

A qualitative exploration of treatment decision-making role preference in adult asthma patients

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Abstract

Objectives To explore preferred treatment decision-making roles, and rationales for role preference, and to identify perceived facilitators to and barriers from attaining preferred role.

Design Qualitative design.

Setting and Participants One secondary care and four primary care sites in North-west England. Purposive sample of 32 adult asthma patients with varied socio-economic backgrounds and disease severity.

Methods Tape-recorded focused-conversation style interviews. Interview topic guide derived from the literature. Sort cards employed to provide the focus for exploration of role preferences.

Results Active ($n = 7$), collaborative ($n = 11$) and passive ($n = 14$) decisional role preferences were identified. Respondents cited level of knowledge; trust; duration of condition; severity of condition at the decisional juncture; lifelong nature of asthma; a perception that 'it is my body'; characteristics of the individual and their response to health professionals as influencing role preference. Perceived facilitators and barriers to participation included condition-related knowledge, practical issues (e.g. lack of time during consultation) and clinicians' interpersonal skills.

Conclusions Most respondents wished to *contribute to* or *feel involved in* treatment decision-making, but not necessarily to *control* it. Some hindrances to participation would be amenable to intervention. The quality of the provider-patient relationship is central to facilitating participation.

Introduction

Service-user participation in treatment decision-making is widely considered to be desirable¹⁻³ and there is some evidence that it can enhance

clinical outcomes.^{1,4,5} Consequently, such participation is frequently encouraged in the literature^{1,3,6} and is central to health policy in many Western countries^{2,4,7} including the UK.⁸⁻¹¹ However, the importance of recognizing that

individuals may vary in their desired level of participation in treatment decision-making has been highlighted^{3,9} particularly as there is research evidence from a variety of fields that some individuals will wish to adopt an active role in treatment decisions, whilst others will wish to remain passive.^{1,6,12–16}

Many of the studies in this area have been quantitative, typically in the form of surveys^{1,15,16} and have explored individuals' desired level of involvement in treatment decision-making (i.e. their *decisional role preference*). Less attention has been paid to the reasons why individuals may prefer a particular decisional role, or what they consider may facilitate or hamper their participation. These areas would benefit from further exploration and it has been suggested that qualitative methods are most appropriate for such endeavours.^{6,17}

Desired level of participation in treatment decisions has been widely explored in some conditions, notably cancer.^{6,12,13,15,16} However, it is less well explored in other areas, amongst them asthma care. Whilst there has been some work exploring asthma patients' attitude towards self-management^{18–20} only two studies^{21,22} both from North America, have to date specifically addressed the extent to which asthma patients would wish to participate in treatment decisions.

Exploration of asthma patients' decisional role preferences is desirable from a number of perspectives. Asthma causes significant morbidity and mortality in the UK and is increasingly common.^{23,24} These individuals therefore represent a sizeable health-service user group in the UK. Much asthma management is undertaken in primary care and most decision-making occurs in the course of what might be described as 'routine' situations (e.g. general practice consultations and review clinics, either in primary or secondary care). This contrasts with the life-threatening situations, notably those relating to cancer diagnosis, which characterize much of the work in this area to date.^{1,16} Asthma patients typically have substantial input into the day-to-day management of their condition.^{25,26} For some patients, involvement will

extend to *adjustment* of therapy – altering medication dose or medications used, typically according to a self-management plan mutually agreed between the patient and their asthma clinician. This requires that patients engage in some degree of independent decision-making regarding their therapeutic regimen. The two existing studies of asthma patients' decisional role preferences have contrasting findings. Adams *et al.*²¹ found that patients wish to participate in certain decisions (e.g. changes to treatment regimen), but preferred to remain passive in most decisions regarding their care. By contrast, Gibson *et al.*'s²² work identified a desire for more involvement in decision-making. The need for further, in-depth studies is consequently apparent.

The aims of the study described here were therefore:

- to explore preferred roles in treatment decisions in a sample of adult patients with asthma;
- to explore patients' rationale for their preferred role and
- to identify patients' perception of facilitators to and barriers from attaining their preferred role.

