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Involvement in treatment decision-making:

its meaning to people with diabetes and implications for conceptualisation

Abstract: (293)

Patient involvement in decision-making is widely regarded as an important feature of good quality healthcare. Policy-makers have been particularly concerned to ensure that patients are informed about and enabled to choose between relevant treatment options, but it is not clear how patients understand and value involvement.

We investigated the meaning of involvement in treatment decision-making for people with diabetes. We conducted semi-structured interviews with 18 people aged between 20 and 79 who had type 1 or type 2 diabetes. We used several strategies to probe their understandings of involvement, including discussion of how they would respond to a question about involvement in treatment decisions that appears on the National Patient Survey used to monitor the quality of healthcare in England.

Participants associated involvement in decision-making with a number of features relating to: the ethos and feel of healthcare encounters (welcoming; respectful; facilitative of patients' contributions; and non-judgemental); communication about health problems (practitioners attending to patients' views and patients feeling listened to; practitioners giving clear explanations based on their professional knowledge and patients understanding these); and communication about treatments (practitioners

explaining treatment rationales in ways that patients understand and enabling patients to feel they have a say).

Our findings have implications for practical attempts to involve patients in decisions about their care and for the conceptualisation and assessment of patient involvement. They suggest that practitioners who aspire to facilitate patient involvement should attend to the ethos they foster in consultations and the way they discuss problems as well as to the provision of information about treatment options and the scope patients have to influence decisions. Models and taxonomies of patient involvement in decision-making need to be developed to accommodate both problem-solving phases and the relational and subjective dimensions of involvement.

Introduction

Patient involvement in treatment decision-making is widely regarded as a feature of good quality healthcare. In many western nations it is advocated by state health departments and leading organisations of health professionals. In the context of decisions about professionally-controlled interventions such as prescription medicines and surgery, attention has generally focused on the information that is given to patients about relevant options, and on ensuring that decisions reflect patients' free, informed, deliberated preferences (Kukla, 2005). This reflects the choice-centred notion of professional respect for patient autonomy that currently dominates bioethics (see Beauchamp & Childress, 2001).

Although efforts to promote patient involvement are not new, research continues to suggest that patients are not routinely enabled to make free, informed and deliberated treatment choices. Studies of consultations identify deficiencies in the extent to which health professionals tell patients about healthcare options and elicit their views about these (Elwyn, Hutchings, Edwards, Rapport, Wensing, Cheung et al, 2005; van den Brink-Muinen, van Dulmen, de Haes, Visser, Schellevis & Bensing, 2006); studies of patients' perspectives on decision-making find that many think that their doctors rather than they made key decisions about their treatment (Ford, Schofield & Hope, 2003; Entwistle, Watt, Gilhooly, Bugge, Haites & Walker, 2004); and studies of patients' understandings of and attitudes towards particular interventions suggest that significant numbers have made some poorly-informed choices about their healthcare (Marteau, Dormandy & Michie, 2001; Fagerlin, Lakhani, Lantz, Janz, Morrow, Schwartz et al, 2006).

However, there is scope to debate why and to what extent these findings reflect problems with healthcare quality. Patients do not always expect or want to be given

information about a menu of treatment options and responsibility for making a choice between these (Say, Murtagh & Thomson, 2006). The reasons for this are still poorly understood, and the implications for evaluations of patient-practitioner communication and decision-making are contested (Entwistle, 2006).

Patients who report preferences not to make or take responsibility for treatment decisions might still say they want to be *involved* in decision-making. A few qualitative investigations suggest that people might consider themselves to have been involved – and value feeling included - even though they have not been informed about and considered all the options and have not significantly influenced the selection of a course of action (Henman, Butow, Brown, Boyle & Tattersall, 2002; Beaver, Jones, Susnerwala, Craven, Tomlinson, Witham et al, 2005; Entwistle, Williams, Skea, MacLennan & Bhattacharya, 2006). Investigations of patients’ responses to structured questions about their involvement have found that people may take a broader range of issues into account than those emphasised in models that focus on information exchange and patient influence (Entwistle, Skea & O’Donnell, 2001; Davey, Lim, Butow, Barratt & Redman, 2004; Entwistle et al, 2004).

