Learning to listen: Improving students’ communication with disabled people

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Abstract

Background: This report outlines the action research used to develop a workshop for interprofessional student groups to enhance listening skills.

Aim: The project aimed to enable students to reflect interprofessionally on the human factors central to effective communication using the power of storytelling by disabled people and their carers.

Methods: Qualitative data from students and participating service users were collected using focus groups and one-to-one interviews over three pilot cycles.

Results: The results from each pilot informed the cyclical development of the project so that each stage of data collection informed the next stage. During the pilots, 20 interviews with service users were completed and a total of 109 students participated. Transcribed data were analysed using principles from grounded theory. Quantitative scored questions on students’ learning were analysed using statistical package for the social sciences.

Conclusions: Both students (health and social care) and users benefitted from the education process which delivered highly relevant explicit learning opportunities, with analysis of how to improve communication for safe practice. Students benefitted from meaningful interactions with service users who shared their experiences and gave feedback on students’ communication skills. The final workshop design resulted in a learning model which reflects the human side of healthcare delivery.

Introduction

Improving quality and safety in healthcare continues to be a national priority in the current context where patients/users shape services (Department of Health 2008). Public dissatisfaction continues to focus on poor and ineffective communication, often but not exclusively, with the medical profession (Pincock 2004; Beyer et al. 2007; Parliamentary and Health Service Ombudsman 2007). These complaints continue alongside a greater emphasis on communication skills training for medical and all other health and social care students (Universities UK 2003; Kinnersley & Spencer 2008; von Fragstein et al. 2008). A healthcare culture of rationed resources and targets that focus on outcomes can compromise professionals’ ability to respond to the needs of individual people (Bate et al. 2008). Complaints about professional communication focus on the loss of humanity when patients present for help and feel they are treated as part of a system and not as individuals; Kindness, humanity and respect—the core values of medical professionalism—are too often being overlooked in time pressured culture of modern healthcare (Chochinov 2007, p. 184). Major failures in health and social care reveal poor communication within and between interprofessional teams as well as clinical errors by individual practitioners (Department of Health 2001; Laming 2003).

Disabled people who require the help and support of a range of statutory bodies and the voluntary sector agencies are particularly vulnerable to ineffective communication (Mencap 2007). They have highlighted how professionals who fail to listen to their perspective often deliver impersonal care as a result (Shakespeare 2000).

‘How many leave hospital healed of their physical illness but hurt in their feelings by the impersonal treatment they received; how many return from their consultations with psychiatrists, psychologists, social workers or counsellors increasingly irritated by the non-committal attitude and professional distance they encountered’ (Nouwen 1976, p. 86; Cited in Shakespeare 2000).

Despite recent improvements, this message is still sometimes heard (Pincock 2004).

Practice points

- Action learning cycles can engage user, carers and students in education design.
- User and carer involvement enhances students’ communication skills development.
- Disabled people and their carers can offer powerful stories to enhance listening skills.
- Communication skill development focussed on listening is relevant for interprofessional learning.
Communication and the ability to interact with disabled people remain a core theme in medical education (General Medical Council 2009). It is universally accepted that communication, with emphasis on the experience of the person, is essential learning for all student health and social care professionals (Universities UK 2003). The recent consensus statement on the content of medical students’ communication curriculum places respect for others at the centre of the communication curriculum (Kinnarsley & Spencer 2008). It is recognised, at undergraduate level, that these are higher order skills (Hastings et al. 2006).

Communication skills remain challenging to teach, learn and assess (Hastings et al. 2006; Kinnarsley & Spencer 2008) compared to profession-specific theory. There is a tension between learning a scripted professional procedure (e.g. the routine of taking a history) and developing awareness of the user experience (e.g. empathy), meaning communication is often taught and assessed in narrow profession-specific contexts. Highly trained actors are often used to ensure a reliable and valid communication assessment with the actors contributing to the assessment rating within Objective Structured Clinical Examinations. Student performance may be scored on, for example, ‘attentive listening’ or ‘explaining diagnosis’; however carefully designed, the depth of the personal and family experiences of a lived health problem can never fully come to life in these contrived situations. Research shows users want doctors who had a personal relationship with them and valued their autonomy (Wright et al. 2004).

