Participating in medical education: views of patients and carers living in deprived communities

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**Objectives** Active patient involvement in community-based education is still relatively novel; in particular, the involvement of patients living in socially and economically deprived areas is still unusual. This study explores the views of patients and carers living in deprived areas on their participation in medical education.

**Design** A total of 36 patients and 18 parents were interviewed at home by Year 1 students undertaking an accelerated 4-year degree programme. Subsequently, taped interviews using a topic guide were carried out with 18 patients/carers. Their views on their active involvement with medical students are presented here.

**Results** Most of the patients in this study did not view themselves as teaching the students but considered their role to be more one of partnership, explanation and sharing. They considered that they were the ‘best judges’ of certain aspects of their illness. These aspects related to psychological, social and behavioural issues, which impacted on both themselves and their families. Patients considered these issues to be as important as the medical condition they were diagnosed with. Patients also raised issues concerning the importance of doctors listening to patients.

**Conclusion** This study showed that patients living in areas of deprivation were positive about being involved in medical education. They considered their personal experience and knowledge of illness to be an important aspect of student learning. They were happy to share this knowledge and they were very keen that doctors should listen to them. The challenge for medical educators is to ensure that this is achieved.

**Keywords** education, medical/ *methods; patient participation; physician patient relations; teaching; socio-economic status; caregivers; attitudes.

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**Introduction**

Patients have taken part in the teaching and training of medical students for many years. This takes place most commonly within the hospital setting, where patients might be used on teaching ward rounds, outpatient clinics and during student assessments. Beyond the borders of the hospital, within ‘community’ settings, the use of patients has tended to be restricted to general practice.1 Now, as greater emphasis is placed on community-based learning, medical students are spending increasing time in community placements where they come into contact with patients at a much earlier stage in their training. Terms such as ‘patients as teachers’,2 ‘parents as teachers’3 and ‘patients teach students’4 are becoming more common and suggest patients are being asked to take a much more active role in preparing Tomorrow’s Doctors.5 Whilst this might be viewed as a positive move, it would appear that most of the patients used in this way come from more affluent and educated sections of society.3,4 Patients living in socially deprived communities or areas may not be used as frequently and therefore their views have not been actively documented. How do patients living in areas of deprivation view being ‘actively’ involved in medical education?

This paper considers the views of patients and carers who live in areas of social and economic deprivation. It considers their own perceptions of their active involvement with medical students and whether they view this as a positive experience that benefits not only themselves but also the student doctors.

The positive personal benefits experienced by patients who have been actively involved with medical students may have important implications, not only in
terms of informing tomorrow’s doctors of the value of learning from the patient, but also for any professional working in the health and social care field.

The educational setting

In September 2000 the Leicester Warwick Medical School (Warwick) accepted its first cohort of biological science graduate medical students undertaking an accelerated 4-year medical degree. One of the first modules undertaken by these students is a community-based course entitled ‘Inequalities in Health’. A shortened version of this module had been running successfully in Leicester for the last 5 years. This was the first time it had run in Coventry and Warwickshire and it was planned somewhat differently.

This module introduces students to the sociological aspects of health and illness and offers a practical as well as a theoretical understanding of inequalities in health and the current initiatives aimed at resolving these. Using the locality profiles of NHS Trusts, the course material identifies 6 localities where social and economic deprivation is greatest. Learning in this module takes place within both the university and community settings, with experienced health visitors and district nurses acting as community-based tutors who guide and facilitate the students’ learning.

A key element of this module involves students coming face-to-face with patients who live in socially and economically deprived areas in their home settings. In this way students can understand not only the impact of the illness on the patient and his or her family, but also how this might be compounded by the area of residence. Students work in small groups (n ≤ 4) and each group interviews the parents or guardian of a child, a midlife patient and an older adult patient. Following each home visit and interview, students interview staff from 3 services who are actively involved in the care of their patient case.

The educational objective of this exercise is to enable the students to discover:

- the variety of agencies, both voluntary and statutory, working in the community setting;
- how medical practice fits into the broader picture, and
- the different priorities patients and agencies might have in terms of meeting individual needs.

