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“My way of giving something back”: Patient and carer experiences of involvement in medical education

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Abstract

Background
Patient involvement initiatives in medical education traditionally focus exclusively on the rationale, need, and potential benefits to learners in developing patient-centred practice.
Objectives
This study explores the impact of involvement on patient educators working in medical education.
Method
A mixed methods approach was used to generate data for content analysis. Participants completed a questionnaire (*n*= *49)* and were then invited for a follow-up interview (*n*=*20)*, both methods explored views on involvement, motives for taking part and the impact involvement has had on their lives.
Results
Participants reported that they valued opportunities to take part in medical education. This provided a means to reflect on their health condition and patient experience; had perceived and real benefits for their health and wellbeing and provided an opportunity to educate students in ways which participants felt had wide-ranging benefits.
Conclusions
There is a need to further develop theoretical understandings of patient involvement in medical education. In adopting a Bourdieuian analysis of involvement the results of this study suggest there is a need both to prepare patient educators for involvement and to provide on-going support to enable individuals to realise the benefits of involvement, which are not automatic.

Keywords: patient involvement

Article

Introduction

Patient involvement initiatives in medical education have traditionally focused exclusively on its rationale, need, and potential benefits to student learners in developing patient-centred practice (Klein et al. 2000, Dammers et al. 2001, Rosenbaum et al. 2005). As the ways in which patients are involved in education, research and service development have expanded, their role has been explored more critically (Rees et al., 2007, Morgan and Jones 2009, Towle et al., 2010, Spencer 2011). Researchers have begun to consider the perspectives of patients in greater detail, contemplating the benefits and outcomes for those who get involved (Stacy and Spencer 1999, Thistlethwaite and Cockayne 2004, Rees et al. 2007, Dogra et al. 2008, Cotterell et al, 2011, Lauckner et al. 2012).

This paper reports on an empirical study that explored the reasons for patients and carers becoming involved in medical education and the impact that this involvement had on individual participants. The study looked at four specific research questions. Firstly, what was it that motivated patients and carers to become, and remain, involved in medical education? Secondly, how did patients and carers perceive the impact of their involvement in medical education? Thirdly, did patients and carers identify any changes in how they experienced their health condition as a result of their involvement? Finally, what were the implications of the experiences of patients and carers in relation to the recruitment, training and support of future patient and carer patient educators?

The language of involvement, collaboration and partnership became central to UK public policy following the election of New Labour in 1997 (Glendinning et al. 2002, Powell and Dowling, 2006) and came into focus again in the wake of the Francis report (Francis, 2012). In the UK this has led to an emphasis on patient and carer involvement in education, research and service development (Department of Health 1999, 2000, 2005, 2006, 2010). Whilst we acknowledge this is a UK study, patient involvement is a common feature of medical education internationally (Towle et al., 2010) which gives this study wider relevance.

The rationale behind many of these initiatives has been a belief that those individuals with personal experience of a medical condition are best placed to inform others (student practitioners, healthcare professionals, managers) about the day-to-day experience of living with; and being in receipt of treatment for that particular health condition (Department of Health 1999, 2001, 2005, 2010). There is also an assumption that, through involvement, patients and carers become more informed about their health and so manage their own care better, which consequently eases the economic pressures on the UK National Health Service (Coulter 1999). Increasingly, patients are increasingly recognised as “experts” in their respective conditions and their views are solicited on a range of topics relating to diagnosis, treatment and illness management (Cotterell et al. 2011), service development and delivery (Clark et al. 2004) and education (British Medical Association 2008, Spencer 2011).

While the language of policy has focused on involvement, collaboration and partnership, historically, patient involvement in medical education has been located within a very different discourse. Patients have traditionally held passive roles in education with learning led by clinical staff. However, changes to health service delivery, notably shorter hospital stays and the predominance of acutely ill patients in hospitals, have had an impact on the opportunities for learning in acute clinical settings. Consequently, current students are less likely to meet a diverse range of patients; or to follow individual patients on their journey through treatment. As a result of this, medical schools now provide additional opportunities beyond the ward environment for patient contact that results in patients and carers taking a more active role in education (British Medical Association 2008, Spencer et al. 2011). This has long been a feature of community based education (Spencer et al. 1999, Dammers et al. 2001, Thistlethwaite & Cockayne 2004, Hopayian et al. 2007) but has been a more recent development in acute care and classroom settings.

