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Patient factors in the implementation of decision aids in general practice: a qualitative study

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Abstract

Background Decision aids (DAs) have been developed to help patients make treatment decisions. Research shows that they are effective in increasing patients' knowledge of treatment options without raising anxiety or conflict. However, they have not been routinely adopted for use in general practice in the UK and there are few reports addressing strategies to introduce them.

Objective To examine patients' views about a variety of DAs for different conditions (heart disease, osteoporosis, osteoarthritis and breast cancer) in order to inform a strategy to introduce them into general practice.

Setting and participants General practice patients over the age of 18 years being or having been treated for one of the conditions above.

Methods Qualitative study involving 12 focus groups with 77 patients evaluating decision aids relevant to their conditions. A semi-structured interview guide was used to generate discussions about the applicability of the DAs in routine general practice.

Results Patients welcomed DAs for their educational and informational content. Reactions to the DAs were influenced by patients' own personal desires for involvement. The main concerns were that the use of DAs would potentially shift the onus of decision making responsibility on to the patient and about the practical challenges to implementation.

Conclusions Clinicians will need to make explicit to patients that DAs are an adjunct to routine care and not a replacement, and therefore do not represent a derogation of responsibility. DAs need to be used as an integral part of the communication and support process for patients who want them.

Introduction

Patient decision aids are interventions designed to help those people facing treatment or screening decisions make choices by providing information on the management options available and the possible health outcomes.[1–3] They may also provide support for communicating the patient's values to clinicians.[4] They come in many formats including booklets, audio and videotapes, interactive computer programs and websites. Decision aids differ from other patient education because they make choices explicit and use the best available evidence to quantify risks and benefits of treatment options. Some decision aids are interactive enabling patients to

clarify their values in relation to the decisions to be made.[5]

A large body of research has shown that decision aids increase patients' knowledge of available management choices and their risks and benefits. They help patients make decisions that are more consistent with their own attitudes towards benefits and risks, without increasing anxiety or decisional conflict. Those decisions tend to be consistent with available scientific evidence and lead to a more informed discourse with their clinicians.[3,6–14] Decision aids are feasible for use in practice and do not necessarily add to the length of consultations.[15–18]

Despite their efficacy, however, decision aids have not been routinely adopted for use in general practice in the UK. Understanding the constraints is a pre-requisite to the effective introduction of decision aids in UK primary care.

There are relatively few reports addressing the strategies used to introduce decision aids into routine practice.[19–22] Patients' reactions and views will be a key factor in any implementation strategy. If patients find decision aids unacceptable, however well written, and designed, they will rarely be used. This paper describes the emotional and practical issues raised for patients by decision aids available for a variety of conditions, some of which are routinely treated in primary care. The findings are part of a larger study (V. Bhavnani, B. Fisher, Unpublished data) evaluating the acceptability of decision aids for use in general practice. We make suggestions for how to usefully respond to the negative reactions to decision aids, with a view to support their use in general practice.

Methods

Ethical approval

This study was approved by the Local Research Ethics Committee and the relevant NHS Trust.

Choice of decision aids

We chose decision aids listed in the Cochrane inventory (updated 2004) which were easy to access via the Internet and/or downloadable.[23]

All were for conditions that are common in general practice or familiar to GPs. All had interactive qualities with an explicit method to help patients to make decisions. We included decision aids concerning heart disease and stroke, osteoarthritis, osteoporosis and breast cancer (see Tables 1–4). These decision aids were all designed for a North American audience.

Recruitment of patients

Recruitment of patients from two general practices took place during September 2005 and again in April 2006. Inclusion criteria for the study were patients over the age of 18 years who had, or were currently suffering from, the conditions under review. Patients in the cardiovascular disease group included those who were being treated for atrial fibrillation and those who were currently taking medications for ischaemic heart disease and stroke. Fifty names for each condition were randomly selected from the general practice database for ischaemic heart disease, atrial fibrillation and osteoarthritis. We contacted all patients in the database who had breast cancer and osteoporosis as the numbers were lower than 50. Due to a poor response from patients from these two groups, we recruited patients from a second general practice and contacted all patients on the database to improve response.

Patients were sent a letter of invitation accompanied by an information sheet and consent form by the principal investigator (a GP at the first practice). These explained the study, gave a brief description of the decision aids to be evaluated and provided a telephone number to call if needed.

