SUPPORTING FAMILIES AFTER A PERINATAL DEATH

BRIEF PRESENTED BY THE CENTRE FOR STUDIES AND RESEARCH ON FAMILY INTERVENTION AND THE CANADA RESEARCH CHAIR IN FAMILY PSYCHOSOCIAL HEALTH

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Abstract

Every year, nearly 100,000 Canadian couples experience perinatal death, whether early (first 20 weeks of pregnancy) or late (between 21 weeks of pregnancy and the first six weeks of the baby's life). Despite the prevalence of this type of death and its psychosocial repercussions, international associations such as the International Stillbirth Alliance[1] have for many years decried the gaps in support services for couples following a perinatal death.[2] While Ontario adopted Bill 141 in 2015 that aims, among other things, to link policy commitments with harmonized long-term support for bereaved parents,[3,4] Quebec is lagging behind on this issue, as is the rest of Canada. While Quebec's 2008–2018[5] perinatal policy makes several recommendations to improve perinatal bereavement awareness and support for families, in practice medium- and long-term support remains poorly structured and organized. More specifically, the provision of health and social services to grieving parents is fragmented, uneven across regions, and often not father-inclusive.[6] The documented impacts on the mental health of fathers and mothers, as well as the effects on the conjugal relationship, indicate the urgent need for better support to parents experiencing the perinatal death of their child,[7-12] making perinatal death a pressing societal issue.

This brief is based on the results of a research program that consists of six studies conducted in Quebec from 2010 to 2019, and is intended to provide a portrait of services for Quebec parents,[6] and to characterize parents' experiences related to early[13] or late[4-6,11,12] perinatal death, in terms of their mental, conjugal, and occupational health, as well as the consequences on child development, with a view to making recommendations.[1]

Overview

In Canada, 20–25% of pregnancies end in early or late perinatal death,[14,15] or about 100,000 deaths for every 376,000 living children. Two major observations emerge from research. First, health and social services for bereaved Canadian families are uneven across provinces, regions, and within regions. Second, access to paid parental bereavement leave is unequal. It is almost non-existent for fathers and varies for mothers depending on province of residence and length of pregnancy. This non-recognition of bereavement limits the father's role to that of progenitor and financial provider. Given their lack of resources, parents often must resort to taking sick leave to grieve, with medium- and long-term consequences on their eligibility for insurance.[16]

Mental health consequences

Perinatal death has real consequences for both parents. For more than 20 years, studies conducted internationally[17-19] and in Québec[20-23] have shown that both bereaved parents experience heavy loss and intense grief and have similar reactions over time. Perinatal death and bereavement have significant deleterious effects on women's and men's mental health up to five years later. Many studies have revealed the magnitude of depression, anxiety, and grief, which can become more complex over time.[11,24] Research has begun to focus on somatization and post-traumatic stress

[1] References for this brief are available upon request or can be consulted at cerif.uqo.ca/en

related to perinatal death.[11,21] A recent Quebec study found 16% of women who lost a child in the first 20 weeks of pregnancy had suicidal thoughts.[25,26] These symptoms persist during the next pregnancy[27,28] and even after the birth of the next child.[29]

Consequences for the conjugal relationship and the development of subsequent children

Although some couples may become closer after a perinatal death, this event increases the risk of marital tensions, separations, and divorces, with associated social costs.[30,31] It also has effects on the development of children born before or after the event. Studies have shown that a child born to a depressed mother is more likely to suffer from depression later,[32,33] and that female babies may even pass on this inflamed gene to the next generation. Prenatal anxiety (higher in women who have lost a baby) is reported to be associated with increased risk of premature birth.[34] Postnatal effects have also been documented in children when a parent is depressed: increased risk of depression and anxiety,[39] as well as of internalized and externalized disorders during childhood and adulthood.[38]

Effects of non-recognition of bereavement in society and at work

Non-recognition of perinatal bereavement occurs in the medical (health and social services), family (extended family), and social (friends) spheres. It is most pronounced, however, in the workplace.[35] The few studies on the subject show perinatal bereavement is often considered a taboo subject in organizations, leaving parents to grieve in silence.[36] Parents also report difficulty in obtaining bereavement leave and often must bear the costs associated with unpaid leave. Terms and conditions for returning to work are often rigid; gradual return or extension of leave is rarely granted. An emphasis on productivity, efficiency, and cost-effectiveness results in parents often receiving comments that devalue their grief and the magnitude of their loss.[37] Moreover, fathers' premature return to work due to lack of paid leave often results in self-distancing, difficulties within the couple, and social isolation.[20]

Consequences of premature return to work: presenteeism/absenteeism

Given the intensity and long-term consequences of perinatal bereavement, it is not surprising that many parents resume working while still in severe psychological distress. This is especially salient among fathers, for whom bereavement leave following perinatal death is minimal. This situation inevitably results in high absenteeism and presenteeism.[2]

Economic consequences: costs of absenteeism and presenteeism in Canada

In Canada, costs associated with mental illness are estimated at $51 billion annually, including nearly $20 billion related to lost productivity in the workplace.[38] Costs related to presenteeism are usually 5–10 times higher than those of absenteeism. For depression alone, absenteeism costs are

[2] Working while unwell, with negative effects on performance due to impaired health status.

about $2.5 billion annually, and $6.8 billion for presenteeism.[39] Symptoms of depression, bereavement, and anxiety are reportedly related to decreased productivity (26% of normal work after 30 days), difficulties in concentration, diminished problem-solving and decision-making skills, and more workplace accidents.[40] No studies have measured the economic cost of early return to work after perinatal death. However, our studies have revealed the distress of parents required to achieve the same levels of productivity and efficiency as before their baby's death, the loneliness of mothers left to manage their grief alone without their spouse, and presenteeism/absenteeism that results in long-term sick leave, resignation, or even dismissal.

