Medical Decision Making

Impact of decision aids in a sustained implementation at a breast care center

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A R T I C L E   I N F O

A B S T R A C T

Objective: We examined the reach and impact of five decision aids (DAs) routinely distributed to breast cancer patients as part of a shared decision making demonstration project.
Methods: From 2005 to 2008, we surveyed patients' change in knowledge and decisional conflict (DC) before and after their review of DAs. Using bivariate tests, we identified significant predictors of change in knowledge or decisional conflict and entered significant predictors into a multivariate regression model.
Results: We distributed 1553 DAs to 1098 patients and received 549 completed surveys. The DAs were associated with increased knowledge and decreased DC. For knowledge, significant predictors of above-average change included: lower baseline knowledge and viewing the surgery decision aid. For decisional conflict, significant predictors of above-average change included: higher decisional conflict; viewing any of the early-stage cancer DAs; and Hispanic ethnicity.
Conclusions: DAs used in routine care were associated with significant knowledge gains and reductions in decisional conflict. Some subsets of patients (those reporting low baseline knowledge, high DC, or Hispanic ethnicity) may benefit more than others.
Practice implications: Breast cancer patients benefit overall from routine distribution of DAs. Our exploratory findings may be useful in generating hypotheses to identify target populations who would most benefit from reviewing DAs.

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1. Introduction

Decision aids (DAs) are tailored educational materials aimed at patients making decisions for which there is inadequate or conflicting evidence, significant potential for harm, or where patients vary in their feelings about the timing, likelihood and value of treatment outcomes. DAs include background information on a disease or condition, probabilities associated with risks and benefits of treatment options, and they present materials intended to help patients clarify their goals or priorities. The Cochrane Collaboration systematic review of DAs for screening and treatment concludes that DAs are associated with reduced decisional conflict, improved knowledge, more realistic expectations and improved satisfaction in randomized controlled trials [1,2]. Systematic reviews of cancer-specific DAs echo the Cochrane overall findings [3–5]. Researchers – along with patients, consumer advocates, policy-makers, and payers – have called for translation of these efficacious interventions into practice, along with effectiveness studies to determine whether their benefits are maintained in pragmatic conditions [3,6].

However, there are few reports regarding the implementation of DAs in routine clinical care. Brackett et al. [7] reported on their efforts to optimize the routine distribution of a prostate cancer screening DA. Sepucha et al. reported on the Breast Cancer Initiative's efforts to distribute breast cancer DAs to non-academic hospitals and community health centers [8–10]. We have previously reported on process and implementation outcomes in an implementation of DAs at the UCSF Breast Care Center [11–13]. However, we have found no reports summarizing the impact of DAs in sustained, large-scale implementations.

The purpose of the present study is to address this gap in the literature by assessing whether DAs in everyday practice at our

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clinic were associated with the kinds of outcomes seen in earlier efficacy studies. As is customary with implementations, we sought to minimize the evaluation burden for patients. Therefore we focused on a subset of the outcomes previously measured in efficacy studies.

Specifically, we asked:

1. How many patients did we reach? What proportion of the eligible population?
2. What were the changes in knowledge and decisional conflict, overall and among patient subsets?
3. What subsets of patients benefited most from use of DAs?

Based on the results from our initial implementation [13] and the Cochrane systematic review [1], we hypothesized that the routine implementation of DAs would be associated with increased patient knowledge and reduced decisional conflict for our patients. We also sought to explore variations and generate hypotheses about predictors of these outcomes. We addressed our study questions by analyzing program records over a 36-month period.

2. Methods

2.1. Study design

This is a case series based on a review of program records, including pre/post survey responses. We obtained ethics approval from the UCSF Committee on Human Research to abstract and de-identify our program records for research analysis and reporting purposes.

