Who participates in palliative care research?
Exploring generalizability and potential effects on cost estimates

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Research is subject to selection bias, and palliative care research faces particular challenges:
- Not everyone with needs is identified and receives palliative care.
- Eligibility criteria set to help ensure feasibility of data collection in this population with declining health, further limit who participates in research at end of life.

Objective
To investigate the effect of eligibility and participation biases on generalizability of a study of costs for community-based palliative care.1

Methods
In 2005, all persons newly referred to the Halifax Palliative Care Program (PCP) were assessed for inclusion in a costing study.2 The first 50 eligible persons who agreed to participate were included in the study. Study participants were compared to:
- Eligible persons who declined to participate
- PCP clients not approached to participate in the study
- Adults who died of cancer in same year and geographic area

Statistical significance was determined using t-tests on means for age, distance, and income, and chi-squared tests for receipt of radiotherapy and medical oncology consults among cancer decedents. Satterthwaite’s method was used for t-tests of age and distance because equality of variances could not be assumed. The log-rank test was used for survival analysis.

Eligibility Criteria
- over 18 years of age
- resident of Halifax County
- speaks English or French
- new client in the Palliative Care Program
- affected by a terminal disease
- no serious mental disorder or cognitive impairment
- living at home, or returning to home after time in hospital (not a nursing home resident)
- receiving care from an informal caregiver (spouse, parent, child, sibling, or friend) who was able and willing to provide information about the study subject’s health services utilization, personal expenses related to care, and loss of income

Results
Study population and comparison groups

- The 50 study participants were younger, lived closer to the PCP, and were enrolled longer before death, than the 110 eligible clients who declined and the 1,010 PCP clients not included in the study.

- Compared to the 1,027 other cancer decedents, the 45 study participants who died of cancer were younger, lived closer to the PCP, and were twice as likely to have had radiation and medical oncology consults.

Conclusions
The study population is not representative of all PCP clients nor of the wider universe of individuals who might benefit from community-based palliative care.

While the cost study findings are important and meaningful for making informed decisions on end of life care for populations similar to the one studied, inaccurate conclusions are possible if cost estimates are applied to those who:
- live in rural areas or further from a PCP
- do not have an informal care provider
- are dying of a chronic disease other than cancer
- are not referred to a PCP, or have a late referral
- have cognitive impairment
- are admitted to a nursing home or receive their remaining palliative care in hospital after a palliative care referral

This limits the generalizability of the study findings, making evidence-based policy decisions more difficult without further study of underrepresented populations.

References

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