Methods

Approval to conduct the study was sought from trust management and relevant research ethics committees. Invitation to participate was by means of a letter from the individual's general practitioner (GP)/consultant. All respondents were provided with an information sheet regarding the study, which was sent out with the letter of invitation and hence received some days prior to the interview. All respondents were asked to sign a consent form prior to being interviewed.

The study took place in the North-west of England. Data were collected from a cross-section of respondents from primary and secondary care. Three primary care sites were selected to facilitate inclusion of respondents from across the socio-economic spectrum (i.e. one from an

affluent area, one from a demographically mixed area and one from a socially deprived area). Two of the sites were group practices and one was a single-handed practice within a health centre. At one site (a group practice), asthma care was primarily GP-led, by a GP with a special interest in asthma. The other two sites had nurse-led asthma clinics, as well as a GP with special interest in asthma. The secondary care site was a specialist respiratory centre in a teaching hospital, which receives patients from across the North-west region.

Inclusion and exclusion criteria for the study are outlined in Box 1. Eligible individuals were identified from clinic lists at the secondary care sites and from asthma registers at the primary care sites. Purposive sampling was employed.²⁷ Selection of respondents was guided by review of the literature^{1,15,16} to identify possible influences on decisional role preference (such as age or social class) and subsequently by issues arising from within the interviews. Where more than one individual met sampling criteria, random selection was adopted.

The study employed a qualitative approach. Data were collected by means of focused conversation style interviews²⁷ which ensured that broadly similar areas were covered with each respondent, but allowed individuals to expand upon particular areas or to introduce new topics. The interview topic guide is presented in Box 2. Selection of topics to be addressed in the interview was guided by a review of the literature, pooling of experience from within the project team and advice from the Project Advisory

Box 1 Study inclusion and exclusion criteria

Respondents must be:

- Aged 18+.
- Able to converse in English.
- Free from any respiratory disease other than asthma.
- Physician diagnosed as having asthma.
- Taking at least bronchodilators for their asthma.
- Have had a prescription for asthma medications in the last 12 months.
- Non-smokers if aged 45 or over (due to likelihood of these individuals having COPD).

Box 2 The interview topic guide

Background information

Enquire about duration, severity and management of asthma

Decisional role preference

Explore:

Types of decisions

Preferred decisional role (use sort cards to focus discussion)

Rationale for choice

Facilitators to and barriers from obtaining preferred role

Types of provider

Demographic data

Identify respondent's age and current occupation

Group, whose members included a lay representative. The interview process was iterative, thus the format of the interview guide developed as the study progressed.^{27,28} Discussion of the types of decisions which might need to be made in asthma care was an important first step in confirming that the study topic was salient to asthma patients. A set of five sort cards (after Degner *et al.*¹⁶) was used to provide the focus for exploration of respondents' general role preferences (see Box 3 for contents of cards). Use of the cards had the additional advantage of enabling confirmation of their transferability to asthma (from their original target population of cancer patients). Identifying rationale for role preference was important as it enabled exploration of why the choice had been made and also of factors which might influence role preference

Box 3 The contents of the sort cards (after Degner *et al.*, 1997¹⁶) used to facilitate discussion of decisional role preference

- A. I prefer to make the final selection about which treatment I will receive
- B. I prefer to make the final selection of my treatment after seriously considering my doctor's opinion
- C. I prefer that my doctor and I share responsibility for deciding which treatment is best for me
- D. I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion
- E. I prefer to leave all decisions regarding my treatment to my doctor

or cause it to change. Identifying facilitators to and barriers from achieving preferred decisional role was important in understanding how and whether respondents' preferences were met. These items also further contributed to understanding respondents choices and what might influence or change these.