Patient and carer involvement in a wide range of teaching, assessment and curriculum development activities is now a requirement of UK medical education (General Medical Council 2001, 2003, 2009). Activities include clinical / communication skills teaching, assessment, simulated patient work, developing teaching resources and delivering workshops on aspects of health. Our medical school in Leeds established a Patient and Carer Community (PCC) network in 2011. The PCC recruits, trains and supports patients and carers, and is managed by a Patient and Public Involvement (PPI) Manager who is also a carer. Individuals are recruited via local patient and carer support groups and adverts in community and voluntary sector publications. As patient involvement initiatives have expanded within the School of Medicine, in line with General Medical Council requirements (GMC 2001, 2003, 2009), patients and carers have had the opportunity to participate in varied educational activities. These include student-patient home visits by students (Thistlethwaite and Cockayne, 2004), delivering training workshops on specific aspects of health (Ewart and Sandars, 2006), assessment (Kilminster et al. 2007) and developing teaching resources (Kilminster and Fielden, 2009). Activities take place across all five years of the undergraduate medical degree programme. In addition to their involvement with undergraduate students, members of the PCC network are also involved in service development with NHS partners and research and innovation projects with members of the faculty research community (Jha et al. 2009, Morris et al. 2010, Muir and Laxton 2012).

The focus of this study was to explore *why* individuals from the PCC network choose to be involved in medical education and to understand *how* they experienced involvement. This is important as it has implications for who is recruited as a patient educator, and how individuals can be best supported in their involvement.

Methods

The study adopted a mixed methodological approach. PCC members who agreed to participate in the study completed a questionnaire and self-selected for a follow-up interview. Semi-structured interviews took place at participants' homes or at the School of Medicine and were carried out by SF. SF was known to some members of the PCC as she had previously developed teaching materials, co-facilitated taught activities and employed network members.

Study Population

Given that many of those involved in the PCC network live with chronic conditions, which can affect their ability to participate, only those active at the time of the study were invited to take part (*n=113*). Of those participants who completed the questionnaire (*n=48*), *46* volunteered to take part in a follow-up interview by indicating this preference, and providing contact information on their completed questionnaire. Of those who volunteered to take part, 20 were interviewed. The sample was selected on an opportunistic basis as to when both SF and study participants were available for interview over a three-week period, as this study was conducted as part of a part-time Masters degree. All participants were still actively involved in medical education at the time of their involvement in this study. Interview participants included participants with both limited and extensive levels of involvement in relation to both length and type of involvement.

Procedure

The questionnaire and interview were designed to track the process of involvement from recruitment and initial training to current activities. This was based on the premise that it would be easier for participants to recall events in sequence, through telling the story of their involvement. General introductory questions, relating to educational and professional background, were also included in the questionnaire and provided quantitative demographic data. This enabled participants to orientate themselves towards their first involvement in medical education and provided a context for their possible motivation for involvement. A set of free text questions focused on how participants became involved in working with medical students, the activities they then participated in, and how they viewed their role. Participants were also invited to comment on the extent of training and support received to carry out their role, and asked to explicitly comment on the benefits and challenges of involvement in medical education. Individual questionnaires were re-read prior to interview and used as a prompt, when necessary, during the interview to explore issues raised in the questionnaire in more depth. Participant interviews lasted, on average 38 minutes (range 17-77 minutes). The questions discussed during participant interviews are detailed in Box 1.

Box 1. Interview Schedule

- Would you like to begin by explaining how you came to be involved in medical education?
- How would you describe your role here in the Medical School?
- What have been the outcomes for you from being involved in medical education?
- Have you changed during the course of your involvement? If yes, what has prompted these changes?
- In what ways do you see your role developing in the future?
- Is there anything else you would like to tell me in relation to your involvement in medical education?

