

Experiencing the Early Loss of a Baby:

An Experience Design Approach to Understand the Conditions for Future Change

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Abstract

This study uses an experience design approach to take a critical look at a complex psychosocial challenge in the healthcare system: supporting parents, who have suffered a perinatal loss, through their entire recovery. Perinatal loss violates innate expectations of nurturing new life, making it deeply impactful and disturbing when an unanticipated death occurs. Consequently, this study takes an in-depth look at this experience, through the auto-ethnographic account of a parent, using context modeling to analyze the experience of living through a perinatal loss, which will highlight gaps in formal and informal supports. It then uses the results of a literature review and expert interviews to correlate auto-ethnographic data with existing knowledge to corroborate findings, identify gaps, and highlight opportunities for future changes.

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Dedication

To my daughter, Gabrielle: there will always be space in our home and hearts.

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Foreword

My daughter Gabrielle was stillborn March 2, 2013. At 25 weeks and 3 days, my wife laboured for 21 hours and delivered our little girl. Gabrielle's umbilical cord had coiled internally and she had died from lack of oxygen. She was beautiful. Her favourite colour is yellow, as selected by us. A perfect little girl – except her heart was not beating. She was 34 centimetres; 1 pound, 2 ounces; she had long fingers; and, she had a button nose just like her brother. Our home and hearts were already prepared for her arrival. To say her death was a profound loss to our family is an understatement.

1. Introduction

It would be common to begin a paper like this with a number of statistics. These, to help you as the reader get a sense of the size and scope of a problem. I am not going to do that in this case. It does not seem appropriate. When it comes to the death of a baby, especially for parents, time stops and the outside world gets instantly shut out, and statistics have no relevance. This study is about understanding the experience of parents who have suffered the loss of a baby. But it is also about more. It is about deep compassion and understanding on a human level. It is about values and beliefs individuals inherit through cultural habits and societal norms. It is about structures and institutions that affect us with deeply imbedded beliefs and ideals invisible to the eye.

That said, this study did not start out like this. At the beginning, it began with the ideal of applying the principles and methods of strategic foresight and innovation with the goal of seeing positive change. This helped frame the study as an experience design project using design methods to systematically map and understand the parent experience. With experience design as the overarching approach, the objective was to illuminate clear issues and challenges that could be the target of innovation through practical solutions. Upon reflection, it has achieved that objective to a degree but has also resulted in more. It has led to the discovery and general understanding of primary structural challenges at numerous scales, which was unexpected.

The realization of the many structural challenges had a significant impact to this study outcome and its ability to leap from identifying issues to proposing solutions. The goal of proposing solutions became somewhat naïve and overly simplistic when considering what could be a practical and feasible solution in a complex environment. Some of the structural challenges found, made seemingly simple and practical solutions far more complex. This is not meant to be a critical statement of judgment, merely an

observable fact as an outcome of this research. It points to the fact that the results of the research evolved during the course of the research, shifting its progression. After all, the point of doing research is to learn and be open to the possibility of being led in unexpected directions. This clearly occurred in this study.

The way I saw my challenge, as a researcher, was to critically question the data presented without being overly rigid in the ways it could be interpreted in order to allow for unexpected results to arise. The research methodology and its design played a large part in making that possible. The methodology had four critical components that worked together in harmony with a distinct purpose. Those main components being an auto-ethnography for critical self-reflection, context mapping for data analysis and understanding, a literature review for contrasting existing knowledge, and expert interviews to test and qualify findings. It is also important to point out that the timing and sequence of the methods was possibly more important than the choice of the methods themselves, which I will elaborate on at a later point. However, the main point worth drawing from this is that this methodology allowed for structuring the journey freely. It allowed for the emergence of critical questioning and new ideas in the face of the common conventions that surround us, yet are hidden in plain sight.

1.1 The Research Question and Its Evolution

The research question played a large part of getting this study off the ground and helping shape the research methodology. As first framed, it looked like this: **How might we improve the supports for parents grieving the stillborn loss of a child to support healing and recovery?**

When this study was first developed, I knew little about this area other than my personal experience and that experience was foggy and unclear at best. But that was the point. When this research question was first discussed it was in order to understand the general parameters of the study's intention and ideals. This was important to kick-off a personal journey of discovery and understanding but also to help others whom have also unfortunately had a baby die.

The next evolution came when starting to look at the existing literature. The new question looked like this: **How might we improve supports for parents grieving a perinatal loss to support their healing and recovery?**

There were only a few changes here but I am conflicted about the reasoning behind the changes upon reflection. I made two important concessions without truly considering them and this research question existed for the majority of the study and was used when speaking to people about the study.

First, I introduced the medical terminology 'perinatal' in a way making the scope of the study more clear. At the time, I did this in order to create an explicit link between this study and the existing body of literature. At the same time, unknowingly and without consideration, I conceded that the term perinatal came along with a medical definition that included specific boundaries. Those being of a baby between the ages of 20 weeks gestation and 7 days after a live birth.

I didn't consider this a significant decision at the time until reflecting upon it later in the study's progression. In terms of the parent's experience, the baby's age is not as significant as other factors and hence it shouldn't have been elevated to that importance. Perhaps obvious, it does have significance to other stakeholders of which the term 'perinatal' has significant importance but I felt it important to be brutally critical, from a human-centred perspective, to ensure my compass was not leading me astray from the

stakeholder this study cares most about: the parents. This was a critical error in judgment whereby I was saying one thing, being human-centred toward parents, but framed the research question in a different direction.

Another error in my judgment came with the removal of the word 'child'. I fell into a similar trap as above. I adhered to conventions found in the literature without considering the consequences. In this case, I innocently removed the most important object in this study: the baby. Everything about this topic as a traumatic life event with a set of experiences revolves around the baby. I washed all of that away in an act that could just as easily have been interpreted as a good choice from a research perspective. In that moment, I hid the death of a baby behind this metaphorical wall, the phrase 'perinatal loss'. Two words that when put together, characterize the experience in a way in which parents would not see it and applies a euphemism that enables a vagueness that tempers the actual experience of when a baby dies.

This may not seem consequential, but it is problematic when considering the death of a baby and trying to deeply understand the parent's experience. It has the properties of dampening and even erasing the memory of what it was like to experience such a challenging life event. I do not suggest that is not a good thing or natural habit to use euphemisms to help protect and adapt ones self as an individual who has had this experience. But as a researcher, I fell into this trap, allowing myself to make changes that I felt impaired my ability to critically think about the experience surrounding the death of a baby.

The next evolution of the research question didn't occur until the very end and, to be specific, occurred during the writing of this final report. It was naturally changing, invisible to my knowing, up to this point but not explicitly recognized until relatively late. Every decision in these late stages has gone through the lens of: "how can I transform this study into something that is usable by those who can benefit the most?" This was not the final research question but instead a guiding principle.

It has influenced aspects of this study like the choice of writing this report as a personal narrative and the way in which I have used existing knowledge to contribute to this.

This guiding principle has had a distinct influence on the final research question and helped pull me back into a human-centred stance. The final research question became this: **What conditions can create a healthy environment for those impacted by the death of a baby?**

This research question has been profoundly changed from its predecessors. For the most part these changes are influenced by the findings of the study. It may seem odd to reframe the research question as one of the last parts of a study but it was necessary to help refocus this study based on how the outcomes have challenged some fundamental assumptions that were ingrained in the earlier research questions.

There are many changes here but the main one is a philosophical difference. The original versions contained the stance that this situation, the death of a baby and the aftermath is a fixable one as it relates to the experience. It presumed that if I analytically understood, or could understand, the different dimensions and applied enough tools and rigor that I could suggest changes that could in some way fix this problem or set of problems. This became a fundamental tension within myself as a researcher as I began to see evidence that a very basic and fundamental flaw existed. It came in the form of a simple belief, that environments are controllable and myself as a researcher and designer could control the outcomes.

This could have, itself, derailed much of what I was working on and did for a period of time, as I was analysing and considering the data. But, it really came to life when the patterns of the data began emerging, which connected societal beliefs to institutional norms to daily human interactions, even to historical constants present as civilization has evolved. Yes, these are big and vague ideas,

some seemingly disconnected to the topic of the death of a baby, but an area I felt I could not avoid. As result, I started simply with some basic questions. What do I believe about death? Where do societal values come from? Why is the death of a baby so painful? Why doesn't society understand? How did we get to this point?

These were big questions and they plagued my mind as I analytically explored the experience of perinatal loss. These questions could not easily be shaken as I was trying to compartmentalize and bind an experience into its connected parts. Instead of fighting off these questions any longer, I embraced them and sought answers. It should come as no surprise that these answers were not truly answers as one might think of them, but they did offer clues to explain parts of the experience. What I was so desperately trying to understand was far bigger and more challenging than I could have possibly imagined. What were first just fragments of thoughts and ideas began to collide in a massive shift in mindset. I had a thought similar to an idea that I had heard before, but not in this context: 'What if the system isn't broken and working exactly as expected?'

This idea caused a profound shift as it relates to the final research question. It caused me to be far more attuned to the interconnected systems outside of the scope of the experience. While technically not originally part of the scope of the study, taking a step outward from my narrow focus to bring other systems into focus became a critical part of the experience modelling process. This was necessary to develop an understanding of some of the critical factors found in external systems and their effects on the experience. Nevertheless, the shift that occurred during the research did not alter the original goal but did make the challenge of attaining it a little different.

This notion of not being able to control one's environment and seeing how the external systems were actually reinforcing current behaviours related to the parent experience, rattled much of what had been done to this point. The notion of how much

perceived control¹ we as individuals have, and our beliefs about control, became a foundational pillar necessary to understanding the experience associated with the death of a baby. This became important because the primary object of the experience, the death of a baby, is unexpected. The death of a baby is in the past relative to the rest of the parent's experience. It is also an outcome that cannot be changed, it has occurred; hence it is not possible to control. This premise dictates the overall nature of the experience and it will be a consistent thread throughout the rest of this story.

¹ Wallston, Wallston, Smith, and Dobbins (1987) define perceived control as "the belief that one can determine one's own internal states and behavior, influence one's environment, and/or bring about desired outcomes." Its dimensions are viewed as important in terms of health outcomes: 1) whether the object of control is located in the past or future; and, 2) whether the object of control is an outcome, behavior or process.

2. Methodology

The development of the methodology has been a critical part of this study. More importantly, the timing and structure for when new data was introduced by sequencing the use of the methods made an important difference². The methods used, and how they were used, made it possible to critically question some fundamental assumptions to decrease bias of longstanding and deeply embedded ideas that may be important to challenge in an effort to arrive at somewhere new³.

Below I'll describe the usage of the methods and how they relate together. But before getting to those details, to add context, the challenge in designing the methodology was in balancing the use of personal experience and existing knowledge together in their associated application⁴. This created a necessary focus, from a methodological perspective, on the rigor needed when using both objective and subjective sources of data in pursuit of developing a meaningful outcome that does not have the appearance of being idiosyncratic.

² It was important to the methodology to avoid the development of any subconscious perceptions without awareness (Merikle, Smilek, & Eastwood, 2001). This was necessary to avoid a cognitive bias impacting the ability to recall the experience but also later enabled critically contrasting the data for inconsistencies.

³ See Ellis, Adams, and Bochner, 2011: "writing personal stories can be therapeutic for authors as we write to make sense of ourselves and our experiences... and [in doing so] question canonical stories—conventional, authoritative, and "projective" storylines that "plot" how "ideal social selves" should live".

⁴ This statement implies consideration of validity and reliability (LeCompte & Goetz, 1982) built into the methodology. In the case of this study, strategies associated with this relate to the process, data collection, data analysis, and data sources, which were critical in this pursuit.

2.1 Auto-Ethnography

Auto-ethnography, as I have learned through its use, is powerful as a social research method⁵. While most research methods shy away from the researcher being a part of the research, auto-ethnography was designed as a method to place the researcher at the centre⁶. This is also why it is often criticized, by having the investigator and participant as one, auto-ethnography has been accused of being founded on biased data⁷. That said, it is well suited for understanding experiences⁸ that are subjective⁹. In the case of experiencing the death of a baby, there are objective facts surrounding the experience but how these facts are interpreted and impact the experience felt by parents are subjectively understood through their perceptions of reality. Consequently, auto-ethnography is useful as a reflective tool for exploring these perceptions, which are critical to understand this experience.

In this study, auto-ethnography has been used for two distinct purposes and was importantly the first method used. Its primary use was in capturing data to reflexively make sense¹⁰ of my personal daily experiences over a period of time. This use was not for later publication but instead for eliciting data for use in developing the experience model. Importantly, this also included reflecting

⁵ Ellis and Bochner (2000) state auto-ethnography is able to open up a larger context in to view, that of the personal and social that connects to the political and cultural.

⁶ Ellis and Bochner (2000) cover a central tenet of auto-ethnography being that of the researcher's interpretation being a critical part to the understanding and communication of phenomena.

⁷ Because auto-ethnography has self-reflexivity built in, there is a tendency for being overly self-absorbed and lose sight of other perspectives inadequately representing those differences (Anderson, 2006).

⁸ "Autoethnography is one of the approaches that acknowledges and accommodates subjectivity, emotionality, and the researcher's influence on research, rather than hiding from these matters or assuming they don't exist" (Ellis, Adams, & Bochner, 2011).

⁹ "Subjective experience can involve a state of individual subjectivity, perception on which one builds one's own state of reality; a reality based on one's interaction with one's environment" (Experience, n.d.).

¹⁰ "Writing is a way of knowing, a method of inquiry" (Richardson, 2000).

on the similarities and differences of others I encountered with whom had also lost a baby; albeit, I did not engage with anyone in a different manner than had I not been conducting this research. Basic parameters were necessary to govern this method but nothing too rigid to avoid excluding key data.

The main technique I used was that of a design probe consisting primarily of a daily journal¹¹ to which I would contribute my thoughts, and whatever was dominating my time and attention. It included thoughts about the past, present, and future. No limitations were placed on the amount that needed to be contributed or even if anything need to be contributed that day. There were days that I would stare at the computer screen and nothing would come to me, and that was fine.

I also used two techniques to support contribution to the daily journal. The first was the development and maintenance of a timeline of significant dates to sequence and reflect upon some major events that had occurred. The second was the jotting down random thoughts, as they occurred during the day, to support remembering them when it came time to reflect and contribute to the daily journal. This process was scheduled to accumulate three months worth of data. Important to this process was not conducting any other methods to avoid introducing a cognitive bias¹² during the capturing of this data. This is not to say that I didn't seek information during the three months, but that the process of seeking information needed to fit my normal patterns and behaviours, not those of a researcher.

¹¹ A design probe as a means to create a loosely structured way to document my personal context at the time and understand and explain that context (Mattelmäki, 2006).

¹² For those first 3 months, I purposefully avoided information otherwise critical to the research agenda but not germane to my daily life to avoid shaping any "perceptions without awareness" (Merikle, Smilek, & Eastwood, 2001) that would lead subconsciously to a cognitive bias.

The second usage of auto-ethnography is related to authoring this study's findings as a personal narrative¹³. This was an important usage as a sense making process for interpreting the collective data of this study. It was used for the process of understanding the experience model, literature review and expert interviews cohesively. This approach was selected to represent the overall understanding considered throughout this study in order to convey it in a relatable and accessible way.

2.2 Literature Review

After the first phase of the data collection was complete through the auto-ethnography, a literature review was conducted. The purpose of the literature review was to understand how the topic has been covered from a scholarly perspective. For this, a number of scholarly articles were reviewed using the search terms "stillbirth", "grief", "perinatal loss", "prenatal loss" and "fetal loss". These terms covered a broad cross section of journals using the Scholar's Portal database as the primary mechanism for the search, secondarily Google Scholar. Each article reviewed was captured and coded¹⁴ by identifying the study's methods, key findings and any limitations found. This was the extent to which I systematically sought knowledge as a formal literature review but to say it ended there would be false.

From beginning the literature through the remainder of the study, key literature and sources were consistently gathered through different means. I sought popular books on the topic recommended to me, requested recommended readings from experts,

¹³ Is a story told from the vantage point of the author relating themselves as a part of the phenomenon under review (Ellis & Bochner, 2000) and itself a process of inquiry (Richardson, 2000).

¹⁴ This structured framework of methods, findings, and limitations was used to extract data from the literature into a separate document. This new document was later used in a systematic analysis against the experience model.

performed one-off searches based on key ideas emerging, and visited Caversham Books to review the available resources from a specialised bookseller knowledgeable on this topic¹⁵. This was all part of an effort to ensure coverage of the key touchstone materials across a wide variety of perspectives, recognizing that exploring every avenue in detail was infeasible. With these different avenues considered, the literature review served three main purposes in the overall context of the study.

The first purpose was to identify areas in which the literature had consistencies and gaps. This was in order to develop any informal hypotheses or questions that could be important to the development of the experience model.

The next part involved determining whether there were any dominant existing theoretical models already developed. The experience model was developed having considered existing theoretical models available and their applicability. An important point in supporting why the auto-ethnographic data collection needed to precede this effort was objectively identifying how the existing models were both adequate and inadequate in explaining the data. This was not a primary objective of the modelling efforts, but did occur as a by-product.

And lastly, I wanted to contrast the data from the auto-ethnography to the literature in order to determine whether there were consistencies or if the auto-ethnography data told a different story. This was used during the modelling of the experience and informed other areas in the study to consider consistencies and discrepancies that were contextually appropriate.

As an overall purpose for the literature review, the key findings were combined, during the analysis and synthesis process of the data, with data from the auto-ethnography to develop the experience model. The literature was a critical part in making sense of the auto-ethnographic data and supporting the development of the model by using existing theory, models, and concepts.

¹⁵ Caversham Booksellers at 98 Harbord St, Toronto, ON is a bookstore solely dedicated to mental health literature.

2.3 Context Mapping

The process of context mapping¹⁶ was used to make sense of the auto-ethnographic data and literature. An experience model¹⁷ was the result of the context mapping process, visually and textually representing multiple layers, scales, and complexity of the experience. In terms of the bigger methodological picture, the development of the experience model played an important role in working with the data in order to understand the current state and make an informed leap from there to the future recommendations. This process followed the analysis-synthesis bridge model¹⁸ as its guide. Specific to this study, the exercise of mapping the data took a sequence of steps.

First, I looked through the data to identify various activities or tasks that occurred, mapping them in a connected process flow. This accounted for the direction of activities from one to the next, identified non-linear activities, and accounted for activities that occurred once versus those of greater frequency. This data was spatially mapped using post-it notes and a large whiteboard to support this mapping exercise. The step primarily drew on the auto-ethnographic data. The following figure represents what the result looked like at this stage.

¹⁶ A generative process aimed at creating context awareness useful for eliciting an emotional response from an audience (Visser, Stappers, Van der Lugt, & Sanders, 2005)

¹⁷ A GIGA Map being a visual representing complexity and interconnectedness of multiple scales and layers of information (Sevaldson, 2011).

¹⁸ See Dubberly, Evenson, & Robinson (2008).

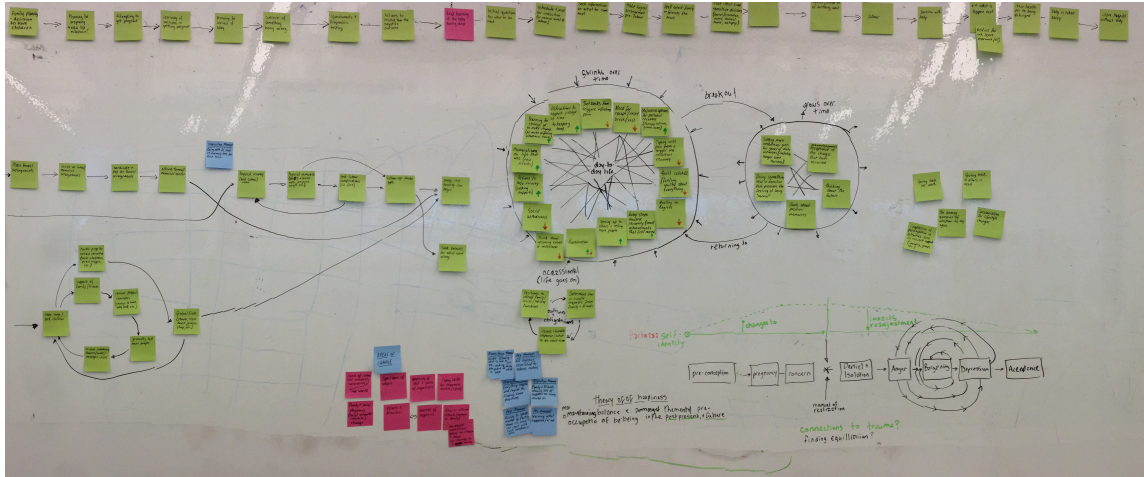


Figure 1: Step 1 – Image of the Working Process of Context Mapping

From there, additional layers of data were added to help identify what different supports were present at different moments, along with the associated feelings and emotions. This data was spatially mapped using post-it notes in association to the different activities or tasks. The activities or tasks were also changing at this stage and other important points were captured; although, the primary focus was as mentioned above. This step also drew primarily from the auto-ethnographic data; although, the use of the literature began to be used in an unstructured way. The result looked like the below figure.

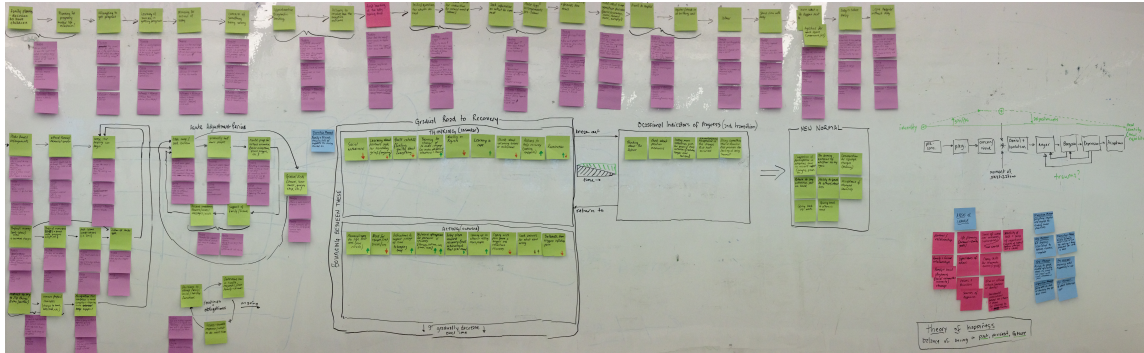


Figure 2: Step 2 – Image of the Working Process of Context Mapping

The next step included reviewing the results from the literature review article by article, assessing the applicability to the model, and making updates. The literature affected all aspects of the data mapped to this point including the specific language choices, identifying gaps in data, and organizing principles. A main objective during this step was to make personal details more generally applicable or relevant to characterizing the experience model. The result after this step looked like the following figure.



Figure 3: Step 3 - Image of the Working Process of Context Mapping

The final step of the development of the experience model came when identifying thematic similarities in the experience model in order to identify its natural stages. This is also the step in which the model transitioned from being represented on a whiteboard as shown in the image above to its current digital form represented in detail and expanded upon later in this document.

While these four steps represent the primary process followed in developing the experience model, it is important to mention that these steps oversimplify the process. From the point the model first began, it has been under consistent review for discrepancies and has been iteratively updated up until the end of the study. The result of this exercise is an experience model in its current visual form as a thinking tool¹⁹, which will later be expanded on in this document. This is a tool for later use in identifying critical issues and considering future changes or interventions. This was its main contribution in arriving at the findings and recommendations of this study.

¹⁹ As a thinking tool, it is designed to meet two purposes. First – in the context of the study “Innovation: Defining areas and points for intervention and innovation” (Sevaldson, 2011). The second – for purposes of future uses “Imagination: Generative, iterative design” (Sevaldson, 2011).