The interviews were conducted at a time and location of the respondents' choice; most chose to be interviewed at home. Interviews were tape-recorded, with respondents' permission. Field notes were made by the interviewer, immediately after the interview, in the form of tape-recorded addenda. All interviews were conducted by the same interviewer (A.C.), which ensured consistency. Quality assurance in the interview process was provided by means of discussions within the project team. The interviewer was a nurse without a clinical background in asthma. This was considered advantageous in preventing preconceptions about asthma and its care, and it was agreed that the interviewer should remain as naïve as possible to these issues throughout data collection and analysis. Respondents were made aware of the interviewer's professional and clinical background. They were further advised that she was working as a researcher and had no involvement in their asthma care. This appeared to facilitate discussion, particularly regarding facilitators and barriers to achieving decisional role preferences.

Data analysis

The interviews were transcribed verbatim and subjected to thematic analysis, using techniques described in detail by Strauss and Corbin²⁷ to enable identification of areas which could be grouped together as themes. This paper presents the main themes identified. An independent analysis was undertaken by all members of the team; there was a high level of concordance regarding the main themes. Discussions were held to reach an agreement where necessary, the main area of debate relating to the overlap between categories. Data collection ceased when category saturation was reached,²⁷ i.e. when no new themes were identified. Copies of the themes

identified by the project team were sent to 10 of the sample, to ensure that they accurately reflected respondents' views, and were confirmed as doing so by all of these individuals.

Findings

A total of 68 individuals were invited to participate, of whom 32 agreed to do so; the potential effects of this are discussed later. Six respondents from primary care were from the single-handed practice (in a demographically mixed area), five from the group practice in an affluent area and two from the one in a socially deprived area (this also being the site without a nurse-led asthma clinic). Demographic characteristics of the sample are detailed in Table 1. Determination of social class was based on the UK National Statistics Socio-economic Classification, NS-SEC.²⁹ Asthma severity was determined using the British Thoracic Society criteria²⁴ which use a step-wise approach, with Step 1 relating to mild asthma and Step 5 to severe asthma. Table 2 presents details of asthma severity in the sample.

Table 1 Characteristics of the sample (*n* = 32)

Age	
Mean	47 years
Distribution	18–84 years
Sex	
Male	<i>n</i> = 17
Female	<i>n</i> = 15
Socio-economic group (after NS-SEC, ONS, 2000 ²⁹)	
1. Higher managerial and professional	<i>n</i> = 1
2. Lower managerial and professional	<i>n</i> = 4
3. Intermediate	<i>n</i> = 4
4. Small employers and own account workers	<i>n</i> = 1
5. Lower supervisory and technical	<i>n</i> = 0
6. Semi-routine	<i>n</i> = 4
7. Routine	<i>n</i> = 0
8. Never worked and long-term unemployed	<i>n</i> = 9
of whom:	
Never worked (housewife)	<i>n</i> = 1
Long-term unemployed (all permanent sick)	<i>n</i> = 5
Student	<i>n</i> = 3
Retired	<i>n</i> = 9
Location	
Primary care	<i>n</i> = 13
Secondary care	<i>n</i> = 19

Extracts from the data within this section represent the dominant viewpoint (SC = secondary care; PC = primary care). Unless otherwise stated, the health-care professional referred to is a doctor.

All respondents were able to identify situations in which decisions regarding their asthma care would need to be made. Thus it was apparent that the topic of study was one with which respondents could identify. The types of decisions typically related to those regarding medications (commencement, changing or adjustment of therapy). Some respondents also mentioned lifestyle decisions pertinent to allergen avoidance (e.g. making adjustments in the home, such as removal of carpets; getting rid of a family pet to which one is sensitized, etc.). In all cases, these were seen as areas on which health professionals could advise, but where the ultimate decision rested solely with the patient.

Table 3 presents respondents' most preferred roles. As can be seen, respondents typically preferred the more collaborative roles, whilst the two extremes were seldom chosen, if at all. Illustrative extracts for the three commonly selected roles are presented in Box 4.

There were no clear patterns of role preference by age, gender or socio-economic group. However, this is not surprising given the study's

Table 2 Asthma severity in sample ($n=32$) per British Thoracic Society Steps (BTS, 1997²⁴)

BTS Step	Number of patients	
	Primary care ($n = 13$)	Secondary care ($n = 19$)
1	2	2
2	7	5
3	4	3
4	0	2
5	0	7
Total	13	19

Key to BTS Steps:

Step 1: Occasional use of relief bronchodilators.

