Chapter 11
Perinatal Death and Grief in Canada

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Introduction

Attempts to count the number of perinatal deaths in Canada have shown that the concept itself of perinatal death is defined differently from one province to another. While some reports stipulate that perinatal death occurs after 28 weeks pregnancy (Statistics Canada, 2010), others distinguish perinatal death from stillbirths. For nine Canadian provinces and three territories, stillbirth occurs after 20 weeks gestation or when the fetus weighs more than 500 g (Statistics Canada, 2013), while in Quebec stillbirth is defined as the demise of a fetus weighing more than 500 g, without consideration for the length of the pregnancy. Meanwhile, the National Institute of Public Health in Quebec stipulates that perinatal death includes all pregnancy losses (INSPQ, 2011). This has a definite influence on how the phenomenon is represented and on the recognition of its importance for families. In keeping with the framework of this book, in this chapter we will use the American definition of perinatal death, which is death occurring after 20 gestation (e.g., stillbirth, neonatal death).

In Canadian studies, the medicalization, depersonalization, and objectification of a baby who has died before birth has contributed to the ambiguous and disenfranchised nature of parental grief (Lang et al., 2011; MacConnell, Aston, Randel, & Zwaagstra, 2012). This is perpetuated, for example, by the practice of framing stillbirth as a "pregnancy loss" in medical and mainstream literature in Canada (Cacciatore, 2010; Robinson, 2014). Healthcare providers have recognized this tension between the biomedical model of care and the lived experience of bereaved parents, especially in the use of medical terminology, such as "fetus," in an attempt

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to distance both the provider and the bereaved parent from the loss (MacConnell et al., 2012). The disenfranchisement of parental grief in the medical literature is also apparent in the emphasis on biomedical investigations rather than on bereavement care in Canadian guidelines for the care of patients after stillbirth (Leduc et al., 2006). The lack of specialized support for families affected by stillbirth, leaving many alone in their grief, is yet another manifestation of this phenomenon.

This chapter presents how perinatal death and the subsequent grief are experienced in Canada, a country integrating various cultures. We begin with a brief historical overview of the implications of loss in this culture. We then examine the experiences of mothers, fathers, extended family members, other children, and health professionals, focusing on information gathered from Canadian research and clinical practice. Excerpts from two clinical vignettes narrating the stories of Melanie and Stephane, whose daughter Erika and son Theo were both stillborn, and of Nick and Sandy, whose son Raphael died 7 days after birth, are presented throughout the chapter to illustrate the experiences and concerns that have inspired the development of an innovative model of care.

Melanie and Stephane's story

"In my first pregnancy, with Erika, there's no denying I was pretty naive. I was the mother of a little baby in the making, and in my head, once we got past the notorious first 12 weeks, I would be home free. It would never have occurred to me that both my first and second pregnancies could end so tragically after nine months of pregnancy. What I remember is that, when I was discharged from the hospital, I felt emptier than I ever had in my life. I had just given birth to a child… and now I was going home with an empty belly, my heart broken by sadness, and my mind in a total state of disbelief. For several weeks, and even months, everything felt so unreal to me. Sometimes I had the impression I was living a parallel life. As if my heart and mind had to protect themselves, because what I was experiencing was too big and overwhelming for my mother's heart right then. Like a tropical storm in the middle of winter… our story was impossible! In spite of ourselves, as time went by, our memories of Erika and Theo became gradually more subdued. We made a place for our children… in our hearts and in our family story. We decided to create this place for them, so that they wouldn't take up all the space in our lives. They're not physically present, but our children live on through us, through the people we have become." (*Mother's voice*)

Nick and Sandy's story

"Sandy went into labor on a Sunday afternoon at 40 weeks pregnant. The birth was uneventful until the very end, when the baby's heart rate started decelerating. As the birth was imminent, a vacuum extractor was used, and a large baby boy weighing 9 lbs. 2 oz. was born, with an Apgar of 6–8. Nick said, "We were so proud and relieved, the baby was breathing, everything seemed to have gone well, and we could feel the relief in the doctors and nurses…. For the first 24 h, breastfeeding was difficult, and Raphael was not sucking very well; he was sleeping and needed to be stimulated a lot. No one was worried, people kept reassuring us. 'Big babies have reserves, they're not as hungry,' the nurse told us. Then on Tuesday morning, they told us he had a fever and that we couldn't go home that day as planned, they had to do some tests. From that point on, things just went from bad to worse. That same day, the nurses hooked him up to a cardiac monitor and a respirator; his heart was beating too fast and he was also breathing very rapidly. The doctor told us he was worried about an infection, and pretty soon we found out this was the case. They gave him antibiotics, but his condition was deteriorating before our eyes. They had to intubate him and give him a sedative so he wouldn't resist the oxygen going to his lungs. But the infection was everywhere. It was horrible. Less than a week after his birth, the team met with us and explained that there was nothing more they could do. The infection was in his bloodstream and his brain had been damaged. We could have decided to continue the treatments, but we saw clearly that this would have caused him to suffer for no good purpose. It's a decision no parents ever want to have to make, taking their own child off life support. We called our parents; we wanted everyone to have a chance to hold Raphael one last time. He died in Sandy's arms, four hours after the respirator was turned off." (*Father's voice*)

Canada, a Broad and Vivid Tapestry

Canada is home to a broad and vivid tapestry of people, with First Nations, Inuit, and Métis inhabitants across the ten provinces and three northern territories, and a large majority of European descendants who have carved out francophone and anglophone regions and culture in communities and cities across Canada. Over the last century, Canada has also seen an influx of refugee, immigrant, and migrant populations from across the globe (Citizenship and Immigration Canada, 2010). While French and English are Canada's two official languages, hundreds of dialects and languages are spoken, and this is especially prominent in large urban centers.

As a Commonwealth nation, Canada's culture has been strongly influenced by the British approach to government, law, and citizenship. This same influence is pronounced in approaches and attitudes to death and grief practices in Canada, which can be traced to the Victorian era, whose period of industrialization saw death and funeral rites moved out of the realm of families and their homes and into the hands of hospitals and funeral parlors (Curl, 2000). At the same time, a growing middle class placed increasing value on social expectations such as purity and privacy, which in part helped define modern funeral customs and mourning. While the remnants of staunch British customs and attitudes toward death and grief predominate in Canada, there are many other traditions whose rituals and ceremonies are observed by Aboriginal, immigrant, refugee, migrant, and emerging secularist populations.

As Canada's immediate neighbor and trade partner, the United States has a strong influence on Canadian culture. The trading of goods and services in a capitalist society has also produced the commodification of death. In Canada, as in other capitalist nations like the US and the UK, death is "managed," not by individuals, but by healthcare institutions and funeral and cemetery corporations. One consequence of the industrialization and capitalization of culture in Canada is the distancing of individuals from important life events such as birth and death, which are increasingly controlled by the use of medications and machines in a sterile environment. Technological innovations in healthcare and other industries, and their ability to prolong life and treat disease, have led to both birth and death being progressively managed, not only adding a technological authority and barrier, but also removing the human element (Davidson, 2008; Holloway, 2007; Jordan, 1997).

While 'individualized care' is an approach that is slowly being integrated into institutionalized care, technology reinforces the processes of a standardized environment in which culture is not easily expressed and assimilation and homogenization become ultimately more practical and economical. Similarly, the modernization of funeral practices emplaces societal values and dependence on technology and convenience with an increased demand for direct cremation, virtual memorials, and services wherein the body is often not present. While there are remnants of traditional funerals in some regions of Canada as well as faith-based rituals in Jewish and Muslim communities, for example, where the body of the deceased figures centrally, the landscape of death and grief culture is continuously being redefined, and mortal remains are becoming seemingly inconsequential (Carlson, 1997; Holloway, 2007). This evolution distances individuals, families, communities, and the nation from physical proximity to the dead, thereby increasing society's discomfort and denial of death (Becker, 1973; Carlson, 1997; Kübler-Ross, 1969; Mitford, 2000).

