

'Permission to participate?' A qualitative study of participation in patients from differing socio-economic backgrounds

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Abstract

Participation in health care is an important element of self-management in chronic illness, and policy emphasises patient's choice. Evidence suggests that this may be inequitable and inadequate, since active participation is strongly associated with socio-demographic variables. This qualitative study explores the perceptions of participation in people with differing socio-economic status with themes related to health literacy and relationship with health-care professionals. Patients perceive participation in different ways, related to their prior expectations of a health-care consultation, cultural expectations and social position. Policies aimed at simply improving 'health literacy' and choice will not be successful if these broader disparities are not addressed.

Keywords

choice, health literacy, participation, self-management, shared decision-making

Introduction

Government policy places emphasis on improving and supporting patient choice in health care (Department of Health (England), 2010), and globally, participation in clinical encounters is considered an essential element of self-management in chronic illness because it provides opportunities for information giving, accessing and mobilising supportive resources, the sharing of problems and technical advice about self-management and enabling an active role for patients. In response to the documented theories of participation, clinicians and public health advocates have focused on addressing information, choice

and shared decision-making (SDM) as a means of promoting participation. Clinically, attention to 'participative' contexts has resulted in a shift towards an awareness of the need for sensitive

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communication, (e.g. patient-centred communication; SDM). (Charles et al., 1999; Mead and Bower, 2000). These approaches may still be inadequate and inequitable given that an active participation is strongly associated with the demographic variables; younger, female, educated and articulate patients of higher socio-economic status (SES) are more likely to participate in their health care (Say et al., 2006).

Current definitions operationalise and describe the patient as a key actor in the process of patient participation. In a review of the intervention strategies to increase the participation in the clinical encounter, Haywood et al. (2006) describe participation as,

an interaction, or series of interactions between a patient and the healthcare system or health care professional in which the patient is active in providing information to aid diagnosis and problem-solving, sharing his/her preferences and priorities for treatment or management, asking questions and/or contributing to the identification of management approaches that best meet his/her needs, preferences of priorities. (p. 13)

Participation is likely to benefit those with a chronic condition from disadvantaged circumstances most, since actively participating patients have measurably better health outcomes than those who do not (Kaplan et al., 1989; Greenfield et al., 1985; Eldh et al., 2008), and intervention strategies designed to increase patient participation are likely to have more advantages than others (Protheroe et al., 2009). However, current definitions fail to refer to equity in the ability and capacity to participate and thus ignore the impact of external contexts, social status and marginalisation on the participation process.

Barriers to participation described in the literature include the status/power differential between the health professional and the patient (McGregor, 2006), the divergence of lay and professional health beliefs and knowledge (Rogers et al., 1997) and 'health literacy'¹ (Edwards et al., 2009; Ishikawa and Yano, 2008). The latter is viewed as the

mediator of information exchange between the individual and the health professional within the consultation (Edwards et al., 2009). In addition, individuals with lower health literacy are considered to be less likely to be adherent to medication instructions and likely to have poorer self-management skills (Berkman et al., 2011; Schillinger et al., 2002; Wolf et al., 2006).

This article explores patients' understandings and experiences of participation in health care, among people with a variety of background (both lower and higher SES). The aim of this study is to explore the aspects of participation and contribute to better understanding and thus facilitation of participation in health care. In addition, this research aims to examine why educated, articulate patients of higher SES (Say et al., 2006) may be more likely to participate in their health care and why those of lower SES are less likely to do so.

Study methods

The study took place in the north-west of England. Initially, four general practitioners (GPs) were approached and agreed to take part in the study. These four were located in relatively disadvantaged areas of the city based on their Index of Multiple Deprivation (IMD). After the initial iterative analysis of these data (early analysis began after the first few interviews, and new themes or areas for exploration were added to the interview schedule), a further four general practice centres were approached from relatively advantaged areas were recruited to the study to further explore themes that had emerged from the initial data.

