Decision aids in routine practice: lessons from the breast cancer initiative

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Abstract

Background Many decision aids have been developed to help patients make treatment and screening decisions; however, little is known about implementing them into routine clinical practice.

Objective To assess the feasibility of implementing a patient decision aid (PtDA) for the early stage breast cancer surgical decision into routine clinical care.

Design Structured individual interviews.

Setting and participants A convenience sample of providers from nine sites, including two community resource centres, a community hospital and six academic centres.

Main outcome measures Usage data, barriers to and resources for implementing the PtDAs.

Results Six of the nine sites were using the PtDAs with patients. Two sites were primarily using a scheduling system and four sites relied on a lending system. For the academic centres, the keys to successful implementation included integrating the PtDA into the flow of patients through the centre and having physicians who recommended it to patients. At the community centres, the keys to successful implementation included an informed staff and the flexibility to get the PtDAs to patients in different ways. Barriers that limited or prevented sites from using the PtDA included a lack of clinical support, a lack of system support, competing priorities and scheduling problems.

Conclusions It is feasible to implement a breast cancer PtDA into routine clinical care at academic centres and community resource centres. Future research should assess the effectiveness of PtDAs in routine clinical care as well as resources and barriers to their implementation in community hospitals.

Introduction

Increasingly, doctors and patients face situations in which there is not one right answer, rather several different treatments may be reasonable.

In some of these cases, there is little evidence that any treatment works better than another. For example, there is fairly minimal evidence of the relative benefits of surgery or radiation therapy compared with watchful waiting for

early prostate cancer. In other cases, there is considerable evidence that treatments work, and are equivalent. For example, overall survival and distant disease-free survival are the same with mastectomy or breast conserving surgery for early stage breast cancer.^{1,2} These choices vary considerably in their morbidity and implications for quality of life, and, patients vary in their desire to accept or avoid the particular side-effects. Thus, a good decision requires making trade-offs based on an informed patient's preferences.

Shared decision-making (SDM) describes the joint process by which doctors and patients work together to make decisions. Encouraging patient involvement in decision-making is increasingly common in the cancer community as clinical practice guidelines and consensus statements explicitly recognize the need for decisions to be guided by patients' preferences.³⁻⁵ To support SDM, researchers have developed tools called patient decision aids (PtDAs). The tools provide information about the treatment choices, help patients clarify their values either implicitly or explicitly and may include support for communicating their values with the doctor.⁶ A high quality PtDA must satisfy strict criteria for development and evaluation, as outlined in an newly produced framework.⁷ For example, PtDAs should provide accurate information about the choices that is balanced and presented in an understandable manner.⁸⁻¹⁰

More than 500 PtDAs have been developed to help patients make choices about screening or treatment for many different conditions, including benign prostatic hyperplasia, heart disease, hormone replacement therapy and breast cancer and other cancers.¹¹ These PtDAs come in a variety of media including paper, audiotape, video, web-based, or a combination. For the most impact, patients need to use them before they have made a decision; often this means after a diagnosis but before they have seen the doctor to discuss definitive therapy. In 2003, a Cochrane Collaboration systematic review aggregated the results of 34 randomized-controlled trials (RCTs) of PtDAs; the results indicated that, in general, these tools increase: patients' knowledge

about therapeutic options and their potential benefits and harms; the agreement between patients' values and their actual choices; the likelihood of realistic expectations among patients; and active participation in decision-making about elective health-care choices. Decision aids have also been found to decrease patients' decisional conflict¹² and the proportion of patients who are undecided, as well as increase their satisfaction with the process of decision-making or the actual choice made.¹⁰ Thirty more RCTs of decision aids are known to be in progress.

