# Patients and carers as teachers in psychiatric education: a literature review and discussion

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**Introduction.** The direct involvement of patients and carers in psychiatric education is driven by policy in the United Kingdom and Ireland. The benefits of this involvement are well known, however, it is important to consider the ethical aspects. This paper suggests how further research could explore and potentially mitigate adverse outcomes.

**Method.** A literature search evaluating the role of patients and carer involvement in psychiatric education was undertaken to summarise existing evidence relating to the following: methods of involvement, evidence of usefulness, patient's/carer's views and learners' views.

**Results.** The Medline search produced 231 articles of which 31 were included in the literature review based on the key themes addressed in the paper.

**Discussion/conclusion.** The available evidence is generally positive regarding the use of patients and carers in psychiatric education. However, available research is varied in approach and outcome with little information on the ethical consequences. More research is required to inform policies on teaching regarding potential adverse effects of service user involvement.

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#### Introduction

One of the aims of a Psychiatry Course is to set the foundation for skills and knowledge that are needed to manage common psychiatric problems in whatever specialty the doctor eventually works.

Whilst lectures and tutorials can help a student achieve a degree of knowledge about a clinical condition, it could be argued that in learning about something as abstract as the human mind and its pathologies, 'presage factors' must be thought out clearly to enable that the 'product' matches intended learning outcomes (Prosser & Trigwell, 1999). While performing day to day tasks as a doctor, in whatever the specialty, if faced with a common psychiatric condition, the importance of tacit knowledge cannot be over emphasised (Knight, 2002). Also, a clearer phenomenological understanding of the pathologies of the human mind, and the need for a deeper approach to learning would be critical.

In the mid 20th century, a group of educators undertook the task of classifying education goals and

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objectives. The intent was to develop a classification system for three domains: the cognitive, the affective, and the psychomotor. Work on the cognitive domain was completed in the 1950s referred to as Bloom's Taxonomy of the Cognitive Domain (Bloom et al. 1956). The idea was to arrange what educators want students to know in a hierarchy from less to more complex. The levels are understood to be successive, so that one level must be mastered before the next level can be reached. The original levels by Bloom et al. (1956) were ordered as follows: Knowledge, Comprehension, Application, Analysis, Synthesis, and Evaluation. Anderson & Krathwohl (2001) revised Bloom's taxonomy to fit the more outcome-focussed modern education objectives, including switching the names of the levels from nouns to active verbs. The lowest-order level (Knowledge) became Remembering, in which the student is asked to recall or remember information. Comprehension, became Understanding, in which the student would explain or describe concepts. Application became Applying, or using the information in some new way, such as interpreting. Analysis was revised to become Analysing, requiring the student to differentiate between different components or relationships, demonstrating the ability to compare and contrast.

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It would follow that to reach the higher levels of learning, something more than just book-based knowledge or didactic teaching would be necessary. To understand, and subsequently apply and analyse would require an appreciation of the first-hand effects of illness.

Therefore, it could be argued, that to understand mental illness, the best source of information to help the process of understanding, would be either someone who has suffered from the illness, or someone who has cared closely for an individual suffering from such an illness. This could be in addition to teaching methods such as lectures or tutorials. Patient contact as inpatients or outpatients is commonly structured into the clinical course and 'bedside' teaching, that is during clinical ward rounds, is carried out. However, initiatives where service users (patients) or their carers could act directly as teachers (or facilitators of learning) for example by delivering either a part or whole lecture to students are not ubiquitous. It must be noted that the use of patients or carers as teachers is driven by national policy in the United Kingdom (Department of Health, 2001) and other European countries such as Ireland (Government of Ireland, 2006). The Royal College of Psychiatrists in the United Kingdom has made it mandatory for psychiatry trainees (postgraduates) to receive direct training from either carer or service users, and checks the implementation of this recommendation on accreditation visits. Within the College of Psychiatrists of Ireland, the carers' subgroup of Recovery Experience Forum Of Carers and Users of Services (REFOCUS) have outlined carer involvement in training as one of their main themes, recommending presentations from carers at all trainee induction days (REFOCUS, 2013).