People on chronic disease registers for diabetes mellitus, chronic obstructive pulmonary disease/asthma and coronary heart disease were contacted by their GP and invited to opt in to the study. Letters were sent out to 10 patients per practitioner at a time, enabling a broad recruitment from all the practitioners' areas. The participants

Table 1. Demographic data for participants included in the study

Demographic	High SES % (n)	Low SES % (n)
Gender		
Female	64 (n = 9)	48 (n = 10)
Male	36 (n = 5)	52 (n = 11)
Age		
45–54 years	21 (n = 3)	0 (n = 0)
55–64 years	21 (n = 3)	19 (n = 4)
65–74 years	29 (n = 4)	52 (n = 11)
75 or over	29 (n = 4)	29 (n = 6)
Ethnicity		
White British	100 (n = 14)	95 (n = 20)
Black Caribbean	0 (n = 0)	5 (n = 1)
Marital status		
Married	64 (n = 9)	52 (n = 11)
Divorced	7 (n = 1)	5 (n = 1)
Widowed	22 (n = 3)	5 (n = 1)
Never married	7 (n = 1)	9 (n = 2)
Cohabiting partner	0 (n = 0)	5 (n = 1)
Missing	0 (n = 0)	24 (n = 5)
Work status		
Retired	71 (n = 10)	90 (n = 19)
Full time employed	29 (n = 4)	0 (n = 0)
Long-term sickness/disability	0 (n = 0)	10 (n = 2)
Accommodation		
Owner occupied/mortgaged	86 (n = 12)	33 (n = 7)
Rented	0 (n = 0)	43 (n = 9)
Other living arrangement (e.g. sheltered housing)	7 (n = 1)	10 (n = 2)
Missing	7 (n = 1)	14 (n = 3)
Chronic disease register		
Diabetes	14 (n = 2)	47 (n = 10)
Chronic obstructive pulmonary disorder	0 (n = 0)	29 (n = 6)
Chronic heart disease	51 (n = 7)	24 (n = 5)
Stroke	14 (n = 2)	0 (n = 0)
Asthma	7 (n = 1)	0 (n = 0)
Other	14 (n = 2)	0 (n = 0)
Co-morbidities		
Yes	64 (n = 9)	76 (n = 16)
No	36 (n = 5)	24 (n = 5)
IMD 2007 score (mean, minimum–maximum)	5.1 (1.4–12.8)	48.9 (19.5–78.1)

SES: socio-economic status; IMD: Index of Multiple Deprivation.

were interviewed in their own homes. The semi-structured interviews were conducted by two researchers (C.G. and H.B.) and were supplemented with some basic demographic questions. The interview schedule covered aspects of taking part in health care identified by the literature. The schedule and the data collection were iterative in nature, and adapted to explore themes emerging from the data.

Interviews were continued until data saturation was achieved. The interviews were digitally recorded, with participant consent, and then fully transcribed. The data were analysed using a framework analysis developed initially by themes agreed through discussion (Ritchie and Lewis, 2003). An initial coding framework was developed with reference to the transcripts, the original study protocol, the research question and the literature. The transcripts were checked against the framework to ensure that there were no omissions. Codes were examined across individual transcripts and then the entire data set and allocated to the framework. The categories were refined and broader concepts emerged from the data linking codes across the interviews. Data were interpreted and analysed within the framework, and the themes were agreed through discussion within the research team.

Findings

In total, 25 per cent of the invited patients consented to be interviewed (35/140) – of these four patients were two married couples who were interviewed together, therefore the interviews were transcribed and analysed as a single interview. Therefore, 33 interviews were transcribed and subjected to analysis. Of these, 19 were with patients who lived in areas of relative socio-economic disadvantage (on the basis of their IMD) and 14 were from patients who lived in areas of relative socio-economic advantage. For the purposes of the analysis, patients were divided into

two groups, described as low SES (if their IMD was 15 or less) or high SES (if their IMD was greater than 15). Basic demographic data were collected and are represented in Table 1.