Analysis

The quantitative data from the questionnaires was analysed for frequencies using the statistical package SPSS™ (SPSS, Inc., IBM, Chicago, IL, USA). Free text questionnaire comments and interview audio recordings were transcribed verbatim. A number of participants were keen to be identified in data, however due to the numbers involved and in order to meet the anonymity requirements of ethical approval all participants were assigned a numeric identifier. We followed Braun and Clarke (2006) to conduct a thematic analysis of the transcribed questionnaire responses and interviews, noting any points that related explicitly to the research questions. Working independently, we compared and agreed themes that were then used to identify trends and significant differences across participants (particularly in relation to length of time and nature of involvement). As each trend emerged, we returned to previous transcripts to check its applicability to other participants. This process was aided by the quantitative data, which provided a summary of who was involved and the regularity of their involvement.

Ethical Approval

The involvement of patient educators in this study raised a number of ethical issues related to disclosure of medical information, potential vulnerability of research participants and confidentiality of data. It was made clear to all participants that involvement in this study was voluntary and that they were free to withdraw at any stage, without consequence. Participants were approached in their capacity as educators, and not as individuals currently accessing healthcare, consequently participants were not asked directly about their medical history. Participants were recruited via a gatekeeper, the School's Patient and Public Involvement Manager who only approached individuals actively involved at the time of the study, and who were therefore well enough to take part. All data was anonymised and stored securely in line with local guidance. Ethical approval was gained for the study from the Medicine and Dentistry Educational Research Ethics Committee at the University of Leeds.

Results

Sample

All 113 members of the PCC network were invited to participate in this study. 48 returned a completed questionnaire, with 46 volunteering to be interviewed. Due to time constraints, interviews were carried out with 20.

Analysis

Results are presented in an integrated manner, which reflects the mixed methods approach used in the study, and in relation to the initial research questions, which explored: (i) Motivation for involvement, (ii) Impact of involvement, (iii) Changes in health and wellbeing and (iv) Recruitment, training and support. Quotations are taken from both questionnaires and interview transcripts to support our observations.

Participants with a varied level of involvement were more likely to identify positive outcomes across all research questions than participants who had been involved in one activity for a significant length of time. This was even more apparent where the involvement activity took place outside of participant homes in clinical or university settings where participants had greater access to support networks and training.

Motivation for involvement

A significant number of participants (61% of study participants) took part in medical education on an unpaid basis, 1:5 study participants were involved ten or more times during the academic year, and 64% of those who took part in the study had been involved in medical education for a minimum of five years. Participants were not motivated by financial remuneration, but by the chance to influence future medical practice:

"It helps me knowing that I have put across some problems I have had with the NHS over the years and that the students can learn from these experiences." (013, Patient)

Participants spoke of involvement as an opportunity to "pay back" for past NHS treatment and/or to alert the next generation to the best and worst approaches to treating patients:

"I know this sounds clichéd, but I feel I am giving something back in return for the excellent health care I have received over the last eight years. I hope my knowledge of good and bad health care can establish better communications and care between future doctors, nurses, etc. and their patients." (008, Patient)

"I have grown and shared my life experiences with them, giving insight to the struggle I found being not listened to… The doctors of tomorrow need real people to learn from." (046, Patient)

When discussing how and why they first got involved in medical education, it was initially clear that participants were driven by a desire to influence practice. As participants discussed their general experiences of involvement more complex motivations emerged, linked to participant's personal circumstances (resources – time, money, mobility) and beliefs (faith, altruism). Furthermore, the impact of involvement on individual participants proved to be a strong motivator for continuing involvement in medical education as evident in the quotation in the following section.

Impact of involvement

A number of participants were no longer in employment following forced retirement due to ill-health. Involvement offered them an opportunity to work in a part-time capacity (sometimes paid, although more often not) at a location convenient to them (involvement activities took place in participant homes, on campus and in clinical settings). The opportunity to work was something that a large number of participants spoke enthusiastically about; it appeared to offer them a form of status, by virtue of being of use to someone:
"I find the experience enjoyable and satisfying… It was a privilege to be able to help them – and I like to think that now, in old age, I am STILL [*participant emphasis*] useful, and I hope, helpful to young people." (005, Patient)

Participants did not restrict their involvement activities to medical education. A number were involved in a voluntary capacity within their local communities, in housing, faith and patient support groups, as a precursor to their involvement in medical education:
"It's almost a volunteer role for people who have always been volunteers who suddenly, their options are limited and so it's suddenly something that you can do…" (016, Patient)

Given that the majority of PCC network members are recruited via patient support groups and adverts in community and voluntary sector publications it is perhaps no surprise that such a large number had prior history of involvement in other voluntary groups.