Step 2: Regular inhaled anti-inflammatory agents.

Step 3: High dose inhaled steroids or low dose inhaled steroids plus long acting inhaled beta-agonist bronchodilator.

Step 4: High dose inhaled steroids and regular bronchodilators.

Step 5: Addition of regular steroid tablets.

Table 3 Respondents' most preferred decisional role (as selected from the vignettes presented in Box 3)

Most preferred decisional role	Primary care respondents ($n = 13$)	Secondary care respondents ($n = 19$)
A. (Fully active)	0	0
B. (Semi-active)	1	6
C. (Sharing)	5	6
D. (Semi-passive)	6	7
E. (Fully passive)	1	0
Total	13	19

sample size. Furthermore, it was not the purpose of the present, qualitative, study to seek to identify correlations between decisional role preference and demographic variables. A higher proportion of secondary care than of primary care respondents selected the relatively active role 'B'. This was interesting, particularly given that disease severity was typically greater in the respondents from secondary care.

Rationales for role preference

The following themes were identified from the data regarding rationales for role preference:

Patient's level of knowledge

This was perceived as being central to patients' ability to participate in treatment decisions. Lack of knowledge was viewed as disempowering:

'I've got the disease or ailment, whatever you call it – I'm not the man with the knowledge – the doctor's the man with the medical knowledge, not me.' (PC02)

'Well I think still the doctor because he knows what he's talking about more than, I mean I'm not medically trained so I don't really know what I'm talking about. He's studied it, he knows more than I do about all the drugs and everything so it should be up to him.' (PC13)

Conversely, possession of adequate knowledge was seen as facilitating participation, both in decision-making and in self-management.

'Erm well because I think it is important to understand your own asthma and your treatment, what is being offered to you and why. Erm and I

Box 4 Typical comments on preferred role in treatment decision-making

'Armed with all the information I can get, I would like to say, yeah, you know give me the long term view, I want the overview of everything and let me say, you know, I'll decide - but don't write me off because I'm disagreeing with you. You know, don't play God, let me have a say in what I can do. Some say in it. If it's, you know, coming to the crunch, obviously they know more than what you do about the drugs, but let's do it together.' (SC02, most preferred role = B)

'Erm, because that way we're both sharing responsibility for which drug I take. He's listening to what I find a problem with, and yet I listen to him about what the side-effects are, and things that I shouldn't take and then that way I can, I think that, we're both happy with (the decision) and that's good for me. Whereas if I took all the decision, I might not have - with not being through medicine or anything, medical school and things like that - I'm not going to know the side effects and things like that, and it wouldn't be a wise thing to do, I don't feel. Because then I'm not taking into consideration any problems that may occur and it might not be right for me at the end of the day. But then I don't want to leave it all to the doctor because he might like, you see, a generic drug, he might just prescribe me that, which is for everybody who's asthmatic, whereas I'd want something that is specific to me.' (PC09, most preferred role = C)

'I'm no expert on the condition of asthma, but it looks to me like, I mean, I read it (the sort card) like he says "he seriously considers my opinion." Erm, so that's like, it's obvious to me that if I had a doctor like that then he would be sitting with me and listening to what I've got to say. You know? As well as him telling me what he's got to say. So I have to listen to his point of view, he's listening to my point of view. and he's basically told me what he thinks would be best for me which, erm, suits me right down to the ground, you know? So if he's convinced me that after listening to what I have to say this is what treatment he thinks would be good for me then I would be quite happy to go away you know with knowing that.' (SC06, most preferred role = D)

like to take responsibility for my own asthma anyway so I think that is important. I think more people could do that if they had the information or they knew more and it makes you feel more responsible for your life. I don't feel completely dependent upon the doctor, which some people do when they suffer from asthma because they have got to go to the doctor all the time. But when I need to see a doctor then I see the doctor and I take his advice as well and I am happy to take his advice or his opinion but I do think it is important to be able to share it (the decision).' (SC14)

