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Attitudes of Patients with Advanced Cancer Toward Research

To the Editor:

There is a great need for an improved evidence base to guide clinical practice and service provision in palliative care, yet research in palliative care has been notoriously difficult, with poor trial accrual and high attrition rates.^{1–3} It is therefore of vital importance to design “patient-friendly” studies that will encourage participation and improve accrual and retention. To design such trials, the views of potential participants need to be known. The systematic review by Todd et al.,⁴ recently

published in this journal, includes studies published up to 2007 and highlights some of the views of advanced cancer patients toward research participation, including altruism, the desire for personal benefit, and the potential for hope. It also points to some of the potential deterrents, for example, concern about placebo arms and the possibility of increased hospital admissions.

In 2008, we published the results of a questionnaire that was designed to determine the views of 101 patients with advanced cancer toward research in palliative care, and particularly toward randomized controlled trials (RCT). We believe the findings of our study⁵ add significantly to this systematic review. It supports the finding reported by Todd et al. that patients are altruistic; 82% of our participants stated that they would participate in studies that might help others and not themselves. We also identified several other major factors that influenced the willingness of patients to participate that were not discussed in this systematic review.

First, our study demonstrated that patients were interested in palliative care trials, in that 88% of participants were interested in studies of symptom control that would have no impact on their cancer. However, patients were greatly influenced by the perceived invasiveness of a trial, with approximately 80% willing to participate in trials of pain education, aromatherapy, or a new mattress, compared with less than a quarter willing to participate in trials that would involve an epidural or placement of a spinal stimulator under a general anesthetic. Potential side effects were also a deterrent, with less than one-third willing to participate in trials of drugs that might have side effects.

Inconvenience associated with trial participation was a deterrent to some but not all in this study. When asked for a weekly commitment, about one-half of all participants were prepared to make extra visits to the hospital, and more than one-third an extra night in hospital. Two-thirds were prepared to answer questions (either by telephone or face-to-face) and more than half were prepared to complete a short questionnaire, with approximately 40% prepared for a detailed questionnaire just as frequently. Many were prepared to have extra blood tests and 33%, extra radiographs or scans at least weekly. Approximately two-thirds

seemed willing to take extra tablets, with 42% prepared for extra injections.

Other factors influencing a decision whether or not to participate in a research study included the opinions of others, with the views of both relatives and treating doctors being very important. Patients were unwilling to participate in a trial that might involve a financial burden, for example, in terms of travel or car parking. Approximately half were not deterred by the use of placebos, randomization, and double-blinding as part of an RCT.

The only demographic factor that influenced a patient's willingness to participate in a trial was age; older patients were less willing to participate. Previous research participation, gender, performance status, level of education, time since diagnosis of cancer, time known to the palliative care team, estimated prognosis, and actual survival did not correlate with willingness to participate in research.

Research in palliative care remains a challenge. Our research adds significantly to the findings of the studies included in Todd et al.'s review⁴ by identifying practical factors that might influence a patient's willingness to participate. These factors should be taken into consideration when designing future trials in an attempt to improve, acceptability to patients and thus trial accrual.

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