

Beyond the consultation: shared decision making in practice

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Abstract

Objective: To explore health care practitioner's perceptions and use of patient decision aids (PDAs) in routine clinical practice as a baseline study prior to an intervention involving the introduction of a suite of PDAs.

Methods: Health Care Practitioners (HCPs) from five general practice surgeries in northern England participated in focus group sessions around the themes of patient decision aids, patient and HCP preferences and shared decision making (SDM). Participation included general practitioners (n=17), practice nurses (n= 5) and auxiliary staff (n=3). Transcripts were analysed using a framework approach.

Results: a) HCPs experience SDM differently at individual and institutional levels b) the language of SDM may not necessarily change the relationship between HCPs and patients c) shared decision making extends beyond the consultation.

Conclusion: We argue for a distributed view of decision making and identify several approaches for taking SDM beyond the consultation.

Practice Implications: a) evaluative frameworks need to address how different institutional settings and cultures modify the introduction of PDAs; b) PDAs could be incorporated into routine practice beyond the confines of the consultation; c) HCPs need support to enable them to do 'real shared decision making' that involves more than training in the methods of implementation.

Key words: shared decision making; routine practice; distributed decision making; patient decision aids, qualitative research

Introduction

Engaging patients in clinical decision making has become a guiding ethical principle underpinning much contemporary and routine clinical practice [1-5]. Development of Patient Decision Aids (PDAs) has been proposed as one component of clinical practice through which to enable evidence-based patient choice (EBPC) and shared decision making (SDM)[4]. PDAs are designed to assist in decision making about healthcare by providing the best available evidence of the risks and benefits of particular therapeutic options in association with the elicitation and incorporation of patient values. When used in SDM it is anticipated that patients will be involved in the decision making process to the extent that they desire, and that decisions will be made in a partnership between patient and physician that acknowledges rights and duties of all parties involved[6].

Despite broad acceptance of the use of PDAs in improving patient based outcomes and health, evidence for their successful implementation and use in extending SDM in routine practice remains scarce [7-10]. Current research has considered the barriers and limits of EBPC and SDM in relation to: shifting power relations between health care practitioners (HCP) and patients[7]; the absence of patient engagement and/or patient and practitioner preferences in the use of PDAs[11]; the heterogeneity and diversity of risk and its communication[12, 13]; time constraints for HCPs[3, 14]; what constitutes a 'good decision'[15]; how PDAs may contribute to or confound shared decision making [13, 16]; and the tensions inherent in engaging patients' values and the goals of disease prevention[5, 15, 17-19]. Despite the wide-reaching implications of SDM to decision making in healthcare, there is little research on how and if PDAs are incorporated by HCPs into their routine practice [8, 20, 21]. To date examination of the practice of SDM has been to general practitioners[22], specifically those who have an existing interest in and knowledge of SDM[10]. Our approach differs in that we include a broad spectrum of HCPs, including those already skilled in SDM and those with little or no knowledge. Moreover, in our analysis we consider the patient/HCP interaction as well as the broader social and organisational context of decision making.

Methods

Five general practice surgeries in northern England were invited to participate in the study. Within each of the participating practices a one hour presentation was given by the principal researcher (RT) to introduce the study, the concept of SDM and current developments concerning PDAs. The presentation included a brief overview of different approaches to decision making and gave

examples of different PDAs and modes of implementation. Participants were asked to reflect on the presentation, to begin to consider the potential for using PDAs in their practice and to identify particular areas of clinical practice where a PDA could be of value. After a two week period for reflection, focus groups were arranged with those interested in pursuing further the topic of SDM and PDAs. This self-selection process was adopted on the basis that how individual practices organise and facilitate care pathways vary, thus identifying and involving those with an interest or role in shared decision making is likely to differ from practice to practice.

A framework approach was used in the analysis of focus group transcripts [23]. As it is suitable for analysing data where the objectives of the research have been set in advance [24]. The main objective of the focus group was to consider issues of relevance to SDM and PDAs in routine settings from the perspective of health care practitioners. A five stage process of analysis [23] was adopted involving: familiarisation with the data through reading and rereading the transcripts for recurrent themes; identification of a thematic framework based on the objectives of the research; a process of indexing in which transcripts were annotated with codes derived from the thematic framework; summarising and synthesising this data into charts that use representative quotes to demonstrate themes (Tables 1, 2 and 3).