In England, the National Patient Survey that is used to monitor the quality of healthcare provision from patients’ perspectives assesses involvement in treatment decision-making with a question that invites patients to evaluate their involvement relative to their own preferences. Referring to a recent healthcare encounter or episode, it asks them “Were you involved as much as you wanted to be in decisions about your care and treatment?” and offers the response options “Yes, definitely”, “Yes, to some extent”, or “No” (Health Care Commission, 2005). (These response options have varied slightly across surveys.) In 2004 and 2005 around 31% of primary care patients and 46% of inpatients indicated that they were not involved as much as they wanted to be

(Health Care Commission, 2006). However, the question does not impose any particular definition of involvement on respondents, and the forms and degrees of involvement that patients regard as desirable are poorly understood.

We undertook a qualitative study to explore what it means to people with diabetes to be involved in decisions about their treatment in the contexts of both outpatient and inpatient care. We hoped to generate information that could inform both practical efforts to improve patients' experiences of involvement and developments in the conceptualisation of involvement.

The rationale for focusing on people with diabetes was that they are usually encouraged to develop an understanding of their condition and to engage actively in its management, so they should be well placed to participate in treatment decisions (Funnell, 2004). Also, they have experience of interacting with a variety of health professionals and of considering and revisiting a number of decisions relating to the management of their condition, so should be able to reflect on situations in which they have been more and less involved.

Methods

The study was approved by Grampian Research Ethics Committee (reference 05/S0802/36).

Recruitment and consent

Adults with diabetes were recruited from four multi-practitioner outpatient diabetes clinic sessions in May-August 2005. Posters advertising the study were placed in the waiting room. MP was present in the waiting room to provide information sheets and explain the study. In the last two clinic sessions, she approached people from the gender/age groups previously under-represented in the sample to offer information

MP took contact details for volunteers and telephoned them at least 24 hours later to arrange interviews if they were still willing. A signature indicating consent was obtained prior to the interview.

Data collection

MP conducted semi-structured interviews in participants' homes within a week of their outpatient visit. She asked participants first to describe the history of their diabetes and the healthcare they had received to date and then to describe their recent consultation(s) at the diabetes clinic, to identify any treatment decisions that were considered, and to comment on how this consultation compared with others they had experienced. She asked participants to answer the question about involvement in decisions from the National Patient Survey with reference to their recent consultation, and then to explain why they chose the response option that they did. People who had described contrasting experiences of healthcare in their initial accounts were asked whether and why they would have answered the question differently in relation to these. People who had been hospitalised in the last two years were also asked to describe their most recent hospitalisation and answer the National Patient Survey question with reference to that. Finally, all participants were invited to discuss what kinds of things made them feel involved or uninvolved in decisions about their treatment, and what involvement meant to them.

Data analysis

Interviews were audiorecorded and transcribed. All authors read a sample of transcripts and discussed provisional themes. MP and then VE worked systematically through all transcripts and created charts to summarise: issues that the researchers identified as relating to involvement in participants' descriptions of their healthcare experiences; responses to the National Patient Survey and explanations given for these;

and participants' statements about what made them feel involved (or not) and what involvement meant to them.

The issues that participants associated with involvement were identified from their explanations for their responses to the National Patient Survey question and from statements explicitly about involvement. These issues were grouped into themes that could have practical relevance for health professionals. The themes were discussed among the authors, refined and checked against the charts to ensure all relevant issues were accommodated.

Findings

Sample characteristics

Twenty-one people volunteered contact details at the clinic and eighteen were interviewed. All participants were white British. They included ten men and eight women from across the 20 to 79 year age range. Seven had Type 1 diabetes and eleven had Type 2 diabetes. They were between one and 31 years since diagnosis and followed a range of management regimes (Table 1).

Participants' accounts of their diabetes care to date were diverse. Most drew some contrasts between their experiences with different practitioners and clinical settings, particularly in relation to communication and perceived quality of care.

Issues associated with involvement in decision-making

Some participants answered direct questions about what it meant to them to be involved in treatment decisions without hesitation and using generalised conceptual statements. Others were more hesitant and some responses took the form of stories about particular healthcare incidents or descriptions of typical healthcare encounters. When asked whether they had thought much about their involvement in treatment

decisions before the interview, most participants indicated that they had not, although several reported having reflected on involvement when they had perceived a lack of it as problematic. However, all participants seemed to have an understanding of involvement that they could apply in relation to decisions about their treatment and use to answer and discuss their responses to the National Patient Survey question.

Most of what participants said about their involvement in decisions focused on decisions about interventions for which health professionals are gatekeepers (e.g. prescription medications) and on communication between patients and health professionals (about health problems, health-related behaviours and healthcare interventions). Some participants also mentioned their involvement on a daily basis with decisions about diet, exercise, lifestyle and medication use. This latter is an important issue, but was not the focus of this study.