Although the cumulative positive evidence about the effects of these PtDAs in the RCT context is very strong, there are relatively few reports addressing the strategies for and consequences of systematic attempts to introduce PtDAs into routine clinical practice.^{8,13} Several studies do report on the feasibility of using decision aids with patients. Generally, patients are very receptive to the materials, and typically materials do not add to the length of the clinical visit with the provider.^{14,15} Three studies surveyed clinicians about their attitudes towards using PtDAs; half the respondents reported that it would be easy to use them in their practice. However, none of the studies presented follow-up evidence to indicate whether the providers in fact used PtDAs.^{10,16,17} Aside from these studies, very little is known about the perspectives of the clinicians and clinic staff who would be most closely involved in actually using PtDAs in routine care.^{10,18,19} Even if a clinical site has indicated an interest in placing effective PtDAs in the hands of their patient populations and appears to have in place the resources that are necessary to make this happen, efforts to follow through could theoretically falter because of real or perceived barriers to implementation.^{6,8,13} However, little is known about how these resources and barriers are actually manifested in a longitudinal empirical study of the dissemination of a particular, disease-specific PtDA. The purpose of this descriptive study was to characterize the 'down-stream' patterns of use for a particular PtDA in motivated clinical sites, the perceived resources used by those sites, and the perceived barriers to PtDA use that were

encountered by clinicians and clinical staff. These insights, although specific to the particular PtDA involved, should have broader relevance for those interested in the implementation of patients' decision aids in general.

Methods

The Institutional Review Board at Massachusetts General Hospital approved all research activities (protocol No. 010364). The PtDA used in this study is a 50-min video- or DVD-based PtDA with accompanying booklet, entitled, 'Early Stage Breast Cancer: Choosing Your Surgery' (©Foundation for Informed Medical Decision Making and Health Dialog 2002).

The authors informed a convenience sample of providers and resource centres at 15 sites across the country about the availability of the programmes through letters and e-mail and offered up to 10 copies of the programme to each site. The sites included two community cancer resource centres, six community hospital/cancer centres and seven academic cancer centres. From January 2003 through August 2003, the authors disseminated a total of 98 PtDAs by mail to 20 providers at the 15 sites.

Assessing whether sites were using the PtDAs

Six to 12 months after the sites received the PtDA, the authors made at least two attempts to contact each provider by e-mail and invite him or her to participate in the study. We carried out structured interviews with all 13 of the providers who agreed to participate. When possible, we interviewed nurses and staff as well as doctors. Each provider was asked to give quantitative estimates of the number of patients who received the PtDA over the course of a year and of the total number of eligible patients seen annually at that site.

Assessing perceived barriers and resources

We focused on obtaining reports about the key resources that allowed sites to successfully implement the PtDA and about the barriers that prevented them from using it (see Appendix A

for a copy of the interview guide). Interviews were audiotaped and transcribed. Following the methods outlined by Miles and Hubermann,²⁰ the investigators coded one randomly selected interview based on a 'start list' of descriptive codes. The authors then revised the codes, creating four major categories that were designated *a priori*. The categories were: barriers (obstacles that prevented or limited use of the PtDAs), logistics (how patients were recruited and how the PtDA was delivered or administered), resources (available support for implementing the PtDA) and benefits (positive impact of the PtDA). See Appendix B for the list of category and subcategory codes. The data were divided into sentences or groups of sentences as units of analysis, coded and analysed for themes based on the frequency of codes and the content of the coded data.

Results

The investigators completed interviews with a total of 13 providers and staff at nine of the 15 sites that were contacted, yielding a site-response rate of 60%. The participating sites included two (of two) community resource centres, one (of seven) community hospital and six (of six) academic cancer centres. Table 1 summarizes the types of sites, the kinds of interviewees at each site and the quantitative estimates of usage. The proportion of eligible patients who had actually viewed the PtDA was used as an indicator for the site utilization rate. The last column identifies which of the two main practice models was used at each site.

Are the sites using the PtDAs?