Four emergent themes described participation in the consultation: the legitimacy of asking questions, active information seeking, using knowledge and understanding of information and relationship with the health-care system and professionals. The data are presented from the themes analysed.

The legitimacy of asking questions

Asking questions of the health professional within the consultation is traditionally viewed as enabling increased knowledge and understanding of one's health condition. Here, there were nuances evident between respondents in terms of whether and what types of questions were reportedly asked in a consultation.

Several participants reported not being able to ask questions at all, despite an expressed desire to do so, because of a perceived lack of opportunity or a feeling that it was inappropriate to ask primary-care clinicians questions, requiring 'permission' to ask. Other patients (from the lower SES group) expressed no desire to ask questions, suggesting that this was not part of their expected role, and even saw it as unacceptably challenging to the health professional.

While some participants in the lower SES group did report asking questions, there were differences in the nature of the questions that were described as being appropriate to ask within a consultation between this group and the higher SES group. The lower SES group tended to report asking questions related to their medication. This contrasted with more in-depth questions, and specific requests, relating to the wider health condition and chronic disease management reportedly asked by participants in the higher SES group.

Box 1. Legitimacy of asking questions.

'... maybe if he said to me first, you know, "you're not sorting, you're not getting this sorted out very well are you and what can we do extra?"'

Pt ID 21 (male, 72 years, CHD and COPD; low SES).

R: 'I'm not seeing the doctor, but then if everything is ticking over with the nurse maybe I don't need to see the doctor, but I just feel that, you know, you should see a doctor'.

Q: Have you mentioned that to ...

R: No, I haven't actually ... No. I'll ask her next time I go. 'How come I've not seen the doctor?' you know, but then she could say 'but what do you want to see the doctor for?' and I'd say, 'well, I don't know' ...

Pt ID 25 (female, 66 years, diabetes, low SES).

'No. They want to do their own job, I'm only a layman, I don't know what they're doing. They know better than me, so leave them and let them get on with it'

Pt ID 23 (male, 74 years, CHD and COPD; low SES).

'well they're supposed to be in a position what they should know right away and people like us, well common people, you can't ask a bloke who's been trained all them years, its rude'.

Pt ID 20 (male, 75 years, CHD and COPD; low SES).

'I'm monitoring my blood pressure myself and I took the readings to him. I also requested, I said, "why don't we do some, you know, the whole gamut of tests" ... he gave me a copy there and then [the test results] and we both had a look at them together, he said, "you've nothing to worry about ... but you should go on medication." He wanted to put me on 5mg [Blood pressure medication] and I said "no, let me monitor my blood pressure and find out if I've got it under control ... I'm not a great believer in overdosing if you don't need to" So the last time he said "well I think I should put you on 5mg, that's the recommendation." So I said, "No, lets keep it at 2.5"

Pt ID 1 (male, 80 years, stroke; high SES).

'I'm interested you know, I want to know what's happening in my body ... what do these tablets do, why will it work, what are the side-effects?'

Pt ID 2 (male, 52 years, renal disease; high SES).

Active information seeking

Seeking information outside of the consultation can be considered to be an expected and essential part of the traditional model of participation. Indeed, ideal type models of patient-centred consultations encourage the formulation of questions based on information prior to seeing a health professional and engagement with external sources post-consultation. The participants who described a variety of information-seeking activities (books, leaflets, media, Internet and medically qualified friends) were without exception from the higher SES group.

Some respondents (most from the lower SES group) described reasons for not seeking information. Some stated that they already had sufficient information from their health professional, others expressed a lack of interest or a desire to do so.

Practical barriers to looking for information (difficulties reading or understanding written information) were identified by a few respondents in the lower SES group. The only finding in which there was no clear split between the participants from lower and higher SES groups was Internet use. The majority of participants who did have access to the Internet (9 of 19, 47%, in lower SES group and 2 of 14, 14%, of the higher SES group had no home Internet access) were wary of using the Internet to explore information about their health. Reasons given for caution were a feeling of information overload and a perceived lack of quality assurance of the information that could be accessed. By contrast, some participants in the higher SES group felt that they had the skills to critically evaluate information accessed through the Internet and from other sources.