We grouped the issues that patients associated with involvement into three broad themes that should have practical relevance for clinicians. Each theme has several related sub-themes:

1. The ethos and feel of healthcare encounters

When describing their healthcare to date, all participants made some reference to practitioners' orientation or manner towards them and to how practitioners' actions and features of healthcare settings made them feel. Participants associated several inter-related, positively valued, features of the 'feel' of healthcare encounters - and the professional behaviours that contributed to these - with 'involvement':

a) Friendly and welcoming

Involvement was associated with practitioners being 'friendly' and 'approachable' and patients feeling 'welcome'. Several participants reported a lack of

involvement in situations in which practitioners made no time for friendly greetings and treated them with detachment.

b) Interested and respectful of patients and their perspectives

Participants could feel involved when practitioners treated them ‘as a person’, ‘took an active interest’ and made them feel ‘on a level’ in discussions. In contrast, they did not feel involved if practitioners asserted their superiority and imposed their own views, disregarding patients’ experiential expertise or feelings. One important aspect of being treated as a person was being recognised as an individual with particular interests and concerns. Several participants indicated that they did not feel involved if practitioners showed no regard for their life circumstances and plans.

c) Facilitative of patients’ contributions to discussions and condition management

Participants associated involvement with practitioners making it easy for them to discuss their problems, inviting questions, ‘really listening’, answering their questions thoroughly, providing relevant information and explaining things well. Conversely, participants reported feeling less involved when practitioners appeared disinterested or were dismissive of what they had to say.

d) Not unduly judgemental or patient-blaming

Involvement was associated with patients feeling able to discuss their difficulties with self-care regimens or the achievement of target weights and blood sugar levels and being confident that they would not be negatively judged. Several participants noted that they had not felt involved when practitioners appeared to blame them for their health problems.

Participants’ comments about involvement often incorporated several of these sub-themes. Examples are presented in Box 1.

Some participants indicated that they could feel involved because they had a good relationship with a practitioner whom they had got to know. Conversely, several regarded a lack of continuity of carer as something that militated against their involvement. Continuity of carer *could* underpin some 'ethos and feel' features. For example, participants noted that it was easier to open up to and ask questions of a familiar, trusted 'regular practitioner', and that their regular practitioners were more interested and caring than others. However, continuity of carer was not always necessary to achieve these: one participant spoke most positively about a consultation with a locum GP, a diabetic himself, who expressed an empathetic interest and explained several issues that the participant had not previously understood.

2. Communication about health problems

Although our focus was on involvement in treatment decisions, communication about health problems featured significantly in the interviews.

a) Practitioners elicit patients' views of their situation and patients feel listened to

Participants' narratives confirmed the importance that patients attach to practitioners eliciting, listening empathetically to and taking seriously the patient's own view of their symptoms, of how their diabetes affected their life (and not just how their life affected their diabetes), and of their current treatment regime. Participants also often associated these behaviours with involvement in treatment decisions. For example, one participant with numerous health problems recounted several occasions on which he had felt obliged to insist that doctors pay attention to the problems he was trying to tell them about. He explained that 'Yes, definitely' was the best answer to the National Patient Survey question in relation to his recent consultation:

Because I'm outspoken! And from past experience, it's to have your input rather than let them tell you. You know your body, you should be telling them [about 'allergies and that']. (03)

Participants could feel a lack of involvement if their own concerns about blood sugar readings, symptoms or side-effects were dismissed or not taken up by their practitioners. For example, one woman (11) had been prescribed Metformin, which she took regularly and 'didn't have a problem with' until she was told to increase the dose. At two tablets daily she started to have problems with diarrhoea. When she was told to increase the dose to four tablets daily, she expressed reluctance but was told she must 'give it a try'. The diarrhoea worsened to the extent that she felt unable to leave her home. When she telephoned the diabetic clinic, she was told emphatically that she must continue to take the tablets. The participant described this incident several times during her interview, stressing how frustrating and humiliating it was when her attempts to explain the effect Metformin was having on her were not listened to. She eventually contacted her GP who took the problem seriously and prescribed a different medication for her diabetes. When asked during her interview how she would have answered the National Patient Survey question if she had been asked it with reference to her contact with the clinic about the problems she had with the Metformin, she said that her response would have been "a definite no".