In this paper the authors will review the available evidence base for patient/carer involvement in teaching.

### Aims

To review published literature and inform a critical discussion evaluating the role of patients and carers in psychiatric education.

### Methods

A literature search was conducted using MEDLINE using the terms 'medical education', 'patient', 'service user', 'carer', 'mental health', and 'psychiatry' from 1 December 1995 to 1 December 2015. Relevant literature was extracted from these searches, and through a search of reference lists. Literature relevant to both undergraduate and postgraduate psychiatric education was extracted. Literature was organised to answer four questions, which were the key emergent themes. Q1. In what ways could service users or carers help in teaching?

Q2. Does user or carer delivered training work?

Q3. What are the patients'/carers' views on their involvement in teaching?

Q4. What are the learner's views on this method of teaching?

#### Results

The Medline search produced 231 articles of which 31 were included in the literature review based on the four key themes below.

## In what ways could service users or carers help in teaching?

In a review of publications from 1970 to 2001, Wykurz and Kelly investigated various methods of patients delivering teaching. They found that several teaching methods had been employed including giving a presentation, facilitating seminars, demonstrating to small groups or providing feedback on performance (Wykurz & Kelly, 2002). Only one of the 23 articles identified from their literature review was related to mental health. In that article by Butterworth and Livingstone (also the only article that was co-authored by a caregiver or a patient) presentations by carers of patients with dementia directly after lectures on dementia received favourable feedback from medical students (Butterworth & Livingston, 1999).

Ahuja & Williams (2005) publication, suggest service users can be involved in web-based discussions, produce videos and reading material for students though evidence for this was not provided. A systematic review by Perry *et al.* (2013) looked at interpersonal skills taught by service users to mental health students and focussed on ten publications. Though they felt that 'many interventions used in studies were poorly defined' they discussed publication from 2005 whereby service users participated in basic interview skills training with the specific aim of improving appreciation of the patient's point of view (Ikkos, 2005).

Jha *et al.* (2009) undertook a systematic review of strategies and interventions for the involvement of real patients in medical education using 47 articles covering all areas of medicine. Primarily it found that service users were involved in teaching and assessment or a combination but rarely in education policy, curriculum development or formal assessment. The reason for using service users included time constraints on faculty and they were better able to explain the psychological, financial and social burden of disease. The paper explored what skills service users should have such as: 'the ability to cope if unpleasant issues arise, time to

devote to teaching, be articulate, able to adhere to guidance and have no personal agenda against the medical profession' (Jha *et al.* 2009).

Livingston and Cooper suggested a need to improve the teaching that can be provided by service users and carers to be in line with the standards expected. However they also state that because they are 'relating their own experiences, objectivity is less important' (Livingston & Cooper, 2004). Service users could also add to the system if they are 'able to point out the inadequacies of services so that they can be improved' (Babu *et al.* 2008).

#### Does user or carer delivered training work?

Apart from surveys of satisfaction, there is evidence that learning from a user or carer can have benefits in terms of understanding, as well as attitude.

A trial in 1995 investigated the effects of using 'consumers as trainers for mental health service providers' (Cook et al. 1995). A total of 57 state mental health professionals participated in a 2-day training course designed to acquaint trainees with the attitudes and knowledge necessary for delivering assertive case management services (services which cater to patients that have a conglomeration of needs and are difficult to engage). Participants were randomly assigned to one of two conditions: one in which they received a second day of training from a 'consumer' (patient) and the other involving training by a 'non-consumer'. Analyses revealed that both training attitudes were significantly more positive for those participants trained by the 'consumer'. Subjective evaluations also reflected positive reactions to the use of consumers as trainers (Cook et al. 1995).