After consent patients received hard copies of the decision aids, website addresses and instructions for their review. Focus groups were held shortly, after patients received the decision aids. Patients were offered a one to one interview if they preferred.

Data collection and analysis

Patients evaluated more than one decision aid (related to their condition) in each focus group.

Table 1 Heart disease decision aids

	Decision aids reviewed		
Title of decision aid	Available at	Target audience	Key features
Making choices: life changes to lower your risk of heart disease and stroke	http://www.decisionaid.ohri.ca/decaids-archive.html (booklet with worksheet available online and printable) online cardiovascular risk assessor-)	Those concerned about cholesterol and blood pressure Those ready to consider or interested in making changes to reduce risk of heart disease/stroke	Defines heart disease and stroke Outlines major risk factors. Presents information on Life changes, lifestyle options and medicine options. Includes steps to help work out and lower risk and make the decision.
Healthwise Decision Point: Should I take statins for high cholesterol?	http://www.healthwise.net/cochranedecisionaid/content/StdDocument.aspx?DOCHWID=aa4406 available online and printable	Patients with high levels of cholesterol and who are considering treatment options	Defines cholesterol and its affects on the heart and risk factors for heart attacks, stroke and coronary artery disease. Provides an online interactive tool to help assess risk. Provides a worksheet to assist patients determine where they might stand on the decision.
Making choices: treatments to prevent stroke in patients with atrial fibrillation-	http://www.decisionaid.ohri.ca/decaids-archive.html. available to download but no audio – for audio contact provider	Patients with atrial fibrillation aged under 65, between 65 and 75 and over 75 at different levels of risk (low, medium and high)	4 decision aids aimed at different age and risk groups. Presents information on Atrial Fibrillation and stroke, the treatment options including no treatment, Aspirin and Warfarin. Includes steps to weighing up benefits and risks of each option through examples and a personal worksheet.
Healthwise decision point: should I take anticoagulants to prevent stroke?	http://www.healthwise.net/cochranedecisionaid/content/StdDocument.aspx?DOCHWID=tx229 available online and printable	Patients with atrial fibrillation	Defines anti-coagulant medicine and its risks (warfarin and aspirin). Provides information on risks. Outlines choices. Provides a worksheet to help patients think about the decision.

Table 2 Osteoarthritis decision aids

Title of decision aid	Available at	Target audience	Key features
Healthwise decision point: Should I have knee replacement surgery?	http://www.healthwise.net/cochranedecisionaid/content/StdDocument.aspx?DOCHWID=uh1514 available online and printable	Aimed at patients with osteoarthritis of the knee	Defines osteoarthritis. Describes surgical treatment options. Provides information on knee replacement surgery. Describes pros and cons associated with surgery. Worksheet to help with thinking about the decision.
Healthwise decision point: Should I have hip replacement surgery?	http://www.healthwise.net/cochranedecisionaid/content/StdDocument.aspx?DOCHWID=1515 available online and printable	Aimed at patients with osteoarthritis of the hip	Defines osteoarthritis. Describes surgical treatment options. Provides information on hip replacement surgery. Describes pros and cons associated with surgery. Worksheet to help with thinking about the decision.
Should you take traditional non-steroidal anti-inflammatory drugs for osteoarthritis? Leaflet (version available July 2005)	http://decisionaid.ohri.ca/decaid-archive.html available online and printable	Aimed at patients who have osteoarthritis and are not controlling pain with NSAIDS	Defines osteoarthritis. Provides information on NSAIDS and benefits and risks. Includes steps to assist patients be clear in what decision is to be made, role preference for decision making and steps in helping patients think about the decision.

Focus groups began with introductions, including a discussion about patients' motivations for participating and the aims of the project. This was followed by the presentation of each decision aid online with one being accompanied by an audiotape. We asked open-ended questions about what respondents liked and disliked about the decision aids and about their usefulness and suitability for use in general practice. This paper focuses only on implementation issues that arose during the discussions.

Discussions were audio taped and notes were taken. Thematic content analysis was performed.[24,25] Transcripts and notes were read and re-read to identify initial categories. These were set up on NVIVO v.2 (QSR international, Melbourne, Australia) and segments of the interviews were coded according to the categories. Categories were modified as further data were collected. Identification of the categories came from the data and was influenced by the literature and background reading. Every care was taken to ensure that categories fit the data. After coding, the categories were summarized into tables to provide an overview of the findings for each decision aid. This process aided the grouping of categories into broader themes. Throughout the analysis, VB and BF agreed on the interpretation of data.

