

Patients as teachers: a qualitative study of patients' views on their role in a community-based undergraduate project

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Objectives Patients have been used in clinical medical education for many years with, traditionally, a relatively passive role. Following the General Medical Council recommendations for curricular change and the development of more community-based teaching, 'ordinary patients' in the community are increasingly being partnered with undergraduate students for particular projects. Very little research has been undertaken on patients' perceptions of this role.

Design Semi-structured interviews were carried out with 20 people to explore the views of patients taking part in a community-based undergraduate medical student project (the 'patient study') at Newcastle Medical School about their role as teachers of medical students, what they felt they had gained from participating, any problems or concerns and suggestions for change or improvement.

Setting Newcastle Medical School, UK.

Subjects Second-year medical students.

Results Two major themes emerged. First, patients saw themselves in active roles as teachers: as experts in their medical condition; as exemplars of their

condition; and as facilitators of the development of students' professional skills and attitudes. Secondly, patients felt they had benefited from participation, through talking about their problems; learning more about themselves; the satisfaction of helping; and from receiving gifts. In addition, a number of other issues were identified including interpersonal dynamics, gender and ethnic differences, inadequate briefing of participants and whether such community-based patient involvement might, in some situations, be felt to be exploitative.

Conclusions The study has shown that patients see themselves clearly as having specific contributions to make to medical students' education and training. This has implications for the further development of community-based teaching.

Keywords Community health services; education, medical, undergraduate, *methods; *patient acceptance of health care; *physician-patient relations; teaching, *methods.

Medical Education 1999;33:688-694

Introduction

The importance of the patient in medical education is widely acknowledged,¹ although it remains a relatively unresearched area. The main focus in recent research has been the 'standardized patient' and their potential role in both teaching and assessment.² Other workers have looked at patient reactions to the presence of students in general practitioner consultations³⁻⁵ and in hospital settings.^{6,7} Traditionally, however, the patient has played a relatively passive role as a medium through

which the teacher teaches, simply acting as teaching 'material'. Most medical schools in the UK are currently undergoing curricular change in line with the recommendations of the General Medical Council in *Tomorrow's Doctors*.⁸ One development is the introduction of projects which involve students working with patients in the community.⁹ Here, the patient's role is different, as their contact with students often takes place over an extended period of time and without the mediation of a professional teacher. Although patients' views about aspects of community-based student projects have been surveyed,¹⁰ there are no reports about patients' specific perceptions of their role in the teaching and learning process.

The aim of this study was to explore what patients involved in such a project thought about their role as teachers of medical students.

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Methods

Newcastle's integrated undergraduate medical curriculum, through its 2-year 'Medicine in Society' course, includes community-based projects which provide early patient contact. One of these, the 'patient study' in the second year, gives students the opportunity to observe and discuss the impact of a long-term condition, or conditions, on a person and their immediate family and carers. It is usually the case that subjects do in fact have multiple pathologies. The person's experience and perceptions of the problems and their impact are the main focus of the project. Patients are recruited to take part as subjects by the course tutors using a network of local general practices. Briefing of the patient is carried out by the recruiting general practitioners who are encouraged to use a standard letter. Students are also expected to explain the project to the patient. The work builds on skills taught for the first year 'family study' and in other Medicine in Society course work. Students have practical seminar exercises on composing a letter of introduction, differences between conversations, interviews and consultations, and practice in role-plays asking difficult questions. The project extends over a 6-month period, during which the students visit the patient several times, in pairs. They each write a report, the grade for which contributes to their summative assessment. This assessment grade is produced using a criterion grid which includes 'reflections and views on undertaking the project' as one of the criteria. The contribution of the patient to the students' learning is often highlighted by the student in this section of the report.

There were 156 students in the year group in the academic year 1994–95. Seventy-eight patients participated in the patient study, all of them registered with eight general practices on Tyneside. A one in four random sample of patients was identified for this study. Each patient's general practitioner was asked to write to the patient inviting their participation in an interview, requesting signed consent. At this stage the general practitioners used their discretion in recruiting patients, for example avoiding those who were very ill. Selection of patients continued until 20 consented to take part.