Canada is not alone in being a death-denying society; this is actually a hallmark of Western culture. In the healthcare system, often the location of death in Western nations, death is seen as a failure (de Montigny, 2010; de Montigny & Beaudet, 1997; Holloway, 2007). Especially in childbirth, where the essence of the event itself is to bring forth life, death is perceived as the ultimate failure. Yet death denial is strangely shadowed by death obsession. Death is splashed throughout the media, on the front pages of newspapers, in film and television. More recently, social media and the Internet have increasingly become instruments for expressions of grief, and yet these expressions are located in technology, a medium in which the death and the bereaved still remain shrouded and distanced from the everyday world. Though omnipresent in the media, death is evacuated from everyday life (de Montigny, 2010).

Conception of Birth and Perinatal Death in Canada

To understand death and grief practices surrounding stillbirth and neonatal death in Canada, we must first examine and consider the evolution of birth practices in Canada. Since the turn of the twentieth century, birth has taken place predominantly in hospitals rather than in homes. Hospitals are traditionally authoritarian places where patients are managed by experts; in turn, those patients place enormous trust in healthcare providers (Jordan, 1997). Historically, patients did not have a voice and were sometimes even "rendered unconscious… physicians used sedation as a technological device to distance themselves from women, to eliminate 'face-to-face discussions'" with women whose babies had died (Malacrida, 1999). Recent advances in patient-centered care and informed-choice decision-making have begun to alter the landscape of maternal healthcare. However, a lack of caregiver training that leaves health professionals not knowing what to say has engendered another kind of silence.

Silence can also be adopted by women themselves, who may choose, for instance, not to announce their pregnancy in the first 12 weeks, in case they lose the baby (Drake, 2010). Combined with the ambiguity surrounding perinatal death, this silence disenfranchises the grief experience, as these deaths generally go unrecognized by society. This lack of recognition is discriminatory to women and their families, since perinatal death is not given the same legitimacy as other deaths and places women, in some provinces, in a position where they might not qualify for parental or bereavement leave, for example (Drake, 2010).[1]

In Canada, the shift away from this culture of absolute silence can be traced to when women started to demand equality, reclaiming their bodies and their births. Layne argues that, since the 1980s, women who have experienced a pregnancy loss have been caught between "sets of cultural forces—long-standing taboos against death, unruly women's biology, and the emergence of fetal personhood and

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[1] This again differs between provinces. In Quebec, mothers experiencing a perinatal death after 19 weeks pregnancy have access to a 20-week parental leave, while a projected law is under study to allow fathers a 5-week leave.

patienthood" (Layne, 2006, p. 602). While the feminist movement helped reclaim homebirth, breastfeeding, and the inclusion of fathers and other birth supporters in the birth space, it also created situations in which, in the event of perinatal death, fathers and birth attendants also needed perinatal bereavement support. The very recognition of stillbirth as a birth, not just a death, was the result of an American bereaved mother's action to change state law (Layne, 2006). The declaration of October 15 as a day of formal recognition of pregnancy loss in Ontario (Bill 200, Queen's Park) and Quebec (2008), as it is nationally in the US (Layne, 2006), is a more public attempt at lifting the veil of silence surrounding perinatal death.

While the literature acknowledges differences in bereavement across cultures, broadly speaking, Western culture tends to value individualism and autonomy and Eastern culture places greater value on social and familial duty (Holloway, 2007). Given Canada's complex cultural landscape, we have attempted to encompass some of these cultural considerations here, as illustrated in Boxes 11.1 and 11.2.

Box 11.1: Birth and Perinatal Death in Canadian Aboriginal Populations

Those studies that have examined birth practices in Canadian Aboriginal cultures have not explored perinatal death practices. The Canadian federal government noted high rates of infant mortality in Aboriginal communities, especially the Inuit, in the 1950s, and this was one of the driving factors for the relocation of birthing women (Jasen, 1997). The birth experiences of rural Aboriginal women are thus influenced by a complex interplay among their remote geographical locations, the impacts of ongoing colonization, and efforts towards self-determination (Varcoe et al., 2013). European colonization has had a detrimental effect on the cultures of First Nations, Inuit, and Metis communities, as well as creating disparities in healthcare and gender equality, and fundamental shifts in death culture and birth culture (Jasen, 1997; Stevenson, 1999). First Nations women who give birth in their home community are typically surrounded by scores of family members ready to celebrate a birth (Varcoe et al., 2013). However, knowledge of traditional birthing practices is continually being lost as a result of the impacts of colonization (Varcoe, Brown, Calam, Harvey, & Tallio, 2013). For example, Inuit and Nishnawbe First Nations mothers in the far north are likely to be transported long distances from their home communities to give birth in hospitals in cities that are unfamiliar to them (Gold, O'Neil, & VanWagner, 2007; Kornelsen, Kotaska, Waterfall, Willie, & Wilson, 2010; Moffat, 2004; O'Neil & Kaufert, 1995; Varcoe et al., 2013). In considering the impact on the woman and her family of this removal from her community, it is easy to understand that she has likely also been removed from regional foods, medicinal herbs, and important rituals at a time that traditionally would be cause for great celebrations (Alberta Health Services, 2009). The continuing legacy of the residential school system, which has left survivors feeling a lifetime of shame and inadequacy, has had an impact on generations of Aboriginal mothers (Ing, 2006; Simpson, 2006; TRC, 2012). In this context, Aboriginal women might experience perinatal death while separated from their traditional circle of support.

Box 11.2: Birth and Perinatal Death in Canadian Immigrant, Migrant, and Refugee Families

Literature on the birth practices of immigrant, migrant, and refugee women in Canada is limited (Bodo & Gibson, 1999; Grewal, Bhagat, & Balneaves, 2008; Higginbottom et al., 2013; Reitmanova & Gustafson, 2008). These studies focused on traditional practices and beliefs related to birth. Fortin and LeGall (2012) state that the perinatal period represents, for immigrant women, a turning point which symbolically integrates them within Canadian society, while underscoring the absence of their traditional social network. While de Montigny and Beaudet (1997) have looked into the funerary rituals surrounding the death of a child in different cultures, to our knowledge, no Canadian research has explored perinatal death culture and practices in immigrant, migrant, and refugee families. We know immigrant women are confident the healthcare system will provide the expertise they need at the time of the birth of their child (Fortin & LeGall, 2012). Even though situations might arise that could cause tensions with health professionals—for example, in relation to gender relationships between pregnant women and male physicians—generally families and health professionals attempt to learn from each other (Fortin & LeGall, 2012).

Rituals Surrounding Perinatal Death Across Canada

In Canada, as elsewhere, there is wide variation in the grief reactions and mourning rituals surrounding both the deceased and the bereaved at the individual and community levels. While early colonization introduced the Protestant and Roman Catholic religions, over the past hundred years Canada has become increasingly secular and diverse. As such, rituals surrounding perinatal death today may stem from religious practices or secular grassroots parent movements. There is limited literature on specific perinatal death practices and rituals in Aboriginal, immigrant, migrant, and refugee communities.

Hospitals in Canada are likely to call the funeral home at a time of perinatal death, but for those of Eastern and Middle Eastern origin living in Canada, the practice might be to transport and prepare their own child for a funeral, bypassing the funeral home altogether (Hébert, 1998). In the province of Quebec, parents have the option of managing the disposition of their child's body themselves with the support of funeral homes. If parents do not choose to take this on, there are some cemeteries that have become affiliated with hospitals to provide a specific place for these deceased infants. As such, in some regions (Québec City, Montreal, Saint-Jérôme), certain locations have been developed to serve as places of contemplation for families. Birth, once a private event within the domain of women, has slowly moved into the public sphere, where any number of familial supports may be invited to participate. Paradoxically, death, once a public event in which mourners were invited to the family home to visit with the body over several days, has become increasingly more private, with statements like “No service by request.” With perinatal death, there seems to be a melding of the two paradigms, with bereaved parents moving out of the private sphere of silence and into a more public forum of online tributes and walks to remember, for example. A micro-culture is emerging around bereaved parents and families that includes colors, ribbons, picnics, memorial stickers on cars, identification with *angel babies*, online forums, annual picnics—all contributing to the emergence of a culture and identity of *orphan parents*.

