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Exploring life with a long-term condition using asynchronous online communication

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ABSTRACT

Objective: We describe the development and evaluation of a novel programme that uses an online patient portal system to provide medical students with early and authentic experience of patient interaction.
Methods: Focus group discussions were held with students, tutors and patients who had taken part in the first year of the programme.
Results: The programme provided an opportunity for early patient interaction in a safe environment. Students were able to practice communication skills learnt elsewhere in the course as well as identifying some of the different skills required for asynchronous online interactions. The approach gave opportunities to develop understanding of aspects of life with a long-term condition.
Conclusion: Using an online patient portal system to interact with a patient enabled students to develop and apply their communication skills in a safe environment and gain a holistic view of a patient's experience.
Practice implications: Medical students need to be equipped with the skills needed to communicate electronically with patients. Current medical curricula currently focus on more traditional models of the consultation. Further research is needed to establish best practice in this rapidly growing area.

1. Introduction

Use of digital technologies in healthcare is not new and increasingly email and more sophisticated web-based patient portal systems are being used to facilitate patient care. Patient portals provide a secure web-based facility that patients can use to access information about their health. This includes access to the medical record and can also be used to facilitate interaction between the patient and the professionals providing their care.

Use of patient portal systems, fits well with the patient involvement agenda and may also help facilitate greater health and social care integration. In England the NHS Long Term Plan promises that digitally-enabled care will go mainstream, with technology playing a central role in giving patients more control over the care they receive [1]. As such medical students should anticipate a need to work with digital technologies in the management of patients. Indeed, the General Medical Council's *Outcomes for Graduates 2018* states that newly qualified doctors must be able to "use methods of communication used by patients and colleagues such as technology-enabled communication platforms" [2]. How this fits within current undergraduate medical education is not clear and to our knowledge the opportunity to experience these technologies and use them in patient interactions is largely missing from existing curricula.

In 2013 the University of Leicester introduced a new programme to the medical curriculum, providing students with the opportunity to interact with a real person from early in their first year. They do this using *Patients Know Best* - a patient portal already used in a number of clinical settings in the UK and internationally [3]. Initially, the project used volunteers who were given profiles that were designed to be representative of the local population. In 2016, real patients from the medical school's Patient and Carer Unit (PCU) replaced the volunteers. The PCU recruits from the local community and allows service users to play an active role in the teaching of medical students. Over five months of the first year of the course, the patients communicate with groups of 8 students using the discussion function within *Patients Know Best*. This allows secure text-based communication, enabling the students to ask patients questions about life with a long-term condition and their experiences of healthcare. Interactions occur asynchronously and are usually initiated by the student groups asking questions relevant to the tasks they have been set. In line with wanting to develop an authentic experience, patients are

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encouraged to respond to their students as and when they feel it appropriate, but on average contact them at least once every two weeks. Students are given two working days to respond to comments or questions from the patient. This authenticity means that the number of messages between the students and patients varies from group to group as does the length and depth of the interactions.

The programme also aims to encourage collaborative and active learning, and to support the development of group working skills. We aimed to provide an authentic and early experience of patient interaction and to provide learning and development opportunities – allowing students to explore aspects of a patient's experience of life with a long-term condition. To achieve this final aim, students are given a set of tasks to complete over the course of the first year:

- ○ Explore the psychological and emotional impact that living with a long-term condition/conditions has had on them as a patient.
- ○ Explore the effect that living with a long-term condition has on your patient's lifestyle and social life and vice versa.
- ○ Explore how good or poor communication and collaboration between professionals helped or hindered their experience of life with a long-term condition.
- ○ Explore whether patients have always received patient-centred care.

Students have a 90 min face-to-face meeting with their patients before starting online communication. The focus of this meeting is to challenge the students' assumptions about how a patient with a long-term condition should look or behave. There is no time within the session to explore the tasks described above, which are reserved for the online interactions which follow. At the end of the first year, the student groups produce a poster and give a presentation about what they have learned. No time is allowed in the curriculum for the online interactions and the student groups do this outside their normal teaching sessions.

The project sits within a wider course – *The Compassionate Holistic Diagnostic Detective Course*, which spans the first two years of the curriculum and covers communication skills, diagnostic reasoning, team-working and patient-centred care. More traditional face-to-face communication skills training forms part of the course, using role play and simulated patients. There are 32 student groups, each allocated a General Practitioner as a tutor. The tutors are experienced in communication skills teaching and are able to monitor the online interactions between the students and patient to ensure student engagement and professionalism. In the second year of the curriculum, the students continue to communicate with their patients online with the focus shifting to social prescribing and lifestyle medicine.