Learning from the community setting

Patients are identified by members of the primary health care team and are approached by the community tutors to establish whether they will agree to being interviewed by the students at home. The community tutors brief the patients and obtain a signed consent form.

The students are based at 1 of 6 community sites (usually health centres) across 3 community health trusts. In total, they interviewed 54 patients between October and December 2000. At each community site, 9 patients were identified. These consisted of 3 child cases (where carers were interviewed), 3 midlife and 3 older adult cases.

Each interview lasted 60 minutes. All the interviews were student-led; no other health professionals were present at the interview unless specifically requested by the patient. Students were prepared by the community tutors and by a structured workbook. Students were encouraged to explore the patient’s view of any strengths and weaknesses in the services involved in their care.

Researching patients-as-teachers

Following completion of the taught module, all patients were routinely contacted for evaluation purposes. The research reported here is an expanded version of this usual evaluation. All 54 subjects were stratified by locality site and lifespan. Eighteen patients (3 from each site) were identified from the stratified list and were sent an explanatory letter asking if they would be willing to take part in this research study.

In all, 16 patients returned a signed consent form and interview dates were arranged. Of the remaining 2, both agreed to be interviewed but were out on 2 successive occasions despite repeated contact; therefore a further 2 patients were identified from the relevant trust.

The sample comprised 5 child cases, 7 midlife cases and 6 older adult cases. Table 1 outlines the patient

Key learning points

Involvement in medical education was considered positively by patients and carers living in deprived localities.

The patients did not perceive their role as that of a ‘teacher’ but rather as involving ‘partnership’.

Patients felt doctors should learn about the patients’ own knowledge of their illness.

Patients wanted the ‘doctors of tomorrow’ to ‘listen’ to them.

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details. One interview (patient 18) failed to record due to a malfunctioning microphone and therefore detailed field notes were made by the researcher immediately after the interview.

All patients were interviewed by 1 researcher (AJ), in their own homes, using a topic guideline (Table 1). Each interview was taped and took between 30 minutes and 2 hours. All interviews began in late January 2001 and were completed by the end of February 2001 (i.e. 3–4 months after the student visit). The focus of the interview centred on how the patients felt about and understood their involvement in medical education. All the tapes were transcribed.

The transcriptions were analysed thematically by 2 researchers (AJ and LB) independently. Themes were identified and labelled individually. The themes, and how to label them in the context of previous research, were then confirmed by both workers. The third member of the team (GH) also read the interview transcripts and discussed the emergent themes with AJ and LB.

The following 4 themes emerged:

- the patient’s feelings prior to and following the interview;
- the patient’s perceptions and description of their role during the interview;
- whether the interviewee considered that they were the best judge of their own or their child’s illness, and
- how valuable this might be to the doctors of tomorrow.

Patients’ feelings prior to and following interview

Half of the patients (9) expressed feelings of anxiety, apprehension or nervousness prior to the interview, although in all cases patients felt that this was normal. In the quotations that follow, the number in brackets after the quotation refers to the case number in Table 2.

‘...I think I was a little bit cautious, a little apprehensive but nothing extreme...’ (1)

‘...just tense...apprehensive...’ (8)

Table 1

<table>
<thead>
<tr>
<th>Topic guide</th>
</tr>
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<tbody>
<tr>
<td>Feelings before, during and following the interview</td>
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<td>Perceived role during the interview – experts?</td>
</tr>
<tr>
<td>Students’ learning</td>
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<td>Importance of using real patients</td>
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<td>Personal benefits</td>
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<td>Benefits to students</td>
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<tr>
<td>Teaching?</td>
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<td>Best judge of illness?</td>
</tr>
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Table 2 Patient details

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<td>4</td>
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<td>77</td>
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</table>
‘Er...I wasn’t nervous...anxious and confident that I could answer the questions...’ (11)

Some patients related this anxiety to not knowing what questions the students might ask:

‘Suppose I was a bit anxious about what they were going to ask me and what not...’ (11)

When asked how they felt following the interview, 6 patients expressed no change in how they felt before or after the interview, using words and phrases such as ‘fine’, ‘no worries’, ‘normal’ and ‘none’.