The past 5 years have seen the emergence of annual ceremonies to commemorate babies who have died during the year. Some of these ceremonies have been organized by healthcare staff in hospitals and others by volunteer organizations, such as Parents Orphelins, Bereaved Families of Ontario, and the Pregnancy and Infant Loss Network. Parents Orphelins, a Quebec organization that provides information, active listening, and advice to bereaved parents, was created by parents in 2008 to compensate for the lack of any such structured organization in society. Parents Orphelins works to sensitize society to the phenomenon of perinatal bereavement. In response to the culture of silence around stillbirth, a group of bereaved families in British Columbia formed Still Life Canada: Stillbirth and Neonatal Death Education, Research and Support Society in 2012 as a concerted effort to build a community of support and to combat the stigma and the grief related to stillbirth (Farrales et al., 2014). The group is actively involved in community-based participatory research projects aimed at addressing the gaps in support, education, research, and policy for anyone affected by stillbirth. The bereaved families are not only actively involved in guiding the research process in partnership with their academic partners, but they are also key in knowledge translation and dissemination of research findings.

Box 11.3: Rituals Surrounding Perinatal Death in Different Cultural Groups

While it is important to understand traditional practices, it is also important to recognize that a person’s cultural identity is highly individual and complex, being formed by a large variety of factors beyond ethnoculturally specific traditions. For instance, an individual’s pre-migration experiences, coupled with the nature of their migration to Canada (immigrant, migrant worker, or refugee), may have significant influences on their cultural identity and on the interplay between this identity and the dominant Canadian cultures (Ndengeyingoma, de Montigny, & Miron, 2014). The lack of services in languages other than Canada’s two official languages may limit the exploration and understanding of individual preferences surrounding ritual, especially when individuals have varying levels of pre-migration literacy in their language(s) of origin. At the same time, these factors may also limit access to mainstream bereavement services and supports.

Apart from traditional funeral rites, rituals related to perinatal bereavement can take several forms. For instance, there are rituals around dates that are significant to the parents. These may be calendar dates, such as Mother's Day or Father's Day, Valentine's Day, or the holiday season (for example, Christmas). There may also be significant dates associated with events that occurred during the pregnancy, or the child's birth or death—the date when the parents announced the pregnancy, the first ultrasound, the birth, or the date when they announced the child's death. Each of these events may be significant to the parents, and being able to organize rituals around these events may offer a source of comfort. Bereavement groups that are open, or drop-in style—i.e., groups that parents can participate in at any stage of bereavement after their infant's death—are places where rituals can be created. Talking about their baby and the emptiness left by the baby's death, about their memories and the events before, during, and after the baby's death, may all represent a form of ritual in which parents devote time specifically to reflection on the effects and the impact of the perinatal death (de Montigny & Verdon, 2015).

The Canadian Community and Cultural Responses to Death

In the following sections, we examine the cultural response to perinatal death from several perspectives. We consider the roles, practices, and responses of healthcare providers, then we discuss current standards of care for bereaved families, and finally we look at perinatal bereavement as it affects the extended family. Here we should point out, however, that there is a notable lack of literature on the perspectives of health professionals and extended families in Aboriginal, immigrant, migrant, and refugee communities in Canada.

Perspectives of Canadian Health Care Providers

Many practitioners are involved and interact with families going through perinatal bereavement: physicians, nurses, midwives, social workers, psychologists, and doulas. As education programs for maternal healthcare providers and midwives focus broadly on *normality*, there is no room for death in normal birth (McKenna & Rolls, 2011). Certainly, death is not a *normal* outcome of birth, and yet, death is as normal as birth. There are also cultural divergences among the healthcare system, healthcare recipients, and healthcare providers themselves. For example, health professionals' education in regard to perinatal bereavement and standards of care is uneven not only within Canada, but in other developed countries as well (Chan et al., 2007; Holloway, 2007; McGrath & Burton, 2013; Williams, Munson, Zupancic, & Kirpalani, 2008). Not only do teaching curricula have trouble addressing sensitive topics such as death, bereavement, and perinatal death, but they also face the challenge of training health professionals who will be capable of providing healthcare services in a respectful way to a diverse population. The lack of research on the experiences of Aboriginal and immigrant families adds to the complexity of this training challenge. However, the concept of *cultural humility* has been put forward as an approach to compensate for this deficiency in training. Cultural humility refers to health professionals' commitment to self-assessment and self-criticism, with a view to rebalancing the distribution of power between patient and practitioner and, by this means, to develop mutually beneficial partnerships that are not paternalistic (Tervalon & Murray-Garcia, 1998). This is part of a reflexive practice supporting individual and family empowerment (de Montigny & Goudreau, 2009) and is also recommended by the MIRIS. This way of being is inspired by methods that enable professionals to look after themselves while looking after others.

In fact, a few studies that have explored practitioners' experiences of perinatal death have shown how difficult it can be for them to deal with repeated bereavements. The suffering of parents and families very often resonates with their own suffering (Jonas-Simpson, MacDonald, McMahon, & Pilkington, 2011; Verdon, 2012; Verdon, Lavoie, & Blondeau, 2012). This situation can represent a form of trauma for the practitioner and lead to compassion fatigue, which arises when the practitioner's resources are inadequate to cope with workplace stress. This suffering may also affect them personally (Buttery, 2009), making them more appreciative, for example, of their lives and their children, even to the point of being over-protective of them (de Montigny & Beaudet, 1997). Nurses have reported that supporting parents through perinatal death is an honor and a privilege suffused not only with difficulties, but also with opportunities for expressions of faith. Connecting with families and supporting them in developing connections with their infant offers some comfort in the presence of inconsolable loss. They try to envision the future, imagining how the mothers will continue their lives after this loss. These nurses have expressed the need for support and time to share their experiences, replenish themselves, and gain some understanding (Jonas-Simpson et al., 2011). It is easier for nurses to have a constructive attitude toward bereaved parents if they practice a religious faith, have received bereavement training, or are supported by their healthcare organization (Chan et al., 2007).

Practitioners often watch for specific behaviors in parents to reassure themselves that their interventions were appropriate. For example, they might assess the quality of their interventions based on the parents' level of well-being. This might lead them to discredit themselves. Later in this chapter we present the MIRIS (*Modèle intersubjectif de la rencontre intervenant/soigné*—IPPEM: Intersubjective Practitioner–Patient Encounter Model), an innovative model to support health professionals in their work with bereaved families (Verdon, 2012).

Current Standard of Culturally Accepted Care Toward Bereaved Families

The World Health Organization's Baby-Friendly Hospital Initiative (1991) was closely followed by the recognition and regulation of midwives as primary caregivers in Canada (1994 to the present) and the formation of perinatal bereavement groups (Perinatal Bereavement Services of Ontario, 1992). Health agencies created policies on the handling of embryonic, fetal, and infant remains and produced a declaration on the rights of babies and mothers at the time of birth and perinatal death (Women's College Hospital, 1984). These Canadian guidelines (Health Canada, 2000) and policies (Ministère de la Santé et des Services sociaux, 2008) describe the in-hospital health services and community services for these parents. These policies are expressed in the Quebec and Canadian health networks as services that are sometimes ritualized, and even prescriptive (de Montigny & Beaudet, 1997; de Montigny, Verdon, Lacharité, & Baker, 2010), organized around a bereavement model that promotes the benefits to parents of having been able to establish a relationship with their child (Williams et al., 2008).