The importance of capturing the real patient experience is highlighted by the finding that medical students rank emotional distress as the most concerning aspect of professional communication (Hajek et al. 2000). All health and social care students require real interactions with users who are empowered to share their experiences of professional communication (Howe & Anderson 2003). Learning from service users is at the heart of interprofessional education (IPE) as defined by the UK Centre for the Advancement of Interprofessional Education (CAIPE 1997). IPE offers the opportunity for students to pool their unique perspectives on professional communication and deepen their learning (Maguire & Pitceathly 2002; Pollard & Miers 2008; Anderson et al. 2009). This type of learning will prepare students to understand how to optimise the skills of their members, share case management and provide better health services (WHO 2010). As disabled people receive care from interprofessional teams, their experiences are the ideal focus for learning about communication interprofessionally (Wykurz 2002; Howe & Anderson 2003; Freeth et al. 2005). IPE events involving service users can also be structured so that students receive realistic feedback on their developing communication skills (Wykurz 2002; Priest et al. 2005).

Stories have been used as a tool within healthcare and healthcare education for a variety of purposes (Greenhalgh & Hurwitz 1999) educators recognise the importance of offering opportunities for students to hear directly from users and carers in order to ensure that Kindness, humanity and respect (Chochinov 2007) are not lost from health and social care provision. Listening to a patient’s story can, teach doctors…things they can’t learn from textbooks (Aronson 2000). This aligns with current aspirations for improving healthcare as communication is central to the delivery of safe, high-quality personalised services:

‘Quality of care … means how personal care is – the compassion, dignity and respect with which patients are treated. It can only be improved by analyzing and understanding patient satisfaction with their own experiences’ (Darzi, Department of Health 2008, p. 47).

A grant from the Higher Education Academy (HEA) supported the development and evaluation of a user-centred interprofessional approach to communication skills teaching. The project was built on our extensive experience of involving users and carers in IPE (Anderson et al. 2003, 2008; Lennox & Anderson 2007; Anderson & Lennox 2009). This forms part of the local IPE curriculum which is assessed using a reflective portfolio. The project established a partnership between service users and academic staff, from a range of professions, who formed a steering group which employed a research process to design a one-day ‘Listening Workshop’. Aligned to CAIPE principles for quality IPE (Freeth et al. 2005), the workshop focussed on the narratives of disabled people and carers (Figure 1).

Method

Study design

This study received ethical permission from Leicestershire, Northamptonshire and Rutland Research Ethics Committee. An exploratory action research design was used; this was a cyclical pattern of planning, observing and reflecting on the experiences of developing a new learning opportunity to improve its delivery (Kemmis & McTaggart 2005). Each pilot phase of the research informed the next cycle of data collection. Qualitative data were collected from service users on their views of the workshop. Both qualitative and quantitative data were collected on students’ perceptions of their learning. There were three phases of data collection (Figure 2) following three pilots. Data collected at each stage led to modifications towards the final workshop format.

Sample

Students of medicine, midwifery, nursing (all branches), pharmacy, social work and speech and language therapy were randomly allocated to this event as part of their interprofessional curriculum. Students were in their mid-to-late training. Service users were invited to participate through local voluntary groups (e.g. the Parent and Carer Council, Laryngectomy Support Group, Down’s Syndrome Association and Parkinson’s Disease Society) and newsletters were distributed at local community centres. People were invited to participate if they had experience in health and social care services, were available and committed to student learning. Participants self-selected using these criteria. Respondents were offered a meeting with the teaching staff at which they were prepared for their participation in the one-day
Introduction and briefing for students (20–30 min)
- Students arrive and register
- Introduction by tutor/facilitators, organisation into interprofessional groups
  (n=4–5), meeting, orientation and preparation time in groups

Set-up for conversation one (approx. 30 min +)
- Facilitators welcome service users
- Coffee and introductions, set-up for first conversations