However, a lack of involvement was not only associated with practitioners' failing to listen to patients' specific problem reports. Attention to patients' feelings about the problems posed by their diabetes more generally was also seen as important. For example:

I just think I would be more involved if he said to me '[First name], I only see you every six months. Tell me, now, how you *really* feel, how you really deal with your diabetes, what problems, what do you feel the next 5 years are going to do for you?' and stuff like that. There's none of that. It's just, get in, 'yeah, yeah, the sugar levels are fine, they are 5.6, that's good'. That's it. (02)

b) Practitioners explain health problems and patients understand

Several participants mentioned that they had received (or taken in) relatively little information about diabetes and its management when they were first diagnosed. Only later had they found out what they now regarded as crucial information about their condition and its management - sometimes only after experiencing severe problems with hypo- or hyper-glycaemia. When talking about involvement, these participants in particular highlighted the importance of clear and timely explanations from practitioners about diabetes and about how and why preventable problems occurred. For example:

I: Can you describe how involved you like to be, then?

P: I like to know why. I don't want to just go into a doctor and say, I am ill, the doctor ask me questions about my illness and then to be given a drug that fixes it – although that is nice sometimes. But with this particular illness [ketoacidosis] I want to know why it happened, what I could have done to prevent it, will it happen again? A lot more information than a “just take these and it won't happen again” sort of situation. (08)

However, the provision of too much complex information about diabetes could also militate against a sense of involvement if it resulted in the patient feeling overwhelmed. One participant, who seemed quite confused about some aspects of

diabetes and its management, explained that he would have responded “Yes, to some extent” to the National Patient Survey question because:

She does involve you, but not to a fuller extent. She tries to explain things to you, and you’re trying to take it all in. Maybe there is a bit too much information, maybe not enough. (09)

3. Communication about treatments

All participants respected and wanted to avail themselves of practitioners’ expertise in relation to the management of their diabetes. They were generally inclined to accept treatment recommendations, although we heard several examples of patients having negotiated for something other than what their doctors first suggested. The few (including a nurse) who talked in terms of making ‘informed choices’ for themselves also noted that they valued a ‘steer’ from health professionals. However, there was a strong sense from across the interviews that people did not feel involved in decisions when practitioners ‘dictated’ a particular treatment without giving them a rationale for that treatment and without giving them any hint of a ‘say’.

a) Practitioners explain and patients understand the reasons for treatment

Participants frequently associated being given understandable explanations about the rationale for proposed treatments with involvement in decisions, as these two responses to the question “How involved do you like to be in treatment decisions?” illustrate:

I prefer to know what is going on... I want to know if I am changing insulin why I am changing insulin... not just getting told “Yes, this would be better for you to change to”. Then you go away thinking “Why am I bothering?” I would prefer to know what is going on, why it is going on and things like that. (05)

I like to be involved. I like to know why I have to take something and what it does to me. When they moved me onto Glimepride, it was explained what they did, and I was quite happy to take them. And I was on Glimepride for a while ..., but the diabetes was getting worse and I needed something more, so they put me on to Rosiglitazone and explained what the Rosiglitazone did... I was quite happy because I understood what she was saying. She was telling me what each of the tablets were doing. (11)

Two participants also suggested that they would feel more involved if practitioners proactively alerted them to the development of new treatments.

b) Practitioners make room for patient influence and patients feel they have a say

In addition to understanding the basis for possible or proposed treatments, all but one of the participants also suggested that to be involved they needed to have some kind of say in or about their treatment. This could happen in several ways. First, some participants talked in terms of practitioners understanding their situation and priorities and tailoring treatment recommendations accordingly. For example:

I think the involvement is “Well, the three drugs here, X, Y, Z. This one will be good for you because you are an active person. This would be good if you were non active, and this, well that’s relatively new...” (02)

Participant 11’s reports of the different responses she received when she complained of severe diarrhoea as a side effect of Metformin (see 2a above) are also relevant here.

Second, some participants focused on practitioners' responses to their own suggestions about possible treatments or self management plans. They could feel involved if practitioners listened to and discussed these. For example:

I: What kinds of things make you feel involved or uninvolved?

