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An Online Narrative Archive of Patient Experiences to Support the Education of Physiotherapy and Social Work Students in North East England: An Evaluation Study

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Background: Patient narratives are a viable process for patients to contribute to the education of future health professionals and social workers. Narratives can facilitate a deeper understanding of the self and others through self-reflection and encourage transformative learning among students. Increasingly, accounts of health and care are available online but their use in health and social work education requires evaluation. This study explored the experiences of stakeholders who contributed to, developed and used an online narrative archive, which was developed in collaboration with five universities and healthcare providers in the North East of England (CETL4HealthNE). **Methods:** Realistic evaluation principles were used to underpin data collection, which consisted of semi-structured interviews, a focus group and observations of educators using narrative resources in teaching sessions with different professional groups in two universities. Participants included educators, storytellers, narrative interviewers, students and a transcriber. Data were analysed thematically by two researchers and verified by a third researcher. **Findings:** Stakeholders reported that listening to patient narratives was challenging. The process of contributing the story was a positive cathartic experience for patients, and the powerful storyteller voice often evoked empathy. Students commented on the ability of the online audio-visual narratives to enable them to see the patient holistically, and educators reported that narratives provided a means to introduce sensitive topics. **Conclusions:** The use of a locally generated online narrative archive is beneficial for storytellers, students and educators, providing an opportunity to influence healthcare professional training. Care needs to be taken when exposing individuals to potentially sensitive narratives.

Keywords: Online narratives, physiotherapy education, qualitative research, realistic evaluation, patient experience, social care education

Introduction

The predominantly paper-based teaching strategies for future health professionals, such as nurses, doctors and physiotherapists, as well as social workers have been described as inadequate,^[1,2] failing to prepare healthcare students “for the subtleties and nuance of care in the real clinical world”, with a “lack of attention

to context and meaning”.^[1] Similarly the use of paper-based cases of two-dimensional patients have been criticised as preventing true interpersonal interactions.^[2,3] In the UK, social care “supports people of all ages with certain physical, cognitive or age-related conditions in carrying out personal care or domestic routines. It helps people sustain involvement in work, education, learning, leisure and other social support systems. It supports people in building social relationships and participating fully in society”.^[4]

These limitations can be challenged through the increased involvement of patients in health professionals’ and social workers’ education curriculum development.^[5-10] Evidence from mental health settings supports the argument for patients to be involved in the education of both pre- and post-qualified professionals,^[11,12] while patients also feel that they can provide a useful contribution to undergraduate education.^[13]

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The use of patient narratives in teaching and learning help to generate meaning in the classroom and place the patient at the centre of the care process.^[14-16] By recognising the value of patient-centred approaches to healthcare and encouraging teaching strategies that promote this, educators can highlight the difference between biomedical understandings of pathophysiological processes of a medical condition and the individual patient's subjective experience of living with that condition.^[17] To fully achieve this, the authentic patient voice needs to be central in the training of future health professionals and social workers;^[18] a task that can be achieved through the use of patient narratives,^[19-21] such as Healthtalkonline.^[22]

The process of storytelling, as much as the act of listening to the story being told, is a powerful tool that can contextualise and humanise the knowledge required by health practitioners, thereby facilitating a deeper understanding of the self (as listener) and of others (as storytellers).^[14] Ultimately, the strength of the story is its ability to communicate meaning by appealing to fundamental, universally held emotions that enable the student to identify with the patient.^[3] If the student is presented with beliefs, values, ideas, perspectives or life circumstances different to their own, they can be stimulated into self-reflection, which in turn can encourage transformative learning by challenging their accepted ways of thinking and operating.^[3]

Although the benefits of patient narratives are established, there is currently a limited understanding of the impact on those who are involved in providing, collecting, delivering and receiving narratives from an online narrative archive. This study aimed to evaluate the use of an online narrative archive in the delivery of narratives to physiotherapy and social work students in higher education, as well as exploring the perceptions of patients providing, and interviewers collecting narratives for the online archive.

Development of an Online Narrative Archive

An online archive of patient narratives was developed and hosted by the Centre for Excellence in Healthcare Professional Education in North East England (CETL4HealthNE). This is a consortium led by Newcastle University with the universities of Durham, Northumbria, Sunderland and Teesside with National Health Service (NHS) partners in the North East of England. Its aim is to foster curriculum development to enhance how employable students are in a constantly changing healthcare service.^[23] The online narrative archive was developed collaboratively by health and social workers' professional groups within partner institutions and linked patient network organisations to create a resource that reflected regional health challenges. Examples of these challenges included being disabled and isolated in an urban environment; ageing and caring for a partner with a long-term condition in a rural location, which included the notion of voluntary euthanasia. Narratives could then be utilised

by health and social work educators to link with modules and learning materials to support the learning of students studying and going on to practice both in the region and further afield.

