

The Challenges of Ambiguity and Disenfranchisement Surrounding Fetal/Infant Death

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OVERVIEW

- Presentation Objectives
- Definition of Ambiguity & Disenfranchisement
- Background – Program of Research
- Study Methods
- Analysis
- Findings
- Discussion

OBJECTIVES

- To identify ways in which perinatal loss is characterized by ambiguity.
- To identify elements of disenfranchisement experienced by bereaved parents following a perinatal loss.
- To discuss the role of the frontline health care professionals caring for couples experiencing perinatal loss.

AMBIGUITY & DISENFRANCHISEMENT

- **Ambiguity**

- “a loss that remains unclear” (Boss, 2004)
- Paucity of exploration of this phenomenon in the perinatal loss context

- **Disenfranchisement**

- “...grief is not openly acknowledged, socially validated, or publicly observed...” (Doka, 1989)

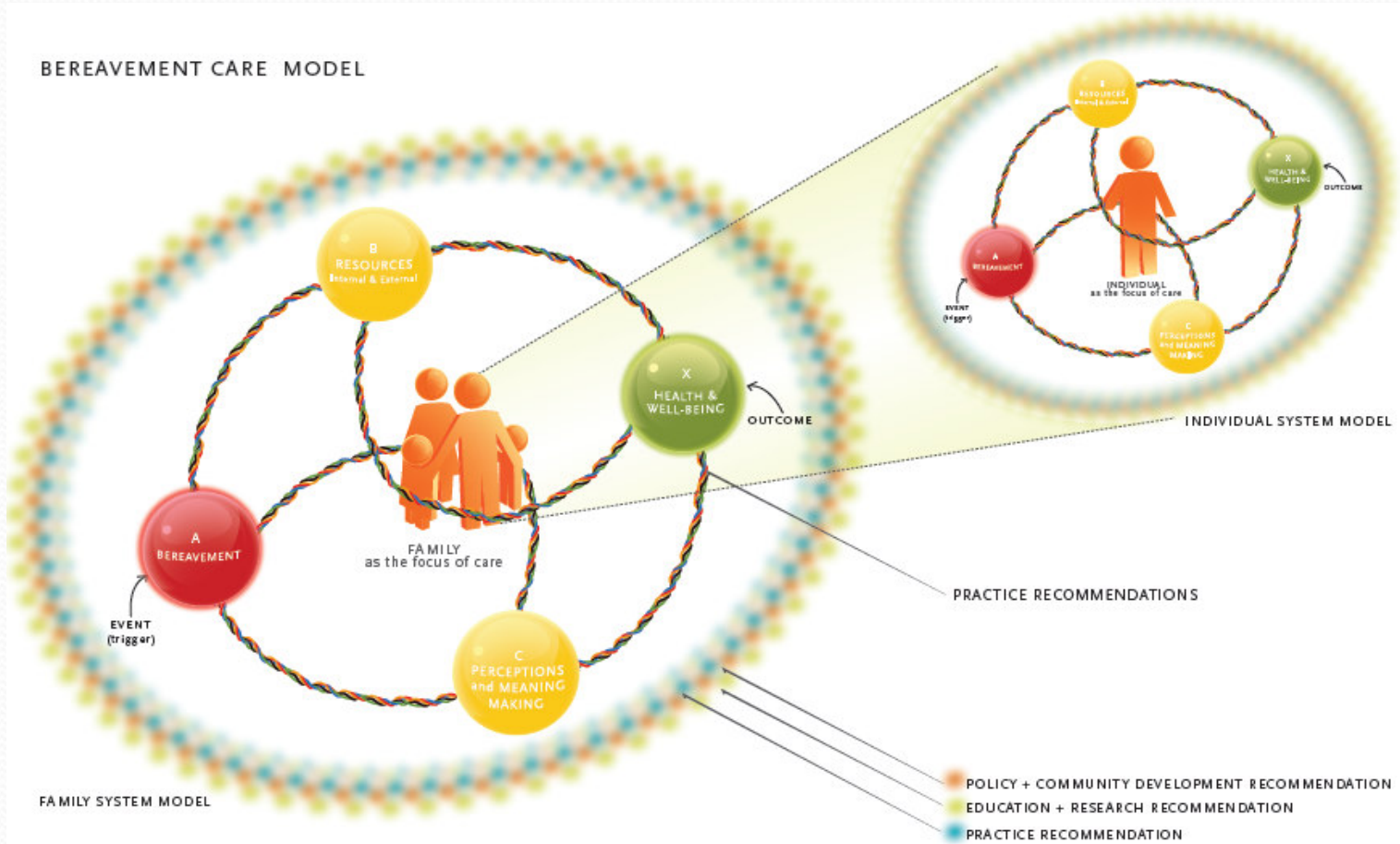
PROGRAM OF RESEARCH

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 ***Primary Bereavement Care*** Best Practice Guideline
- **Phase 3-** Implementation of Best Practice Guideline in:
 - Acute care (Quebec & Ontario)
 - Home & Community (Nova Scotia)

PRIMARY BEREAVEMENT CARE MODEL

BEREAVEMENT CARE MODEL



METHODS

- Longitudinal study with qualitative interviews at:
 - 2 months (T1), 6 months (T2), and 13 months (T3)
- Seven Montreal-area university hospitals
- Couples lost of their baby during pregnancy or first year of life
- 14 complete sets of interviews (clear, variety)
- 42 transcripts

Qualitative Interviews: 2 questions

- **NOT** specifically about ambiguity or disenfranchisement
 - T₁ : “Can you tell me a little bit about what happened?”
 - T₂ & T₃ : “Can you tell me about what has been happening since our last visit?”