Semi-structured interviews were carried out by an experienced qualitative researcher. They were used to explore the patients' understanding of the purpose of the project, what they gained from participation, perceptions of their role as teachers of medical students, any problems or concerns about the project and finally their suggestions for change or improvement. The interviews took place between 1 and 6 months after the end of the student project. They took 0.5–1 h and were audiotape-

Table 1 Patient details

Pt ID	Sex	Age	Main health problems
1	F	69	Rheumatoid arthritis
2	M	77	Chronic renal failure, hypertension
3	M	87	Stroke disease
4	F	78	Diabetes, arthritis, hysterectomy, ileostomy (bladder cancer)
5	M	50	Ischaemic heart disease
6	M	74	Valvular heart disease, prostatism
7	F	28	Systemic lupus erythematosus
8	F	72	Cervical spondylitis, osteoarthritis, ischaemic heart disease
9	F	67	Diabetes, chronic obstructive pulmonary disease
10	F	48	Sero-negative arthritis, depression
11	F	78	Epilepsy, peripheral neuropathy
12	F	87	Lymphoma, retinal haemorrhages
13	F	68	Rheumatoid arthritis, diabetes
14	M	51	Depression, diabetes, mobility problems
15	F	81	Depression, ischaemic heart disease
16	M	79	Peripheral vascular disease
17	F	11	Cerebral palsy
18	F	72	Stroke disease
19	F	80	Blind, stroke disease, ischaemic heart disease
20	F	79	Epilepsy, diabetes, ileostomy, asthma

Average age 66.8 (range 11–87 years, median 74 years) 14 female, 6 male.

recorded and transcripts produced. These were analysed using a grounded approach¹¹ to identify themes arising from the data. The interviewer also recorded her own observations and reactions to the patient's home environment and health situation and to patients' comments about the students. These observational notes were used to supplement interview material.

Results

Twenty-four patients were randomly selected, of whom four were felt to be unsuitable for recruitment by their general practitioner (two were in hospital, two were very ill). No one recruited in this way refused to be interviewed. Twenty patients from five general practices were interviewed. A summary of patients' details is presented in Table 1. Two interviews (patients 4 and 8) did not record due to technical failure but the interviewer made immediate detailed field notes. The themes are shown in Table 2 and discussed below.

Patients as teachers

The following teaching roles were identified: patients as experts in their condition; as exemplars of their medical

Table 2 Patients' views about being teachers in the project

Patients as teachers	
(i) as experts in their condition	
showing	managing disability clinical aspects
telling	technical description health care experiences of the illness feelings
(ii) as exemplars of their condition	
(iii) as facilitators of the development of professional skills and attitudes	
How patients benefited from participation	
through talking	
through learning about their condition	
through learning about the training of doctors	
by recognition of helping students' learning	
by feeling useful in providing practical help to students	
receipt of appreciative gifts	

condition; and as facilitators of the development of students' professional skills and attitudes.

As experts in their condition

There were two aspects of patients as experts in their condition. First, some talked of showing or demonstrating things to the student, or in some cases wishing they had been able to demonstrate functional impairment due to their condition. For example, a woman with rheumatoid arthritis said:

'Yes, I could have shown him how I managed to get up and down stairs, how I handle the kettle, pans, knives. Had he been a woman I could have shown him how I manage to wash my hair and get rollers in' (patient no. 1).

A woman with glaucoma noted:

'They helped me up and down the stairs to see how I got up and down...I come down backwards...' (patient no. 19).

In one instance, the patient not only showed the students her chair lift but also demonstrated it. They sat in it and used it to go up and down the stairs (patient no. 18).

Others showed, or wanted to show, students things related to the clinical aspects of their condition. In one case, the patient's husband thought the students would

learn from seeing her during an epileptic fit, but the patient herself felt:

'I wouldn't like them to know what does go on' (patient no. 11).

One woman had wanted to show them her ileostomy stoma but had felt that the male student of the pair might have been embarrassed by this (patient no. 4).

However, several took out their medications to show the students:

'I had the impression they were just training. When they were asking me about medicines and that, they weren't too sure, were they? We had to get the medicines out to show them' (patient no. 5).

The second broad area of expertise was in telling students about the condition by providing technical descriptions:

'He was interested in my condition because I'd got a pacemaker in and I've got heart trouble. Well it was new to him. I took off work poorly in 1966. They put a pacemaker in for 10 years, then they took it out and put another one in. He was very interested. I have a book there and it shows you where the pacemaker's situated. Whatever questions he asked me we could give him a truthful answer, and he was taking notes all the time' (patient no. 3).