Similarly, in 1999 it was demonstrated that nursing students who had more 'user involvement' in their training had better outcomes (Wood & Wilson-Barnett, 1999). In this study, triangulation of methods was utilised; this consisted of classroom observation, student questionnaires and focus group discussion to evaluate the user involvement. A measurement tool was developed that provided a measure on three dimensions: the use of terminology and jargon, empathetic understanding, and an individualised approach when identifying and responding to clients' needs. The outcomes indicated that students exposed to 'user involvement' in classroom work differed from those in the same cohort who had not been exposed to similar user input - they used less professional terminology and jargon, were more able to empathise and more likely to take an individualised approach to assessment and intervention (Wood & Wilson-Barnett, 1999).

In 2006 another study found evidence of improvement in pre and post test scores following a teaching session on rheumatoid arthritis led by 'patient-instructors' (Bideau *et al.* 2006). Whilst rheumatoid arthritis is not directly related to mental health, it could be argued that skills involving the assessment of the patient are transferable and relate to most medical conditions.

A systematic review in 2013 found that: 'there was an improved attitude toward people with mental health difficulties' through a variety of instruments. In addition, 'this type of teaching was acceptable to students and of value' (Perry *et al.* 2013). However, it has been noted that evidence on the long-term impact of service user involvement is lacking despite much positive evidence over the short term (Jha *et al.* 2009).

# What are the patients'/carers' views on their involvement in teaching?

Studies that looked at this question found that carers and patients who were involved in teaching considered this to be a largely positive experience.

They appreciated sharing their knowledge, using their condition to facilitate learning, and contributing to doctors training. Patients described feeling empowered by the experience (Wykurz & Kelly, 2002).

In a study by Newcastle Medical School in 1999, patients taking part in teaching medical students underwent semi-structured interviews. From 20 patient interviews (three of whom had a diagnosis of depression), two main themes emerged. First, patients felt they could contribute to student learning as experts in their medical condition and as 'memorable' examples of their condition, whilst at the same time developing student's professional skills (e.g. interview and listening skills) and 'bedside manner'. Second, patients felt that they themselves had benefited from being able to discuss their problems and from the satisfaction of assisting students in their educational journey (Stacy & Spencer, 1999).

Jha *et al.* noted in their review of 47 papers in 2009 involving service users in teaching, 30 did not make any mention of seeking ethical approval. Themes they highlighted as areas for consideration when involving service users in teaching included: patient confidentiality, exploitation of patients (primarily if repeated examination could lead to ill effects such as fatigue) and possible patient attraction towards students regarding longer-term follow-up. Increased selfesteem for the service user was also mentioned (Jha *et al.* 2009).

In a letter to the British Medical Journal 2002 Sir Nil, a patient activist, argues that mental illnesses are ideally suited for patients to be teachers and describes this as being especially true for schizophrenia. Mr Nil goes on to say: 'as the public is prejudiced about schizophrenia, so are students. Thus they should meet patients with controlled disease rather than those with acute psychosis on hospital wards'. If students were allowed to meet recovered patients and patients with stable disease, the paper's authors are sure that psychiatry would become a more attractive discipline, which in the long term should have a positive effect on the quality of psychiatric care (Nil, 2002).

A study conducted in 2008 using focus groups explored the views of service users in planning, providing and evaluating training for undergraduate trainees. The participants felt that service users could play an important role in 'helping students see the whole person' and in providing an understanding of the illness in the context of a person's life. They also believed that they could address key myths surrounding mental health and offer positive aspects of their experiences within the mental health setting (Dogra *et al.* 2008).

