EVALUATION ARTICLE

Humanising Medicine: teaching on tri-morbidity using expert patient narratives in medical education

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Abstract

Expert patients have recognised benefits for both students and patients in medical education. However, marginalised patients such as homeless patients are less likely to participate. Learning from such individuals is crucial for future doctors, who can, in turn, aid their inclusion in society and improve access to healthcare. A 'humanising medicine' lecture was delivered to Year Four medical students at Norwich Medical School. The lecture utilised narratives from patients with experience of homelessness and tri-morbidity (physical and mental health problems and substance abuse). We used a qualitative approach to evaluate this teaching and understand the experience of both students and patients. Students were asked to complete questionnaires, whereas expert patients were interviewed. We thematically analysed data using an inductive approach. Students reported an increased understanding, empathy and preparedness to consult with marginalised patients. Expert patients described positive feelings about their involvement, giving something back, and the therapeutic benefits of telling their story. We found that including marginalised patients in medical education had positive benefits for both students and patients. Our findings suggest that expert patient narratives are valuable in medical education particularly in teaching and learning about medical complexity and tri-morbidity.

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Introduction:

In medical education, there is an increased recognition of the human side of medicine and a need to readdress the balance between this and 'hard' sciences within medical curricula [1]. The successes of including medical humanities and narrative medicine in the curriculum are well reported. Learners can be enabled to understand patients in a way technical science does not always allow. For example, by providing insight into life events which trainee doctors themselves may not have experienced [2]. This may aid medical students' understanding of the impact life events can have and allow them to relate better to patients and show humanity [3]. Understanding and empathising with patients is key to empowering them and re-balancing the relationship between the doctor and patient [4].

Marginalised groups, whose lives may appear chaotic to medical staff, can struggle to form doctor-patient relationships. This can create obstacles to accessing appropriate healthcare [4]. Marginalised patient groups include those from homeless backgrounds, prisoners, substance users and sex workers [5]. 'Tri-morbidity' refers to an individual with a history of co-existing but not causal substance misuse, physical and mental health problems, often associated with homelessness [5]. It is widely known that despite the NHS being set up to provide access to healthcare for all, access and provision is inequitable [6].

Two recent publications on inclusive health found that individuals from socially excluded populations have a mortality rate eight times higher among men and 12 times higher among women compared to the average UK population [7, 8]. A recent report from Crisis, a UK charity working with homeless individuals, stated that the average age at death is 44 years for homeless men and 42 years for women, compared to the UK average of 74 and 80 years for men and women respectively [7]. Therefore, learning how to engage with, and offer effective healthcare to, marginalised groups is essential for equitable care and reducing health inequalities.

Involving expert patients from marginalised groups provides an opportunity for students to hear the real challenges of navigating healthcare systems and offers highly valuable insights into the key components of tri-morbidity which impact on health mortality. Medicine is often learnt in a linear fashion with a set of symptoms and examinations which alongside clinical reasoning provides a diagnosis, and evidence- based treatment. However, a homeless person's life is complex with particularly challenging health and social needs. They often present with disorganised symptoms or fail to 'adhere' to evidence-based treatments [5, 8]. Expert patient narratives delivered by those from marginalised populations can therefore

provide students with a real learning experience of patient complexity highlighted in cases of tri-morbidity [3, 4].

From a student perspective, the use of expert patients can help to overcome the disparity between medicine taught through text books and that practised in the real world [8]. Students exposed to expert patients can benefit from enhanced communication skills and clinical reasoning, positive attitudes and increased empathy [9, 10].

Expert patients may also benefit from teaching medical students through experiencing greater purpose and empowerment, increased self-care and a better understanding of the healthcare system [10, 11]. Both patient and student are thought to gain a better understanding of the doctor patient relationship, and the difficulties of balancing this partnership [11]. However, the selection of expert patients can be problematic. Well-educated patients form the majority of patients involved in teaching [14-16]. This offers poor representation of the patient population and narrows the students' understanding of the patient experience to those who are more socially well connected [14-16]. It has the potential to increase marginalisation in seldom-heard populations [12]. Research from Jackson et. al, who specifically targeted socially deprived groups, highlights how seldom-heard groups experience health inequity in medical education, health policy and resource distribution [13].