We present findings of from focus group discussions done to evaluate this novel approach to teaching from a student, tutor and patient perspective.

2. Methods

We conducted a total of five focus groups with a total of 30 participants. Two groups were held with GP tutors supporting the students, two with first year undergraduate medical students that had engaged in the learning opportunity and one with patients also engaged in that opportunity. Focus groups were chosen as the most appropriate method for data collection due to their ability to generate discussion that could help to explore experiences and perceived challenges and benefits [4].

All of the GP tutors (N = 20) involved in supporting students in this part of the curriculum were approached via email and provided with an information sheet outlining the purpose of the discussion. They were also provided with a consent form and had the opportunity to ask questions prior to deciding whether they would like to participate. Of the 20 approached, 10 agreed to participate. Patients were approached in the same way, with all patients involved in the teaching programme given information about the discussion and again given a consent form and the opportunity to ask questions. Of a total of 16 patients contacted, 7 participated in a group discussion. Students were selected randomly from a single year intake of 242 students. A total of 30 students were contacted by email, provided with written information and asked if they would like to participate. Of the 30 contacted, 13 responded and volunteered to participate.

The topic guide used in the focus groups covered the learning opportunities the use of asynchronous online communication offered to students, tutors and patients involved in the programme and views on use of this form of communication in clinical care. The topic guide was developed to reflect the aims and objectives of the evaluation and also drew on the findings a student survey completed as part of an evaluation of the first iteration of the teaching programme delivered in 2013.

The focus groups were audio-recorded, transcribed verbatim and thematically analysed using Framework Analysis methodology. As described by Pope et al, framework analysis is a thematic analysis method that uses a-priori themes (themes that are in line with specific objectives and questions) but also allows for the identification of other themes that emerge from the data collected [5]. The analysis has several stages, the first is data familiarisation and development of a thematic framework. This framework is then applied to the data and a charting exercise completed that summarises the data according to the framework. There was consensus as to the key themes identified before interpretation and the implications of these in relation to the teaching programme were discussed, disagreements identified and worked through.

3. Results

The focus groups identified a number of ways in which this approach helped develop student understanding of long-term conditions. This included challenging assumptions and helping them to develop a more holistic view of the patient and the impact a long-term condition has. It was also felt that this approach helped to develop communication skills, including sometimes overlooked skills around non-verbal communication. These issues are discussed in more detail below.

3.1. Understanding living with a long-term condition

Developing understanding of long-term conditions, including the patient's experience and how living with a long term condition impacted on daily life, was a key aim of the teaching programme. Students participating in the evaluation felt that they had learnt a lot through their interactions, both in terms of the condition/s experienced by their patient and around how this impacted on their life and social networks. What came across strongly was that this insight often challenged their assumptions or previously held stereotypes, and they felt this was in itself an important part of the learning experience:

> *"I feel yeah the whole stereotyping thing was definitely an element . . . it has taught me actually don't stereotype, because our patient is so active . . . .. She did pilates at this age and with all these, not disabilities, but you know, she was quite active. So, yeah, I think just to teach you genuinely like when you approach a patient and go into a consultation, just have an open mind".* Student group 2

Communication being asynchronous seemed to aid rather than hinder openness around the difficulties and challenges faced by patients living with a long-term condition. Patients reported that they felt able to be open about concerns and issues, partly as they could spend time thinking about how these could be phrased. This was also reflected in student responses and they reported that having the time to reflect and develop a response gave them useful thinking space that they wouldn't usually get in a face-to-face setting. The value of this added time to reflect was also raised by GP tutors. For example, one tutor described how a group had requested support around a particularly challenging exchange, and how that was used as a learning experience to help the students develop their own thinking and response in a safe environment:

"I had, thinking about it, an experience where the students had a very emotional response back from the patient and they tackled me in a face-to- face teaching session and said 'we don't know how to respond to this. Can you help us?' and I went away and I read the response from the patient and I thought I can do this one of two ways. Either I can tell them what to do, how I think they ought to respond, or I can get them to do it themselves and I elected to choose the second one and said 'look, you go away, you draft a response, you email it to me first and I'll see what I think'..'have a bash. You're not putting this down, you're emailing it direct to me' and I gave them my work email address and it was superb, fine, 'go for it. You've done that really well'." GP tutor: group 1.

