



MEDICAL DECISION MAKING

How much do cancer patients really want to participate?

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When there's a choice

Depending on the type and stage of cancer, planning appropriate medical treatment may be straightforward or may involve choosing among several options. The advantages and disadvantages of each option carry different weights for a given individual. How can we ensure that each patient receives the treatment most appropriate for his or her individual circumstances? What is the best process for making treatment decisions, in terms of efficiency, outcome and patient satisfaction? What factors influence preference for involvement in treatment decisions, and do these factors change over time? What do patients actually experience in terms of involvement? Does the approach to decision making have any effect on treatment?

This article presents research into the fundamental issue of patients' desire to be involved in making decisions about their medical treatment, as well as factors influencing these preferences, changes in preferences over time and discrepancies between preferences and actual experiences. It calls for more research into how participation in decision making may influence psychosocial outcomes.

The consumer culture of North America reinforces the assumption that cancer patients want a significant degree of involvement in making decisions about their medical treatment. Another assumption is that these patients frequently do not obtain the level of involvement they desire, resulting in frustration and dissatisfaction with their medical practitioners.

A group of research colleagues has examined these assumptions in a series of studies on women with breast cancer and men with prostate cancer using the Control Preferences Scale to measure the construct "preferences to participate in medical decision making." The Control Preferences Scale consists of 5 cards depicting a range of potential roles in treatment decision-making — from making the decision themselves, to sharing responsibility with their physician, through leaving all treatment decisions to the physician (Figure 1).¹

MEASURING IDEAL AND ACTUAL INVOLVEMENT

To use the Control Preferences Scale, participants first sort 5 cards by considering the cards 2 at a time and placing them in order, thus revealing their "ideal point" with respect to preferred level of involvement in treatment decision-making. Next, we ask them to identify the card that most closely represents the level of involvement they actually experienced in the initial treatment decision-making for their cancer. This enables us to determine the congruence between their preferred and actual degree of involvement.

A large survey reported in 1997 of 1012 Canadian women with breast cancer² showed that about one-third (34%) preferred to leave treatment decisions to their physicians, 22% preferred to make the decisions on their own and 44% preferred a collaborative role with the physician. Educational level was the most important predictor of wanting an active role in decision making (odds ratio 3.24 for women with high school education compared to those with lower levels of education).

The only group with a good (80%) chance of achieving their preferred role were those who chose the most passive option

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as their first choice (“I prefer to leave all decisions regarding treatment to my doctor”). Only about 20% of patients who preferred either active or collaborative roles in decision making reported having achieved these levels of involvement.

Cultural factors

To examine whether decisional preferences might differ by country and/or culture, the same study protocol was implemented in women newly-diagnosed with breast cancer in Liverpool, England (n = 150)³ and Stockholm, Sweden (n = 201).⁴ A clear gradient was seen across the countries, with Europeans preferring less decisional control: in England 52% and in Sweden, 66% of women preferred passive roles. The good news was that as a result, the Swedish women were the most likely (72%) across the 3 countries to report achieving their preferred roles in decision making.

Clearly, differences across cultures, countries and health-care systems do influence the degree of participation that women with breast cancer want to achieve during initial treatment planning to combat their disease.

Do men with prostate cancer differ from women with breast cancer? A series of studies by Davison and colleagues in 2 Canadian cities show that a dramatic shift has occurred over the past decade toward men’s preference for increasing involvement in medical decision-making at time of diagnosis. In data collected in the early 1990s, 58% of men wanted to leave treatment decision-making to their physicians,⁵ whereas in 2002 only 7.5% fell into this category.⁶ Today’s men also want their partners to be actively involved in making initial treatment decisions, while the partners themselves may be less likely to want active involvement.⁶

Patient and physician perception

Discrepancies are evident in both North American and European studies of preference for involvement in decision making. A prospective study in 78 U.S. patients undergoing initial assessment for outpatient palliative care by Bruera et al⁷ found that physicians predicted less patient preference

Research on psychosocial outcomes

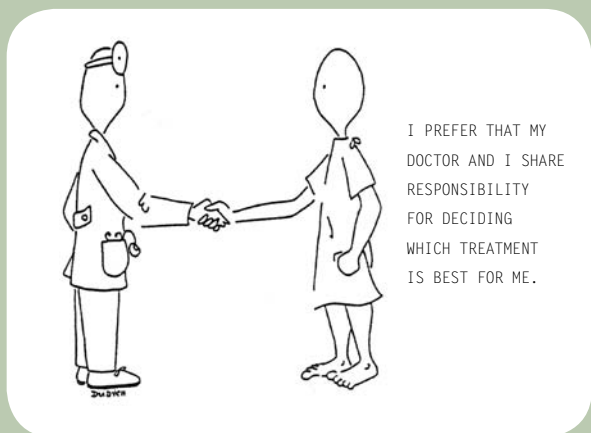
- In a limited prospective study of 233 newly-diagnosed Australian cancer patients, Gattellari et al¹⁴ found higher levels of satisfaction with initial consultations about treatment in patients who reported a shared role in decision making compared to those who reported that decisions were made by either themselves or the physician.
- Deadman et al¹⁵ found that British women advised to have mastectomy because of tumour characteristics performed worse on several psychologic scales, before and after surgery, than did those who were involved in choosing treatment. Further, among patients who ultimately had mastectomy for cancers for which several treatment options were considered appropriate, those randomized to be given final responsibility for the decision had more positive psychologic outcomes than those randomized to be strongly advised by a surgeon as to what course to follow.

for a shared approach than patients in fact indicated, and that age or sex did not significantly alter decision-making preference. Congruence occurred in 38% of cases. Auvinen et al⁸ randomized 210 newly diagnosed Finnish prostate cancer patients to 2 groups, one with greater patient participation in the choice of treatment. Among those who participated in choosing treatment, those not eligible for radical prostatectomy chose nonsurgical endocrine treatment more frequently compared to those not given a choice.