Finally, there are political and institutional drivers for engaging expert patients from marginalised groups in medical education [14]. Academic institutions and the General Medical Council (GMC) are encouraged to involve expert patients, not only as a government initiative, but also to demonstrate social responsibility, promote self-care and community engagement [11]. GMC guidance states that: 'patients can contribute unique and invaluable expertise to teaching, feedback and assessment' and furthermore that there should be potential for their involvement in curriculum design [14].

Our aim was to explore the student experience of patient narratives from marginalised groups such as homeless people, and to understand the expert patients' experience of delivering their narratives; illustrated by a case study; of a teaching intervention which involved expert patients with a history of tri-morbidity.

Methodology:

A qualitative approach using the case study 'humanising medicine', a teaching intervention to understand patient and students experience of narrative medicine in the context of tri-

morbidity, was applied [15]. Learnings from the design, delivery and evaluation of this teaching intervention have been described to shed light on this area of medical education and share ideas for future teaching or research in narrative medicine involving marginalised groups.

Case study: A teaching intervention- 'humanising medicine'

Researchers (HGK, EP and SN) and expert patients delivered a 50-minute compulsory lecture as part of the core curriculum, three times a year, between 2017-2019, to Year Four medical students. Expert patients were invited to teach by their doctor (HGK, who is a GP) delivered some of the lecture and is experienced in working with marginalised patients. Careful consideration was given to ensure that patients did not feel coerced into teaching, that they were carefully prepared and that they were at a suitable place in their journey to be able to share their narrative. Expert patients were aware of and of the lead researchers' position as an academic GP and her interest in integrating patient narratives into medical education. They were informed of the service evaluation and collection of student and expert patient feedback from the outset of the project.

The main themes covered in the session included the inverse care law [5, 6], stigma and shame [16], complexity [17], biography versus biology [18], communication [4] and the appreciated patient [4, 16, 18]. Each theme was brought to life with examples from expert patient narratives. Before the session students were signposted to a Technology, Entertainment, Design (TED) talk on addiction via the University online portal [18].

Sampling of participants:

Inclusion criteria were year four medical students who had attended the lecture during their psychiatry module and expert patients, with a history of tri-morbidity, who had taught at more than one of the sessions. Convenience sampling was used. All students who had attended the lecture and expert patients who helped in the delivery of the lectures were approached [19]. Anonymous questionnaires which were co-designed by expert patients and lecturers were completed by students (see appendix 1). These were distributed by the expert patients at the beginning of the session to students who were asked to complete them immediately pre and post teaching. The questionnaires included free text narrative responses.

Informal interviews were conducted by EP, a white, middle-class, female, academic GP qualified for 5 years as a doctor, with the expert patients after the first year of teaching to

evaluate and develop future sessions. The lead researcher (EP) has a background as an academic clinical fellow in primary care and is undertaking a master's in medical education. At the time of starting the teaching intervention, the lead researcher did not have a pre-existing relationship with the expert patients. Notes were taken by hand by the lead researcher at the time of interviews.

Analysis: Using thematic analysis data was analysed inductively by the lead researcher for both student and expert patient data sets [19, 20]. We had discussions with the expert patients to member check our themes, ensure that we had accurately understood both knowledge and meaning and that the research was as co-constructed as possible. Text from questionnaires was transcribed verbatim onto Microsoft Excel enabling the researcher EP to familiarise herself with the data. Transcripts were shared with the other researchers (HGK and SN) and discussed in detail. From this the initial codes were formed, and preliminary themes derived. These were checked across each lecture cohort by the primary researcher. These themes were then shared with other researchers (as above) and SH for discussion and further refinement [20]. Analysis was led by EP as the lead researcher and monitored by regular meetings with HGK and SN throughout the process. This enabled cross-checking of both emerging ideas and interpretation of the data. Discrepancies were discussed with HGK, SN, EP and expert patients and primary data readdressed in this case. Management of the data was aided by using Microsoft Excel.