Results

Participant characteristics

This study was conducted in two neighbouring practices in SE London. The population of these practices included 20% white British and Irish and 13% Caribbean and Black African and 20% from other ethnic backgrounds. For over 47% of the patients registered at these practices ethnicity was either not recorded or stated.

Twelve focus groups were carried out with a total of 77 patients (see Table 5). The mean age of patients was 66 with a range 42–83 years. There were 62 females and 15 males. Ninety-three percentage (72) of patients were White/White British with 7% (5) from other ethnic groups.

Table 3 Osteoporosis decision aids

Title of decision aid	Available at	Target audience	Key features
Osteoporosis decision: should I take alendronate	http://decisionaid.ohri.ca/docs/Rheumatology/... No longer available	Those with osteoporosis and considering treatment options	Defines osteoporosis Summarizes treatment options Provides details about alendronate and evidence of its effectiveness. Provides steps for patients to consider its use
Osteoporosis decision: should I take Etidronate	http://decisionaid.ohri.ca/docs/Rheumatology/... No longer available	As above	As above but with Etidronate
Osteoporosis decision: should I take HRT	http://decisionaid.ohri.ca/docs/Rheumatology/... No longer available	As above	As above but with HRT
Making choices: osteoporosis treatment options (version available August 2005)	http://decisionaid.ohri.ca/AZlist.html - hard copy only with audiotape to purchase from provider	As above	Booklet with audio Provides information on a range of treatments (including those above) and their risks and benefits Includes steps to help patients think about the decision Provides a worksheet to help the process

Main findings

Patients expressed appreciation of the information value of decision aids. We report here comments made by patients concerning the use of decision aids, their potential impact on promoting involvement in shared decision making and suitability for use in general practice. Quotations, shown in brackets, indicate which decision aids were being discussed.

Variations in the desire for involvement

Whilst there was overwhelming support for the notion of being involved, patients varied greatly in their views about the impact the decision aids would have on promoting shared decision making. These were influenced by patients' own preferences for information and involvement in decision making.

Patients across all groups felt that they would have been happy to receive information about their conditions when first diagnosed. Decision aids were seen as good starting points to promote discussion with clinicians and to start clarifying their views about treatment options and management strategies.

> It's a good starting place and then you can go and do more research in your own time. You tend to sort of get asked what do you want or what do you feel the next step is and you think, 'I have only just been told, I have no time to really take that in and I would like to take my time a bit and think about it' and this is the sort of material you need to help at least to start that process. R1 Male (Should I take anti-coagulants).

> It's a major decision (surgery) and I think most people when you get to this point, you just want to get out of pain and you will do almost anything for it, but your really need to consider like with the hip or knee surgery, the long term effect this is going to have on your life. It's a good starting point…this to me is step one. I wished I had read up a lot more ahead of time to be kind of mentally prepared. R3 Female (Should I have hip/knee surgery)

However, many of those in the breast cancer and heart disease focus groups who perceived their clinicians as a trusted source of information expressed a desire for the clinician to assume decision making responsibility and guide them accordingly.

> It would help me understand what I was taking but I wouldn't question its use… If the doctor says to me, you have to take statins, I would take statins, I wouldn't question it. R2 Male (Heart disease DAs).

Table 4 Breast cancer decision aids

Title of decision aid	Available at	Target audience	Key features
Should I have breast-conserving surgery or a mastectomy to treat early-stage breast cancer?	http://www.healthwise.net/cochranedecisionaid/content/StdDocument.aspx?DOCHWID=tv6530	Patients with breast cancer considering surgical options	Defines breast cancer Provides information on surgical options including links to definitions of technical terms and graphics if used online Provides information on the risks and benefits associated with mastectomy and lumpectomy. A worksheet is included to help patients think about the decision.
Making decisions about the removal of my breast cancer	http://www.cancer.ca no longer available	Patients with breast cancer considering surgical options	Describes surgical options and their advantages and drawbacks Shows graphically the difference between lumpectomy and mastectomy Also presents information on the possible removal of lymph nodes Describes radiation therapy and drug treatment Provides steps for patients to weigh up the benefits and drawbacks of different treatments using examples of other patients. Provides steps for patients themselves to weigh up benefits and drawbacks.