P: I don't know if it is relevant... but [I prefer to see doctors older than myself] to me that is important because I feel they do listen, and if I was to make a suggestion, even if it wasn't a balanced suggestion, then they wouldn't dismiss it but they would find something to work round it as well... I feel that the younger doctors are very headstrong and it is their word and that is it. (19)

Third, and most frequently, involvement was associated with practitioners recommending rather than ordering particular treatments, phrasing treatment proposals as suggestions, asking patients for their opinions and in some sense giving them an option. For example:

I: Why would you say that? ['Yes, definitely' in response to NPS question]

P: When I was asked if I wanted to test myself, the doctor didn't say I *had* to, he said if I *wanted* to. (20)

I: So what kinds of things make you feel involved?

P: I think being asked how I feel about what they are suggesting. I think being given choices, you know, things being explained properly to you and then the question being put to you, well how do you feel about this, or how will this fit into your lifestyle... I think if people took the time to sit with you and say, OK, here is where you are at, here are our concerns, if we offered you this, how

would it fit in with you, or there is an alternative to this, and give you choices that way. I think that would make me feel a lot more involved.

I: So what kind of things ... make you feel not involved?

P: I think when you're told this is what you need and there you go that is it.

When it is as black and white as that then I don't feel involved - when people are not taking account of how you are feeling. (01)

For most participants it apparently sufficed that they felt they had scope to safely query and say no to the practitioner's recommendation, and be confident that a reasonable alternative would be found if necessary.

I: How possible do you think it is for you to be involved in decisions about your care?

P: I think it *is* possible really, because if I don't want to do something or take something then I can just say and he will come up with a different – like an alternative. (20)

A few participants mentioned appreciating being told explicitly that if they tried a particular course of action and it did not suit them, an alternative could be found.

Several participants stressed that having a say was of little use if they lacked relevant information or were unable to have a 'meaningful discussion' with their practitioners about what was being recommended and why. Few participants talked in terms of being given a menu of possibilities and information about each and being encouraged to select an option, but some did mention discussing possible medication changes in one consultation with a view to making a decision in another.

Discussion

We have identified a number of features relating to communication about health problems and treatments and to the ethos and feel of consultations that people with diabetes associate with their involvement in treatment decisions. After considering the strengths and limitations of our study, we discuss the implications of our findings for the conceptualisation and assessment of patient involvement in decision-making and for practical efforts to promote patient involvement in decision-making.

Our study has several strengths. Our participants included men and women of different ages with diverse experiences of diabetes. We invited them to discuss involvement in decision-making in specific recent consultations and previous healthcare episodes, and they were able to refer to a range of treatment decisions and to compare and contrast their experiences of involvement in these. We used several questioning strategies to explore what involvement meant to people. Also, for each of the features that we identified as important for involvement we have examples of (a) patients who experienced these features associating them positively with involvement and (b) patients who did not experience these features associating their absence with a lack of involvement.

The main limitations of our study are: we studied only the views of people with diabetes; some participants may not have experienced or been aware of some possible forms of involvement in decision-making; and we did not ask participants to comment on features of healthcare that others had associated with involvement in decision-making. Our interest in understanding what people consider when responding to the National Patient Survey question about involvement led to a focus particularly on involvement in the kinds of decisions considered during consultations with health professionals (mainly decisions about interventions to which health professionals control access). We acknowledge that different issues would probably have emerged if

we had focused on patients' views about involvement in decision-making in relation to their daily self-management of their condition.

Implications for conceptualisation

We organised the issues that participants associated with involvement into three groups relating to: the ethos and feel of healthcare encounters; communication about health problems; and communication about treatments. These are not mutually exclusive. Communication about health problems and treatments may contribute to and reflect the ethos and feel of healthcare encounters, and communication about health problems and communication about treatments may overlap – consider, for example, discussions about treatment side effects. However, our groupings serve to draw attention to two issues (communication about problems and the ethos and feel of consultations) that have been neglected in considerations of patient involvement that have focused particularly on the exchange of information about treatment options and patients' influence on treatment selection.

Communication about problems

Clinical/academic models of patient-professional interaction during decision-making about the treatment of health problems often assume a clear and agreed problem (usually a specific diagnosis) as a starting point. Many of our participants, however, included communication about their health problems among the topics they associated with involvement in treatment decision-making. Involvement was associated with health professionals attending to patients' experienced difficulties, understandings of their problems, and priorities for treatment and life.

This finding is consistent with an analysis of consultation recordings that identified attention to patients' thoughts about health problems as an important feature of 'bilateral' approaches to decision-making by practitioners (Collins, Drew, Watt,

Entwistle, 2005). It may have been particularly apparent in our data because all participants had a long-term health problem. However, it lends support from a patient perspective to recent suggestions that models of patient-professional interaction or patient involvement during decision-making need to accommodate problem clarification and prioritisation, especially if the health problems to be addressed are complex or may be differently understood and prioritised by patients and health professionals (Entwistle & Watt, 2006; Murray, Charles and Gafni, 2006; Bugge, Entwistle & Watt, 2006).