2.2. Setting

The UCSF Breast Care Center (BCC) is a high volume clinic providing multidisciplinary care in an NCI-designated Comprehensive Cancer Center at the University of California, San Francisco. The BCC has integrated Decision Services into routine care to promote patient education, participation, and aid in decision-making. Decision Services makes use of a suite of five DAs created by the Foundation for Informed Medical Decision Making and routinely mails appropriate titles to newly diagnosed patients before their decision-making appointments with doctors at the BCC.

2.3. Population

Our sample was drawn from the population of new patients treated for breast cancer at the BCC. In 2008, the BCC served a total of 610 new patients, 64% of whom were White, 20% were Asian, 7% Hispanic, 5% African American, 2% were classified as missing race or ethnicity, or and 1% were classified as other. Virtually all patients were insured, the majority (68%) through private insurers, and the remainder through government or state programs. The average age at diagnosis was 55 with 67% diagnosed as Stage I or II, 18% diagnosed Stage 0 (Ductal Carcinoma In Situ), and 15% diagnosed Stage III or IV (metastatic).

2.4. Intervention—routine distribution of DAs in clinical care

The Foundation for Informed Medical Decision Making in collaboration with Health Dialog, has created five DAs designed to assist breast cancer patients at five different decision crossroads. As part of a demonstration project, the Foundation agreed to provide resources to implement and evaluate decision support at the BCC, including the five DAs. As a result of a needs assessment and evaluations showing very high levels of acceptability and satisfaction among our patients for the DAs [12,13], Decision Services oversees the distribution of the programs as part of routine care while measuring process and outcome data such as program distribution demographics, patient demographics, DA acceptability, and patient levels of decisional conflict and knowledge. Fig. 1 shows our schema for measurement and intervention, while Fig. 2 shows a graphical model of the relationship between and among our predictors and outcomes.

Decision Services field personnel contact new patients by telephone to offer decision support materials and services. These include DA materials; question listing, audio-recording and note-taking services; and referrals to other support services [11,14]. During this outreach call, program associates consult with the patient to determine if any of the DA titles might be applicable to their situation. If none of the programs are appropriate, patients are referred to the Cancer Resource Center, located in our hospital lobby, for help seeking additional resources. Sometimes patients will decline our offer to send DAs and we honor those requests. Our goal is to get the right DA to the right patient at the right time, usually before an upcoming specialist appointment. Once a program associate has requisitioned a DA for a patient, a Decision Services administrator mails it to the patient within 24 h.

Each DA includes a survey tailored to that program (see Appendix A). A cover letter instructs patients to begin the survey before reviewing the DA, and complete the second half of the survey subsequent to viewing. The packets contain postage paid envelopes for patients to use to return completed surveys and the DAs. Fig. 1 summarizes the overall design of the intervention and data collection points. Often patients will first be sent one set of DAs when making their surgical appointments and subsequently be sent additional titles such as Hormone Therapy and Chemotherapy when seeing a medical oncologist at a later date.

2.5. Outcomes, measures, instruments, and analysis plan

2.5.1. Study question 1: how many patients did we reach? What proportion of the eligible population?

Reach is defined as the absolute number, proportion, and representativeness of individuals who participate in a given initiative [15]. To calculate reach and proportion of the population we served, we compared the total number of patients sent DAs to the total number of new patients seen in the clinic. Because each visit could potentially require its own DA(s), we also counted the total number of DAs sent and compared this to the total number of new patient visits.
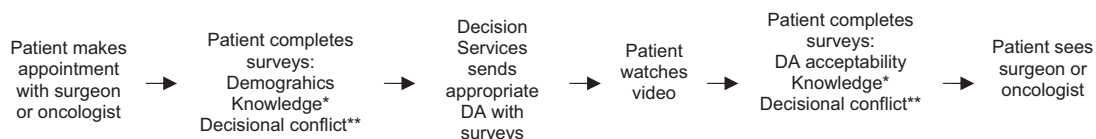

Fig. 1. Design, intervention and data collection flowchart. DA denotes decision aid. *Knowledge quizzes tailored to condition. No knowledge quiz for metastatic DA. **3 subscales O'Connor DCS.