

Decision Support and Participation in the Jefferson Pancreas Tumor Registry

A Jefferson multi-disciplinary research team recently assessed the effect of a novel decision support intervention on patient participation in the Jefferson Pancreas Tumor Registry (JPTR), a specialty cancer registry that was established in 2008 and is maintained by the Department of Surgery of Thomas Jefferson University Hospital (TJUH). JPTR recruitment involves providing eligible patients with print information about the registry, obtaining consent, and completing a baseline survey questionnaire that records personal and family background and selected medical history, lifestyle, occupational and environmental exposures. From February to December 2011, a total of 175 patients with pancreatic tumors who underwent resection at TJUH were invited to participate in the JPTR. During this period, about 25% of patients treated in the Department of Surgery at TJUH consented and completed the JPTR baseline survey questionnaire.

Specialty cancer registries provide important information that can be used to learn about disease etiology and discover new approaches to prevention and treatment. Recruitment to specialty registries has been challenging; and finding ways to maximize participation is an important problem in cancer research. The study described here was designed to assess the impact of the Decision Counseling Program® (DCP), a software program designed to aid in shared decision-making, on recruitment to the JPTR.

The DCP can be used by a trained health professional to help patients clarify personal values and preferences related to any health decision (e.g., whether or not to participate in a cancer registry). Using the DCP, a healthcare provider may meet with a patient, review important information about the specific health decision under consideration,

explore the pros and cons associated with available options, identify important factors that influence decision making, weigh the influence of relevant factors, clarify the patient's preferred option, and produce a 1-page summary of the session for use in shared decision-making.

The research team identified 51 patients who underwent surgical resection for pancreas cancer, had not registered for the JPTR and returned to the clinic for a 1-month post-operative follow-up visit. A trained health educator met with an Intervention Group comprised of 20 patients who consented to participate in the decision-making study. Information about the JPTR was reviewed and participants completed an interactive exercise using the DCP to clarify personal preference related to registration in the JPTR. A Control Group was retrospectively identified, which included a convenience sample of 20 patients who had not participated in the decision-making study. Both study groups were comparable with respect to demographic background and disease stage. At 90 days, patients in both groups were contacted to determine how many had completed the JPTR survey.

At the conclusion of the study, we found that JPTR participation was significantly higher in the Intervention Group than in the Control Group (55% vs. 10%, $p=0.01$). Frequency analyses of the decision counseling showed that the distribution of pro and con decision factors did not differ markedly between participants and nonparticipants (15 pros and 10 cons versus 12 pros and 10 cons, respectively). Closer inspection of patient decision factors, however, revealed that the magnitude of importance assigned to pro factors was

substantially greater among participants than nonparticipants.

The importance of benefiting others was mentioned more often as a primary factor in decision making among participants than nonparticipants. This finding highlights the role of altruism as a motivating force for registry participation. We also noted that while concerns related to the complexity and time involved for the registration process were cited by both participants and nonparticipants, these factors tended to be identified as secondary or tertiary factors in both groups. JPTR participants did not express concern about the confidentiality of registry information, but nonparticipants did have concerns. Both registry participants and nonparticipants identified feeling overwhelmed by the recovery process as a barrier to joining the JPTR. However, nonparticipants were more likely to identify this barrier as a primary decision factor.

Findings from the study reported here are consistent with the view that more proactive strategies are more likely to generate higher participation in tumor and cancer registries. We believe that efforts to increase participation in the JPTR, and perhaps other specialty registries, may benefit from efforts to provide decision support, minimize the burden of registration, address concerns about data confidentiality, and engage patients in the registration process at a time when they feel a greater sense of physical and emotional well-being.

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RESOURCES

1. Myers et al. Decision counseling and participation in a cancer registry. *J Registry Management*. 2014; 41 (4):196-200.
2. [Jefferson Pancreas Tumor Registry](#)
3. [Center for Health Decisions, Decision Counseling Program](#)