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RESEARCH ARTICLE

# Involved stakeholders or voiceless backseat drivers: Volunteer patients' experiences and perceptions of undergraduate pharmacy education

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## Abstract

**Objective**: The shift towards patient-centred care is a driver for increasing stakeholder involvement in the education of health professionals. This study explores volunteer patients' perceptions and experiences of being involved in undergraduate pharmacy education. **Methods:** Three focus groups were held with volunteer patients. The focus groups were analysed using thematic analysis. **Results:** There were four themes identified: organisational restrictions, impact on students, motivators and experience of being a volunteer patient. The patients perceived their value to be in bringing authentic patient experience to the students especially when they could share their own narrative as opposed a pre-prepared scenario. There was a desire for greater interaction and partnership. **Conclusion:** The patients perceive themselves having a vital role in the training future pharmacists. Their experience has been mainly positive but more needs to be done to involve them as stakeholders whose voice is listened to in the education of students.

## Introduction

Across the health care sector, patients are becoming more involved in all aspects of their care, including delivery, research, policymaking, and education (Towle *et al.*, 2016). Increased attention is being given to the importance of shared decision making in clinical situations and how this needs to be part of healthcare professionals' routine practice (Elwyn *et al.*, 2012). The patient benefits of active engagement in clinical decision making include continued learning and being able to assess the care they receive (Pomey *et al.*, 2015) and being empowered to suggest adaptions, thus potentially enhancing the care they receive. There is a shift to patients and caregivers as stakeholders with a voice rather than being passive recipients of care.

The changes in practice need to be mirrored in the way future healthcare professionals are educated. There is a growing imperative to have the patient voice present in the education of health and social professionals as early as possible (Towle *et al.*, 2016). In the United Kingdom (UK), the King's Fund has actively advocated for the role of collaborative care planning in healthcare curricula (Coulter *et al.*, 2013). Yet, in reviewing current patient involvement initiatives in medical and health education, it seems that the focus is on one-off patient initiatives rather than building ongoing programmes of patient involvement (Spencer *et al.*, 2000; Towle *et al.*, 2010). Involving patients offers opportunities for educators and students to engage with the stakeholders and indirectly with wider society.

A commonly used pedagogic framework in teaching clinical skills is Miller's pyramid, where the emphasis is on moving students from 'knowing how', and 'showing how', to 'doing' (Miller, 1990). Unlike other clinical and health-related professional degrees in the UK, pharmacy programmes do not always include longitudinal placements during undergraduate training, thus limiting patient contact that would

naturally occur in a practice setting. Therefore, involving patients in the teaching setting would give pharmacy students an opportunity for patient contact, which they would otherwise not have on a regular basis. This increases opportunities for students to move from 'knowing how' to be patient-centred to 'being' patient-centred. Yet, a review of service user and caregiver involvement in healthcare education by Morgan and Jones (Morgan & Jones, 2009) did not identify any initiatives with pharmacy students, with most research being in undergraduate medical training.

Furthermore, across health professions, there has been a limited focus on the perceptions and views of patients themselves concerning their experience of involvement in education (Aronson & Janke, 2018). The existing studies place emphasis on the learning achieved by the student, not the experience of the volunteer patient (Plaksin *et al.*, 2016). However, when patient perspective has been included, the findings suggest that the experience is challenging but positive, with patients describing a tension between the vulnerability of sharing personal information and making valued contributions through meaningful sharing (Lauckner *et al.*, 2012).

Exposure to patients from early stages of training has been found to be beneficial to students; however, the relationship has been objective, with patients being more like exhibits than involved partners. To fully and meaningfully engage with patients as stakeholders in the education of future pharmacists and other health care professionals, it is vital to know what the patients' perceptions and views of their involvement have been to the date and how they can be meaningfully involved in the future. This study aims to explore the perceptions of volunteers' patients of their role and impact on students' learning experience and their experience of volunteering to help in the education and training of pharmacy students.