Six of the nine sites were using the PtDA with patients and three were not. The procedures used to get the programmes to patients fit into two main practice models, a scheduling model and a lending model, based on providers' descriptions of the logistics of distributing the programmes. The scheduling model was structured and tightly integrated into the clinic process, with patients being 'scheduled' to view the

Table 1 Sites, interviewees, utilization rates and distribution models

Organization	Interviews	Annual estimate of patients who used PtDA	Eligible patients (%)	Distribution model
1. Academic Center with Resource Center	Director of Breast Center Director of Resource Room	150	80	Scheduling and lending
2. Academic Center	Director of Breast Center Registered Nurse	300	60	Scheduling
3. Academic Center with Resource Center	Co-directors of Resource Room	250	40	Lending
4. Academic Center with Resource Center	Director of Resource Room Resource Room staff member	25	5	Lending
5. Academic Center	Surgeon	0	0	None
6. Academic Center	Director of Decision Support	0	0	None
7. Community Hospital	Nurse Manager	0	0	None
8. Community Center	Director	12	80	Lending
9. Community Center	Director	40	80	Lending

programme at the clinic. The lending model was less structured and less integrated, with patients taking the programmes to home and returning them after a period of time.

What key resources allowed sites to implement the PtDA?

The investigators identified several themes that seemed to be critical for success from those sites that were implementing the PtDAs with a large percentage of patients. For the academic centres, the themes included integration into patient flow and having positive recommendations from the surgeons. For the community centres, it was critical to have the flexibility to get the PtDAs to patients in different ways and an informed staff to recommend them.

Theme 1: Integration into patient flow at academic centres

At the academic centres, the PtDA could be successfully implemented if it was integrated into the flow of patients through the system. Those sites that made the PtDA an automatic part of the patient care routine had the highest utilization rate. However, this was accomplished differently at each site.

At Academic Center 1, each patient was automatically scheduled to view the video when

she made her appointment with the surgeon. According to the director of the centre, this integration into patient care was the key piece.

'The challenge of making people aware that we have it and having them self-refer or having doctors refer them here is something we don't have to worry about because they're all automatically made aware of it. Which I would have to say is a much more effective way to get shared decision-making tools into people's hands than just letting people know it's here and hoping they'll come and watch it...' (Academic Center 1).

At Academic Center 2, the nurse practitioner called each eligible patient to have her appointment early to view the PtDA. A surgeon at Academic Center 2 explained the importance of making the video a part of the standard procedure:

'I think building it into an expected part of your consultation rather than an optional, an "if you want to do this at the end of your consult, there's some more information for you" or something like that ... is much more likely to get a high rate of patient acceptance.' (Academic Center 2).

At Academic Center 3, the PtDA was only a routine part of patient care for one of the surgeons. That surgeon asked patients to come in and pick up a copy before the visit and the vast majority did, but not all of the surgeons followed that practice.

Theme 2: Physician champion at academic centres

Physician champions of the PtDA played a key role in the successful implementation of the videos by familiarizing other physicians with them. At the first two academic centres, the champion was also the director of the centre and was able to encourage colleagues to adopt the PtDA. At Academic Center 1, the champion arranged for each of the surgeons at the centre to view the PtDAs, which made the doctors more comfortable recommending them. She said,

'I think because I have acted as a champion of the video, and our surgeons like the video, and our patients like the video, that it's been pretty easy to implement routine offering of the video to our patients.' (Academic Center 1).

At Academic Center 2, a surgeon at the centre advised others who were interested in using the PtDAs that the key was to:

'make the physicians that they work with aware of the video and also have them view it as well so that they understand the importance and the significance of having patients view it.' (Academic Center 2).

A smaller proportion of patients used the PtDA at Academic Center 4 because none of the clinicians was recommending it. Only those patients who happened to find the video in the resource room watched it.

Theme 3: Flexibility at community centres

Having the flexibility of several methods of getting the PtDAs to patients was important at the community centres. The community resource centres that had the needed equipment (TV and VCR) and space to view the videos were able to offer PtDAs either onsite and/or to take home, making it easier for more patients to use them. At Community Center 2, there were several ways that patients or their families could obtain the PtDA:

'We watch the video in the office with them and talk with them about it. Then we give them the video and booklet to take home if they're in the process of making the decision, especially if they're confused. Sometimes we mail the video out because there are relatives or friends from out of town who are concerned.' (Community Center 2).

