EVIDENCE-INFORMED
GUIDELINE FOR PROVIDING
PRIMARY BEREAVEMENT CARE
FOLLOWING PERINATAL DEATH

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THE RESEARCH TEAM

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OVERVIEW

- Objectives
- Primary Bereavement Care
- Program of Research
- Best Practice Guideline project
  - Beginnings
  - Overview of evidence
  - Best Practice Guideline purpose
  - Best Practice Guideline development process
  - Best Practice Guideline recommendations
- Issues to ponder
OBJECTIVES

- To describe the development of an evidence-informed *primary bereavement care* guideline.
- To discuss the recommendations put forth in the guideline in the context of *primary bereavement care*.
- To discuss the potential benefits / challenges of strengthening our focus on *primary bereavement care*. 
WHAT IS PRIMARY BEREAVEMENT CARE?

- Nurses and other healthcare professionals capturing and creating opportunities to be with and supporting individuals/families in their experiences of grief and mourning *regardless of the type of loss or where the death occurs*

- Indicated *across-the-board* for all bereaved individuals/family members

- Primary prevention and/or primary healthcare interventions at both the provider and organizational / systems levels
PRIMARY BEREAVEMENT CARE

Essential components:

- Acknowledging and validating both the death and experiences of bereavement
- Providing anticipatory guidance related to grief reactions
- Ensuring a network for continuity of care
- Appropriate resources (time, staffing, experts/teachers, physical space, funds)
- Developing and implementing primary bereavement care-centered initiatives and policies
PROGRAM OF RESEARCH

Focus on home care safety (mitigating risks for clients, caregivers, and providers) with emphasis on primary bereavement care, perinatal bereavement, & palliative/end-of-life care

- **Phase 1** - Testing a Primary Bereavement Care Model
  - 110 couples (2, 6, & 13 months post loss)

- **Phase 2** - Development of Best Practice Guideline

- **Phase 3** - Implementation of Best Practice Guideline in:
  - Acute care (Quebec & Ontario)
  - Home & Community care (Nova Scotia)
PRIMARY BEREAVEMENT CARE MODEL

BEREAVEMENT CARE MODEL

FAMILY as the focus of care

EVENT as the focus of care

OUTCOME

PRACTICE RECOMMENDATIONS

POLICY + COMMUNITY DEVELOPMENT RECOMMENDATION

EDUCATION + RESEARCH RECOMMENDATION

PRACTICE RECOMMENDATION

BEREAVEMENT

RESOURCES - Financial & Emotional

PERCEPTIONS AND MEANING MAKING

HEALTH & WELL-BEING

INDIVIDUAL SYSTEM MODEL

VON CANADA
CHANGING THE FACE OF GRIEF

- Family is the focus of care.
- Promote health and nurture strengths, rather than treat pathology.
- There is a wide range of normal reactions, each reaction is unique.
- Distance ourselves from stages of grief.
- There is no “closure” or “resolution”. There is living with a new NORMAL.
OVERVIEW OF THE EVIDENCE

- Deleterious effects on the health of the bereaved
  - Physical, emotional, social, and financial issues/concerns
  - Increased morbidity and mortality
  - Increased risk for hospitalization including psychiatric hospitalizations
    (Stroebe et al., 2001; Lang et al., 1996; Christakis & Allison, 2006; Li et al., 2003)
- Lead to:
  - Higher healthcare costs
  - Decreased vibrancy and productivity
  - Diminished health and wellbeing
NURSES AND OTHER PROFESSIONALS OFTEN FEEL ILL-PREPARED. . .

- This discomfort can lead to ethical dissonance, emotional distress, and contributes to potential burnout. (Granger et al., 1995; Tse et al., 2006)

- Words and actions from staff surrounding the time of loss are not forgotten.
  - “heartfelt comforting words or touches can become sustaining memories that promote healing just as callous indifference can make painful scars.” (Leon, 1992)

- Care providers can actually intensify grief when they fail to recognize how their actions may impact on the experiences of individuals and families.
  (Ujda & Bendiksen, 2000; Leon, 1992; Ryan et al., 1991)
Bereaved parents and families often describe receiving inappropriate care surrounding the death of their fetus or infant despite the existence of a “Perinatal Bereavement Program”.