At the time of data collection, the online narrative archive consisted of five patient narratives, accessible via a combination of audio-visual recordings, transcripts, artwork and poetry. These were collected by both educators and patients who received training in narrative theory^[4] and interview techniques, in addition to technical training in practical recording skills. Simulated narrative interview practise using role play was undertaken. Narratives were originally collected from hard-to-reach patients who were identified through a mobile library service and from existing patient contacts of educators. They provided informed consent for their narratives to be included on the online narrative archive. Once narratives had been collected, the audio-visual materials were transcribed and reviewed and approved by those who had provided them, with CETL4HealthNE management ensuring confidentiality.

Evaluation of the Online Narrative Archive

Existing evaluations of patient involvement in the education of healthcare professionals primarily focus on students and patients.^[9] In developing the narrative archive, there was potential for all collaborators to benefit from the processes involved and the resource produced. The aim of this evaluation was to explore the experiences of a number of key stakeholders. These included *educators*, who were higher education physiotherapy or social work lecturers; *storytellers*, who were patients providing a narrative; *narrative interviewers*, who collected the narratives from the storytellers; *students*, who the educators were teaching using the narratives; and a *transcriber* who was responsible for transcribing the narratives to provide a text-based account of the story to go alongside the audio-visual material on the online narrative archive.

Methodology

Realist evaluation^[24] principles were used to underpin the evaluation methodology, with the aim of exploring what in relation to the online narrative archive (the resource/intervention) works for whom and under what circumstances. The archive development was set within the social context of collaboration on the curriculum for training a range of health and social work undergraduate students within higher education. The mechanism by which a change occurs as a result of an intervention involves reasoning stimulated by the resource. This evaluation explored whose reasoning changed, in what ways, in response to what aspects of the archive and what behavioural outcomes might ensue.

Full ethical approval was granted by Northumbria University (School of Health, Community and Education Studies) Research Ethics Sub-Committee.

Sample and Data Collection Methods

Participants were identified and recruited to the study using a convenience sample. The participants were already engaged with the online narrative archive and patient involvement in education work with CETL4HealthNE, for example the educators were exploring ways in which to involve patients in their teaching sessions, storytellers had contributed to the online narrative archive and narrative interviewers had undertaken training in narrative interviewing and had collected material for the archive. Each of these key collaborators contributed to the evaluation through one or more of the following:

- semi-structured interviews with Educators (3), Storytellers (4), Narrative Interviewers (3) and a Transcriber (1);
- a focus group with CETL4HealthNE Partner Representatives (7);
- observations of Educators (2) using narrative resources in teaching.

Physiotherapy and social work student participation included:

- observations of teaching sessions at two CETL4HealthNE partner institutions using narrative resources (4); Social work module (2) and Physiotherapy module (2);
- semi-structured interviews with physiotherapy students (2);
- secondary feedback data from 131 physiotherapy students at one CETL4HealthNE partner institution following teaching using narrative resources from 2006 to 2010. Students rated how successfully the five aims for the teaching session had been achieved (1 = Poor, 2 = Fair, 3 = Good, 4 = Excellent), and provided additional written comments if they wished to, with most choosing to do so.

The two semi-structured interviews with students were one-year after they had used the online narrative archive. These two students had previously provided feedback, one as part of the 2009 cohort and the other as part of the 2010 cohort, and volunteered to participate in a follow-up interview.

Data Analysis

Data were coded into emerging themes independently by two researchers (SP and JS) using NVivo 8 in relation to the aim of the study. The emerging themes from each researcher were then compared and any jointly identified themes were provisionally accepted. A decision was made between the two researchers to include or exclude any themes that were not jointly identified. A third researcher (LS) reviewed and verified all themes before their final inclusion. Some collaborators represented more than one role within the evaluation, but are reported independently and labelled accordingly. When coding data, the researchers ensured that there was no duplication or unequal weighting of findings as a result of some collaborators having dual roles, such as being an educator and a narrative interviewer and being interviewed independently for the two roles.

Findings

Impact of the Narrative Archive upon Teaching and Learning Experiences

Educators highlighted the ability to introduce potentially difficult and sensitive topics, along with giving patients a voice that would otherwise be unavailable to students.

