Grief and the Family

Grief and Families: Perinatal Loss and Parental Grief

By Ariella Lang, PhD and Andrea R. Fleiszer PhD, BSc, BN, RN

Perinatal death, defined as the death of a baby, can include such losses as ectopic pregnancies, miscarriages, stillbirths, and neonatal deaths (Callister, 2006). Perinatal loss has well-documented detrimental effects on the health and well-being of the bereaved parents individually, and as a couple (Bennett, Litz, Lee, & Maguen, 2005; Lang, Goulet, & Amsel, 2004; Vance, Boyle, Najman, & Thearle, 2002). Yet many parents who suffer a perinatal loss feel disenfranchised in their grieving processes compared to those mourning more traditionally accepted and acknowledged deaths. Compared to other types of mourning, like the loss of a parent or a sibling, the loss of a child is associated with a grief experience that is particularly severe, long-lasting, and complicated — with symptoms that fluctuate in intensity and duration (Rando, 1986; Zeanah, Danis, Hirshberg, & Dietz, 1995). Among healthcare professionals and society at large, however, perinatal loss is generally viewed as a less traumatic or prolonged experience than the death of an older child or an adult. Yet perinatal loss is a potentially life-transforming event for bereaved parents and their families.

More often than not, parents do not receive appropriate care; this is despite the fact that widespread consensus on care and support exists in the literature and among professionals in the field. In our Canadian experience, many hospitals have protocols and checklists of procedures following perinatal loss (Radestad, Steineck, Nordin, & Sjogren, 1996; Ryan, Cote-Arsenault, & Sugasman, 1991), typically created to guide nursing care. Instructions that focus on the “dos and don’ts” tend to dictate the parent-caregiver interaction. Although some direction is preferable, rigidly applying prescribed protocols may interfere with a caregiver’s empathic approach to supporting families (Leon, 1992).

In support of better care for individuals, couples and families, a program of research focused on prevention and health promotion amidst bereavement has spanned 25 years. It stems from Lang’s (co-author) clinical nursing work with bereaved families following perinatal loss and is dedicated to improving evidence-informed practices and outcomes. Over time, through practice and research experience and efforts, there has been increasing recognition of the need for changes at multiple levels of the system. This systems change is more than just clinicians working with bereaved individuals and families. It recognizes that other changes within the healthcare system and other social contexts must be in place to support effective “primary bereavement care” (e.g., policy adjustment, implementation of research evidence, inclusion of bereavement content in undergraduate and graduate healthcare curricula, etc.).

Primary bereavement care is defined as health care professionals capturing and creating opportunities to be with and support individuals/families in their experiences of grief and mourning surrounding the death of a loved one. These supportive practices are indicated for all bereaved individuals / family members, to differing extents (Joanna Briggs Institute, 2006), whether it is five minutes in an emergency room or five months in palliative care. Bereavement care is often focused on “pathological” responses or “complications” experienced by the bereaved and is frequently provided by bereavement care specialists (e.g., psychologists, psychiatrists, social workers, etc.). In contrast, the emphasis of primary bereavement care is on prevention of negative sequelae and on health promotion for the bereaved. To this end, a guideline entitled “Evidence-informed bereavement care: A primer of interventions towards health systems change” (Lang, Duhamel, Fleiszer, et al., 2012) has been developed to describe optimal primary bereavement care, and to identify the priorities, strategies and interventions for providing sensitive, appropriate and effective primary bereavement care. The term “primer” signifies a package of systems interventions that serve as a foundation and catalyst to improve care to individuals, families, and communities around the death of a loved one. It is anticipated that this primer will be a valuable tool for clinicians involved in caring for bereaved family members and friends. More specifically, it is intended to be relevant across a variety of healthcare settings and situations (emergency to community, acute to chronic, sudden to palliative); with diverse populations; and in all types of death and bereavement experiences.

Both the clinician (as the provider of primary bereavement care), as well as health and social care organizations and academic institutions (as supporting the clinician), must be “best practice participants” in providing interventions to bereaved individuals and families. Each group has responsibilities across four categories or domains of interventions: practice, education and continued professional development, research, and policy and community development (see Table 1). With these domains of interventions as a framework for primary bereavement care, there are seven key recommendations for clinicians to integrate into their work with the bereaved (see Table 2).

This article highlights the enduring opportunities for health and social service professionals to provide improved and appropriate care to bereaved families, and in particular, those suffering perinatal losses. By means of the creation of a “primer of interventions,” it also provides an example of an innovative resource to guide and support excellent, research-based, proactive care.

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Table 1: Summary of Evidence-Informed Recommendations Towards Systems Change

<table>
<thead>
<tr>
<th>Practice Recommendations</th>
<th>Education Recommendations</th>
<th>Research Recommendations</th>
<th>Policy and Community Development Recommendations</th>
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<tr>
<td>1. Proactive practice includes bereavement care with family members.</td>
<td>1. Clinicians develop, nurture, and evaluate an ongoing awareness of themselves in relation to bereavement and bereavement care, both personally and professionally.</td>
<td>1. Clinicians stimulate and advance research about bereavement and bereavement care as an integral part of their daily practice.</td>
<td>1. Clinicians and organizations, in partnership, advocate for changes in public policy.</td>
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<td>2. Clinicians acquire the knowledge, skills, attitudes, and aptitudes to approach bereavement care with compassion.</td>
<td>2. Clinicians are committed to ongoing professional development of their knowledge, skills, attitudes, and aptitudes in bereavement care.</td>
<td>2. Researchers who study bereavement and bereavement care seek opportunities to share research outcomes and new knowledge and their applicability to the practice setting. Researchers also seek opportunities to listen to and learn from the voices and experiences of practicing clinicians.</td>
<td>2. Clinicians and organizations, in partnership, facilitate and promote inter-sectoral, interdisciplinary, and stakeholder collaboration to support the health of bereaved individuals, families, and communities.</td>
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<td>3. Clinicians ensure continuity of care for the bereaved.</td>
<td>3. Academic programs (entry-level and advanced) include education about bereavement and bereavement care.</td>
<td>3. Organizations assist in developing and advancing research about bereavement and bereavement care.</td>
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<td>4. Organizations value and support bereavement care with family members.</td>
<td>4. Organizations include education about bereavement and bereavement care in all orientation and continuing nursing education initiatives, regardless of practice settings (i.e. emergency, obstetrics, medical/surgical, out-patient clinics, etc.).</td>
<td>4. Organizations include education about bereavement and bereavement care as an integral part of their knowledge, skills, attitudes, and aptitudes in bereavement care.</td>
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<td>5. Organizations recognize and support the clinicians who provide bereavement care.</td>
<td>5. Organizations utilize best practice guidelines for quality and safety improvement initiatives around bereavement care.</td>
<td>5. Organizations ensure continuity of care for the bereaved by building and sustaining connections and relationships with other health and human services.</td>
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Table 2: Key Recommendations for Evidence-Informed Bereavement Practices

Competent practice in primary bereavement care for family members includes these central elements. Clinicians:

- actively and openly acknowledge and validate the death of a loved one and the experience of bereavement;
- are emotionally and authentically present;
- consider the family as the focus of care, in the context of a larger system;
- are attentive to the narratives of family members about their experiences of loss and bereavement;
- recognize that bereavement care is based on effective communication;
- explore the family members’ main concerns;
- identify, acknowledge, promote, and reinforce family members’ strengths and potentials; and,
- provide appropriate and discerning anticipatory guidance about grief reactions and bereavement experiences.

References (cont.)


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