Theme 4: Informed staff at community centres

Providers at both community resource centres remarked that it was important for their staff members to be aware of and familiar with the PtDAs so that they could recommend them to patients. At both centres, the staff had viewed the PtDA, valued its content and actively identified eligible patients. The directors reported that having a knowledgeable staff was key to getting the PtDA to patients in the right window of time, because it was one of a number of resources that were offered and most patients do not come in asking for decision support. Similarly, at a resource centre within one of the academic centres, the directors commented that if more of their staff were aware of the content of the PtDAs, they would be more likely to suggest them and patient usage would increase. However, the staff members served the entire cancer centre so it was difficult to familiarize them with all of the material in the centre.

What barriers interfered with PtDA use?

Several themes emerged from these discussions regarding common barriers that prevented the PtDAs from being used or kept them from being used widely. These included a lack of clinical support for the PtDAs, a lack of system support for integration, competing priorities for information or decision support, scheduling problems and a lack of resources.

Theme 1: Lack of clinical support

Physicians could be barriers to the implementation of the videos if they did not refer their patients to the video, either because they did not know about the video, had not seen it, or considered it optional. Providers from two of the three sites that were not using the video and two of the six sites that were using the video mentioned this as a problem.

At Academic Center 2, only about half of the eligible patients viewed the PtDA, partly because some of the surgeons considered it optional:

'I think the other physicians are sometimes a little bit more optional about watching it than I am. So their percentage who watch it probably isn't quite that high.' (Academic Center 2).

At the community hospital where the PtDA was not being used, the nurse manager said that she would need to get a buy-in from the doctors before she could use it.

Theme 2: Lack of system support

Whether a scheduling model or a lending model was used, it was essential to have an established system of getting the PtDA to patients. Providers at all of the sites that were not using the PtDA raised concerns about the logistics of implementing it, including identifying eligible patients consistently, scheduling them to watch the PtDA, and monitoring a lending system.

'We also want to pay attention to where we keep them, who gives them out, keep track of getting them back ... So how do you really implement from a purely logistical standpoint when you have a scarce resource like five videotapes around how do you make sure you keep them circulating so people really use them.' (Academic Center 6).

Theme 3: Competing priorities

The PtDA was one of many resources for patients at each of the sites and at a few sites this became a barrier. For example, at Academic Center 2 the staff was concerned about overwhelming patients with too much material before the appointment. At Academic Center 5, other videos were being used with newly diagnosed patients instead of the PtDA. Academic Center 6 had a coaching service for all patients facing a decision point that the director thought worked well for patients. Providers also had other needs for improving patient care that could be more pressing:

'Patients get through the process and they feel very well supported at the breast care center here. Frankly, what patients really complain about here is not the decision support or anything it's the follow-through and the logistical stuff like the schedule's always running late, things drop through the cracks in terms of, "Where are my films, where are my test results?"...' (Academic Center 6).

Theme 4: Scheduling problems

Patients need about an hour to view the programme and they need to view it at the right time, after diagnosis and before they choose what type of surgery to have. At Academic Center 2, many patients did not get to see the video because of time constraints:

'... we end up having so many people who are having their imaging before their appointment too that they get held up in imaging and by the time they finally get over here they need to be with the physician so they don't watch the video.' (Academic Center 2).

Getting the PtDA to patients during the time period when it would be beneficial was also an issue.

'The single biggest barrier is getting the video or the program to the patient in a timeframe so that the information can be used as part of the consultation process ...' (Academic Center 5).

Theme 5: Lack of resources

The lack of adequate space to view the PtDAs also caused problems with scheduling. Two of the sites mentioned a lack of space as a barrier.

'we have two rooms that have VCRs ... [and] we have psychologists, we have nutritionists, and we have physicians who use those rooms for consultations with patients.' (Academic Center 2).

