Implementing breast cancer decision aids in community sites: barriers and resources

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Abstract

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Accepted for publication

3 October 2007

Keywords: clinical care, community, decision aids, early stage breast cancer, feasibility, implementation

Objective To assess the feasibility of implementing four patient decision aids (PtDAs) for early stage breast cancer treatment decisions into routine clinical care in community settings.

Background There is very limited information available about implementing decision aids into routine clinical practice and most of this information is based on academic centres; more information is needed about implementing them into routine clinical practice in community settings.

Design Structured individual interviews.

Setting and participants Providers from 12 sites, including nine community hospitals, a community oncology centre and two academic centres.

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

Results Nine of the 12 sites were using the PtDAs with patients. All of the sites were lending the PtDAs to patients, usually without a formal sign-out system. The keys to successful implementation included nurses' and social workers' interest in distributing the PtDAs and the success of the lending model. Barriers that limited or prevented sites from using the PtDA included a lack of physician support, a lack of an organized system for distributing the PtDAs and nurses' perceptions about patients' attitude towards participation in decision making.

Conclusions It is feasible to implement PtDAs for early stage breast cancer into routine clinical care in community settings, even with few resources available.

Introduction

Mastectomy or lumpectomy? Chemotherapy before surgery or after surgery? Reconstruction with a flap of your own tissue or implants? A

diagnosis of breast cancer brings about multiple-decision situations in which there is not one right answer. Rather, patients and their doctors must sort through the medical evidence and figure out which choice will work best for each patient.

Shared decision making refers to a collaborative decision-making process in which the doctor and patient share information and values in order to make an informed choice, that is based on the patient's values.¹⁻⁵

Patient decision aids (PtDAs) inform patients about treatment or screening options, help elicit patient's values and encourage patients to be involved in their medical decisions.⁵ Over 500 PtDAs have been produced in a variety of formats, including video, DVD, audio, paper and web-based tools. These PtDAs cover a range of medical conditions such as benign prostatic hyperplasia, breast cancer, prostate cancer and heart disease. A systematic review of randomized controlled trials of PtDAs show that they increase patient knowledge of treatment options, satisfaction with decision making and realistic expectations and decrease decision conflict.^{6,7}

There is mounting evidence for efficacy of PtDAs in clinical trials, however, less is known about their effectiveness. Three studies, one in the UK and two in the US, have explored the use of PtDAs in routine care and reported mixed results. Stapleton *et al.* studied the implementation of 10 *Informed Choice* leaflets to five maternity units in the United Kingdom.⁸ About 75% of women reported receiving the leaflets, however, few leaflets were actually reviewed by patients and the dissemination did not make a measurable impact on perceptions of informed choice.⁹ In this study, many providers disagreed with the content, which both prevented the leaflets' dissemination and muted their potential effect. Holmes-Rovner *et al.* evaluated the implementation of two PtDAs, (for heart disease and breast cancer) at three hospitals. Each site had strong physician buy-in; however, only 24 patients were referred from 34 providers over 7 months (about 15% of eligible patients). The lack of time for patient education (with surgery and procedures being scheduled quickly) seemed to be a major barrier to wider use.¹⁰ A third study, by two of the authors, Silvia and Sepucha examined the use of a breast cancer PtDA in nine sites across the country.¹¹ Six

sites were using them with patients, and on average the sites reached about 50% of eligible patients. The sites not using the programs were still interested in trying, but needed to overcome many of the same barriers highlighted in the prior two studies, such as lack of time, lack of integration into clinic process and lack of staff resources.

The majority of successful sites in the Silvia study were academic medical centres. As PtDAs have been developed and tested in the academic setting in the US, it is not surprising that they may be better suited for use there. However, the majority of breast cancer care is delivered in community settings in the US.¹² Thus, it is important to understand how the implementation of PtDAs may differ in non-academic settings. The purpose of this study is to learn about current resources and barriers to implementing breast cancer PtDAs into routine clinical practice in community settings.