DOES TAKING AN ACTIVE ROLE REDUCE ANXIETY?

In 1997, Davison and Degner showed that men with prostate cancer could be “coached” to assume more active decisional roles.⁹ Six weeks later, men in the intervention group reported lower anxiety levels than those in the control group. The link between active involvement in the treatment decision-making process and improved psychosocial outcomes remains to be determined, although studies of British women with breast cancer suggest lower anxiety in women treated by surgeons with a collaborative decision-making approach.^{10,11} Regarding longer-term outcomes, 205 breast cancer patients in a recent study completed the scale (also called decisional role preference scale) at the time of surgery and 3 years’ followup, along with a quality of life scale (EORTC QLQ-C30).¹² Those who indicated highly active involvement in choosing their surgical treatment had significantly higher overall quality of life at followup than those whose involvement was passive. There was no correlation, however, between quality of life and either preferred involvement or reported congruence between preferred and experienced involvement.

FIGURE 1. Card representing the collaborative role, 1 of 5 in the Control Preferences Scale



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TOOLS

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A COMPUTERIZED TOOL

A touchscreen computerized adaptation of the Control Preferences Scale⁶ can be used to assess a patient's preferred level of involvement in treatment decision-making — within a few minutes at each visit. The patient simply touches the screen as pairs of cards appear in a fixed order, indicating his or her preferred role within each pair. Upon completion the patient receives a printout showing the dimensions (keep, share or give away control over decision making) with an arrow directed to the patient's ideal point. The printout can be used to inform discussions around medical treatment — ongoing trials are testing its utility in consultations between patients and physicians.

Evidence from a randomized controlled trial of a convenience sample of 749 patients in 3 urban Canadian outpatient oncology clinics suggests that simply encouraging women with breast cancer to use the printout at their medical consultation is ineffective in helping them achieve their preferred level of involvement in decision making. The women completing the touchscreen task were significantly more likely (34.4% versus 27.5% in the control group) to prefer the most active roles in decision making,¹³ but this did not mean the system could respond effectively to their enhanced preference for control. It appears that simply completing the touchscreen task caused women to ponder their role in treatment decision-making and consider more active involvement. Without parallel coaching of clinic staff, patients seemed to be put in the position of wanting more involvement, and therefore getting less than they desired, as a result of this coaching intervention.

Perhaps more consideration should be given to how information technology — such as the touchscreen approach described here — can be used to enhance the patient's role in treatment decision-making. For example, this approach could also be useful in engaging cancer patients for entry into clinical trials. Dr. Joyce Davison and her colleagues in Vancouver are undertaking further testing of the touchscreen approach.

NEXT STEPS FOR RESEARCH

The timing, nature and cost-effectiveness of interventions to help patients become more active in medical consultation need to be systematically evaluated, as do the potential benefits of such involvement. In particular, longitudinal studies that link participation in treatment decision-making at time of diagnosis to health services utilization throughout the cancer treatment trajectory are needed. Do patients who focus their efforts to get the best the system has to offer at the onset of treatment use fewer health care resources later in the trajectory? Finding the answers to such questions is critical to understanding how psychosocial issues are drivers of our cancer treatment system. 

References

1. Degner LF, Sloan JA, Venkatesh P. The Control Preferences Scale. *Can J Nurs Res* 1997;29(3):21-43.
2. Degner LF, Kristjanson LJ, Bowman D et al. Information needs and decisional preferences in women with breast cancer. *JAMA* 1997;277:1485-92.
3. Beaver K, Luker KA, Owens RG et al. Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nurs* 1996;19:8-19.
4. Wallberg B, Michelson H, Nystedt M et al. Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. *Acta Oncol* 2000;39:467-76.
5. Davison BJ, Degner LF, Morgan TR. Information and decision-making preferences of men with prostate cancer. *Oncol Nurs Forum* 1995;22:1401-8.
6. Davison BJ, Gleave ME, Goldenberg SL et al. Assessing information and decision preferences of men with prostate cancer and their partners. *Cancer Nurs* 2002;25:42-49.
7. Bruera E, Sweeney C, Calder K et al. Patient preferences versus physician perceptions of treatment decisions in cancer care. *J Clin Oncol* 2001;19:2883-85.
8. Auvinen A, Hakama M, Ala-Opas M et al. A randomized trial of choice of treatment in prostate cancer: the effect of intervention on the treatment chosen. *BJU Int* 2004;93:52-56.
9. Davison BJ, Degner LF. Empowerment of men newly diagnosed with prostate cancer. *Cancer Nurs* 1997;20:187-96.
10. Fallowfield LJ, Hall A, Maguire GP, Baum M. Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *BMJ* 1990;301(6752):575-80.
11. Fallowfield LJ, Hall A, Maguire P et al. Psychological effects of being offered choice of surgery for breast cancer. *BMJ* 1994;309:448.
12. Hack TF, Degner LF, Watson P, Sinha L. Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psychooncology* 2006;15:9-19.
13. Davison BJ, Degner LF. Feasibility of using a computer-assisted intervention to enhance the way women with breast cancer communicate with their physicians. *Cancer Nurs* 2002;25:417-24.
14. Gattellari M, Butow PN, Tattersall MH. Sharing decisions in cancer care. *Soc Sci Med* 2001;52:1865-78.
15. Deadman JM, Leinster SJ, Owens RG et al. Taking responsibility for cancer treatment. *Soc Sci Med* 2001;53:669-77.