Most patients (10), however, were very positive about the interview and the educational project:

‘Fine, fine. Yes, I was very glad I had done it.’ (1)

‘I was quite pleased actually, because I thought, well it’s about time something was done.’ (4)

‘I was pleased that we had taken part.’ (10)

‘I felt as if I had done a good job.’ (17)

Only 2 patients reported anything that could be construed as negative statements. One of these related to a midlife male who had felt slightly anxious prior to the interview and who had been left with a feeling of confusion following the interview – not knowing whether the students had learned anything and whether it had been of any value. On further questioning, it appeared that the particular group of students who had interviewed this patient had focused on the patient’s present day medical condition only and had not asked anything about the rest of his life:

‘Well, I felt that they weren’t asking as you say now, they were only going by what they were told...my gastric problem. That was the main thing through my life but I thought, “Well why haven’t you asked me other questions?”...I mean...Oh I just thought have they learned anything from this? Or I don’t know I didn’t know at the time really.’ (11)

For this person, the close focus of the interview had been troubling, and this could perhaps have been avoided. The second was different and was related by the mother of a 3-year-old child who had cerebral palsy. This was the first time she had actually talked to anyone about the sequence of events that had preceded his diagnosis and the impact of her son’s condition. She felt anger because it had made her realise how badly she had been treated at the time:

‘I don’t think I had ever spoken about it before...it all seemed a bit of a blur really and it kind of reawakened a lot of things I’ve probably forgotten or buried or whatever. It made me angry after...not at the students...at the way we were treated.’ (5)

Despite these experiences, both these patients commented that they would take part again and saw only positive gains for the students in such learning.

The patient’s role: teaching medical students?

We asked participant patients how they had perceived their role. Within this study, only 4 patients chose the word ‘teaching’ to describe their role. One said he ‘felt like a talking textbook’, which probably reflected the breadth and depth of knowledge his family as a unit had on their rare genetic illness. Another, a young man who was quadriplegic, had an in-depth understanding of his condition and used it to teach the students about spinal injuries:

‘Yeah spinal injury...there’s just so much to know um...You know, levels of injury, it just goes from one extreme to the other and...’ (7)

When prompted, other patients were not sure that ‘teaching’ was an appropriate word to describe their role. They felt strongly that if they were teaching the students anything, it was not about the medical aspect of their illness but more about the emotional aspects:

‘I was teaching them what they hadn’t known, they might have known about the medical history but didn’t know the emotional side of it.’ (6)

The majority of patients (10) felt that they were definitely not teaching the students. When asked to describe what they felt they were doing, they used phrases such as ‘helping’, ‘informing’, ‘jogging them along...like a mother does her children’, ‘advising them’, ‘having a conversation’ or simply ‘sharing my experiences’:

‘No I wouldn’t have described it as teaching, it was more...sharing my experiences.’ (5)

‘Wouldn’t say teaching them...informing them.’ (2)

‘Teaching means that you have all this knowledge whereas we, in fact, are just giving experiences.’ (12)

Clearly then, most of the patients in this study did not choose words associated with formal teaching, as these words did not describe their role. While they did have something to contribute, they did not consider it the type of knowledge they would associate with teaching.
The best judge of your illness?

Other studies\(^2\) have identified the fact that patients are quite certain that they are experts in their condition. Patients in this study were asked whether they felt that they were the best judges of their own, or their child’s, illness.

The majority of patients (all of the parents) believed that they were the best judges of their illness by virtue of living with the illness on a daily basis or caring for a child 24 hours a day:

‘I certainly am the best judge of my illness’ cos I have to deal with it every day anyway, so how I deal with it is how it affects everything.’ (Father 3)

‘No one knows him better than me or his dad.’ (5)

Being the ‘best judge’, however, did not appear to relate to their own or their child’s medical condition, but instead concerned knowing what was usual/unusual behaviour or being aware of the different emotional and psychological feelings which affect a patient’s health and well-being. The examples of positive medical encounters cited by patients/carers always included this element of acknowledgement on the part of the health care team that patients are persons with feelings:

‘You know I can’t diagnose my child as being ill with this, that or the other but I knew something was wrong and I said over there [to staff at a different hospital] they will listen more to the parents if they think something’s wrong…then they will follow it up.’ (2)

‘The difference is um…they looked at you as a person not as er…um, not just medically, but where in the hospital they say this is what’s wrong with you and blah, blah where as they saw both sides of you – saw the medical and the person you are…’ (6)

Being the ‘best judge’ related to what the patients felt, what they knew about their feelings and how this impacted on their ability to cope and deal with a medical condition. It seemed that this was ‘knowledge’ and ‘expertise’ that patients had and doctors did not.