Changes in health and wellbeing

Participants were positive about the impact of involvement in medical education on their own health and wellbeing:
"I [find] their youth and enthusiasm very refreshing, helping me to take my mind off the pain and discomfort of my condition." (036, Patient)

Participants spoke of perceived and real benefits to their mental health and identified improvements in self-confidence and self-esteem as a consequence of involvement:
"It has helped me enormously. When I first started working with the medical school, I was at a very low point in my life. I was in the process of accepting that I could no longer continue my career in [company name] because of my health problems. I had lost a lot of self confidence and self esteem." (008, Patient)

Furthermore, participants described how their involvement in medical education had influenced their interactions with health and social care professionals. Participants made reference to how their improved understanding of doctors' training led them to appreciate healthcare practices more:
"Being involved in medical education… has made me more confident in speaking out and challenging healthcare situations when necessary. It has … given me a language I did not have before." (047, Patient & Carer)

This in turn gave some participants a confidence in their own expertise, which informed their relationships with their own medical team:

"I think it's made me more pro-active I think before I was involved with medical students I was a much more passive patient …I don't think I'd ever realised actually that I was the expert of my condition which sounds a bit naïve … I think it just opened a whole a whole [*sic*] new way of thinking for me … when I'm talking to a consultant or a or my own GP I feel it's much more balanced partnership." (015, Patient)

Where participants were only involved in one or two activities each year, they were less likely to identify any changes in their health and wellbeing as a result of involvement in medical education. One participant who was involved once a year disclosed the emotional challenges of involvement in medical education:
"I have this brave face on right and I don't get emotional. I'm upset afterwards because I'm re-living it but I don't tell them what I've told you… I make sure I'm not telling them too much personal history and that I don't get upset." (012, Patient)

This participant had continued to be involved each year despite the emotional challenges involved to ensure future patients could benefit from his experience. The participant considered the opportunity to be involved a "privilege" and felt that he had developed strategies to cope with the emotional fall-out of taking part. This participant's experience raises a number of ethical dilemmas in relation to working with patients and carers who have complex and difficult experiences that require additional support.

Recruitment, training and support

Participants who were involved once or twice a year (in student-patient home visits) were less likely to identify any training or support provision and/or need in relation to their involvement:
"I've no need to train as far as I'm aware I just tell them whatever they want to know… they seem to come with a set of questions and just start talking I think I sometimes go on a bit probably giving them answers to questions that they haven't thought of asking…some people don't like talking about their illness and things but it doesn't bother me…" (028, Patient)

A small number of participants did express some anxiety or apprehension prior to their first involvement, due to a lack of experience and/or preparation. In all cases, participants felt more prepared once they had taken part in the first session.
Where participants took part in involvement activities that were located on campus or in clinical settings, more training and support was available and participants had face-to-face contact with teaching / support staff and the wider network of PCC members. This was particularly valued by participants:
"I think it's really helpful [training] I think it's all part of that vital support network which is what makes it so easy to work with-with medical students because there is that really good back up… We've also got the support of the medical school and all the-the training and de-briefing sessions err and we've got our own network amongst the patients where we-we talk about err everything and anything…" (015, Patient)

Participants who were regularly involved in medical education did not disclose how, when or why their role and opportunities expanded. The majority of participants involved only once or twice each year appeared to be unaware of the additional opportunities for patient involvement at the School of Medicine, or that they were part of a wider network as reference to the network was notably absent from their responses.

Limitations

A number of limitations with this project restrict the generalizability of its findings. Research participants were recruited from one Medical School, consequently conclusions are not necessarily generalizable across other Medical Schools, or other departments where patients are involved in education (for example, Social Work, Nursing and Allied Health). As a member of staff within the School of Medicine SF had previously worked with a number of the participants involved in this study during teaching activities in the School, and this may have influenced some participants when completing the questionnaire and during interviews. However, as a qualitative study the concern was with the experience of patients and carers at a specific UK medical school, there was no pursuit of generalizability, which is not unusual in this field (Hardy, 2012; White, 2014).

