making, ‘represents both a commitment to good scholarship and a feminist politics of resistance to the accelerated timelines of the neoliberal university’ (Mountz et al. 2015: 1238). To structure this argument, we use Tronto’s five phases of care to map the quilt’s production. These phases explain care as a process which begins with *identifying a need for care*, followed by *beginning to care* about something or someone, prompting the *provision of care*. The sticky ethical space is found here, between care giver and receiver, because the *reception of care* is not always as the giver may have hoped. Lastly is the *reflection on care*’s relational contribution to ‘justice, equality and freedom for all’ (Tronto 2013: 23). While, in practice, these phases of care are not discrete or necessarily linear, we use them to structure this chapter to show how care can be a form of activism and that the process of creating the quilt produced a politically charged textile which belies its soft colours and gentle stitching (Figure 2.1).

Phase One: Identifying a Need

Tronto’s first phase is where a need for care is identified. The initial research demonstrated this need, and led to identifying the nuanced care required for health practitioners to engage productively with research findings while reflecting on their own practices to improve hospital-based lactation care for bereaved families. In response to these entwined needs, the idea to create a quilt was born. Through interviews conducted with 114 health professionals and 24 bereaved parents (17 mothers and 7 partners), we found that experiences of lactation after loss were highly variable (Waldby et al. 2023). *If* lactation care was provided to bereaved families, it was limited to brief encounters and aimed at facilitating lactation suppression (Noble-Carr 2021). Further, we found that bereaved parents’ lactation experiences and grief can be mediated through offering informed choice and control over lactation and breast care practices (Waldby et al. 2023). For some parents in the study, expressing and donating their milk following the death of their infant was an important component of grieving and meaning-making. Others fed their surviving twin while grieving the loss of the sibling, and some found comfort and relief in immediate pharmaceutical lactation suppression. Most bereaved mothers spoke of wanting to use



FIGURE 2.1 Lucy Irvine and Rebecca Mayo in collaboration with Katherine Carroll and Debbie Noble-Carr, Lactation After Loss Commemorative Quilt, side two 110 × 144 cm. Plant dye (*Hardenbergia violacea*, *Salvia rosmarinus*, *Lavandula augustifolia*, *Eucalyptus mannifera*, *Prunus cerasifera*), breast milk, iron, copper and alum mordants, cotton, hemp, linen, silk.

Photo credit: Brenton McGeachie

their expressed milk purposefully. As applied researchers, Katherine and Debbie brought long-standing collaborative modes of research-based engagement and capacity building practice within the health and community service sectors. This has, at its core, a praxis of *caring about* how to generate and disseminate research findings to bring about effective change in practices and policy. Thus, it is fitting that we made a connection between the patchwork of a quilt and the visualisation of the diverse, complex, and often ambiguous nature of bereaved parents' lactation experiences, and their variable expressions of agency with lactation and breastmilk during grief.

Quilts have a long-standing history as a slow, handmade form that communicates shelter, warmth, and care while recording women and marginalised people's lives and creative expression on their own terms, without the filtering that often occurs for a public audience. Emboldened by this soft quality of interpersonal and intersubjective intimacy, quilt-makers have also used their work to agitate for change by strategically taking domestic and intimate practices of caregiving into public space. For example, the Aids Quilt, conceived in 1985, remembers the lives of nearly 110,000 people who died because of the AIDS pandemic through naming them on its panels.³ Bringing their names into public space and celebrating their lives through the intimate form of quilting pressured government to fund research into cures, therapies, and preventative medicines. The power of quilt-making and the use of quilts as art-driven activism are non-hierarchical in political and epistemological intent. Knowledge is collectively made, generated through the assembly of meaningful pieces, evoking the presence of absent bodies and voices in its form.

In phase one, we identified the need to enable health professionals to gather and discuss, without judgement, ways to improve upon quality and safety so that the research could be heard in conjunction with health professionals' rich frontline experience in delivering reproductive healthcare (Pedersen and Mesman 2021). This mode of engagement enabled our research to catalyse change in the delivery and reception of care across structural, practice, and policy levels. In Baradian terms, the quilt enables a diffractive methodology in the workshops, by focusing on both the attending health professionals' experiences and those of the bereaved parent's experiences as a starting point from which to affirm and build, what Barad (2014: 187) terms as fresh 'patterns of understanding-becoming.' By holding space for health professionals to see, hear, and feel their own and the bereaved parents' diverse lactation experiences and practices, we hoped for fruitful discussion for improving individual and collective practices tailored to the specific institutions of attending professionals.

