How users and carers view their involvement in nurse education

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User and carer participation in health care is central to care planning and delivery. From an educational perspective, their input is beneficial in terms of enhancing the quality of the education process. The study reported in this paper explored the experiences of user and carer participation in nurse education from the perspective of the key stakeholders involved in the process. By pinpointing key issues of concern for participants, the study aims to help inform the ongoing development of practice in this area.

The rationale for user and carer involvement in planning, delivering and evaluating health service provision centres largely on issues of individual empowerment and participation (Department of Health, 2001), and the maintenance and improvement of care delivery standards (Brooker, 1997; Department of Health, 1999) in meeting the needs of the individual.

User and carer involvement is not an entirely new concept – the World Health Organization (WHO) identified the importance of patients’ involvement in their health care more than two decades ago (Flanagan, 1999). From an educational perspective (Wykurz and Kelly, 2002; Flanagan, 1999), user and carer involvement has also been identified as beneficial in terms of enhancing the quality of the educational process.

Policy initiatives (DoH, 1989; 1994; ENB, 1996) have offered guidance with regard to both the scope and direction of involvement in health care provision, with user and carer participation in education and training programmes being recognised as an essential component of the process.

While user and carer participation in developing education programmes and care delivery is well established in many areas, a number of important questions remain to be answered on the value of such an approach. These include the extent to which user and carer involvement has been translated into meaningful, ‘active’ partnerships, rather than simply remaining at the level of rhetoric (Maslin-Prothero, 2000) or ‘tokenistic consultation’ (Forrest et al, 2000).

It has also been recognised that the nature of the user-professional relationship, in terms of the perceived balance of power, raises issues regarding the necessity to provide clear reciprocal structures for successful participation (Forrest et al, 2000). In addition, there have been concerns about the ethical implications of user and carer involvement in nurse education, for example with regard to confidentiality, consent, and causing harm to patients (Bindless, 1998).

**Aims of the study**

There is a dearth of evidence on how user and carer involvement can be incorporated effectively into nurse education programmes. In the study reported here, the authors sought to draw on their own experiences of user and carer participation in nurse education programmes in an attempt to address this gap in knowledge. The study explored the process from the perspectives of the key groups involved and to:

- Explore stakeholders’ experiences of user and carer participation in nurse education;
- Highlight the key issues that arise for participants involved in this process;
- Identify pivotal issues to inform the development of practice in this area.

**Method**

The research was undertaken in the east Midlands, with potential participants recruited through a school of nursing and a local user and carer support group. The study followed a qualitative approach and involved focus groups, lecturers involved in developing nurse education programmes, service users, and nursing students.

Three focus groups, which were facilitated by the lead researchers, were involved: service users (n=5); nursing students (n=6); and lecturers (n=5). The purpose of the groups was to explore individual user and carer experiences of involvement in nurse education – to identify key issues of concern and to help shape the development of user and carer participation. The interviews were audiotaped with the participants’ permission and later transcribed. A topic guide, which consisted of factual questions and key areas for exploration arising from the literature review and prompts, was used as a framework for group discussions.

Lecturers from across the school of nursing were approached to take part. Their ages and experience varied but they all had direct experience of facilitating user and carer involvement in their areas of teaching. The researchers explained the nature of the study in the first instance verbally, provided written information and invited participation.

Nursing students were approached through the student representative committee. Again, the study was...
themes. Working in this sequential manner enabled the first independently and then jointly to discuss emerging concepts. This method of analysis was based on the principle of constant comparison (Strauss and Corbin, 1990). At each stage of analysis, the researchers worked first independently and then jointly to discuss emerging themes. Working in this sequential manner enabled the researchers to discuss the emerging concepts and to confirm the validity of the coding frame.

Results
The findings are presented for each focus group using the main themes identified during data analysis. Interview extracts have been selected to illustrate each theme and, as such, are representative of the data for each of the focus groups. The following categories were identified among teaching staff (Box 1):
- Experience as a resource;
- Careful planning;
- Support for users and carers.

Among students, the following categories were highlighted (Box 2, p38):
- Opportunity for the user/carers;
- Positive experience.

Service users pinpointed the following categories (Box 3, p39):
- Reasons for involvement;
- Positive experience;
- Structure of session;
- Contributing to knowledge;
- Factors to be gained from teaching nursing students.

Discussion
User and carers are not only identified as the focus of health care provision (DoH, 2001; 1999), they also have a central role in developing and delivering educational programmes (UKCC, 1999; DoH, 1994). It has also been explained in the first instance verbally, and information letters were provided to explain the purpose of the study and to invite participation.

The student participants included study years one to three and came from all branches of study. Service users were initially approached by information letters via a local user-carer group (sent to the organisation manager in the first instance rather than to individuals) to invite participation, with tear-off return slips for those who wished to participate.

At each of the proposed focus group sessions, the nature and purpose of the study was again explained in detail, and consent sought. All participants from the user-carer group were service users, had a variety of backgrounds in terms of user experience and all had been directly involved in nurse education from a service user perspective.

Ethical approval was obtained from the local research ethics committee and issues of consent, confidentiality, and data protection were considered and addressed.