Trust in health professionals and in efficacy of treatment

This theme was closely linked with knowledge – many respondents felt that they had to place themselves in professionals' hands because of lack of knowledge. Trust was also related to decisional role preference. Typically, those with a greater level of trust in health professionals and/or their treatment regimen were more willing to adopt a passive role in treatment decision-making:

'I think it's just trust, trust in the doctor. You know, I don't think I can say any more than that really ... Even if I'm just a little bit, er, or if I've got a bit of a cough he'll say, oh come on, we'll have a listen ... And he tells me exactly what's going on ... and er, he always seems to get things right for me.' (SC09)

Length of time with condition

Respondents indicated that the length of time they had had their asthma was an important factor in the extent to which they could participate in treatment decisions. Typically, greater duration of asthma was associated with a greater perceived level of knowledge about the condition and its management and thus was seen as facilitating participation in treatment decisions and, indeed, in self-management decisions:

'I certainly think erm you have got to have experience of your own asthma to be able to make the decision because I wouldn't have made the decisions I make now 15 years ago. I didn't know enough about it, I did not know about my own asthma and it is only experience of that that lets you know really what to do and why. I don't think anybody that is newly diagnosed with asthma could really know when to actually take their own drugs and be able to manage it that way.' (SC14)

Severity of condition at decisional juncture

Most respondents reported that they would prefer to leave decisions in the hands of health professionals if their condition was severe at the decisional juncture. This was typically related to

situations where they might be experiencing an asthma attack, especially if this required hospitalization:

'I think in an emergency situation in the majority of cases the decision about what medicine is used is more a medical decision than a patient decision. Any decision about not using a particular medicine has to be taken out of the context of the actual situation where the person is in dire need.' (SC01)

Other related factors perceived as reducing the individuals' ability to participate were physical or mental incapacity (e.g. unconsciousness or cognitive impairment).

Lifelong nature of asthma

This was distinct from duration of the condition and related to the chronicity of asthma. It related to a perception that, asthma being life-long, the individual will have to live with the consequences of any treatment-decisions and hence should be involved as of right:

'It's me that has to deal with the medication, with the treatment the doctor doesn't. He doesn't have to live with it 24 h a day, I do. He hasn't got the problem. I've got to consider how it's going to affect my quality of life.' (SC02)

Perception that 'It is my body'

Respondents expressing this view felt that they should always be involved to some extent in treatment decisions, because it was 'their body' into which treatment would be ingested. There appeared to be two elements to this – first, a desire for control over what would happen to them:

'Well it gives the patient some sort of decision about how their life is run and that's what the person should have ... because it is your body.' (SC01)

'It's your body, your life, what's going to happen to you is, is up to you.' (PC10)

The second element was a dislike of being treated as merely as a passive recipient of therapy, as one respondent put it

'... more or less as if you're like an animal really. I mean you take an animal to the vet and he does all

the work and that's what happened there (at the hospital). They do it and they never asked me what I wanted they just said "Oh, you've got asthma we'll cure you in fortnight". And that was it.' (PC02)

Characteristics of the individual

The respondents identified a number of such factors which, in their view, would impact on an individual's ability to participate in treatment decision-making. Older individuals and children were seen as more dependent on others with respect to decision-making. It was interesting that old age was considered by respondents to increase passivity, given that there was actually a range of preferred roles in the older individuals in the sample.

Some respondents suggested that intelligence could affect ability to participate in decision-making:

'But I think it's going to vary very much from patient to patient, except for reasonably intelligent people that can manage it themselves, where perhaps like some less fortunate people would probably have to be told what to do.' (PC04)

The individual's degree of curiosity and assertiveness were also suggested as potentially influencing participation:

'You know if the sufferer, if the asthmatic is not prepared to go out and try and find it, the GP is not psychic, he can't know what to tell you. So it is a two-way thing, you as in the medical side need to tell us make us more aware, make others more aware, make us aware of what's going on, the new issues and we, if we are concerned about our own health, need to come out and start asking the questions and getting the answers.' (SC19)