Phase Two: Taking Responsibility

Katherine and Debbie invited Lucy and Rebecca to think together and explore the possibility and potential of creating a quilt together, thus commencing Tronto's second phase of care: 'assuming some responsibility for the identified need' (2015: 106). For Tronto (Ibid), '(t)aking care of involves notions of agency and responsibility in the caring process.' In this new collaboration, the four women undertook complementary and supportive roles in the development of the design and form of the quilt. The artist researchers and the sociologists resisted the pressures of academic timelines and instead took the time required to build genuine and trusting relationships. A shared care-full purpose amongst the team grew from a commitment and responsibility towards the interviewees, their

individual experiences, and to the broader research findings. This included the truncation of maternal subjectivities promulgated through the lack of discourse surrounding lactation practices and care available to bereaved families (Sweeney et al. 2020). Our common goal to respect the experiences of bereaved mothers, while providing health professionals with a way to action the delivery of comprehensive lactation care following infant death, underpinned our approach. Our collaboration, through an ethics of care and sense of broader purpose, went far beyond using art practice to illustrate academic findings.

Lactation and breastmilk harbour immense symbolism in mourning and meaning-making. Yet only when breastmilk is visible, from leaking breasts or stored in a hospital freezer, are health professionals prompted to attend to bereaved mothers' lactation care (Noble-Carr et al. 2022). The powerful potential of breastmilk led us to include it in the materiality of the quilt. Thus, the milk itself (like the plants, sociologists, researchers, and parent data) became another agent and agitator for recognising the support required for bereaved parents in the fourth trimester. To do this we needed to test if it would modify colour in natural dyeing.

The process of procuring breastmilk for the purposes of textile art quickly positioned it as 'matter out of place' by University protocols (Douglas 1966). Douglas implies that 'a set of ordered relations and a contravention of that order' (Ibid: 44), renders something dirty. This is a relative term, as matter may be dirty or clean, depending on context and situation. Initially we planned and obtained ethics approval to receive donated breastmilk from local women. However, the University's Work Health and Safety (WHS) regulations and compliance requirements for the safe handling of human tissue required us to use serologically screened and pasteurised breastmilk. This milk could only be sourced from a human milk bank. Careful negotiation and a second human research ethics committee review from the human milk bank, managed by Red Cross Life Blood Australia, resulted in Life Blood generously providing donor milk which had failed their stringent testing requirements and therefore could not be fed to babies. Despite screening and pasteurisation of donated milk, University WHS policies required full personal protective equipment while handling the milk in our Dye Lab. Elsewhere on campus, childcare workers feed babies expressed, unscreened breastmilk in a setting where breastmilk is understood to be a highly valued normal food for infants in their care. Meanwhile, Katherine was applying to the Australian Breastfeeding Association to accredit the University as a Breastfeeding Friendly Workplace. While a considered analysis of societal taboos, slippage of institutional definitions, and navigation of risk in relation to breastmilk are outside the scope of this chapter, these concurrent stories made us acutely aware of the complex position lactation and breastmilk hold, reflecting how women's bodies are socially supported, marginalised, and policed. These insights and experiences established and informed our novel iterative and care-full method of collaboration, in which transdisciplinary knowledge co-production built awareness of 'interdependency as the ontological state in which humans and countless other beings unavoidably live' (Staffa et al. 2022). For us, this translated to a growing understanding of where and when the politics of breastmilk embody states of visibility and invisibility in fourth trimester care for mothers and infants alike.

Our decision to work with breastmilk in the quilt's fabric was prompted by two things: firstly, our desire to foreground the value of human milk and lactation, especially its significance to parents as they grieve their infant's death; and secondly, we hypothesised that the protein in human milk, like buffalo and soy milk, would work to modify

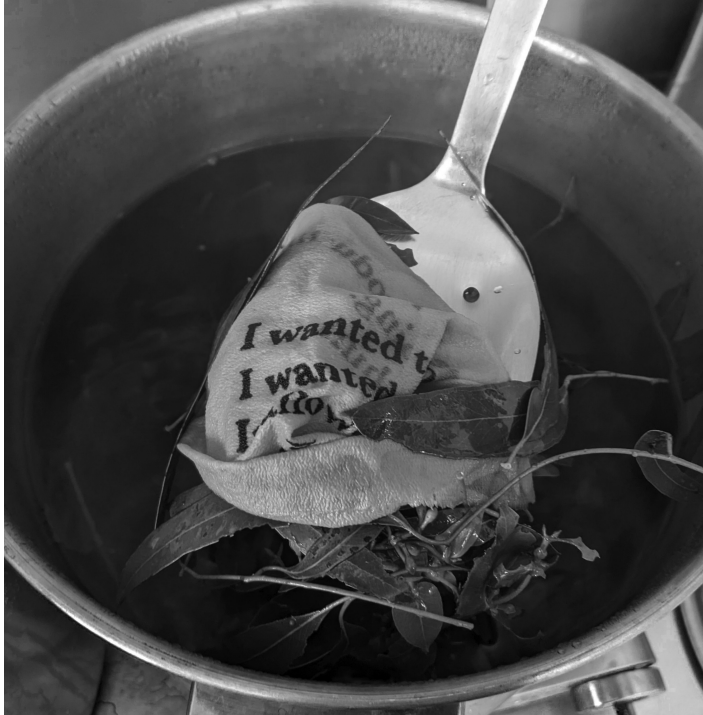


FIGURE 2.2 Dyeing printed fabric with *Eucalyptus mannifera*.