Conversation one (approximately 1 h)
- Each student group talks with a service user

Review of conversation one (30 min +)
- Tutor facilitator’s support service users to write feedback
- Student groups discuss first conversation and note key learning points
- Setup for conversation two

Conversation two (40 min to 1 h)
- Student groups meet a different service user

Lunch, review and reflection (1 h to 1 h 30 min)
- Lunch
- Student groups review both conversations and summarise key learning points
  on a poster
- Service users review conversations with tutor/facilitators

Students report learning for discussion (1 h)
- Student groups presents key messages from the two conversations
- Service users look at posters in detail and discuss with student groups
- Service users may add comments to student posters
- Service users are thanked

Reflection on teamwork and communication skills
- Students share group achievements and discuss suggestions for future
development
- Students receive feedback from service users

Students complete post-course evaluations

Figure 1. Outline of workshop day.
Note: “Facilitators speak to service users before and after each workshop for preparation and debrief.

student workshop. Consent was obtained for involvement in the project.

Students. At all three pilot phases, focus groups were held with randomly selected students, at the end of the workshop. These lasted approximately 45 min and were led by the researcher (LNT); consent was obtained for audio-taping. At the third pilot phase, the students also completed a pre- and post-course self-assessment questionnaire on knowledge change relating to the learning outcomes. Students rated their learning using a 5-point Likert scale where 1=poor knowledge/ability and 5=excellent knowledge/ability. The questionnaire had additional space for free text responses.

Users and carers. After each pilot workshop, users and carers who participated for the first time were invited to take part in a one-to-one home interview with the researcher (Figure 3).

Analysis
Transcribed data from the focus groups, interviews and free text comments from questionnaires were typed into Microsoft Word and analysed (LNT and ESA researcher/teacher). Repeated themes were identified separately for student focus groups and for user and carer data. Themes were coded and sorted using the principles from stages one and two of grounded theory (Strauss & Corbin 1998). The first stage (open coding) involved the identification of broad themes in which the data were taken apart and examined for differences and similarities. These first-level categories were then broken down into further subcategories (stage two, axial coding). The emerging themes were ranked in order of prominence and summarised. The quantitative data on student learning were analysed using the statistical package SPSS; non-parametric tests were applied.

Results
Student qualitative data

Focus groups. Thirty students took part in these interviews (medicine 8, midwifery 2, nursing 2, pharmacy 3, social work 8
and speech and language therapy 7) (Table 1). The focus group themes related to the value of a new approach to communication skills learning; the interprofessional element was especially important to them (Figure 4). The central role of the service users and carers was a vital ingredient for student learning, in particular, as students received feedback from them. Students suggested that additional professions should be involved. Several felt this was the best IPE course they had participated in to date; they would recommend the workshop to others. There were a few negative comments about operational issues after the first pilot only.

‘At medical school we are taught to take histories. The patient’s story is regimented according to the doctor’s agenda. The Listening project was therefore a challenge. We were told to shut up and listen: less questions, more attention and for the first time in a long time I sat and listened to the patient’s story in the way they wanted to tell it’ (Focus Group extract).

Questionnaires. The free text open comments on pilots one and two (n = 49 students), 47 (96%) questionnaires were returned (Figure 4). The majority (90%) were positive with students highlighting the benefits of learning under the following themes; time to listen and reflect; working with users and carers and in particular, how this had enabled emotional engagement with their experiences; and enjoyment of working with students from other disciplines. There were few negative comments, but these related to organisational issues and feeling unprepared on arrival.

Of the 60 students attending pilot three, 54 (90%) gave free-text comments in response to the following questions; Question 1: what was your key learning?; Question 2: What was the best aspect of this workshop?; Question 3: What
Figure 4. Student qualitative data.
was the worst aspect? Ninety per cent (n = 47) rated meeting service users and hearing their stories as the best aspect of the workshop and reported learning from them. Forty-eight percent (n = 26) of the students identified key learning about improving communication interprofessionally. A further 15% (n = 8) explicitly linked this learning to their future inter-professional practice.