'I'd wrote a book as well,...this was all about [daughter] from when she was four and I lent that to the students as well, which they found very helpful 'cos it had all the information in, about all of her fits and the heart operation...what caused the brain damage' (parent of patient no. 17).

One patient taught the students about the health care team she was served by.

'... getting the medical team and home carer and everything like that sorted...they were interested in that aspect. I've got a social worker now, occupational therapist, brilliant medical team...from the GP down. We have a home carer three times a week...all this sort of thing, I think it was interesting for them' (patient no. 10).

For others the telling was of experiences of the illness, how it felt, what the symptoms were like and so on. For example:

'...by knowing what I've gone through and how it affected me – and what was what – getting up in the middle of the night breathless, hanging out of the window looking for breath and things like that. They were very interested in

that. In future they might ask some of their patients: "did you get breathless at night-time?"' (patient no. 6).

The third type of telling was that of conveying feelings. This included patients describing the ways they had of coping, or what it felt like to be disabled by their condition. One patient observed:

'The students said that I had made them aware of the, you know little things that catch you with disability really – getting on and off buses, very minor things that you take so much for granted when your faculty is full and functioning well. But even more so when you're young and full of energy, and what not. I think that impressed them quite a bit. [The little things?] Yes, I mean the anger that you feel within yourself when you can't cope' (patient no. 13).

As exemplars of their condition

Some patients thought that students would learn simply from having seen a memorable example.

'In future when they see a similar condition they'll remember me' (patient no. 18).

In other cases patients recognized the value to students of talking to someone about the broad social and psychological aspects of their condition.

'You can talk to them and learn them different things – I told them about this heart problem what I've got...and how I feel about, you know, I cannot work so you've just got to console yourself that you cannot work, which annoys us – and I get that depression. I'm not a great intelligent man, but I think these students can learn a lot by speaking to people like me' (patient no. 15).

Some patients felt it was important that students understood that the same disease can present in different ways.

'I would say the thing they can learn from me without learning from books is how I reacted to the effects... that you don't have to be a cripple to have heart trouble...I may have been a fortunate one, but I can only say how they may have thought about what I was like and then they may see someone else and say, well it affects different people different ways' (patient no. 6).

As facilitators of the development of professional skills and attitudes

In this context the patients were acting in a more passive role than as experts or exemplars. Several

patients commented that they thought the students had gained experience of meeting and talking to them as people, in taking a history and in developing a 'bedside manner'. For example:

'It helps them get used to asking, to delving into illness. Asking about the pain and the symptoms' (patient no. 2).

'Patience or something, insight into what people are like. I think doctors have to be good listeners' (patient no. 9).

'They were always very aware that some days, I think it was just once he phoned and I was having a really, really bad time of it, I'd really hurt my back and he picked up on my voice on the phone. He said "Oh you don't sound your usual self". I thought, "That's good, even across the telephone he's picking up on how I'm feeling". So that's what I felt about him, he's going to be good, because I was pretending I was fine, but obviously he had picked up that I wasn't' (patient no. 10).

How patients benefited from participation

It was clear that in addition to their perceived role as teachers, patients felt that they themselves had gained in several ways.

Several thought they had benefited from simply being able to talk with someone. Talking to the students was described as a welcome relief from loneliness, enjoyment of company, feeling that they (the patient) had been able to open up, or appreciation of having someone who was willing to listen to them talking about their condition.

'I'm afraid of boring people to death so I am inclined not to talk about it if I can help it. I could to someone who wanted to listen, who was wanting to know about my condition' (patient no. 1).

'It is nice having somebody to talk to. Other than your family. Because you can talk to other people where you can't talk to your family' (patient no. 20).

'As I say, if I can help them, by all means I'll help them, I mean I've got nothing to lose, you know. If they can come here and get a bit of help it doesn't inconvenience me, I mean we divent gan that far, you know, and as I say, it's nae sweek really. Specially winter nights would be good like...I think that would be a nice thing..for them to come and visit, like, because in the winter nights it's dark and cold outside. It'd be nice to see what you can do and if it helps them, at the same time it helps you because it gives you a bit of company and talk and different things and that, you know' (patient no. 15).