While patients did not have expert knowledge of their actual medical disease, they did possess knowledge of, or intelligence about, behavioural changes, emotional feelings and previous experiences. Patients attributed great value to this type of knowledge and felt these changes, feelings and experiences were essential in helping diagnose a condition.

The value of listening

In these interviews, patients repeatedly used the word ‘listening’ – ‘if the doctor listened’ – or said that the interviews were good because the students had ‘listened’ and had been ‘interested’. These were the terms patients used in response to prompt questions when asked what they felt students would learn from this type of patient contact:

‘The qualities that I would personally like, is some one that will listen, not someone sitting there taking notes constantly and then close the file “OK then we’ll see you when next round”…To me, that’s not a doctor – you need to really say how are you feeling? How are you on the emotional side of things?’ (6)

‘I thought it was quite nice to get the view of a parent across…and for them to know what goes on when you have a child at home. Who else is involved. It was nice to be able to explain and put them into the picture. And they did seem very enthusiastic. I think they need to know all aspects of the patient’s care really. Who is involved, what they do and how the parents cope at home…’ (1)

‘Very interested. They used to ask a few questions and I would answer them as far as I could. But they were very, very interested in what I was talking to them…’ (13)

‘Yes, yes I felt relieved that someone’s listening to me…you know that someone’s going to do something different you know, going to alter the system…’ (17)

Listening seemed to represent the fundamental way by that doctors could gain access to the knowledge that patients felt they were experts in:

‘Sometimes you do get doctors that will listen, and it is so much easier if they will listen to what the parents have got to say and not just take it as what’s written in the notes, you know, and I found it very rewarding and I thought that if they [medical students] go on and they do take to heart what parents have said, it’ll be very, very worthwhile.’ (1)

‘Well I thought that if they listened they’d understand what it was really like and it’s not just something that’s written down on a piece of paper…there is lots of different things with MS it’s not just one thing…I explained to them that it can affect people in different ways…’ (10)
Listening was rated very highly; patients genuinely believed that by listening, these medical students were being given ‘a head start [that would] make them better doctors’.

‘Well actually I’m pleased that somebody did come and listen to me. Because I couldn’t get no one to listen to me…Well I think they would learn more because they sit and listen to you more than what they’d listen down the hospital.’ (13)

‘And it should have been done years ago but being as it’s someone’s taking that attitude or method you know, that it would be better in the long run. It won’t help these doctors already in there but er…it will certainly help the ones that’s coming in...’ (17)

There was little doubt that patients believed that this type of involvement and contact with medical students was extremely important. Many saw it as a way of improving the health service.

We did not conclude that patients were challenging technical knowledge. Overall, patients did not challenge medical opinion in relation to diagnosis and were quick to acknowledge how clever they believed doctors to be. What they did challenge was not being heard and the frustration, panic and worry that this could cause for not only the patient but also the family:

‘Well you get a parent, you know, or a relative takes whoever it is into hospital and then they’re sent home [with] “Oh you do it now.” You freeze. You are scared stiff. Because you’re not...there’s nothing there for you to learn about. There’s no resources to say right well this is what he/she’s got, whatever the age. You just, “Oh give’em this. Give ’em that.” and [you say] what happens if this happens? What happens if that happens. “Oh well bring’em back.”’ (4)

‘You start getting all panicky and this, that and the other...Oh there is something wrong with her, I know there’s something wrong with her...they’re not doing anything about it...they’re just leaving her.’ (2)

‘Yes and er...[the consultant] he sat me in the office and he just said to me, “There is no easy way of telling you, you’ve got MS.” and that was it. Just nothing. He didn’t tell me that there was an MS society or anything. It was my own GP that got me all the details.’ (2)