Photo credit: Lucy Irvine

and enhance plant colour in natural dyeing (Sardar 2003; Miller 2020). We found that breastmilk enhances and strengthens the colour of the plant dye in cloth. In an act of reciprocity, plant colour reveals the staining and presence of the breastmilk. Together, they enhance each other. To work with plant colour is to embrace ever-changing variability: dye colours shift between plants, even of the same species, from one season to the next, depending on rainfall and climate and from the duration of heating and steeping in the dye bath (Figure 2.2).

The material language of plant dye, in its range and nuance, echoes the variability of bereaved parents' experience. Combined with breastmilk, the variability of plant colour is further enhanced, their intra-actions 'emerg[ing] through and as part of their entangled intra-relating' (Barad 2007: ix). This becomes a material expression of the complex grief and uncertainty surrounding infant death, which, as this research shows, requires health-care professionals to listen to and provide clear choices to bereaved parents (Noble-Carr et al. 2023). The false assumption that suppressing milk is best practice is challenged by the presence of breastmilk in the quilt's fabric. Its stains and marks raise questions about 'matter out of place' (Douglas 1966) and aim to encourage reflection on the policing of women's reproductive rights, including when and where it is acceptable to lactate and express milk, and for whom. By incorporating breastmilk in this unexpected way, we

seek to gently and quietly politicise the shortcomings of lactation care after infant death in Australian reproductive healthcare practices.

Phase Three: Nurturant/Nonnurturant Care-Giving

Tronto's third phase of care, which comprises the physical labour of caregiving, was enacted by making a cot-sized quilt, designed to signify and acknowledge the warmth, love, and comfort central to the health professionals' and bereaved parents' experiences. We also reflect on Mignon Duffy's distinction between nurturant and nonnurturant care to theorise our labour of quilt-making as straddling and recontextualising nurturant and nonnurturant care. Nurturant care, Duffy proposes, 'includes labor that is inherently relational, that is, the core labor of nurturant care workers ... involves intimate and face-to-face relationships with the people they are caring for' (Duffy 2011: 6). She defines nonnurturant care as labour that facilitates nurturant care, such as hospital orderlies. Duffy uses the distinction between nurturant and nonnurturant to map the gendered and racialised histories of care work in and out of the home (Duffy 2011: 113). As artist/researchers we are certainly not performing what Duffy calls 'the dirty work' and, as we discuss in the fourth phase of this chapter, our labour embedded in the quilt is highly visible to workshop participants. Furthermore, our skill and expertise are discussed and admired. If we are not providing face-to-face care directly to another person then it follows that the care we provide is nonnurturant. But if we are to embrace the power of the bereaved parent's words, to hold space for their voices and to pay attention to the value and potential of breastmilk beyond a foodstuff, then our process of working with the elements of the quilt is relational, and therefore also nurturant. Furthermore, the making of the quilt cannot be divorced from the purpose for which it is made: the highly relational and frontline care act of facilitating health professionals' dialogue with each other about lactation care after loss. This is a highly relational setting, amongst researchers, health professionals, the quilt, and the voices of mothers held by the quilt.

By inhabiting this active space between and through both nurturant and nonnurturant care, we bring to life Fisher and Tronto's expansive yet precise definition of care:

On the most general level, we suggest that caring be viewed as a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves and our environment, all of which we seek to interweave in a complex, life-sustaining web.

(Fisher and Tronto 1991: 40)

Through the caregiving embodied in the making of the quilt, we have practised nurturant and nonnurturant care as we paid attention to and took responsibility for the larger life-sustaining webs of care we were working with. Barad demonstrates what we can learn by paying attention to the spaces and moments where matter becomes entangled and in doing so yields new context and meaning (Barad 2007). Likewise, we took time to attune ourselves to the nonnurturant care and agency produced between specific intra-actions where milk-soaked cloth, text and plant colour coalesce and matter. Barad

describes the focus on ‘specific intra-actions’ as ‘enacting agential cuts’ in which ‘entities are co-constituted as determinately distinct, bounded and propertied.’ Unlike Cartesian cuts, which presuppose ‘an already distinct and discrete ontological subject and object,’ an agential cut forms a way through complex entanglements of matter and entity. In this move, there is a sense of ‘cutting together/apart’ without falling back on assumed or pre-existing relations (Murriss and Bozalek 2022). At each stage of the process we have paused and reflected on how these materials and processes interact and intra-act with us and each other, allowing us to witness and understand the ways meaning and agency are produced through the quilt-making processes. By embedding colour and breastmilk with the voices of bereaved parents within the silk, linen, cotton, and hemp patches we materialised these human voices in text form, quietly positioning them for their work as advocates and change makers. Our more-than-human collaborators worked with us, in the studio and as politicised matter, to effectively produce and influence the shape and form of the quilt.