The ethos and feel of interactions

It was striking that in their reflections on involvement in treatment decisions, our study participants placed a significant emphasis on the tone or manner of health professionals' communication, the interpersonal or relational messages that were conveyed by this, and the way they felt during consultations. Their subjective experiences of being respected, encouraged and enabled (or not) were important influences on their sense of involvement (or otherwise) in treatment decisions. This is in some contrast to the emphasis within the dominant policy/professional discourse about patient involvement which emphasises the content of information exchanged about treatment options and patients' preferences relating to these options.

The identification of features of the ethos and feel of interactions as important aspects of patient involvement in decision-making might in part be an artefact of patients' tendencies to bring a broad range of concerns to interviews and be willing to associate anything good about communication in healthcare with involvement in decisions about their treatment. However, several considerations lead us to think that these features should be considered integral to the concept of patient involvement in treatment decision-making.

First, in our own study, participants referred to these features frequently, including in response to carefully worded questions about decision-making. They spoke about issues relating to involvement *with* practitioners even though questions were phrased in terms of involvement *in* treatment decision-making (see Entwistle & Watt, 2006).

Second, the published findings from studies of patients' perspectives on related concepts also suggest that features grouped under our 'ethos and feel' heading are considered by patients to be salient for involvement in decision-making. For example: consumers who were asked about the outcomes that should be assessed in research into shared decision-making noted that they could not achieve the confidence required to participate in shared decision-making if they did not feel respected (Edwards, Elwyn, Smith, Williams & Thornton, 2001); adults who had been nominated as expert self-managers of their diabetes reported in the context of a study about empowerment that participatory decision-making was difficult to achieve when practitioners positioned themselves as the expert or sole authority (Paterson, 2001); acute medical and surgical patients who were asked about their preferences for involvement in decisions about their care identified clinicians' disinterest as a barrier to participation (Doherty & Doherty, 2003); and UK citizens who were asked about involvement in consultations made comments to the effect that: informing a patient is insufficient for involvement if there is 'no contact' in the discussion; there is a need for rapport and a feeling of having a discussion over and above an exchange of questions and answers; and it is of key importance that patients feel that they and their opinions are valued (Thompson, 2007).

Third, involvement does have a relational dimension and it is a function of subjective perceptions of engagement and affinity as well as of the more readily

observable aspects of action and information exchange. There is no obvious reason for excluding these from considerations of patient involvement in decision-making.

All this suggests that the models or taxonomies of patient involvement that emphasise information exchange and patient influence over option selection will need to be expanded or modified to accommodate the relational and subjective factors that our 'ethos and feel' features relate to. There have already been a few moves in this direction. Montori, Gafni and Charles (2006) recently suggested adding 'establishing an ongoing partnership' as a new first phase of the shared treatment decision-making model, and encouraged recognition that this partnership would and should evolve over the course of patient-professional communications. Entwistle and Watt (2006) proposed a conceptual framework for examining involvement in decision-making in which communication relating to decision-making was presented as central and patients' and clinicians' feelings and views about their relationships with each other featured as two of six other domains of involvement. Our findings endorse the inclusion of at least the patient's subjective perspective on the relationship. They also suggest that the central domain of this framework might need to be developed to emphasise other aspects of interpersonal communication in addition to the transmission of information about particular topics. These could include verbal and non-verbal cues that signal or foster understanding, respect, trust, relational orientation and commitment.

The incorporation of ethos and feel factors within the conceptualisation of patient involvement will complicate attempts to assess the extent or quality of patient involvement. They tend to broaden the focus of interest out beyond a punctate treatment decision. Also, while they are at least partially constituted by or within instances of information exchange, they nonetheless form an additional dimension of interest and will thus be difficult to incorporate within hierarchical taxonomies that distinguish

between levels of involvement on the basis of patterns of topic-focused information exchange and influence over option selection.

The relative significance of ethos and feel factors within an overall assessment of involvement is likely to vary for patients with different characteristics and facing different decisions. The weighting that should be given to them will need further consideration. However, their importance was highlighted by a survey of recently discharged hospital inpatients which found that being treated with respect and dignity, and having confidence and trust in healthcare providers were more strongly associated with patients' willingness to recommend a hospital than having been given enough say about treatment (Joffe, Manocchia, Weeks & Cleary, 2003).