3.1.1. Taking a holistic approach

Linked to developing an understanding of long term conditions, students were tasked with building a more holistic picture of their patient's needs, both as a patient and as a carer, or as part of a family and social network. Initially we questioned whether these potentially complex and multi-faceted issues could be explored using this type of interaction. However, it was reported by participants across all of the groups that the students were able to construct questions and discussions that allowed this understanding to develop:

"I was quite impressed with how quickly . . . they realised how much it impacted on your social life, on the family, then they were asking questions about my husband and how he was managing and what interests we would have in the future. And I thought they seemed to mature quite quickly along that line and I was quite impressed with how they put things together." Patient group participant

A holistic approach to understanding a patient and their condition also includes learning about the range of support provided through the health and social care system. As well as developing an understanding of the teams across the system that work to provide care for patients, the role that health and social care can play in both supporting but also sometimes hindering patient health and wellbeing was also an important part of the student's learning. Patients shared experiences of good care, but also of fractured care and care that had left them feeling frustrated or unsupported. These experiences also added to the learning experience and at times students were surprised at both the amount of services involved in a patient's care and how this was at times experienced by the patient:

"*Certainly there were quite a few things with the patient we had which they [the students] were quite surprised by how he'd been treated by medical services and not just doctors in hospitals but you know, his occupational health department work and other places. It was a real eye-opener that all these people were involved and how they treated the patient going forward"*. GP Tutor Participant: Group 2.

3.2. Developing communication skills

There was a good degree of consensus across all focus groups that this approach to communicating with patients was useful in terms of developing communication skills. This included how it helped students think beyond traditional face to face interaction and focus more on how we use language and how that language can be interpreted:

"So, I think the first thing is that it gives them a chance to think about how written word can be used in communication with patients– we focus a lot on how you speak to patients and body language and non-verbal cues but actually communicating in type and font is different. So actually they think about the language they need to use, how it can be interpreted, and it actually gives them a chance to think through the [response] which I think is a different skill to be used." GP tutor: Group 1.

Both the patients and tutors felt that in most cases the students demonstrated good communication skills. This was the case even though they had received at this point in their education, only a small amount of communication skills training with no specific teaching around non-face to face communication. As well as providing another avenue to develop these skills, both tutors and patients felt that it helped build student confidence:

"I think it's a great way to initially introduce students certainly to communication and giving them an appreciation that these are the types of things that you can ask patients and also initially they're quite reluctant to ask them any questions because they feel as though they're prying on their lives, etc., but suddenly they'll start realising when they get responses coming back that actually it's OK to ask questions and it kind of builds their confidence really." GP Tutor: Group 2

"And I would hope it's given them more confidence that they actually realise right from the absolute start that they're actually really rather good, that they can communicate and that they actually are able to do it, because they can and they have". Patient participant

3.2.1. Empathy

Empathy and the ability to demonstrate an empathic approach is an important aspect of communication and the ability to convey empathy and warmth in non-verbal communication is often raised as a downside to online asynchronous approaches. Student participants acknowledged this, stating that it was difficult at times to demonstrate empathy and emotion without that face to face interaction:

"It's hard to convey empathy and it's hard to convey certain emotions and it might feel very remote as if you're just communicating with a computer screen. So, the non-verbal cues aren't there and it's just hard to like they're sometimes, there are some things that you say in a particular tone that may help the situation, but you can't do that with written communication". Student Participant. Group 2.

However, it was reported that students were able to demonstrate an empathic and caring approach in their communication with patients:

"I was incredibly impressed with the way they actually grappled with empathy and I do believe when we talk about a lot of professions, we look at ways of getting them to experience how to convey that they're being empathetic because, even if they are, it doesn't always come over. I didn't feel that with my two groups. I felt we were on a journey together and they were really, they were there and they were questioning and I was responding and they were coming back to me, so it really was a journey". Patient group participant

This view was supported by one of the GP tutors:

"I found them [the students] very good at putting things in a caring way, because my worry with it before we started was that it would come over like emails so sometimes, very harshly, but they were really good at avoiding that and whether that's something because of the fact they've grown up with emails, I don't know, but they did seem really good at that. And putting the patient at ease even though it was done remotely". GP Tutor: Group 2

Where patients reported that students didn't demonstrate empathy, this seemed to be linked to their overall approach to the task, with groups that were less engaged sometimes failing to come across as empathetic:

"I felt sometimes, it was they'd got an exercise to do, perhaps that's what came through with the lack of empathy". Patient participant

For some the issue of empathy was also linked with the student's feeling that coming across as polite and professional at times trumped what could have been a more natural response:

"I know they were empathic but I'm not sure it always came across, it just looked a bit formulaic at times, we've been told we must open with a polite greeting and then express our understanding of your situation and then ask our question." GP tutor: Group 2

4. Discussion and conclusion

4.1. Discussion

To the best of our knowledge, we believe that the University of Leicester is the only medical school in the UK, and possibly internationally, using a patient portal system to give students experience of e-consultation and e-communication. Findings of the evaluation suggest that the programme is likely to be associated with several benefits to learners. Students are given an early, authentic but safe experience of patient interaction. There is the opportunity to practice communication skills learnt in more traditional settings, whilst challenging students to consider how e-communication changes the way in which they interact with a patient.