Ethical considerations:

This study was approved by the Faculty of Medicine and Health Ethics Committee at the University of East Anglia as a service evaluation 2017/18 - 152. Expert patients gave written informed consent for informal interviews. Expert patients were debriefed pre and post sessions and received payment for their work as expert patients in the lecture. There were no other monetary gains from participation in the research itself.

The study followed the consolidated criteria for reporting qualitative research [19].

Results:

A total of 102 student questionnaires from five educational sessions were analysed. The themes and subthemes we identified are shown in Tables 1 and 2.

Insert Tables 1 and 2 near here:

All students (102) attending the lecture completed the questionnaires. They reported an increase in confidence in consulting following the session. Of note, only three of the 102 students had prior experience of working with marginalised patients from a homeless background prior to the session. Analysis of the questionnaires identified a rich learning experience for students; listening, stimulating empathy, and developing understanding of the complexity and challenges homeless patients face when accessing healthcare (Table 1). Two of the four expert patients involved in the teaching gave informed consent to be interviewed, at a café on the University campus. They reported a positive experience with two themes identified - the benefits of telling their story, and the opportunity to give something back (Table 2). Two expert patients who were not interviewed only attended one of the teaching sessions and were not available again to take part.

Discussion:

The themes identified highlight the positive benefits of using patient narratives to the students and expert patients. Placing value on expert patients' narratives can reduce the ingrained paternalistic values that are often present within the hidden curriculum [20]. GMC guidance recommends inclusion of expert patients in medical education [14]. However, expert patients involved are often retired professionals such as teachers or healthcare professionals [14]; with patients from marginalised groups unlikely to be involved [11]. This case study adds to the body of knowledge on how marginalised patients as 'experts by experience' can make an important contribution to learning [11, 21]. A systematic review by Luchenski et. al (2018) on what works in inclusion health discussed the need for education and training for healthcare providers on barriers to exclusion [22]. They identified that patients report fear as a reason for exclusion from services, alongside judgemental attitudes [22]. Interestingly, fear and anxiety were also the main barriers we identified from the student perspective on the pre-session questionnaire, which, if not addressed during medical school, could continue into practice. Fear on the part of the doctor and the patient could arguably result in a dysfunctional relationship [3-5]. This highlights the importance of pre-empting and preventing judgemental attitudes which can lead to poor communication, rather than trying to remedy it after relations have broken down [6-8]. Addressing this anxiety, fear and ignorance early in a medical career with exposure to expert patients could conceivably address this, with benefit to both patient and doctor [13].

In the same way that doctors may need to adapt their consultation to hear a patient narrative [8,17], our study lends evidence to the importance of including expert patients from marginalised groups more systematically in medical student teaching.

Strengths and Limitations:

The evaluation of the intervention took place at levels 1 and 2 on the adapted Kirkpatrick model [23] see Appendix 2. This is sometimes a criticism of research analysing the impact of expert patients in medical education, that change in behaviour and change in practice which impacts patients in the future, are not evaluated [15]. Due to multiple factors it was not possible to survey or interview students after a period to evaluate outcomes; whether behaviours had changed, and whether learning on level 3 of the adapted Kirkpatrick model had been achieved [23]. Despite the lecture being compulsory, not all students attended, increasing the risk of participation bias; those attending may already have an interest in this area, limiting its impact on the whole medical student cohort, and increasing the chance those attending are likely to be positive about the topic and lecture [23]. Furthermore, feedback was collected from students immediately after the session, of which the lead researcher EP was present and delivering parts of the lecture, this may impact student responses and increase the chance of social desirability bias [24]. Expert patient' feedback is also at risk of social desirability bias, with expert patients having a good relationship with the lecturer (HGK) [24]. To minimise this, debriefing interviews were carried out by the lead researcher (EP) with each expert patient, however, the lead researcher was involved in the lecture and this may have impacted their responses. Honesty from expert patients was encouraged and value placed on their views to bring about change and improvements to the lecture, to try and minimise any bias which may have arisen from the lead researcher as interviewer. However, these interviews were not audio recorded and themes were derived from notes, although member checking was carried out to increase credibility. Expert patients were keen to have their voice heard and were involved reviewing the information collected from the interviews and familiar with the themes seen in table 2. Member checking was not possible with student data due to anonymising of questionnaires. We did consider using Nvivo for managing the data. However, we decided to store and manage it in Microsoft Excel for coding and sharing with the team. Furthermore, although coding of themes was discussed with all researchers, coding carried out only by lead researcher might have resulted in reduced reliability. A strength of this study is the co-construction with expert patients who were involved in the design, delivery and evaluation of a teaching intervention, which involved an often-underrepresented group of patients, in the core curriculum for MBBS students. Moreover, we feel this intervention attempts to address the fact that some learning in medical school can occur in silo's and that it can be difficult to connect new knowledge when this is the case, expert patients highlighting complexity can assist with this. We would be happy to share the details of our intervention with other medical schools on reasonable request.