As well as characteristics of the patient, respondents also identified characteristics of health professionals which could affect patients' involvement in decision-making or influence their preferred role:

'The way he talks, the way he treats patients, his manner, his listening ability, his supportiveness, maybe his sympathy sometimes, his tolerance, his acceptance of, er, his acceptance of the importance of the patient, of what a thing might be, as against

the importance he sees it – which I think is very important. I just think to communicate again.’ (PC07)

‘We changed doctors to this one ‘cos the other one, he was always – he never made us feel as though he wanted us there. And you have to feel as though you can discuss something with your doctor, and if he doesn’t want you there he’s like trying to get you out of there so he can see somebody else. And he didn’t seem to put all the effort into it or prescribe you such and such a thing. And his attitude in general – the whole family thought “get lost”.’ (PC09).

Patient’s response to health professionals

Views under this theme were polarized into those who took the view that ‘the doctor knows best’ and those who rejected this stance. Those who felt that the doctor knows best typically considered the doctor, as a medical professional, to be the most appropriate person to make treatment decisions, as the following extracts illustrate:

‘He has got expertise and at the end of the day, you know, he is the one that is going to help me, yes, so I just feel that, because I do have faith in the doctor, and I know that he knows what he is talking about.’ (SC04)

‘I am quite happy if the doctor says X, then that should be what happens. All the treatments I have ever had, which isn’t particularly many are formed that way.’ (SC08)

‘I mean, if your car breaks down you don’t go to a plumber with it do you?’ (PC02)

Not surprisingly, those adopting this type of approach typically preferred a passive role in treatment decision-making.

By contrast, other respondents considered this passive faith in the doctor to be an old-fashioned and inappropriate response:

‘... (it’s) a form of idol worship, I suppose really, which I just don’t believe in, but a lot of people do because a lot of people think if you’ve got a degree you’re something special to begin, where I don’t.’ (PC07)

Respondents adopting this type of approach typically preferred a collaborative or active decisional role.

Facilitators to and bars from participating in treatment decisions

Respondents highlighted a number of factors which could facilitate their participation in treatment decisions (see Box 5), or conversely could hinder their doing so (see Box 6). There was some overlap between these and the factors contributing to an individual’s most preferred role. It was interesting to note that many of the factors, particularly the bars to participation, related to professional–patient relationships.

Other considerations

Specialism vs. generalism

Some respondents, from both primary and secondary care, highlighted differences in the roles of specialist health professionals as compared with generalists. Typical views are illustrated in Box 7. Secondary care respondents typically indicated that specialist care was preferable for asthma patients. ‘Specialists’ for these respondents were always hospital-based, predominantly consultants, with some also mentioning the specialist nurse and one the physiotherapist. The views of primary care-based respondents were

Box 5 Perceived facilitators to patient participation in treatment decision-making

- Possession of sufficient information.
- Health professionals being willing to listen.
- Good provider–patient relationship.
- Continuity of care.
- Assertiveness on the part of the patient.
- Length of time with asthma.

Box 6 Perceived hindrances to patient participation in treatment decision-making

- Lack of knowledge regarding the condition and its treatment.
- Health professionals with poor inter-personal skills.
- Lack of time.
- Personal characteristics of the patient.
- Health professionals’ unwillingness to listen or accept patients’ expertise.
- Being in a life-threatening situation.

Box 7. Typical views on the roles of specialists and generalists

'You know I wouldn't expect him (GP) to be a specialist in just the things I suffer because the next patient is going to have something completely, completely different. So he can't be a master of all trades in that respect. But so long as he appreciates that, not just asthma but anything, he could put you through somebody else in his practice or there is someone else that he can send the patient that he understands more, then he should have the decency to say that.' (PC03)

'Erm my GP has got a limited knowledge whereas somebody like Dr X has specialised in it. He is the most important one definitely. If I had to cut out one it would be the GP ... For something as serious as asthma yes definitely. If it was eczema, it's a different situation, it's not life threatening, but asthma is and it can affect me so badly you know that sometimes I cannot even get out of bed, I can't brush my teeth, I can't breathe, that badly. So yes definitely it is important that I have got that specialist knowledge.' (SC19)

more mixed, with some indicating that 'specialist' meant hospital-based care, whilst others recognized specialist knowledge as existing within primary care. Typically, however, there was a view that the knowledge of primary care practitioners was bound to be limited, because of the wider range of patients with whom these professionals have contact, as the extract in Box 7 illustrates.