## Methods

As part of the Master of Pharmacy programme in question a mix of volunteer patients and paid role players (professional actors specialising in clinical skills role play) were involved in various aspects of teaching across all four years of the programme. These sessions included clinical skills, preparation sessions for clinical skills examinations, as well as formative and summative Objective Structured Clinical Examinations (OSCEs). Role players only take part in scripted scenarios rather than sharing personal experiences as a patient; the volunteer patients are also involved in patient voice seminars, where they share their lived experiences of ill health as well as some scripted scenarios.

The volunteer patients did not receive any formal simulated patient training but had a briefing about the course and its aims before becoming involved. Volunteer patients had no contractual arrangements and were not paid, unlike the role players. The volunteer patients were given gift vouchers depending on the number of sessions they had been involved in.

All of the patients from the programme volunteer patient mailing list, who had taken part in sessions over the previous year (n=26), were invited to take part in a focus group at the end of the academic year. Paid role players were excluded as they do not share personal experiences as a patient. Three focus groups were held, with a total of 13 participants. The study used voluntary sampling. No measures were put in place to prevent selection bias as this was deemed low risk due to the relative uniformity of the sample population. Participants received an information sheet before taking part in the focus group. At the start of the focus group, copies of the information sheet were available for the participants to read, and they had an opportunity to ask questions from the facilitator (LL) before signing a consent form.

Each focus group started with the sharing of ground rules, such as only one person speaking at a time. A topic guide was used to direct the discussion in the focus group (Appendix A). The questions within the topic guide focused on the participants' experiences, perceived contributions and the format and structure of the teaching sessions they volunteered in. The facilitator of the focus group moved the conversation onto the next question once each participant had contributed all they wanted to a particular question. All of the focus groups were audio-recorded, transcribed verbatim and coded inductively (Linneberg & Korsgaard, 2019), and thematic analysis was applied to the data to identify key themes (Anderson *et al.*, 2019). The initial coding was undertaken by the first author (LL) and checked and agreed upon by the second author (CR). Themes were constructed jointly. The study received ethical approval from Durham University, School of Medicine, Pharmacy and Health's ethical committee (ESC2/2017/PP08).

## Results

### *Participants*

Of the participants (n=13), six were male, and seven were female. The mean age of volunteers was 68.5 years (Standard deviation (SD) is 11.6). Three of the participants also acted as volunteer patients for other courses such as medicine or nursing. Most of the

volunteer patients had been involved with the programme for at least three years (SD 1.2).

***Themes***

As part of the thematic analysis, four themes were identified from the data: organisational limits, impact on students, motivators and being a patient. Each will be discussed in turn below. For each quote, the gender of the participant as well as the focus group has been indicated; each participant was numbered in order of speaking, *i.e.* F1 is the first female to speak. Each theme was discussed across all the focus groups, but a varying emphasis was used during the conversations. Table I presents the ranked order of themes for each focus group, with '1' being the most discussed topic based on coded references in the transcript and '4' being least discussed.

**Table I: The ranked order of themes discussed in each focus group based on the prevalence of coding**

| | FG1 | FG2 | FG3 |
|---|---|---|---|
| Organisational limits | 1 | 2 | 1 |
| Impact on students | 3 | 1 | 2 |
| Motivators | 2 | 4 | 4 |
| Being a patient | 4 | 3 | 3 |

***Organisational limits***

When the patients spoke about the effect the organisational structures had on their involvement, there was a sense of restriction and an unknown associated with it. For the patients, the lack of understanding of the content and the context of the course meant that they were hesitant to suggest potential changes or improvements as they felt they did not know how this fitted into the 'bigger picture'. If someone had an idea for improvement, they felt that knowing it aligned to the curriculum gave it validity; more than their own role and experience as a *de facto* stakeholder for the programme.