Results

Health Care Practitioner and patient roles and relations

HCPs understandings and perceptions of their roles and relations in respect to patients ranged from an implicit understanding and commitment towards the principles of SDM to protective paternalism (Table 1). Different *practices* adopted approaches more or less consistent with the principles of SDM. Transcripts from FG1 demonstrated the least familiarity with principles of SDM, and FG2 and FG3 the most. One GP in FG1 demonstrated a protective paternalistic approach to HCP/patient relations in suggesting his role was to “explain what I think is best” to the patient. HCPs in FG1 appeared concerned that PDAs might threaten their current roles. Two GPs associated PDAs with technological change and a declining role for human HCPs, invoking dystopian images of “virtual GPs” (FG1-GP3F – Table 1). Moreover, participants in FG1 appeared to have difficulty contrasting information giving with SDM. Asked how SDM was enabled in the practice one participant replied “I do share with patients’ information and the main source of information is my brain” (FG1-GP2M – Table 1). Participants also appeared reluctant to devolve decision making arguing that patients may not understand, may act irrationally with information

given and may not act in the interests of public health. In contrast, FG2 appeared, most consistently, to recognise and support a role for HCPs in facilitating patients' involvement in decision making. A key principle underlying SDM is that patient values can and should be incorporated into the decision making process. HCPs in FG2 were particularly sympathetic and responsive to the importance of values clarification in the consultation, despite one describing patient competencies negatively and suggesting that the basis of individual's decisions were "probably...irrational" (FG2-GP2M- Table 1). Participants in FG2 were able to refer to key literature on SDM and demonstrated they had applied the principles in practice by recording shared decisions when they occurred (FG2-GP2F – Table 1). In FG4 participants expressed surprise that SDM was considered as something new. When asked to reflect on SDM one GP suggested that most people wish to engage at some level, and that sometimes this engagement occurred outside the consultation as patients could (and sometimes did) reject what the HCP offered as a treatment option. Despite recognising that decisions could be modified by patients because of the values they held, there was little mention of eliciting values as part of the consultation process itself, and not in any systematic way.

Even those practices and participant HCPs sympathetic to SDM found the idea of sharing responsibility for decision making difficult 'in practice'. First, some patients try to devolve responsibility for decisions to HCPs or expect the HCP to take the decision. Second, HCPs recognised that shared decision making often involved areas of uncertainty where neither the HCP nor patient had sufficient information upon which to base a decision. Third, some patients were reported to be more indecisive than others and some HCPs found their role difficult because it involved assessing patients decision making desires and abilities. Fourth, HCPs reported it was difficult to remove themselves from the role of decision maker. One GP suggested it was hard not to "push the decision", referring to the example of the older man who had shared a decision not to take preventive medication and who had subsequently had a stroke. She suggested that "a little bit of me thinks I should have been more forceful" [in making him take the medication] (FG2-GP2F- Table 1). In such a situation the patient made a choice, but its legitimacy for the HCP came into question with the perception of a 'wrong' outcome. Therefore, despite a recognition that "this generation don't like telling people what to do" (FG2-GP1M – Table 1), there are powerful rhetorics at play in which responsibility is still seen to ultimately rest with the HCP. While participants in FG2 considered it desirable to empower patients, "real shared decision making"(FG2-GP1F – Table 1) involved a sometimes uncomfortable and difficult transition in HCP

roles. HCP across all focus groups suggested patients also failed to enact shared roles in decision-making. One respondent in FG2 suggested SDM felt more like “collusion” – a simulacrum of choice in which the role of the HCP is to authorise patient decisions through the rhetoric of shared decision making; and most often when it suited the HCP: “I often find it easier to be involved in real shared decision making where I don’t feel strongly either way”(FG2-GP1F -Table 1).

Thus participants and practices varied in their awareness of the changed relationships inherent in the move towards patient-centeredness and SDM. HCPs roles and relationships with patients were both institutionally driven and individually mediated. Where practices demonstrated commitment to principles of SDM and patient-centred practice, HCPs were more comfortable with the use of SDM language and principles and were able to recognise that SDM involved the shift of power implicit in the term. However none of the HCPs felt completely comfortable with SDM or absolved from adopting more paternalistic roles with patients.