Table 5 Number of focus groups undertaken per condition

Conditions and subgroups	Number of focus groups	No of patients in focus groups
Heart disease patients	2	13
Stroke/atrial fibrillation	2	16
Osteoarthritis	2	14
Osteoporosis	4	20
Breast cancer	2	14
Total	12	77

> Frankly, I wouldn't have wanted to read any of that beforehand. I had every faith in the surgeon and he answered all of my questions with absolute honesty and on the spot and that was all I needed to know and all I wanted to know. R6 Female (Breast cancer DAs).

> Above all you are scared to death in the early stage and what you want is some expert telling you what's the best thing for you. R1 Female (Breast cancer DAs)

Preferences for decision-making responsibility

Patients expressed concern that decision aids would place the onus of decision making solely on the patients.

> It's (the DAs) putting the onus on the patient to decide what's best for him rather than the doctor. R5 Male (Should I take statins)

> I think this should just be for information on what they suggest you know. I mean the comparison of different drugs is good, but to leave the decision to the patients is not realistic. But not to be left to your own devices, all the decision aids have to be looked at with somebody who knows what they are talking about. R3 Female (Making choices – osteoporosis)

For some patients, particularly those who evaluated the breast cancer decision aids, there was a concern that clinicians in speciality care would become reliant on decision aids to deal with sensitive treatment options. Patients often compared favourably the information and care they had actually received from clinicians with the impersonal nature of the decision aids. Decision aids were seen as poor substitutes for people and some patients were concerned that their introduction might lead to a reduction in emotional support.

> The doctors and nurses are your biggest resource, nothing ever takes the place of a good doctor and a good nurse who are articulate and look at the patients face, not the computer or not like this

> [pointing to DAs]. I don't want it [DAs] to get into our culture, but you have it as a minor resource yes, read all about it but don't take the human element away. R11 Female (Breast cancer DAs)

> We are asking for human resources first for everyone and this would be a substitute. R13 Female (Breast cancer DAs).

There is a suggestion here that decision aids will enable clinicians to divest themselves of the responsibility of dealing with difficult issues face to face.

The control of decision making

Patients were also concerned about whether clinicians would allow them to take control of decision making. In particular, patients often talked about having different opinions to their clinicians as a consequence of using the decision aids. In this context, the use of decision aids may result in a stalemate situation with the patient not being able to secure their preferred treatment.

> You can't go to the doctor and say oh in this (DA) it says that such and such as a drug is good for me, may I have some please…it doesn't work like that, you go in with pain, you tell the doctor, he asks you questions and you provide the answers and he says what you can or can't take. R2 Female (Osteoarthritis and painkillers)

> You might go to the doctor and he might say, 'well fine, you have answered all these questions but I don't agree with that', Where do you go from there? R1 Female (Osteoporosis DAs)

Practical challenges to implementation

Patients talked at length about the practicalities of using decision aids in practice. Many felt that the time taken in diagnosis and start of treatment was too short and did not facilitate the introduction and use of decision aids.

> I was wondering at what stage will this decision aid be given to the patients, and if you give it to them before the interview with the consultant, I think it's going to tell the consultant what to do, and if you give it after your interview with the consultant, umm you have already had your interview with the consultant and may not get another, umm, so in order to use this, especially the questionnaire, you'd need 2 lots of interviews with the consultant wouldn't you, which most of us wouldn't get. R2 Female (Making decisions – breast cancer)

Respondents felt that several consultations would be required to make decisions about treatment using the decision aids and that this would not fit into the system without radical change.

> You know, to sort of share your thinking with your doctor; the way the health service is geared you don't really have that opportunity to clarify what you need to decide. Looking at the pros and cons, decide what you want, what role in choosing your treatment, but you can only do what you are allowed to do within the practice. R1 Female (Osteoporosis DAs)

Some patients, although having a positive view about the material presented, felt that it might delay definitive treatment.

> I thinks it's good, but if you have just been told you have osteoporosis you would want to know something about it, but if you were given this to go away and study it, I would feel lost and I was thinking, why not start treatment right away, I wouldn't want to leave it any longer, start me on something and then I will read this. R5 Female (Osteoporosis DAs)

Discussion

This study has focused on the reactions of general practice patients to decision aids. Patients valued and welcomed decision aids for their educational content and as good starting points for increased involvement. Patients liked the idea of being able to have access to decision aids, and viewed their availability in general practice as positive, even for conditions routinely dealt with secondary care.