This third phase of caregiving involved carefully using excerpts from the bereaved parent interviews in ways that communicated their experiences and emotions directly (Figure 2.3). Lucy and Rebecca’s initial design incorporated some of these excerpts. Their haphazard yet overwhelming presentation prompted Debbie to revisit the selected quotes and reorder them in relation to each other. To do this, Debbie printed the quotes onto

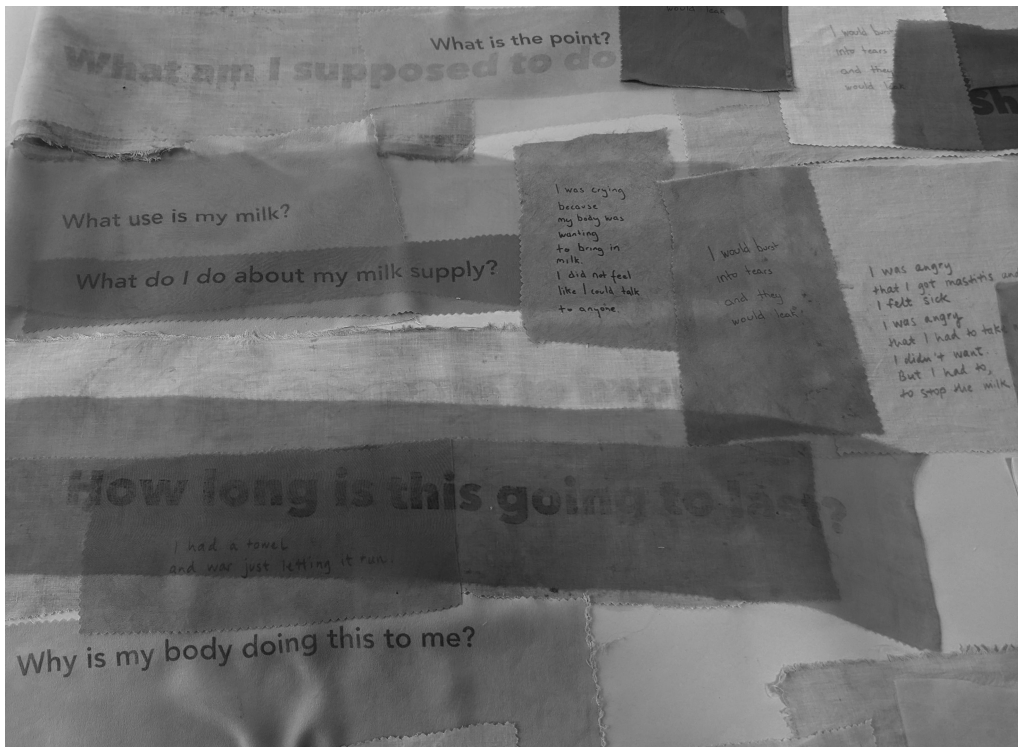


FIGURE 2.3 Grouping and arranging the printed and dyed fabric pieces during construction. Photo credit: Lucy Irvine

paper and cut them up, so that each quote sat on its own sliver of paper. This allowed her to move the pieces of paper around, visualising how they worked in different groupings and arrangements. Not yet producing a quilt, Debbie's approach nevertheless mimicked a free-form approach to quilting, where pieced fragments allowed her to see how these words worked together and in context. Debbie's process recalls American literary critic Elaine Showalter's argument that quilting practices are a way of understanding feminist writing, in particular the short story. She suggests 'that a knowledge of piecing, the technique of assembling fragments into an intricate and ingenious design, can provide the contexts in which we can interpret and understand the forms, meanings, and narrative traditions of American women's writing'(Showalter 2016: 160). Where Showalter uses American quilting to interpret women's writing practices, we push this connection in a different direction, showing how text fragments can be the fabric of the quilt, arranged and eventually stitched together, side by side, above and below, in concert not competition.

As Debbie's reorganisation of the chosen text more fully represented the range of experience and choice, we began to consider how different typographic approaches could convey the words and new subcategories that had emerged. We began with large bold lettering for the immediate questions bereaved mothers asked, such as, 'what is wrong with me?'. These questions, often unspoken or unanswered, gently welcome the healthcare professionals and their important role, inviting them to commence taking responsibility to care for bereaved mothers' lactation experience. As the text became more personal, we moved to smaller printed text and handwriting. Embedding the written word into the cloth, produced piecework where women's voices merged with breastmilk, conflating and complicating the sorrow and healing captured in the quilt.