The role of health professionals other than doctors

As the sort cards (Box 3) mentioned only the doctor's role in treatment decision-making, respondents' views on the role of other health professionals in treatment decision-making were also explored. Some respondents did identify an actual or potential role for other professionals in the decision-making process; however, most felt that this process was typically doctor-led and that this was as it should be. The extract in Box 8 – made by a respondent from a primary care site with an active nurse-led asthma clinic – is typical of respondents' views on the role of others in treatment decision-making. Amongst those who did see a role for other health professionals, nurses, either the hospital-based res-

Box 8. Data extract illustrating typical view on role of health professionals other than doctors in treatment decision-making

'I think they (nurses) should (be involved in treatment decisions), to be honest with you the answer is yes. But I don't think it's acceptable at the present stage, because I don't think the public have enough respect for them - which they should have ... But I think the final word has got to come from the doctor or from the consultant. And the nurse is very good for saying "Dr So would do this or Dr X advises that". They (patient) would listen to that quite healthily, but I don't think they (nurses) should tell you what to do. Although they might know better more so than the doctor 'cos they're doing more of it. I mean the perfect example, is nurses with injections in the arm or the hand. Well the nurses can do it just like that, and consultant maybe one a month and he's faffing and faffing. But some people want the big man to do it, but the big man can't do it whereas the little girl can do it. But I think when it comes to that kind of decision (i.e. re treatment), it's got to come from a qualified (person).'

(PC07)

piratory specialist nurse or the practice nurse, were the group most commonly cited; one respondent also mentioned the hospital-based physiotherapist. Interestingly, a number of respondents commented that nurses were valuable in terms of providing explanations or in making suggestions to the patient and/or doctor about changes in the treatment regimen – but that the ultimate decision-maker was the doctor.

Discussion

This study presents a unique insight into asthma patients' perspectives on participation in treatment decision-making, and in particular why it is that they prefer a particular role.

Fourteen of the 32 respondents (43.7%) preferred a passive decisional role. This is similar to findings from studies in cancer patients^{12,16} which is interesting given that asthma is a chronic condition in which self-management is encouraged.^{25,26} The high proportion of respondents preferring a passive decisional role is notable given that recent UK health-care policy promotes consumer participation in such areas as treatment decision-making.^{8,10}

As the data presented here illustrate, respondents in this sample were happy to acknowledge health-care professionals' expertise in asthma care, but typically felt that they too wanted some input into the decision-making process. Such input extended to their feeling included in the decision and having their views respected, but the majority did not want to take control of decision-making. This is consistent with the shared decision-making models described by such authors as Degner *et al.*¹⁶ Charles *et al.*³⁰ and Emanuel and Emanuel.³¹ It was also apparent, as the first of the extracts in Box 4 illustrates, that these respondents were typically not prepared to give unconditional acceptance to professionals' recommendations, but rather needed to be persuaded of their benefits. Deber *et al.*³² discriminate between aspects of treatment decision-making which require technical expertise and those which require personal knowledge of the patient and their preferences or values. Respondents in this study identified these as contributions for, respectively, the professional and the patient, professionals bringing clinical expertise and knowledge regarding medications and so forth, whilst the patient brings the personal knowledge.

