

Discourse

Ethics and Decision-Making: Lessons from the "Cancer Wars"

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North Americans, when healthy, hold to the widespread belief that they would want to be involved in making decisions about their medical treatment if they were suddenly to be diagnosed with a life-threatening illness. This belief is conditioned by the prevailing culture of "take control," which emphasizes the role of the individual in determining his or her own fate. The belief is perhaps most developed in the United States, where the purchase of health-care services is possible and where, by purchasing the "best" services, you could think you might actually be able to dodge the bullet of disease and disability. The need to believe that one actually has a degree of control over health-related events is deeply rooted and implies that one's survival may in fact be determined by the strength of character and resilience one demonstrates in the face of catastrophic events. Nowhere are these beliefs better illustrated than in the "cancer wars."

In 1970 President Nixon declared War on Cancer. I remember being a young graduate student at the University of Washington in Seattle when this announcement was made, to much excitement across the United States. Those of us studying in the field of cancer nursing shared this excitement, perhaps naively. While the past three decades have seen impressive gains through reduction of disease morbidity and mortality in certain types of cancers, most notably and thankfully in those that strike children and young adults, it is still the case that half of individuals diagnosed with cancer will die from their disease. The surface implication of this statistic is that no matter what one does in the face of a life-threatening disease such as cancer, the chances of dying from the disease are significant. Why, then, bother to become involved in treatment decision-making, to lobby for the right to do so, to seek out

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the best treatment available? New studies are shedding some light on the public need to "take control" over treatment decision-making during the cancer trajectory.

The work of our research team and that of others have documented an interesting phenomenon: before being diagnosed with cancer people believe they would want a high degree of control over treatment decision-making, but immediately after being diagnosed they are less inclined to seize the opportunity to make their own treatment decisions (Degner & Sloan, 1992). Certain groups of individuals clearly prefer to leave treatment decisions to their physicians, particularly those who have low levels of education, those who are over 70 years of age, those who are male, and those who are experiencing a high level of disease severity (Cann, Hack, & Degner, 2002). But then, as the years pass after initial diagnosis and treatment, the cancer "survivor" reverts to the stance of wanting to be very actively involved in treatment decision-making should he or she be faced with serious illness once more (Hack, Degner, Watson, & Sinha, submitted). This phenomenon supports the hypothesis that people newly diagnosed with cancer would want fairly active involvement in decision-making if they were not immobilized by fear and that we are justified in evaluating coaching interventions to help them gain a higher level of participation than might otherwise occur because of their diagnosis-induced decisional "paralysis." The question of whether or not this hypothesis has substance requires more study through large clinical trials, but preliminary evidence is promising (Davison & Degner, 1997). There may be an important role for nurses in helping individuals achieve their preferred level of involvement in treatment decision-making.

But the real question is: does participation in treatment decision-making at time of diagnosis really improve one's chances of survival? A recent large review found no empirical evidence to support this hypothesis, and indeed found no studies on that question in the context of cancer (Cann et al., 2002). There is evidence that people who participate more actively in decision-making at time of diagnosis have better psychosocial functioning at follow-up, as documented in British women with breast cancer (Fallowfield, Hall, Macguire, & Baum, 1990). But even trying to answer this question in a meaningful way is difficult. We know that the best predictor of participating in decision-making is educational level (Degner et al., 1997), which is closely related to income. Is participation in decision-making just a "marker" for higher socio-economic status, which in turn is associated with better psychosocial functioning? Even within the context of a life-threatening illness such as cancer, do people function better, including taking a more active role in

treatment decision-making, as a result of having more personal and economic resources? Studies conducted by the Manitoba Centre for Health Policy demonstrate that place of residence is a strong predictor of premature mortality, even within a publicly funded health-care system (Frohlich, Fransoo, & Roos, 2001).

The difficulty in documenting the characteristics of disease and treatment — the critical intervening factors in examining the relationship between participation in decision-making and survival — has clearly inhibited psychosocial researchers from studying this question. Perhaps the only context in which the question could be studied is that of a pre-existing clinical trial for a medical intervention, but such trials recruit very few patients from naturally occurring populations of differing types and stages of cancer, and so their results would hardly be generalizable. Until these design difficulties are addressed, it is unlikely that we will be able to answer the question of whether or not participation in decision-making is predictive of survival from disease. This is clearly a research question that can be answered only by groups of investigators working together at the edges of their disciplines.

Why is it so important that we address this question? Because there is an underlying assumption that the answer to the question is "yes." This assumption influences the behaviour of very important groups in our society, as evidenced in my own province, Manitoba, where a major inquest was held into infant deaths that occurred after cardiac surgery. The view that parents could have prevented the deaths if only they had more information about the surgeon prevails, and has resulted in the institution of a mechanism whereby members of the public will be able to readily access information about their physicians. But in a health-care system where individuals do not control the availability of specialists and where most members of the public do not have the resources to travel across the border to seek such services, treatment decision-making is actually shaped by recruitment and retention of specialized health-care providers in the various provinces. In my own field and in my own province, shortages of medical oncologists and radiotherapists, and the lack of specialized oncology nurses to provide transition services that in the United States are proving to save lives (McCorkle et al., 2000), severely limit the real and meaningful participation that newly diagnosed cancer patients can have in maximizing their survival. Would you want your elderly parent to receive transition services between home and hospital by a specialized oncology nurse if you knew that such services would enhance your parent's chance of survival? You probably would. But could you access such services? As long as you cannot, real and meaningful options are limited.

If these issues are not recognized and addressed, the need to study patient participation in treatment decision-making becomes somewhat superfluous. If important options that could maximize survival are not available in our health-care system, why study patient participation? In more and more cases, there is no real choice — defined as availability of evidence-based interventions — because resources, including nursing resources, are severely limited. In spite of this we create the illusion that there is a choice. Whether this illusion really helps people facing life-threatening illnesses to deal with their disease and treatment remains to be seen.

I recently had the opportunity to discuss with an American nursing colleague the struggle she went through when her son was diagnosed with Hodgkin's disease at the age of 20. First-line chemotherapy based on the most recent trial results was provided at one of the leading cancer centres in the United States, but the disease returned within 6 months. The boy then underwent "salvage" chemotherapy and a stem cell transplant, which was approved by her health insurance. She said the most difficult moment was when she and her son, who of course were reading the medical record to keep themselves informed, read that the transplant brought with it only a 5% chance of cure. But they reframed this terrifying statistic to think: why could he *not* be in the 5%? Luck and hope still play a very important role in the cancer wars. Five years later her son is alive and, more importantly, enjoying life, and she is immensely relieved and grateful. We have an illusion that we are "in control," but are we really? Ethics and decision-making at the individual level are becoming less relevant as targets of study, while the same topics at the system level are becoming increasingly relevant. The next generation of studies will need to tie these two solitudes together, so we can determine the extent to which policy decisions that expand or contract the real options available to patients impact their quality of life and survival.

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