Some said they had learned new things about their condition, in particular their own responses to it.

'I think I did because I think I was quite depressed by the illness at first...it's five years now, so I've come to terms with it. But I think as I was talking through it with them it brought home to me that I had been very depressed about it. As we went through the whole tale...a pattern emerged of how I had been and how I was dealing with it' (patient no. 10).

Also, one woman learned how valuable it was to talk about the emotional side of illness. She had apparently begun to cry when telling students about her hysterectomy and she had learned from them that it was not only a normal reaction but that it was all right to work through such emotions (patient no. 4). Others valued being involved in learning something about the training of doctors and were interested to know how 'their' students might be progressing through the course.

Some patients gained a great deal of satisfaction from helping students educationally, by assisting them with their course work, while others helped in practical ways.

'Oh heck. I felt great. I was even the chauffeur – I was taking them home at night' (patient no. 6).

Finally, there were material gains in the form of gifts from the students including postcards from holidays, Christmas cakes, flowers and boxes of chocolates.

'The first time they came, they brought a lovely spray of flowers...Lovely, there was all sorts, irises, carnations, they were beautiful. I was nearly in tears when they give us it' (patient no. 14).

'When he was going home (for the vacation) he was very kind and sent a Get Well card to my wife and a box of chocolates. I thought it was very thoughtful. And some flowers he sent' (patient no. 3).

Other issues

A summary of other issues that were raised by analysis of the interview material and interviewer's notes is given in Table 3.

Patients recruited for the study may or may not live alone, bringing in an issue of interpersonal dynamics between the patient and their carer. In some of the interviews the carer did most of the talking for the patient.

'I never knew what to do at interviews like this – a participant who seemed reluctant to speak, with a carer who did all the talking for her. Certainly when her

Table 3 Further themes arising in and from patient interviews

Other issues
Interpersonal dynamics between patient and carer
Gender and ethnic differences
Inadequate briefing of students and patients about the project
Exploitation vs. empowerment

husband left the room she seemed to talk quite a lot' (interviewer's notes, patient no. 11).

This suggested that a similar process might have prevailed during the students' visits and interviews, and raised issues of how the students should handle this, and how it might affect their analysis and interpretation.

Some patients reported that in mixed-sex pairs of students it was often the female in the pair who facilitated the visit and did most of the questioning, while the male observed or took notes. A gender issue in the patient–student relationship was also outlined by one woman who described wanting to 'mother' the young man of the pair of students who visited her.

'...he didn't really get down to the point, of course it could have been shyness. I mean he just looked like a school boy...it was concern for him I felt...I mean, I find it difficult not to try and mother him' (patient no. 1).

This sort of caring responsibility is also demonstrated in the following quote, again from a woman patient.

'They came to see me at the end of the year...I was a bit worried when they rang up and asked if they could see me after their exams. I thought what am I going to do [laughter] if they've failed or anything – how could I cope with that? So I said, if I see your face smiling I'll let you in, but if you're not smiling I'll turn you away' (patient no. 13).

Where students were of a different ethnic background from the patients, some interviewees expressed concern and embarrassment that they could not pronounce the student's name and one talked of having to rephrase colloquialisms so that the student could understand them.

'One thing he did say which I thought interesting – he couldn't pronounce the name of the male student. His wife went and found a letter on which this student was named and showed it to me and...none of us, me included, actually knew how to pronounce his name, and in fact the respondent never did get to know that young man's name' (interviewer's notes, patient no. 2).

The interviews also highlighted deficiencies in the understanding of both the patients and students in relation to the purpose and processes of the project, despite the structured briefing that each was supposedly given.

'I didn't know what kind of questions they were going to ask [So you never knew what to expect?] No' (patient no. 5).

'[What did you see as the purpose of them coming, how was that explained to you?] They didn't really say actually, my GP just asked me and she just asked me if I'd mind and I said "Not at all" ' (patient no. 10).

In other cases, however, students had clearly followed the guidelines.

'He showed me the letter that one of them had written to the patient, and it was a very nice letter, asking permission to call and explaining who they were...the student did say that the patient would be allowed to see the report that was written' (interviewer's notes, patient no. 14).

Finally, in the few instances where any dissatisfaction was expressed, we identified an issue of possible exploitation rather than the positive empowerment associated with feeling expert in their condition, being exemplars or acting as facilitators.