Implications for policy and practice

Our findings suggest that if policy-makers and healthcare practitioners aspire to involve patients in decisions in the ways that patients appreciate, they will need to ensure that patients feel welcome, respected, supported as contributors and cared for in healthcare encounters; that their experiences of and concerns about their health problems and treatment are seriously attended to; and that they are given explanations about the medical view of their health problems that they can understand. Our participants varied in terms of their expectations about information about treatment options and their influence over decisions, but it seems that a minimum requirement for a sense of involvement is having an understandable rationale for any proposed treatment and a belief that they could safely query and decline any proposed treatments and explore alternatives with their clinician if required.

Patients' views about what matters are increasingly regarded as normative guides to the development and delivery of health services, but our study participants' views cannot serve as comprehensively indicative of the forms that efforts to promote

patient involvement *should* take. We do not think our findings imply that efforts to ensure patients are well informed and enabled to appraise treatment options themselves are all misguided. Our participants might not have experienced or been able to imagine being offered information about several treatment options simultaneously and being supported in the appraisal of each of these against their relevant preferences. The forms of involvement they expressed interest in were probably constrained by what they were familiar with. The appropriateness in different contexts of different approaches to informing patients about options and enabling them to have a say remains contested.

Our study findings also have practical implications for those tasked with addressing problems flagged up by responses to the National Patient Survey. They suggest that people who indicate they were not as involved as they wanted to be may be reflecting on disrespectful and disempowering communication from staff and/or a lack of attention to their views about their health problems as well (perhaps) as a lack of information about treatment options and/or a lack of opportunity to influence treatment selection in more than a veto-holding way. Healthcare providers who achieve low patient feedback scores on this question might need to do more than provide treatment menus and offer choice.

Conclusion

Our investigation of patients' understandings of involvement in treatment decision-making has highlighted the insufficiency of models and practices that focus narrowly on the exchange of information about treatment options and the activation of patients as choosers. It leads us to suggest that clinicians and researchers with an interest in patient involvement in decision-making need to attend to communication about health problems and to the ethos and feel of patient-practitioner interactions.

Attention to the more diffuse relational and affective aspects of patient involvement in decision-making would be consistent with, and perhaps facilitative of, a proposed shift in emphasis for normative thinking about communication and decision-making in healthcare. In particular it would be congruent with suggestions that bioethical concern should focus less intensely on ‘choice’ about ‘punctate decisions’ as a means of respecting autonomy, and pay more attention to a broader set of ethical considerations relating to respect for patients as persons (Joffe et al, 2003; Kukla, 2005; O’Neill 2002).

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Table 1: Participants' self-reported characteristics

ID	Age group, Gender, Diabetes type, Time since diagnosis.	Current medication/management	Current state of diabetic control (blood glucose (mmol/L) or HbA1c (%) if reported)	Other health issues	Main topics discussed and decisions made at recent visit
01	40–49 Male Type 2 19 years	Oral medication	Worsening slightly (Not checked “for quite some time”)	Obesity	Recent weight loss. Medication not changed.
02	40–49 Male Type 1 31 years	Insulin Prescribed doses	Well controlled	None	More “modern” insulin. No changes made.
03	50–59 Male Type 2 1 year	Diet only.	Well controlled 5.3%	Asthma, chest infections	Weight, diet, cholesterol. Cholesterol-lowering drug prescribed.
04	60–69 Female Type 2 2 years	Diet only	Well controlled 8.2%	Pernicious anaemia, uterine prolapse	Slight increase in blood sugar levels. To pay particular attention to foot care.
05	20–29 Female Type 1 10 years	Insulin Prescribed doses	Generally well controlled, but more ‘hypos’ recently.	None	‘New’ insulin. Participant to consider insulin options.
06	70–79 Female Type 2 22 years	Insulin Prescribed doses.	Well controlled	Heart and chest ‘complaints’	Insulin doses. No change made.
07	70–79 Female Type 2 4 years	Oral medication	Unclear 9.7%	Heart and thyroid ‘problems’. Recent pneumonia.	Improvement in blood sugar levels. No change to medication.
08	30–39 Male Type 1 8 years	Insulin Self-adjusted doses	Well controlled	None	Weight. Insulin regime not altered.
09	40–49 Male Type 1 6 years	Insulin Prescribed doses	Unclear (patient appears confused about diabetes).	None	Blood sugar readings. No changes to insulin regime or diet. Review in two weeks.
10	50–59 Female Type 2 10 years	Insulin (Unclear).	Improving after recent switch to insulin	Obesity	Recent weight loss. Insulin regime not altered.
11	60–69 Female Type 2 14 years	Oral medication	Well controlled	None	“Nothing much”. No medication changes.
13	40–49 Male Type 1 17 years	Insulin Self adjusted doses	Well controlled but intentionally has blood sugars around 10mmol/L to avoid ‘hypos’ on long outings.	None	Weight. Advised to lose 4lbs.
14	50–59 Male Type 2 13 years	Oral medication	Poorly controlled (medication changed after heart attack)	Depression, cardiac problems.	Reasons for changes to diabetes medication during hospitalisation. No further changes.
15	50–59 Male Type 2 18 years	Insulin (Unclear)	Well controlled	Recovering alcoholic	Blood sugar levels, weight, smoking and drinking. No changes to insulin regime.
16	60–69 Male Type 2 4 years	Oral medication	Quite well controlled	Cardiac problems Cellulitis	Additional Metformin 500mg daily prescribed (patient not sure why)
17	50–59	Oral medication	Well controlled	Angina, high	All current medicines.