Discussion

Findings from this study highlighted a number of positive outcomes for patients and carers in relation to their health and wellbeing. These included increased confidence, self-esteem; benefits associated with reflecting on their condition and experience of healthcare (with students, staff and other members of the PCC network) and improved relationships with their medical team (related to improved understandings about the training and education of doctors and healthcare professionals).

Findings in previous studies suggest (Walters et al. 2003) patients and carers identified a sense of reward and pride in the opportunity to “pay back” the NHS for past treatment, and through investment in the education and training of future doctors. Through sharing their stories with students, members of the PCC network were able to discuss their experiences, raising difficulties, sharing examples of what was helpful and clarifying their own thoughts on their experience which in turn validated their experiences. These findings are supported by the literature on patient involvement in healthcare delivery where involvement provided an opportunity for patients to “live well” (Cotterell et al. 2011).

Despite this, there remains a concern in practice and in the literature that repeated storytelling of illness narratives can have a detrimental impact on the psychological and emotional wellbeing of patients, carers and students (Gregor and Smith 2009, Jha et al. 2009). Members of the PCC involved in this study did not report negative outcomes of involvement in relation to their health and wellbeing, with the exception of one participant. Given the response rate of 44% it may be that individuals who were more likely to identify negative outcomes of involvement were less likely to respond to the invitation to take part in this study, or may have withdrawn from involvement entirely. Additionally, patient involvement opportunities at the University of Leeds at the time of the study focussed predominantly on teaching activities related to communication skills and team work skills, and at the time of this study not clinical skills and patient safety. This may influence which individuals are recruited to take part, and what patients and carers discuss with students. Furthermore, the PPI Manager at Leeds has developed an induction programme, called the *Patient Learning Journey* which is intended to prepare and screen patients and carers for involvement to ensure that those involved are student-centred and at a point in their own health journey where they can have a positive role in medical education (O’Neill 2005, Morris et al. 2010). This will therefpre limit which individuals are recruited, and consequently narrow the range of patient experiences students are exposed to.

Participants involved in this study were asked to comment on the level of preparation and support provided by the University to enable them to carry out their role. Patients and carers made reference to a number of opportunities, including inductions, briefings, formal training sessions, de-briefs, feedback and identified University staff that were available to support them in their role. Concerns from practice and the literature identify training and development opportunities as the potential catalyst for the formation of professional identities amongst patient and carer educators (Kilminster and Fielden, 2009). For some, this is viewed as undesirable and problematic as it dilutes the "authentic" patient voice. However, findings from this study suggest that training offered those involved the opportunity to prepare for their role, understand the perspective of the student and the wider curriculum, reduced anxiety and gave participants entry to networks of peer and academic support.

It could also be argued that findings from this study illustrate the importance of 'capital' in relation to those involved (Bourdieu 1992). Patients and carers with a background in education or healthcare have a degree of cultural capital in the form of knowledge (understandings of theories of learning, the role of doctors, and the medical curriculum), which made them more likely to be involved and, in some cases, accelerated their level of involvement. Consequently, those who were regularly involved had access to forms of 'social capital' in the form of training, feedback and access to networks that opened up additional opportunities, notably paid opportunities which improved their economic capital. Findings from this study illustrate how a Bourdieuian analysis may help identify why certain groups (young adults, ethnic minorities) are not involved in medical education and therefore contribute new understandings about the nature of patient involvement in medical education.

Access to training and debriefing opportunities appeared to be dependent on the type of activity patients and carers were involved in. Where participation was limited, for example student-patient home visits a minority of participants, who had limited involvement, identified feelings of isolation, and/or were unaware that they were part of a wider group of patients and carers involved in medical education. Participants appeared to value preparation, training and the support of other members of the PCC network, and staff members when carrying out their role. This appeared to be valued more than financial remuneration, which was only commented on by one participant. However, as the questionnaire and interview asked few direct questions about financial remuneration this may explain why it was not raised by other participants.

