

Comparison of preferences for end-of-life-care (EOL) among patients with advanced cancer and their caregivers: A discrete choice experiment*

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Cancer treatment for those with advanced cancers is often expensive. Advanced cancer patients also face difficult decisions on which treatment to undergo, if any. These decisions are typically influenced by cost and expected survival, among other considerations. Informal caregivers, such as children or spouses, typically have a significant role in influencing the EOL treatment decisions. As patients and caregivers may have different values on health related quality of life and life extension, the paper measures the value that they place on end of life care by determining their willingness to pay for life extending treatments and end of life improvements.

Two hundred and eleven advanced cancer patients and their primary caregivers were interviewed from February to March 2013. They were asked to select from a series of end of life scenarios with the different aspects consisting of severity of pain from diagnosis until death, amount of care required from family or friends, expected length of survival, quality of health care experience, expected cost of treatment from diagnosis until death, source of payment and place of death. The relative importance of each aspect in influencing the choice of the scenario was then quantified by determining their willingness to pay estimates. Additionally, the patients and caregivers were asked to indicate on a 4 point Likert scale their preferences for life

sustaining treatment such as artificial feeding, use of a breathing machine and cardio-pulmonary resuscitation (CPR).

The study quantified the value of life extension and other end of life improvements for advanced cancer patients and their caregivers. Results show that patients are willing to pay \$18,570 to extend life by 1 year; \$31,256 to die at home; \$22,199 to avoid severe pain; \$16,191 to receive a high quality health care experience; and \$4,051 to not be a burden on family and friends. As compared to the patients, the caregivers, on the other hand, are willing to pay more – \$61,368 – to extend the patient's life and provide other end of life improvements. Furthermore, the caregivers' readings on sustaining treatment show a higher percentage: for artificial feeding 73.5% vs 55.9%; for a breathing machine, 67.8% vs 55.8%; and for CPR, 69.2% vs 58.8%. This reveals that caregivers want life sustaining treatment more than the patients themselves do.

These findings suggest that patients who are still capable of decision making should also be involved in their own treatment and end of life decisions. Decision making should not be left solely to the caregivers and efforts should be made to incorporate patients' end of life preferences.

* Based on: Malhotra C, Farooqui MA, Kanesvaran R, Bilger M, Finkelstein E. Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment. *Palliative Medicine*. 2015 Mar 24. pii: 0269216315578803. [Epub ahead of print]