2.4 Expert Interviews

The expert interviews²⁰ were the final method conducted after all other methods had been formally completed. Seven interviews were conducted and the interviewees had distinctly different backgrounds related to the subject matter.

The interviews were designed to follow a consistent semi-structured²¹ format for all participants to elicit similar input from a variety of expertise, all of whom influence and impact the topic area differently. The interview consisted of asking each participant the same three questions and allowing for follow up probing questions. Concisely put, the questions were: What are the issues? What are potential solutions? And, what are the barriers to realizing change?

As an important point of context, the interviewees were purposefully not introduced to any interim findings of the study nor were any probes used to test any hypotheses. Any follow-up probes²² were used strictly to keep searching for additional data related to the original question while avoiding leading the interviewee's focus in any particular direction. This was done to allow the data from the interview to have value from two different purposes.

The first purpose of the interview data was to determine how the comments from the interviews either supported or contradicted the findings to this point, relative to the experience model. This was a critical way of qualifying, in an unbiased way, the findings beyond the personal accounts found in the auto-ethnographic data.

²⁰ The interviewees, in qualifying as being experts, self-identified as having working knowledge or domain expertise through interacting directly or indirectly with parents whom have suffered the death of a baby during the perinatal period.

²¹ Semi-structured referring to the questions being formulated prior and consistently asked during all interviews with the questions being designed to allow for open-ended answers subject to follow-up probes (Schensul, Schensul, & LeCompte, 1999).

²² Interview probes were used to clarify and ask for more, not to start a new line of questioning (Schensul, Schensul, & LeCompte, 1999).

The second purpose of the interview data was far more subtle but of equal importance. By having the questions left open-ended and not attempting to clarify specific issues found elsewhere in the study, the data from the interviews could be used to postulate what was not being said and why. Part of this study's purpose was to explore fundamental assumptions and conventions. The comments not provided during the interviews, or how something was said, offered a valuable perspective on certain critical gaps and further confirmed foundational assumptions. With that said, the absence of something is not proof of something else. This type of contribution from the interviews did not offer any conclusive evidence for use in this study, nor were they represented as such, but they did offer an important perspective for directing further investigation.

The results of the interviews have contributed data that was synthesized and reported on in all the different areas of the study, as contextually appropriate. Some results reinforced or altered the context, some influenced findings from the experience model, and some influenced the recommendations.

The data from the interviews was handled in three main steps. First, detailed notes were taken from the audio playback for each interview and the data was made anonymous. Second, the data from all the interviews, as a collective, was analysed and coded in order to identify common findings, themes, and emerging questions for further consideration. Finally, the data was analysed and synthesized alongside the other findings of the study. This final step served a critical purpose. This purpose being to assess the other findings up to this point and determine whether the interview findings supported or contradicted the other findings, and why. This was a critical component in order to achieve an objective outcome for the study through the use of multiple sources of data.

2.5 Methodology in Summary

Through the use of the above four methods, this study has been developed to deliver against its original intent as an experience design project. In summarizing the methodology, the methods selected span a continuum of being subjective and objective in orientation and, when brought together, the overall methodology offers a balanced framework, both rigorous and analytical. The methodology, through the descriptions in the previous sections, has accounted for issues of validity²³ and reliability²⁴ by drawing on multiple data sources, enabling strict processes for data collection, and incorporating an analytical approach to analyse and synthesize the data.

What is worth coming back to, now that the methodology has been discussed in detail, is in regards to the expectations being placed on the methodologies used. With auto-ethnography as a central component of the methodology, it is important to be clear on the meaning this has on the outcome. Auto-ethnography is judged by its ability to illuminate unfamiliar cultural processes and consequently places a different meaning on generalizability²⁵. Its pursuit is not for generalizable knowledge in the traditional sense but instead its general applicability is to help move and inform its readers by offering them the ability to understand and feel a connection to the experience of others, whether it speaks directly to them or more to the lives of others²⁶. Its goal is to be generally

²³ Validity is concerned with the accuracy of a study's findings (LeCompte & Goetz, 1982).

²⁴ Reliability refers to the replicability of a study's findings should other researchers attempt to reproduce (LeCompte & Goetz, 1982).

²⁵ See Ellis, Adams, & Bochner (2011)

²⁶ See Ellis, Adams, & Bochner (2011) in which the authors point out that there is a shift in what generalization means for an auto-ethnography. Instead of focus being on the number of respondents in the study as the in predictor of generalizability to shifting that responsibility to the reader to determine if the story speaks to them.

resonant, not generalizable. This is the goal of this methodology, the purpose behind its design, and explains the way in which the methods operate together.

Next, I will be discussing the bulk of the study's contribution by starting with the context that surrounds the experience when the death of a baby occurs.

3. Context

The context of the experience, similar to the evolution of the research question, emerged late in this study. There was a starting point from which it began; although it has morphed throughout the study, as more layers came into focus. I'll cover the contextual layers starting from the scale of an individual parent and zoom out from there.

But before getting in to these details, it is important to point out the purpose of this section. This section is meant to provide a particular perspective on the dominant themes and the forces, which have an affect on the experience. It is not to cover all the permutations or possibilities. That type of understanding can already be found in books such as *Empty Cradle, Broken Heart* (Davis, 1996), which provide a thoughtful and comprehensive account in that regard. The ideas in this section align with those found in the above-mentioned book but also seek to go a bit deeper to add additional insight and nuanced detail.

3.1 A Parent: As an Individual

For those who have experienced the death of a baby like myself, one of the most dominant feelings is that of isolation²⁷ and time standing still. It is not only amidst the raw pain and shock, but it is immediate and hits with concussive force. In those horrific moments immediately after the loss, my priorities instantly changed, and there was a feeling that emerged: that a new world was opening up and coming into view. Once acquainted, it was clear to me that this world has always been there, just hidden in plain sight,

²⁷ Davis (1996) attributes feelings of isolation to the fact that parents are the only ones to have known the baby or perceived to care, thus making the grief very painful.

its membership shaped by boundaries courtesy of society's general lack of empathic understanding for this type of loss²⁸. Each painful, awkward, misguided, and avoided interaction stings and raises walls higher and thicker.

At first, these interactions were subconscious to me but the pain was clearly there. It raised questions of whether these reactions were normal²⁹. Over time, my awareness became more acute until a point at which it then began receding from the foreground. Herein lies a hidden truth I found. Societal ignorance is a two-way street. It is easy for a parent like myself to speak of the feelings of isolation and blame society's ignorance but, in reality, the change is not instantaneous. It was something I learned and a new understanding that I needed to figure out for myself.

Why I think this an important idea to keep in perspective is that the route from being ignorant oneself to decrying ignorance is a process that evolves. It's learned, absorbed and constantly shifting over time. I found this to be a fundamental influence relating my expectations toward others as well as myself. Upon reflection, I found it unfair to decry ignorance, especially early on when I too was ignorant to even acknowledge what was ignorant about those around me, not to mention what should be reasonable to expect. Not to say that decrying the ignorance of other was not a normal reaction for to me to have in the moment. However, it didn't seem to be enough to explain what was going on below the surface. This is to say that the ignorance was as much a part of me as it is in society as a whole. This shifting awareness in my perceptions of societal ignorance was important because it spoke to how my implicit and explicit expectations changed over time.

²⁸ A primary finding from the interviews conducted, consistent across all participants, was that society in general and in every setting (healthcare, work, community, etc.) is ignorant to this kind of loss. Characterized as being treated and associated in the same way as a miscarriage.

²⁹ See Davis (1996) pages 32 – 46. Davis dedicates a number of different sections to the different topics associated with making sense of whether feelings or situations are normal and in doing so is covering the fact that an early hurdle for parents is making sense of whether what they are seeing and feeling is 'normal'.

This is an important thing to consider when thinking of informal and formal supports. My foundational understanding and expectations changed over time as it related to what I expected from society. Whether that was: leave me alone, guide me, help me, talk to me about something else, surprise me, as just a few examples. It impacted what I needed, what I was willing to do, how I interacted with others, and what I expected from others. The notion of time and one's awareness as a progression is critical when considering what to offer, and how to offer it, in order to not reinforce the issue of societal ignorance and the divide it creates. This transition is also a constant backdrop to the experience of recovering from the death of a baby.

3.2 Siblings: Always Around and Whose Reactions Aren't Well Understood

While not always the case in situations where the death of a baby occurs, in our case our family unit had an energetic two year-old alongside my wife and I. Leading up to the unexpected loss of our daughter, we were actively talking with our son about becoming a big brother and encouraging thoughts and discussion about what it would mean for him. This resulted in both prompted and unprompted comments from him relating to his soon-to-be role of becoming a big brother.

Shortly after the death of our daughter, we sat him down and as a family discussed that he was not going to be a big brother, for now at least, and that mommy and daddy loved him. That was about it. The conversation was over quickly and he went on playing as though it was a regular interruption. That was the only time it directly came up. But a change had occurred, a subtle one, but clearly

evident that we had the conversation. The comments that were becoming a daily routine about being a big brother stopped³⁰. No other visible changes to his demeanour or daily routine changed, just those types of comments ceased.

I really had no idea what was going on with our son or what I needed to do to support him. I had the perception that seems to be a common one: that kids are so 'resilient' and the result was that I did nothing further. I was aware and concerned and I watched for signs that something more was going on, but the reality was that there was a lot more going on with me at the same time so this aspect was not constantly on my mind. But when it was, questions arose such as: How much does he understand? Should he come to the funeral? Should I do anything or just leave him be? How is he reacting to seeing my wife and I upset?

The results to these questions and others resulted in a stance of doing nothing and erring on the side of caution. This meant shielding him from as much of what was going on as possible. To this day I have no idea whether these decisions were right or not but it points to an important conclusion I have drawn about the experience. There is a lot that is happening, particularly early on, and it is easy for other children's needs to get lost in the chaos. They are a part of this experience and observing what is occurring³¹. To this extent, their needs can easily go unrecognized and unsatisfied unless a visible reaction prompts otherwise³². As a parent operating in

³⁰ This comment evident of emotional disengagement (Emotional Disengagement, n.d.) in my son's attachment to the idea of being a big brother.

³¹ See Packman et al. (2006), "Children's grief and fear may be compounded by witnessing parents' distress and vulnerability".

³² Packman, Horsley, Davies, and Kramer (2006) point out that this is potentially problematic yet common. Children grieve differently from adults and adults are ill equipped to identify more subtle cases of children suffering.

these conditions, it is perplexing to apply good judgment³³ as to what to do; especially, amidst the other personal emotions and changes occurring concurrently. Because of what I was feeling and going through myself, I felt like I was unable to be there for him and be a good parent. During this journey, at no point did I come across any available supports or existing wisdom that could either support him directly or lead me to any sound decision making for what I could do to support him.

3.3 Family, Friends and Acquaintances: From the Outside Looking In

It's hard as a parent to appreciate, especially during the early pain, but those surrounding my family and friends were also affected. Many were significantly and visibly affected. But it was hard for me to appreciate what this pain looked like and what was different about it. While it was clear over time that what was also lost was not only a son or daughter, but also a grandchild, a nephew or niece, a play date buddy, among others, this appreciation and understanding did not exist until I was able to get beyond the acute grips of my own grief³⁴. Similarly, it was also hard to appreciate early on, but others felt despair associated with wanting to help but feeling helpless in doing so and not wanting to cause further pain³⁵.

³³ Packman et al. (2006) found that creating and maintaining continuing bonds toward a deceased sibling was important in enabling healthy readjustment for living children as it relates to a child's grief. This includes the recognition that even very young children can have grief albeit they are unable to communicate as such. This study calls for mental health professionals as the ones to help encourage parents to support 'continuing bonds' to develop. That said, this study, and other literature, do not offer any unique considerations that may exist in terms of when the death of a sibling occurs during the perinatal period.

³⁴ Davis (1996) covers how relatives', grandparents', and friends' react to the loss with their own grief response.

³⁵ Davis (1996) covers how relatives, grandparents, and friends pain also includes the pain associated with not knowing how to help or relieve a loved ones pain.

Until I could get to this place of understanding rationally and emotionally, it was impossible for me to relate to the perceptions of others. I was stuck in my own world with my own problems. This made it really tough for me to interact with the outside world. The realization came later that this situation was not only unfamiliar to me but those around me as well. This meant unfamiliar social interactions that often added pain and negative emotions, not because I rationally believed at any point that there was malicious intent, but because there wasn't a common ground of understanding³⁶. The reality for me was that nowhere in my life leading up to the death of my daughter had I had any comparable exposure or experience, making me as much to blame for this uneven understanding as anyone else. For much of the time, I had no idea what to ask for or to communicate what I was expecting and this only became more apparent after the fact.

Part of the challenge, as I see it, is how can those who surround bereaved parents support them with uneven and differing understandings of the experience? This is not to say that knowledge and understanding does not exist in this area, it does. But instead,

³⁶ Rainer (2013, p. 3) covers the connection between grief (internal experience) and mourning (social expression) along with the role of mourning in relieving the emotions of grief: "Mourning is observed in cohesive communities where the pain of death is shared by members having common knowledge of the deceased and coming together in various rites and rituals of the dead. In a community, those grieving are surrounded by mourners having a similar experience."

the death of a baby occurs infrequently enough³⁷ and is hidden enough from social consciousness³⁸ that a lack in familiarity also leads to a lack in shared understanding.

3.4 Healthcare Professionals: Those Present When a Baby Dies, and After

Healthcare professionals play a very unique and important role in helping those through the death of a baby, most especially in the early stages. One of the most vivid and heart-warming ideas that I take away from an otherwise horrifying and traumatic experience was how genuinely compassionate total strangers could be. It was obvious to me that they were not operating under guidelines or practices but instead just being a part of a human experience, one that possibly violated guidelines more so than adhering to them.

But I later learned that our experience was far from being the norm. When my wife and I later joined a peer support group³⁹, we would share and hear stories from others that showed us just how different the experience could be. This stood out to me as being a puzzle. Why is it that in an institution, like that of healthcare, which strives for the best possible care, can there be such a large range of outcomes when it comes to the experience of parents? I would later learn, through the course of this study, the answer to this has many

³⁷ The topic of 'frequency' came up during the interviews consistently, although they were two contradictory sides. First, statistics were cited as illustrative of and associated to the argument that this phenomenon regularly occurs. The other side was related to supports and practices associated to the question of "why isn't more being done?" The primary answer was that the occurrences were relatively infrequent enough to which it isn't practical (both implicitly and explicitly referring to the associative costs).

³⁸ The topic of 'social awareness' was a theme from the interviews. The subject was cited as not making it into the general public consciousness because of discomforts people have with the topic (death), and in particular that of a baby, making this subject one that gets filtered from public attention. Also from the interview data and associated, is the point that organizations that have the means to create public awareness are uninterested in being associated with the topic as a factor contributing to a lack in awareness.

³⁹ Biweekly support group meetings hosted by the Pregnancy and Infant Loss Network (PAIL).

facets and is complex: healthcare professionals, as it has been found, have their own personal views toward the topic⁴⁰, are professionally socialized to think in a certain way⁴¹, are required to complete medical procedures with relative efficiency⁴², have had limited education opportunities for developing necessary relevant skills⁴³, and have developed professional skills as an emotional defence⁴⁴.

When I reflect on these findings and consider them in the context of how the experience is perceived by parents, it is no wonder to me why and how tensions in the experience can arise. Amidst the shock and pain I felt, and with what little ability to focus I was able to muster in the moment, there was neither an appreciation for what was to happen nor how that would affect us. Paradoxically, I later learned that during the early shock and vulnerable moments in the hospital, my wife and I were also very sensitive to and able to recall even some of the most seemingly innocuous comments or actions that didn't make sense to us at the time.

In my view, this makes for a particularly challenging issue impacting the parent experience and practices in the hospital, and it comes in the form of a question: How can healthcare professionals open up to the idea that, at this time, parents have broader needs

⁴⁰ The results of the interviews found that personal beliefs play a role in a healthcare professional's practice in absence of formal education.

⁴¹ Healthcare professionals, primarily doctor's, are professionally socialized to apply wisdom and reason to solve problems (Expert Interview).

⁴² Authors reflection and analysis toward the issues commonly found in media with respect to inflating healthcare costs and the implications. It is foreseen that these pressures affect things like wait times, parameters for when a patient is discharged, the amount of time professionals spend with patients, being the main ones.

⁴³ See Davis (1996, p. 172): "some doctors do not know how to support grieving parents. Grief education is not routinely included in medical training, and death is not a regular feature of obstetric or pediatric practice." This was also a found in the interviews, in that education in this area is limited and the majority is handled on the job through experience and mentoring.

⁴⁴ Healthcare professionals are equally in need of supports for emotional coping (expert interview).

and yet are incapable of expressing or unaware of such needs? This is not to say that I think it should be the place to necessarily intervene, but in the least, healthcare professionals need to be sensitive to some of the issues can have an impact on the experience.

3.5 Employers: Their Priorities in Operation

Most professional environments I have encountered are moving rapidly to satisfy demands and remain relevant. While employers are generally getting better at handling more complex personal issues relating to their employees⁴⁵, there are caveats that always exist based on a overarching need to stay in operation⁴⁶. That said, leaders and managers in organizations generally wouldn't take action⁴⁷ until a point at which it is absolutely necessary. This means, very rarely will personal issues of employees be accounted for with proactive measures to account for a lack in productivity.

The above mostly considers factors when generally discussing the topic of personal issues in the workplace. In the case of the death of a baby during a perinatal period, the challenges previously discussed related to the general societal ignorance, also become a factor compounding the challenges faced in the workplace. Beyond the awkward and painful social interactions, this can lead to a lack in sympathy and understanding when it comes to realistic expectations for an individual's return to previous levels of productivity⁴⁸.

⁴⁵ Employment environments, generally speaking, are far more sympathetic to personal issues than they ever have been in the past (expert interview).

⁴⁶ Any sympathy will be overridden by the need to achieve business objectives (expert interview).

⁴⁷ Businesses/organizations are generally dynamic environments with constant competing priorities. Leaders and managers will only take note if a problem affecting a business priority emerges (expert interview).

⁴⁸ Ignorance of this type of loss leads to poor (implicit) expectations for reintegrating and returning to previous levels of productivity (expert interview).

3.6 Societal Norms Related to Death: The Attitudes and Venues of Death

The pursuit of this research resulted in identifying many indirect relationships to the issues, which resulted in arriving at large and challenging questions. One of the big questions for me was determining what is my attitude when it comes to death. What are my beliefs here? How does this shape how I feel? And then connecting down to the level of how has it impacted my experience through the death of my baby? In pursuit of insights I started to apply a broader lens to the research question to get a sense of the cultural context related to death and society.

There is a lot that could be discussed but perhaps the best place to start would be with Stephen Cave. Stephen wrote a book⁴⁹ on dominant attitudes and beliefs that we, as a civilization, have toward death, although he refers to beliefs about immortality as opposed to being directly on the topic of death. His account covers many ages and cultures stretching back to early human civilizations. It is quite a compelling story in the way he links the past with the present, and illuminates longstanding social structures that have evolved to reinforce these beliefs⁵⁰. But what is most interesting to me isn't that these attitudes and beliefs have such a long legacy but instead what implications these have in terms of how we experience the death of a loved one.

The topic of where the death of a loved one takes place and the implications to the experience has been researched and documented⁵¹. In the not so distant past, it was common to have a loved one cared for at the end of life in the comfort of their home, or

⁴⁹ See Cave (2012). The book is entitled "Immortality: The quest to live forever and how it drives civilization".

⁵⁰ See Cave (2012). The author covers four narrative archetypes found through story and myth in human history, across all of human civilization that reinforce a belief that death can be cheated and also draws connections between these claims surrounding how this has impacted how humans have lived and their pursuits.

⁵¹ See Rainer (2012, p 6-18) for a historical synopsis.

someone else's. This provided an opportunity to invite others in to say goodbye, provide care, and valued the importance of coming together as a communal experience⁵². This is very different to that which is common today where the norm is being an observer and not often a participant⁵³. Going back even further in history, it was common for family members to be a part of preparing a loved ones body after they have died⁵⁴.

But what is worth drawing out, is that death is and has been removed from contemporary social life and has been professionalized⁵⁵. With this, there are issues whereby the changing venues of death and associated mourning rituals are impacting the social and communal experience that act as important opportunities to release the emotions associated with grief⁵⁶. This is particularly problematic in the death of a baby because the life was so short and many, if not all, family and friends have had no connection to the baby as an individual. This makes it hard for those to acknowledge the life of the baby in a similar way to that of the parents.

Mourning is an important part of grief as a social expression of the loss and the use of communal rituals is critical to acknowledging this⁵⁷. But the challenge, and where this process breaks down, is in this difference in understanding of the loss.

⁵² See Rainer (2012, p 9).

⁵³ By mid-twentieth century, "in the proceedings following death, the deceased's family and friends appeared to be onlookers rather than participants, and the tasks of preparing the dead for burial and managing surrounding rituals were professionalized." (Rainer, 2013, p. 9)

⁵⁴ See Rainer (2012, p 7-8), during the Romantic Age including the late 19th century.

⁵⁵ "In the early decades of the twentieth century, a significant and sudden change occurred: Once practised as a public and communal event, death became private. The process of dying was progressively hidden from public view and excluded from social life. The deathbed moved from home to hospital" (Rainer, 2013, p. 9).

⁵⁶ "The individual's grief work centres around four basic tasks: 1. recognising the loss; 2. releasing the emotions of grief; 3. developing new skills; and, 4. reinvesting emotional energy in the present" (Bar-Yitzchak, 2002).

⁵⁷ "Mourning is the external demonstration of grief. To mourn is to find social experience in acts expressive of grief" (Rainer, 2012 p 3).

Consequently, with death pushed to the social fringes, compounded by the fact that those surrounding parents have an uneven understanding of the loss, the social and communal aspects important to mourning the loss are strained, or perhaps non-existent, making the experience of a loss very lonely and isolating for parents.

3.7 Culture: Cultural Differences and Diversity in Canada

The last topic related to the context is that of cultural difference. It is challenging to determine the direct implications of cultural beliefs as it relates to the experience, but it is important to acknowledge its relevance as an important part of the experience. This is especially important in a country like Canada known for its diversity⁵⁸. Cultural attitudes and associated religious beliefs can impact how the death of a baby is viewed by parents and surrounding family and friends.

In extreme cases, when the death of a baby occurs, cultural beliefs can turn into serious situations such as women being socially ostracized, raising questions of women's and human rights⁵⁹. The topic of culture raises not only superficial differences in values, attitudes and beliefs but can also trigger very serious issues requiring other interventions, such as legal, necessary to protect people from abuse. When considering an example like the above, it shows another layer of the experience and just how problematic it can become.

⁵⁸ With so many different cultures represented in Canadian society it is hard for individuals and professionals to know what is appropriate and inappropriate to say (expert interview).

⁵⁹ An insight shared as a type of illustrative example for an extreme case, but also pointed out in the interview was that it was not far from actual cases encountered (expert interviews).

The area of culture in the context of the death of a baby is a big and challenging topic. Admittedly, this study has not directly explored how different cultural contexts affect the experience and it seldom came up in the data. That said, it is a topic that, despite of having rarely come up, cannot be ignored as an important point of context in this study.

3.8 Context in Summary

The context I have covered is neither positive nor negative. It just is. My point for addressing these topics as relevant to the context of the study is to illuminate some context to help make sense of conditions present. By doing so, this section should help frame the understanding of the experience as it fits within the bigger picture. Part of the purpose of this section is to point out that there are forces acting on the experience from various directions.

This is not to say that change isn't possible in these areas nor should they be avoided but instead to help highlight that certain realities are more entrenched and complex than what initially appeared on the surface. The context helps understand the conditions that need to be considered when thinking about future changes to benefit the experience.