How would providers use unlimited resources?

During the interview, we also asked participants to describe what they would do to improve decision support services if they had unlimited resources. Responses to this question helped to clarify some of the barriers and associated resources using the PtDA. For example, two providers said that they would use the resources to set up a scheduling system for the PtDAs and four providers said that they would like to be able to give the videos away to patients. Other responses provided ideas for future directions for SDM. Several providers suggested technological improvements that would make the PtDA more accessible and convenient for patients, including using a

CD-ROM or web format and making the program interactive. Suggestions also included for classes to teach decision-making in schools, physician reimbursement for SDM and a patient hotline.

Discussion

The investigators conducted this study to fill in a gap in the literature about implementing PtDAs into routine clinical practice. Although many PtDAs have been evaluated in RCTs, very little information is available for providers about how to use them successfully in everyday practice. The results of this study show that it can be feasible to use this breast cancer PtDA in routine patient care with either a scheduling or a lending model. The majority (six of nine) of the sites were using the programmes and most of those (five of six) were reaching a significant portion of eligible patients. Over the course of a year, approximately 800 patients viewed the breast cancer PtDA at these sites. The authors were surprised by the ease with which the PtDAs were used and the extent of penetration to eligible patients at these five sites.

Models of delivery

Each of the sites relied on either a scheduling or a lending model of delivery and providers at each site were fairly vocal about their preference for their dominant model. At the scheduling sites, providers focused on the benefits of being able to make sure patients viewed the PtDA and having clinical staff available to debrief patients. Those who employed the lending model focused on the benefits for patients of being able to watch the PtDA in the comfort of their own home, at their own pace, and being able to share it with family and friends. It is not clear whether one model is more effective than the other, although the limited data collected here suggest that the scheduling model may result in higher utilization rates. This is an area for future research in the dissemination of PtDAs.

Perceived resources

For some sites, it is clearly feasible for providers to integrate a decision aid into routine clinical care. At the academic medical centres, this was more likely to happen when there was a clinical champion (ideally the director of the breast center) and when the PtDA was automatically integrated into patient flow. At the community resource centres, this was likely to happen when there was some flexibility in the means of delivering the PtDA (on site, lending and mail) and an informed staff.

Perceived barriers

Not surprisingly, a few centres had difficulty getting the PtDAs to patients reliably, and three did not use them at all. The main barriers included lack of clinical support, lack of system support, competing priorities for patient education and support, and scheduling problems. Even though three of these sites had a clinical champion, this was not enough to overcome some of the other barriers to using the PtDAs. Logistical issues were also reported as a perceived barrier by some participants in a previous study of doctor attitudes towards three decision aids.¹⁷ The top two barriers reported by doctors in that study were the cost of the decision aids and that they would be too time-consuming to use. In our study, the PtDAs were free, so cost was not a barrier and none of the sites remarked on the time. Each of the three sites that were not using the PtDAs expressed great interest in integrating them in the future. The investigators plan to follow-up to document strategies that may overcome these barriers.

Limitations and strengths of the study

These results need to be interpreted with some caution, as there are several limitations with this small study. The reporting sample of sites was heavily loaded with academic medical centres. Despite repeated attempts, we were only able to speak with one of seven community hospitals that received the PtDAs. Issues at these centres

may be very different than at academic medical centres or community resource centres. This represents an important gap in our understanding of the implementation of these PtDAs. As a result, the authors have launched a separate project targeting community hospitals. To date, 20 additional community hospitals have received the PtDAs and have agreed to share their experiences. A separate study will explore resources for and barriers to implementation in community settings.

Further, there are several characteristics of breast cancer that may not extend to other conditions and patient populations. The 1990 NIH Consensus guidelines as well as almost every other set of guidelines for surgical treatment of breast cancer have emphasized the importance of patient preference in determining optimal treatment. In other medical situations, there may not be as great a consensus about the importance of patient preferences in the choice of treatment. This may limit physician support of decision aids. In addition, women with breast cancer are a motivated, information-seeking patient population. Other patient populations might not be as receptive to participation in decision-making or to PtDAs.