Debbie grouped the quotes into questions, initial feelings and responses, and expressions of the choices and conversations the bereaved parents wished they'd had. This led us to create a quilt with two sides, rather than the traditional 'top' and backing (Figure 2.1 and 2.4). By creating two sides with differing piecework we began to discuss how the quilt's design would establish the structure and flow of the workshops. Both sides are equally important, generating powerful inter- and intra-actions between workshop participants and the quilted elements. The layers of a quilt, including the 'fill,' can be visualised as a fabric sandwich (Witzling 2009: 632). These layers are held together either by continuous stitching (quilting) or by single or groups of stitches at regular intervals across the surface of the quilt (tying or knotting). The quilt was constructed by quilting each 'top' to a backing, after which we sandwiched the two sides, tying them together with small cross-stitches across the surface of the quilt. Working in this way allowed us to build each side on its own terms.

The relation between time and labour, manifest in the piecework of quilting, a job that can be picked up and put down, connect closely to the temporal phases of grief and to the rhythm of expressing milk. For many of the mothers and partners in the study expressing milk to donate gave them purpose and structure as they grieved. Like all care-work, grief is never done, but with time it takes new form. Our process of printing the text onto cloth, dyeing the cloth with locally collected plants, assembling and reassembling the pieces of cloth, and finally stitching them together attended to the iterative transformation present in grief, care-giving, and lactation.



FIGURE 2.4 Lucy Irvine and Rebecca Mayo in collaboration with Katherine Carroll and Debbie Noble-Carr. Lactation After Loss Commemorative Quilt, side one 110 × 144 cm. Plant dye (*Hardenbergia violacea*, *Salvia rosmarinus*, *Lavandula angustifolia*, *Eucalyptus mannifera*, *Prunus cerasifera*), breast milk, iron, copper and alum mordants, cotton, hemp, linen, silk.

Photo credit: Brenton McGeachie

Phase Four: Care Receiving—The Evaluation of How Well the Care Met the Caring Needs

The fourth phase of care took place in seven pilot workshops, which ran across diverse hospital- and community-based healthcare institutions, charitable foundations, and tertiary educational settings in Australia. Participants included midwives, lactation consultants, maternal and child health nurses, neonatal intensive care clinicians, bereavement counsellors, peer support workers, and parent advocates. The workshop format was designed to facilitate deep participation at a local level using a complexity approach to thinking, behaviour, and practice change that honours visceral connection and experiential learning (Burns et al. 2021). Such an approach centres ownership and discussion amongst the care providers in the context of their workplace, so participants can tailor solutions within the constraints and possibilities of each institutional setting (Burns et al. 2021). Care is thus not only embodied in the quilt, but also the caring design of the

workshop itself, and in careful facilitation where participants' experiential and embodied knowledge, including their own personal and professional losses, are honoured. In examining how well the care embedded in the quilt and in workshop facilitation was received by participants, we draw on Barad's notions of diffraction and the agential cut to show how the quilt enabled a 'form of affirmative engagement' between workshop participants (Murriss 2021: 140). Diffraction, unlike critique, does not position different approaches in opposition, or offer an explicit or foretold solution. Rather, a diffractive methodology approaches texts or situations with care and attention, and with the aim of producing new ways of approaching or understanding a situation or set of conditions. By articulating their work practices and experiences, in concert and response to the parents' voices via the quilt, the healthcare workers undertook a process of becoming with the voices and materialities of the quilt. This allowed them to discuss lactation after loss frankly and openly in the context of the possibilities and limitations of their workplace.

The workshop format followed a considered structure that was iteratively refined after each pilot workshop to make changes based on feedback and discussion. The labour of the workshop begins well before setting foot in the institution through conversation with lead representatives from each cohort. Conversations include the content and purpose of the workshop, content warnings, suitable space and equipment, support structures, and the intentional limit of eight participants per workshop. Lastly, we share invitations for participants, explaining how bereavement and loss will be covered, enabling individuals to make an informed choice to attend.

The workshop facilitator begins with an Acknowledgement of Country,⁴ followed by an introduction to the topic including information about bereavement support.⁵ The purpose and context of the research are introduced to the group. We share a short 90-second video of the processes of printing, dyeing, and sewing. Soft music rather than voiceover accompanies this footage. This interlude creates a reflective silence in which the 'expert' academic is decentred. After laying the quilt on a tabletop, with the landscape formatted side facing up (side one), the facilitator symbolically and actively steps back giving the bereaved parents' voices centre stage. While placing the quilt, the facilitator explains that this side represents mothers' initial thoughts, feelings, and meanings regarding their lactation or breastmilk in the hours and days that follow the loss of an infant. Participants are invited to gather around, touch and handle the quilt, and read the printed words. To alleviate the chaotic and overwhelming nature of the experience presented in the quilt, and to better facilitate group viewing, side one is designed so participants can stand on either long edge of the quilt and read the right way up. To read the other half of this side, participants need to move around the table. This is usually a time of quiet, where participants may point things out to each other, some people may cry, and gradually quiet conversations or comments begin to emerge from the group. This side holds the large printed universal questions 'Why did this have to happen?' and 'What is wrong with me?', interspersed by the smaller printed and handwritten text which provides more detail and context of the immediate feelings and memories of their baby, their loss, and their lactation experiences: 'I think I was in shock'; 'I was exhausted'; 'Your body is crying out for a baby that is not there'; 'Suppressing it felt wrong, it was like severing yourself from something you didn't want to be severed from.'

