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Potentially Non-Beneficial End-of-Life Care: Clinical, Ethical, Population-Based, Organizational, and Economic Considerations

English summary

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SUMMARY

Potentially Non-Beneficial End-of-Life Care: Clinical, Ethical, Population-Based, Organizational, and Economic Considerations

Introduction

Approaching the end of life in the context of chronic illness is often accompanied by a deterioration in health and increased use of health care and social services. Depending on the person's expectations and preferences, their health status, prognosis, and the anticipated effectiveness of the interventions under consideration, certain treatments or care provided at the end of life may not provide any benefit to the person with the illness. Such practices can have significant repercussions for patients, their families, the healthcare team, and the health and social services system as a whole.

The direction Santé physique et pharmaceutique of the ministère de la Santé, de la Prévention et des Aînés (MSPA) has entrusted the Institut national d'excellence en santé et en services sociaux (INESSS) with the following mandate: 1) to clarify the concept of care that may not be of benefit when provided to people at the end of life; 2) to identify examples of such care; 3) to examine practices in this regard in the Quebec context; and 4) to provide an overview of the associated costs.

Methodology

A rapid review of the scientific literature and consultations made it possible to define the concepts associated with potentially non-beneficial care, to identify factors that may influence such care, and to provide examples that may fit this concept in the context of hospital care.

To analyze care that falls under the concept of potentially non-beneficial care (PNBC), a retrospective cohort was established of adults who died in 2018, 2019, or 2022, in order to exclude deaths related to the COVID-19 pandemic. These individuals were categorized into three end-of-life trajectories likely to benefit from palliative and end-of-life care: 1) cancer or terminal illnesses; 2) organ failure; and 3) conditions of physical and cognitive frailty. The classification was based on the disease or trauma that triggered the morbid progression leading directly to death, according to information from the death registry.

An estimate of the costs associated with the volume of certain clinical activities was conducted, focusing on care provided during the final months before death. It should be noted that these cost analyses do not claim to encompass all potentially non-beneficial care, much less to quantify the exact proportion of care that is actually non-beneficial in Quebec. The data required for all of these analyses were extracted from the clinical and administrative databases of the MSPA and the Régie de l'assurance maladie du Québec. Costs associated with medications, such as systemic treatments, were not included in the analysis due to difficulties in documenting them. This is a significant limitation that tends to underestimate the overall costs

Results

Concepts, factors, and impacts related to the notion of potentially non-beneficial care

A variety of terms are used in the literature to describe treatments or care that may be considered non-beneficial, which creates ambiguity in terms of concepts and definitions. Care is deemed inappropriate if it conflicts with the patient's values, if it is inconsistent with the stated care goal, or if it is recognized as having no positive impact on the person's health. Non-beneficial care, on the other hand, offers limited or no benefits, has little impact on quality of life, and may place a burden on the individual, their loved ones, healthcare professionals, and the healthcare system. **This study is based on the concept of "potentially non-beneficial care" (PNBC)**, where the term "potentially" acknowledges the need for an assessment and discussion between the patient and the care team, combining values, preferences, and professional expertise.

Several factors must be considered when determining which cares might be deemed potentially non-beneficial, including personal factors, clinical factors, and individuals' values and beliefs. For its part, the healthcare team is bound by professional and ethical obligations to provide scientifically appropriate care that is reasonably likely to yield positive clinical outcomes, including quality of life—a concept often fraught with uncertainty. Ethical issues create tension between the values and beliefs of patients and their loved ones, professionals, organizations, and society, compounded by important considerations of distributive justice, equity, and the judicious use of the healthcare system's limited resources.

PNBCs can cause complications, adverse effects, and suffering, and may even lead to other PNBCs. These types of care can cause distress, frustration, and feelings of guilt among healthcare providers. PNBCs contribute to the burden on the healthcare system and can hinder the appropriate reallocation of resources toward palliative or supportive care, for example.

Potentially non-beneficial end-of-life care: the Quebec context

Hospital resources: People who died in one of the three end-of-life trajectories accounted for 66,5% of all deaths in Quebec during the years analyzed. More than half of these deaths occurred in a hospital. Variations are observed in the use of acute care or palliative care beds depending on the trajectories. Emergency department visits, hospitalizations, and intensive care unit admissions are more frequent during the month preceding death, particularly among individuals on the cancer and organ failure trajectories.

