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Title The role and views of volunteer patients in undergraduate pharmacy education: involved stakeholders or back seat drivers?

Submitter Dr. Laura Lindsey, Prof. Cate Whittlesea

Full title: The role and views of volunteer patients in undergraduate pharmacy education: involved stakeholders or back seat drivers?

Background
Across the health care sector, patients are becoming more involved in all aspects of their care, including delivery, research, policy making, and education. Patients and carers are seen as stakeholders with a voice and not just passive recipients of care. Consequently, the importance of shared decision making in clinical situations and how this needs to be part of clinicians' routine practice is receiving more attention. For patients themselves, the benefits of active engagement include continued learning, being able to assess the care they receive and enabling them to adapt to enhance the care they receive.

These changes in practice need to be mirrored in the way the future health professionals are educated. There is an growing imperative to hear the patient voice, as early as possible, in health and social care professional education. King's Fund has been actively advocating the role  of  collaborative care planning in the curricula. Yet, in reviewing current patient involvement initiatives in medical and health care education, it seems that the focus is on one-off patient initiatives rather than building an on-going programme of patient involvement.

In teaching clinical skills, the framework that is often used is Miller's pyramid where the emphasis is on moving students from knows how and shows how to does. Unlike other health professional degrees in the UK, pharmacy students do not currently have long placements during their undergraduate training. Therefore, the involvement of patients in an educational setting offers them an opportunity for patient contact earlier than they would otherwise have. From reading reflective accounts students have written as part of their coursework, it appears that meeting volunteer patients in a teaching setting, receiving feedback from them, and learning to conduct a consultation could be a threshold concept in becoming pharmacists.

There is limited research on the perceptions and views of the patients on their experience of involvement. Patient involvement offers opportunities for educators and students to engage with the stakeholders and through them the wider society directly. The focus of existing studies is on the learning achieved by the student - not the experience of the volunteer patient. Of the studies that did include the patients’ side, one found that for the patients, the experience is challenging but positive and the tension patients felt was between the vulnerability in sharing personal information and making valued contributions through sharing meaningfully. To meaningfully engage with and further develop the role of the patients in education with on-going involvement, it is vital to know what the volunteer patients’ perceptions and views of their involvement have been to the date.
Aims
This study aimed to explore the volunteers’ perceptions of their role and impact on students’ learning experience. It also focused on the experience and impact the volunteering on the participants themselves.

Methods
All the volunteer patients (n=20) from the volunteer patient mailing list, who had volunteered for sessions in the previous year, were invited to take part in the focus groups at the end of the academic year. Three focus groups in total were held (n=13). The focus groups were audio recorded and transcribed verbatim. Thematic analysis was used to analyse the data.

Findings
Preliminary themes from the data analysis are: being advocators of reality, kudos and knowledge, and feedback. Bringing real life in to the students was an important part of volunteers’ involvement. They saw themselves as preparing students for meeting patients from diverse backgrounds – real patients with issues such as hearing loss or autism. Volunteers valued being able to give feedback and they preferred volunteering in sessions where they could do this. Volunteers appreciated seeing the students take the feedback on board and improve as they progressed through the years.
For the patients themselves there was an element of kudos they received from being volunteers at the university, there was almost a pride associated to it. They had a sense of privilege - the opportunity of being privy to the world of academia in such a unique way. Many of the volunteers had been involved for years and had accumulated a level of medicines related knowledge through their interactions with the students that had enabled them to advice their family to ask certain questions from their pharmacists, with one of the volunteers jokingly saying ‘at times I feel like I could almost be a pharmacist’.

Conclusions
The volunteer patients are a vital part of training future pharmacists. The volunteer patients’ experience has been mainly positive but more needs to be done to involve them as stakeholders with a voice in the education of students. The findings will be utilised in shaping and refocusing the patient involvement further with one main focus being how to give feedback well.