In hospitals, the health services are sometimes reorganized in such a way that the family is paired with a pivot practitioner, in a private room with a marked door. Most often the hospital stay is a maximum of 24 h. The interventions arising out of the policies mentioned above are aimed at creating and preserving parents' relationship with the child, such as recognizing their child's existence (e.g., holding the infant) and creating mementos (e.g., photos) (de Montigny et al., 2010). As noted previously, Victorian-era customs were present in early Canadian culture, including the practice of memento mori, or photographs of the dead. For mothers whose babies had died, memento mori served as a keepsake and a death notice to family abroad, who might otherwise never have seen the baby. Where once there was a considerable normalcy to this practice, it eventually fell out of fashion. Interestingly, this practice has recently been rekindled, as the taking of digital video or photos has become nearly as commonplace for stillborn babies as for live births. Over the past few years, parents have thus become more open to creating rituals with their child (taking personal photos, gathering items by which the babies are remembered, taking measures for disposition of the body, observing rituals at the funeral parlor). Perinatal death resources and materials such as educational leaflets, blankets, and tags for vital information are some of the supports now available to women and families, as are stillbirth awareness organizations (Layne, 2006; Still Life Canada, 2012).

However, the bereavement model upon which these practices are based does not take into account the experience of couples dealing with early perinatal death, nor cultural influences. It proposes rituals that are often strange to members of different ethnic groups (de Montigny et al., 2010). Likewise, health institutions might be perceived as non-inclusive or discriminatory, for example, if they fail to support the use of traditional herbs for smudging rituals in Aboriginal culture.

The continuum of care between in-hospital services and community-based services is unevenly developed from one region to another and within regions, as there are several different organizations providing care (local community health centers, hospitals, community agencies). This means the range of services available to bereaved parents will be limited or robust depending not only on the region in which they live, but also on the institution in which their infant died. Because of this, for example, nearly one-quarter of Quebec couples who have experienced a perinatal death will not receive any telephone follow-up (de Montigny et al., 2010). When there is such follow-up, or home visits, these are most often carried out by a nurse, midwife, or sometimes a social worker. In some regions, there are interventions to mobilize social support for parents either through self-help or support groups, or through mentoring arrangements.

Beyond the unevenly distributed service offerings and the diversity of practices, there are also very few resources specifically devoted to fathers or to same-sex partners. Likewise, women living through an early perinatal death are not automatically included in a continuum of care. There is every reason to believe services need to be harmonized in Canada, in accordance with a more systematic intervention model that includes support for children and for couples who have experienced an early perinatal death, and for men, as well as pre-conception counseling or counseling during subsequent pregnancies (de Montigny et al., 2010). This continuum will be described later in this chapter.

Extended Family

Perinatal death affects a variety of members of the extended family, including grandparents, uncles, aunts, cousins, and so forth (Foran, 2010). The experience redefines how family members communicate with each other and their capacity for mutual support. This section describes particularly the experience of grandparents and siblings, both those living at the time of the baby's death and those born afterward.

Perinatal Death: Grandparents' Perspectives

In Canada, grandparents tend to play an active role in the lives of their children and grandchildren, when they live in proximity, whether by providing childcare or emotional support (Bowen, 2013). From the moment of conception, grandchildren come alive in their future grandparents' imaginations. When pregnancy ends in perinatal death, the grandparents are just as affected as the parents, albeit differently. They also experience the loss of their dreams and plans for this child and of the relationship they had expected to enjoy. They are also losing, or postponing, the role of grandparent, and at the very least, grieving the loss of being grandparents to that particular child. Added to this sorrow is the pain of watching their own child and his or her partner suffer and react to the death. This death may also reactivate memories of their own experiences of perinatal death or other major bereavements. In addition to the suffering itself, which may be reawakened for awhile, the grandparents will be revisiting memories related to these events in their own past. It will be a challenge for them to distinguish between their own experience and that of their child and his or her partner, so that they can better understand that couple's needs and respond to them. Another challenge is that their relationship with their son- or daughter-in-law will be redefined. On the one hand, each of them undergoes a process of self-discovery in terms of their capacity to be open, to reveal themselves, and to support and be supported. On the other hand, the young couple's privacy has been breached, requiring implicit renegotiation of the notions of distance and privacy. Likewise, the grandparents can act as advocates for the bereaved parents' needs and help the extended family to provide the most appropriate support. It is therefore not surprising that grandparents experience bereavement and need to have their own pain acknowledged (Roose & Blanford, 2011). For grandparents who are estranged from their children, perinatal death may also become a time of reconnection. Grandparents have to support each other while being present for their child and his or her partner in their grief over a sustained period of time. Their resources for managing this will include both their own coping strategies and their social network. Participating in bereavement support groups can provide a much-appreciated safety valve, both for grandparents and for the grieving parents (de Montigny & Verdon, 2015).

Nick and Sandy's story
Raphael's grandmother (Sandy's mother)
"I never would have believed that I would welcome the life and death of my grandson. I'm grateful to my son-in-law for allowing me to share that moment with them. In the weeks after that, I didn't know what I could do to be useful to my daughter, to my son-in-law. It was difficult for me to manage my own grief, while watching them suffer; I felt so powerless. I was angry at life. I attended a meeting of a bereavement support group. That helped me to understand that even if my daughter told me on one day that she was doing well, it didn't mean she would still be fine the next day. I had to accept that her emotions came in waves. Also, I understood that I should continue to offer support, prepare meals, and suggest going for walks or to movies, and to not feel rejected if she said no."
Raphael's grandfather (Nick's father)
"My son and I are not much for talking. I offered to help make the coffin, and he accepted. I chose some beautiful wood. We worked many hours together side by side, making the little coffin. We didn't talk. But I think he knows I love him. He understood that this child was important to me, too. Raphael had a beautiful coffin; it was all I could give him to show my love."

Perinatal Death: Siblings' Perspectives

Perinatal bereavement has repercussions on children already in the family at the time of death as well as on those born later (de Montigny & Verdon, 2012). In Quebec studies, these repercussions have been observed in the parent–child relationship, which can be influenced by the flow of communication between them, whether verbal or non-verbal. Thus, whatever the children's ages, reactions emerge and are modulated according to the parents' experience. In fact, children are sensitive to emotional changes in adults and will react in different ways depending on their stage of development (Masson, 2010). Several factors explain their reactions to bereavement, including the age of the deceased infant, the time of the death (during pregnancy or at birth), the degree to which they have been prepared, and previous discussions about the arrival of a baby in the family (Erlandsson, Avelin, Saflund, Wredling, & Radestad, 2010). Some children's reactions take the form of subtle changes in certain behaviors or demands for more of their parents' attention. For others, there may be a regression in psychomotor skills or the emergence of new and unusual behaviors (Masson, 2010).

Explaining death and bereavement to children is not easy, as parents often must talk about things that they themselves find difficult to express. Also, some parents may limit the amount of information given to children in order to protect them. Others hide their own reactions, believing these could be damaging to their children. Yet children need to know the reasons behind the changes they are experiencing in their environments (physical, psychological, emotional, social) (Masson, 2010). There is an observed reduction in children's reactions when parents provide them with simple explanations, talk about what they are feeling, and include them in ritual activities and public memorial events, such as picture-taking and funeral services. Children who know about what is happening and their parents' sadness are more reassured and less anxious; otherwise, they are faced with silence and taboos (Masson, 2010).

On top of this, the birth of other children after a perinatal death elicits reactions in parents. These reactions may be positive, but may also be riddled with challenges and difficulties. Parents may feel relieved and happy to have given birth finally to a living child in good health, while at the same time feeling wistful and aware of the void left by the deceased child. They may fear experiencing another loss and, because of this, be wary of becoming too attached to the new baby. As a consequence, the new child may be at risk of parental over-protection or neglect as well as over- or under-investment on the emotional level. The "replacement" child is a significant reality because often, if the parents had not lost the one child, they probably would not have wanted another one. In such cases, practitioners have noted that the new child may suffer psychological sequelae if the parents' sense of bereavement is pathological or chronic. Pathological bereavement is characterized by a lack of movement in grief responses and by the pursuit of a relationship with the deceased child through rituals that prevent parents from living a healthy family life (de Montigny & Verdon, 2012).