Discussion emerging from the group can range from observations of the quilt techniques (there are often quilters in the group), pointing out milky stains in the fabric, and

firsthand anecdotes or thoughts prompted by the words (and their juxtaposition to each other). After reading and empathising with the mothers' experiences, participant discussion transitions to 'identifying a need' to respond to the questions. They begin to wonder out loud what their role, as healthcare professionals, is in answering questions, or in assisting mothers to make sense of the feelings and potential meaning-making they were reaching for. After about 10–15 minutes the facilitator turns the quilt over to side two. This side is portrait format, and the participants are brought together at the base of the quilt (as if at the foot of a bed). This side is more ordered and spaced than the first. Here the voices of the parents articulate what they did with their lactation decision making and breastmilk, or what they wanted to do had they been offered the choice, or what they wished for in hindsight. The healthcare workers read and hear words like: 'This is something you should get to control. To be asked, 'What would you like to do?' You should get a choice'; 'I couldn't just collapse down into myself. Expressing and donating the milk was keeping me up. It was my good thing saying: You can do this. It helped a lot.' This side positions the health professionals' own care work in direct dialogue with the full range of options they can present to parents to ensure comprehensive lactation care is provided. Making these possibilities and strategies available, we see the quilt actioning and providing the most care to both the healthcare workers *and* the bereaved parents.

In the workshop, the quilt facilitates discussion as it orients the parents and their experiences as present and central. This ethical and care-informed presence respects evidence that patient perspectives are critical to informing perinatal bereavement and healthcare practice improvements (Rice et al. 2019; Heazell 2022) without placing the burden on bereaved families to re-tell their story or advocate directly. For Sara Ahmed, orientations matter, and in turn, matter is 'affected by orientations' and by our proximity to matter (Ahmed 2020: 234). Our considered decision to place the quilt on the horizontal plane on a table, around which the workshop participants can gather, is a choice in orientation, and according to Ahmed to be 'oriented in a certain way is how certain things come to be significant' (2020: 235). This further secures the non-hierarchical structure built by the form and construction of the quilt, where voices sit side by side, the stitched pieces holding, supporting, and giving each other space. Rachel Blau duPlessis describes a pure form of women's writing to be 'breaking hierarchical structures, making an even display of elements over the surface with no climactic place or moment, having the materials arranged into many centres' (Showalter 2016: 160). Similarly, the quilt arranges and stitches together bereaved parents' voices to represent their unique and variable experiences, so workshop participants can listen to each experience in its complexity. This patchwork of story fragments articulates the need for parents' to be presented with information and the time and space to consider the range of options available to them.

A non-hierarchical approach, grounded in a need to deliver the most effective care with the best outcomes for healthcare professionals and bereaved parents, is enabled by the quilt. Rather than the academic researcher standing at the front of a group delivering didactic recommendations they place themselves in the background: the quilt is the starting and focal point of the workshop. In addition to the academic taking a position at the back or to the side, their background position has a 'temporal dimension' (Ahmed 2020: 240). That is, they are available to tell the story of the quilt and the research and to answer questions as they arise. If the academic chooses to prompt or facilitate the

conversation in a particular direction, their background orientation allows them to do so with a sense of curiosity and affirmation without the risk of closing or limiting discussion.

In the intimacy of the workshops, milky matter is brought *into place* through its presence in the fabric of the quilt, and its important role as plant colour modifier. As we described earlier, the milk was repeatedly out of place, its non-conventional use in textile practice pushing it further from the bodies who produced it in the first place. But here, in the workshops with healthcare professionals, the milk is oriented beside, within and behind the parents' voices. This central position communicates its value and purpose, reshaped by its potential to make meaning through the grief and loss. This includes how, for some women, milk production is an affirmation that their bodies do know what to do.

The matter of the quilt, its embedded milk, plant colour, parent voices and the hours of printing, dyeing, stitching and quilting held in its fabric, ensures that throughout the workshop and the discussion the parents and their experiences are present. The agency produced between quilt, parents' voices, and workshop participants enables fruitful, respectful conversations to take place. Ideas that change is too hard, workers are too busy, and processes are set in stone are put to one side as the participants actively discuss their experiences, concerns, and ideas for change.

