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PRACTICE POINT

Supporting and communicating with families experiencing a perinatal loss

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Paediatr Child Health 2018 23(8):549 (Abstract) (https://academic.oup.com/pch/article/23/8/549/5193244?searchresult=1)

Abstract

Perinatal loss is one of the most devastating events a family can experience. This practice point focuses on circumstances that are likely to involve paediatric health care professionals. Recommendations are provided for compassionate communication, bereavement, sibling care and counselling to support families.

Keywords: *Counselling; Palliative care; Parental grief; Perinatal death; Perinatal hospice*

Perinatal loss by miscarriage (< 20 weeks), stillbirth (≥ 20 weeks gestation), or neonatal death (newborn through 28 days of life) is one of the most profound losses a person can experience. Since the last statement on this topic by the Canadian Paediatric Society [1], genetic testing, related technologies and shared decision-making have evolved, along with the societal roles of partners and fathers. In the absence of robust studies, recommendations offered in this practice point are based on limited available evidence and expert opinion.

Communicating with families

Compassionate communication with families should be guided by honesty and respect, with information provided in clear, timely and sensitive ways that enhance collaborative decision-making [2]-[4]. Whenever possible, both parents should be present for significant conversations, ideally with the physician and trusted team members identified by the family. When parents are not fluent in the language of their health care professionals (HCPs), translation by a trained interpreter is essential. There should be ample time for dialogue, questions and emotional expression. More than one encounter is usually needed and meetings should generally occur in a quiet, private space. Many parents prefer to have personal conversations in a small group rather than a large, conference-style setting. Language is important and HCPs should consider when using the word 'baby' may be preferable to 'fetus'. If the baby has been named, it is important to many parents that HCPs use the child's name, spell it correctly, and refer to the baby by the appropriate gender pronoun. Active listening and allowing for silences are often as important as the information relayed.

Palliation versus termination of pregnancy

Many anomalies that can be detected antenatally give rise to decisions about continuing pregnancy. Accurate medical information must be provided to parents to support such decision-making and any uncertainty regarding a baby's future health outcomes should be openly acknowledged. Whether to terminate pregnancy or continue with palliation is an intensely personal decision for parents [5][6]. Offering the option to continue pregnancy and support newborn palliative care should have equal validity to termination, and either choice must be actively supported [7]. Being familiar with the legal requirements for termination of pregnancy in instances of life-limiting conditions, including gestational age (GA), as outlined by provincial/territorial Colleges of Physicians and Surgeons, is essential for HCPs working in neonatal care settings.

Withdrawing or withholding life support

In modern intensive care environments, death usually occurs after a decision to limit or withdraw life-sustaining treatments, when it becomes apparent that continuing treatment may prolong suffering without improving quality of life [8]. The current care emphasis is on parental autonomy and shared decision-making. Final life-changing decisions often rest with the parents, as long as these align with the primary consideration of being in the infant's best interests. When limits on or withdrawal of life-sustaining treatments are being contemplated, the health team should initiate discussions with families. Parental guilt and regret can be mitigated by having an HCP raise these issues [7]. Some studies have found that asking parents to decide often ignores the complex moral and emotional dimensions of their decision. They suggest that "when CPR [for example] is highly unlikely to achieve the therapeutic goal or will merely prolong dying", physicians should not burden parents with the decision to forgo life-saving protocols. Rather, they should assume primary responsibility for this decision and use an informed assent model with parents, always allowing for their respectful disagreement [9]. Such decisions and discussions are complex and require the HCP to be sensitive and responsive to each family's needs.

HCPs should help prepare parents for the dying process in advance by initiating discussion of how their baby will be cared for, including pain management. HCPs should advise parents that is often difficult to predict how soon a baby will die following withdrawal of life support [2]. When duration of survival is uncertain, preparing parents for the possibility of a lengthy survival is important. Tissue and organ donation may be possible depending on eligibility criteria (e.g., GA and birth weight) and local transplantation services. Be sure to ask parents whether such procedures might fit with their beliefs and values.

Supporting parenting and grieving

Activities that help parents develop an early and intimate bond with the baby they are losing can also build a sense of identity around their child. Parents may need guidance from HCPs on how to approach their baby and are often willing to take caregiving cues from staff.

In the past, babies who died were usually soon removed by well-meaning staff, leaving parents upset because they never got to see or hold their child. Current evidence is ambivalent regarding the relative risks and benefits of seeing and holding a deceased or dying baby. Some studies have reported post-traumatic stress symptoms in mothers, while others indicate a positive experience when guided by compassionate staff [10]. Therefore, all parents should be offered this choice and their decisions supported. HCPs also need to prepare parents for their baby's physical appearance when the baby is extremely preterm or born with a congenital anomaly.

"Meaning-making" is an important task for grieving parents. Whether or not they have particular spiritual affiliations, existential questions such as 'Why now?' or 'Why us?' are bound to arise. These questions have almost universal human and psychological meaning, and many parents benefit from grief counselling or spiritual and psychosocial guidance as they grapple with loss [11]. Studies suggest that much of the medical information given by neonatologists around care decision-making during prenatal counselling is later largely unrecalled by mothers [12]. However, faith and personal beliefs may be the cornerstones of such decisions, and integrating spiritual care in the process can engage and build understanding around parental perceptions and preferences.