In the next section I will cover findings through analysing the experience model.

4. The Experience Model: Unraveling the Experience

The development of the experience model represents an analytical process of interpreting, decoding and sense making used to represent both the data from the auto-ethnography and key findings from the literature. The exercise of developing the model has resulted in multiple visual representations expressing the different dimensions and abstractions of the experience and their interrelated parts. By the very nature of the ambition behind this exercise, representing something as complex, contextual and nuanced as an experience, it is important to clarify what can be feasibly expected of the model and its purpose.

In the next section I will explore how to understand and use the model. But perhaps what is most critical to state up front is that its use is meant to be a tool, primarily a critical thinking tool⁶⁰. In this context, it is an oversimplification of all the moving parts and does not reflect all possibilities. To attempt to cater to all possibilities quickly washes away the experiential context, which is critical to understanding the experience⁶¹. This alludes to a critical challenge in the development of the model: synthesising the data from all sources and striking an important balance between having personal and emotional underpinnings, making it relatable as an experience and ensuring it considered the objective facts and existing sources of knowledge. It is important such that the experience modelling exercise did not become a cramming of all permutations, at which point it would become a cataloguing of characteristics and

⁶⁰ As a critical thinking tool it is designed to serve two purposes. First, relating to the findings and recommendations: "Innovation: Defining areas and points for intervention and innovation" (Sevaldson, 2011). The second, for purposes of future uses: "Imagination: Generative, iterative design" (Sevaldson, 2011).

⁶¹ The purpose of the development of a context map is to raise awareness of a particular context (Visser, Stappers, Van der Lugt, & Sanders, 2005). Implicit to this statement is its necessity for accessibility to a reader in order to be consumable and digestible.

no longer represent a relatable human experience. This tension was persistent throughout the model development without a clear or definable resolution.

Its utility is as a tool for eliciting further information. The experience model has been used to find critical issues that exist and at which point in the experience, as part of the analytical exercise. But it can also be used as a tool for facilitating dialogue. It can ask difficult questions such as: What is contained and why? What is missing? What is actually happening versus what is commonly believed? Where are opportunities for new types of thinking? These questions are a few general examples. There are other questions that can be more explicit and targeted.

Working with specific stakeholders who have a specific purpose also comes to mind. An example could be using the model to initiate dialogue with academic stakeholders, contrasting academic knowledge with the model and determining how to bridge identified gaps. Another example could be framing dialogue with the Canadian Association of Midwives to discuss ways in which midwives can better support mothers both before the death of a baby and after. These are just a few examples. There are many possible uses for the experience model. That said, the point worth returning to and emphasizing is that the model is most valuable as an active tool.

4.1 Incorporating Existing Models and Knowledge

As part of the development of the model, I searched for and reviewed existing models for their applicability with the expectation to reuse or extend any existing frameworks. This search coincided with the literature review but extended beyond the

primary topics as covered when discussing the use of the parameters that I earlier described as part of the literature review. Three models were considered, two of which were incorporated.

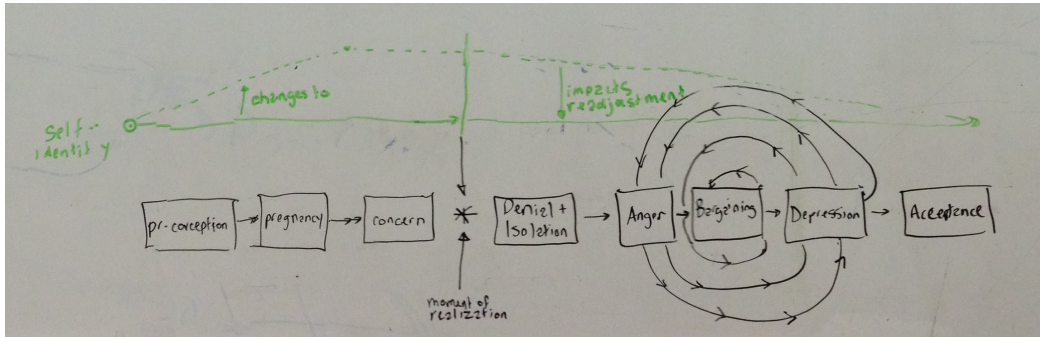


Figure 4: Early Sketch Attempting to Extend Kübler-Ross Model

The first model I reviewed was the most commonly cited and familiar: the five stages of grief or the Kübler-Ross model⁶². Given that it is the most widely known, it made sense to look at it first to determine its applicability. I began by trying to apply it as a framework when mapping the data of the experience and I also used it to consider the experience leading up to the moment of loss. The following figure represents an early sketch representing this direction, which was later abandoned. The problem I found with attempting to extend the Kübler-Ross model as a framework was that the framework was unable to accommodate some of the other activities not directly associated with grief. The contrast was most stark with procedural aspects of the experience like submitting employment insurance paperwork, which is part of the experience but not directly applicable to any of the five stages. When I tried to map the data to this model it simply didn't make sense.

⁶² Denial and isolation, anger, bargaining, depression, and acceptance (Kübler-Ross, 1969).

The next model reviewed and later incorporated was that of the balanced time perspective based on research connecting it with subjective well-being⁶³, which includes happiness. The basics of the balanced time perspective, as applied by Zhang, Howell and Stolarski (2013), found that those who are able to focus on the past, present, and future, in even proportions, correlates positively to general life satisfaction. I chose to use the balanced time perspective as a model to help illustrate the dramatic changes that occur during the different stages in the experience model.

This helped bring to life what a parent's mindset is after the death of a baby but also helped show how parents are over indexing in a future perspective⁶⁴ prior to the loss. This is important because becoming a parent, as a life event, is such a profound identity shift that it invariably promotes thinking, dreaming and planning for the future. After an unexpected death occurs, the balance, which is already over-indexing toward the future, is thrown into a state of flux before returning to a more even state of equilibrium.

The last model reviewed and later incorporated came from the literature reviewed. An article reviewed related to stillbirth stated that an individual's grief work centres around four basic tasks: 1. recognizing the loss; 2. releasing the emotions of grief; 3. developing new skills; and, 4. reinvesting emotional energy in the present⁶⁵. I gravitated toward incorporating this thinking for a few reasons. The first was that this framework is oriented toward 'tasks' aligning it well with the kind of data this study focused on. The second was its characterization of an 'individual's grief work'. This aligned well to the auto-ethnographic data; although, this was found to be most clearly applicable to one stage of the experience model (Learning to Live with the Loss) which is viewed as the more active

⁶³ See Zhang, Howell, & Stolarski (2013).

⁶⁴ The loss is not only related to that of a baby but also the future hopes and dreams as part of you (Davis, 1996 p 5-6).

⁶⁵ See Bar-Yitzchak (2002).

stage and aligns with the idea of 'grief work'. It was also limited in its application to one type of information presented in that stage, that of the tasks and activities, but nevertheless it was useful for organizing and presenting information during this stage.

Additional data and knowledge has been incorporated into the model from the literature review but the above section covers the literature most directly considered and incorporated as critical elements of the model. In the bibliography, at the end of this paper, there is a subsection entitled 'Grief Literature Review'. The references found in that section were those directly used to analyse and develop the experience model as described in the methodology section.

4.2 Interpreting the model

I will now introduce the overall facets of the model, what to expect, and how to read it. At a high level, the model consists of three layers of information that are interconnected.

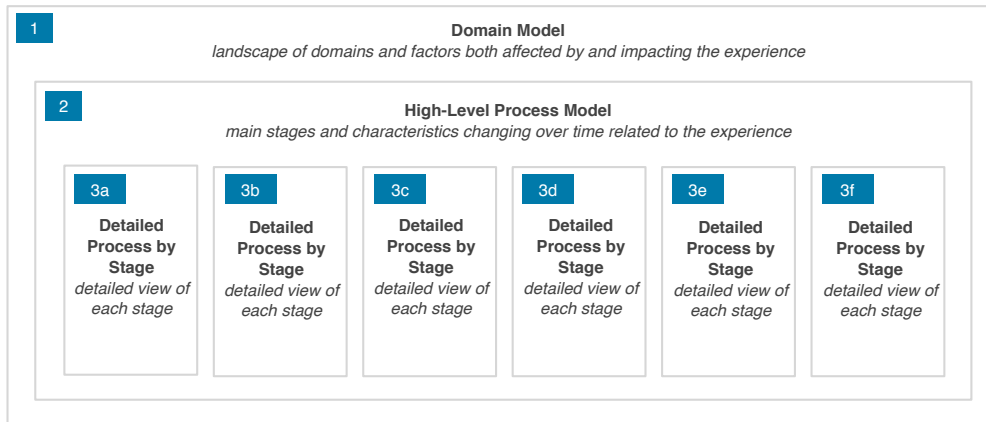


Figure 5: Relationship Amongst Layers of Information

The first layer is the domain model. It looks at the various domains that are primarily involved when it comes to the death of a baby representing the overall landscape surrounding parents. The purpose of looking at this level of information is to demonstrate the primary factors that are in a state of change. It does not claim to represent all possible factors or variables but it does intend to capture a majority in order to illustrate the experience. As represented, it is a snapshot of the primary areas affected but it does not give a sense of how they change over time or what the results of such changes are. These questions are addressed as the domain model is connected to the further layers of information, which will be discussed next, although, there are limits to the level of possible explanations before getting too dependent on individual circumstances.

The second layer of information is the high-level process model. It looks to encapsulate the main stages and characteristics of these stages in an effort to show how things are changing over time. The stages are not as cleanly separate as the model visually suggests but its main intent is to show that there are important thematic transitions that occur during a given stage, and this is an important lens to consider when thinking about support for parents. It also creates a connection back to the domain model to show which domains are primarily affected during a given stage to help capture how things evolve over time.

The last layer of information takes the next step down from the high-level process model to representing a detailed view of each stage. This is meant to capture what is happening during each stage and identify some critical issues. The issues identified are also linked back to the domain model in an effort to highlight where potential supports or interventions could be targeted, or at whom. This layer of information focuses on demonstrating an illustrative process. It is not absolute in terms of its representation. Meaning, it's representing processes that are linear or non-linear for illustrative purposes but the reality is far more complex. There was a fine line I tried to achieve in terms of these representations in that some of the visual conventions used are meant to both represent objective

information and elicit an emotional understanding for what is happening during each stage. I will later cover a legend associated with the conventions used to develop the model although some of these descriptions will be purposefully abstract to achieve the balance I described above.

As a whole, these three layers of information work together in common purpose. That purpose is to represent a holistic understanding of the experience for parents when it comes to the death of a baby to help invite further understanding and critique for what can be done to better the experience. The last thing worth raising, before getting into details of the experience model, is with respect to the context previously shared in this report and their connection to the model.

The context as previously described is the backdrop for the experience and critical to its understanding. To be specific, I see context as helping to frame the realities that have direct impacts on the experience but are largely unchangeable elements as they relate to potential practical interventions. The context describes facets of our current societal and cultural norms related to the experience.

Now I will get into the specific details related to introducing the model.

4.3 The Domain Model: Factors of the Experience

The following domains illustrate factors affected when parents experience the death of a baby. These factors vary in severity and length of time because they are largely individualistic and based on specific circumstances. They play a role in how parents respond over the course of the recovery lifecycle, both positively and negatively. I will first introduce the model and then expand on each domain.

The domain model as I have presented here is represented based on my analysis and synthesis. It does implicitly represent knowledge found in the literature based on the methodology followed but it does not directly draw on the literature in an attempt to make these domains and factors comprehensive or rigidly adhere to the existing literature. That said, I have compared the domain model to information found within *Empty Cradle, Broken Heart* (Davis, 1996) as a way to test the validity of the content but not with the intention to fully describe all possibilities. This is to say that what is presented here is done to place an emphasis on the domains and factors as they are framed. None of following domains have been found to contradict any information found in the above-mentioned book.

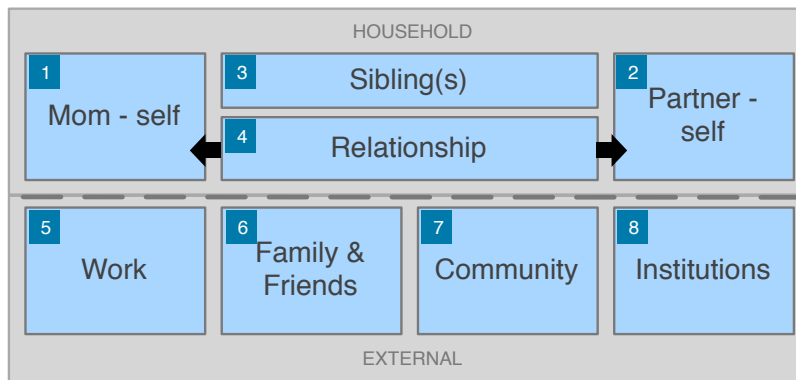


Figure 6: Domain Model

The model is primarily broken in to two fundamental categories: 1) domains within a household, or family unit; and, 2) those external to the home. Each of these domains have a variety of primary factors when it comes to the areas of change that are occurring,

albeit not an exhaustive list. The factors associated with each of the domains emerged as part of the context mapping exercise when analysing the areas changing over the course of the experience.

4.3.1 Domain 1: Mom as self

This covers the main factors of the experience as related to mom as an individual and covers areas that impact her being.

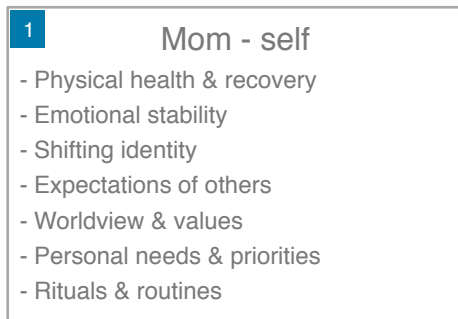


Figure 7: Factors Affecting a Mom

4.3.2 Domain 2: Partner as self

This covers the main factors of the experience as related to a mom's partner, either male or female, as an individual, and covers areas that impact their being. It should be noted that this domain may not exist in particular circumstances.

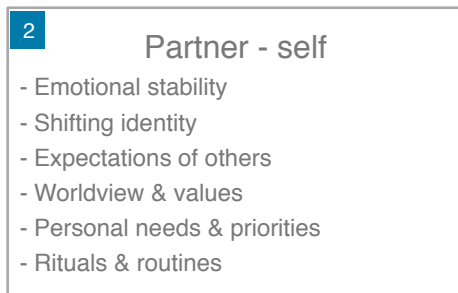


Figure 8: Factors Affecting a Partner

4.3.3 Domain 3: Siblings

It is not always the case that parents have living children at home prior to the death of a baby: But this domain addresses some of the complicated factors that arise when the experience includes siblings whom also need support during this experience.

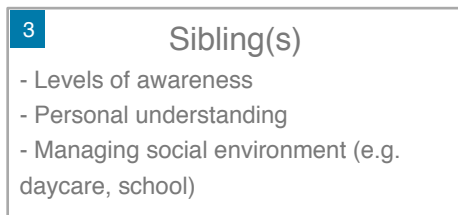


Figure 9: Factors Affecting Siblings

4.3.4 Domain 4: Relationships

As a domain, the relationship between a mom and her partner includes some critical factors and can be both the source of negative tension or positive support as the experience proceeds over time.

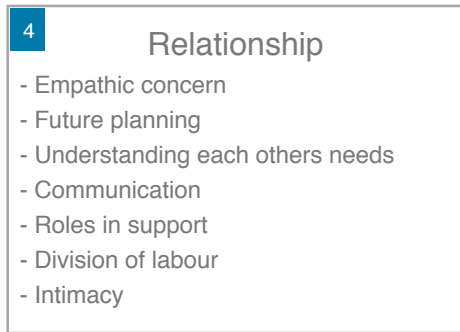


Figure 10: Factors Affecting a Relationship

4.3.5 Domain 5: Work

This domain considers the realities for both mom and her partner in terms of earning money for the family unit and related considerations that influences the experience.

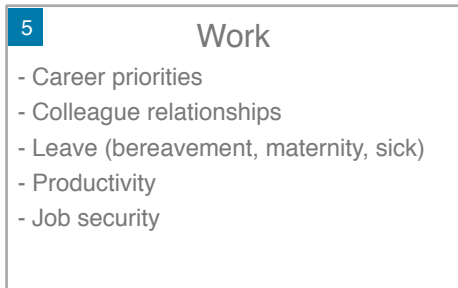


Figure 11: Factors Relating to Work

4.3.6 Domain 6: Family & Friends

Family and friends are those whom have surrounded mom and her partner prior to the experience and play an important role in taking on support roles in helping a family unit as a whole. The experience can have the affect of reshaping the nature of these relationships. This not only includes factors relating to mom and her partner, but can also include supporting siblings and relieving pressures identified in the relationship domain.

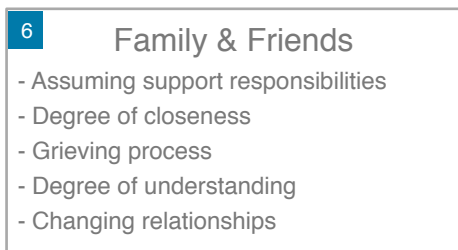


Figure 12: Factors Affecting Family & Friends

4.3.7 Domain 7: Community

The community groups mom and her partner were members of, relate to social and professional networks based on some common interest. These include physical and virtual communities like new mom groups, alumni networks, running groups, organizational boards, sport teams, etcetera whereby mom, partner, or both are participants in community and social activities. With this comes an implicit importance placed on communities relative to parents' shifting needs, impacting their participation levels and the perceived roles these communities play in parents' lives. The role of community continuously evolves over the course of the experience.

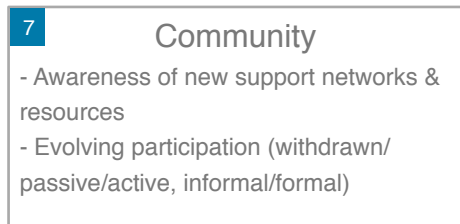


Figure 13: Factors Affecting Participation in Community

4.3.8 Domain 8: Institutions

Institutions refer to complex organizations that are important to navigate in terms of understanding and accessing certain supports but also necessary in terms of satisfying bureaucratic processes necessary for handling that death of a baby. These institutions include: government, medical, day-care/school, volunteer organizations, social services, and funeral homes.

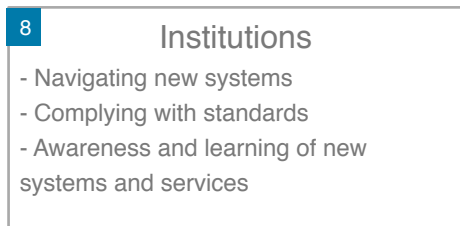


Figure 14: Factors Relating to Involvement in Institutions

4.4 The High-level Process Model: View of All Stages

The high-level process diagram denotes the major stages and characteristics generally applicable to each stage. This model is meant to help clarify the experience parents go through over time and helps illustrate the types of supports that would be most valuable. These stages are not as clearly separate from one another or sequential as the diagram suggests, but instead notional to represent an illustrative process. First, I'll introduce the architect of the process model view and then I'll introduce distinct charts that contain the detailed information that characterizes the experience at each stage relative to the others.

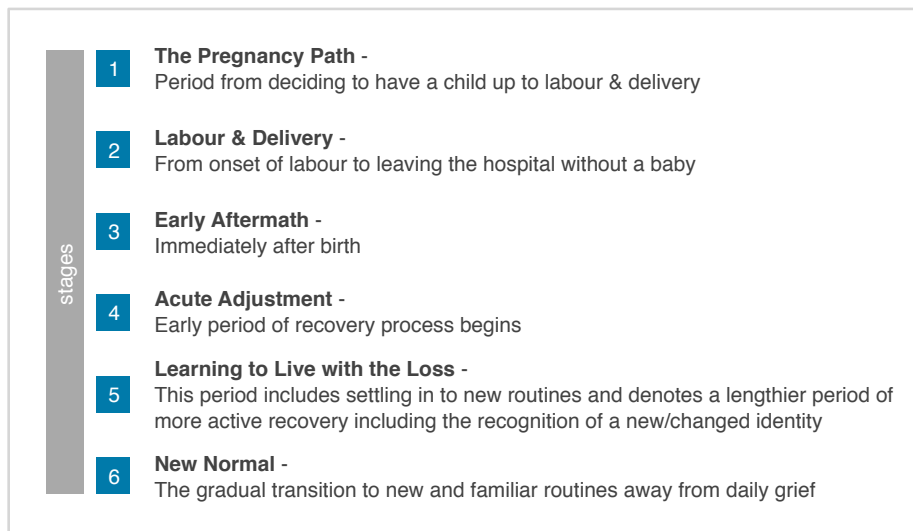


Figure 15: Summary of Six Stages of the High-Level Process Model

The above model represents six stages related to the experience including that of the pregnancy leading up the death of a baby. Some stages, more than others, have a clear starting and stopping point while others have blurring boundaries in that regard. In

addition, the amount of time a particular stage could take is highly variable based on individual circumstance's, so the treatment of time is notional although the model does emphasize that the 'Learning to Live with the Loss' stage is of particular emphasis compared to the others. The purpose of structuring the stages in this way was to understand where the bulk of supports and influences are occurring during the stages and the nature of those influences.

4.4.1 Supports and Influence during 'The Pregnancy Path'

The primary area that is changing during this phase is the transformative shift toward parenthood, an identity change. Sources of support and influence are varied but the majority arise from social influences, including that of family and friends as changes. These influences are critical as personal identities of a mom-to-be and her partner prepare for what is to come and are critical related to learning to navigate toward the anticipated outcome: a new baby. Medical professionals are important at this stage but due to an 'ignorant bliss⁶⁶', the parent-to-be mindset that is associated with this stage, the influence is lessened and is not as influential relating to the identity shift toward parenthood.

4.4.2 Supports and Influence during 'Labour & Deliver'

This stage is very procedural in nature in its current form as a result of medical institution. Even those under the care of midwives or doulas are transitioned in this direction when the unexpected death of a baby occurs. Consequently, the supports and

⁶⁶ Based on author's personal reflections. This idea became really clear for me when you hear conversations surrounding other pregnancies and hear problems arise like being perplexed on matters like 'how to choose the best stroller?' and then reflect on the fact that this was no different for us before the death of our baby, but now we wouldn't look at such problems the same way.

influences are predominantly those of medical professionals. To a great degree, implicit trust and offloading of decision-making occurs, placing it in the hands of medical professionals, whether knowingly or not. The types of supports and questions occurring at this stage are predominantly about what will happen next⁶⁷.

4.4.3 Supports and Influence during the ‘Early Aftermath’

The nature of this stage is an early need for mom and partner to dampen pain and make sense of what just happened. It is characterized by a high degree of shock⁶⁸. A few different types of supports are critical to this stage and occur concurrently. First is the physical health and recovery of mom, which looks to the medical institution for support and care. Second, is support in navigating procedural concerns by reaching out and asking questions of various institutions: work, funeral home, and government services. Third, supports come primarily from family and friends in terms of taking on or offloading daily concerns, such as cooking meals, and potentially including offloading some of the above procedural concerns. Very little proactive effort to seek supports are made at this stage by parents beyond the bare necessities.

⁶⁷ Based on author’s personal reflections. The types of questions I asked were very indirect, basic and uninformed. Any question I would ask was basically a probe sent out in the hopes that it would result in better information so I could ask better questions.

⁶⁸ Based on author’s personal reflections. It felt like walking through a fog and I remember thinking ‘Is this really happening?’ I was clearly doing stuff, and remember doing it, but at times it didn’t feel real.