'Sometimes I found them a bit patronizing...some of the questions they asked me, they didn't seem to have thought how I would feel about being asked such questions' (patient no. 7).

'When I said I would like to see this report that they'd written, they said something about, "well, we would have to write something different if you were going to see it"...it made me think that maybe they would make a few things up, which scared me a bit' (patient no. 7).

Discussion

This study has provided a new perspective on the role of 'ordinary' patients in medical education, highlighting their perceived expertise in a number of areas, not least their unique illness experience, something that is already recognized in respect of doctor-patient communication.¹² Despite the contention of one author that 'those patients who "teach" us about how to give care effectively and humanely are not usually aware of doing so',¹³ it seems that, when asked, patients *do* see themselves as having specific contributions to make to medical students' education and training. For some patients learning was clearly a two-way process, as in findings of other research on attitudes of patients in a

hospital maternity unit.¹⁴ Even with no explicit briefing on a role as teachers, many patients seemed to understand how they could actively facilitate the students' learning. In addition others, in seeing themselves as exemplars of their particular medical condition, intuitively acknowledged the importance in medical education of the development of 'illness scripts', cognitive structures that describe the features of prototypical patients.¹⁵

Patients appeared to derive considerable satisfaction from their role in teaching, along with other benefits such as having someone to talk to and relief from loneliness, as well as the small material benefits. This is similar to results of other workers looking at the views of mothers of new babies participating in a community-based family case study project¹⁶ and other qualitative studies that explore respondents' perceived benefits of having someone to talk to.¹⁷

Despite these findings, it is important to question the extent to which using patients as teachers in this sort of undergraduate project work exploits people in the community. It uses their time and skills for no monetary reward, but it may conversely empower them as experts in their conditions and enhance their relationship with health professionals. Some innovative schemes have addressed this issue. In a project at St Bartholomew's and the Royal London Hospital School of Medicine ('Patients as Partners'), people called patient-partners are linked with individual students on a one-to-one basis; students visit them at home and accompany them on various visits. The difference between this approach and more traditional attachments is that the patient-partners attend briefing meetings, help students set learning objectives, contribute to assessment and are given modest remuneration. Evaluations have been positive.^{9,18} A similar hospital-based project is under way in a Newcastle rheumatology department. Here, patients receive formal training, at the end of which they have to pass an examination, and will be paid for their contribution to teaching (D. Walker, 1998, personal communication).

The Newcastle 'patient study' has been an essential part of the undergraduate course for over 20 years and informal feedback from participants has generally been positive. It is particularly important as a forerunner and example for other medical schools, which are developing their own similar projects. It is probably successful because it is part of an integrated course, and despite the evidence presented here of some lapses in understanding of the project protocols by students and course tutors, its good standing with patients is likely to be due to careful recruitment by the tutors as well as programmed seminar support work for students.

This study has given insight into important dynamics between carers, where present, and others; between patient and a student; patient and student pair; and between the pair of students. Patients already see themselves as having an active role in students' learning, and with further briefing their contribution could be considerably enhanced. As a result of this study the Medicine in Society Course Director (RS) has produced information booklets for patients, general practitioner tutors and for the students in order to provide clear and concise information about the patient study project and expectations of participants. In the past, Medicine in Society course work has not explicitly included experiential or theoretical material on gender roles. It appears that students are possibly perpetuating well-recognized differences in interpersonal skills and communication,¹⁹ rather than compensating by sharing roles. This raises the issue of the need to incorporate such teaching in relation to this and similar projects in other medical schools.

In conclusion, the model of the patient as a passive party in the consultation is outmoded.¹² In a similar way our findings challenge the traditional scenario of the patient as passive teaching material and vindicate the call for a more patient-centred approach to teaching.²⁰

Acknowledgements

We are grateful to the general practitioners who recruited the patients; Anne Corradine who arranged the interviews; Dr Anne Spendiff who conducted them, Louise Walker who transcribed them, Mary Scott, Nancy Noon and Margaret Levy for typing the manuscript; and to the patients themselves for being generous with their time. In addition, we appreciated the helpful comments provided by three anonymous referees.

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Received 24 July 1998; editorial comments to authors 30 September 1998; accepted for publication 16 December 1998