In conclusion, marginalised patients and their narratives are valuable in medical education when learning about medical complexity and tri-morbidity. Furthermore, involvement of expert patients in designing and delivering teaching to undergraduate medical students can provide a fresh perspective and be beneficial to both students and the patient. Importantly it can also reduce health inequalities by promoting engagement of marginalised patients with healthcare, clinicians and education.

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1 Table 1: Student experiences

Student Feedback Theme	Subtheme	Quote
Compassionate Care	Humanity	'I would feel like they may have a lot of issues they may need help with and not to pre judge them' st 1.8 'It was fascinating to hear the patients' stories. It was an invaluable experience and it will encourage to be more empathetic in future consultations' st1.2 'I would see the human side, consider it just as important as the medical side' st 1.36 'to not judge patients by their appearance as we don't know their story or how they got there. Be humble, we're humans like them. Talking to them with dignity. Can make a massive difference to them' st 2.12 'They're just a human with a difference story- no need to treat them any differently. Attentive kindness' st 3.12
	Empathy & Listening	'I would feel I should listen to them and that I can help them by being kind and attentive to the person in front of me' st 1.21 'Listen, explore and empathise. Treat the person and not just what they present with' st 1.4 'to not assume and to listen to their stories. Give time.' st 3.12
	Holistic care	'I would now act more compassionately and focus on the patient holistically taking into account their past experiences and the underlying causing for their addiction and try to help change or deal with that as opposed to just focusing on the addiction.' st 1.26 'Remembering to see the whole patient, their story and follow up where possible, ongoing care' st 1.16 'I would want to enquire about a lot of aspects of their health. [housing, physical health, mental health, substance abuse, dental health]' st 4.20

Confidence in Consulting	Pre questionnaire: 'fear and anxiety' st1.36 Post questionnaire: 'more confident, useful to ask them how are you?' st 1.36 'more confident. Like I'd have an idea of how to start and that I could maybe make a difference' st 1.24 'Better at taking a 1 priority at a time stepwise approach' st 3.6 'highlighted the importance of things like eye contact/ using patients name to help them feel welcome' st 4.10
Complexity for marginalised groups	'Hearing the individual experiences of 3 marginalised patients was enlightening. Hearing about the 'shame' they felt in front of medical professionals and fear of being rejected and judged deferred them from getting treatment' st 1.26 'understand the importance of shame and stigma. Ask how are you? How can I help?' 'it's shown me how hard it can be for a homeless person to access healthcare' st 1.19 'I appreciate how difficult it is for them to come in to see GP and take them seriously' st 1.32 'Understanding how hard it is to seek help with barriers and how much mental reserve this takes- importance of patience'

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2 Table 2: Patient experiences

Theme	Quote
Benefits of telling personal stories:	'like therapy' pt b 'moving your story on every time you repeat it, validates a forward direction' pt a 'pleasure to tell story because life is no longer chaotic and you feel proud and feel expert' pt b 'orders life story in your head like refiling or decluttering and you feel better every time' pt a
Giving something back:	'a drive to change things for the better' pt a 'want to give something back' pt b 'honour to be able to speak and to hopefully change things in the future. I survived this, others can too' pt a

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