“We can go to places in those sessions [...] that I simply wouldn't go without the patient introducing the topic. So in the archive, we have an audio clip of this individual reflecting on a particular picture, where she talks about voluntary euthanasia” [Educator 2].

“What it offers to the students is a first-hand account of the [...] deficits that they've learned about in their lectures; it's that 'voice'” [Educator 1].

These were supported during observations of teaching using the narrative resources with physiotherapy students by Educator 2. In addition the educator expressed that patients can be 'experts' in their condition, and that students and practitioners (as novices) have a great deal to learn from 'expert patients'.

The following findings include data from physiotherapy students who attended sessions delivered by *Educator 2* from 2006 to 2010 on living with Parkinson's disease (PD). The aims for these sessions are set out in Tables 1 and 2, and how well students felt they were achieved is displayed in Figure

Table 1: Experiences of using the online narrative archive: students', educators' and other collaborators' perspectives

Students' and educators' experiences

- Provides an opportunity to introduce difficult, sensitive topics within physiotherapy and social work curriculum
- Students gain patient perspective and greater understanding of a particular illness
- Narratives evoke empathy among students for patients

Other collaborators' experiences

- Provides an opportunity for a patient voice to be heard in physiotherapy and social work education
- Patients contribute their experiences of health and social care as experts
- Patients' storytelling experience can be positive and cathartic
- Narratives evoke empathy among narrative interviewers and transcriber
- Storytellers anticipate narratives will have a positive impact upon students' behaviour in health and social care settings

Table 2: Educator's aims for online narrative archive-based teaching session on Parkinson's disease (PD) with first year physiotherapy students

Students should be able to:

- | | |
|-------|--|
| Aim 1 | Gain a patient perspective on PD |
| Aim 2 | Identify impairments, activity limitations and participation restrictions |
| Aim 3 | Identify helpful characteristics in healthcare professionals |
| Aim 4 | Identify potential physical management approaches |
| Aim 5 | Consider how a user/carer perspective/contribution could help in the education of healthcare professions |