Potentially non-beneficial care: A rapid review of the literature, supported by consultations with an advisory committee and combined with the availability of clinical and administrative data, led to the identification of 18 PNBCs for which an analysis within the Quebec context was feasible. These 18 PNBCs were grouped into three categories: life-sustaining care, treatments or interventions, and diagnostic tests. The analysis

reveals important variations in their use during the 90 days preceding death, ranging from a marked increase in the last 30 days of life (e.g., CPR, ventilation-intubation, acute renal dialysis, bronchoscopy), to relatively stable use (e.g., hip surgery, pacemaker implantation), or even a decrease in use (e.g., radiation therapy, artificial nutrition, spirometry).

The results should be interpreted with caution: they do not measure the quality of a clinical decision per se but rather highlight areas of concern that call for the identification of trends, discrepancies, or contexts where the proportionality of care warrants further examination. However, they do not capture the full scope of potentially non-beneficial care, nor do they precisely quantify its actual frequency.

Economic considerations related to end-of-life PNBCs

According to three economic studies reviewed, end-of-life PNBCs are associated with increased resource utilization and substantial costs, often without demonstrated clinical benefits.

For the three years and the three trajectories examined using Quebec data, costs related to fee-for-service medical compensation increase during the final months of life. Similarly, the costs associated with the 18 PNBCs analyzed are predominantly concentrated in the final days preceding death: they rise rapidly during the five days prior to death and peak on the day of death itself.

During the final month of life, the costs associated with fee-for-service payments for medical specialists primarily relate to PNBCs in the “treatments or procedures” category. In contrast, costs associated with family physicians are more attributable to life-sustaining care.

Across the three care pathways, 18% of patients received at least one of the 18 PNBC analyzed, with regional variability ranging from 10% to 22%. Among these PNBC, those with the highest volume and overall costs were CPR and intubation-ventilation. Certain PNBCs, such as the use of extracorporeal membrane oxygenation (ECMO) or certain surgical procedures, are costly but were provided to a substantially smaller number of patients. Some PNBCs are observed more frequently among hospitalized patients, those visiting the emergency department, or those in intensive care. However, this finding should be interpreted with caution, as it is based on retrospective analyses of a cohort of deceased individuals. These analyses do not allow for a comparison of the use of these care and services among all individuals who received them, including those who survived and may have derived clinical benefit from them.

Estimates of the costs associated with potentially non-beneficial care remain very approximate, since not all costs could be included in the analysis and it is impossible to estimate the proportion of procedures that were actually non-beneficial among the entire cohort analyzed.

Factors influencing the use of potentially non-beneficial care and leverage points for action

Societal values oriented toward action, progress, and autonomy of choice, as well as medical training focused on healing and increasing life expectancy, are among the factors that may contribute to the use of potentially non-beneficial care. Care provided in isolation or without continuity for patients with multiple comorbidities, uncertainty regarding prognosis, the inability to predict the timing of end-of-life, and insufficient or delayed palliative care also influence the use of care.