Melanie and Stephane's story

"Erika and Theo are part of our family. There are some photos of them in the house. Even though they're not physically here, we have never wanted to deny their existence. Their little brother has been in our lives for almost two years, and when the time comes, we'll tell him the story of his sister and brother. If it hadn't been for Erika and Theo, I would certainly not be the mother that I am today for our precious little Alek. Life doesn't have the same color or taste. Now I see everything through the colors of Erika and Theo, but I have this deep conviction that I enjoy every little daily pleasure more fully… no matter how small. Our family is very different from others, I'll admit, but it's *our* family, and it's wonderful in spite of everything.

When I was going through my pregnancy for Alex, I kept reminding myself that this child had his own story. Whenever I was seized by the fear that everything would fall apart, I reminded myself that I was pregnant and that everything was going well. Despite our history with Erika and Theo, I needed, and had the right, to believe in him and to offer him all the love in the world." (*Mother's voice*).

Individual and Family Reactions to Loss

Over the past 30 years, a body of knowledge has been building up internationally on the experiences of men, women, and couples in relation to perinatal death. Canadian studies have recognized that the death of a child during pregnancy causes as much sorrow as do other types of bereavement (Malacrida, 1999). Several authors have studied the vulnerability of parents who have experienced a perinatal death (de Montigny & Beaudet, 1997; Verdon, 2004). This vulnerability may be expressed both physically, through a variety of health problems (de Montigny, Beaudet, & Dumas, 1996) and psychologically, through a whole range of emotions—anger, sadness, guilt, a feeling of emptiness—and losses. Waves of sadness alternate with periods of well-being, often short-lived, in keeping with oscillation theory (Stroebe & Schut, 1999). Caught in this spiral, couples may feel they can see no end to their sorrow. This can lead to psychological distress, conjugal dissatisfaction, anxiety in subsequent pregnancies, and even problems of attachment to their other children (de Montigny & Beaudet, 1997). Even though couples are deeply shaken by a perinatal death, most will be able to find a new equilibrium. Often they will feel closer to each other, because through this trial their knowledge of each other will have deepened and they will have learned how to support each other (de Montigny & Verdon, 2015).

Melanie and Stephane's story
"It's easy to love each other when everything is going well. But when we're in the middle of a raging storm… we have to love each other even more. Alphonse de Lamartine said, 'Shared suffering creates bonds a thousand times more than shared joys.' It was with a great deal of love and respect for each other that we went through these unavoidably painful times. We never tried to measure our sorrows or compare the magnitude of our grief. We were two bereaved parents and we needed each other in order to survive. With my husband, I could be honest and authentic, because I didn't have to pretend. We didn't need to talk to understand that the other person was having a more difficult day. Together, even the silence was easier." (*Mother's voice).*
"The important thing is to understand and accept that the other person isn't going to be feeling the same thing you're feeling at every step of the way. Each person goes through grief at their own rhythm, and you need to respect each other's rhythm and just be there for them." (*Father's voice).*

A Quebec study conducted in 2003 identified the needs of heterosexual parents in bereavement. Emotional needs predominated and referred to parents' needs to be heard and for their rhythm to be respected. Fathers needed to be recognized as bereaved persons just as much as their spouse. They also needed to be in control of events and involved in decisions. Over time parents' emotional needs changed, but they continued to need acknowledgement at times of anniversaries. At the cognitive level, parents expressed a variety of needs for information—on bereavement, grief responses, coping strategies, and how to tell their families or their children. Physical needs, such as for food, sleep, and distractions, were less critical, but could be met by family and friends who brought prepared meals and provided respite by looking after older children, for example. Before they could integrate this new reality, parents had spiritual needs that they addressed through certain rituals or by attempting to find meaning in the experience (de Montigny, Beaudet, & Dumas, 2003).

Today, more than 10 years later, it may be that increased social recognition of perinatal bereavement in Canada has modified this needs profile, but recent studies show no evidence of this. We do know, however, that these deaths have different repercussions for men and for women, and that the specific experiences of each warrant illustration.

Mothers' Reactions

From the moment their pregnancy is announced, women see themselves as future mothers. They become anchored in this reality in a variety of ways—for example, through visits with their physicians or midwives, or as they begin to notice changes in their bodies. Their emotional commitment to their child is forged in these moments. It follows, then, that they will experience a whole range of emotions when they learn their child has died. On top of everything else, they will have to make decisions and choose, among other things, how they would like this birth to unfold. Some choose to give birth naturally, without an epidural, to have the experience of labor. Others will ask for an analgesic, or even a cesarean, finding it inhumane that they should suffer for a dead child (McGrath & Burton, 2013). Some mothers might have difficulty expelling their child, which may symbolize a final 'holding on' to their babies, as they realize this is really the end. It is at times necessary to help mothers move on with the birth while symbolically beginning to face the death, by encouraging them to "let go." (McGrath & Burton, 2013).

After childbirth, the mothers must deal with the hormonal and physiological changes of the postnatal period, among them notably postpartum lactation, an important and symbolic occurrence. Even though they have just lost a baby, for some, their milk coming in is accompanied by a certain sense of elation and gratification for this confirmation that the pregnancy has been "real" (McGrath & Burton, 2013). For others, however, this symbolic event is a cruel reminder of the experiences they will not have with their child (de Montigny & Verdon, 2015).

Sandy's story
"When I left the hospital, it was totally unreal, a bad surprise, to leave the hospital without my baby in my arms. For one month, I hid at home with Nick. I didn't want to see anyone who would ask me how the baby was doing. I didn't know how to respond, how to tell them the baby had died. Saying nothing? Friends brought us prepared meals, my mother and mother-in-law did our laundry; otherwise we would have just eaten cereal in our dirty clothes.
Raphael was our first child. Am I a mother or not? I consider myself to be the mother of a deceased child. I have a friend who finds that morbid. She wants me to hide my photos of my son. She doesn't realize that he's always in my thoughts, in my heart…. I don't need photos to remember him. I have good moments and bad moments… in the beginning, my feelings changed from minute to minute… then I came to grips with this sadness…. When I smile, sometimes I feel guilty because I tell myself I shouldn't be happy, since my baby isn't there.
I wonder where he is, if he's alright…. I wonder where we go after we die…. I found it difficult to bury my baby…it's not normal to outlive your child…. I feel that my grief will last for many months, and I think it will be full of waves and that it will be related to events that I was looking forward to experiencing." (*Sandy, Raphael's mother)*

While multiparous mothers might find comfort in looking after their older children, they may also find it difficult to be attentive and available to respond to those children's needs with sensitivity. Primiparous mothers, on the other hand, question the legitimacy of their status. The death of the child who would have confirmed this social status makes them doubt whether they are entitled to identify themselves as mothers. Most will choose to refer to themselves as mothers of deceased children, even if this status is not always revealed to everyone. Sometimes they will avoid mentioning their deceased child, so as to avoid having to explain and justify their experience (de Montigny & Verdon, 2015). Naming the baby, collecting mementos, and incorporating the infant who died into the everyday lives of families are ways of validating the experience as first having had a baby, who then died (Davidson, 2008).

Many mothers must come to terms with their concerns about the possibility of another pregnancy, in terms of both the timing and the chances of carrying a child to full term and a live birth. Some also express worries about potential infertility. One thing is certain—they will not go through a subsequent pregnancy with the carefree and naive attitude that characterized their first one, and some will even have to contend with strong feelings of anxiety (Caelli, Downie, & Letendre, 2002).

Fathers' Reactions

Quebec is a leader in Canada with regard to the scope and variety of studies carried out over the past 20 years on men's mental and physical health (Dubeau et al., 2013). Other Canadian researchers across Canada have also recently begun to investigate men's mental health in the perinatal period (Fame Team-de Montigny et al., 2014). Even though Canadian fathers' experience of perinatal death is considerably less well documented than that of mothers, their experience is consistent with trends observed internationally (de Montigny, Beaudet, & Dumas, 1999, 2003). There is consensus that careful attention should be paid to fathers (Verdon, 2002), as they often feel ignored and not recognized as legitimately grieving parents (de Montigny et al., 1999; Lang et al., 2011). Their grief is expressed differently than that of mothers, often as powerlessness, irritability, anger, and aggressiveness. Families and practitioners find it difficult to connect with men in crisis (Dubeau et al., 2013). Generally speaking, social support is mainly directed toward mothers (de Montigny et al., 1999; Verdon, 2002). Even though mothers could be a source of comfort, fathers often feel isolated, as they might not be very available (de Montigny et al., 1999; de Montigny & Verdon, 2012).

