

Medically Necessary? The Case for Fully Funded End-of-Life Care

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Introduction

The current work of provincial and national health commissions, and the release of some preliminary reports, is focussing attention on the issue of medically necessary health services. This is not the first time that the issue of medically necessary has been debated. Since the formation of the Canadian health care system in the 1960s, and its reinforcement in 1984 by the Canada Health Act, the concept of “medically necessary” has broadly defined which health services will be publicly funded. As the concept of medically necessary could also define which services will not be publicly funded, it stands to reason that the issue of defining health services on the basis of whether they are considered medically necessary or not is of critical importance to Canadians.

Medically necessary health services are all those which physicians deem to be necessary for individual clients. This definition has largely resulted in all Canadians having a wide range of medical and hospital services readily available to them when needed. Yet, at the same time, an illness-oriented, hospital-dominated health system has been the primary outcome of this legislated aim to ensure provinces universally provide, at a minimum, medically necessary health services. However, our health system has evolved and continues to evolve into a more diverse and community-based system. Obviously, there are other influences on our health system. These influences are illustrated by the physician fee-for-service schedules negotiated by health ministries, and political as well as regional health authority policy-making. In short, there are many influences on what is and what is not in our current basket of publicly-funded health services. In some cases, these additional influences result from technological and educational advances, as in the case of laparoscopic procedures replacing many of what were previously major invasive surgeries. The widespread but still variable substitution of day surgery care across Canada, along with a shift in the cost of health care supplies

and the responsibility for providing pre- and post-operative care to the home, are among the most common outcomes of this single technological advance. Additional influences have also arisen out of fiscal prudence, as was the case in the 1990s when provinces furthered a shift from inpatient to outpatient care. Still other influences have arisen out of the identification of unmet health care needs. Inner city primary health care programs are but one example.

Although laudable, the programs that result from these additional health system influences are often only available in select communities. Home care is one such boutique or designer program, with each province and also each regional health authority determining if home care will be provided, and how it will be funded and delivered to community residents.¹ Although targeted programming assists residents of one community, people in other communities normally have similar health care needs. Universal programming is therefore often indicated. This paper argues for a fully funded home-based palliative care program for dying Canadians.

Why is There a Need For This Publicly Funded Health Service?

Approximately 220,000 Canadians die each year now, three quarters of whom are aged 65 or older.² Most of these 220,000 deaths are not unexpected. Death today most often follows a variable but still notable period of declining health due to advanced aging and/or progressive chronic illness.³ During an ongoing decline in health to death, it is reasonable to expect that some care needs will occur.⁴ A key question is: where does this care take place?

A recent study of hospital use by dying Albertans over a five year period found one admission in five years was the most common frequency of hospitalization.⁵ As this

hospitalization was the one that ended in death, it is remarkable that no admissions to hospital occurred in the five previous years. It is also remarkable that the hospital stays which ended in death were not typically treatment intensive.⁶ In 52% of cases, nursing care was the primary, if not sole, health service provided in hospital. As such, no surgery or major diagnostic procedures were performed, a situation which indicates that a dying state was recognized in advance for half of all terminal cases in hospital. This recognition of a dying state explains the absence of diagnostic testing and cure-oriented treatment. Furthermore, this study found only half of all deaths in Alberta over this five year period in the 1990s took place in a hospital bed.⁷ Alberta is not dissimilar to other provinces in regard to the type of care provided in hospitals and hospital care trends. These research findings should therefore do much to dispel a common myth of extensive and expensive, but largely futile care in hospital for terminally ill and dying Canadians.

Another myth is that many deaths are taking place in long term care facilities now, as a result of a shift of death and dying from hospitals or other places to long term care facilities. This myth has also been disproved. A recent study of Statistics Canada mortality data found only approximately 3% of all deaths in Alberta or other provinces have taken place each year since the mid 1970s in nursing homes or auxiliary hospitals.⁸ An even more remarkable finding of this study of Statistics Canada mortality data is that hospital deaths in all provinces have been declining in both number and proportion of deaths, with this shift beginning in Saskatchewan during the early 1980s.⁹ Since then, the home has become a much more common, although largely unrecognized, place of death in Canada. More significantly, the home is also an unrecognized place for the end-of-life care that often precedes death.

End-of-life care is costly to families in terms of both time and expenses.¹⁰ Many hours of home care may be provided each day, and for many days, by family members.¹¹ Family caregivers often try to balance this care requirement with their paid employment and other personal commitments through adopting part-time hours of work or through stopping outside work altogether. Home care supplies are also often prohibitively expensive; medications alone can cost hundreds of dollars each month. Private insurance may reduce some of these costs, but most home care expenses are borne privately. This problem is often a result of home

care, even when it is publicly funded, being strictly rationed.¹² As few as two hours each week in home care support are provided in regions across Canada that do provide palliative home care, with recipients often having to pay a portion of this cost. In addition, home care supplies are often provided through co-payments. To date, home care has not been considered a medically necessary or otherwise essential health service for all Canadians in need, which explains why half of all recently surveyed Canadians who reported a need for home care did not receive it.¹³ Nor is palliative home care, a form of short-term comprehensive home care, universally provided across Canada.¹⁴

Amazingly, a universal palliative home care program exists in the United States, a country with few universal health care programs. Medicare Hospice Benefits are available to all Americans who are eligible for Medicare Part A (hospital insurance), are certified terminally ill and probably have less than six months to live, and who choose to accept hospice care.¹⁵ The goal of hospice care is to care for individuals and families, not cure an illness.¹⁶ This universal palliative care program is broadly defined to meet all health care needs, including all necessary home care supports and services to enable a home death. Death may also occur in a non-hospital hospice. Although some non-hospital or free-standing hospices have opened in Canada, many hundreds exist in the United States. Hospice care aims to ensure a good death for individuals and their families.

Palliative care, a synonymous Canadian term, similarly aims to ensure a good death for individuals and their families. In Canada, palliative care beds and programs are normally situated in acute care hospitals, with home care generally not a component of these programs.¹⁷ As such, there may be a complete lack of continuity of care between the home and hospital. This, and the fact that private funds and extensive family caregiving are needed for palliative care in the home, often means dying people who would like to stay home cannot do so. Some research indicates many dying people would avoid hospitals if possible. Many families would also provide home care if their efforts were recognized, and if enough financial and caregiving assistance were provided. Currently, in Canada, inpatient hospital care and supplies are publicly funded, while the same care and supplies in the home are not.

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Conclusion

The increasing number of deaths at home in Canada, and the need for ongoing end-of-life care of dying persons in the home introduces a need for a universal program of home-based end-of-life care in Canada. Such a program would reduce the personal and societal costs of admission to hospital. Although some people may argue against boutique or designer programs, a fully-funded home palliative care program would benefit individuals, their families, and all communities across Canada. There is obviously a universal need for such a program. This program would also be in keeping with current trends in the shift of palliative care to the home, and the social value in Canada of humanistic health care.

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