4.4.4 Supports and Influence during the ‘Acute Adjustment’ Period

This phase is characterized as the period immediately after the majority of procedural tasks have been completed and these are no longer present as distractions. At this stage it is much easier to tune out the rest of the world and begin to reflect on what has happened. Also at the stage, very little proactive efforts are made and parents are still highly dependent on family and friends for basic support but the same family and friends may also need to remove themselves to resume other responsibilities they temporarily put on hold.

4.4.5 Supports and Influence during the ‘Learning to live with the Loss’ Period

This period is characterized as being a more proactive period in which mom and her partner do what they believe is necessary to recover, both as individuals and as a unit. In some cases, that may mean compartmentalizing grief, but in others it means actively seeking relevant supports for emotional healing. This generally begins with the medical institution but includes reaching out to other areas to see what is available. These include things like Employee Assistance Programs from a workplace, connecting with others to seek advice and guidance, and seeking options as published through various available mediums such as the Internet⁶⁹. These supports are in some ways built into new routines that are relevant at this stage.

⁶⁹ Based on author’s personal reflections. The Internet was an important source because questions emerged quite frequently and it was a beneficial source to seek immediate answers while the thought was still fresh in my mind.

4.4.6 Supports and Influence during the ‘New Normal’ Period

This stage is characterized primarily as an acceptance stage in which actions are associated with relinquishing supports that were critical during the period of recovery. At this point, formal supports are replaced by a new internal confidence and internal or personal supports enabling one to move away from any formal external supports. It doesn't mean these are forever removed, but are no longer a dominant part of regular routines. One's self becomes the most significant influencer in support of the self, one's partner, and potentially sibling(s). This also turns the idea of parents needing support to now becoming a supporter for others in similar circumstances⁷⁰.

⁷⁰ Based on author's personal reflections. The idea of the 'new normal' was a common one discussed during PAIL support group meetings. It meant acknowledging that life would be forever different and the memory never die, but that one was ready to resume a 'normal' lifestyle.

4.5 The High-Level Process Model: Details for All The Stages

The detailed view of the high-level process focuses primarily on bringing to life the interrelated facets of the experience in a way that helps make sense of the entire experience. This is a way to help contrast the different stages and notionally related characteristics.

4.5.1 High-level Process Model Detailed View (Chart 1)

The following chart focuses on depicting the characteristics of the full six stages as they pertain to the modes and mindsets of parents and resultant domains affected.

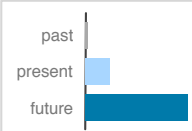
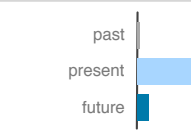
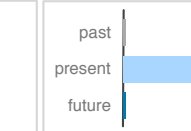
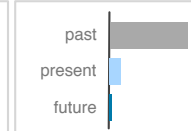
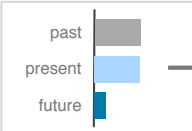
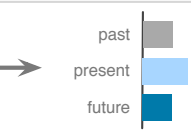
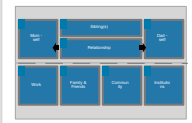


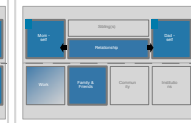

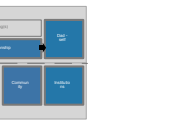
	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
stages	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity	The gradual transition to new and familiar routines away from daily grief
modes & mindsets	 <p>Parents' mindset is oriented in the future beginning to assume future identity both in terms of planned and dreamt changes.</p>	 <p>An abrupt shift occurs immediately superseding future dreams, bringing parents to an immediate focus on the next few moments; although, the abrupt shift causes shock and an inability to clearly focus.</p>	 <p>A clear focus on the present with a heavy dependence on others around to help clarify and explain things to come.</p>	 <p>Another abrupt shift occurs to reflect on and relive the traumatic events. Responsibility for the present is offloaded as much as possible to available supports.</p>	 <p>A sense of rebalancing begins with the idea that the worst is over and healing can begin. A past and present focus begins to dominate with the use of distraction and escape to help diminish emotional distress. Looking forward the future slowly comes into focus but guardedly and in relatively short timeframes that slowly expands.</p>	 <p>Sensitivity surrounding the past and looking forward diminishes with an attitude of acceptance of the past events while still being unpleasant.</p>
domains affected	 <ul style="list-style-type: none"> - All domains are being affected as parents prepare for a new baby. - Changes in the domains are helping parents prepare for this new identity. 	 <ul style="list-style-type: none"> - Normal routines are abruptly halted. - An immediate dependence is placed on the healthcare system/supports to determine appropriate course of action and make sense of the situation. In certain cases, critical decisions are offloaded. - New roles are intuitively assumed. 	 <ul style="list-style-type: none"> - A flurry of activity and decisions. - Early communication and processes with individuals or institutions needing to be aware (close family, work/HR, school/caregiver, government). - Early decisions (funeral, autopsy, name, memorializing). 	 <ul style="list-style-type: none"> - Parents intuitive response shapes new behaviours. - New roles and a lack of understanding within a relationship can introduce tension. - Family and friends take on new and varying roles to support. Tensions can arise from interactions - For Partner, work considerations. 	 <ul style="list-style-type: none"> - A more active and aware stance begins in seeking resources and support in terms of personal changes for mom and partner. - For mom, considering how and when to reintegrate to work. - For partner, an eventual shift from attempts to fix things for mom and focus on own grief. - Navigating institutions and communities - seeking resources and support, whether for active or passive participation. - New patterns and stability are returned to the relationship as mom and partner develop new understanding of one another. 	 <ul style="list-style-type: none"> - Acceptance sets in regarding new personal identities with better emotional stability and mature coping abilities. - Relationship begins to foster discourse for considering the future. - New community relationships and participation are formed. - Begin to relinquish institutional supports for recovery.

Figure 16: High-Level Process Model Detailed View (Chart 1)

4.5.2 High-level Process Model Detailed View (Chart 2)

The following chart focuses on further details extending the previous. The details contain both the dominant emotions and feelings for a given stage along with its primary activities.

	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss		New Normal
stages	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity		The gradual transition to new and familiar routines away from daily grief
emotions / feeling	<ul style="list-style-type: none"> - Many emotional highs and lows - Imagining a new future - Many unknowns = stress and anxiety - Joy and optimism 	<ul style="list-style-type: none"> - Disbelief (and still hopeful) - How will we get through this? - Grateful for time with baby - This is cruel / physically violated - I want to be invisible - Barely able to think or process what happened - Uncertainty, what happens next 	<ul style="list-style-type: none"> - Need to keep busy (partner) - Unable to perform activities of daily living (mom) - Unable to think clearly - It is getting worse - I need space - It hasn't sunk in yet - Cruel reminders are everywhere, including my body (mom) 	<ul style="list-style-type: none"> - Everything overwhelms - Guilt spiral - No one understands & feelings of being helpless - Extreme fatigue - Pressure to act normal - Intense sadness - How can this be 'fixed' 	<ul style="list-style-type: none"> - Frustration with progress (lack) - Physical and emotional fatigue - Need for escapes - Wanting distractions - Need to hold it together in certain situations (work, social functions) - Constant stress and anxiety - Easily overwhelmed 	<ul style="list-style-type: none"> - Fear of others' expectations (family/ social routines/work) - Constant need for change - Past activities/passions no longer have same meaning - Desire to make major lifestyle changes - Gradual shift to being positive 	<ul style="list-style-type: none"> - There are still inner conflicts (am I a parent?, how do I speak of my child?) - Pain is still there, but it is manageable - Ability to allow feelings of personal joy back in - Resistance to 'move on'
activities	<ul style="list-style-type: none"> - Planning for pregnancy (desired checklist for being ready) - Attempting to get pregnant - Learning of successfully getting pregnant - Navigating healthcare options - Sharing news and celebrate - Monitoring and appointments - Planning and preparations - Dreaming of the future 	<p><i>note: sequence varies</i></p> <ul style="list-style-type: none"> - First learn of baby's death - Initial questions & seek information on 'what next' - Schedule and prep for induction or natural onset - Logistical arrangements (e.g. work) - Share news with select family/friends - Labour - Spend time with the baby - Collect mementos - Make initial time sensitive decisions (burial/cremation, naming, funeral home, autopsy) - Leave hospital without a baby 	<ul style="list-style-type: none"> - Prepare funeral arrangement (arrangements for body) - Post-partem recovery - For mom, physical reminders occur (e.g. breast milk) - Follow-up appointments to monitor recovery - For partner, instinct to attempt to fix things and get back to 'normal' - Tell/support siblings 	<ul style="list-style-type: none"> - Isolation - Lean on close family and friends for getting through the day - Pain from a lack of others understanding - Receive condolence flowers/cards/ messages/visits - Gradual firsts (getting out of bed, showering, walk outside) - Waiting to hear what went wrong 	<p><u>Recognizing the Loss</u></p> <ul style="list-style-type: none"> - Opening up to others (sharing memory box, talking with others) - Physical objects/ memorials - New behaviours in memory of baby's life - Imagine baby's identity 	<p><u>Releasing the Emotions of Grief</u></p> <ul style="list-style-type: none"> - Accept changes - Anger and dwelling on regrets - Coping with triggers - Rumination - No win situations (catch22) 	<ul style="list-style-type: none"> - Readjustment/returning to work - Return to activities placed on hold - Ability to comfortably speak to others about the baby - Acceptance of new identity - Planning for future - Considering whether to attempt another pregnancy - Discontinue/finish activities associated with grieving and see progress as an accomplishment - Develop new rituals to remember/memorialize
					<p><u>Developing New Skills</u></p> <ul style="list-style-type: none"> - Evaluate options for personal/family recovery - Better understand partner - Develop coping strategies - Seek experience of others 	<p><u>Reinvest Emotional Effort</u></p> <ul style="list-style-type: none"> - Gradual steps to larger goals - Yearn for change - Consider how to connect with/to others 'like me' - Consider future plans 	

Figure 17: High-Level Process Model Detailed View (Chart 2)

4.6 Detailed Process Model: Details for Each Stage

The following series of visualizations depict the experience by each stage. The result is not only a representation for what is happening but also the identification of key issues that are occurring at each stage. These issues are then linked back to the domains in which they most appropriately originate. The relevant information for each stage is self-contained in each visual and the legend for interpretation will be described next.

4.6.1 Legend: Decoding the Detailed Process Model by Stage

Before getting into the details for each stage, the following legend covers the primary elements I used in the visual representations for this layer of the experience model. Any one-off deviations to the conventions used or particular points of context specific to a view will be further address using footnotes.

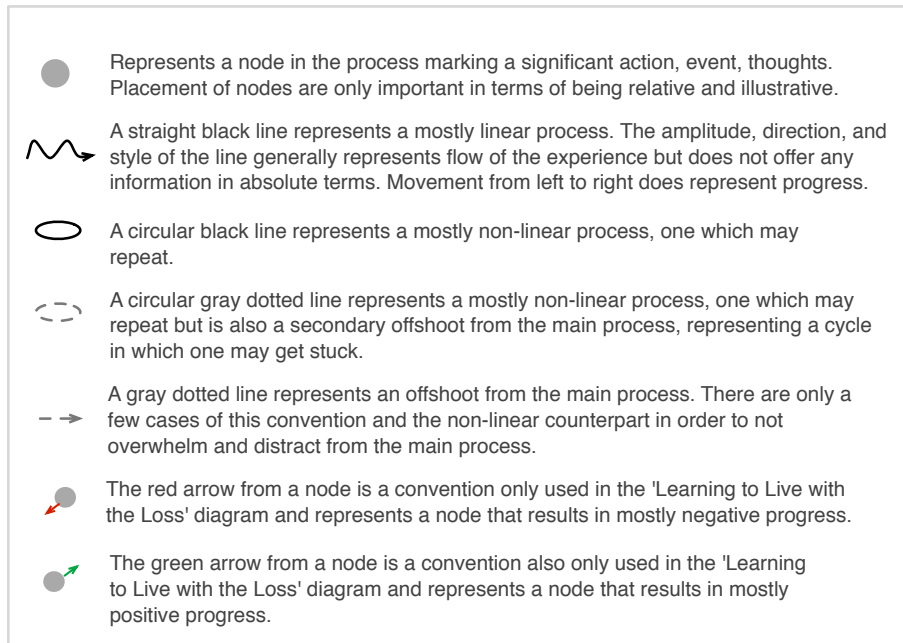
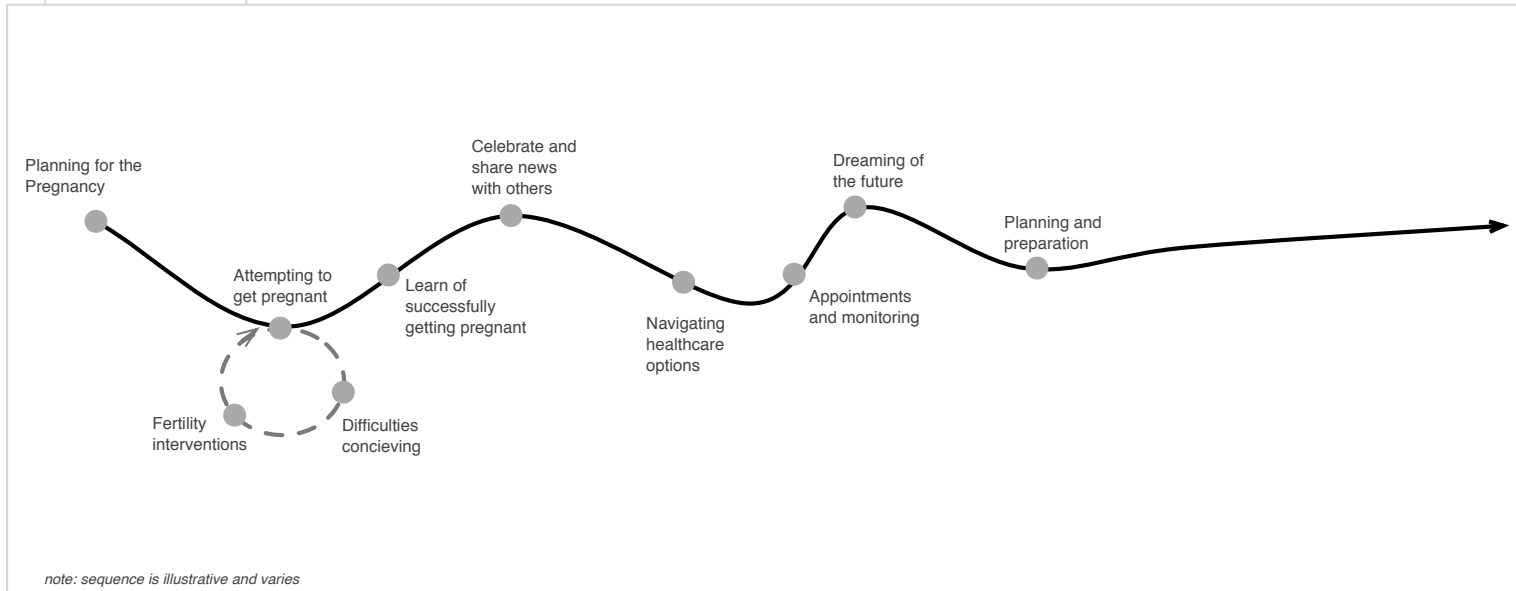


Figure 18: Legend for Reviewing Detailed Process Model

4.6.2 Detailed Process View: The Pregnancy Path

This stage is dominated by a shift toward a future identity as a couple - a move toward parenthood by either starting or growing a family. This can include both extreme emotional highs and lows depending on the path leading up to and during a pregnancy. The experience and preparations leading up to and during a pregnancy, along with the degree to which new identities are assumed in advance, has a direct impact on the severity of the initial impact of a loss and the subsequent grief response on the path toward recovery.

stages	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity	The gradual transition to new and familiar routines away from daily grief



ISSUES

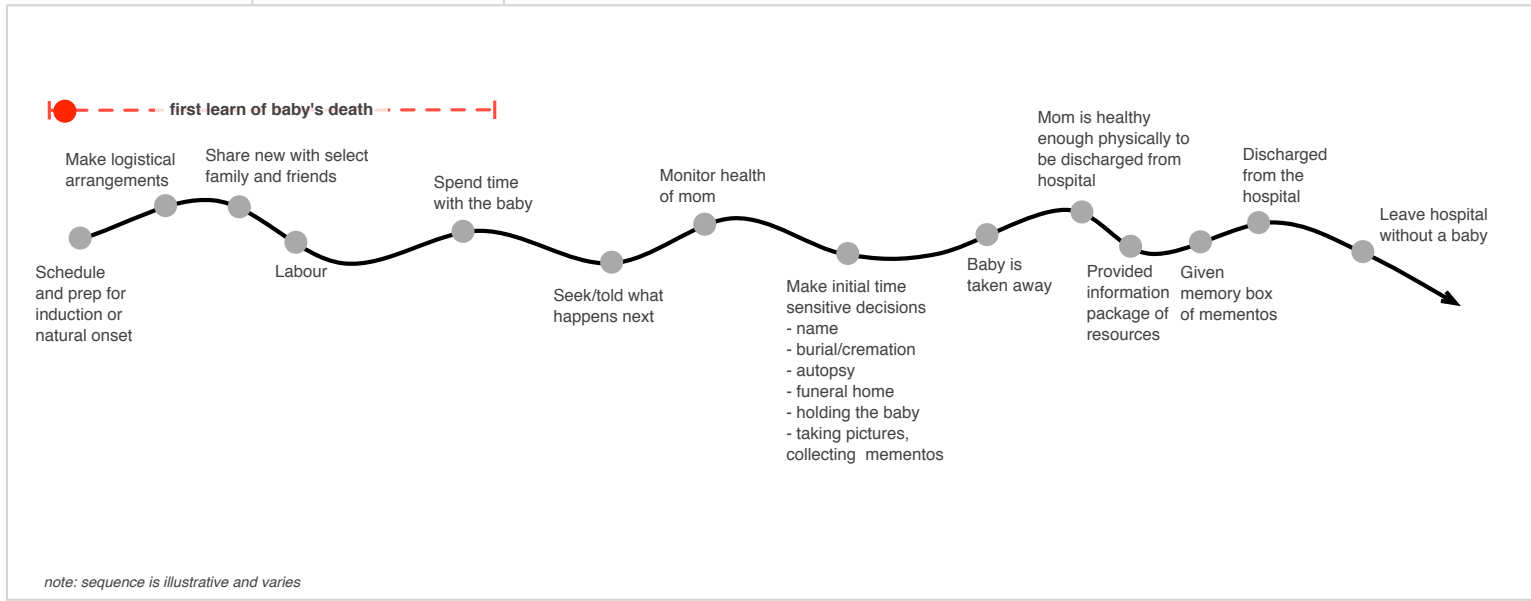
<p>Dependence on healthcare professionals for monitoring health status during pregnancy</p> <p>8</p>	<p>Stress and anxiety associated with difficulties conceiving - adding pressure to other areas</p> <p>1 2 4</p>	<p>Pregnancy and related areas dominate all areas of life, shifting personal identity</p> <p>1 2 4</p>	<p>Expectations and social pressures from family and friends</p> <p>6</p>	<p>Tensions associated with expectations at work leading up to informing boss and leading up to leave.</p> <p>1 5</p>
<p>legend for domains related to issues: 1 Mom - self 2 Partner - self 3 Sibling(s) 4 Relationship 5 Work 6 Family & Friends 7 Community 8 Institutions</p>				

Figure 19: The Pregnancy Path - Detailed Process View

4.6.3 Detailed Process View: Labour & Delivery

This stage can be characterized as one in which to-be parents submit a significant degree of decision making and judgment over to healthcare professionals and go with the flow as dictated to them. It is generally accompanied by shock, disorientation, and disbelief, as to-be parents are overwhelmed with the actions going on around them, too quick to appropriately digest and consider. Decisions are required but implications minimally considered. When the dust finally settles from this whirlwind, newly bereaved parents face the most solitary task imaginable, leaving the hospital without a baby.

stages	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity	The gradual transition to new and familiar routines away from daily grief



ISSUES

Critical decisions are made during this stage that can/do lead to later guilt and regret	Some decisions are made on behalf of parents who would have considered differently if given informed choice	Lack of awareness of what legally needs to occur after the baby has died	Limited guidance provided as to options, including implications, related to the above time sensitive decisions	Parents are not warned or prepared for when they walk out of the hospital (e.g. breast milk, visual triggers)	Supports for emotional pain and trauma not available in the hospital	Poor interactions with healthcare staff can have long lasting effects at a very vulnerable time	Euphemisms used when delivering the bad news can lead to initial misunderstanding during a period of shock
1 2	1 2	8	7 8	1 2	1 2	1 2	1 2

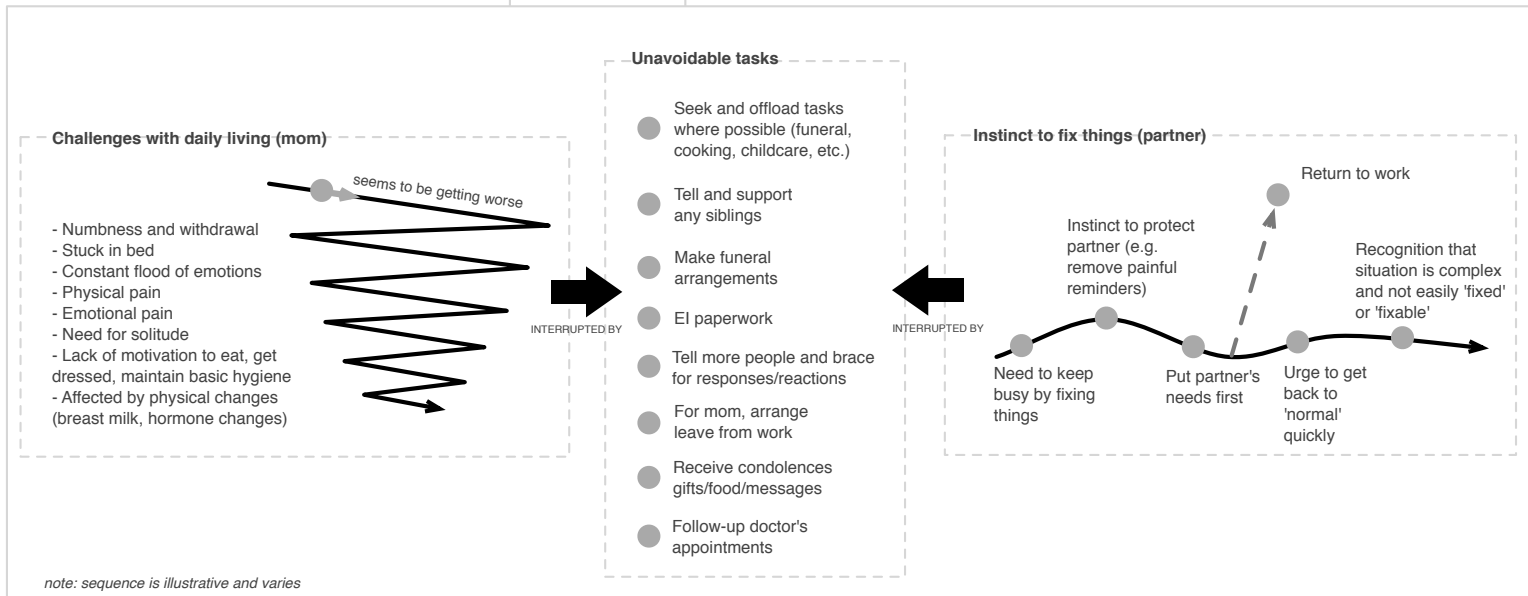
legend for domains related to issues: 1 Mom - self 2 Partner - self 3 Sibling(s) 4 Relationship 5 Work 6 Family & Friends 7 Community 8 Institutions

