

Palliative care viewed as a stigma, despite improving quality of life

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The term palliative care carries a stigma for patients and their caregivers, who regard it as synonymous with impending death. Education, and possibly a name change, will be necessary to be able to integrate palliative care into routine advanced cancer care, according to new research in *CMAJ (Canadian Medical Association Journal)*.

Palliative care is designed to improve the quality of life of patients with a serious illness and their families. The World Health Organization and all major national and international cancer societies encourage early access to [palliative care](#). Research indicates that for people with advanced cancer, early palliative care benefits both physical and mental health and can even extend life.

However, a new study found that even patients who have benefited from early palliative care feel stigmatized because they see it as being associated with the end of life.

The study, conducted at Princess Margaret Cancer Centre, Toronto, Ontario, included 71 participants (48 patients and 23 caregivers) in a randomized clinical trial of early palliative care versus standard cancer care. Of the participants, 40 had received early referral to palliative care (in addition to standard cancer care), and 31 had received standard cancer care alone. Participants had cancers from the five most common types: lung, gastrointestinal, genitourinary, breast and gynecologic, and had an estimated survival (by their oncologist) of 6-24 months. At the end of the trial, researchers interviewed the 71 patients and caregivers

about their attitudes and perceptions to palliative care.

"Patients with advanced cancer and their caregivers described palliative care as carrying a negative stigma associated with death and with care at the very end of life, which provoked fear and avoidance," writes Dr. Camilla Zimmermann, Princess Margaret Cancer Centre, University Health Network, Toronto, and her coauthors. "Participants' perceptions often originated from interactions with [health care professionals](#)."

"A prominent theme was that palliative care should be explicitly rebranded," the researchers found, with participants suggesting public education, better explanation by [health care](#) professionals and routine involvement of palliative care at cancer diagnosis to break down stigma.

The authors suggest that the study has implications for clinical practice and [health care policy](#).

"[Our findings show that] the persistence of the definition of palliative care as end-of-life care in the minds of patients and their caregivers, despite an international change in that definition more than a decade ago," write the authors. "A name change may be considered, but would achieve nothing without a fundamental shift in the manner in which palliative care is practised and portrayed."

The authors caution that the way in which physicians inform patients and their caregivers about palliative care has a major impact on how it is perceived. Many health care professionals still suggest palliative care as a final option or as an alternative to further treatment.

In a related commentary, Dr. Anthony Caprio, Department of Family Medicine, Carolinas HealthCare System, Charlotte, North Carolina, writes that the study shows that "[patients](#) and [caregivers](#) view health care professionals as having an important role in explaining and

recommending palliative care. Although changing the name to supportive care may help promote a more positive view of palliative care, the stigma will persist if this type of care is recommended only as default treatment when curative or life-prolonging treatments are deemed ineffective or undesired."

Palliative care should begin at diagnosis and continue throughout [cancer care](#), regardless of prognosis.

More information: *Canadian Medical Association Journal*,
www.cmaj.ca/lookup/doi/10.1503/cmaj.151171

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