Walters et al. assessed the impact of participating in undergraduate teaching for patients with common mental disorders. They used questionnaire surveys and qualitative in-depth interviews of patients, students and participating general practitioner tutors in a community-based undergraduate teaching programme for fourth year students completing an attachment in psychiatry in London (Walters et al. 2003). Participating patients expressed high levels of satisfaction in the questionnaire, and this was supported by the follow-on interviews. Other therapeutic benefits identified by patients include validation, empowerment and raised self-esteem, along with the development of new insights into their 'illness narrative' and a strengthening of the patient-doctor relationship. One of the patients, who was suffering from psychosis and depression stated 'in a way it was quite...not flattering...but it was giving my situation some kind of credence of some kind of, you know, validity, that what I had been through was, you know, it was worthy enough to go along and talk to students' (Walters et al. 2003). As with the Newcastle patient study, many patients described benefitting from having time to talk to an interested 'neutral' individual (Stacy & Spencer, 1999).

A recent publication explored the potential benefits for service users in sharing their experiences in a 5-day training course on dual diagnosis developed within the Irish Forensic Mental Health Service (Rani & Byrne, 2014). The authors were able to observe psychological, personal and social benefits within the service users who took part in the training course. They were also able to identify potential challenges such as preparing and participating in public speaking, interacting with trainees and resource limitations arising from organising and supporting service user involvement (Rani & Byrne, 2014).

The effects on patients of participating in teaching were by no means exclusively positive in literature. Patients reported feelings of anxiety before meeting students, anxiety about 'getting things right', finding interviews emotionally up heaving and potentially intrusive (Walters *et al.* 2003). Similarly, stress whilst exploring potentially painful issues, has been highlighted elsewhere in previous literature (Stillman *et al.* 1980).

## What are the learner's views on this method of teaching?

Wykurz & Kelly's (2002) review showed that meeting patients who had first-hand experiences of a condition conferred particularly important educational benefits including access to personal knowledge and experience of a condition, deeper understanding, an increase in confidence, acquisition of skills, increased respect for patients and putting knowledge into context.

In 2004 another group further explored the various levels of mental health service user involvement in a study involving medical student training at the University of Sydney. The authors found that mental health users trained as tutors were able to sustain the delivery of a service-user led tutorial programme over a 4-year period and directed the general trend towards improving attitudes of medical students to learning from and working with the service users. One of the medical students before the training programme commented, 'For our purposes, consumers lack the ability to instruct us with relevant information' (Owens & Reay, 2004). Shortly after the programme, the same student provided a more accepting view, 'The consumers give us insight into what it is like to be on the other side of the mental health system. This is invaluable in helping us to be better doctors and increase our empathy'. As highlighted, the programme worked to expand the student's expectation of not only being able to manage violence and unpredictable behaviour, but also to build rapport and participate in meaningful engagement with the service users (Owens & Reay, 2004).

A questionnaire survey in 2006 of trainee psychiatrists' views in South West London showed that the majority of trainees supported 'user' involvement in examinations. However, trainees were concerned about the objectivity of the service user in an examination rating and their use as an expert on assessing a trainee's skill (Vijayakrishnan *et al.* 2006).

Some students might find the involvement of patients in this process unhelpful. In a study evaluating the outcome of using patients as teachers in workshops on 'basic interview skills' psychiatric senior house officers found patient's 'overtly democratic values in the treatment process' unhelpful (Ikkos, 2003). Another doctor perceived 'clashes between users and doctors'. Another perceived 'the underlying feeling that user attitudes and expectations are necessarily valid or reasonable in practical terms' as a complaint and suggested that carers 'tended to forget that it was a training programme for students, emphasising their own agenda, spending more time than required over it' (Ikkos, 2003).

In a recent paper it was noted that students 'were concerned that the people teaching them were not sufficiently representative of most people with mental health difficulties' (Perry *et al.* 2013). However, the opportunity to be taught interpersonal skills by service users 'made professionals reflect more deeply on the way they communicate' (Perry *et al.* 2013).

Babu et al. carried out a questionnaire that asked trainee psychiatrists from senior house officer to higher trainee level in Southern England about their experience of service users and carers in psychiatric education. Of 77 responses, 84% felt their involvement would be beneficial and 6% did not. 'Those who disagreed thought that service users and carers might be too emotionally involved and have irrational expectations' (Babu et al. 2008). Concerns were expressed over 'dilution of their authority'. Less than a quarter were in favour of having service users and carers as assessors or observers, reasons to the contrary included being seen as 'fallible humans' reducing their confidence. Significantly the questionnaire found that only 36% heard the opinion of service users or carers over the previous year and only 26% were aware of this requirement in training (Babu et al. 2008).