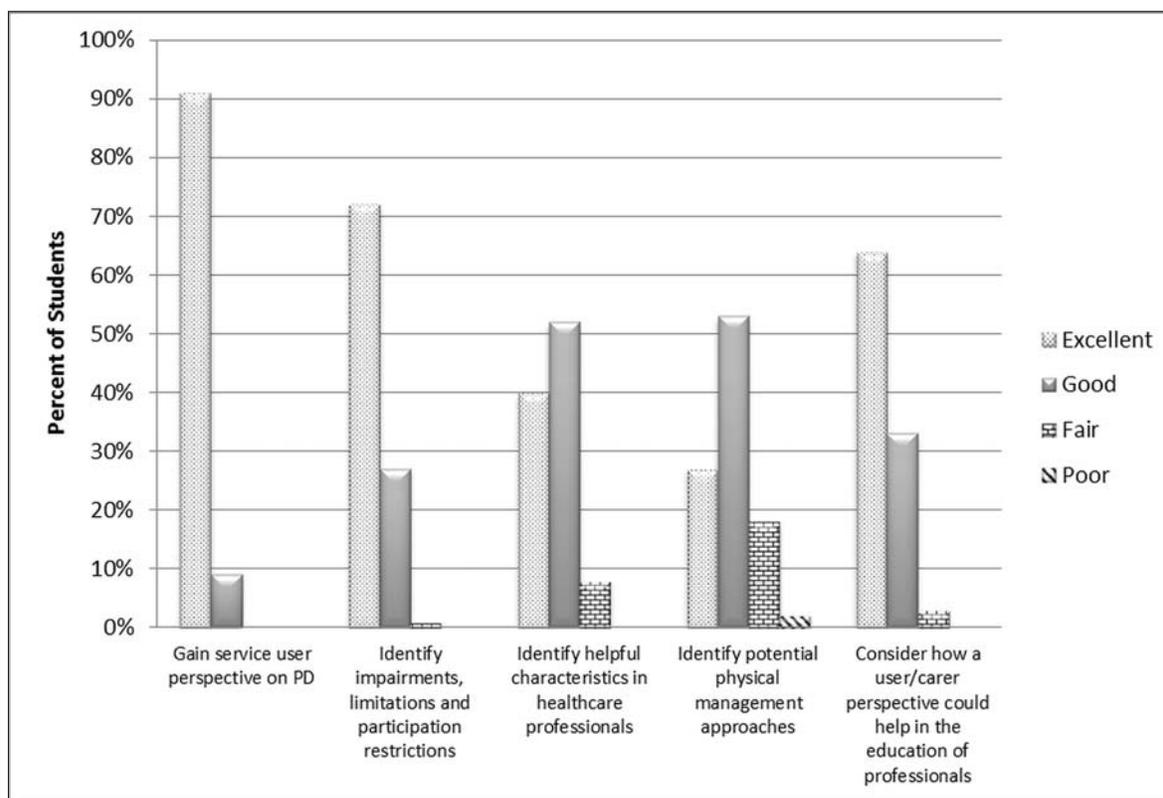


Figure 1: Physiotherapy student feedback on how well aims for online narrative archive-based teaching session on Parkinson's Disease were achieved ($n=131$)

1 [Table 2].

Physiotherapy students reported that the use of narratives enabled them to gain a patient perspective (aims 1 and 5), and they were able to map the narratives back onto the International Classification for Functioning framework^[25] (aim 2). The majority felt that the seminar that utilised the narratives was useful in identifying helpful characteristics of healthcare professionals (aim 3) and potential physical management approaches (aim 4) [Figure 1].

Students' written comments from feedback forms immediately following the session provide further insight into the value of teaching using narrative resources. The particular outcomes suggest that students have gained a greater understanding of the illness than using traditional teaching methods, along with gaining an awareness of the expert role patients can play in their healthcare.

"Here we had a real person, not just a case study on a sheet of paper, and I think that challenged us all to look beyond the physical symptoms to the emotional and social repercussions of PD". (2006 student)

"You get a much greater sense of an illness if you can understand what it is like to live with the condition". (2007 student)

"The patient may very well understand their condition much more than the physiotherapist treating them so don't just

assume they don't". (2008 student)

Educators described realism as key to fostering empathy between student and patient:

"...[we have] a real person's experience that students can relate to and understand what it actually means to that individual". (Educator 2)

Interviews with two students from the 2009 (student 1) and 2010 (student 2) cohort provided further insight, highlighting the ability of narratives to encourage empathy.

"...that was another thing that appealed to me...that I was going to actually hear from somebody real [...] It gave the group the opportunity to experience genuine empathy because it was a real person". (Student 1)

"...these are people, not just medical problems – they're real people". (Student 2)

Impact of the Online Narrative Archive upon Other Collaborators

In addition to the impact of narratives provided to educators and students, there was also potential for impact upon other collaborators in developing the online narrative archive. In particular these included the storytellers, narrative interviewers and the transcriber.

Storytellers

The impact upon storytellers was largely positive as they held the hope that their story would have an impact upon students, along with the process of telling their story being a cathartic one.

"I mean even if it got through to one final year medical student or one final year nurse doing a degree course at least, or they still cared after what they've done". (Storyteller 1)

"...it was a completely new experience to be able to share something at that time that was quite personal and also quite emotional [...] I think in some respects it was quite cathartic". (Storyteller 4)

The narrative archive was integral to further opening up education to patients, for example via their assessment of students, which Educator 2 believed could increase patient confidence in health and social work students.

"We've embedded the patient voice in the teaching and we've embedded the importance of patients in their assessment [...], this is all about making those links and it starts with the archive material..." (Educator 2)

"We know from the patients [...] they absolutely value this opportunity to listen... its building confidence of the patients in the quality of our students". (Educator 2)

This was in part due to the belief that their stories would generate change in post-qualification clinical practice, similar to that which can be generated through the narrative archive.

"...you know that the information you're giving to those [students], they're going to take it with them and they're going to make things a lot better". (CETL4HealthNE Partner Rep 1)

Narrative Interviewers

Despite concerns about the emphasis placed on narrative theory during training for narrative interviewers, it was deemed largely positive, particularly relating to the opportunity to practice using the equipment used to collect stories. However, the process of collecting stories was challenging when the story evoked empathy or confronted professional concerns.

"...there was a recollection within the narrative interview of issues of lack of care in an acute hospital setting and that again was difficult to hear and not have the power to change". (Narrative Interviewer 1)

Transcriber

Similarly to the narrative interviewers, the transcriber highlighted the difficulties in hearing the narratives.

"I just found it quite sad because looking back, seeing what they said and then comparing it to [family member's] experiences [...] it would just be nice to sort of go back and say to [family member], 'and now I know what's going on in your life and I'll be more patient and more helpful'". (Transcriber)

Discussion

In evaluating the experiences centred around providing, collecting, delivering and receiving narratives in relation to an online narrative archive used in the education of future physiotherapy and social work students, this article has gone some way to exploring the potential of the online narrative archive to involve patients in education on a regional level.