Methods

This study was approved by the Institutional Review Board of Massachusetts General Hospital (protocol #010364). The PtDAs used in this study were four video or DVD-based breast cancer shared decision-making programs entitled 'Early Stage Breast Cancer: Choosing Your Surgery', 'Early Breast Cancer: Hormone Therapy and Chemotherapy – Are They Right For You?', 'Breast Reconstruction: Is It Right For You?' and 'Ductal Carcinoma *In Situ*: Choosing Your Treatment' (© Foundation for Informed Medical Decision Making and Health Dialog). In the summer of 2004, the authors identified 50 breast care centres and hospitals in MA (see Fig. 1). One author contacted all sites by phone and attempted to identify the person responsible for education for breast cancer patients. Seven sites did not respond and six did not interact with women who were making decisions (most of these provided mammography screening services only). The remaining centres were offered the four decision aids. Thirty-four of these centres were interested, and asked for the PtDAs to be mailed to their centres. Follow-up phone calls

Figure 1 Responses to the invitation to use decision aids.

were made to determine interest in using the programs and desire to receive additional copies of the programs for use with patients. In the fall of 2005, the authors contacted the providers at the 23 sites who had expressed an interest in using the PtDAs to invite them to participate in this study. Each provider was contacted at least twice by e-mail and/or by phone. The authors conducted semi-structured interviews with all participants.

The interviews focused on the experiences using the PtDAs, the resources that enabled providers to successfully implement the PtDAs and the barriers that prevented or limited their use. The closed questions from the interviews were summarized with frequencies, e.g. to provide estimates of usage. The authors audio-taped and transcribed the interviews, and analysed the open-ended questions following the methods described in Miles and Huberman.¹³ All three authors coded one randomly selected interview using the codes that were designated *a priori*. These codes included four major categories: barriers (obstacles that prevented or limited use of the PtDAs), logistics (how patients were recruited and how the PtDAs were delivered or administered), resources (available support for

implementing the PtDAs) and benefits (positive impact of the PtDAs). Using the calculations outlined by Green,¹⁴ agreement between the three authors for the 18 codes was very high ($\kappa = 0.96$). Based on this interview, we revised and added to the subcategory codes. Two of the three authors coded each of the remaining 11 interviews.

Results

The authors conducted interviews with providers from 12 of the 23 sites that were contacted (52% response rate). The sites had been using the programs for an average of 11.23 months (range 6–14 months). The sites included two academic medical centres, nine community hospitals and one community oncology centre. Table 1 describes the types of sites, the providers interviewed and the estimated patient PtDA usage at each site.

Most of the sites were using the PtDAs

Nine of the 12 sites were using the PtDAs with patients. All of the sites were lending them to patients to watch at home. Four sites also offered patients the option of viewing the PtDA in the clinic, but reported that most patients preferred to take it home with them. On average, sites were reaching 39% (range < 1–100%) of the eligible patients.

Two of the three sites that were not using the PtDAs planned to use them. At the Community Oncology Centre, the patients coming for treatment had already made their decisions, and the provider gave the PtDAs to a referring surgeon's office.

What key resources allowed sites to implement the PtDAs?

Two themes came up as we analysed the transcripts of those who were successfully getting the PtDAs to patients. These resources were nurse and/or social worker interest and success of the lending model (in other words, patients returned the programs in timely manner).

Table 1 Description of sites, usage and distribution models

Organization	Interviews	Monthly estimate of patients who used PtDA	Eligible patients (%)	Distribution model
Community Hospital 1	Nurse	1–2	100	Lending
Community Hospital 2	Nurse manager	1	50–100	Lending
Community Hospital 3	Breast care co-ordinator	4	40	Lending
Academic Centre 1	Nurse practitioner in breast centre	7	35	Lending or viewing
Academic Centre 2	Nurse co-ordinator of breast health centre	2	30	Lending or viewing
Community Hospital 4	Program administrator for cancer services	5–10	20–40	Lending/ viewing in different locations
Community Hospital 5	Co-ordinator of the breast Centre	2–4	14–31	Lending or viewing
Community Hospital 6	Nurse in outpatient oncology clinic	1	17	Lending
Community Hospital 7	Director of oncology, social work, and community outreach	0–1	< 1	Lending
Community Oncology Centre	Social worker	N/A	0	None
Community Hospital 8	Nurse in oncology department	0	0	None, but will probably lend.
Community Hospital 9	Oncology outreach co-ordinator	N/A	0	None