	Female Type 2 2 years			cholesterol, under- active thyroid	No changes made.
19	20-29 Male Type 1 26 years	Insulin Self-adjusted doses	Well controlled 7.3%.	None	Weight and HbA1c level. No changes to insulin regime.
20	30-39 Female Type 2 1 year	Diet only	Well controlled, improving. 6.6%	Hypertension, obesity	Self-testing blood sugar at home. Participant will start.

Note: Participant ID numbers were allocated when people agreed to be contacted about the study. The people allocated ID numbers 12, 18 and 21 were not interviewed.

Box 1

'Involvement' and the 'ethos and feel' of healthcare encounters

Responses to questions about "What kinds of things make you feel involved?"

... Just getting the opportunity to say what you want to say. You never feel that there is anything I couldn't mention to my doctor. And again I don't feel that I have to mention things... I don't think that he would pressure me into saying anything... You don't feel that they are saying "This is what you have to do" or "Whatever happens to you is your fault" kind of thing. (05) 1c, 1d

Involvement. ... just giving me some flexibility and understanding about my lifestyle and my personal life and not dictating going back to the old school doctoring diabetes. And a bit of leeway. It makes me feel more confident that I can ask more and I hear more what they have to say as well. (19) 1b, 1c

Mainly discussion. I mean as a patient you do tend to think (well, I do!) if you try and get involved in the discussion process, is the consultant or the doctor feeling that "Look, I am the expert, don't question me. You are asking questions. Don't question my ability" type of thing. Are you interfering? You do sometimes feel that. (13) 1b, 1c

Explanations for responses to National Patient Survey question

[Yes, definitely] Because ... I got the feeling that if there was anything that I wanted to ask her she would have answered to the best of her ability and she was very open and friendly. She wasn't the least bit intimidating or anything like that. (04) 1a

[Yes, definitely] ... Well, the fact that she asks [about various other problems as well as diabetes]... So I feel that she is taking an active interest not only in my diabetes, in everything. (06) 1c

[Yes, to some extent] ... I think the impression I've always had with the diabetic clinic is they try really hard to deal with the patients they have. I don't think they have time to do themselves justice you know because I suppose they're just seeing a line of people going past. There's no relationship with a doctor or nurse... They just see you as a face that's going past them. Did you have cotton wool in your ear. They take the blood, they scribble it up, they write a number on it, "OK, down you go and sit down there"...[14] 1b

[Yes, definitely] ... I feel I am in very good charge of my own diabetes because I have had it for so long... They have recommended, obviously they like me to exercise ... and I did say that it has been a bit hard to do it at the moment [due to working long hours in response to an opportunity with tight deadlines]... I am comfortable in the fact that I can take a week off being a strict regimental diabetic as long as I keep an eye on my levels. ... I'm comfortable enough to tell my doctor this and he is comfortable enough knowing the fact that I will go back to being in control again. (19) 1d

Other questions

I: Is there anything else you would like to say about involvement in decisions? 1a, 1b
P: I cannot see how you can be involved when it's so impersonal... You cannot get involved... I get the impression you get these young doctors that are doing 6 months in the diabetic clinic and it's knocking in time for them (11)