The findings give important insights into patients' views on the nature of *participation*. Some individuals preferred decisional roles which closely accord with a consumerist approach. This model is not, at present, widely adopted in UK health-care, which is primarily state provided. Others selected a collaborative role, typical of the type advocated in recent UK health-care policy.^{8,10} Some of those respondents who selected a passive decisional role appeared to have made a conscious choice to defer to health professionals in this regard, typically because of their belief that 'the doctor knows best'. This might be described as 'actively choosing to be passive'. The need for both policy makers and practitioners to be aware of differences in individuals' preferences regarding their level of participation in treatment decision-making has been highlighted.^{3,9} It could be argued that *choosing* to be passive is a valid form of

participation and should be acknowledged and respected as such. Others who reported adopting a passive role indicated that they did so because they felt they lacked the knowledge, experience or confidence to participate. These individuals could be viewed as being disempowered, rather than choosing to adopt a passive role. It may be that with appropriate attention to information-giving – or to some of the other factors highlighted as bars to participation (e.g. lack of time, health professionals' poor communication skills) – these individuals could play a more active role in treatment decision-making. Neufeld *et al.*³⁴ for example, have reported on a successful intervention designed to increase an individual's level of participation in treatment decision-making.

It is also notable that there were many similarities in what was desired in terms of decisional role – being *included* in the decision, receipt of information, listening *and* being listened to. When viewed alongside the perceived facilitators to and bars from participation (Boxes 5 and 6), it would appear that the quality of the professional–patient relationship is crucial with respect to patients' participation in treatment decision-making. The centrality of this relationship to the process of treatment decision-making has been highlighted by Roter.³ Likewise, the communication style adopted by a health professional has been noted to be central in either facilitating or preventing patient participation in treatment decisions.^{3,6} The present study's findings would suggest that there is still some way to go in improving the quality of patients' experience in this regard. Mechanic and Meyer³⁵ identified factors which contribute to development of trust in health professionals; the quality of the patient–professional relationship was central to these. Trust was an important factor in decisional role preferences in the study reported here. This accords with earlier UK findings.^{12,14} It would appear that trust is still as strong today as it was in earlier studies – a notable finding, particularly given that several 'health scares' (e.g. the Harold Shipman case) have arisen during the intervening period (and indeed were on-going during data collection for the present study).

The extracts in Box 4 serve to illustrate differences in approach to the professional–patient encounter according to most preferred decisional role. This suggests that health professionals may need to adopt a different consultation style according to the patients' preferred decisional role – which in turn requires that the role preference is known. As the respondents themselves highlighted, and has been suggested elsewhere^{4,33} this can be difficult in a short consultation and where the patient and clinician are unfamiliar with one another.

Limitations of the study

The present study's qualitative design gives it high internal validity, but low external validity and hence limited generalizability. Further, quantitative studies exploring the extent to which the themes identified here recur in other samples would be of benefit.

The recruitment rate in this study was approximately 50%. The use of purposive sampling, with selection of respondents being guided by relevant literature and issues highlighted during data analysis will to some extent have compensated for the low recruitment rate; however, it must still be acknowledged as a limitation of the study. Recruitment was lower in primary than secondary care. Although this reflects a nationally reported problem in primary care-based research in the UK^{36,37} it may have influenced the themes arising from the data, particularly regarding specialism vs. generalism and the role of professionals other than doctors.

The exclusion of individuals from minority ethnic groups who could not hold a conversation in English is recognized as a limitation of the study, as it is possible that their decisional role preferences may differ from those of the majority population.^{2,38}

Conclusions and recommendations for further work

The findings from this study suggest that patients have identifiable preferences regarding their role in treatment decision-making. These

can be elicited through appropriate questioning – which in itself can be facilitated by, for example, using vignettes such as those employed in the present study.

The data suggest that most respondents wished to *contribute to* or *feel involved in* treatment decision-making, but not necessarily to *control* it. A number of factors, some of which would be amenable to intervention, were identified as hindrances to participation. The quality of the provider–patient relationship appeared to be central to facilitating participation.

Given the increasing role that nurses play in asthma management in the UK, especially in primary care, it would be interesting to conduct future work exploring asthma patients' views on nurses' roles in treatment decision-making. This would be particularly timely given the recently announced expansion in the UK of nurse prescribing.

Exploration of decisional role preferences in asthma patients from different localities and from health services in different countries would be worthwhile to confirm the external validity of these findings. It is essential to explore decisional role preference in asthma patients from minority ethnic groups and not to extrapolate these results to the whole population.

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