There are important cultural differences in how death, and particularly the death of a baby, is managed. Some cultural and faith traditions do not allow for creation of mementos, photos or naming the baby, for example. Never make assumptions. Always ask parents how their cultural, spiritual or personal beliefs impact care preferences before taking action (13). Memory-making activities, when they are possible and welcomed by the family, may include talking to, holding, bathing or dressing the baby; engaging in religious or naming ceremonies; introducing the baby to other family members, and capturing these interactions in photographs. Siblings may wish to be involved in this care, but need to be supported. Mementos may include hand and footprints, a lock of hair or hospital bracelet. Parents may want photographs taken when their baby's face is free of medical equipment, even if these images cannot be taken until after the baby has died. Some Canadian centres offer the services of professional photographers for this purpose.

The grieving process

While perinatal bereavement is as painful as other types of bereavement, there are some important distinctions. Perinatal loss often involves a sense of biological failure, loss of identity, feeling the lack of shared memories, and declining hopes for the future [14]. Parents who lose children before birth never have the opportunity to interact with them as separate, living individuals. Parents who lose infants after a period of neonatal care may never have the opportunity to care for them at home. Grieving after a perinatal death resembles other forms of bereavement, with shock, profound sadness, depressed mood, anger, irritability, preoccupation, anxiety, and changes in eating and sleeping patterns all being typical responses. Distress can preclude return to many normal activities for months after a baby's death, and significant distress is often experienced for years [14]. Complications such as major depression or post-traumatic stress symptoms may also occur, and parents should be made aware of signs and symptoms. Ongoing consultation with a mental health specialist may be essential in these situations [14].

Fathers and other partners can experience similar feeling around perinatal loss, including helplessness and loneliness, and their grief should be acknowledged and supported along with the mother's pain [15]. Relationships between couples can either break down or become stronger, partly depending on the how supported each partner feels by the other throughout the grief experience [10].

Pregnancies that follow a perinatal loss are often complex, with women experiencing heightened anxieties, fears of recurrence or post-traumatic stress symptoms. Apprehensions may become more pronounced around the gestational age that the previous infant died. HCPs need to be especially sensitive during this stage [16][17] and take care to provide regular contact and psychological support [17]. When the new baby is born (referred to as a 'rainbow baby' in popular media), many parents wrestle with balancing joy and the grief they still carry from their previous loss. Infant loss support groups are well attuned to these issues and HCPs can help make parents aware of local resources.

Siblings

The impact of infant bereavement on siblings also warrants attention. HCPs can help parents understand how other children may be interpreting this death. While young children may not fully comprehend the permanence of death, they certainly can feel their world has become a less secure place. They may also fear that a baby's illness and death is somehow their fault [14]. Helping siblings to understand that nothing they did, said or thought caused illness or death is essential to family healing, along with reassuring siblings that they are healthy, safe and loved. Older children may feel a strong and lasting sense of loss. The death of one or more babies in a multiple pregnancy where one or more babies survive is not uncommon and can give rise to conflicting emotions [18].

After-care

Birth, death and stillbirth registration is required by law, and timely reminders not to overlook this step may be needed. Offering autopsy to parents is a quality of care indicator yet is often not performed, with HCPs judging that parents have been "through enough" or that they would certainly decline [19]. There are recommended investigations for stillbirth [20][21]. Information about funeral arrangements should be readily available. Many funeral homes provide infant burial or cremation services at reduced cost, and such services can be screened and recommended as appropriate.

Timely notification of primary health care providers is important to ensure appropriate follow-up for emotional and mental health care, or for further genetic testing if indicated [2], as well as to cancel pending prenatal or other appointments. All mothers will need anticipatory guidance about lactation suppression and human milk donation (if available).

HCPs who come into regular contact with parents who might lose a baby (from diagnosis through bereavement) may find that developing skills in palliative or bereavement care is beneficial. A palliative care team should be involved—where available—for parents receiving antenatal diagnoses of life-threatening conditions in their infant, or for other life-limiting conditions that arise in the neonatal period. The work of providing end-of-life care for newborns and their families is intense. Supports for staff that have cared for the family include debriefings, counselling and employee assistance programs.

Counselling and other therapeutic interventions

Despite the many bereavement practices in use at neonatal intensive care units and infant-loss programs, one recent Cochrane systematic review could not identify any high quality trials concerning support for parents after perinatal loss [10]. While parents appreciate the compassionate acts of a health care team [3], the extent to which these practices actually effect parental coping or well-being remains unclear [11]. Peer support may benefit bereaved parents because it connects them with families who have experienced a similar loss [22][23].Studies have firmly established the importance of parents being invited to review their infant's care and death 2 to 3 months after the loss [7][14][24]. Meeting parents to explain autopsy findings is also a meaningful opportunity to re-engage. Parents truly value HCP efforts to find out how they are coping, share information, build a cohesive picture of the experience and assess future risk [24].

Summary

Experiencing a perinatal loss is one of the most profound events a family can endure. HCPs should support families through compassionate communication, shared decision-making, creating meaningful memories, acknowledging grief, sibling care, and family care in the period following their loss. Improving HCP skill and knowledge around palliative and bereavement is essential to quality care.

Acknowledgements

We thank Carmen Victoor, M. Ed. Counselling Psychology, for her review and suggestions. This practice point was reviewed by the Community Paediatrics Committee of the Canadian Paediatric Society. It has also been reviewed (with thanks) by representatives of the Society of Obstetricians and Gynaecologists of Canada and the Canadian Association of Perinatal and Women's Health Nurses.

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Last updated: Feb 12, 2020