Figure 20: Labour & Delivery - Detailed Process View

4.6.4 Detailed Process View: Early Aftermath

This stage includes a divergence in the type of responses by each individual in a relationship: mom and her partner. On one hand, mom is overwhelmed having challenges with basic daily functions and on the other hand her partner attempts to fix the situation as a stoic impulse. While these two distinctly different responses are occurring, other areas need attention and are a forced distraction away from each others' initial responses to process and deal with what needs to happen. This early stage is largely a blur and dedicated to the most basic modes of survival, participating in only what is absolutely necessary. Emotional and physical pain is very raw.

stages	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity	The gradual transition to new and familiar routines away from daily grief



ISSUES

Differences in initial grief response between mom and partner can lead to misunderstanding and tensions in the relationship 4	Interactions with family and friends, while generally well intentioned, can lead to further pain and tensions in these relationships 6	Lack of knowledge, understanding, and resources for what to do to support a sibling(s) 3	For mom, overwhelmed by everything and unaware of what to be prepared for until something occurs 1	For partner, may need to return to work before grief process has even had a chance to begin 2 5	Follow-up doctor's appointments taking place in the same environment as the loss, causing additional pain 8
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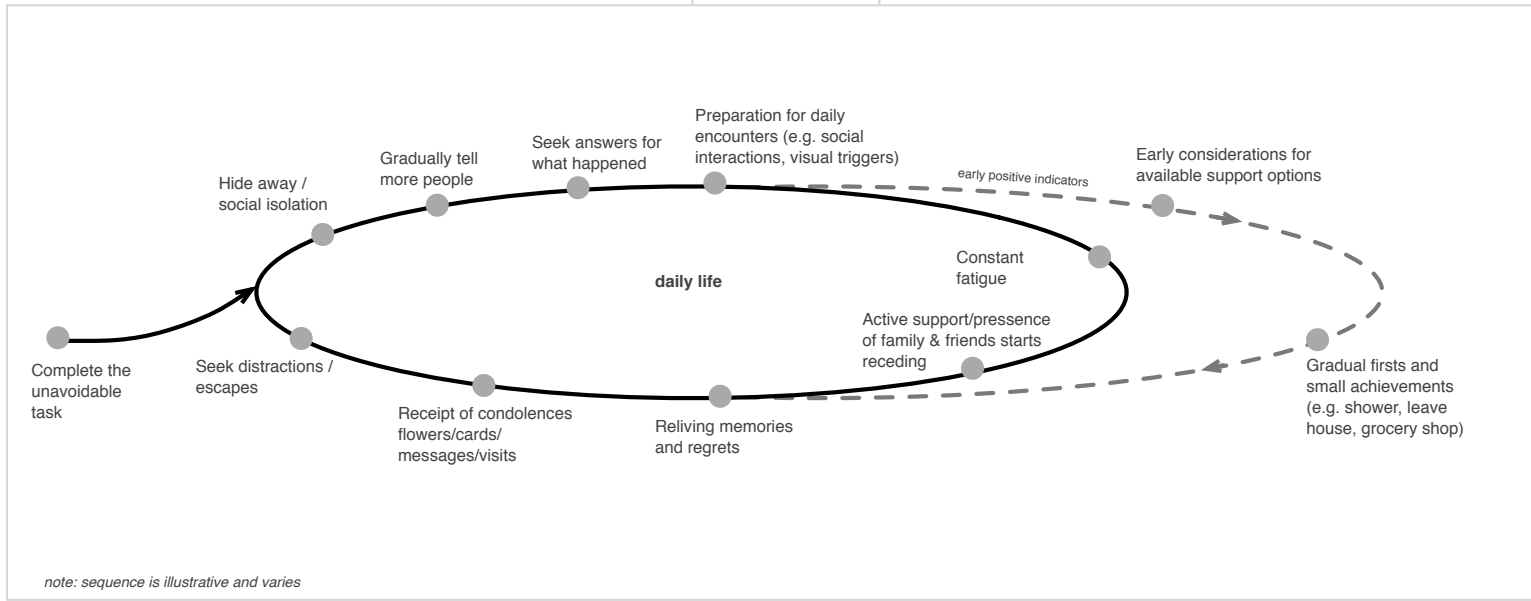
legend for domains related to issues: **1** Mom - self **2** Partner - self **3** Sibling(s) **4** Relationship **5** Work **6** Family & Friends **7** Community **8** Institutions

Figure 21: Early Aftermath - Detailed Process View

4.6.5 Detailed Process View: Acute Adjustment

By this stage, the reality has begun to set in. The pain is still very raw, but fewer undesirable distractions need direct attention. Staying isolated or close to home dominates this stage as overall energy levels are extremely low. Most of those who have needed to know about the death of a baby have been made aware but now the news gets shared more voluntarily and more people find out second hand. Many people, including family, friends, and acquaintances, make misguided remarks that are hurtful and reinforce feelings of isolation - others seemingly do not understand.

stages	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity	The gradual transition to new and familiar routines away from daily grief



ISSUES

Family and friends have begun to move on resulting in less support 6	Pain and fatigue impacts proactive attempts to get support 1	Few resources for family or friends in terms of how to support the bereaved 6	Lack of understanding of how changes in daily behaviour and routines are impacting any sibling(s) and what to do about it 3	Feeling for parents that no one understands and parents question whether it is normal to have these feelings 1 2	Minimal online resources available 1 2 4 6	Support options require proactive efforts to seek out at a time when minimal energy is available 1 2
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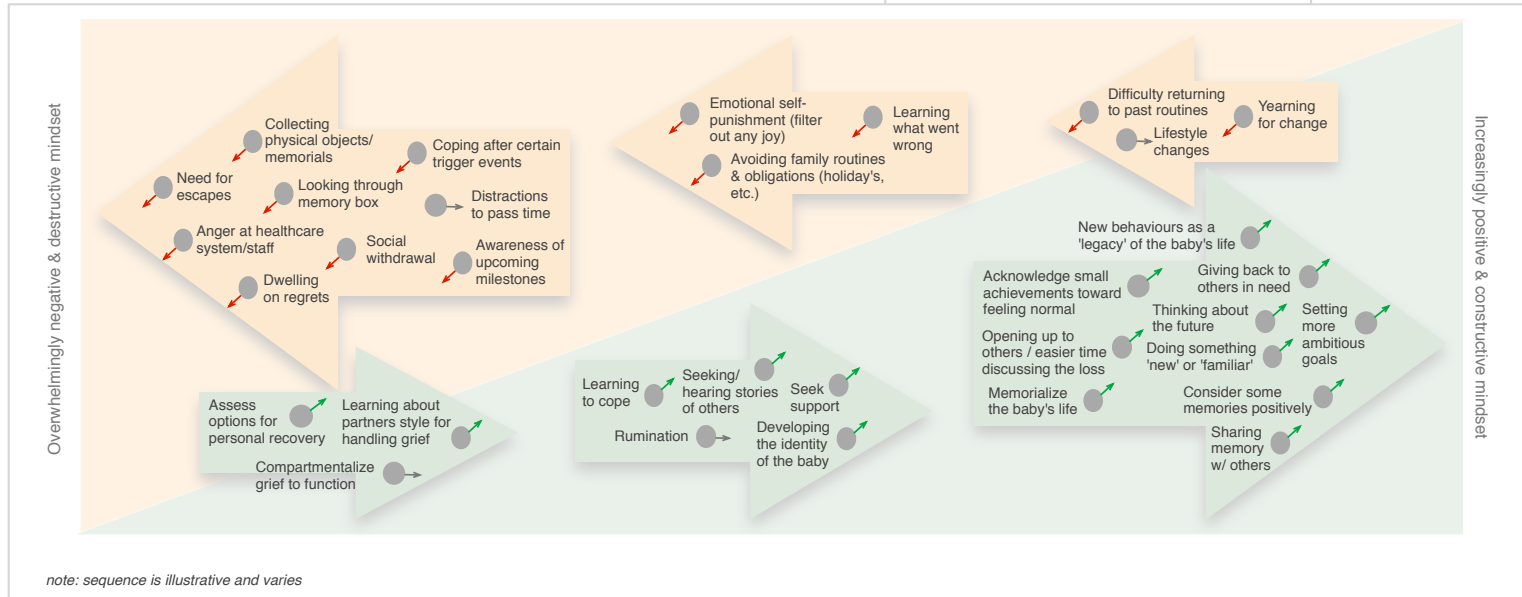
legend for domains related to issues: **1** Mom - self **2** Partner - self **3** Sibling(s) **4** Relationship **5** Work **6** Family & Friends **7** Community **8** Institutions

Figure 22: Acute Adjustment - Detailed Process View

4.6.6 Detailed Process View: Learning to Live with the Loss

This stage is primarily a complex learning process for parents and includes many setbacks along the way. It includes relearning about one's self in terms of personal priorities and needs, learning about changes a partner is experiencing, and the development of new understanding within a relationship. It also involves learning outside of the household with a more proactive stance taken to navigate options for support, whether from friends, communities, and/or professionals. Initially the learning process is myopic satisfying only short-sighted issues but gradually broadens.

stages	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity	The gradual transition to new and familiar routines away from daily grief



ISSUES

Time pressures to resume 'normal' activities creates tensions in terms of expectations placed on parents (social, work, holidays)

- 1
- 2
- 4
- 5
- 6

Challenges navigating and a lack of understanding for what support options exist and which are well suited to individual needs

- 1
- 2
- 7
- 8

Pressure to move on and accompanying fear of showing vulnerability

- 1
- 2

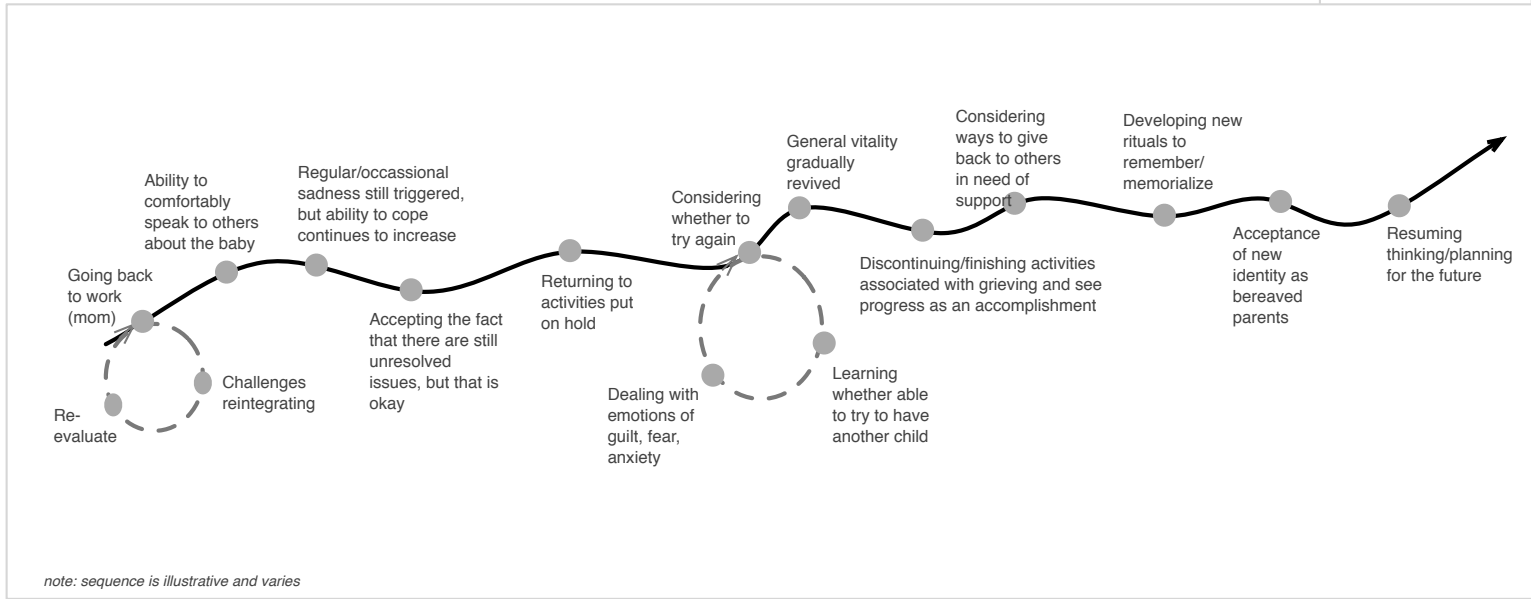
legend for domains related to issues: **1** Mom - self **2** Partner - self **3** Sibling(s) **4** Relationship **5** Work **6** Family & Friends **7** Community **8** Institutions

Figure 23: Learning to Live with the Loss - Detailed Process View

4.6.7 Detailed Process View: New Normal

This stage is characterized as the transition back to normal living and away from interim behaviours and routines associated with actively grieving the loss. This stage is not without its painful setbacks and reminders but coping mechanisms are more advanced, enabling parents to not be disrupted as abruptly or often. The challenge at this stage is how to resume a healthy lifestyle that does not forget the past but instead incorporates the past's painful events and memories as an integral part in a reshaped identity.

stages	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity	The gradual transition to new and familiar routines away from daily grief



ISSUES

There may be some personal issues that remain unresolved

Minimal options for how a bereaved parent can give back and help others

1 2

7 8

legend for domains related to issues: 1 Mom - self 2 Partner - self 3 Sibling(s) 4 Relationship 5 Work 6 Family & Friends 7 Community 8 Institutions

Figure 24: New Normal - Detailed Process View

5. Findings

With all of the data collected in and analysed, in this section I will go over the major findings of this study. While the experience model has been designed to contain specific issues associated with the different stages in the process, the following findings will address the main themes covering all that has emerged from this study. This will include combined findings from all the sources of data: the experience model, literature, and interviews. The findings will also cover topics addressing stakeholders beyond themes solely related to parents.

5.1 Lack of Support for Healthcare Professionals

As covered in a variety of places in this report, there is a gap a healthcare professionals' education for how to support parents through a loss⁷¹. This gap exists for a variety of reasons. It exists because of the embedded belief in the medical institution as a place for solving problems⁷². It exists for practical reasons; the education process is already lengthy enough for professionals and all possible medical cases cannot be covered⁷³.

⁷¹ "Grief education is not routinely included in medical training, and death is not a regular feature of obstetric or pediatric practice" (Davis, 1996, p 172).

⁷² This finding was found in the interviews and literature. Doctors are professionally socialized through intense education to develop reason and apply wisdom toward fixing problems (Pitkala & Mantyranta, 2003). The health system demands this in an efficient manner.

⁷³ Identified as a barrier from expert interviews.

For those reasons among others, healthcare professionals are not getting the support they need to properly handle and cope with certain situations⁷⁴, in particular an unsolvable problem⁷⁵ like the death of a baby. The result for healthcare professionals is that much of the critical learning is being done on the job⁷⁶. This is learning that can be emotionally taxing to professionals, just as it is for parents, but is an occupational reality. This can lead to healthcare professionals responding intuitively but not necessarily based on the best possible practices, which contributes to unpredictable and inconsistent experience for parents.

This is a situation that is beneficial for no one. Stress, anxiety, and dissatisfaction are on all sides. But there are bright spots amidst this problem. There are examples of volunteer-based organizations that have run educational seminars containing panels of parents whom have lost a baby. Parents share their experiences as a way to shed light on this topic for healthcare professionals. The use of personal stories is said to be an effective approach for creating an empathic understanding between healthcare professionals and bereaved parents⁷⁷.

But this is far from enough. Supporting those who support bereaved parents is critical in developing a better foundation of empathetic understanding between parents and professionals. And while approaches like the above are great at making headway in this area, more is needed.

⁷⁴ Expert interviews.

⁷⁵ I refer to the this as an 'unsolvable problem' because the only way this problem could be solvable, from a parent's perspective, would be by bringing the baby back to life, which is not a possibility.

⁷⁶ Expert interviews.

⁷⁷ Example shared and indicated as being helpful for healthcare professionals (expert interviews).

5.2 Barriers to Knowledge Sharing Within and Between Hospitals

It has been found that limited knowledge sharing exists across and within hospitals for handling topics like the loss of a baby. While this finding is less clear in terms of where structural gaps are or how this compares to other topics, it came from a number of sources over the course of this study. First, it came up during the auto-ethnography when observed that parents had very different experiences⁷⁸. For example, the types of professionals that interacted with them, whether anyone followed up with them, and the types of mementos parents were (or were not given) leaving the hospital. It also came up both directly and indirectly during the interviews when discussing barriers for change.

From what was found, information is being shared from one hospital to the next, but it is occurring by informal means. It is happening when employees change jobs bringing with them past experience. It is also occurring during networking functions and other events whereby practitioners are coming together from different locations. These are the primary modes in which this study found evidence of ways in which practices were permeating inter-hospital boundaries.

Challenges with knowledge sharing also relates to practices within a particular hospital. It was found that cases where specific practitioners, with the previous experience in this domain, were being scheduled when a loss was expected. This places an uneven burden on those individual practitioners but also contributes to on-the-job experience not being evenly distributed. This is critical when considering that currently on-the-job mentoring is one of the primary means for practitioners to learn about this domain⁷⁹.

⁷⁸ Based on author's personal reflections. This occurred when reflecting on stories shared amongst peers at PAIL meetings.

⁷⁹ Expert interviews.

But these challenges are likely a more important finding when considering a broader range of relevant topics, not just the challenges associated with the death of a baby. This is an important challenge in considering how to become more efficient, an endemic problem of healthcare.

It is entirely possible, and unclear from the data supporting this finding, that this challenge is not related to that of knowledge sharing practices but instead has other characteristics. It could be more related to what criteria is used to define what is shared. It could be that knowledge is being shared it just isn't being used or implemented in to practice. It could be related to power dynamics appropriating attention based on a given set of priorities. It could be related to the numerous administrative challenges demanding a focus on core priorities first, which potentially don't support collaborative practice.

These are just speculative examples to illustrate that while it was clearly evident that limited knowledge sharing exists for topics such as the death of a baby, it is unknown from the findings what is the real cause and problem behind this. Further research and investigation, specific to this topic, is required to better understand this finding as it relates to the death of a baby.

5.3 The Need to Humanize the Initial Hospital Experience

The most consistent and dominant finding of the study was that surrounding the importance of the hospital experience in those moments close to when the baby first dies. It was consistently found that the way in which the parent experience developed over time was linked to decisions and events that occurred during that initial experience in the hospital⁸⁰. These being connected to

⁸⁰ Based on author's personal reflections. Found in personal reflections and confirmed as a primary theme from the expert interviews.

significant later activities and actions fuelled by regret, anger, trauma, stress, anxiety, among others triggered when a parent later has the capacity to reflect.

There are more nuanced variations, but these issues primarily arise based on the interactions that parents have with healthcare professionals and related medical procedures. What is important in these crucial moments was whether those interactions demonstrated a level of empathy and were understandable by parents.

Even though parents are generally disoriented and in a state of disbelief, their senses and resultant ability to recall even those most subtle details are highly attuned during this time. This includes examples like recalling minor word choices by practitioners that didn't quite make sense, unanswered questions around why certain things were done with the baby's body, to cite a couple. The point is, the little things are in fact the big things when it comes to the experience. The little human touches that occurred during those moments, aside from the necessary medical procedures, go such a long way to being important to the experience, even if not acknowledged or realized until much later.

Upon reflection, parents can generally rationalize that the event was terrible and traumatic, but what is challenging for parents are the unknowns surrounding certain decisions that go unanswered or those demonstrating a lack of empathy, even if unknowingly⁸¹. There is a yearning for some level of acknowledgement as to the emotional pain that is being experienced⁸².

But there are examples that describe how some experiences were better than others. The starting point comes from healthcare workers that are able to make an empathetic connection with parents, but goes further to a hidden truth. This hospital

⁸¹ Author's analysis and reflection.

⁸² Importance for acknowledgement came up as a secondary factor in the interviews related to the primary theme of societal ignorance.

experience is not only an opportunity to monitor, assess and resolve immediate health concerns but it is also the opportunity for parents to be parents for their baby⁸³. In the case when the death of a baby occurs, it is the primary chance to directly be in contact with the baby and it is a window of time that is finite and precious. This is implicitly why decisions like taking the baby away from its mother for a period of time, even if medically important, are particularly painful, especially when a parent is not informed of the rationale.

Some examples of where healthcare professionals who have had this understanding are in cases where they encouraged parenting choices for parents to do things like: hold the baby⁸⁴, read the baby a story, take photos, provide space for parents to be alone as a family, to name some, but there is more to be done along with greater consistency being applied. Because this window of time is so short amidst a time of great shock and pain, the more healthcare professionals are making time to lessen the emphasis on medical processes and encourage parents to be parents goes a long way toward laying the groundwork for painful memories being replaced⁸⁵, in the longer term, with precious and important memories, even fond memories.

⁸³ This idea was shared in an interview and later became a simple way to characterize a number of different challenges in the hospital experience (expert interview).

⁸⁴ "In 1985, the Royal College of Obstetricians and Gynaecologists in the UK published guidelines, recommending that after a stillbirth "staff should create an atmosphere which encourages parents to see and hold their baby" (Hughes, Turton, Hopper, & Evans, 2002).

⁸⁵ Author's conclusion based on the collective evidence of the study. It is acknowledged that this conclusion is not supported by other research.

While the literature does not directly⁸⁶ speak of healthcare professionals encouraging parents to parent, there are some practices that implicitly acknowledge the importance of that early parenting time in the hospital. Specifically, the practice of encouraging parents to hold their baby after the baby has died. Some recent research calls in to question that longstanding wisdom and directive suggesting that parent's closeness to the baby (holding, seeing, or not seeing) has a direct negative correlation to the level of post-traumatic stress symptoms⁸⁷. While this literature doesn't call for the abolishment of this practice, in my view it offers evidence of how different domains of literature can offer differing perspectives regarding a phenomenon, leading to potentially conflicting conclusion.

To illustrate this point, there is a separate thrust of research related to 'continuing bonds⁸⁸', primarily found in death studies, that suggests a gradual detachment by continuing a relationship with the deceased is critical to healthy readjustment, this being a perspective that would support the notion of holding a baby. The research referred to above regarding PTSD provides a mental health perspective; the research is associated with understanding the negative medical conditions that can result, such as complicated grief⁸⁹ or PTSD⁹⁰. Those findings appear to lean in the direction of suggesting practices like that of holding a baby are actually problematic,

⁸⁶ Gold (2007) covers, through a systematic literature review, the beneficial and problematic interactions between parents and healthcare professionals. As part of this review, many beneficial practices are included that coincide with those discussed in this study although it doesn't draw any conclusions or state why these practices are beneficial. It is my view that drawing a connection directly is important for healthcare professionals to provide the necessary context to help empower their judgment.

⁸⁷ "Suggest that mothers who elected not to see and hold their stillborn infant had a better outcome than did those who did see and hold the infant" (Hughes, Turton, Hopper, & Evans, 2002).

⁸⁸ See Packman, Horsley, Davies, & Kramer (2006).

⁸⁹ Complicated grief is defined as when feelings of grief are inhibiting ones ability to function in daily life.

⁹⁰ Post traumatic stress disorder.

while it should be pointed out that the particular research I am referring to still recognizes that the most important factor is that of offering choice.

There isn't an easy explanation or resolution to these perspectives. The reasoning of both seems logical, sensible, and well intentioned to me as a reader not deeply immersed in either school of thought. With that said, the important thing to take away from the above illustration is that both domains have different objects of inquiry leading to built in bias and an associated set of foundational assumptions. On the mental health side, the focus being on medical conditions as the primary object: such as PTSD. Death studies on the other hand, focus on the state of relationships between the living and deceased along with the transitional states of those relationships. In both cases, it occurs to me that there is something unexplained but critical to the experience: the connection to supporting a parenting experience and through that lens empowering choice. Without adding this important context related to experiencing the death of a baby, neither seems to satisfactorily explain the importance of or consideration for the parenting experience, particularly during those early moments. I think both examples provided above, along with any others applicable, need to embed an understanding of the factors associated to being a parent as the most critical part of understanding the experience, and future research needs to account for this. It is only through this lens that research will be able to offer support for what different professional perspectives can best offer parents under these circumstances.