As the roles of doctors and nurses are becoming more flexible with increased cross over it is helpful to acknowledge the survey regarding service user involvement in teaching mental health nurses in New Zealand, reported that there was a 'reduction in fear that students felt about working with people who experience mental health issues' (Schneebeli *et al.* 2010). The feedback indicated that the service user involvement developed a positive attitude and belief about mental health and service users.

#### A critical discussion

The teaching of general psychiatry to medical undergraduates and postgraduates should encourage a deep approach to learning and aim to teach transferable skills (Hughes & Williams, 1998). The literature summarised above reflects that the use of patients or carers in the delivery of such teaching offers multiple positive benefits for the patients as well as the students but has some potential limitations. The most striking benefit for the learner in our opinion is the 'deeper understanding' and 'putting knowledge in context' cited in literature. The paper's authors would agree with this, as the very nature of medical training is such that deep learning is underpinned by contact with patients. Furthermore, benefits cited by patients cannot be ignored, especially patient empowerment cited in the majority of publications. The paper's authors will not repeat the positive implications of this method of teaching in our discussion, as they are arguably obvious as demonstrated in literature. As a result, our discussion may appear skewed towards concerns we have with the approach. This skewing is not intentional; it attempts to raise considerations that are not fully debated in literature.

It is important to note at the outset that what national policy is seeming to drive (and what this literature review relates to) is the use of patients or carers as teachers for example standing in front of a class delivering or participating in a lecture, not just contact with students in their usual clinical setting such as hospital wards. This is an important distinction as the latter is a *sine qua non* for medical education. This discussion relates only to the former.

Despite the literature demonstrating the benefits of using patients or carers as teachers, few publications touch on the subject of ethical considerations needed in this situation. The latter finding, and the predominance of publications suggesting a positive implication of the issue may raise the possibility of a publication bias in a subject strongly driven by national policy where attempts to healthily debate the issue could see the opponents as 'politically incorrect'. To be able to support the views of national policy, the authors think that there is an important fifth question (in addition to the four questions reviewed above) that needs to be addressed.

# What are the ethical considerations when using patients or carers as teachers?

When using patients as teachers, the person arranging such a teaching session would be a doctor; most likely to be part of the patient's care team. Given a doctor's primary responsibility as a medical professional to 'first do no harm' and an intrinsic responsibility to avoid conflicts of interest to their duty of care, arranging such teaching is not without its ethical dilemmas.

When considering ethical perspectives on any issue in medical sciences, there are three principles that need to be assessed; the principle of *beneficence* (does the issue benefit my patient?), the principle of *non-maleficence* (does the issue harm my patient in any way?) and the principle of *autonomy* (does my patient have the ability to exercise free choice?).

Whilst the literature cites various benefits for patients when participating as teachers including raised self-esteem and empowerment, it is also clear that the experience was not entirely without limitations

(Stacy & Spencer, 1999; Wykurz & Kelly, 2002; Walters et al. 2003). Articles from 1980 to 2003 have commented on negative impacts for patients including stress, anxiety and emotional upheaval (Stillman et al. 1980; Walters et al. 2003). A quote from a patient suffering from depression states, 'maybe some of the questions were to churn up all the past, and when that happens the emotions tend to start ticking over as well.... She was harping on about why you don't think you can work..... because she couldn't understand..... I found with the other students that they were more up for listening' (Walters et al. 2003). A 2003 project based in Israel documented how 'male patients felt uncomfortable being interviewed by women' (Greenberg & Cohen, 2003). In whatever setting the service user is involved in teaching, cultural considerations and this being a large topic is not explored here. Given that stress, anxiety and emotional upheaval are potential precipitating and maintaining factors for most psychiatric conditions, we would argue that even if experienced by a minority of patients when delivering teaching, this impact and its social cost for the individual patient affected cannot be overlooked. Another article adds that service users found public speaking, preparing for the talk and taking questions from the trainees as the main challenges (Rani & Byrne, 2014).