> *"Yeah, and then some situations as well where you've got two people sitting there because you would, wouldn't you? A lot of times, your partner or your mother or father or daughter comes in with you, or your carer, or whatever, to see how they would then deal with which person do they talk to and…" [F1]*
>
> *"That's interesting." [M1]*
>
> *"But it depends on the syllabus, without knowing the syllabus." [F2; FG (focus group) 1]*

From a course delivery perspective, the patients understood the need for both teaching and assessment (OSCE) sessions. However, they all preferred being part of teaching sessions rather than formative and summative OSCEs. The patients understood assessments to be a necessary component of the curriculum but felt that they were able to be more involved in the teaching sessions where there was an opportunity for authentic interaction with the students. There was a sense of constraint that the patients felt in the OSCEs.

> *"Because at the end of it you can actually give an impression of how they've done and give them some tips and I find that very rewarding, the OSCEs are a little bit more mechanical because they have to be. But once you've gone through the same scenario 20 odd times…" [M1; FG2]*

At some points, the volunteer patients also took part in sessions where they were given a script or scenario to follow. The content of the scenarios or case studies was an issue the volunteers struggled with. Due to the restricted number of volunteer patients involved in the programme and the very similar age profile of them, many of the patients said that in sessions where they were given a script, they often found themselves acting a role that was not the most appropriate for them. The patients felt that, at times, this made things harder for the students. They thought the scenarios were repetitive and also lacked the challenge of having more complexity both in terms of the case or the required communication. This criticism was often paired with the acknowledgement that the patients did not know whether this was something the students did in additional sessions where they were not involved.

> *"The point I was making, it could be an autistic person who comes in to talk to the pharmacist." [M1]*
>
> *"But they're OK." [F1]*
>
> *"But do they get practice with that?" [M1; FG3]*

***Impact on students***

The patients felt that their role was to bring reality to the students. In agreement and with strong emotion, they perceived themselves to be the representatives of real people to students. Being 'real' had many facets to the patients, such as forgetting the names or strength of medicines or having disabilities. Meeting real people was, for the patients, an essential part of preparing the students for the world that existed outside of the somewhat sheltered walls of academia.

> *"Some of the medicines, I can't pronounce them at all." [F3]*

*"But then you wouldn't in real life, would you?" [F1]*

*"No, I can't pronounce them in real life." [F3]*

*"I got mine on a bit of paper here." [M2; FG1]*

Through this, the patients perceived themselves to have a role in preparing the students for practice. The patients particularly felt that the students were becoming more empathetic and aware of patient's varying abilities. For those who had been involved for number of years, seeing the development in the students' skills and abilities as they progressed through the course was satisfying. Speaking too fast or too quietly and forgetting to greet the patient as they entered were often mentioned by the patients as limitations of the student's interactions, but also being too focused on the task and not seeing the patient as a person were things that the students could improve upon.

"I think they've now had an experience of talking to patients, although it's an artificial situation, when they become pharmacists themselves they'd be happier to come out and speak to the patient because they've had an experience with us." [M1; FG3]

Being able to provide feedback to the students was one of the main contributions the patients felt they were able to offer to the students. Patients did not like the sessions where there was time pressure and limited opportunities for giving feedback. The patients felt that more time was needed to allow feedback to be given well. For them, the aim of the feedback was to facilitate an opportunity for the students to consider the patients' perspectives in their consultations.

*"…when each session would have a minute to two extra at the end so that you could give your point of view and any advice. Well, I mean you give your advice as to how you've seen it and so that they get the experience of just talking to people in a normal situation." [F1; FG2]*

***Motivators***

The main reason for the patients' involvement as a volunteer patient was the opportunity to help others. Some patients expressed this in terms of being altruistic and just being able to do something good for others. For others, it was more about feeling useful themselves and being able to contribute towards the students' development.