There is much more research to be done in this area to fully understand how this experience can be dominated less by medical procedure by offering touches of humanity in a medical environment⁹¹. But, it is an important environment to consider as the hospital experience relates so significantly to many emotional challenges that follow during the later parts of the experience.

5.4 The Need to Empower Choice Throughout the Experience

Related to the initial hospital experience, but also extending later on in the experience, is the challenge of parents' low level of awareness surrounding what their choices and options are. As has been found consistently in this study, there is an on-going learning process that is occurring in parallel, while intertwined, with the process of grieving. This process can start with some of the most basic questions like, what will happen with the baby's body? Do I give the baby a name? – but, continue later with questions like: How do I handle communicating with others? What are our options for support and which are suitable for me/us?

It is remarkable how little baseline awareness there is as to what happens to parents and what their choices are⁹². This has been found to be particularly problematic when it comes to the initial hospital experience because there is such sensitivity surrounding what is happening at that time, especially with the early shock and disbelief, accompanied by the fact that choices are very individualistic⁹³. This makes it particularly challenging for anyone to guide parents through what is to come. What invariably happens

⁹¹ This came up as part of the interviews. Hospital environment were characterized as a 'sterile' and 'inhumane' environments. This is supported by the literature citing that death had been 'professionalized' (Rainer, 2012, p 9) implicitly meaning less personal and more efficient.

⁹² Author's reflection and analysis.

⁹³ The interview findings reaffirmed the individuality of the experience and the implications on perspectives of what can and should be done (expert interviews).

is a number of choices are made on behalf of parents without them having a full understanding of whether these choices are appropriate for them⁹⁴. The result in case where choices were particularly out of sync with the parent's sensibilities is painful regret after further reflection on those decisions.

This is a truly complex challenge that to the best of my knowledge, from the collective data of this study, does not come with any examples of outliers who have understood this challenge. I did not come across examples of healthcare professionals who artfully or gracefully guided parents through choices and their implications. There are examples of proactive choices made on behalf of parents that have a positive longer-term benefit, such as hospitals that connect parents with an organization like *Now I Lay Me Down to Sleep*⁹⁵, an organization of professional photographers who take photographs for remembrance. But even in such a case, little is done to help parents make sense of such a choice, it is still a choice made on their behalf.

This is a particular challenge when it comes to the hospital experience because there are many early, time sensitive decisions and choices come and go very quickly. As a fairly consistent practice across hospitals, parents are discharged from the hospital and given a package of informational pamphlets related to resources for them⁹⁶. The challenge is however, at this point it is too late for many of the important choices. Why isn't more information being provided earlier? Even though some of these choices do not have right or wrong answers, what is important is parents get information and feel empowered as to their choices.

⁹⁴ Author's analysis and conclusion.

⁹⁵ <https://www.nowilaymedowntosleep.org/>: this example was shared during one of the interviews

⁹⁶ Data from interviews (expert interviews).

This area would benefit from further research in determining better approaches to proactively consider the importance of choice and decisions made relative to the experience. I have focused primarily on the early parts of the experience in the above examples but it is important to point out that the notion of a learning process as a critical and on-going part of the experience.

5.5 Limited Social Spaces Accepting of Grief

An important finding that emerged from a variety of sources in this study is the importance of grief as being a social process⁹⁷. And by social process this doesn't necessarily mean a more commonly understood social process associated with grief, that of mourning together, although that too is important, but it covers a parent's shift in identity⁹⁸ and how that affects their fit with their social world as they know it.

With death generally being pushed from social view and the societal ignorance⁹⁹ toward understanding the death of a baby, it is hard for parents to find social spaces in which they can participate without a lack of understanding resulting in awkward or painful social interactions. While not found as having malicious intent, this is instead linked to a societal ignorance alongside a parent's lack of understanding and experience for handling new possibilities in social situations. This can create a toxic combination that has resulted

⁹⁷ See Rainer (2012).

⁹⁸ See Davis (1996, p 232 – 234), Davis covers how perceived identity shifts can have an affect on priorities surrounding career and motherhood.

⁹⁹ Covered in the context section of this paper.

in longer-term implications to friendships, family relationships, community participation, personal identity, and career, to name some¹⁰⁰.

Grief as a social process has been found to affect one's personal identity and sense of belonging in social spaces, which requires parents to develop new coping mechanisms and communication skills for effectively managing interactions. This includes things like parents pretending everything is fine for fear of others feeling awkward, which leads to later exclusion from social situations. This includes parents feeling like they need to lie or make excuses in order to avoid judgment, whether a fear merely perceived or justly expected. This includes receding from certain relationships to proactively avoid future interactions, which may impact family holidays along with other social functions and community gatherings no matter how small in scale.

The above are more negative examples and situations that illustrate how parents respond to social situations they are faced with. But, there are also positive examples. These include when relationships are actually strengthened and other social situations are not perceived as threatening. The best examples that I have come across that have created more positive conditions have the common idea that there is nothing to fix and individuals and groups surrounding parents can just be there for one another. These are not conditions for which advice is doled out or even an understanding for what one is going through is expected or necessary. It is really quite simple, these conditions simply call for surrounding those in need by those who simply care¹⁰¹. Going beyond that to think that there is a way to fix the problem or a clear path to resolution is a mistake. When simplified it is the need for a safe space for parents to grieve whether openly, quietly, or however they choose, but importantly characterized by feeling safe from judgment.

¹⁰⁰ Author's analysis and conclusion.

¹⁰¹ Author's analysis and reflection on the collective data alongside the notion of 'being present'.

The idea of ‘being present’¹⁰² was shared with me recently. I think it represents an important idea when it comes to creating safe spaces for grief, and covers much of the positive attributes described above, as a critical principle in recognizing what parents need to feel supported. What it means, as I understood and interpreted it, is to be uninterruptedly focused in the moment and not feel the need to say or contribute anything no matter how awkward that may seem. It is literally just being there with no presumption or need for understanding. While empathy is important, a parent can negatively interpret such attempts because of a common perception: “How could you possibly know what I am going through?”¹⁰³

While this idea is really simple, there are many reasons this is a much tougher challenge, as has been learned throughout the study. It is tough to create these conditions because while the passage of time may have a different priority for parents, that is not the case for those surrounding parents. Not to mention, a fast-paced Western culture does not promote standing still for too long and attention spans are limited.

This finding is a critical one, both in terms of what has emerged from the study but also in terms of how to develop meaningful change. At the moment, the creation of safe spaces for grief is fairly limited to healthcare professionals and volunteer organizations¹⁰⁴, which in my view is insufficient. I am not suggesting that these are inadequate in their successes, but I have found that they do not reach those parents with diverse needs and preferences. More investigation is required to adequately consider how to create safe spaces for better accommodating those who cannot find what they are looking for within the options that currently exist.

¹⁰² Connected with mindfulness: “the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding of experience moment by moment” (Kabat-Zinn, 2003).

¹⁰³ Auto-ethnography.

¹⁰⁴ Finding from reflecting on the development of the experience model.

5.6 Inability to Support Diverse Situations and Needs

The next major finding refers to the lack of overall resources and supports; specifically, when it comes to supporting different vantage points and cases. Some are currently being better handled, than others. But, areas that have been explicitly identified warranting further attention include supports for fathers, resources for employers, resources for how family and friends can support, options for medical terminations, same sex couples, relationships including surrogates, these being the primary cases found¹⁰⁵.

There is not much more to be added in terms of expanding upon any of the above beyond pointing out why these gaps exist. The main barrier having been found affecting why these gaps exist primarily comes down to a lack of resources and the resulting inability to direct efforts to these areas¹⁰⁶. The other factor is that some of these unique cases are only now emerging and becoming more common. Consequently, they are early in their consideration and understanding. The main point here is that these gaps are known but practical challenges regarding resources mean they are mostly unaccounted for as of yet.

5.7 Needs of Siblings Go Unacknowledged

Possibly the most striking findings of the study is the sheer lack in resources and support for how parents can support any siblings during the experience. This first came up during the auto-ethnography but continued when reviewing the literature related to the subject. To clarify, the literature does offer some considerations on how siblings may respond¹⁰⁷ and there are clinical supports

¹⁰⁵ Expert interviews.

¹⁰⁶ Expert interviews.

¹⁰⁷ Davis (1996) dedicates a number of sections to the book to this topic.

available for extreme situations. That said, there is next to nothing accessible for a parent's practical needs¹⁰⁸. Should a sibling attend the funeral and what are the implications? How to handle day care or school?

It appears that there are resources for the extreme cases such as institutional and professional supports, for example, child psychologists. But there is little to prevent those extreme cases from occurring¹⁰⁹. Even when discussed amongst parents¹¹⁰, many choices were made with little confidence that the outcomes were understood, positively or negatively, and in the best interest of the sibling(s).

This topic is a large gap and filling this gap is critical in helping parents and siblings. Nothing has been found throughout the course of this study that suggests there are any examples of this area being addressed. This is an area that could benefit from further research but also some immediate practical supports to fill the void.

5.8 Organizational Contributions are Fragmented and Constrained

This study found that there is a lack of motivation for organizations¹¹¹ to get involved in this area, or be more involved. The primary reasons for this being, first, the lack of public consciousness toward the issues parents face with the death of a baby. And

¹⁰⁸ By practical needs, I mean information and guidance for common issues that arise and, importantly, when they arise. While *Empty Cradle, Broken Heart* (Davis, 1996) is a shining example of a useful book, the likelihood of seeking out the book and buying it during the early period of recovery when it would be most beneficial is low.

¹⁰⁹ Insight shared during an interview but in the broad context of preventative supports for parents. I have presumed the same context is true for siblings.

¹¹⁰ Author's personal reflections from discussions at PAIL meetings.

¹¹¹ Expert interviews.

second, the topic is not a desirable one for an organization as there is little marketing value in being associated with it publicly. There is the presumption that no one wants to hear about the death of a baby for it hits such a visceral chord with people.

This isn't to say that no funding or attention is paid to this area but more is necessary to support change¹¹². The other challenge is that the issues surrounding the death of a baby have different characteristics compared with other causes that have gained mass public awareness. The recovery after the death of a baby does not fit into a similar category such as cancer or depression¹¹³.

Cancer, as an example, while it shares many commonalities relating to grief, it fits into a very different construct and public narrative¹¹⁴. There is the enemy, cancer, and there are the allies, the collective individuals and organizations motivated to find a cure to cancer. This 'us versus them' narrative is a powerful one that has resulted in a cohesive mobilization in the fight¹¹⁵ against cancer. In the narrative for the death of a baby, that galvanizing force of having an enemy as an object for collective and consistent attention does not exist. There are system issues but there isn't a common purpose that can unite a collective action.

While efforts have been observed to be very well intentioned, they are fragmented and limited in their affect at scale. Many of the current efforts for change in this area are coming from the bottom-up. This is not to say that such efforts are not valuable, but they

¹¹² Expert interviews.

¹¹³ It is important to point out that I recognize scale of those affected by cancer or depression, given these are the examples chosen, does dramatically differ from those affected by the death of a baby. But the point I am making here is surrounding the comparable characteristics and how these causes are connected to the public consciousness.

¹¹⁴ Author's analysis and conclusion.

¹¹⁵ Cancer.org, as an example, commonly uses the term 'fight' in its public messaging. This has the beneficial affect of reinforcing the disease as being an object helping to support an 'us versus them' narrative.

are heroic in their affect taking significant energy and time to affect change. This means that such bottom-up outreach not only takes time but it also means areas in need are excluded¹¹⁶.

The result of the above mentioned challenges are that constraints are placed on any top-down efforts. One area where this is most prevalent is in rural areas, creating exclusion criteria for access to supports, and few options for more specialized cases. But this is only one example of where professionals and volunteers alike are limited in their abilities to affect change in their individual efforts.

5.9 Bereaved Parents are Motivated to Support Change

One of the most heart-warming findings of the study came in the realization that there is a significant motivation for individuals to affect change in this area¹¹⁷. Whether coming directly from bereaved parents, those close to parents, or professionals, it has been clearly demonstrated amongst all the data that there is the appetite and motivation for change. Whether that comes in the form of helping others by publishing learning's, volunteering, reaching out to others, or other self-directed initiatives to cite a few. This very study is also evidence of this.

It has been observed that there is a transition throughout the experience that can occur from getting personal supports to giving back to others. This is not a universal statement for all but many have been observed having followed this pattern¹¹⁸. It is an important part of a cathartic experience¹¹⁹ toward a healthy recovery.

¹¹⁶ From interview data, these limits were discussed as a barrier in a shortage of available resources, mainly people.

¹¹⁷ Primarily from the expert interviews and author's analysis of the experience model.

¹¹⁸ Author's analysis and reflections on the experience model, with consideration given to the stories of others that have followed a similar pattern.

However, the challenge related to this has come up in terms of offering the appropriate variety and personally meaningful ways in which individuals can contribute¹²⁰. In addition, it has been observed that the barriers for those contributions can be prohibitive, resulting in those self-selecting out of giving to this area¹²¹.

While indirect and in many ways coming from the opposite end of the spectrum of the experience studied, this finding is potentially the most significant in terms of being able to make meaningful change in supporting bereaved parents. Making headway on increasing the spectrum of ways to contribute along with reducing the barriers can enable greater bottom-up contributions. This having potential in going a long way to filling the discussed gaps in a meaningful way, both on a local scale and broader scale over time.

¹¹⁹ By this I am also considering a reaffirmation of ones progress in recovering.

¹²⁰ Issue identified as part of the process of developing the experience model.

¹²¹ Author's analysis and reflection.

6. Recommendations

With the above nine findings in mind, the next obvious question is: So what? What does this information mean? These are two very difficult questions to answer. Based on the findings of the study, and interpreted needs implied, the following six recommendations are viewed to offer the opportunity to positively impact the experience as a whole, and its parts identified in the experience model. While the six recommendations are separate and can be treated as independent ideas, they are also interconnected and support one another. I'll walk through the six recommendations prior to offering some concluding thoughts. Before getting to the specific recommendations, it is important I provide some additional context about the nature of the recommendations.

The process of analysing the data and coming to terms with what it was telling me was a significant challenge at times. There was a period during this study in which I had significant uncertainty with respect to what I was going to be able to report on. In order to get through these challenges, I found myself needing to be very open-minded and rethinking some of my biases and assumptions in order to be able to see the data more clearly. I briefly wrote about this earlier in regards to how the research question evolved but it is worth bringing up again with respect to the recommendations.

After reviewing the data numerous times, I realized that the majority of the factors making the experience problematic were both systemic and acting from outside of the experience. I realized from here that I needed to change my perspective. By necessity I shifted my view away from my early aspiration of being able to report on narrowly focused and practical interventions to improve the experience. The side effect of broadening my perspective and acknowledging the systemic connections to larger systems resulted in being humbled by the fact that this study has only scratched the surface regarding that broader perspective. While I am not suggesting

the validity of this study should be questioned, all efforts were important and necessary to come to that conclusion. Instead, I want to acknowledge and be respectful of the fact that there are many questions that still need to be asked and answered in considering the full complexity associated with this topic. I feel it is appropriate given the sensitivity of the subject matter to err on the side of caution regarding the level of assertiveness that is to be found in the subsequent recommendations. The result of this sensitivity will be noticeable in the recommendations that are framed to be directional while not reaching further to offer specific solutions without having the necessary diligence. I view each of these recommendations as being a starting point for framing six individual research endeavours in the pursuit of establishing positive conditions for change.

6.1 A New Public Narrative for the Death of a Baby

The death of a baby, while horrible as it may seem, is an unfortunate reality of the human experience. Everyone dies. The only question is when¹²². This realization was particularly important for me in order to accept the death of my baby. This idea or fact doesn't make it any easier for parents like me, or anyone else, but resisting this fact only reinforces how horrific an experience it is. Not addressing this elephant in the room will only lead to further stigmatizing the topic and will continue to keep it out of social view.

This topic needs a new public identity that doesn't create or have such a divide between those who have suffered a loss and those who haven't. It needs a new narrative, or combined with another, that can be more inviting toward dialogue, promoting

¹²² Cave (2012) points out this truism as a central part of his book on immortality.

understanding, and facilitating action. Consequently, this recommendation is calling for re-evaluating and redesigning the public image that is currently represented in way that can build bridges between the gap, currently characterized as societal ignorance.

This means reconsidering the closeness of this topic as it currently exists with medical institutions. Grief is a natural process¹²³, not a 'condition'. While it's important this topic continues to be addressed in medical institutions, it should not be the primary venue. There needs to be other venues.

Over professionalization of death management and associated grief has consequences as previously noted. Particularly problematic is the perception of something being wrong, which is a problem that plagues mental health¹²⁴ and is more broadly applicable than this topic on its own. This association only further reinforces both the external stigma and individual feelings of failure, shame and alienation by association¹²⁵. Again, this is not to say mental health supports are unnecessary but they cannot be the dominant supports if we want to create conditions for change in developing a new public image.

Unfortunately, what this could look like or who could undertake this is uncertain to me and outside of the scope of this study. But, what is clear is that creating conditions for positive change necessitates the need to bridge the gap bereaved parents feel as being part of a sub-culture; specifically as this relates to feeling disconnected from society. Important to this is decoupling attributes of a

¹²³ "Grief happens as a natural response to loss" (Rainer, 2012, p 2).

¹²⁴ Centre for Addiction and Mental Health (CAMH) as an organization dedicates efforts to de-stigmatizing issues of mental health (expert interviews).

¹²⁵ It was noted in interview data that some people don't reach out to get support because of the shame felt when acknowledging the need for help as a sign of failure. It is my contention that this is associated with the fact that the public is socialized to see the medical institution as a place to solve problems, the act of reaching out for help implicitly acknowledges and concedes that there is a problem.

human experience from the association of death being a medical condition. Without addressing this, the pattern of societal ignorance and the impacts on the experience will persist.

6.2 Promoting New and Safe Social Spaces for Grief

It is critical to the experience that new venues be created to support safe spaces for those to be able to grieve on their terms along with supporting awareness of these spaces. While the options that presently exist - support groups, talk therapy, phone support, among others - are good, these options as they currently exist are not for everyone¹²⁶. New avenues for connecting people with people and resources across a spectrum of mechanisms needs to be considered in order to ensure those who want support can get it. Important to achieve this is also to consider they can get it in a way that is comfortable to them as individuals when they want them. And these supports can and should live both inside and outside of formal healthcare. The spectrum of new spaces can be as commitment free as requiring no self-identification when accessing content or tools online, to connecting with others directly, whether professionals or other bereaved parents.

This is not an idea limited to parents whom have suffered the loss of a baby. This is also an idea for connecting others in need of supports such as family members of parents who have lost a baby or healthcare professionals who have cared for parents during the labour and delivery at the hospital.

¹²⁶ Data from interviews, and supported by reflections on the experience of how I bounced around different support options before finding what worked for me.

Contemporary for this recommendation, is the use of the Internet as an avenue for lowering the barriers for accessing content¹²⁷ and connecting people. It is a rich territory of opportunity in this area. It is particularly important as a way to support those who wish to remain anonymous and not self-identify as being in need, even if only for personal reasons.

That said, part of what is meant by creating safe spaces is recognizing there are vulnerable people involved. Consequently, while not everything can be controlled, and the Internet has its share of criticism as being uncontrollable, critical control mechanisms need to be in place to protect the vulnerability of individuals while not getting in the way of promoting healthy spaces for grief.

Considering the Internet as an avenue for new types of virtual supports also has the additional benefit of addressing the issue of reach scale and lack of rural supports. This could mean something like a Google Hangout¹²⁸ support group that allows people to connect from afar. Another example is, instead of strictly developing group support within the boundaries of an organization, developing tools for people to self-organize their own supports and run events, such as offering open tools for how anyone can run a support group. These examples, among others, are critical in lowering the barriers for inclusion by introducing greater variety.

6.3 Prompting Open Discourse to Improve the Experience

Critical to realizing change is unlocking certain elements related to the hospital experience making them open for debate, critical review, and change. The Internet as a platform could be a critical part of this. An example of where this could be valuable is in enabling an open debate surrounding a given hospital's protocol for handling a stillbirth or when a baby dies during labour. Numerous

¹²⁷ Books like *Empty Cradle, Broken Heart* (Davis, 1996) have content of greater utility if made more accessible via the Internet.

¹²⁸ A social platform enabling groups to see and speak to one another online.

findings are addressed through this single example. The result of such an open debate could address educational needs of professionals, inter-hospital communication, enabling meaningful volunteer contributions, address issues related to the labour and delivery experience, these being the most directly applicable.

But this is only a singular example. Another could be opening up the conversation related to what information is provided to parents when discharged from the hospital and how that information is shared, or even should it be shared, in a different way. These examples and many others can make a significant impact, especially when considering the use of the Internet as a vehicle for broader and open participation, both to benefit parents and hospitals with valuable information.

6.4 Reducing Participation Barriers to Affect Change

Reducing barriers of participation is a key idea necessary to attract the interest of those keen to participate in some way in relation to this topic but have not been provided the means or opportunity to do so. This recommendation means developing mechanisms and creating conditions that bring together multiple stakeholders and enable the development of content, participation in debate, participation in meaningful connection, and the distribution of ideas. For illustrative simplicity, it could be as simple as developing a specialized wiki with a designed purpose akin to Wikipedia albeit it could be much more. It is applying the philosophy of

openness introduced by the open source movement¹²⁹, which is now being replicated and applied to many other domains that were previously closed systems¹³⁰ where big challenges exist, such as government¹³¹.

This too would require appropriate controls in place and mechanisms to facilitate productive connections and contributions that are safe. But the important point is that abilities to contribute should not be thought of as limited to being online and primarily related to content. By creating conditions for open participation (reducing the barriers of participation), the possibilities are far more limitless and emergent when considering how to help enable and facilitate people to use their skill sets and experience as part of a bottom-up process.

Boundaries and controls would still be necessary as it would not be in the public's interest to open up surgical procedures for public contributions and debate. This would simply not work. But that doesn't mean that there aren't other areas that could gain from being more open, particularly in relation to administrative challenges. Thinking more broadly than the domain of the death of a baby alone, enabling access to challenging areas like wait-times, could yield some potentially innovative results. Yes, this process could be messy and viewed as unruly, but not without precedent in other closed systems outside of healthcare. It is also particularly important when considering resource constraints previously covered.

This recommendation is an important one that has the ability to touch most of the critical issues and findings from this study but also goes well beyond the scope of this study.

¹²⁹ Synthesize as: enabling universal access and inherently disrupting control of closed systems (Open Source, n.d.).

¹³⁰ Closed system being referred to as a system whose actors and processes control the system from within. Changes or affect does not easily permeate these boundaries by those outside.

¹³¹ An example like Open-data (<http://data.gc.ca/eng>) demonstrates this shift, albeit it is far from a pristine example.

6.5 Foster Parenting Opportunities in the Hospital

It needs to be acknowledged that I recognize this recommendation could be perceived as quite controversial but that initial time in the hospital is too critical to how the rest of the experience unfolds. Crucial to the topic of improving the experience means considering what is happening during that initial time in the hospital. It is important to educate healthcare professionals that this time is not only important as a medical process but it is also critical as a sacred time for parents to parent their baby. This very idea is critical, as it need to be the lens for considering what occurs during this time and how medical procedures and processes are communicated. Small touches of humanity are necessary along with practices to consider how to gently encourage parents to treat this time as a parenting opportunity without being decisive and intrusive. This is a highly sensitive area and very individualistic for the parents but an area that is pivotal to improving the experience.