Fathers on bereavement and work

"It would be important to be able to take leave because we suffer as much as the mother, maybe not physically, but psychologically… Seven days after the baby's death is too short, we don't have time to recover."

"I struggled emotionally to be strong for us both. I couldn't work, I was useless.… My manager called me into his office to see how I was doing and I broke into tears in his office."

"It happened in January. I returned to work in mid-late January, then at the end of March, I lost my job because things were no longer going well there. They said I'd lost my passion."

In conclusion: direct and indirect economic consequences still unknown

Our studies in Quebec have shown that parents experiencing early or late perinatal death use health and social services repeatedly after miscarriage and more intensively in the months following the event and during the next pregnancy. These health system costs are undocumented. Likewise, the social and family costs, in terms of psychological consequences for children already in the family and for extended family members (e.g. grandparents) are not negligible. The consequences of such an event on families from diverse cultural backgrounds or recent immigrants, already coping with the stresses of immigration, are also unknown. Lastly, while costs associated with mental health problems in the workplace are documented, the portion attributable to perinatal bereavement remains unknown.

Recommendations

1) For Statistics Canada

Whereas Canada does not have accurate statistics for all categories of perinatal deaths, as these are inconsistently documented in each province, and

Whereas this lack of statistics affects budgets allocated to research and health services for these parents,

We recommend:

- Requiring provinces to produce accurate and comprehensive statistics.

2) For leaders of societal bereavement recognition campaigns

Whereas both fathers and mothers need recognition of their bereavement, and

Whereas such recognition is achieved through greater visibility of perinatal deaths in society,

We recommend:

- Promoting and implementing awareness campaigns to recognize the magnitude of the effects of bereavement on parents, siblings, families, caregivers

3) For relevant provincial and federal departments, including Service Canada

Whereas parents need time to recover from this loss, both physically and mentally, and

Whereas couples need to be connected in their bereavement,

We recommend:

- Providing flexible bereavement leave for both parents for 24 weeks, the period identified as most intense in terms of bereavement symptoms,[41] depression, and anxiety.[25]

4) For leaders of public health and education planning in federal and provincial departments

Considering the conclusions resulting from the need for service integration, and

Whereas political actions to support grieving parents must target different ministerial levels (federal: e.g. Service Canada, Health Canada; provincial: e.g. Ministry of Health and Social Services; Ministry of the Family; Ministry of Employment and Immigration; and municipal: e.g. occupational health policies, family policies),

We recommend:

- Compiling a pan-Canadian portrait of services for bereaved parents;
- Developing a comprehensive, up-to-date website for parents, the general public, and health professionals that presents information on bereavement, lists services for parents, and includes a crisis line (e.g. https://www.beyondblue.org.au/; INSPQ https://www.inspq.qc.ca/information-perinatale/fiches/deces-et-deuil-perinatal; https://www.cchst.ca/topics/wellness/mentalhealth/#ctgt_wb-auto-8)

5) For managers developing practices in service institutions

Whereas parents have the right to be supported by sensitive and competent staff who recognize their cultural specificity and bereavement pathways, throughout the continuum of care, and

Considering the lack of an efficient and effective service corridor to support these couples, both inpatient [42] and outpatient, and the great distress of mothers[25, 42] and fathers[21] over time,

We recommend:

- Developing, implementing, and evaluating care and service trajectories from intra-hospital care through to the birth of the next child;
- Incorporating father-inclusive approaches into the entire trajectory of care and services;
- Evaluating the impact on parents of services (ex. Early Pregnancy Clinic – EPAC) and of practices (e.g. bereavement groups) within these services.

6) For managers and employers

Whereas perinatal bereavement is poorly recognized in the workplace,

We recommend:

- Implementing perinatal bereavement awareness programs in the workplace;
- Providing training workshops to equip Employee Assistance personnel and managers.

7) For program managers in professional training institutions

Whereas professionals lack knowledge and do not feel competent to support grieving families,[44] and

Whereas professional training plays a key role in the development of values and beliefs adopted by professionals, and

Whereas, in training institutions and on-the-job training, there is still little content specific to the development of practices for bereaved persons, and this impedes health professionals' sense of competence,

We recommend:

- Developing, implementing, and evaluating health professional training programs, online courses, and reflexive training workshops, and
- Training pan-Canadian trainers and implementing proven innovative training programs such as "Supporting bereaved fathers", "Miscarriage in the emergency room", "Bereavement among health workers", and "Living through perinatal bereavement".

8: For federal and provincial granting agencies and researchers involved in perinatal bereavement research

Considering the need to advance knowledge, practices, and services adapted to the needs of bereaved Canadian families,

Considering the prevalence of qualitative and cross-sectional studies, the scarcity of large-scale studies conducted in Canada, and the dearth of information on outcomes of various interventions implemented for bereaved parents,

We recommend:

- Funding research teams and projects focused on the priority area of bereavement in general and targeted clienteles in particular;

- Measuring and documenting, through interdisciplinary longitudinal studies, the long-term effects of the perinatal death experience on the physical and psychosocial health of parents, couples, siblings and families;
- Accurately measuring and documenting the direct and indirect consequences of perinatal bereavement on the workplace, the health system, and families experiencing the event;
- Examining the perinatal bereavement experiences and needs of vulnerable groups, such as immigrants, refugees, Aboriginal people, LGBTQ families, surrogate mothers, etc., and develop support strategies for them;
- Documenting the experience of health professionals working with bereaved families to better support them.