

The demon in *deeming*

Medical paternalism and linguistic issues in the palliative care setting

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Despite considerable efforts in public health policy since 1995 to promote and advance palliative care in Canada, no more than a third of Canadians access palliative care when they need it.¹ This number is tragically low when compared with the 90% of Canadians who could benefit from palliative care in the final phases of their lives.¹ Although the reasons for this are multifactorial, we submit that medical paternalism together with linguistic issues are important contributing factors. In addition to posing a barrier to accessing palliative care services in a timely fashion or at all, medical paternalism and linguistic inaccuracies and euphemisms might reflect a failure to act in a truly ethical and patient-centred manner.²

Framing the issue

Medical paternalism is exemplified by deeming. The language used by physicians when discussing palliative care is often vague and ambiguous, whether unintentionally or deliberately.³⁻⁶ A common and classic example of a paternalistic practice in health care occurs when physicians state that they are *deeming* a patient *palliative*. Deeming by the physician suggests that the physician is in charge of deciding if and when it is appropriate to refer the patient for palliative care and what type of treatments the patient should receive, if any. Given that the term *palliative* is widely and incorrectly used as a euphemism for actively dying patients needing end-of-life care,^{6,7} physicians are thus most likely to refer patients to palliative care when they are unequivocally end stage. Yet a patient might elect for a completely conservative palliative mode of care (ie, “comfort measures only”) from the onset of her or his incurable illness.

A recent trend to promote early introduction of palliative care is exemplified by having palliative care clinicians integrated within oncology programs.⁸ In such models, patients are offered treatments that range from disease-modulating therapies (chemotherapy and radiotherapy) and active medical care (antibiotics, transfusions,

artificial nutrition, hydration, etc) to pain and symptom management. In a truly patient-centred manner,² it should be patients who decide what combination of treatments they desire along their disease trajectory.

Medical paternalism might be motivated by conflicts of interest. There might also be inherent bias in the referral process depending on the particular specialty of the physician involved. Specifically, this process might be influenced by conflicts of interest. A systematic review has demonstrated that financial relationships among industry, researchers, and academic institutions are highly prevalent, and that conflicts of interest from these liaisons can greatly influence the results and translation of biomedical research.⁹ Recent studies in oncology settings suggest that chemotherapy and radiotherapy trials that were associated with financial sponsorship tended to enrol patients with later-stage cancers and higher-risk profiles.^{10,11} Thus, active interventional physicians, such as oncologists, might feel more inclined to carry on with treatments that have only marginal and short duration of effect instead of referring patients to palliative care at an earlier and more opportune point in their disease trajectories.

Palliative care is a plan of treatment that requires consent. Deeming a patient to be *palliative*, if carried out unilaterally by physicians, clearly contravenes the ethical principle of autonomy. Ideally, decisions regarding treatment plans should be done in a shared decision-making¹² mode, in which the patient arrives at a decision after being counseled comprehensively by the physician. Ideally, this should involve a full disclosure of the diagnosis, natural history of the disease, prognosis,¹³ and available treatment options together with the patient’s respective associated outcomes (short term and long term), possible benefits, burdens, and risks. Thus, as a plan of treatment, palliative care requires consent from the patient or, if the patient is incapable, from the substitute decision makers.^{14,15} Therefore, a physician does not have the legal or ethical authority to designate or *deem* a patient *palliative*.

It is not only imperative that a physician receives consent for a plan of treatment such as palliative care, as per Ontario’s Health Care Consent Act, but also that the consent be *informed*.^{14,15} Consent that is incomplete or uninformed is not aligned with the principles of patient-centred care,² which encompass respect for

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patients' preferences, values, beliefs, and expressed needs. Furthermore, intrinsic to patient-centred care is the need to satisfy patients' information needs through effective communication.² The language used by physicians has a strong influence on a patient's and a substitute decision maker's understanding of the diagnosis, natural history of disease, prognosis, and treatment options, and therefore the words of physicians should be chosen carefully and thoughtfully, while avoiding vague terms and euphemisms.