More is necessary in terms of researching and understanding what supports can be beneficial in this regard, in particular for healthcare professionals. For example, it might mean having some children's books on hand for parents to read a story to their baby, but this may also be seen as intrusive. Unfortunately it is out of the scope of this study to propose such solutions beyond the use a couple of examples or consider all the factors germane to considering an ethically appropriate approach. More investigation would be required to propose more definitive strategies associated with this recommendation. That said, what is critical as the important takeaway from this point is that what is happening during this time is more than medical procedures and processes, and change in a positive direction starts with a mindset and recognition that this time is also a time for parenting and making a connection with the baby.

6.6 Supporting a Learning Journey Using the Experience Model

As I have previously discussed in this study, the idea of learning processes being present and critical to experience is pervasive throughout the different stages of the experience model. Learning processes are inseparably intertwined with the process of grief but supporting one aids the other.

As a general finding of this study, it has been observed that there is plenty of insightful and knowledgeable contributions to this domain. The problem as it applies to enabling learning processes isn't in a lack of knowledge, it is in how that knowledge permeates down to parents and is beneficial to them. This means the problem is more germane to accessibility: who has access to knowledge and who is it developed for. This is why future considerations for the development of supports can look to the institution of education as inspiration, for its main purpose is the dissemination of knowledge and empowering its utility¹³².

The experience model can be considered an active tool in this pursuit and can aid in sequencing and filling gaps related to accessible knowledge, both in its curation and creation. This includes learning processes for things like: what to expect next, planning a funeral, understanding how you have been affected, nurturing a relationship during a tough time, communicating with others, navigating government forms for maternity leave, support options and choosing the best options for you, among others but these are a short variety of examples. These are examples of areas in which content exists, but isn't easily accessible or timely available.

Considering these areas, among others, as learning processes is an important idea because many of these are completely new to parents. Parents do not currently have any way of proactively learning which invariably leads to learning through the painful

¹³² Author's definition.

experiences of when things happen. In the literature, grief is identified as a learning experience, mostly in considering the idea of learning about oneself. But I am calling for an important consideration, in the case of the death of a baby, to extend that notion of the learning process to other areas of the experience: practical, personal and social.

As mentioned, this recommendation is not just about the development of content in new ways but also reconsidering how that content is delivered and disseminated. As a personal reflection on the current system, there are many important concepts for parents found in scholarly works authored for healthcare professionals. This knowledge may be consumed by healthcare professionals and amalgamated in professional practice but this knowledge is not accessible to the public. Meaning parents need to seek those with knowledge to be delivered to them through professional judgment and reason. It should go without saying, but there are important merits to this generally speaking, but the unfortunate side effect or trade off is access to this knowledge and its value is limited and controlled to defined venues and people.

I am not calling for the complete abolishment of those controls but instead recognizing that knowledge needs to be made more accessible when it is needed most, not after the fact. This is where the experience model as a guide is useful as a starting point, but it would only be the starting point. By considering this in context with the fourth recommendation, 'Reducing Barriers of Participation', the opportunity exists to not only fill the immediate gaps identified by the experience model but also the additional cases that are more nuanced through open participation. As a final thought related to this recommendation, the important point to take away is the core principle of the experience being a learning process, not only a process related to grief, and it is important to foster conditions that support and provide tools so learning can occur when it is contextually appropriate and most valuable.

6.7 Summary: Overlaying the Recommendations to the Experience Model

In an effort summarize the recommendations in a single visual form, the following illustration contrasts the recommendations to their areas of relevance in the experience model accompanied by one or two examples. The following figure depicts how the recommendations relate to the experience model. The connection is admittedly forced in the case of recommendations one and six; nevertheless, relating the recommendations back to the experience model is useful context as a summary.

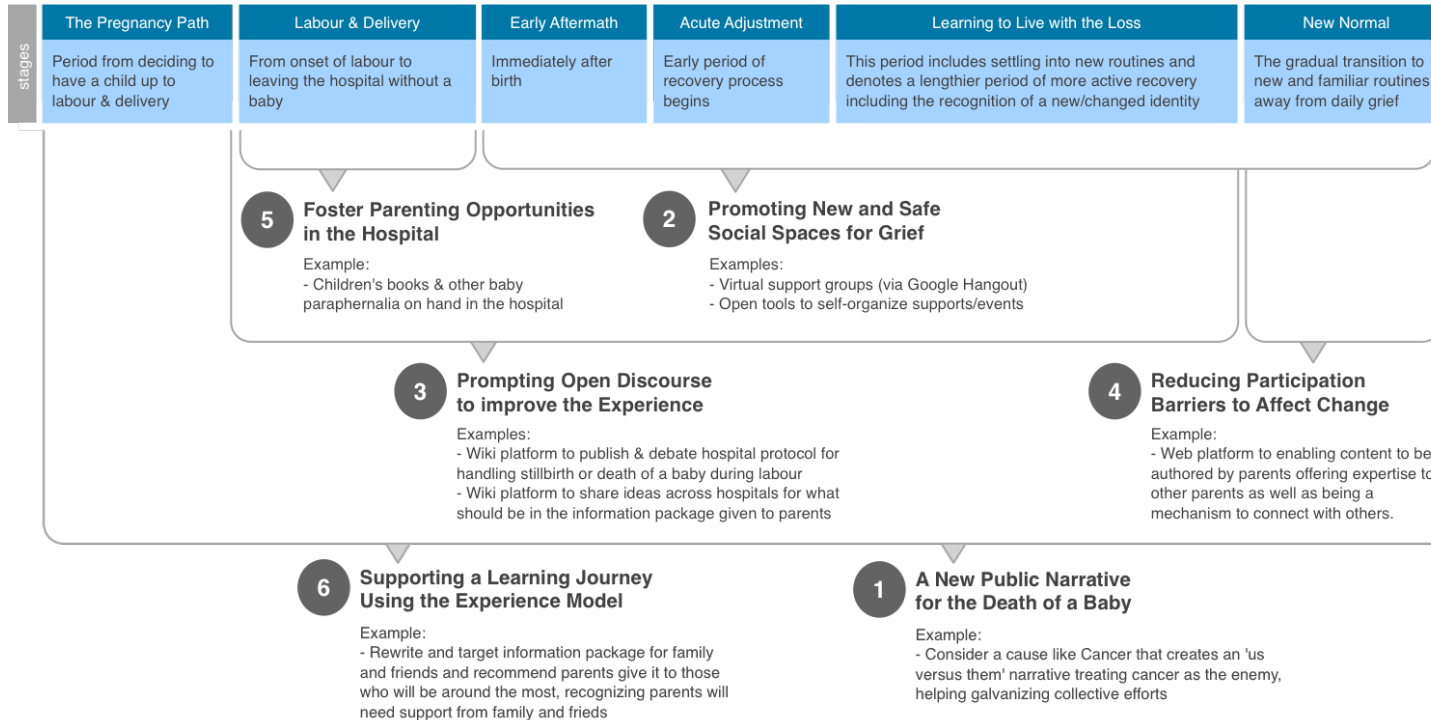


Figure 25: Overlaying Recommendations to the Experience Model

7. Conclusion

When I began this study I admittedly had no idea or real active hypothesis for what I was to find or test. This innocence was important as I was not hindered by existing knowledge. This enabled my ability to critically consider what is occurring in the experience. The other side to this innocence came with a limited appreciation for what I would be reporting on at this point in the study. This was a leap of faith I knowingly took at the beginning of this study. My original goal was to arrive at practical solutions for supporting parents. But, while this study has achieved this through the recommendations, in the context of seeing these ideas become an implementable reality, I feel like I have only shaved off the surface.

For maintaining the scope and purity of the purpose of this study, it was critical to maintain a strict focus on the parents' vantage point in order to ensure the experience represented it. But further research is required to develop these recommendations with a deeper understanding of the complex systems, and other stakeholders related to the experience, to make these recommendations more broadly relevant to all the stakeholders.

I had no idea that when I started to peel back the layers of this topic area that I would find such deeply entrenched belief systems and structures embedded at all scales, which have such a direct impact on the experience. While I have discussed the general impacts toward parents through the experience from cultural, societal, economic, and institutional perspectives, what has emerged is how these factors systemically reinforce conditions that make the experience surrounding the death of a baby what it is. Also, these conditions are critically important to realizing change.

This is something that I could have only found through this study. Had I known this prior as a baseline, a different approach and methodology would have perhaps been warranted. However, this is a chicken and egg kind of issue. To move the recommendations

through the next stage, additional research is required to take a more detailed look at the different vantage points. For example, understanding critical stakeholder needs and how they can influence change would be a critical next step. The use of causal layered analysis comes to mind as a way to understand the interconnections of differing scales amongst these systems and cultures. Also, more system mapping techniques for understanding the interconnected systems and stakeholder analysis would also be a critical part of this pursuit.

But this is with an eye on what's to come next, not what has been done. As far as what this study has achieved, by designing a methodology to critically look, through an auto-ethnographic account, at the experience of recovery after the death of a baby and using multiple data sources to develop a model to explain that experience, this study identified a number of valuable things. It has provided a contribution to the fundamental factors that explain the conditions for the experience. It highlights issues in the experience and a tool for discussing related issues. It addresses gaps in existing supports and knowledge. It helps highlight issues such as how accessible knowledge is and limitations to it reach. And most importantly, this study provides a directional starting point for how to create new conditions having a positive impact on the experience.

To sum up what I learned on this journey and judge its ultimate outcomes, it can probably be best put like this. Thinking of this topic and experience in terms of issues and solutions is a problematic way to think about it. This way of thinking presumes control and there are no absolute solutions when it comes to this topic. This is a wicked problem¹³³ space - too complex, with too many

¹³³ "A problem that is difficult or impossible to solve because of incomplete, contradictory, and changing requirements that are often difficult to recognize" (Rittel & Webber, 1974).

stakeholders, conflicting belief systems, systems of all scales, and these are all constantly changing. Instead of thinking of solutions, or even a system of solutions, I have found it better to think in terms of platforms.

There is a need to consider platforms that can create positive conditions for change and enable solutions to emerge. This is the shift in thinking that occurred once the findings of this study were known and this shift impacted the type of recommendations. The recommendations of this study are meant to be platforms for creating positive conditions for change. Whether beginning with a mindset shift or a literal platform (as in a technology), these recommendations are foundationally important but not solutions on their own. They are meant to empower and create space for solutions to this topic area to emerge. As this study evolved to this conclusion, this is what I sought to achieve as its contributing outcome through the recommendations: the development of platforms to change societal views, spur collaboration, empower change, reduce barriers, shift control, and humanize supports with the ultimate goal of reconsidering the basis by which we understand the experience when the death of a baby occurs for all involved and the healing process afterward.

8. Discussion

It is hard to consider and express the amount of change that has occurred in me as a researcher, having conducted this study. It is even harder to re-imagine and contrast any original assumptions, even if latent, to those that have now developed through creating the experience model and the analysis of its meaning. Surprises emerged when analysing the deeply embedded personal and societal beliefs, which related to areas like control over one's environment, societal attitudes toward death, economic demands for professional efficiency, an individual's value within society, which have a foundational importance and directly impacted the experience. These beliefs have long shaped current institutions, community, people, and societal values that act as the backdrop of the experience.

Once these realizations began to emerge, I found myself consistently asking 'Who is best served by this situation?' A human-centred lens was necessary for applying to each situation reviewed as a means for being critical of individuals and systems involved. An underlying question of control and who has the control in these situations has a foundational underpinning to this and the notion of control being a critical part in realizing change.

What has been found inductively through this study is that the medical institution is the consistent answer to the above question and has a current monopoly on the management of death and its related procedures. This has been found to create a tension in how death is experienced through the over professionalization of an otherwise fundamental part of the human experience.

While at the other end of the life spectrum in contrast to the death of a baby, it is critical commentary or evidence of this fact when other studies have found things like the elderly fearing the transition to nursing homes greater than that of death itself. "With a generation or two (rates varying by social class, religion, etc.) having died within institutionalized isolation, Americans are forgetting

about how to learn to focus on dying as a human process” (Kearl, n.d.). From a sociological perspective, Kearl reinforces an important point associated with this shift that has occurred when he states “cultural coping mechanisms have not kept pace with the dramatic changes in when and how we die” (Kearl, n.d.). What I draw from this is the process is continuing to shift and affects are only beginning to come into focus.

I recognize that this is not as simple an argument as the above may suggest and I will not attempt to do it justice. The considerations are far too vast. It should be pointed out that this issue, as a by-product, is part of the flip side of a coin that has also had miraculous successes and seen steady innovations toward saving lives. In the broader context, conversations I have had discussing the area of healthcare often results in its praises for being able to seemingly and consistently overcome challenge after challenge. Comments like, “10 years ago this would have not been possible” is part of the ever-hopeful narrative placed on medical innovation, now and in to the future. But the questions are, what are the impacts to the human experience and at what costs?

The medical institution does not have all the answers relating to the human experience and my point for raising the above is to draw attention to the known side effects. This point relates directly to this study. With the recommendations posed in this study, I recognize that the majority of the ideas implicitly suggest control be shifted outside of the medical institution. Not only that, I am calling for those stakeholders within the medical institutions to be an active part of shifting that control. Saying that I recognize these are not trivial suggestions is putting it far to mildly as a gross understatement.

This is no more obvious than in the recommendation calling for greater openness suggesting a need to open a currently closed system. Control is an important principle in healthcare, and the medical profession in particular, to protect people from undue risks¹³⁴. This is evident given the many government and non-government organizations dedicated to ethical and safe practice standards for protecting the public and professionals alike¹³⁵.

It's also important for me to acknowledge that, up to this point in the study, the topic of risk has not come up. This is not to suggest that the recommendations presented have no consideration for risk, but a comprehensive review related all stakeholders' and related risks was not part of this study's scope. Nevertheless, this is acknowledged as an important step toward implementing the recommended changes.

At a general level, in the absence of a comprehensive risk assessment, the argument I would put forward is this: the important consideration is how are the risks of the current state relative to what they would be should the recommendations be implemented, for stakeholders directly affected. This is to say that the recommendations put forth are acknowledged to contain risks, particularly with respect to certain control mechanisms, but the question is how do these compare with the benefits. And then collectively, are these recommendations riskier than that of the current state. By earlier suggesting that this problem is a wicked problem I was implicitly recognizing that fixing any problems will invariably introduce problems elsewhere in the system. That said, when considering the

¹³⁴ One of Health Canada's stated objectives - "Prevent and reduce risks to individual health and overall environment" (retrieved from: <http://www.hc-sc.gc.ca/ahc-asc/activit/about-apos/index-eng.php#mission>). Implicit in this objective is the necessity for control.

¹³⁵ Referring specifically about the professional Colleges and associations that, as organizations, are mandated to protect the public and professional interests through governance and regulation.

potential benefits of enabling collaboration, some pressures currently in the system could be relieved, resulting in benefits elsewhere in the healthcare system, and hence the risk profile of these recommendations may begin to look quite different.

This is not to suggest that the recommendations are more or less risky. A future assessment of this would be necessary. What I am proactively suggesting in accompaniment to the recommendations and findings of this study that their validity be considered through the lens of what does the entire profile of pros and cons now versus what it would be after. Loosely applied, it is the idea of relative risk¹³⁶. But regardless, I would argue that the directional validity offers greater benefit collectively than the current state and warrants further consideration and investigation, certainly when considering the lens of the experience.

As closing thoughts, there is also great reason for hope in this area. Not only are there a great many emotionally invested in making a difference, but also there is a lot of great knowledge out there to be shared. The book *Empty Cradle, Broken Heart* by Deborah Davis exemplifies a wonderfully detailed account of most topics and challenges through experiencing the death of a baby. Its very existence and all those who have contributed their personal heart wrenching stories is evidence showing us that the knowledge is out there and there are people who care. But this great source of knowledge, and other knowledge, are only the first chapter. The next chapter is all about how to get the knowledge that parents need in their hands and hearts when they need it most. This knowledge would empower parents to act and navigate through their experiences and grief on a healthy path to recovery. This future is one of making knowledge accessible and empowering the ability of parents to act.

This is where the experience model developed and presented here within can act as a tool in support of this mission. By drawing contextual awareness to the experience parents have recovering from the death of a baby, the experience model can be useful

¹³⁶ Defined as the probability of an event in an exposed group occurring versus not in a non-exposed group.

to spur dialogue and action toward making much needed changes. It is far from the answer to the problems discussed but if used for its intended purpose it can act as a catalyst in taking single steps in a much longer journey.

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Appendix A: Findings from Interviews

The following represents the collective findings that came from the expert interviews conducted. Because some of the contributions were viewed as containing professionally sensitive perspectives, the interview participants and their cited contributions has not been included for all cases in order to protect and treat all contributions consistently.

Main Findings *(areas that came up in the majority of the interviews and central to the discussion during the interviews)*

- Perinatal loss is not understood within society and general awareness is very low. Most commonly understood in the same terms as miscarriages.
- Perinatal loss is a taboo subject resulting in no one wanting to talk about dead babies and few organizations wanting to fund betterment in this area.
- The parent experience is highly individualistic in terms of what they need and expect.
- How perinatal loss is handled varies greatly depending on the practices in place at a given hospital and individual practitioners. This includes variances in choices provided and information given while in the hospital.
- Education for healthcare practitioners on perinatal loss is more or less nonexistent whereby most education is on the job.
- Limited support resources for parents, especially for special cases requiring unique considerations (e.g. medical terminations).
- Information is hard to get in the hands of parents; in particular, immediately after a loss - choices are not known.
- Does not receive sufficient funding and attention.
- Tension between the caregiver wanting to provide support while the organizational expectation is to be efficient.
- Solutions primarily call for doing more of what is already being done: introduce more funding, raise awareness, more groups, more resources, more education.
- Barriers include many challenges: costs for parents, accessible resources, societal values, undesirable topic, empathic understanding from society.

Additional Findings *(areas that came up in multiple interviews as core to the discussion but not common to all)*

- Societal values incongruous with women's issues and rights (e.g. motherhood versus career).
- Generally, healthcare practitioners social and emotional skills become of higher importance during perinatal loss to avoid additional pain to parents.
- Minimal resources for fathers.
- Issues of grief can be problematic for doctors to handle appropriately because training centers around the diagnosis and treatment of symptoms. Grief does not easily fit this mindset until it leads to greater problems. This can lead to doctors handling these cases ad hoc, some of which are not being handled as best they could.
- Issues in how different cultures view the death of a baby (e.g. some women can be viewed as failures to cultures highly valuing childbearing).
- Communication issues within a hospital and amongst other hospitals.
- Rural areas have limited options, many are forced to travel to urban centers.

General findings about the interviews *(and reading between the lines)*

- The personal opinion and professional expertise were not easily separable when it came to responses shared during the interviews. Personal beliefs seem to play a significant role in the responses shared even when directly asked to comment on behalf of bereaved parents. Hypothesis: may implicate a practitioners personal beliefs playing a large role the healthcare environment, this conflicting what is implicitly expected from parents.
- Hypothesis: It appears as though societies ignorance to the area of perinatal loss, as a whole, is the root cause of most problems. This manifesting itself in a lack of empathy from others. Also, this impacts how and why organizations are or aren't taking action. Healthcare practitioners, while well intentioned, are not appropriately educated in this area and have to fallback on their general knowledge for guidance leading to wide variances in how parents experience the death of a baby.
- Observation: A significant amount of responses directly implicating the hospital experience and issues/supports there within. What is unclear is whether this is a bias where they believe the appropriate supports should be developed or that the most important/problematic breakdowns in the experience are at the hospital.
- Observation: Surprisingly little was mentioned or addressed regarding social challenges beyond the general statements associated with 'societal ignorance'. The majority of the focus in terms of issues gravitated toward the initial in hospital experience.

Appendix B: Printable Version of the Experience Model

The following pages contain the standalone visuals of the experience model for the purpose of making the model easily printable as full size for future use.

1 Mom - self

- Physical health & recovery
- Emotional stability
- Shifting identity
- Expectations of others
- Worldview & values
- Personal needs & priorities
- Rituals & routines

2 Partner - self

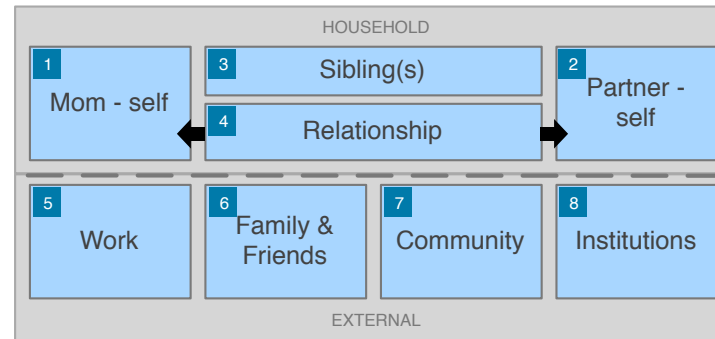
- Emotional stability
- Shifting identity
- Expectations of others
- Worldview & values
- Personal needs & priorities
- Rituals & routines

3 Sibling(s)

- Levels of awareness
- Personal understanding
- Managing social environment (e.g. daycare, school)

4 Relationship

- Empathic concern
- Future planning
- Understanding each others needs
- Communication
- Roles in support
- Division of labour
- Intimacy



5 Work

- Career priorities
- Colleague relationships
- Leave (bereavement, maternity, sick)
- Productivity
- Job security

6 Family & Friends

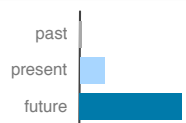
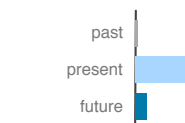
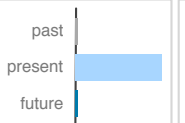
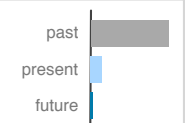

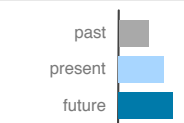


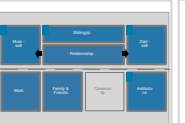

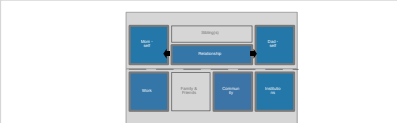

- Assuming support responsibilities
- Degree of closeness
- Grieving process
- Degree of understanding
- Changing relationships

7 Community

- Awareness of new support networks & resources
- Evolving participation (withdrawn/passive/active, informal/formal)