The findings of this study highlight the ability of educators to use narratives to introduce highly sensitive topics with greater ease; in this study the topic of voluntary euthanasia was introduced to students via the patient narrative. This supports existing literature that narratives have the ability to give students a perspective on health and illness that would otherwise be unavailable to them using traditional teaching methods. Examples include highlighting the difference between biomedical understandings of pathophysiological processes of a medical condition and the individual patient's subjective experience of living with that condition,^[1,14,17] which can help avoid dehumanising the patient.^[3]

The students involved in the evaluation also responded positively to the narratives, obtaining a greater sense of the illness being studied while challenging them to look beyond physical symptoms and understanding that the patient can be an expert in their own condition, which was demonstrated in both student interviews and seminar feedback. This echoes findings from previous research,^[26] and provides a strong basis for the further development of an online narrative archive and implementation within health and social work programmes. First year physiotherapy students found it harder to identify useful characteristics of healthcare professionals and physical management approaches from presented narratives, perhaps due to their lack of clinical placement experience. However, one-year follow-up of physiotherapy students also supported the longer term positive effects of patient narratives in education upon student approaches as future clinicians.^[14,17]

Existing literature suggests that some educators show concern about the negative effects of using patient stories, including the erosion of the 'expert/novice' boundary between lecturer and patient.^[26] However, this was not raised as an issue among educators participating in this research. This may be due to the self-selecting nature of the use of narrative resources from the archive, and further research would benefit from exploring this in a larger sample of educators in relation to the narrative archive.

This article also outlines the impact upon other collaborators that are essential for an online narrative archive of patient experiences to exist and develop further. The storytellers interviewed reported that the experience of telling their story was a positive one, in particular the realisation they gained that their story was powerful. This is a useful benefit to those

patients willing to share their experiences as it has previously been shown to increase confidence in the education of healthcare professionals. Similarly the finding that storytelling can be a cathartic process supports previous research.^[26,27] A toolkit is currently under development in order to make the process of collecting narratives easier.

Although the impact upon all collaborators in this study was largely positive, it is also important to address potentially negative experiences associated with the collection and use of narratives. Of particular note was the sensitive nature of the narratives and the emotions and empathy that these triggered in stakeholders who encountered the narratives. These had the potential to unintentionally cause psychological harm or distress to those who encountered the narratives. Taylor and Bradbury-Jones^[28] highlighted a protection paradox in healthcare research, whereby the sphere of potential psychological harm from sensitive issues should be expanded beyond the participant and researcher. The same paradox appears in the development and use of an online narrative archive.

Although most collaborators were briefed on the potential psychological harm or distress in this study, it became clear from speaking with the transcriber that everyone coming into contact with them should be prepared prior to exposure and offered an opportunity to be debriefed.^[29] While this was common practice for other collaborators participating in this evaluation, it is useful to highlight this issue and ensure it continues in any future work, particularly with those potentially lacking in professional experience of dealing with such issues, such as students and transcribers.

Limitations

As the online narrative archive was in the early stages of development, there were only a small number of educators and students recruited to the evaluation. Furthermore, the archive was only used within the education of physiotherapy and social work students during this developmental stage. This may impact upon the transferability of findings. While there was some long-term follow-up of physiotherapy students, no data were collected with social work students, partly as the use of narratives was in the process of being introduced to the curricula for the first time. Future evaluations should include a longer follow-up period, particularly with students post-qualification now working with the related conditions, to assess the impact that the use of an online narrative archive has upon their behaviour in clinical practice.

This evaluation was based upon realist evaluation principles. Future evaluations of online narrative archives could utilise fully the strengths of realist evaluation by building on the theoretical insights generated from this study, for example in relation to empathy and holism, to test out more theoretically grounded context, mechanism and outcome configurations.

Conclusion

The use of a locally generated online narrative archive is beneficial for storytellers, students and educators. It provided an opportunity for the regional patient voice to be heard in physiotherapy and social work education, providing storytellers with the opportunity to influence training future healthcare professionals. The narratives were a positive cathartic experience for storytellers, which evoked empathy in all collaborators and provided the opportunity for educators to introduce difficult, potentially sensitive topics to students. Care needs to be taken when exposing anyone to the potentially sensitive nature of narratives, whether in an education setting or professional setting of developing and maintaining an online narrative archive.

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