

Summary of Policy Interviews RESULTS

A Mixed-Methods Policy Research Study of Dying at Home: A SSHRC-Funded Project



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BACKGROUND

This summary report highlights policy-focused interviews with organizational and governmental professionals (n=17) regarding the policy landscape around dying at home in Canada. It details perspectives on: 1) the development of policy related to care for persons dying at home, 2) whether current policies and programs match with public opinion about home dying, and 3) how policy and practice have been changing due to the Covid-19 pandemic. Participants included current or former health executives, directors, policy analysts, clinical nurse specialists, social workers, MDs, and researchers with expertise related to end-of-life care policy in three provinces (BC, n=5, Manitoba, n=3 and Québec, n=7), as well as two participants at the federal level.

SUMMARY RESULTS

- **The structure of the Canadian healthcare system creates difficulties around responsibility and authority, which complicates policy related to dying at home.**
 - For example, long-term care and home care are not covered under the *Canada Health Act*. Decision-making collaboration and priority synchronization between federal and provincial/territorial authorities is limited largely to that associated with transfer payments. This results in different palliative care policies and practices between the provinces and territories.
- Provincial policies, funding, and delivery of palliative care services across settings are primarily based on **anticipated need** (e.g., aging population), **direction and leadership from sitting governments**, and **funding concerns** (including concerns about costs of hospital deaths).
- **Provincial policies (regulations, standards, legislation, financing) are often implemented regionally (through health authorities), generating variation within provinces.**
 - The challenges of federalism and the organizational structure of regional healthcare delivery complicate policy-makers' abilities both to address priorities at the local level and to predict the implementation outcomes of a specific policy.
 - Health authorities' relationships with the province are particularly important.
- **Provincial policy development exhibits inconsistent engagement with advocacy organizations, community groups, and the general public.**
 - Key stakeholder groups are not consistently included in provincial policy-making related to dying at home; mechanisms tend to be informal and network-based. Moreover, information channels between government agencies and stakeholders do not always function properly.
- **Metrics should be given to quality of care and death rather than proportion of home deaths achieved.**

- Most interviewees articulated that strong public demand for dying at home, or at least advocacy, is an important driver of policy development. At the same time, participants identified systematic limitations (particularly poor availability of palliative home care) and inequities, highlighting that current policies may employ the rhetoric of the benefits of dying at home without also prioritizing necessary funding and implementation strategies.
- **The public may have unrealistic expectations of dying at home.**
 - The public may tend to idealize dying at home, due to inexperience, being uninformed, or having unrealistic expectations, including the role of family and the limitations of public services.
 - There is also the need for policy attention to developing formal services and investments (including in support of family caregiving) if proportions of home deaths are to be expanded.
- **Need for locally and culturally appropriate policies to support dying at home.**
 - Generalized policies need adjustment based on local community culture and priorities, especially in rural areas where dying persons lack access to both specialized and basic services available elsewhere.
 - For instance, one participant referred to how familiarity and long-established relationships with one another in smaller or rural communities can reduce barriers in bringing together allied health professionals to plan care and support in the community.
 - Indigenous and visible minority groups are doubly vulnerable because of their need for palliative care services and disadvantaged social determinants of health.
- **Dying at home during COVID-19 requires further support and innovation.**
 - COVID-19 has increased existing challenges in supporting dying at home. More people are choosing to stay home at the end of life, yet some lack access to services needed to support this.
 - The pandemic highlighted the need for innovative alternative means of care provision including virtual tools and platforms. Some were put in place quickly, yet other policy decision-makers may have been reluctant to innovate, causing delays. Nonetheless, a more permanent reliance on and expansion of these tools may emerge, raising issues of inequities around access to the technological applications and internet, which must be addressed by policymakers.
- **Lack of national standardized data on dying at home makes comparison difficult between provinces.**

WHAT THIS MEANS

Our results further understanding of policy complexity related to dying at home in Canada. Results highlight whether and how policymakers engage, understand, and incorporate public opinion, key stakeholders, and advocacy organizations. We are continuing our analysis, including cross-province comparisons. It will be important to trace the effects of top-down policy initiatives (especially the 2017 federal framework for palliative care), as well as the expansion and scaling up of ‘bottom-up’ initiatives in particular communities, to most fully understand the policy landscape in this area.

Note: The research team appreciates participants’ time and interest. If you have further questions, please contact Dr. Laura Funk, lead researcher, at Laura.Funk@umanitoba.ca. Stay tuned for future reports of findings from this and other aspects of our project: <http://www.dyingathome.ca/>