N/A: not applicable

Theme 1: Nurse or social worker acceptance

The authors mainly worked through the nurses, social workers and/or patient educators at each of the sites. They were the ones initially contacted, who reviewed the materials and for most sites, the ones who decided whether it would work for their patients. Their enthusiasm and acceptance of the programs was critical for implementation:

I think they're wonderful. I think they were done in an easy-to-understand manner. And I liked how you had both views. You know, you had the person that wanted this, the person that wanted that – and it's good because it's not biased. (Community Hospital 8)

Although the nurses informed the physicians and in some cases, tried to get the physicians to review the programs, they often had control over the educational material given to patients:

I don't think the surgeons actually watched them to be quite honest. I had said I thought they were good, is it okay if we start using them and they were like 'Yup!' They kind of leave those kind of judgments up to me... (Academic Centre 2)

The positive patient feedback to the programs also encouraged and motivated the providers to offer the programs. The nurse at Community Hospital 3 said,

The patients love them. They keep telling me how wonderful the videos are. (Community Hospital 3)

Theme 2: Success of lending model

One of the constraints of the project was that sites could only receive up to 10 copies of a program. That necessitated a lending type model that all nine sites employed. Two of the sites had a formal sign-out system in place, but the other seven sites did not have an organized lending system. Several providers mentioned that they expected PtDA returns to be a problem. However, none of the providers reported that this actually was a problem, and four sites specifically mentioned that they did not have any trouble getting PtDAs back from patients. More patients received the programs when the nurses were involved in

recommending or distributing them, compared to programs that were simply placed in a patient library for patients to find.

What barriers limited or prevented use?

The authors identified several common themes from the interviews that seemed to limit or prevent the use of the PtDAs with patients. One common barrier was a lack of support from physicians. Not having an organized system for distributing the PtDAs, also limited or prevented their use and patient attitudes about their diagnosis and treatment were barriers at some sites.

Theme 3: Lack of physician awareness and support

At seven of the nine sites that were using the PtDAs, the physicians had not viewed the program. This became problematic at two sites because the physicians wanted to approve the material before distributing it, but then could not find the time to watch them:

getting the doctors comfortable giving out the tapes from their office means they have to support what's in them, right? So they should review them and be comfortable with whatever message is being passed on to their patients. But getting them to look at them – that has really been a very hard thing for me. (Community Hospital 4)

At other sites, the physicians were more ambivalent about watching them. Providers from three sites said that physicians were too busy and usually forgot to refer patients to the PtDAs. Physicians did not play a significant role in distributing the programs at any site. The provider at Community Hospital 4 described how she believed this had influenced patient usage of the PtDAs:

I was surprised that one of the surgeons didn't want to have this in her office but would rather just direct people to the library. Because my fear is that she's probably not directing people, she thinks it's a great idea. But it showed me that some of the doctors feel overwhelmed by all the stuff they have to do and probably all the paperwork they have to do and really didn't want their office taking on any more stuff, including these tapes. (Community Hospital 4)

Theme 4: No organized system of distributing the videos

Most of the sites did not have an organized, consistent way of getting the PtDAs to eligible patients. Only one site (Community Hospital 3) had a staff member who met with each patient to provide educational materials and to help the patient navigate through the different aspects of treatment. At the other sites, many eligible patients were never offered the PtDAs. For example, at Community Hospital 6, the nurse only met with patients who were eligible for clinical trials. Of the patients that she met, she offered a PtDA to those who were eligible, whenever she remembered. She said:

So it's more like having time to set it up in the first place, having a way of distributing. Because I think if we had a way of having a nurse distributing the video it would be happening. But it's not formalized. So I think it's a matter of getting everyone in a meeting room at the same time and getting them to make a decision that's proving very difficult. (Community Hospital 6)

Providers explained that they were overloaded already and did not have the time to set up an organized system for disseminating the PtDAs to patients.