*"With me it's that giving something back because of what I've had over the years. I was given a good schooling, I have a daughter and a grandson and they've both had a leg up from other people, from university in the case of my daughter and I would hope that somebody like me, would be prepared to help them altruistically." [M1; FG3]*

Even though wanting to help was the underlying reason for patient involvement, many of them recognized that there were benefits for themselves too. Keeping their memory active, having something to do when retired or unemployed, meeting new people were some of the reasons the patients talked about. Being able to spend time in a university setting and getting a different perspective on how universities work through meeting staff and students was also mentioned. There was also a sense of kudos attached to volunteering at the university that some patients felt.

*"I must admit, I do, not boast about it, but if they say 'where are you going to?' 'ooh, I'm off to the uni'. I just enjoy doing it." [F1; FG1]*

***Being the patient***

On the whole, the patients liked the experience of being volunteer patients, but they did also find some challenges in their involvement. Practical things like learning the scenarios, especially if someone was called in on short notice to cover for someone else, were discussed in detail. The patients shared that when they had first started volunteering, they used to be nervous about forgetting the scenario, but after doing it for a while, they had become more confident at not knowing all the minute details of the scenarios as the students rarely asked that detailed questions. Patients discussed the individual strategies they had for learning the scenarios, such as highlighting or making notes.

*"My highlighting pen used to come in very handy. I could put it down there and it was all highlighted the important points. It was quite useful." [F1; FG3]*

As alluded to in the organisational restrictions theme, the volunteers preferred the sessions that were not a formal student examination. The patients noted how in an OSCE, the student's behaviour was more focused on making sure they did everything they needed to, almost going through a mental tick-list in their mind, rather than focusing on them as a patient, which made the patients comment on how robotic this could be.

Having a full day of repeating the same or similar scenario was tiring to the patients. Also, practical aspects such as having the time to discuss the scenario with the assessor before the start of the session or examination or not having sufficient time to learn the scenario were highlighted by the patients. Patients felt a sense of responsibility for contributing to the graded assessment of students' communication skills.

> *"It's the marking. I find the marking very special because I know it matters to them. And also it slightly worries me that I am being generous and was the person acting my part in the morning, were they equally generous?" [M3; FG1]*

The patients perceived themselves to be more interested in the students compared to the role players that the School of Pharmacy also use. As the role players received formal payment for their involvement, this was perceived as the main motivation for their involvement by the patients. On the other hand, the patients felt that using actor patients was more appropriate for more challenging scenarios that required the skills of being able to portray certain characteristics. For themselves, they felt that being real, reflecting on their everyday experiences was their main contribution to the students, and through that, being able to depict the patient perspective to the students to encourage them to care.

> *"Whereas I think for the people who do it as actors, they're usually jobbing actors and it's a bit of cash for them. So they haven't, they're very clear what they do, but they haven't got the same investment in it. So that's just my personal opinion." [M1]*

> *"That's true, because the last one I did here there was a guy who was an actor and when I went in he was saying, well this is what you have to do and I do this all the time, that's his job as an actor doing all these OSCEs an all these things." [F1; FG2]*

## Discussion

This study gives a unique and timely perspective to the experiences of volunteer patients involved in the education of future pharmacists. A major finding of this study is that patients prefer sessions where they could be genuine, real and share their experiences. They are concerned about telling the students the wrong information or focusing on the wrong elements of the interactions in case that would misrepresent the context and negatively impact the students learning. Despite this, the patients' disfavored sessions where they followed a standardised script. For the patients, the main impact of their involvement in students was creating a safe space for practice. Another perceived impact was through increasing student awareness of patient experiences, thus potentially encouraging empathy in the students' future practice.

The volunteer patients were open to giving feedback, and this was rewarding to them. This followed the same division where the patients preferred the more informal teaching sessions of sharing real, lived experiences over an assessment-based or scripted interaction. This finding is consistent with those by Lucas and Pearson (2012), who found that patients perceived the value of their contribution in clinical education to be bringing authenticity and insight into their lived experience (Lucas & Pearson, 2012). The scope of this research was not to explore the educational benefit from the student perspective as this is more researched; however, the course evaluation feedback suggests that students do appreciate the opportunity to hear real patient stories in the low stakes setting of a classroom.