‘Gaining an insight into the service users’ perspective – listening to their experiences and analysing this to identify how it can improve my individual practice’ (Social work student).

The importance of communication within the multi-disciplinary team, as well as between the health care professionals and the service users became very apparent’ (Midwifery student).

Student quantitative data

In pilot three, additional students had completed a pre-and post-course questionnaire on their learning. Fifty-two (87%) students completed these scored questionnaires. Their perceived knowledge gains were significant (p = 0.001) (Table 2).

Service users/carers interview data

A total of 20 bone interviews were completed with users and carers. These included four users who had undergone a laryngectomy and two of their wives, six carers (mothers of disabled children) and eight adults aged between 38 and 62 with a range of chronic health problems, e.g. Parkinson’s disease. Five people had some previous informal experience with a laryngectomy and two of their wives, six carers (mothers of disabled children) and eight adults aged between 38 and 62 with a range of chronic health problems, e.g. Parkinson’s disease. Four people had some previous informal experience with a laryngectomy and two of their wives, six carers (mothers of disabled children) and eight adults aged between 38 and 62 with a range of chronic health problems, e.g. Parkinson’s disease. Four people had some previous informal experience with a laryngectomy and two of their wives, six carers (mothers of disabled children) and eight adults aged between 38 and 62 with a range of chronic health problems, e.g. Parkinson’s disease. Four people had some previous informal experience with a laryngectomy and two of their wives, six carers (mothers of disabled children) and eight adults aged between 38 and 62 with a range of chronic health problems, e.g. Parkinson’s disease. Four people had some previous informal experience with a laryngectomy and two of their wives, six carers (mothers of disabled children) and eight adults aged between 38 and 62 with a range of chronic health problems, e.g. Parkinson’s disease.

The whole experience of sitting down and talking to someone who’s been through it is completely and utterly different to just reading it in a book and more memorable because of it and will be more useful I hope ….’ (Mother of disabled child A).

‘I just think it is a wonderful idea, and I think it should be compulsory everywhere, before anybody is let out there on “real” people. Practise on us, listen to what we have got to say, then the same mistakes won’t be made’ (Mother of disabled child B).

The main themes were as follows (Figure 5):

- There was a relaxed atmosphere.
- It felt comfortable talking to the students.
- Users were able to tell their stories in the way they wanted.
- Students would benefit in their future practice.
- Mistakes might be prevented in future.

All reported personal benefits as a result of participating in the workshop. Different benefits were identified, including a therapeutic effect similar to counselling, increased confidence and a sense of personal satisfaction from taking part. Users consistently reported that students had worked well together. Service users enjoyed being present when students reported their learning (Figure 5).

‘Well they all listened and you can tell when somebody is interested. They all listened intently to me and every one of them bar one of them asked me a question’ (Service user with laryngectomy).

‘From the feedback they gave at the end, I feel that they picked up a lot of what I wanted them to take on board’ (Mother of disabled child B).

‘I think it helps to get rid of some of my negative thoughts and experiences in a very effective way’ (Disabled adult).

A few users felt uncomfortable about giving feedback to students on their communication skills. Some users commented that they would like some information from the students on what they found most valuable. Two felt that some teacher training would be useful for them.
It did leave you thinking what have I put on my form and are they going to see it straight away? But then I thought about what I had put on the form and thought well it’s all quite reasonable and that’s ok. But I could have been in a position where I thought, ‘oh god they’re going to know exactly what I’ve said about them’ (Mother of disabled child C).

In some ways it would have been useful to have gone back into our individual groups again, and to hear more directly whether we had made a difference to that individual group or not’ (Mother of disabled child B).

‘It would be nice in a way to know how I could improve on my performance, and there was talk about having a session on teaching to non-professionals. I think this would be an excellent idea’ (Disabled adult service user).

The idea of teaching people like myself how to put things across from a teaching point of view could be helpful’ (Disabled adult service user).

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Generally, users were enthusiastic about continued involvement. Several were willing to take on a more leading role in future.