Palliative is an adjective to describe a philosophy of care. An additional linguistic issue is the misuse, overuse, and euphemistic use of the word *palliative*. The term *palliative* is often erroneously used as an adjective to describe a patient's diagnosis, status, prognosis, or care team, which, in addition to being ambiguous and misleading, can undermine the identity of the specialty of palliative medicine.⁵ There also exists variable understanding of the term *palliative* among patients, families, and health care professionals. Moreover, many health care professionals assume that *palliative care* is nothing more than a euphemism for *terminal care*^{6,7}; however, end-of-life care is but one facet of palliative care. In actuality, *palliative* refers to an approach to care that has the goal of alleviating pain and symptoms and maximizing comfort, dignity, quality of life, and quality of death. Furthermore, a palliative care referral can be made at any time in the course of an advanced illness.¹⁶

Palliative care: the glass is half full rather than half empty. Palliative care is best described in terms of what it is and what it offers rather than in terms of what it does not offer. For instance, a physician should describe palliative care in terms of its focus on pain and symptom management, dignity, family involvement, and spiritual care, rather than simply listing off interventions typically not included in palliative care, such as "no cardiopulmonary resuscitation, no intravenous fluids, no feeding tubes, and no antibiotics." The latter description does not sufficiently capture palliative care and in fact offers an inaccurate, incomplete, and negatively biased view of palliative care. Thus, language inaccuracies, euphemisms, and differing conceptions of palliative care create the likelihood that the process of obtaining truly informed consent will be compromised.

A study that surveyed physicians who had participated in the Ontario Consent and Capacity Board process to resolve disputes about best interests at the end of life recommended that palliative care treatment plans be framed "in the positive instead of negative."¹⁷ For example, as opposed to simply proposing *withdrawal of life support* or *1-way extubation*, physicians might say, "We believe that attempts at curative treatments have failed, and we are proposing a palliative approach where the

patient would receive pain and symptom management and comfort measures only." **Table 1** outlines a list of commonly used terms and expressions that can lead to ambiguity and misperceptions, as well as our suggested replacement terms.

Table 1. Problematic versus preferred phrases used in palliative care

PROBLEMATIC PHRASE	PREFERRED PHRASE
"That patient has been deemed palliative"	"The patient has chosen to adopt a palliative approach to her or his care"
"Palliative patient"	"Patient with a life-limiting illness who has chosen a palliative approach to her or his care"
"Palliative diagnosis"	"Advanced illness," "incurable illness," "terminal illness," or "life-limiting illness"
"Doing nothing"	"Abstaining from procedures that are ineffective, burdensome, and futile"
"The patient will no longer be receiving treatment"	"The patient will be receiving comfort measures only from this point"
"Withdrawal of care"	"Withdrawing ineffective, burdensome, and futile treatments"

Conclusion

Now more than ever, palliative care is one of the most dominant discourses in Canadian health care, as evidenced by the November 2011 report from the Parliamentary Committee on Palliative and Compassionate Care,¹⁸ the 2014 annual report of the Office of the Auditor General of Ontario,¹⁹ and the February 2015 Supreme Court ruling (*Carter v Canada*)²⁰ that found that prohibition of medical assistance in dying violates the Canadian Charter of Rights and Freedoms, which led to Bill C-14.²¹ Furthermore, the aging population and increasing prevalence of chronic life-limiting illnesses will translate into an increased need for accessible and timely palliative care services. Therefore, it behooves physicians to understand and refine the language they use when counseling patients with advanced illness.

By refraining from the use of euphemistic and paternalistic language, physicians can ensure that they are using and explaining the term *palliative* accurately and unequivocally, thereby decreasing misunderstandings and ambiguity, obtaining consent that is informed, and exemplifying patient-centredness, which is a cornerstone of a palliative care philosophy. Consequently, this might lead to more overall referrals to palliative care, as well as earlier referrals to palliative care, which will promote positive outcomes for patients, their families, and the health care system. First and foremost, physicians should

refrain from unilaterally and paternalistically deeming a patient palliative and start facilitating and enabling the process of patients deeming themselves palliative. 🌿

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Competing interests

None declared

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