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FINDINGS

• **Participants**

- Age range 28 - 44 years
- Married or living together 1-13 years
- Nearly 75% completed a university education
- Mixed cultural background reflective of Montreal's mosaic
- Of the 14 deaths:
 - 9 occurred \leq 20 weeks gestation
 - 2 were stillborn after 20 weeks
 - 3 died after delivery, including one to SIDS
- None of the pregnancies were terminated voluntarily

FINDINGS

Ambiguity & Disenfranchisement

- Played a major role in couples experiencing fetal or infant death
- Significant factors that contributed to their suffering emerged in different forms and circumstances

Findings: Ambiguity

- **Ambiguity:**
 - About the viability of the pregnancy
 - About the physical process of losing the pregnancy
 - Around arrangements for the remains
 - In sharing the news of the loss

Ambiguity about the viability of the pregnancy

“You always worry.... until the baby comes out and you actually see the baby... until the doctor tells you everything is fine...you always worry a little bit.”

(Neonatal loss, 26 weeks gestation.)

“To me, the hardest part was the roller-coaster ride because nothing could be done... The uncertainty... Even the doctors could never give us a 100 percent that the baby was gone. That was probably the worst part.”

(Fetal death, 9 weeks gestation.)

Ambiguity related to the physical process of pregnancy loss

“They told me that in the worse case scenario it could take up to two or three days and that seemed...horrendous... To prolong the grief and the suffering was just... Thank God it went as quick as it did.”

(Fetal death, 32 weeks gestation.)

“They don’t really tell you how to deal with it or what options there are. So the only thing that she [the physician] offered was: ‘Well, go home. Maybe in a couple of days or so the baby will pass. What you do is you put it in a plastic bag...’ ”

(Fetal death, 15 weeks gestation.)

Ambiguity about arrangements for the remains

“When you lose a parent or someone in the family, the mourning period is sitting Shiva, and the burial and everything. That’s supposed to help you... You get to talk about the person. You get to feel... You get to cry, to get the support from the community. When you lose a baby, and especially early on ... nobody knows about it.”

(Fetal death, 10 weeks gestation.)

Ambiguity regarding sharing the news of the loss

Couples asked questions such as *“What did we lose? Was it a baby or a ‘specimen’? Was it a boy or a girl?”*

“Are we parents or not?” “Do you see us as bereaved parents or as patients undergoing a medical procedure?”

Findings: Disenfranchised Grief

- Disenfranchised grief:
 - Within the marital relationship
 - When communicating with health professionals
 - When interacting with extended family and community

Disenfranchised grief within the marital relationship

“She talked about it for a while and then enough is enough. Now maybe other men would have let it go a lot longer than I did. But for me, it is just you have to get on with life. And it’s not big deal.”

(Fetal death, 10 weeks gestation.)

“What struck me was how long it took for her to grieve that loss... That was a surprise to me. I mean at one point, I even became impatient. I said, you know, ‘Get on with the program!’”

(Fetal death, 9 weeks gestation.)

Disenfranchised grief when communicating with health professionals

“Why do you want to have a funeral?” the nurse asked, adding that it was too late to request funeral arrangements. “In my mind she was saying: we threw your baby out and it’s over now, you can’t get it back,” (Fetal death, 19 weeks gestation.)

Disenfranchised grief when interacting with extended family and community

“I went to a salon maybe two weeks ago, and... somebody asks me: ‘Is this your first baby?’ ...No! I’m not scared to say that she died and why she died. For me, I like talking about it...Even though she was there for... four hours. And that lady...she said: ‘No! She wasn’t alive!’ You shouldn’t say that to people.”

(Neonatal death, 26 weeks gestation.)

One mother described how her husband was the only other person who remembered the significant date, *“Nobody said anything at all. It was just really hard as the day went on...It’s not like it happened 20 years ago. It happened a year ago...”*

(Fetal death, 19 weeks gestation.)

Summary

- There are many facets of ambiguity and disenfranchisement that bereaved couples face in interactions with family, friends, society, and healthcare professionals.
- Ambiguity and disenfranchisement are pervasive and contribute to suffering
- Ambiguity and disenfranchisement arises in different ways
 - Conceptual clarity was / is a challenge
 - It is tough to define and then illustrate these concepts
 - E.g., ambiguity in the experience versus ambiguous loss; disenfranchisement versus disenfranchised grief

Summary

- A lack of perceived support affects the entire bereavement experience and may jeopardize the health of individuals who are unable to draw on their resources

(Lang et al., 2004).

Conclusions / Implications

- There can be misunderstanding among some care providers about the range and scope of parental feelings surrounding perinatal loss.
- During this critical time of loss, the words and actions of health care staff, whether positive or negative, can be long lasting.
- Healthcare professionals can offer support around helping couples to understand and cope with ambiguity and disenfranchisement.

Discussion

- How have these themes arisen in your practices / experiences?
- Can you share some specific examples of ambiguity and disenfranchisement from your practice?
- What strategies (helpful/unhelpful) have you used to support individuals/families around ambiguity and disenfranchisement?

Acknowledgments

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