It has been observed that, in the short term, men organize themselves to support their spouse and their children, if any. This gives meaning to their experience. Their attention is taken up with decisions surrounding the birth process and the disposition of their infant's body, as well as with the continuing business of everyday life. Attentive to their spouse's needs, they are often at a loss for ways in which to support her.

They are quick to propose a return to daily activities and to wish for life to return to normal. Studies have shown that, over the long term, fathers who have experienced a perinatal death are twice as likely to have an elevated score for depression 11 months after birth, compared with fathers who have never had that experience. These fathers also display a higher level of parental stress, expressed as problems in interactions with a child born after that perinatal death and a tendency to perceive that child as more difficult (de Montigny et al., 2011).

Stephane's story

"In the beginning, a shell was created, to try to make myself believe that I was doing all right, and that I had to be strong for my wife, who needed me. This period wasn't very pleasant, but it wasn't the worst. The worst is when this shell disappears, and you realize you're in a bad state. You need to give yourself permission to feel your emotions. It hurts, but you have to go through it, give yourself the right, and do whatever it takes to get through it." (*Father's voice*)

Nick's story

"I had never imagined that I could suffer like that. And I saw Sandy suffering, and I was totally powerless, I didn't know what to do, what to say. My son was dead! But Raphael was the baby she had carried for nine months. We expected a life, and we didn't get it. Sandy said she felt empty, and I was afraid for her. I asked myself if we would be able to get through this. How would we do it? When we went to the bereavement support group, I was relieved to hear other men say out loud what I had been thinking to myself. I understood there were many ways to experience bereavement. No recipes. Now it's been four months since Raphael was born and died, and I can honestly say I would not want to turn back the clock and not to have experienced the pregnancy and those long months of happiness, or not to have known my son. I have every hope that one day we'll give him a brother or sister, when Sandy is ready. Meanwhile, we are discovering each other a little more every day. To get through each day, I admit that I need to be active and change my thinking. When Sandy isn't doing well, I wish I could change her thinking, too.... Her moods affect me, I feel responsible for her suffering. So when I'm feeling bad, I try to hide it from her so as not to add to her pain. I often feel alone and isolated. Also, my friends and family keep asking me how she's doing. They almost never ask me how I'm doing…. I suppose it's because she carried our son and gave birth to him." (*Father's voice*)

Factors Influencing Perinatal Bereavement

There are certain factors that influence bereavement in parents, siblings, and family members, and that may intensify or facilitate grief reactions. In Canada, it is difficult to know how this situation is experienced by the persons affected, as there is still not enough accumulated knowledge about the trajectories of complicated bereavement related to perinatal death. Nevertheless, we know bereavement can become complicated in cases where there is a history of mental health disorders, such as depression or anxiety (Rowlands & Lee, 2010) or when the person's relationships with others are generally disorganized (Bonanno & Kaltman, 2001; Weiss, 1993, 2001).

A recent study of francophone bereaved parents (de Montigny & Verdon, 2015) found that certain circumstances appeared to influence the bereavement trajectory, such as whether or not the couple had other children, the length of pregnancy, and the unfolding of events at the time of death. Indeed, parents remembered every detail associated with their infant's death, and their reactions to these depended on the support—conjugal or social—they had received. The more their perceptions of the events were negative, the more their grief reactions were intense. Already in 2004 Verdon had noted that parents' perceptions of the event played a major role in their expression of grief reactions. Thus, the intensity of grief reactions does not depend on the number of weeks of pregnancy, but rather on the parents' perceptions of the magnitude of their loss. This explains why a mother experiencing a miscarriage in early pregnancy can react just as strongly as the mother of a full-term infant who dies hours after birth (de Montigny & Verdon, 2015).

Studies in Quebec have noted several other factors that influence parents' grief reactions. Among others, the parents' willingness to go through another viable pregnancy (also identified by Brier, 2004), the resilience that comes from their capacity to summon up personal resources to cope with their situation (Lang, 2002), and their ability to give meaning to life after this event (Verdon, 2002, 2004) are factors that facilitate the bereavement process (Brier, 2004; Corbet-Owen, 2003; de Montigny & Verdon, 2015).

These results suggest certain health indicators that can enhance our understanding of families' experience of perinatal death. Personal resources, such as the capacity to make sense of one's life, and contextual factors, such as social support, can help parents to navigate bereavement and cope with the loss of their baby. Rituals can be used to refocus suffering into concrete action. Thus, participating in support groups can facilitate the bereavement process for some parents, whereas it might immobilize others (Di Marco, Menke, & McNamara, 2001). Bereaved parents claim that maintaining bonds with their dead babies "helps them overcome, rather than act on their feelings of anger, resentment, shame, envy, humiliation, and self-doubt" (Klass & Gross, 1999, p. 18).

Ideal Culturally Appropriate Continuum of Care for Canadian Bereaved Families

The ideal continuum of health services for bereaved families is the result of a meta-analysis of more than 15 years of studies in Quebec with parents, practitioners, and health managers affected by perinatal death.[2] A number of recommendations can be drawn from this analysis that will have an impact on parents' grief reactions in the short, medium, and long terms. These care guidelines are structured around pivotal moments in parents' grief trajectory.

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[2] For the past 15 years, de Montigny and Verdon have carried out, both individually and together, a series of studies on the trajectories of bereavement and of care and services for parents experiencing a perinatal death, as well as being clinically active in providing support to families. More than 2,000 couples have been interviewed or have completed questionnaires. Likewise, more than 1,000 practitioners and 200 managers working in health services that provide care to these parents took part in the DÉPART project and in various workshops led by these authors.

When the Diagnosis and the Inevitability of Death Are Announced

In Canada, the service trajectory sometimes begins with a consultation requested by the mother-to-be for reassurance about symptoms she is experiencing. More often, this trajectory is activated by an event, such as a placental abruption or the determination of a diagnosis implying that the infant's life is in danger, or even that the infant has died. Whether the message involves fetal cardiac arrest, a fatal illness, or imminent labor involving the death of the infant, this is a defining moment in the parents' life. Indeed, this situation is described as creating a momentary shock in which they are transported into a universe where everything subsequently said to them is lost in a haze. During this period in which nothing seems real, the parents feel as if they are living a nightmare. This is very soon followed by denial, anger, and weeping. Faced with all these reactions triggered by the news, the practitioner needs to adopt a particular rhythm. The practitioner knows the parents will repeatedly revisit their images of this event associated with the news after they have left the hospital and in the months following the death. To help the parents absorb this news, the practitioner will take the time to say things slowly, with compassion and respect. Parents may find it difficult to understand and make connections between events. The practitioner will need to verify their perceptions and repeat the information as required.

Melanie and Stephane's story

"When the hospital staff came to see us in the room, I could see their compassion and sympathy in their eyes. Even though there were no words that could comfort us in our tragedy, their respect for our wishes, for our silence and tears, did us a lot of good." (*Mother's voice*)

During the Birth

After receiving the news, parents become caught up in a turmoil of decisions and procedures related to giving birth to the child, or to how they will accompany their child in his or her last moments of life. In Quebec healthcare establishments, most parents who have experienced these situations say these procedures unfold at a very fast pace. In fact, they are presented with a multitude of questions about the next steps, e.g. the care of their child's body, rituals at the time of death, what kind of follow-up they want. It can be difficult for parents to decide on these things before their child has even been born. If time allows between the diagnosis and the birth, parents can be guided in preparing a plan that covers these topics, to minimize repetitious questioning. In an ideal service continuum, practitioners would have a protocol to guide them in the procedures to be followed. This would enable them to offer parents a set of choices and to avoid variations in service from one practitioner to another. Likewise, each practitioner would take the time and give parents all the time they need to make decisions regarding themselves or their child, which would give them a greater sense of control over events. It is essential that health practitioners be aware of Western ideals and practices as they relate to perinatal death.