Box 2. Active information seeking.

'I've got that BMA book that I like, an encyclopaedia of health, and that's very, very good I think. So if I think there's something I might have, or someone in the family, I have a quick look there first 'cause I think that's very reliable. Erm occasionally on the internet for some things, but I think that there's a danger that you get every possible

(Continued)

Box 2. (Continued)

American kind of thing that ever been written and sometimes it can go over the top’.

Pt ID 19 (female, 64 years, CHD; high SES).

‘they know what they’re doing so I leave it to them’ ‘I’ve seen leaflets there, and programmes on the telly – it doesn’t bother me’

Pt ID 23 (male, 74 years, coronary heart disease and COPD; low SES).

‘you can read anything in books and papers, but I think in the end he’s [GP] the one who knows better’.

Pt ID 20 (male, 75 years, CHD and COPD; low SES).

‘I don’t think there’s anything else I need to worry about’.

Pt ID 32 (female, 67 years, diabetes, CHD and COPD, low SES).

‘I think sometimes you can know too much, you can look into things too much and um, think that you’ve got things that you haven’t got maybe ... I tend to jog along and hope for the best’

Pt ID 5 (female, 63 years, asthma; high SES).

Using knowledge and understanding

Using health knowledge to take part in decision-making about treatments and active self-managing was identifiably linked in peoples’ narratives to active information seeking, and again was almost exclusively reported by respondents from the higher socio-economic group.

In contrast, a lack of understanding of one’s own health condition could be viewed as acting as a barrier to participating in decisions about management and effective self-management. Some respondents from the lower socio-economic group described ways in which they had tried to overcome limited health knowledge, for example, by accessing the health knowledge resources within personal social networks, such as family members or friends in health-related

employment; other patients expressed a desire for greater use of lay terminology within consultations.

Box 3. Using knowledge and understanding.

R: So I just thought about it and thought well you know, I could do this myself. So I go to the gym now and I’ve been, I’ve set myself things to do like standing on one leg and turning round on the other leg and bouncing down on my knees and all that sort of, thing. It ...

Q: You’ve set yourself goals?

R: And I read a little bit about strokes and it said that whilst some of the nerves get destroyed during the course of the event, the other nerves with practice take over ...

Q: Right.

R: ... their function, what’s been destroyed and that seems sensible to me because, as I say, I am getting, I am improving.

Pt ID 1 (male, 80 years, stroke, high SES).

‘Well I always thought it was Type 1 you know, ... but I don’t know, I don’t really know you know? I’m on a lot of insulin ... It confuses you quite a lot’. [Uncertain whether diabetes is Type 1 or Type 2 – difficult looking on the internet]

Pt ID 21 (male, 72 years, CHD and COPD; low SES).

‘I wish they would speak in a language you can understand’

Pt ID 32 (female, 63 years, COPD, CHD and diabetes; low SES).

The impact of relationships with the health-care system and professionals

Many respondents conveyed a strongly held sense of what was expected of them as a ‘patient’ and what they in turn expected of health professionals. Some of the expectations of health professionals were referred to in paternalistic terms conveying a passive role for the patients, that is, that the doctor should ‘look after’ the patient. Expectations of the patient’s

role referred to the need to express their concerns fully, answer questions as honestly as possible and then await the doctor's medical opinion telling the patient what to do. It is for the health-care professional to worry about patients, to be the guardian of information (diagnosis, test results and information) and to monitor the patient and check that they are on 'correct' medications.

Linking to the previous theme, these expectations about 'patient roles' often precluded the task of asking questions, seeking and using other sources of information. Many of the respondents were content with this situation, and considered themselves to be participating in their health care, by conforming to a set of demarcated and limited 'roles'.

These normative expectations about the relationship between the patient and health-care professionals were held by the majority of respondents from the lower SES group and could be considered a significant barrier to the traditional notion of active participation, which requires more engagement on the part of the patient. The respondents from the higher SES group perceive more responsibility for looking after themselves and for checking up on the health professionals requiring much more work engaging with information; this is demonstrated by looking for second opinions, or corroborating medical advice with written information.