All patients involved in this research expressed a belief in how important they felt this type of patient contact was. All patients involved in the module were visited at the end of the module and all were willing to take part again the following year. One mother felt that a single contact of this sort was not sufficient and she outlined what she thought was necessary and why:

‘I would like to think that when they actually carried on their training they actually remember the normal everyday people that they come out to see. And remembered how they felt being thrown in at the deep end with something like this. Being thrown in at the deep end and actually...I think personally they should...it should be brought in that they have a course to go on actually dealing with people. I think this stage is very important for them to see it before they start off. So they can appreciate and start as they mean to go on. But I think they would benefit a lot more...You know after they’ve sort of gone a couple of years into their studies and they’re actually on the wards, I think that is the time, I think it should be done in 3 stages. One at the beginning like you have. Two, when they’ve done say 6 months on a ward. and then...I think right at the end of qualifying there should be, or even 6 months into qualifying, I think they should have to do this again. Because it’s quite easy. Once you’ve got the confidence and you’re confident yes I’m a fully qualified doctor now or, you know, I know this, I know that. I think that is when they need another shot at reality.’ (4)

Discussion
Few studies have examined how patients living in socially and economically deprived areas may view this type of involvement in professional education. This study has shown that, irrespective of social background or economic circumstances, there are patients who enjoy being involved, consider that they have something valid to offer and believe it to be an important aspect of medical training.

These findings agree with those of other studies in that they established that the patients who took part enjoyed their involvement and were willing to take part again.

It was clear that the patients in this study felt strongly about their experiences and were determined to speak for themselves and give their viewpoints. Most of the patients clearly associated the idea of a teaching role with formal education. They considered their own role more in terms of partnership, explanation and sharing.

They considered that they were the best judges of certain aspects of their illnesses. This ‘expertise’ related to psychological, social and behavioural issues, which impacted not only on the individual patient but also on...
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the family unit. Patients considered that these issues were as important as the medical condition they were diagnosed with.

Patients were articulate and clear on the need for doctors to listen to them. They were able to demonstrate exactly what they meant in terms of why the doctor needed to listen, in what way the doctor and patient would benefit and how important an issue they believed it to be.

Through the interviews, the patients were able to share, inform and advise the students from their own perspectives. Medical anthropologists refer to lay experiences of a sickness as ‘illness’ and to a medically labelled condition as ‘disease’. Kleinman7 compares the explanatory models of illness that patients hold with the models of disease held by health professionals and suggests that it is important to identify elements of congruence and difference between them.

Investigating patients’ perceptions may appear threatening to professionals, in that it might be considered to challenge medical competence, but this study does not support that view. There appeared to be very little in the way of challenge to medical opinion by patients in terms of their diagnosis or treatment; in fact most patients stressed their recognition of the intelligence and learning that doctors possess. Several patients spoke of the lack of time available to doctors, which they suggested partly explained doctors’ perceived ‘failure to listen’ to the patient.

The interviewees hoped that by meeting patients early in their training, the clear message of the importance of ‘listening’ would be remembered by future doctors. However, there is evidence to suggest that by the time these students qualify, they may have lost this ability or forgotten the message and instead have become experts in taking a medical history.8 This is the challenge for medical education.

Tomorrow’s Doctors5 clearly states that ‘doctors must be good listeners if they are able to understand the problems of their patients...’ If we use patients in this way, the very least we can do is ensure that the skills of listening, appreciating and interpreting patients’ stories come to represent a set of core clinical skills in the medical curriculum. This will increase the likelihood of the doctors of tomorrow firmly grasping the lessons ‘taught’ by the patients of today.

In conclusion, we suggest that patients and carers are positive about their involvement in medical student training. Many patients do not see their role as that of a teacher, but instead as an advisor, informer and sharer of their knowledge and the fact that this knowledge stems from their experiences. The patients and carers interviewed by the medical students were quite clear about the importance of ‘listening’ as a skill that doctors need. They knew that their experiential knowledge needed to be acknowledged and their voices heard. Through the willing and continued participation of patients and carers as lay experts, the medical students involved had the privilege of hearing patients’ perspectives early on in their training as the doctors of tomorrow.

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References


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