The main strength of the study is that it was based on feedback about resources and barriers from providers' experiences trying to implement a specific PtDA. Providers' responses reflect their actual experiences instead of their expectations or perceptions about using a hypothetical programme. As the PtDAs were not being implemented as part of a research study, the results are more relevant for providers who are interested in using the programmes in everyday clinical practice.

Implications for theory and future research

To date the development and evaluation of decision aids has followed a medical model, which separates research and practice. In medicine, most interventions must first be developed and then validated through randomized-controlled clinical trials. It is not until efficacy has been demonstrated that issues of implementa-

tion are addressed, and often, the issues of implementation are left completely up to the practitioners. It can be problematic to leave issues of implementation until after clinical trials have demonstrated a benefit, especially for interventions such as decision aids, which aim to change patient and doctor behaviours. A framework described by Ruland and Bakken²¹ highlights the importance of addressing implementation issues in the design of the system. They suggest assessing resource requirements, feasibility, acceptability and organizational issues as part of the design process for PtDAs. They also²¹ identified several possible barriers to implementation, including the organization's attitudes towards innovations, the degree to which established routines have to be modified and a lack of leadership support.

Despite the availability of decision aids, they are not widely used. This suggests the need for more research to bridge the gap between the field of researchers developing and evaluating decision aids and the practitioners and staff who will distribute the aids. This study provided important evidence that these tools can be integrated with varying effort into the clinical process of care. However, there are several questions that still remain. For example, how effective are decision aids in routine practice? What is the impact of different methods of delivery on the quality of decisions? As decision aids become more widely used, many important lessons will be learned from the implementation experiences and these lessons will be invaluable in shaping the design of the next generation of decision aids.

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Appendix A Interview guide

Interview Code # _____

Title:

Credentials MD RN LCSW Other _____

Are you currently using the video with patients?

If not using video, are you currently using/supporting shared decision making with patients?

If no, what's preventing you (biggest barriers)?

If yes, how?

What would need to happen to make it attractive/feasible to use the video?

What are the biggest challenges implementing the video?

If using video, describe typical process (identify patients, get video, consultation, return video)

How do you recruit patients?

How many patients/month (How many eligible per month?)

Are you formally measuring decision quality or patient satisfaction with decisions?

If so, how? What data to you collect? Do you have IRB consent? Can we use/cite/analyze your data?

If not, do you have a general impression of patient's reactions to the videos? Physicians? Nurses?

Would you be willing to pilot some measures that we have developed?

Do you/your organization provide any other decision support services (coaching, education, etc.)?

What are some of the biggest benefits of the video?

What are your current plans for using the video in the next year?

If you had unlimited resources, how would you envision decision support services?

What advice do you have for others interested in using the video?

Any other comments?

Appendix B Codes

Category	Code	Description
Barriers	BAR-RES	Lack of PtDAs, money, staff
	BAR-MD	Doctors' style, training, skills, acceptance, motivation
	BAR-LOG	Logistics for viewing PtDAs in clinic, identifying and/or scheduling patients
	BAR-OTHER	Other reasons why PtDAs are not used or are only used on a limited basis
Resources	RES-MD	Doctor support for implementing the videos
	RES-LOG	Staff and ability to integrate the video into the clinic
	RES-OV	Other resources that support implementation of the video
	RES-OTHER	Other resource or services for decision support
	RES-WANT	The resources that providers would choose if they had unlimited resources to support decision-making in general
Logistics	LOG-VR	How the clinic recruits patients to watch the video
	LOG-VD	How the clinic actually delivers or administers the video
	LOG-OR	How the clinic recruits patients for other decision support services
	LOG-OD	How the clinic actually delivers or administers other decision support services
Benefits	BEN-VP	Benefits of using the video for patients
	BEN-VMD	Benefits of using the video for providers and clinics
	BEN-O	Benefits of other decision support services