The respondents also described different relationships with respect to the health-care system. Almost all of the respondents expressed a desire for continuity of care with their health professionals but reported varying degrees of success with this. A barrier that was repeatedly cited by respondents from the lower SES group was of the increasingly complicated appointment systems in place in primary care. Many respondents reported that they relied on chance and the system, some felt frustrated by this system but felt that they could do nothing about it. The respondents from the higher SES group, however, consistently reported being able to navigate the system in order to see their preferred health-care professional.

Box 4. The impact of relationships with the health

care system and professionals.

R: I'm good for another 12 month

Q: So that's just every 12 months is it?

R: Oh aye, they send for me

Q: Okay

R: Its no good making an appointment because I forget. Nearer the time, they either phone me or send me a letter

[Talking about recent review appointment]

Pt ID 23 (male, 74 years, coronary heart disease and COPD; low SES).

'To see that I was alright and that the drugs I'm taking agree with me and all that'

[describing a review appointment]

Pt ID 28 (male, 55 years, coronary heart disease; low SES).

'I'm a great believer of getting a second opinion if I don't agree with the first one ... if the second opinions and the third opinion corroborate what opinion number one is saying, then obviously you feel that the information you're getting is right'.

Pt ID 7 (male, 53 years, diabetes; high SES).

R: Yeah, not so much the nurse but the doctor um, I wouldn't say that she understands me, no, um, and I wouldn't say she really listens to me. She knows, I think she knows, she's probably heard it over and over again from different patients, the same things, so I always feel as though she's, she's looking at something else, or doing something else when I'm trying to explain about ...

Pt ID 24 (female, 71 years, diabetes; low SES).

R: It's very, very difficult to, I mean you, you're supposed to start phoning at eight o'clock in the morning, you can be on the phone till twenty to nine continually ringing and ringing and ringing, and then they ring, then someone picks it up, answers it, and all the appointments have gone.

Pt ID 17 (male, 80 years, CHD and stroke; low SES).

'you just have to understand how the system works and use it as you find it'

Pt ID 7 (male, 53 years, diabetes; high SES).

Discussion

Participation in health care, as traditionally conceptualised, involves patients asking questions and seeking information to improve knowledge and understanding of their condition in order to take part in sharing decisions about treatment and management, which are commensurate with improved health outcomes (Haywood et al., 2006; Ishikawa and Yano, 2008). Policies encouraging participation have assumed that all individuals are equally disposed to this notion of participation. However, this analysis has shown variations between individuals of different SES across all of these assumptions.

Patients from lower socio-economic groups generally reported feeling *less* able to ask questions of the doctor. Questions that are commonly asked by this group in the consultation seem to be related to medicine use and the side effects of medications. This is in line with previous literature that identified medication as a legitimate topic to discuss (Kennedy et al., 2003). Some patients do not consider it appropriate to ask questions at all, feeling that this is not their role and it may be even construed as a lack of faith or trust in the doctor (e.g. the notion of a 'good patient' being one who does not challenge the doctor and adheres to the doctors' decisions). The wider notion of more proactive questioning and discussion of diagnoses and management plans was reported only among patients of the higher socio-economic group. This is further reflected in reported information-seeking practices outside of the consultation, which impacts significantly the patient's understanding of his or her health condition, limiting or increasing their ability to participate in the consultation.

In addition, for respondents from the higher socio-economic group, understanding the details of one's chronic illness and its management positively reinforces engagement with active self-management and shared decision-making. Understanding and using the information in order to benefit one's health is part of the notion of health literacy (World Health

Organization (WHO) definition). This includes the confidence and ability to challenge or confirm to a medical opinion by seeking alternative or confirmatory opinions in the literature or from other professionals. Health literacy also includes the ability to navigate the health system, and this is demonstrated in this study particularly by the ability to navigate the complicated appointment systems in order to achieve desired continuity with their GP. Furthermore, it is apparent that 'participating in one's health care' is perceived differently by different individuals and that this is related to one's expectations of a health-care consultation and the cultural resources to question what is on offer. This finding is in line with an article by Smith et al (2009), which demonstrated that people with different levels of education might conceptualise being involved in decision-making in different ways (Smith et al., 2009). Definitions of participation do not take into account different groups in the population; they just assume that everyone has the ability to participate.