Rather than pushing these ideals with neocolonialist attitudes, they should ask permission, listen and respect families' wishes for care, in particular when caring for Aboriginal or immigrant families.

During the birth of a child who has died in utero or whose prognosis is poor, the parents' experience takes precedence, and the circumstances of this birth should be as supportive as possible: carefully managed pain, a calm environment, explanations provided in rhythm with the pace set by the parents. It is important to create a good birth experience, even at a time of loss (Hey, Itzin, Saunders, & Speakman, 1996). In addition to negotiating the death of their child, mothers and fathers are also negotiating hospital policies, equipment, medical jargon, and decisions surrounding disposition. Most often it is not words they need (in fact, words, especially clichés, may do more harm than good), so much as someone to listen and to be with them, so they can express emotions and have their experiences validated (Daley & Limbo, 2008).

It may make some parents very sad to receive care in a place where they can hear other families nearby who are experiencing a happy childbirth. Nevertheless, it has been shown that, in the medium term, giving birth in a unit with staff who are skilled at supporting them through this experience helps to reinforce the couple's feelings that they are parents even if their child has died. Providers also able to recognize the couple's need for privacy and support, as well as their worries regarding their infant's appearance, for example. From the moment of birth, the infant will be handled very carefully, and the staff will help prepare the parents for the infant's appearance. By using positive terms and focusing on the normal features of the infant, the health professional can help make this encounter between the parents and their child a precious memory for them. For instance, in cases of infants with severe deformities, such as anencephaly, a knitted cap can facilitate this first contact by diverting attention from the deformity.

The perinatal death environment is a perinatal care specialty, and training in Canadian provinces such as Quebec is aimed at supporting practitioners so they can properly support parents, whether in hospitals or midwives-led birthing centers. Going through the experience of death on another care unit could put parents into a more problematic environment where practitioners are not adequately trained in the specific skills required.

Support After Childbirth, in the Postnatal Period

There is evidence that parents who are able to see their babies and to touch and hold them in their arms are able afterward to retain an image and grieve their child, who is then very real in their memory. Perceptual and sensory confirmation of the loss of their child also appears to play a crucial role in the integration of bereavement. Sometimes, however, it happens that parents do not wish to see their baby for a variety of reasons, some of them cultural. When parents feel they do not have sufficient energy or support, or that the requirements of the situation are beyond their capacities, they often prefer not to see the infant. If the parents have never had any contact with death before, or if they have had an experience with death that was traumatic for them, they may be afraid that seeing their child will cause even more suffering. The practitioner can facilitate this encounter, at whatever pace suits the parents. She or he might explain that the grieving process often leads people to change their minds and to see the situation differently over time, such that they might wish to see their child later on. Given this, parents are invited to take some time to consider their decision. Logistics must be flexible to allow for changes in decisions. The practitioner can also help parents to confirm the reality of their child's life and death in other ways. Certain symbols—such as a mold of the baby's foot or hand, a lock of hair, a certificate with their child's name and the date, time, and place of birth, photos, the hospital bracelet, the umbilical cord clamp, or even a beautifully crafted box to hold the parents' mementos—can be sources of comfort. Photos can be taken of the infant in the arms of a family member. Photos can also be taken of the infant's profile, hands, feet, or other details that will capture the distinguishing features and the emotions in the moment. In some cases, parents might want to hold their baby, and to wash and dress the baby and present him or her to the extended family, siblings, or friends. The important thing is to offer possible options and to support parents in whatever other ideas they may have.

Melanie and Stephane's story

"Despite the pain of the sorrow permeating my entire body and soul, I very much wanted to meet our children. My heart needed to kiss them, rock them, hold them in our arms, but especially to finally see the beautiful faces of these little beings whom we had cherished for the previous nine months. Unfortunately, we would never have the chance to add to those memories. These hospital bracelets, locks of hair, little pajamas, foot molds, and photos—too few of them—have become our most precious treasures. We held funerals in the week after their deaths. We needed this ritual to let people know that our baby was no longer in this world, that we were grieving, and that our pain was legitimate. There is a monument in the cemetery where our names are engraved above those of our cherished children. Erika and Theo were buried side by side, as if they were holding hands. When we talk about them, we call them by their first names, since for us, even though they were here only for a short time, they existed. Every year we acknowledge their birthdays privately. These days are more for remembering than for celebrating, but it's important to us that we send them a little signal." (*Mother's voice*)

Advice on Discharge

When parents leave to return home, they need guidance from staff. Practitioners are encouraged to provide documentation that is up-to-date and gives parents information to support their physical, psychological, and spiritual needs. This information should include explanations about normal grief reactions that they might expect to experience over the days, weeks, and months following their child's death. It is also important to emphasize that every person experiences bereavement in his or her own way and that reactions can differ from one person to another. Topics that should be covered in the information provided to parents are, for example:

- Parents' bereavement and their potential reactions
- Grandparents' bereavement
- Siblings' bereavement
- Reactions of family and friends
- Physical reactions in the mother following a perinatal death: lactation and physical and psychological changes
- Sexuality and communication after a perinatal death
- Paid parental leave and alternatives for fathers (e.g., sick leave)
- Coping strategies
- Community resources
- Funeral arrangements and other rituals
- The autopsy and anticipated results
- Planning a subsequent pregnancy
- Any other information considered relevant

The Return Home

After the couple has returned home, it is important to provide continuity of care for the bereaved families. In Quebec, most postnatal care includes telephone follow-up, sometimes as soon as the community nurse is informed of the mother's discharge following the death or during the subsequent days or weeks. In fact, practitioners are not entirely sure when is the best time to contact the family, and added to this is the fact that every parent is different. The perinatal bereavement support training offered in Quebec stresses the importance of contacting parents early and then doing regular telephone follow-ups as needed in each case. The nature of bereavement changes over time, and in these follow-ups practitioners listen, reassure, and accompany parents wherever they may be in their process in terms of life experiences and support from family and friends. Home visits are also encouraged, to provide more concrete support in the bereavement process. It is important to explore the parents' satisfaction with the social support they are receiving from family and friends and to assess how they are doing at least 6 months after the event. This is especially important for fathers, who are likely to receive much less support than mothers. Planning these visits to coincide with dates that are meaningful to the parents (e.g., expected date of delivery, baby's birthday, date of death, etc.) can provide a source of comfort that is essential.

Home visits with bereaved parents provide opportunities to talk about their daily lives and to explore with them ways of living with and adjusting to their baby's absence. Health practitioners need to be aware of legislation regarding parental leave in their province, so as to guide both parents. Mothers will often have apprehensions about returning to work and need to be equipped to face reactions from colleagues, employers, and even friends. Gagnon and Beaudry (2013) found that support was uneven, parental leave rights were not always respected, and suffering was unrecognized. They recommended parents be allowed a flexible schedule and psychological support to ease in the transition back to work.