Institutional and practical considerations for introducing SDM and PDAs

Time

Time was identified as a key constraint identified across all practices (Table 2) and recognised in other studies [10, 22, 25]. While it was observed that SDM may well have long term benefits in health outcomes, participants in FG4 shared the view that “selling” SDM to their practice would need to include some benefit that would at the very least, not increase time spent with patients. The perception of SDM as time-consuming was used as a rhetorical device by a HCP in FG1 to explain the lack of patient decision aids in that practice (FG1-GP1M – Table 2). In such views time was treated as a fixed constant of the patient/HCP interaction such that SDM could be cast, problematically, as an *additional element of the consultation* (FG2-GP2M– Table 2). Yet time, however much a hindrance, was not necessarily viewed as an immutable barrier. While one HCP suggested “the big limiting factor is time”; he later observed that SDM might be thought of as “going on between consultations”(FG2-GP2M– Table 2). Another HCP suggested PDAs could help make durable decisions that “save time in the future” (FG4-GP1M-Table 1). Other participants reported that receptionists could play a screening role identifying patients with particular health concerns, directing them to HCPs (including the practice nurse) with particular areas of clinical expertise – thus reducing the possibility that two consultations would be necessary; but also potentially creating a new space for SDM and PDAs outside the consultation.

Communication

The diversity of skills, methods and resources for sharing information with patients appeared to reflect *individual* as well as *practice based* differences. In FG2 sharing information about risk was viewed by some HCPs as “spurious” (FG2-GP2M – Table 2) and unhelpful, whilst for others risks were useful “to grapple with” (FG2-GP3M – Table 2). Participants in FG2 had also been involved in ongoing communication skills training and the expression of different opinions within the focus group and inclusion of all participants in the discussion demonstrated inclusiveness and openness to the views of others. In contrast, communication skills were not emphasised in FG1 or FG4 but rather expectations about communication were based on common assumptions that participants would adhere to guidelines (FG1-GP1M – Table 2). Different communication practices in the focus group may not reflect what happens in consultation. Different practices had invested more or less time and resources towards communication and in pursuit of the particular goal of SDM as a “theory and an ideal” (FG2-GP2M- Table 2).

Shared institutional practices

Development of a shared culture within some practices contrasted sharply with those practices operating on a more individualistic basis. In FG2, FG3 and FG4 discussion of SDM centred on what they had done *together as a practice* toward such aims. HCPs and practices that tended to demonstrate a more paternalistic approach to patients, also adopted paternalistic roles towards more junior members in the practice, for example FG1-GP1 (Table 2) discounts the view of a nurse practitioner concerned about the IT resources available within the practice .

Decision aids in routine practice

What is apparent across all focus groups was that HCPs had limited experience of PDAs *in practice* or in *hypothetical situations* to draw upon to describe how PDAs might be incorporated successfully (Table 3). When asked to reflect on the availability and use of PDA in their practice, none had routinely used PDAs though there were isolated examples where PDAs were used in communication about patient values. In FG3 two PDAs identified as used “regularly” were a risk/benefit table for using HRT (Hormone Replacement Therapy) and a Framingham derived computerised risk assessment for cardiovascular risk (by practice nurses and GPs). In both situations HCPs recognised that family history and values were not incorporated in the use of the tools, and that the HCP role was in part to elicit values. Moreover, the presentation of risk was used “reinforce what you are saying” (FG3-GP1F – Table 3). The advantage of using a PDA was

viewed in terms of surveillance of the patient's health beyond the consultation. One GP suggested a blood pressure monitoring machine for home use "really helps me to make a decision" (FG4-GP3F – Table 3) about whether or not to increase medication. Incorporation of patient values was not included by GP1F as a legitimate part of the decision making process. In FG3 one participant suggested the tool had been particularly useful for improving HCP knowledge (rather than facilitating SDM with the patient). Despite this, there was a perception across the practices that PDAs were not designed with 'real life' consultation pressures in mind. As one participant suggested of a computerised PDA, it had been unfathomable to imagine how it could be incorporated into a 10 minute consultation. Accessibility and lack of "faff" (fuss) appeared to be foremost in the minds of participants (FG2-GP2F – Table 3). At the same time there appeared to be different motivations underlying the generally positive support and desire to develop SDM and use PDAs where possible. For one GP, PDAs were equated with simplified systems for information giving such that an "NHS bank of information and decision aids" that would reduce the current deficiencies of information retrieval and hand-outs (FG1-GP4M – Table 3). Other participant HCPs were more reflexive of their desire to work towards "real shared decision making" and equality in the decision making process, but recognised they had limited skills or resources to do so.