Patients preferred to use the decision aids to increase their knowledge about conditions and treatments, but wished to continue to delegate decision-making responsibility to the doctor. Involvement in decision making was therefore related to being informed, improving knowledge and promoting discussions with clinicians rather than influencing the direction of treatment. Previous qualitative research has shown that patients' views about whether or not they were involved in decision making depended on a variety of factors for example, being informed

and feeling involved in the consultation process and not necessarily taking on the responsibility of treatment selection.[26,27]

The preference to delegate decision-making responsibility to clinicians was marked amongst heart disease and breast cancer patients. Previous research has shown that a significant proportion of patients with serious illnesses prefer to leave treatment decisions to their doctors.[28,29] Research has also highlighted the multi-dimensional nature of preferences where decisions to participate can be influenced by an interplay between illness characteristics such as clinical condition being presented, severity and stage of illness and contextual factors.[30–36] Preferences for involvement can also be influenced by the way in which risks and choices are presented by clinicians to patients.[37,38] So, decision aids are only one factor in this mix. They may be more acceptable for some conditions, with some people, at different times.

Patients were concerned about the impact of decision aids on their relationship with clinicians. First, they were worried that having used the decision aids, their views and ideas about treatments may conflict with those of their clinicians even in less serious clinical areas where patients might feel that they could have more influence. Second, patients were worried about having to work through the decision aids without assistance or supervision. Third, there were concerns that using decision aids would shift the onus of responsibility for decision making entirely onto the patient. Fourthly, that their implementation may foster a culture of reliance on decision aids over the human touch. In particular, personal factors such as emotional support, having enough time during consultation and being listened to have been found to outweigh the need to be directly involved in decision making in previous quantitative and qualitative studies of decision making in breast and colorectal cancer and diabetes.[26,39–43]

It seems that even specific support for shared decision making, even in clinical areas in which patients feel able to take decisions many be insufficient to give patients the courage to offer a different view to that of their doctor. However, concerns and worries of this nature may not arise where clinicians provide or actively encourage their patients to use decisions aids. This may also result in patients being more open to the idea of discussing treatment options with clinicians thereby being more involved and playing a role in influencing treatment decisions.

It is likely that decision aids will not be suitable for all patients and clinicians will need to be aware of patients' preferences before offering them. This raises the important issue of whether clinicians are able to assess their patients' preferences for involvement and/or decision making. The literature suggests that clinicians are poor at this, though they can learn to do it better.[44–46] Clinicians may not be adequately skilled in risk communication to convey information effectively to patients.[45]

Patients identified practical challenges to the successful implementation of decision aids. These concerned time constraints, the need for more and potentially longer consultations and the timeliness of delivering decision aids.

Strengths of the study

The main strength of the study lies in the large number of focus groups and participants. Another strength is that, it offers insights into patients' views and concerns relating to the use and implementation of off-the-shelf decision aids. Despite the cumulative positive evidence about the effects of decision aids in RCTs, there are relatively few reports addressing the strategies used to introduce decision aids into routine practice.[19,20,47,48]

Limitations of the study

The study's weakness lies in not having a group of patients who were newly diagnosed and at the point of making decisions about treatment and care. The decision aids were reviewed by patients who were established on treatment or who had completed treatment. The conditions chosen also tended to select an older group of patients with the majority being women.

The study was carried out in the patients' general practices. We were aware of the potential difficulties of interviewing patients in their

own practice and therefore used a researcher who was independent of the practice to collect the data and analyse it. We found that patients in this study gave a range of views both positive and negative about the decision aids and were ready to raise their concerns about the implementation of decision aids in practice.

Conclusions

This study gives the basis for advice on using decision aids in primary care. This study confirms that patients value decision aids either to increase their knowledge about existing conditions or to potentially involve them in decisions about their health care. It suggests that decision aids should be seen similarly to an intervention or a prescription: they need to be used with an understanding of the patient's level of understanding. They need to be offered as part of personalized care, and it needs to be made explicit that this is not a derogation of responsibility. Patients will need to be assured by their clinicians that decision aids are to be used as an adjunct to routine care and not as a replacement. In addition, this paper stresses that clinicians may need to be flexible and aware of patients' information needs in order to use decision aids most effectively. Decision aids must be used in the medical encounter as an integral part of the communication and support process. If handled with sensitivity, decision aids can fulfil their promise of a practical intervention to empower patients in shared decision making for those who want it.

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