Melanie and Stephane's story
"Some of our friendships got redefined. Our ordeal and our sadness were sometimes frightening, and a few friends preferred to keep their distance or even avoid being around us because it made them much too uncomfortable. But other friendships became more meaningful. I remember one friend who took the time, without any fanfare, to drop off a freshly baked banana-chocolate bread at our door. She sent us a little message to let us know there was a little something waiting for us on our door sill. This thoughtful act meant a lot to us, and I'll always remember it.
We had to distance ourselves for awhile from some friends who were going through the joy of welcoming a new baby into their lives. This situation was too difficult for us to deal with at that time and brought back the sorrow of not having our children. We needed to protect ourselves from this sadness and keep our distance from the happiness of others. I can tell you, our friends showed a great deal of friendship and love in understanding our absence and waiting for our return." (*Mother's voice*)
"One difficult aspect of perinatal bereavement is always there, every day. We have to continue spending time with our friends, co-workers, etc., and for them, life is good. We watch our friends go through their pregnancies and listen to our co-workers talk about their children. Just when you think you're back on an even keel, there's always some event (a friend announcing her pregnancy, an invitation to a child's birthday party, etc.) that hits you like a slap in the face and reminds you that your family life is not 'normal' or 'easy'. It's hard to keep going through events that plunge you back into your emotions and remind you of your story." (*Father's voice*)

Follow-Up During a Subsequent Pregnancy

When considering a future pregnancy, parents experience many doubts and anxieties. In interviews, it has been observed that these concerns can surface at any time after the death. Some think about it from the moment the death is announced (at the hospital or birthing center) and want to make decisions on this very quickly, whereas others refuse to think about it for a long time and even believe they would never want to go through another pregnancy. This situation is specific to each parent, with his or her own personal history, expectations, and perceptions of the event. Indeed, there is no ideal moment at which to embark on another pregnancy after having experienced the death of an infant. Some practitioners focus on the mother's physical condition, suggesting that it is good to let some time pass and allow the body to recover. From interviews with parents, we know that becoming invested in a project or another pregnancy can help some of them cope with grief reactions. Others will find it very difficult to go this route again because of the anxiety generated by another pregnancy. In follow-ups, the practitioner can raise a number of questions that can help parents make the decision that is right for them.

Very often, a new pregnancy also provides a useful and much-needed opportunity to experience the emotions attached to the perinatal death. Practitioners are encouraged to explore with parents how they feel about this new pregnancy in relation to their previous experience. This enables parents to see how the bereavement process is evolving, and to understand that the new pregnancy cannot repair the pain of the emptiness left by their baby's death, such that their emotional reactions are likely to alternate between the joy of another pregnancy and sadness over the loss of their previous child.

The studies done in Quebec highlight the importance of ensuring parents receive significant psychological and emotional support during any subsequent pregnancy. It is strongly suggested that parents receive personalized care to avoid sources of anxiety that could easily be managed by simple interventions (fetal heart monitoring, regular visits with the nurse, emotional support, and reassurance about the baby's health status).

The MIRIS: An Innovative Theoretical Approach

Practitioners have many questions about their relationships with patients, and in cases of perinatal bereavement, they feel a certain urgency to respond. Indeed, the types of relationships that nurses, physicians, and other health professionals develop with parents in this tragic situation are often described as being a heavy emotional strain, as it is never normal to be dealing with life and death at the same time. Given this complexity, and the fact that human beings are sensitive and have life experiences that incline them to feel the suffering of others, it is normal for professionals to ask themselves what form this relationship should take and what boundaries they should set with bereaved parents. In fact, practitioners report that their knowledge is mainly centered around the importance of creating supportive relationships, and of being therapeutic, neutral, and objective, all the while maintaining a certain emotional distance from the parents. Some practitioners even wonder whether it is acceptable to show their emotions. Some do so instinctively, while others avoid contact with families or do not pursue the matter any further when parents decline a home visit, persuading themselves that these parents do not necessarily need or want to talk with them. In short, the interactions and resulting relationships produce a variety of reactions among practitioners.

Along these lines, Verdon explored this matter and confirmed, by analyzing the literature on human relations, that there is considerable ambiguity around the notion of relationship, its boundaries, and the conditions leading to its development (2012). Verdon's analysis showed that the body of knowledge about relationships—among others, as taught to nurses—has not been clearly defined. The specific character of what is called the 'therapeutic' relationship is difficult to determine, and yet that concept is pervasive. Consequently, this ideal relationship appears to suggest to practitioners that there are specific words that should be said to parents to comfort them and to be therapeutic. This may no doubt explain the impact of this type of support on practitioners, who described feelings of powerlessness, suffering, and being caught off-guard by the unexpectedness of the situation (de Montigny & Verdon, 2015).

In an attempt to find another way to describe interactions between practitioners and parents, Verdon (2012) developed a new model, the intersubjective practitioner–patient encounter model (IPPEM/MIRIS—*Modèle intersubjectif de la rencontre intervenant/soigné*). This model describes intersubjectivity in three spheres: connection, passage from self to other, and communion between two persons. These spheres are what enable a relationship to exist. Ultimately, this model orients the relationship toward another goal than what is usually proposed. Rather than developing a relationship in order to help another person—searching for the right thing to say—this model proposes a totally different goal, which is to acquire self-knowledge through encounters with others.

When practitioners try to help others, it is with the aim of having an effect on them, and hence during that time they are not in relationship with those others because they are more concerned about the effect they are producing. Thus, while thinking of what to say, they are not in relationship. The relationship inspired by MIRIS, on the other hand, requires practitioners to open up to themselves, to develop a shared intensity with the other, and to create a symmetry with that person. As such, there is no specific objective of saying any particular thing or having a specific effect on the other, but rather just of being there, in presence with that person. Conversely, when the ingredients for intersubjectivity are not there, the relationship cannot exist; instead, there is only a functional communication in which the practitioner is essentially focused on the patient and has a need to feel useful, to say the right things, and to comfort with words.

When practitioners stop taking their own selves into account (with the other), the relationship no longer exists. In effect, the relationship requires that practitioners also look after themselves. This model enables practitioners to see that, in situations of perinatal bereavement, there is no need for any specific recipe to comfort grieving parents. If the goal of the relationship is to develop greater self-understanding through interaction with others, practitioners are less likely to feel powerless, uncertain, and overly self-critical. Along the same lines, this approach requires practitioners to work on themselves to discover what it is that affects them particularly in the parents' experience. If emotions arise in contact with bereaved families, the MIRIS model invites practitioners to distance themselves from their own emotions rather than from other people, and in this way actually to get closer to others.

Where We Are Now, and Where We Are Going

The aim of this chapter has been to present how perinatal death and the attendant grief are experienced in Canada. Various challenges have been highlighted. First, and fundamentally, the lack of agreement on the definition of perinatal death among provinces, and among institutions within a province, and even in regard to families' own definitions, affects policies and consequently health services offered and, ultimately, parents' experiences. A second challenge lies in the fact that Aboriginal, immigrant, and refugee populations have historically not had a strong voice in contemporary Canadian culture, and consequently there has been limited research on the topic of perinatal bereavement within those cultures.

Social economics, technology, and globalization—defining features of present-day culture in Canada—have profoundly affected how we view death and grief in a continuously evolving context (Chalmers, 2004, 2013; Holloway, 2007; Malacrida, 1999). While technology has changed the landscape of birth by opening opportunities for attachment in early pregnancy, for instance, as a result of being able to 'see' the baby through ultrasound photography, this attachment may heighten the intensity of grief in the case of perinatal death. The expanding discourse and legislation surrounding the right to die (currently active in Quebec) and the emergence of perinatal hospice open the way for controversial discussions on prenatal testing and its consequences (Layne, 2006). These developments illustrate the ways in which cultural attitudes toward perinatal death are evolving in Canada.

The continuum of care following a perinatal death is also evolving to respond to a diversity of family experiences, and so are health professionals. While health professionals must have cultural competency, there is enormous variation in the rituals and beliefs of bereaved parents, caregivers, communities, and institutions, and this chapter emphasizes the importance of individualized care. Though knowledge of cultural practices is helpful, we must remember that, like other emotions in life, grief reactions vary among individuals and groups even within the same community. Health professionals need to adapt their interventions within a continuum of care that must not become prescriptive, but remain flexible to reflect each individual's and family's reality. To respond to these needs, health services must be accessible and appropriate in every region of Canada. To achieve this and to keep up with rapidly evolving cultural conditions, Canadian research must pursue different lines of inquiry, exploring individuals' and families' grief trajectories, same-sex partner bereavement, the bereavement experience of vulnerable populations such as Aboriginal and immigrant populations, and developments in mental and physical health services, in order to better understand how supporting bereaved individuals and families today helps to promote the overall well-being of these Canadian individuals and families tomorrow.

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