Online asynchronous communication may provide many benefits to patients, including convenience and the ability to spend time constructing and reading messages [6]. Patients can find it easier to discuss sensitive topics using this method [7]. Barriers to adoption include fear of increased workload [6] and concerns around empathy and the ability to pick up on emotive cues and non-verbal communication [8]. Introducing early exposure could help normalise this mode of consultation for our future doctors, enabling them to consider how to address these concerns early in their careers. Some student groups demonstrated empathy through their communication, but this was not universal. Understanding the reasons behind these differences will be important as this area of communication develops.

Giving students early (i.e. pre-clinical) experience of authentic patient interaction is a key aim of the programme. Providing this is associated with a number of benefits, including improvements in how students communicate with patients, increased student satisfaction and providing useful context to aid understanding of basic medical science [9]. Authentic experience includes real rather than simulated interaction with a human. It is different to the use of virtual patients where interactions are computerised and simulated, and to the use of standardised patients who are essentially trained to play the part of a patient. Students highly rate their experience of standardised or virtual patients, but consider interactions with real patients as having the added benefit of authenticity [10,11].

The introduction of real patients to this programme adds a human and unpredictable element to the interaction. The patients only receive training on how to use the system and are provided with no medical education, nor primed to respond in a particular way. They are encouraged to ask their own questions and to challenge students if they are unhappy with a given response. The asynchronous nature of the interaction also brings benefits, as the patients can choose when they post questions and responses and are able to do this in any location with internet access. This degree of flexibility is likely to at least partially explain why the programme is associated with high levels of volunteer patient retention and successful recruitment of new volunteers; something that can be problematic in more traditional approaches requiring face to face interaction [11,12]. The flexibility created by the asynchronous nature of the interactions also had the benefit of allowing the programme to fit into a crowded undergraduate curriculum without the need for timetabled sessions or even teaching rooms. The student groups arranged meetings in their own time to discuss their questions and responses before posting them on Patients Know Best.

This relatively "hands off" was not without its disadvantages. Although overall student engagement was good, some student groups did engage less than others in the task, with fewer interactions with the patient. In other groups there was a feeling that one or two students were responsible for much of the interactions. It was not clear whether the rest of the group were "lurkers" – described by Rovai as as "learners who are bystanders to course discussions, lack commitment to the community, and receive benefits without giving anything back" [13]. Perhaps of more concern would be if those students were actually "passive participants" [14] –not engaging and gaining nothing from the course, eventually becoming frustrated and dissatisfied. An attempt was made to resolve these issues by involving the GP tutors in monitoring the interactions – posting reminders to stimulate discussion where needed. Further evaluation is needed to assess the reasons for the non- engagement of some students and to find solutions for this.

Long-term conditions affect over 15 million people in the UK, accounting for over 50% of GP appointments [15]. This programme gave a students a valuable insight into what life with a long- term condition is like from the patient's perspective, using very little curricula time. It gave an opportunity to apply and develop communication skills but also challenged assumptions of what it is like to live with a long term condition. As one student group stated in their final presentation:

"We found that our patient had a very positive outlook upon their long-term condition, which in turn influenced what we thought about the condition itself"

5. Conclusion

The programme achieved its aims of providing an authentic and early experience of patient interaction in a safe environment whilst allowing students to explore aspects of life with a long-term condition. The students were able to rehearse and apply communication skills learnt in more traditional face-to-face teaching sessions and started to identify some of the different approaches required when communicating in this way. Maintaining engagement of all students in the task needs consideration and ways of robustly monitoring levels of engagement and then addressing variation will develop as the programme progresses.

5.1. Practice implications

As online communication with patients expands, medical schools will have to develop teaching to prepare future doctors for this form of interaction. In addition, the extent to which validated frameworks used to develop and assess face to face communication skills can be applied to this sort of patient/healthcare provider interaction warrants further investigation.

Ethics approval

Ethics approval was provided by the University of Leicester Medicine and Biological Sciences Research Ethics Committee.

Declaration of Competing Interest

None. The authors have no financial interests in *Patients Know Best.*

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