This study demonstrates that patients from practices in lower socio-economic areas do have lower 'health literacy' than those patients from practices in higher socio-economic areas. However, this study demonstrates that it is not simply lower health literacy, and therefore lack of health knowledge, that is the cause of reported differences in participation. The observed lower health literacy is compounded by the differences in role expectations between the groups of different SES and the experiences of prior use and expectations formulated in socio-cultural context. The policies aimed at simply providing information, even information directed specifically at generating improved health literacy, will not be successful if patients are not in a position to, or willing to, engage with information.

The study has a number of strengths and limitations. Using qualitative research methods enabled access to the complexity and depth of participation as a social phenomenon. Recruiting participants from lower and higher

socio-economic groups did enable exploration of why 'educated, articulate patients of higher socio-economic status' (Say et al., 2006) tend to participate more frequently in their health care. Similarly, participants in the lower socio-economic group may have been less willing to participate in a lengthy written questionnaire. However, a limitation is that we recruited participants above the age of 45 years only, and the majority of participants were above 60 years. This is due to the nature of long-term chronic disease in primary care; we recognise the potential importance of age on willingness to participate but feel that these data are representative of a currently large population of patients with long-term chronic disease who are being managed in primary care. Finally, we were able to only recruit a majority of White, English-speaking participants; barriers to participation in other ethnic groups, and among patients for whom English is a second language, will likely be even more complex.

The challenge then is to address how we can work with patients' expectations of health care and disrupt the notion that going to the doctors, answering questions and reporting back on medication use constitutes participation and 'being a good patient'?

This study has shown some examples of strategies, which can be employed to increase patients' engagement with increasing knowledge and understanding of their health (health literacy) and therefore increase the likelihood of participation in their health care. Access to resources and the mobilisation of resources are important. The disadvantages of lower individual health literacy have been ameliorated by some participants taking advantage of their social network, such as a friend who is a nurse, or a son-in-law who is a pharmacist. Development of health literacy appears to have been promoted in some instances by the use of lay terminology by health professionals, and difficulties navigating the health system to achieve continuity have been overcome in some cases by the practice system allocating patients to the same health professional each time they attend. Thus, clinicians can

play an important role in actively giving patients 'permission to participate' and being aware of the impact of social and domestic circumstances and expectations that might militate against active engagement.

Implications for practice

If policymakers, public health advocates and clinicians wish to encourage wider participation in health care, they need to acknowledge and recognise the current disparities in participation and how these are shaped historically and according to social position and culturally shaped practices and agendas. More important than focusing on simply providing information, and the potential of 'choice', would be for the policy to focus additionally on addressing the components that traditionally lie outside health literacy by specifically focusing on engagement and addressing assumptions about role expectations as part of the consultation. Raising public expectations of what should constitute participation in one's health care could be part of a social marketing approach to participation using the media to raise the profile of how to engage with one's health-care providers? Perhaps policymakers could learn from the world of advertising. As a result of billions of US dollars spent on advertising prescription drugs in the media, patients can be encouraged to attend their health-care practitioner and query whether they should be receiving a particular medication (Kravitz et al., 2005). In addition, addressing the needs that patients have about access to and use of medications would permit the introduction of new and broader agendas about health and illness, including the components of negotiated responsibilities of managing health and illness in a way which is more in line with the notion of active participation.

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Ethics approval

The study was approved by the Bolton Research Ethics Committee. REC reference number: **07/H1009/58**.

Conflict of interest

No known conflict of interest exists.

Note

1. Defined by the WHO as:

‘the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health’.

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