Theme 5: Patient readiness and attitude for participation

Seven of the providers mentioned sensitivity to individual patient's attitudes. They reported that some of their patients are too overwhelmed to take in information about their treatment, and some of their patients preferred not to know about their options, relying instead on their doctors' judgment. As the provider at Community Hospital 7 explained,

I just sometimes believe that there are certain patients and families that only want to talk to the doctor. They don't want to hear anymore, they're on overload; they just want somebody to make the decision for them. And for that type of person, those videos might be overwhelming. But I don't think that should stop us from doing what we're doing. (Community Hospital 7)

At two (Community Hospital 2 and Academic Centre 1) of the nine sites, the providers did not

offer the PtDA to patients who seemed too overwhelmed or who did not want to be involved in decisions about their treatment. Two other sites (Community Hospital 3 and Community Hospital 6) mentioned that their elderly patients often preferred not to be involved in their treatment decisions. When patients did not want the PtDAs, providers from those sites said that they offered them to family members instead.

Ideas for improving decisions

The authors asked each provider what they would do with unlimited resources to improve decision making. Three of the sites said that they would like to have a multi-disciplinary team of providers working with patients to integrate patient care. Providers at three sites wanted a point person, or navigator, who would meet with each patient, provide education and coordinate cancer care and be in charge of distributing these programs. The sites also mentioned other resources, such as more time to spend with each patient, expanded patient libraries, the ability to provide more treatment options (such as radiation) on-site, and the ability to offer more complementary therapies.

Discussion

Current research concerning implementation of PtDAs in clinical practice is limited. Four studies have been identified^{8–11} that address this issue, and although they begin to fill this gap, much remains unknown about the implementation of PtDAs in routine clinical practice. The Picker Institute in Oxford, UK has undergone practice improvement projects focused on implementing PtDAs in the area of prostate cancer and benign prostatic hyperplasia.¹⁵ This year long project found that the decision aids could be implemented successfully despite initial doubts of the staff and indicated that training of the staff involved and a strong local leadership were critical to success. Together, this body of work suggests that there is growing interest in

the use and implementation of decision aids in clinical practice, yet much remains to be learned in this area.

The current study investigates the implementation of PtDAs in routine care beyond the academic medical centre setting, specifically targeting community hospitals. Although the overall response rate for this study was not high, the majority of the sites interviewed were using the PtDAs in routine care, whereas only a few of the sites interviewed (three of 12) had not yet been able to establish use of the PtDAs. However, the per cent of eligible patients who used the PtDAs at these sites ranged from <1 to 100%, suggesting implementation was extremely successful at some sites, while it was limited at others. Only two sites were able to facilitate usage by 50% or more of the eligible patients, whereas five sites achieved between 25 and 50% usage by eligible patients, and two sites were able to reach only <1–2% of eligible patients. The approximate percentage of eligible patients who received the PtDA in this study was similar yet lower than that in the previous study involving an earlier version of one of the same PtDAs, 'early stage breast cancer: choosing your surgery' (© Foundation for Informed Medical Decision Making and Health Dialog).¹¹ In this study, an average of 58% of eligible patients viewed a PtDA across the six sites that were using the PtDAs as compared to 39% in the current study. Although the success in reaching all eligible patients was quite varied across the study sites, these results suggest it is feasible to successfully implement PtDAs in the community setting as well as the academic setting.

Each of the sites implementing the PtDAs used a lending model of distribution and surprisingly, very few of the sites (two of nine) relied on a sign-out system when using a lending system for the PtDAs. None of the sites interviewed stated that return of the PtDAs when using the lending model was a problem, implying an honour code method of lending seemed to be equally effective as a formal sign-out system. This is an encouraging finding for those centres that are interested but may not have significant resources to dedicate to support PtDA implementation.