Phase Five (Conclusion): Understanding Relations of Care

In her fifth and final phase of care, Tronto suggests we need not only to evaluate the reception of the provision of care, but also to understand the ways in which these relations of care operate and play out. In sum, this chapter has been a continuation of our rich and fruitful discussion and collaboration. The writing process has enabled us to revisit each stage of our collaboration and to examine the important work the quilt is now doing. Using Tronto's logic and our hindsight we have unpicked, remembered, and reconnected with our careful process. Through this we have drawn new understandings and insights into our care-laden, responsive, and continuing collaboration. Barad's diffractive methodology provided further structure through which to concentrate our attention towards and amongst what mattered. Drawing on the meaning-making potential of breastmilk, evidenced in Debbie and Katherine's research, we resisted institutional pressures, instead taking necessary time and space for the complexity of this important area of reproductive healthcare to become visible, tangible, and felt through the fabric and matter of the quilt. Parent choices and experiences, lactation care and milk, healthcare professionals and their important work, infant death, grief and healing come together in the quilt, softly showing the complexity of this often unspoken yet common human experience.

To date, the quilt has been used in a series of pilot workshops with healthcare and bereavement services on the eastern seaboard of Australia. The reception of the quilt in the workshops has been overwhelmingly positive. Our observations and the participant feedback demonstrate the quilt workshops have productively and supportively opened dialogue for improved care, between healthcare and bereavement professionals and volunteers from a wide range of institutional and healthcare settings. The trust built through the making of the quilt, and the nurturant and nonnurturant care we employed, plays out in the workshops. Our material and care-based approach of 'soft-advocacy' is a model of research-based and practice-led activism which continues to inform our work. Tailored

to different healthcare and bereavement settings and to the highly variable experiences and complex needs of families as they navigate unbearable loss, these workshops and the changes they will bring are long overdue. The quiet activism of the Lactation After Loss Commemorative Quilt has the potential to enact real change in reproductive healthcare in Australia. Gently and softly, the quilt enables women's voices to be heard and responded to. Offering choice in lactation care during and beyond the fourth trimester is essential to mothers, regardless of whether their baby survives birth or infancy. In the workshops, the quilt has taken on a momentum of its own, decentring experts and dissolving hierarchies as it brings milk and mothers together in the present, offering new ways to enact justice in reproductive healthcare.

Notes

- 1 Australian Research Council Discovery Project 2018-2023. DP18100517. 'Lactation After Loss in Contemporary Motherhood and Health Care Delivery'. Chief Investigators K Carroll & C Waldby.
- 2 Serologically screened and pasteurised breastmilk that could not be used to feed babies was provided by Red Cross Lifeblood with the consent of milk donors, none of whom were donating following infant death.
- 3 <https://www.aidsmemorial.org/interactive-aids-quilt>.
- 4 An Acknowledgement of Country is an opportunity for anyone to show respect for Traditional Owners and the continuing connection of Aboriginal and Torres Strait Islander peoples to Country (*Acknowledgement of Country and Welcome to Country*, 2023).
- 5 24/7 Red Nose Bereavement Support Line.

References

- Acknowledgement of Country and Welcome to Country*. 2023. *Reconciliation Australia*. Available at: <https://www.reconciliation.org.au/reconciliation/acknowledgement-of-country-and-welcome-to-country/> (Accessed: 10 November 2023).
- Ahmed, S. 2020. 'Orientations matter', in *New materialisms*. New York, NY: Duke University Press, 234–257. Available at: <https://doi.org/10.1515/9780822392996-013>.
- Barad, K. 2007. *Meeting the universe halfway: Quantum physics and the entanglement of matter and meaning*. 1st edn. Durham, NC: Duke University Press. Available at: <https://doi.org/10.1515/9780822388128>.
- Barad, K. (2014). Diffracting Diffraction: Cutting Together-Apart. *Parallax*, 20(3), 168–187. <https://doi-org.virtual.anu.edu.au/10.1080/13534645.2014.927623>
- Burns, D., Howard, J. and Ospina, S.M. 2021. 'Challenges in the practice of participatory research and Inquiry', in *The SAGE handbook of participatory research and inquiry*. 55 City Road: SAGE Publications Ltd. Available at: <https://doi.org/10.4135/9781529769432.n2>.
- Douglas, M. 1966. *Purity and danger: An analysis of concepts of pollution and taboo*. London: Routledge & Kegan Paul.
- Duffy, M. 2011. *Making care count a century of gender, race, and paid care work*. New Brunswick, NJ: Rutgers University Press. Available at: <https://doi.org/10.36019/9780813550770>.
- Fisher, B. and Tronto, J.C. 1991. 'Toward a feminist theory of care', in *Circles of care: Work and identity in women's lives*. Albany, NY: State University of New York Press.
- Geerts, E. and Tuin, I. van der. 2021. 'Almanac: Diffraction & reading diffractively'. *Matter: Journal of New Materialist Research*, 3, 173–177. Available at: <https://doi.org/10.1344/jnmr.v2i1.33380>.
- Matambanadzo, S.M. (2014) 'The fourth trimester', *U. Mich. JL Reform*, 48,
- Hezell, A.E. 2022. 'Managing stillbirth: Taking care to investigate the cause and provide care for bereaved families'. *Journal of Perinatal Medicine*, 50(6), 642–644. Available at: <https://doi.org/10.1515/jpm-2022-0271>.