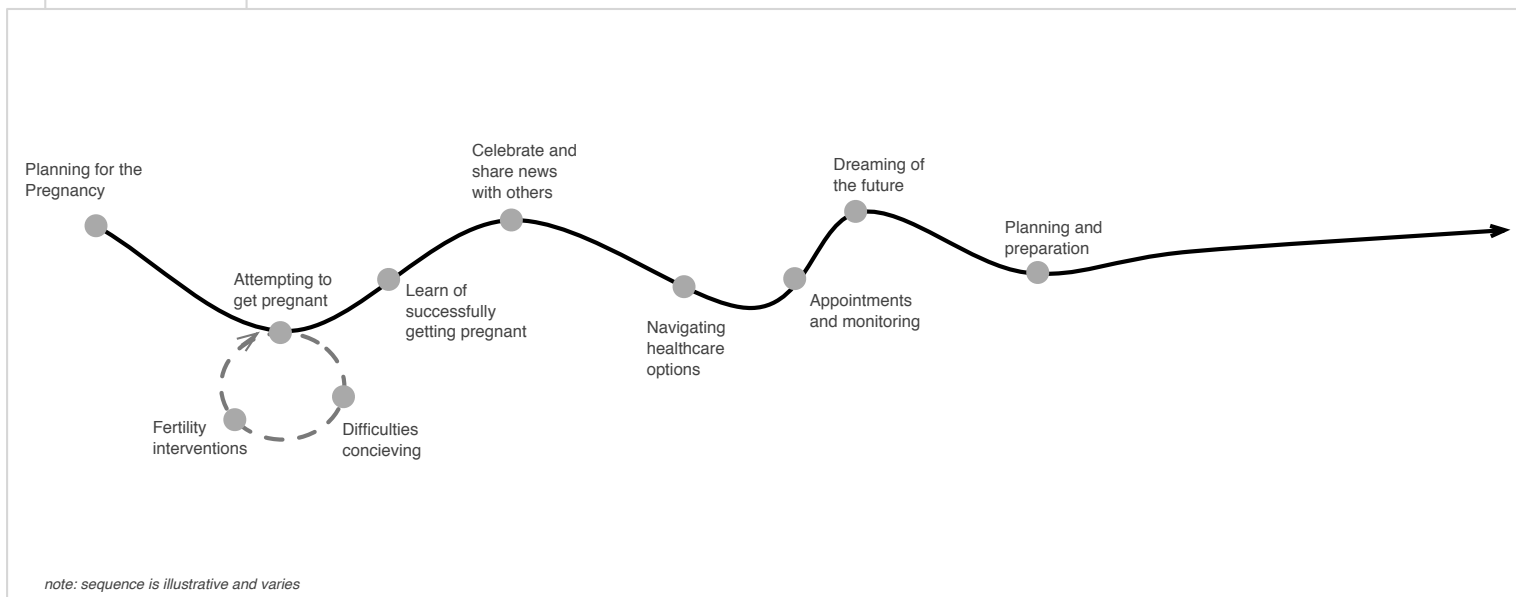
8 Institutions

- Navigating new systems
- Complying with standards
- Awareness and learning of new systems and services

stages	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
modes & mindsets	 <p>Parents' mindset is oriented in the future beginning to assume future identity both in terms of planned and dreamt changes.</p>	 <p>An abrupt shift occurs immediately superseding future dreams, bringing parents to an immediate focus on the next few moments; although, the abrupt shift causes shock and an inability to clearly focus.</p>	 <p>A clear focus on the present with a heavy dependence on others around to help clarify and explain things to come.</p>	 <p>Another abrupt shift occurs to reflect on and relive the traumatic events. Responsibility for the present is offloaded as much as possible to available supports.</p>	 <p>A sense of rebalancing begins with the idea that the worst is over and healing can begin. A past and present focus begins to dominate with the use of distraction and escape to help diminish emotional distress. Looking forward the future slowly comes into focus but guardedly and in relatively short timeframes that slowly expands.</p>	 <p>Sensitivity surrounding the past and looking forward diminishes with an attitude of acceptance of the past events while still being unpleasant.</p>
domains affected	 <ul style="list-style-type: none"> - All domains are being affected as parents prepare for a new baby. - Changes in the domains are helping parents prepare for this new identity. 	 <ul style="list-style-type: none"> - Normal routines are abruptly halted. - An immediate dependence is placed on the healthcare system/supports to determine appropriate course of action and make sense of the situation. In certain cases, critical decisions are offloaded. - New roles are intuitively assumed. 	 <ul style="list-style-type: none"> - A flurry of activity and decisions. - Early communication and processes with individuals or institutions needing to be aware (close family, work/HR, school/caregiver, government). - Early decisions (funeral, autopsy, name, memorializing). 	 <ul style="list-style-type: none"> - Parents intuitive response shapes new behaviours. - New roles and a lack of understanding within a relationship can introduce tension. - Family and friends take on new and varying roles to support. Tensions can arise from interactions - For Partner, work considerations. 	 <ul style="list-style-type: none"> - A more active and aware stance begins in seeking resources and support in terms of personal changes for mom and partner. - For mom, considering how and when to reintegrate to work. - For partner, an eventual shift from attempts to fix things for mom and focus on own grief. - Navigating institutions and communities - seeking resources and support, whether for active or passive participation. - New patterns and stability are returned to the relationship as mom and partner develop new understanding of one another. 	 <ul style="list-style-type: none"> - Acceptance sets in regarding new personal identities with better emotional stability and mature coping abilities. - Relationship begins to foster discourse for considering the future. - New community relationships and participation are formed. - Begin to relinquish institutional supports for recovery.

	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss		New Normal
stages	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity		The gradual transition to new and familiar routines away from daily grief
emotions / feeling	<ul style="list-style-type: none"> - Many emotional highs and lows - Imagining a new future - Many unknowns = stress and anxiety - Joy and optimism 	<ul style="list-style-type: none"> - Disbelief (and still hopeful) - How will we get through this? - Grateful for time with baby - This is cruel / physically violated - I want to be invisible - Barely able to think or process what happened - Uncertainty, what happens next 	<ul style="list-style-type: none"> - Need to keep busy (partner) - Unable to perform activities of daily living (mom) - Unable to think clearly - It is getting worse - I need space - It hasn't sunk in yet - Cruel reminders are everywhere, including my body (mom) 	<ul style="list-style-type: none"> - Everything overwhelms - Guilt spiral - No one understands & feelings of being helpless - Extreme fatigue - Pressure to act normal - Intense sadness - How can this be 'fixed' 	<ul style="list-style-type: none"> - Frustration with progress (lack) - Physical and emotional fatigue - Need for escapes - Wanting distractions - Need to hold it together in certain situations (work, social functions) - Constant stress and anxiety - Easily overwhelmed 	<ul style="list-style-type: none"> - Fear of others' expectations (family/ social routines/work) - Constant need for change - Past activities/passions no longer have same meaning - Desire to make major lifestyle changes - Gradual shift to being positive 	<ul style="list-style-type: none"> - There are still inner conflicts (am I a parent?, how do I speak of my child?) - Pain is still there, but it is manageable - Ability to allow feelings of personal joy back in - Resistance to 'move on'
activities	<ul style="list-style-type: none"> - Planning for pregnancy (desired checklist for being ready) - Attempting to get pregnant - Learning of successfully getting pregnant - Navigating healthcare options - Sharing news and celebrate - Monitoring and appointments - Planning and preparations - Dreaming of the future 	<p><i>note: sequence varies</i></p> <ul style="list-style-type: none"> - First learn of baby's death - Initial questions & seek information on 'what next' - Schedule and prep for induction or natural onset - Logistical arrangements (e.g. work) - Share news with select family/friends - Labour - Spend time with the baby - Collect mementos - Make initial time sensitive decisions (burial/cremation, naming, funeral home, autopsy) - Leave hospital without a baby 	<ul style="list-style-type: none"> - Prepare funeral arrangement (arrangements for body) - Post-partem recovery - For mom, physical reminders occur (e.g. breast milk) - Follow-up appointments to monitor recovery - For partner, instinct to attempt to fix things and get back to 'normal' - Tell/support siblings 	<ul style="list-style-type: none"> - Isolation - Lean on close family and friends for getting through the day - Pain from a lack of others understanding - Receive condolence flowers/cards/ messages/visits - Gradual firsts (getting out of bed, showering, walk outside) - Waiting to hear what went wrong 	<p><u>Recognizing the Loss</u></p> <ul style="list-style-type: none"> - Opening up to others (sharing memory box, talking with others) - Physical objects/ memorials - New behaviours in memory of baby's life - Imagine baby's identity 	<p><u>Releasing the Emotions of Grief</u></p> <ul style="list-style-type: none"> - Accept changes - Anger and dwelling on regrets - Coping with triggers - Rumination - No win situations (catch22) 	<ul style="list-style-type: none"> - Readjustment/returning to work - Return to activities placed on hold - Ability to comfortably speak to others about the baby - Acceptance of new identity - Planning for future - Considering whether to attempt another pregnancy - Discontinue/finish activities associated with grieving and see progress as an accomplishment - Develop new rituals to remember/memorialize
				<p><u>Developing New Skills</u></p> <ul style="list-style-type: none"> - Evaluate options for personal/family recovery - Better understand partner - Develop coping strategies - Seek experience of others 	<p><u>Reinvest Emotional Effort</u></p> <ul style="list-style-type: none"> - Gradual steps to larger goals - Yearn for change - Consider how to connect with/to others 'like me' - Consider future plans 		

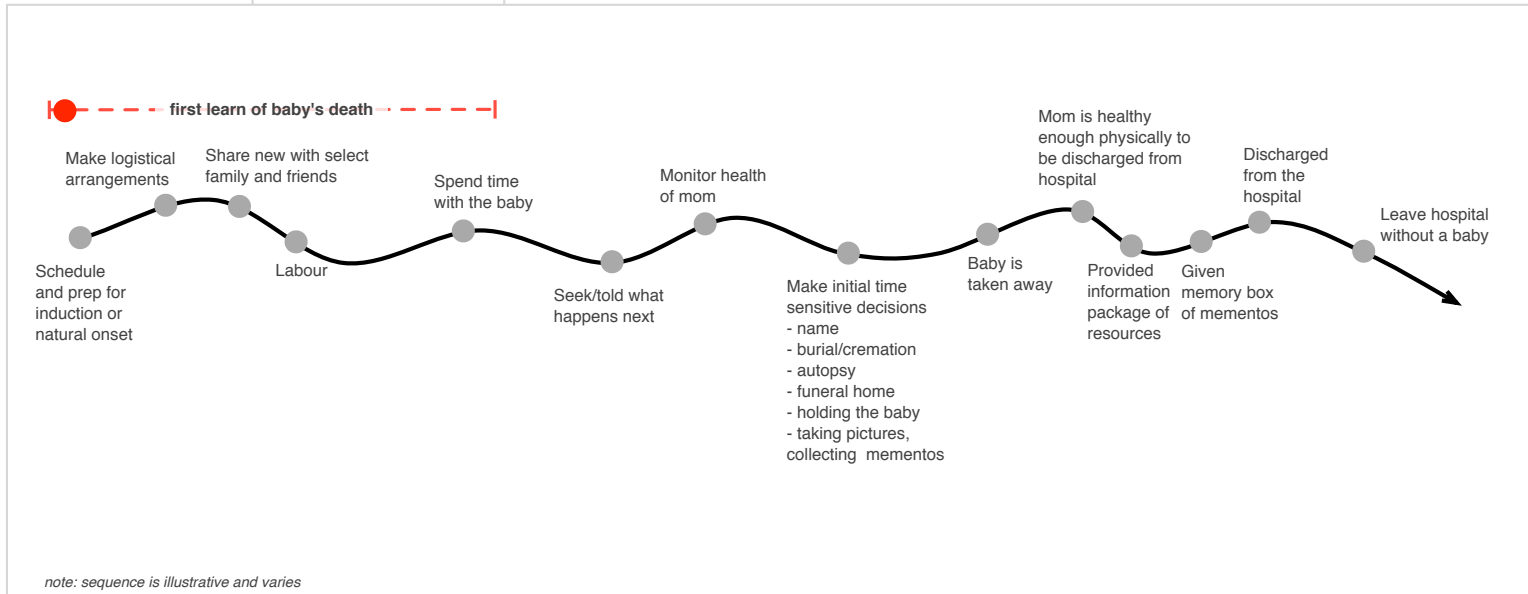
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ISSUES

legend for domains related to issues:	1 Mom - self	2 Partner - self	3 Sibling(s)	4 Relationship	5 Work	6 Family & Friends	7 Community	8 Institutions
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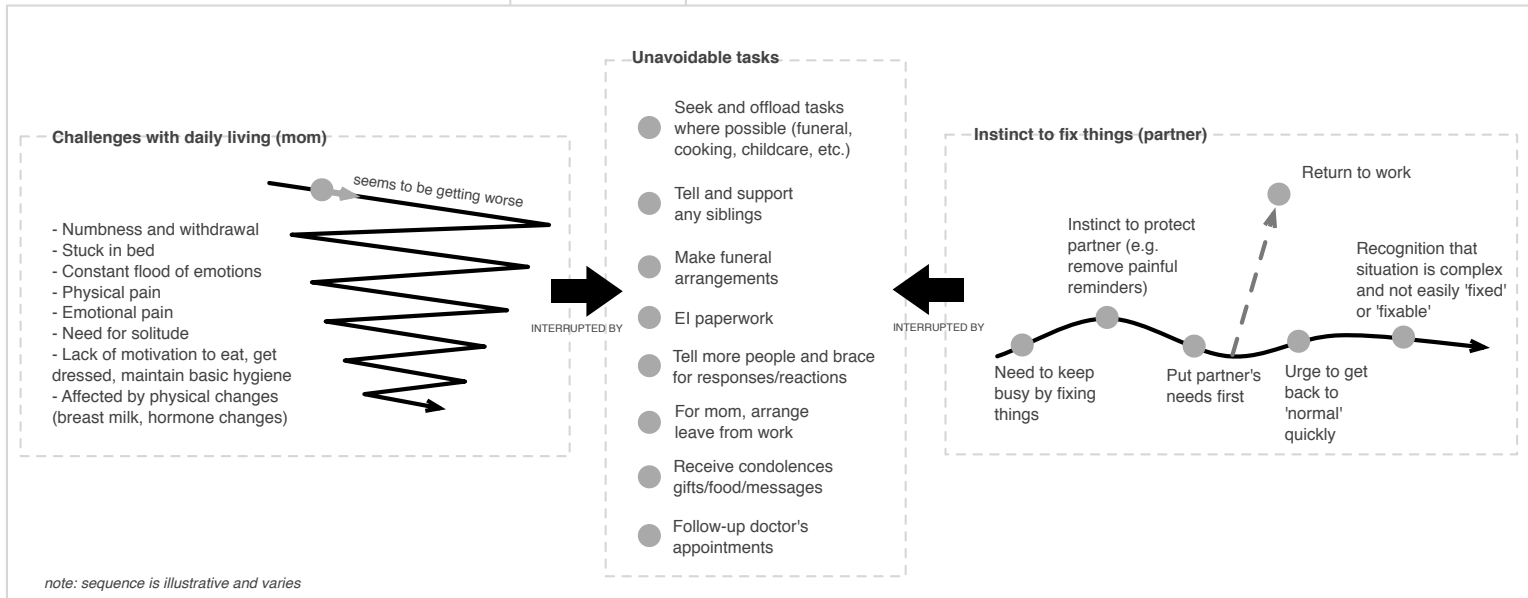
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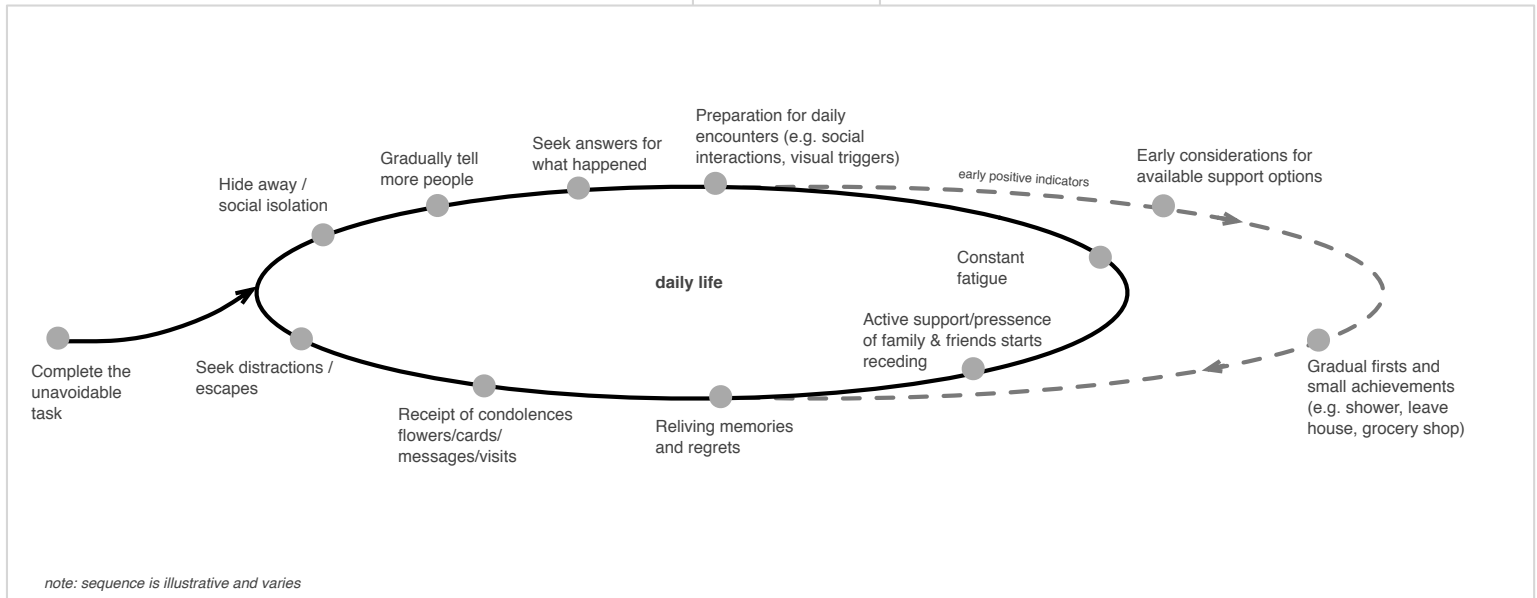
stages	The Pregnancy Path	Labour & Delivery	Early Aftermath	Acute Adjustment	Learning to Live with the Loss	New Normal
	Period from deciding to have a child up to labour & delivery	From onset of labour to leaving the hospital without a baby	Immediately after birth	Early period of recovery process begins	This period includes settling into new routines and denotes a lengthier period of more active recovery including the recognition of a new/changed identity	The gradual transition to new and familiar routines away from daily grief



ISSUES

legend for domains related to issues:	1 Mom - self	2 Partner - self	3 Sibling(s)	4 Relationship	5 Work	6 Family & Friends	7 Community	8 Institutions
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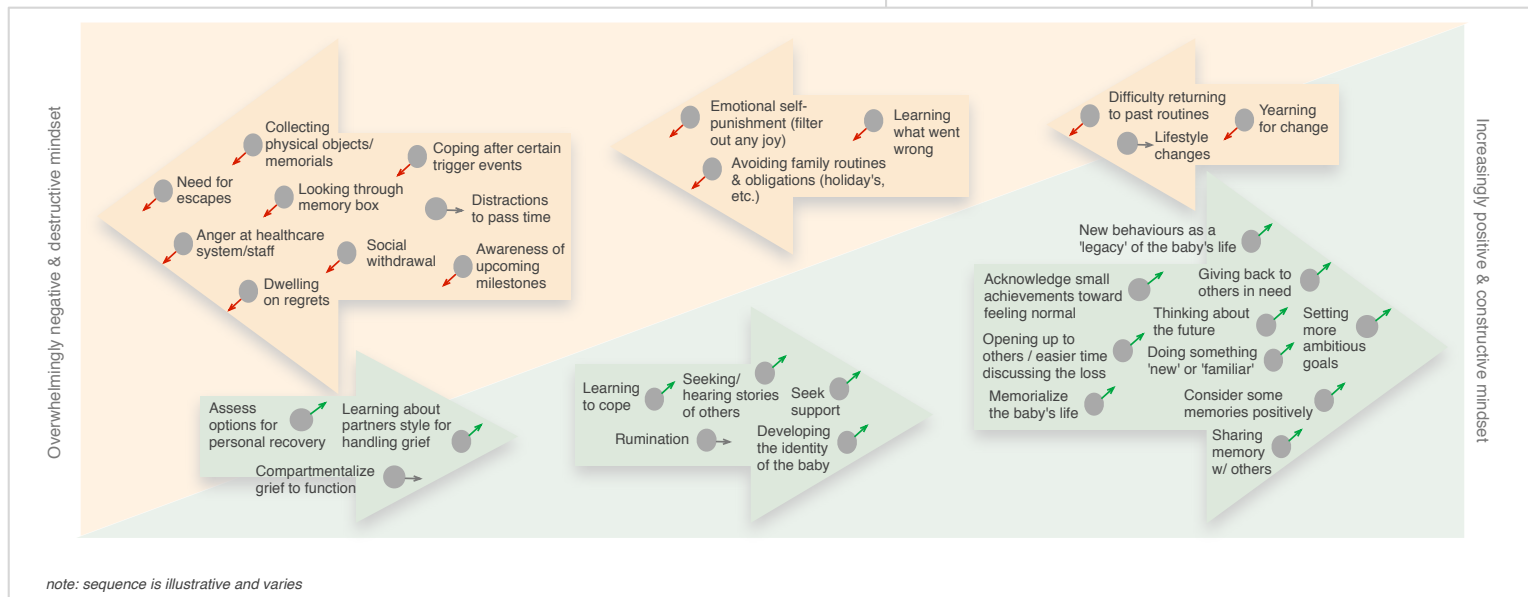
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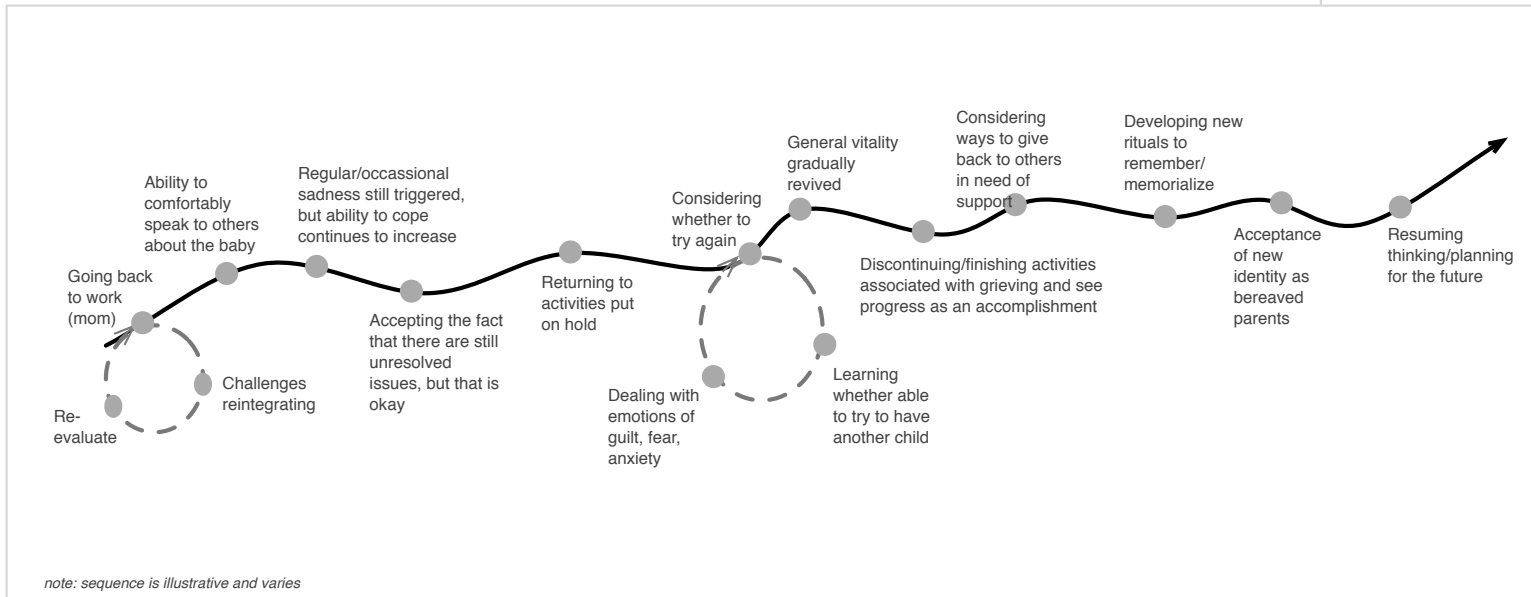
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