Furthermore, in most teaching programmes, patients or carers if used, receive remuneration or gifts. Given that psychiatric morbidity has a large overlap with poverty both in aetiology and effect, can it be said for sure that the process is not exploitative? How can we be sure that our patient is exercising free choice (autonomy) when making the decision to teach on a course rather than being motivated to talk about intimate aspects of his personal life by a need (not a desire) for money?

Third, there is a problem with confidentiality. The need to maintain confidentiality of patient information is one of the most important duties of a doctor (General Medical Council, 2013). In order to maintain such confidentiality, when consulting on a one-to-one basis or indeed in bedside teaching, a patient has the choice not to see a doctor (or student) who may be in the patient's social circle (or indeed be a family member) to safeguard his personal information. It could be argued that it is less possible to do this when participating in a workshop or a lecture where a number of students are present at the same time or within smaller communities. This is particularly important in psychiatric illnesses due to stigmatisation.

Lastly, another potential problem could include a sense of obligation to the patient delivering the teaching by the doctor who organised the teaching. This could blur boundaries within the doctor-patient relationship, which is a key therapeutic ingredient in psychiatric practice. Can such a conflict of interest be overlooked or minimised? Furthermore, perhaps the patient feels they have a special relationship with their doctor due to the teaching and so are entitled to special treatment.

We have not discussed our concerns in relation to using carers as teachers separately, as the ethical concerns we have are similar with both patients and carers, both of whom we argue are equally vulnerable.

#### Conclusions

The move in current teaching practices towards the use of patients or carers as teachers is driven by policy. From the review above, there are obvious benefits in using patient experience as a powerful teaching technique including a deeper understanding for students and a sense of empowerment for the patient or carer.

Essentially, carers and patients should make good teachers as nobody is more involved in their illness but themselves. With this in mind, policy suggested the incorporation of carers and patients into pre and postgraduate training programmes and some training bodies have made such incorporation mandatory.

However, little by way of evidence has been forthcoming to show that the actual utility outweighs potential adverse effects in the way this policy has been implemented to date. The evidence gained from this literature review suggests there is great heterogeneity of such teaching methods and measures of success, although appearing to have largely positive attributes.

The paper's authors have argued that an awareness of ethical issues is important when utilising service users in teaching. This includes awareness not only for the organising doctor but also for the student, for whom, dealing with patients ethically and professionally is a core learning objective.

In addition to such awareness, to be most beneficial for both the learner and the teacher, practical safeguards could be recommended when organising such teaching. The practicalities would have to be well thought through to deliver the intended benefits and minimise if not eliminate potential negative impact to patients. This would include thinking carefully through aspects such as selection of patients' (one, who is not likely to be emotionally disturbed by telling their story), provision of appropriate remuneration whilst avoiding exploitation, avoiding the blurring of doctor-patient boundaries and the use of clear learning objectives so as to give a balanced view of a mental disorder to students. A practical perspective on service user involvement in psychiatric training has been described (Haeney et al. 2007). The patients and carers involved would need to be briefed before the session using material such as those supplied by the NHS Executive Mental Health Task Force User Group for service users

working as trainers, speakers and workshop facilitators (NHS Executive Mental Health Task Force User Group, 1994). It would be important for debriefing following the session to deal with issues that the patient might have brought up during a session, which could be distressing either for the patient or for the students.

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#### **Conflicts of Interest**

None.

#### **Ethical Standards**

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committee on human experimentation with the Helsinki Declaration of 1975, as revised in 2008. The authors assert that ethical approval for publication of this study was not required by their local REC.

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