Participants often discussed their role in medical education in the context of their beliefs about community and faith. For those who took part, involvement was not so much about them and the task they performed, but the opportunity to contribute to the development of others. A number of participants spoke about being in a position to help students due to their experience of living with a chronic condition, accessing healthcare and having the time available to support medical education. Participants valued civic engagement and felt a responsibility to help others, which was illustrated by their comments about their reasons for participating, their involvement in other sectors of their local community (housing, faith and patient support groups) and in the response rate to the invitation to take part in this study. This suggests that individuals who choose to get involved value civic engagement, but also have the resources available to participate in these activities. These findings suggest involvement is not just what they do, but who they are as individuals. Issues of identity and representation are visible in other literature on patient involvement (O'Neill 2005, Rees et al. 2007, Williamson 2007). There are concerns that those individuals attracted to involvement opportunities are rarely representative of the general population or locality. There is an assumption that the majority of those involved are from white, middle class backgrounds and have prior experience and membership of committees and professional bodies. Furthermore, there is a perception that patients and carers who are heavily involved in teaching activities are out of touch with the concerns of ordinary patients, and there is the suspicion that their willingness to engage shows they have a particular 'axe to grind' (O'Neill 2005). This area is poorly addressed in the literature, although it would be reasonable to assume that patient and public involvement (PPI) initiatives in medical education experience the same difficulties as other organisations in involving a diverse range of people. Issues of representation and identity are important as they have implications for how patients understand education and learning, and impact on how they behave in the classroom.

The majority of participants who took part in this study were motivated to get involved following positive experiences of healthcare; only a minority were motivated by negative experiences. Almost absent from the accounts in this study were the voices of those individuals with experience of prescribing errors, failures in teamwork and breakdowns in communication. It may be that participants chose not to discuss these issues, or perhaps, that these groups do not get involved, or are not encouraged to get involved in medical education. The rhetoric of patient involvement may suggest a ‘democratization of services’ but decisions about how individuals can and should be involved, and which patients and carers should be involved, may remain under the control of professionals (Cowden and Singh 2007). This is a complex issue, this study highlights the ways in which patients and carers report positive experiences of health and social care but this is clearly not the experience of all individuals accessing NHS services and perhaps this needs to be better reflected in the contribution to medical education from the patient and carer community.

Conclusion

There are a number of implications from the findings of this study. Firstly, if the purpose of patient involvement is to develop patient-centred care, it is a concern that students are not seeing a sample of patients that reflect the local population (specifically young adults, those from non-white ethnic backgrounds and patients with experiences of failures in care). This will have implications for how confident and able students are in speaking to, treating and managing patients from these groups. Furthermore, Universities have a moral and social responsibility to engage with all members of their communities which are not currently being met and should seek to find new ways of involving underrepresented groups.

Secondly, there is a value in preparing and supporting patients and carers in their involvement and enabling individuals to take advantage of networks. Benefits of involvement aren’t automatic but are dependent on appropriate levels of support and training. Ensuring those involved feel supported in their work should override any concern that support and training may lead to a shift in patient identity and the “professionalization” of those involved (Wright and Rowe 2005, Cowden and Singh 2007, Jha et al. 2009). When developing patient involvement in medical education it is neither possible, nor necessarily desirable to provide “authentic” patient encounters all of the time. Instead educators need to be mindful of scaffolding learning opportunities, taking into consideration the needs and well-being of both the student and the patient at all times.

Finally, the findings report significant health benefits to involving patients in medical education. The participants involved in this study identified several therapeutic benefits. These included improved understandings of the healthcare system, the role of the doctor and healthcare language and terminology. These benefits impact upon individual patients and their families, but also have a potential benefit to healthcare resources because individuals make fewer demands. Consequently, involvement in medical education may have a small but significant impact on rates of prescription, dependence and doses of medication, appointments times and rates of compliance at a time when cost-benefit provision is under pressure.

Ethical approval

Ethical approval was gained for the study from the Medicine and Dentistry Educational Research Ethics Committee at the University of Leeds.

Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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Take Home Messages

Notes On Contributors

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Appendices

Declaration of Interest

The author has declared that there are no conflicts of interest.