Successful implementation of the PtDAs at the study sites appeared to be facilitated by success of these lending models, and the level of commitment or engagement of both the clinic staff responsible for implementation. In settings that had a designated staff person, either a nurse, social worker, patient educator, or clinic co-ordinator, who was responsible for outreach to eligible patients, implementation of the PtDAs appears to be higher than settings that do not have these types of dedicated resources. This was further evidenced by the results low usage rates (<1% of eligible patients) at Community Hospital 7 that relied on the hospital library for distribution for the videos.

The most common barrier across the study sites was lack of physician support. This result is consistent with the all four of the previous studies of implementation of PtDAs into routine clinical care.⁸⁻¹¹ The implementation strategy used in this study was effective at engaging nurses and social workers, other approaches that may engage doctors more effectively should be explored and compared. The fact that providers had trouble finding the time to set up an organized system of distributing the PtDAs was also consistent with the time constraints that were reported in other studies.^{9,10} A barrier reported by the current study that was not reported in the previous studies was nurses' sensitivity to patients' interest in or inclination for participation. In seven of 12 sites, providers did not give programs to patients who were overwhelmed or reluctant to be involved in the decision-making process. Age might partially explain this result. About 33% of patients were older than 60 in these study sites, whereas only about 20% were older than 60 in the sites in the previous Silvia study. There were no other apparent differences in demographics (race/ethnicity, stage at diagnosis, possession of medical insurance) across sites. Multiple studies have shown that younger cancer patients are more likely to prefer a more active or collaborative role in decision making, whereas older patients are more likely to prefer a more passive role.¹⁶⁻²⁰

Overall, about 20% (9/44) of the eligible sites actually implemented the intervention. Although

a minority of sites did implement the programs, simply providing the intervention for free is not enough for widespread dissemination of decision aids. In particular, the small number of interested providers who actually used the programs strongly suggested a need for better strategies, tools and methods to help interested providers successfully implement the programs.

The generalizability of the results of this study is limited for several reasons. Firstly, we were only able to interview providers from 12 of the 23 sites that had received the PtDAs. It is likely that providers who did not agree to be interviewed were having more difficulty implementing the PtDAs or faced different types of barriers. Secondly, we did not have any data from patients about the effectiveness of the decision aids and whether they had an impact on the quality of decisions. Finally, all of the sites in this study were located in MA. Resources for and barriers to implementing PtDAs may be different in other regions of the United States or other parts of the world.

Despite these potential limitations of this study, it can be inferred that PtDA usage can be successfully implemented in routine clinical care in the community hospital setting. Although the number of breast cancer patients seen at a community hospital is often less than at an academic medical centre, this study demonstrates that these settings can still use PtDAs and benefit from them. Patient usage of the PtDAs is likely to be higher when a physician champion is actively involved in recommending or distributing the PtDAs and when an organized system of distributing the PtDAs is established. Although the absence of these two factors may be barriers of PtDAs implementation, it does not appear to prevent the use of PtDAs entirely. In fact, this study suggests that it is possible for nurses, social workers, and co-ordinators of cancer care to successfully facilitate access to PtDAs as a part of routine clinical care with very little physician or organizational support. This study begins to shed light on the potential use of PtDAs in the community setting, however, much research is still needed. In particular, research that identifies effective strategies to engage

doctors in addition to nurses and social workers, research that focuses on the development of tools or methods to help interested providers actually use the programs, as well as tools or methods to help increase the percentage of eligible patients reached by the programs, and finally, research to evaluate the impact that the PtDAs in routine care have on patients' decisions.

Acknowledgements

The project was funded by the Foundation for Informed Medical Decision Making, a not-for-profit organization dedicated to improving the quality of medical decisions through developing and disseminating decision support tools and methods. The four PtDAs disseminated to the sites were produced by the Foundation for Informed Medical Decision Making.

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