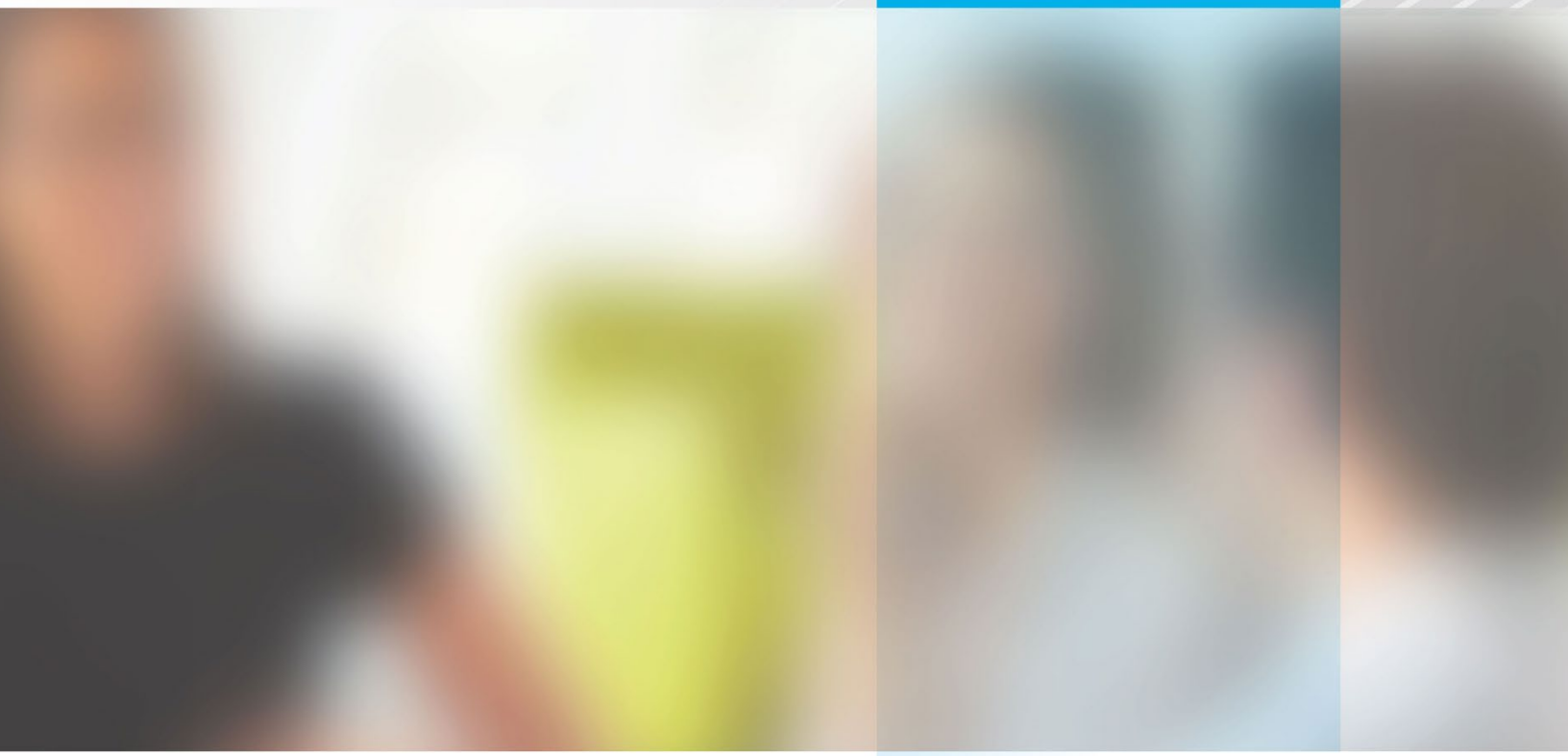
According to the literature and consultations conducted, improved and timely home or long-term care, tailored support, and accessible palliative care could serve as an important lever for reducing the use of care that is less likely to be beneficial to the patient.

Scope and limitations of the study

Clarifying the concepts, issues, and levers surrounding potentially non-beneficial care is essential to the discussion of care pathways and to improving the quality and appropriateness of end-of-life care.

One limitation of this study is that the care identified and examined consists of procedures or episodes of care that are considered “potentially” non-beneficial in certain contexts and can be measured using the data available to INESSS. The probability that a particular care intervention was actually provided remains unknown, since the methodology—based on a retrospective cohort—does not allow for knowledge of each individual’s clinical status, progression, prognosis, or care goals. According to the various stakeholders consulted, the information generated in this report should primarily be used to support clinical discussions about end-of-life care and to inform a collective reflection on the conditions that promote or hinder the provision of care consistent with the needs and values of people at the end of life.

It is also important to highlight the selection bias inherent in the retrospective approach used. Examining only cases of PNBC among deceased individuals does not allow for a comparison with the care and services that might have proven clinically relevant for survivors. A prospective analysis based on data from clinical records—including, in particular, the decision-making context, prognosis, course of the disease, and care goals for each patient—would provide a more nuanced and comprehensive picture in this regard.



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