Bereavement care tends to focus on those who present with complications rather than on primary prevention and health promotion interventions.

Addressing the needs of the bereaved in an upstream, preventative, and health promoting manner calls for a shift in the way professionals interact with individuals and families surrounding the death of their baby.
PRIMARY BEREAVEMENT CARE BEST PRACTICE GUIDELINE PROJECT

- **Original purpose**: To tailor 2 existing guidelines
  - Supporting and strengthening families…
  - Establishing therapeutic relationships

- **Revised purpose**: SSF + ETR as foundational; *primary bereavement care* as a complement / additional set of core competencies

- The need for co-creation: voices of nurses, families, leadership, researchers, experts, and other stakeholders
PURPOSE:

- Create a comprehensive and up to date representation of primary bereavement care.
- Create opportunities for nurses and other health care providers to reflect on, challenge, and evaluate their practices with the bereaved surrounding perinatal loss.
- Provide a springboard for organizations to build, expand, and focus their competence in supporting primary bereavement care with families.
- Emphasize the responsibility of professionals to recognize sensitive and effective primary bereavement care as a priority.
Document Foundations
- Expert two-day panel meeting
- To identify key primary bereavement care concepts

BPG Outline / First Draft
- Based on the work of core research team
- Integration of peer-reviewed + grey literature

Second Draft
- Feedback from expert panel members + research team

Third Draft
- Feedback from 2 phases of focus groups
  (nurses, managers/directors, and bereaved family members)

Revisions
- Feedback from > 50 key stakeholder reviewers Canada/US

Final Version
- Product of phases of evaluation, revision, and redrafting
# Summary of Recommendations

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<th>Participants</th>
<th>Professional Nurse</th>
<th>Organizations (Health Care &amp; Academic Institutions)</th>
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RECOMMENDATIONS: PRACTICE

- Proactive practice includes *primary bereavement care* with family members
- Actively and openly acknowledge and validate the death of a baby and the experiences of bereavement
- Consider the family as the focus of care, in the context of a larger system
- Identify, acknowledge, promote, and reinforce family members’ strengths and potentials
- Ensure continuity of care for the bereaved
Develop, nurture, and evaluate an ongoing awareness of oneself in relation to perinatal loss and primary bereavement care, both personally and professionally.

Commit to ongoing professional development of one’s knowledge, skills, attitudes, and aptitudes in primary bereavement care.

Take responsibility to ensure the wellbeing of ourselves and our colleagues.
RECOMMENDATIONS: POLICY

- Stimulate and advance research about *primary bereavement care* as an integral part of daily practice

- Researchers who study bereavement and *primary 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 practitioners
RECOMMENDATIONS: RESEARCH

- Professionals and organizations, in partnership, advocate for changes at the local, regional and national levels.

- Professionals and organizations, in partnership, aim to support the health of bereaved individuals, families, and communities by facilitating and promoting:
  a) Inter-sectoral collaboration (hospital and community)
  b) Interdisciplinary and stakeholder collaboration
CONCLUSION

- Need to improve linkages between bereavement research and practice in order to determine and promote the most appropriate and meaningful care for bereaved families following perinatal loss.

- Strong collaborative relationships among researchers, and practitioners, as well as clinical and policy decision-makers are central to the effective uptake of evidence into practice, and are the basis for building capacity for systems change. (CFHA, 2003; Graham et al., 2006; Lomas, 1997)
FUTURE DIRECTIONS

- **Partnerships for Health Systems Improvement**
  (CIHR Research Grant Submissions)

  - **Acute care**
    - 4 large university affiliated organizations in Quebec and Ontario
      - "Implementing Evidence-Informed Primary Bereavement Care: An Embedded Comparative Case Study of Four Acute Care Hospitals"

  - **Home and Community Care**
    - **Urban & Rural Nova Scotia**
      - "Implementing Evidence-Informed Primary Bereavement Care in Home and Community Care"
ISSUES TO PONDER

- *Primary Bereavement Care* as a public health issue
  - How to facilitate continuity of care between acute care and home/community care?
  - How to present this as a population health promotion/prevention priority?
  - How to tackle the (daunting) need for large systems change?
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REFERENCES