Discussion and conclusion

The findings reported here are reflected in other studies and contribute to further examples that "open up a debate between 'prescribed' and the 'described'" elements of patient-centred methods [7]. We are thus able to reflect on the different understandings of SDM, different approaches to it, and different needs across practices and HCPs. From our findings we propose that: SDM involves more than a change in practice and requires a new way of seeing the world; some HCPs are more successful than others in recognising such a shift but still find practice difficult; HCPs views about their own and patient roles in decision making varied considerably across practices and individuals; HCPs/practices shared different understandings of where and when decision making gets done; HCPs were not equally skilled or knowledgeable about SDM; information needs and SDM are conflated; SDM language can be used to describe paternalistic relations of care; PDAs were used as a means of surveillance of patients; SDM is sometimes perceived by HCPs as not 'real'; and HCPs have few examples on which to draw that demonstrate how PDAs can work in practice.

For some, SDM involves a philosophical reorientation away from earlier paternalistic models and a new forms of thinking about patient HCP relations [7, 30]. O’Flynn and Britten [30] view such a reorientation in terms of the biomedical model, suggesting that the ability of HCPs to share decisions and devolve power to patients is, in reality, circumscribed because it is fundamentally in opposition to the practices through which they gain their professional identity. In this view it is not surprising that there are “low levels of SDM observed in practice” [see also 8] because practitioners are ‘socialised’ to a particular way of viewing HCP/patient relations. O’Flynn and Britten [30] surmise that practitioners need to do ‘identity work’, a reflexive re-examination of their role, if they are to achieve the goals of SDM. Elwyn [7] also describes a shift in HCP/patient relations. In his view however, the process of renegotiating patient/HCPs roles is a challenge but is also inevitable given the growing recognition of uncertainties associated with decision making. The focus group findings we present here support the proposition that such a transition is underway, but one that is recognised and advanced by some HCPs more than others.

Several recent studies have sought to address the apparent lacuna in understanding HCPs views on PDAs in clinical practice [9, 14, 21, 22]. Findings of these studies tend to be conceptualised around ideas of ‘barriers’ and ‘facilitators’ to operationalising SDM [22, 25]. In these views issues of time and lack of applicability for particular consultations are routinely represented as roadblocks to the successful implementation of SDM. We do not dispute the importance of these observations in helping to explain many of the difficulties HCPs associate with introducing PDAs into practice, or in helping develop solutions to some of the practical barriers and the identification of training needs of HCPs. However, the expectation that SDM occurs only within the consultation setting and between GPs and patients limits opportunities for introducing SDM in practice based settings. Moreover, such accounts do not take into consideration variations between institutions and individuals in how SDM is experienced or that use of SDM language does not in itself guarantee that SDM is being adopted.

Conclusion

Our research demonstrates two orientations towards SDM: patient-centred and HCP-centred. In the first, practitioners recognise a changed relationship between HCPs and patients in *how* decisions get made. In the second, SDM exists along a continuum of more and less paternalistic models: a philosophical reorientation of patient/HCP roles is not evident in even the least

paternalistic on this continuum. Rather, the SDM is adopted in relation to issues where there is either uncertainty about the risks and benefits of particular treatment options, or in particular relation to prevention focused interventions. For HCPs historically charged with responsibility for a patient's welfare, the ability to devolve power is more difficult than might be suggested by the descriptions of SDM.

Implementation of PDAs in clinical practice must involve a more explicit recognition of the challenge of this approach and the implicit reordering of power that it may involve. First, evaluative frameworks and modes of delivering SDM tools into practice need to address how different institutional settings and cultures modify the introduction of PDAs. Second, PDAs could be incorporated into routine practice beyond the confines of the consultation. Third, HCPs may need more supportive frameworks to enable them to do 'real shared decision making'. Support that involves more than training in the methods of implementation and addresses the legal implications for HCPs that make devolving responsibility to patients immensely difficult.

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Declarations

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3. No conflict of interest exists.

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.