‘I’d love to be involved again…and I don’t mind being involved at a different level’ (Mother of disabled child A).

Following the first pilot, there were a few concerns relating to access and suitability of the venue for disabled people. There was helpful feedback on minor organisational issues such as name badges for participants.

**Discussion**

The workshop was a positive experience for both students and users and carers. The evidence demonstrates that learning took place in the domains of knowledge, attitudes and skills relating to professional and interprofessional communication. There was a high degree of convergence between the perceptions of students and users and carers over the benefits (Figures 4 and 5): the uniqueness of each person; the importance of listening effectively; interprofessional teamwork; how communication is vital to improve the quality of care.

Our results confirm the service users’ enthusiasm, commitment and motivation to participate in events like this. They were sustained throughout by positive interactions with the students and they valued hearing them report back on their key learning. This is in contrast to some models of service user involvement in education which have failed to consider the experience from the service users’ perspectives, leading to claims of disempowerment or even exploitation (Wykurzg 2002; Allain et al. 2006). A core component in the success of the study reported here was the relaxed learning environment, which took place outside the university in neutral community.
venues. This was made possible by external funding. This achievement was built upon extensive previous experience of working with users and carers in the community (Anderson et al. 2003; Lennox & Anderson 2007). Within this relaxed atmosphere, the users and carers were able to realise their aim to change practice by...helping a generation to think and to communicate better in their dealings with patients and by doing...something to prevent the mistakes...from happening again. Our data suggest that this was due to the shared ownership of the workshop design which included giving feedback to students. As a part of the cyclical nature of this research, a consultation with experienced service users redesigned the feedback process following the first pilot.

The cyclical research process was crucial to the development of this workshop. The robust qualitative analysis of the users’ views played a central role in shaping the learning model and ensuring an equal partnership throughout. This was made possible by the external funding for the independent researcher who accessed the views of all stakeholders (Anderson et al. 2008).

There were limitations to the study. Student learning was only assessed using a self-perception assessment scale and it has not yet been possible to assess changes to communication competence in practice. The study did not gather the views of the facilitators at the workshops. The action research methodology employed here was resource intensive.

The students endorsed the experiential nature of this learning opportunity. Student data clearly highlighted the impact of the patients’ story in the way they wanted to tell it compared to even very well designed formal teaching. The service users perceived that deep learning was achieved, for instance, Well you’ve only got to look at what they come up with and what they put on them boards.... (extract from interview with service user). The learning cycle combining experience, analysis and reflection was completed because service users were present at all stages making debate and discussion integral. This is unusual as students typically present their learning from service users only to clinicians and colleagues, rarely to the service users themselves (Byron & Dieppe 2000; Deartment of Health 2006; Dieppe et al. 2006). The power of receiving feedback from service users highlighted to students their individual and team learning needs for effective communication. Without a doubt, the success of this work results from its alignment with internationally recognised quality standards for IPE, namely:

- placing users and carers at the centre of the learning partnerships
- active interactive learning, and
- the ultimate goal of improving practice (CAIPE).

Conclusion

This project has produced a quality teaching model which addresses a number of high-priority policy agendas (Department of Health 2008). The challenge now will be to sustain and replicate this work without compromising the key components. This will require a high level of continued resource, to provide accessible venues and to support and pay users. Education providers will have to consider how resources are released from other valued parts of the curriculum if such models are to be sustained. There is an ideal opportunity for partnership working with health and social care service providers in the community.

Following this project, the workshop was delivered to over 400 students in one academic year. An annual cycle of at least six workshops has now been integrated into the IPE curriculum and is assessed using the IPE portfolio. The service user contact list currently comprises around 60 people. New volunteers approach the universities after hearing about the workshop from personal contacts and discussion is taking place about how to engage other groups, e.g. people with learning difficulties.

Having demonstrated the ability to work in partnership and the success of this approach, the logical next step will be to further empower users and carers to move into more leading roles. This will require a commitment to an appropriate level of resource to build and sustain supportive relationships with participating service users.

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