Tew and the authors discussed the concept of involvement in terms of a ladder and identified five different stages of involvement of patients and caregivers, ranging from no involvement to partnership (Tew *et al.*, 2004). The involvement of the volunteers in the programme is closest fitted to the limited involvement stage. However, from what the patients articulated, they had a desire to be more involved at the level of either growing involvement or even collaboration. There was a desire for more and more meaningful engagement, yet none articulated a wish for the involvement to reach the level of partnership, the highest rung on Tew's ladder. This reflects the findings of Anderson and the authors (2018) on transitioning patients from storytellers to leading interprofessional education workshops (Anderson *et al.*, 2019). If the voice and involvement of patients are not fully appreciated at the stage of education and is given tokenistic value, how will person-centred care be expected to take place when the students go out into practice?

In recent years the training of healthcare professionals has been driven by standardization of teaching and examination. There is true, a time, a place and a need for such objectivity and standardization, such as high stakes examinations (Van der Vleuten *et al.*, 1991). Yet, Ten Cate and Regehr (2019) make an argument for moving towards a more subjective experience that better reflects the realities of practice (Ten Cate & Regehr, 2019). The volunteer patients in this study expressed frustration and concern about not understanding the bigger picture of the curriculum. Perhaps a move towards increased inclusion of non-standardized interactions would better involve patients as stakeholders in healthcare professional courses. This would better reflect the realities of practice and would also enable a more meaningful involvement of patients. The same could be true of feedback whereby rather than training patients to give feedback objectively, we could train students to receive subjective feedback directly from patients in the same way that they will in practice. This may also help to re-humanise the clinical relationship by patients being seen as people with

personalities and stories behind them, not merely as an archetype of the patient with a particular illness (Karan, 2019).

A limitation of this study is that it only gives a snapshot of the patients' experiences rather than a longitudinal assessment of the educational benefit. Using a different qualitative methodology like appreciative enquiry could open a greater potential for creating cultural change at the organisational level (Richer *et al.*, 2010). Additionally, the study did not include the experiences and views of students or staff members, thus offering a single perspective. Yet, the existing research on patient perceptions is limited; thus, the findings of this study offer a valuable contribution to the pedagogic narrative on patient involvement and person-centred care.

## Conclusion

Patients, and their stories and experiences, are a vital part of the training of future pharmacists with a unique role in preparing students to become person-centred practitioners. The volunteer patients' experience has been mainly positive but more needs to be done to involve patients as stakeholders with a voice in the education of students rather than passive exhibits. The findings encourage the shaping and refocusing of patient involvement towards a more meaningful shared relationship between patient and student. The challenge for educators is to yield to the ongoing shift from a mainly didactic curriculum, often operated with a dearth of patient perspectives, to one introducing and embracing elements of subjectivity in order to train professionals who are prepared for co-creation of care.

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# Appendices

## Appendix A: Topic guide

***Introductory question***

Think of your experiences of being a volunteer patient in the pharmacy programme, is anyone happy to share a memorable experience with others?

***Guiding questions***

- What has been your best experience?
- What have you found the most challenging in being a volunteer patient?
- What is the expertise/added value you think your involvement brings for the students?
- What are your thoughts on the format of the sessions?
    - OSCE exams, clinical skills, polypharmacy?
- What are your thoughts on the content of the sessions?
- What are the main issues you think need addressing?
    - How would you change the sessions?
- What do you think is good about the way the sessions are run?
- How do you think students benefit from your involvement?
- Do you think there have been any benefits for you? If so, what do you think they have been?
- Has the involvement as a volunteer patient changed the way you communicate with health professionals? If so, how?

***Concluding questions***

Of all the things we've discussed today, what would you say is the most important thing to you?