- Miller, K.I. 2020. *Art Quilt Collector #1 (SAQA Publication) by SAQA - Issuu*. Available at: https://issuu.com/saqaart/docs/saqa_aqc-1 (Accessed: 13 December 2023).
- Mountz, A., Bonds, A., Mansfield, B., Loyd, J., Hyndman, J., Walton-Roberts, M., ... Curran, W. (2015). For Slow Scholarship: A Feminist Politics of Resistance through Collective Action in the Neoliberal University. *ACME: An International Journal for Critical Geographies*, 14(4), 1235–1259. <https://doi.org/10.14288/acme.v14i4.1058>
- Murris, K. 2021. *A glossary for doing postqualitative, new materialist and critical posthumanist research across disciplines*. 1st edn. United Kingdom: Taylor & Francis (Postqualitative, New Materialist and Critical Posthumanist Research). Available at: <https://doi.org/10.4324/9781003041153>.
- Murris, K. and Bozalek, V. 2022. *In conversation with Karen Barad: Doings of agential realism*. Milton, United Kingdom: Taylor & Francis Group. Available at: <http://ebookcentral.proquest.com/lib/anu/detail.action?docID=7121455> (Accessed: 10 November 2023).
- Noble-Carr, D, Carroll, K & Waldby, C 2021, 'Mapping Hospital-Based Lactation Care Provided to Bereaved Mothers: A Basis for Quality Improvement', *Breastfeeding Medicine*, 16(10), pp. 779–789.
- Noble-Carr, D. et al. 2022. "It was a shared duty": Bereaved fathers' perspectives, experiences and practices in relation to their partner's lactation after infant death'. *Breastfeeding Review*, 30(1), 7–17.
- Noble-Carr, D. et al. 2023. 'Providing lactation care following stillbirth, neonatal and infant death: Learning from bereaved Parents'. *Breastfeeding Medicine*, 18(4), 254–264. Available at: <https://doi.org/10.1089/bfm.2022.0242>.
- Pedersen, K. Z., & Mesman, J. (2021). A transactional approach to patient safety: Understanding safe care as a collaborative accomplishment. *Journal of Interprofessional Care*, 35(4), 503–513. <https://doi.org/10.1080/13561820.2021.1874317>
- Rice, R. et al. 2019. 'Parents and clinicians: Partners in perinatal bereavement research –experiences from the international stillbirth alliance conference 2017'. *Research Involvement and Engagement*, 5(1), 4. Available at: <https://doi.org/10.1186/s40900-018-0137-8>.
- Sardar, M. 2003. *Indian Textiles: Trade and Production | Essay | The Metropolitan Museum of Art | Heilbrunn Timeline of Art History, The Met's Heilbrunn Timeline of Art History*. Available at: https://www.metmuseum.org/toah/hd/intx/hd_intx.htm (Accessed: 12 December 2023).
- Showalter, E. 2016. 'Piecing and writing', in J. Hemmings. ed. *The textile reader*. London: New York: Bloomsbury Publishing Plc, 157–170.
- Staffa, R.K., Riechers, M. and Martín-López, B. 2022. 'A feminist ethos for caring knowledge production in transdisciplinary sustainability science'. *Sustainability Science*, 17(1), 45–63. Available at: <https://doi.org/10.1007/s11625-021-01064-0>.
- Sweeney, L. et al. 2020. 'Lactation after infant death: An Analysis of Australian healthcare agencies' online health information'. *Health Sociology Review*, 29(1), 45–61. Available at: <https://doi.org/10.1080/14461242.2019.1708206>.
- Tronto, J.C. 2013. *Caring democracy: Markets, equality, and justice*. New York, NY: New York University Press.
- Tronto, J.C. 2015. *Moral boundaries: A political argument for an ethic of care*. New York, NY : Routledge.
- Waldby, C., Noble-Carr, D. and Carroll, K. 2023. 'Mothers, milk and mourning: The meanings of breast milk after loss of an infant'. *Sociology of Health & Illness*, 45(1), 109–127. Available at: <https://doi.org/10.1111/1467-9566.13551>.
- Witzling, M. 2009. 'Quilt language: Towards a poetics of quilting'. *Women's History Review*, 18(4), 619–637. Available at: <https://doi.org/10.1080/09612020903138351>.