The lead researchers carried out analysis of the data. This was managed using NUD*IST Version 4, a software package designed to undertake qualitative data analysis. The data content was coded line by line. Data was then grouped into recurrent themes until no further themes emerged. Interrelated themes were then developed into categories. This method of analysis was based on the principles of constant comparison (Strauss and Corbin, 1990). At each stage of analysis, the researchers worked first independently and then jointly to discuss emerging themes. Working in this sequential manner enabled the researchers to discuss the emerging concepts and to confirm the validity of the coding frame.

References


recognised that users and carers have a vital role in developing and delivering education programmes.

But while the value of user and carer involvement in nurse education programmes has been emphasised, it has also been pointed out that there has been little in the way of guidance on how this can be achieved effectively (Masters et al, 2002).

This study intended to explore stakeholders’ experiences of user and carer participation in nurse education and, in so doing, to highlight the key issues that emerged for participants as part of the process.

The findings illustrate that different groups focus on different priorities in terms of user and carer involvement but also that there are clear areas of agreement across groups. The results are discussed in the context of the literature, and the implications for nurse education are considered.

All participants felt that the involvement of users and carers in nurse education was valuable and offered insight into personal experiences of illness and care.

Both students and staff spoke primarily of the importance of ‘understanding’ what it was like to be a user or carer, of the value underpinning ‘personal experiences’, and of individuals ‘telling their story’. The service user group also highlighted the importance of improving care for participants as part of the process.

The need for adequate preparation of teaching staff has been highlighted (Costello and Horne, 2001), again underlining the importance of adequate preparation as a prerequisite for fostering effective and supportive involvement by all participants.
if user and carer participation in nurse education is to be explored further. The degree of experience of talking to groups of people before their involvement with nurse education varied from the very experienced ‘professional’ speakers to those having little or no experience.

Comments included: ‘The reason I became involved is because I like to talk. I get involved with talking to people’ and ‘I got involved because the [charitable] organisation asked me to – the condition I have is rare, so the nursing students are not likely to have come across it.’

POSITIVE EXPERIENCES

Users reported that participating in nurse education was a rewarding experience – the sessions were helpful to their well-being, and they felt that talking and listening to students was beneficial. They also said that as a result of talking to groups of people, their confidence had increased.

Patients’ comments included: ‘the fact that you’re able to speak to someone about your illness is a help.’

‘There are people a lot worse off than myself, obviously, but it gives me confidence to stand up in front of trainee nurses – it’s a learning stage for me going to the school,’ was another comment.

STRUCTURE OF SESSIONS

Users identified the need to have more structured sessions. Ideally, they wanted an hour to talk and then 20 minutes for questions. Users were concerned that on occasion students did not ask any questions or did not have time to do so. This resulted in the format of sessions being revised.

‘This time we did it [the session] differently and spoke first – because of the lack of time, no questions were asked. But for the next one we will allocate, say, 20 minutes to listen to people.’

Users also felt it would be helpful to have guidelines for the session. More specifically, they cited issues of confidentiality and the nature of the material covered. One said: ‘I think there need to be guidelines, on confidentiality, for example. I think sometimes you’re not quite sure what we’re supposed to be doing.’

CONTRIBUTING TO KNOWLEDGE

Users stated that it was obvious that nurses and doctors did not always have the knowledge they expected them to have.

‘When I was in hospital, at the start I couldn’t do anything. I couldn’t speak and a lot of doctors didn’t know about my condition,’ said one user.

Users identified what they saw as a ‘theory-practice gap’ and felt that they bridged this chasm by being ‘experts’ in their field. They also argued that their role as ‘teachers’ could be extended to involve practising nurses and doctors.

‘It’s the practice that is needed, not the theory. What I mean is that the doctors have the theory but they haven’t got the practice. Now, if you get someone such as one of us who can speak out, it’s very credible.’

BENEFITS ARISING FROM TEACHING NURSING STUDENTS

Users stated that both nursing students and patients benefited from participation in the classroom. They hoped primarily that patients’ lives would be made more comfortable. Users felt that if students were cognisant of their needs, they would transfer this knowledge to meeting patients’ care requirements.

One said: ‘I think the thing I enjoy is that you can actually tell them the little things that would make your life easier.’ Another commented: ‘From my point of view, I feel I’m trying to help someone else, not particularly myself, but someone else coming into it.’

Conclusion

The study explored the role of service users in nurse education but due to the fact that this was a small-scale exploratory study there are limitations to the conclusions that can be drawn. However, the research illuminates the perceived role and experiences of users and carers in nurse education from the standpoint of all key participants in the process.

The findings show clearly that to achieve meaningful involvement of users and carers in nurse education is not simply a matter of including them in the process – it is rather a task that can be accomplished only through careful consideration and partnership at every stage of the development process. In addition, a number of key issues – for example, individual expectations, planning, and support – need to be explored further if user and carer participation in nurse education is to achieve its optimal value in health care provision.

As nurse education, alongside health care services in general, continues to put emphasis on the importance of involving service users and carers (Masters et al, 2002), due consideration must be given to how this can be achieved effectively in practice. As Masters et al (2002) have highlighted, although there is recognition that user and carer involvement in nurse education should extend beyond classroom participation (ENB, 1996), there is a paucity of exploratory evidence in this area.

The results of the study reported here will be used to identify pivotal issues for further exploration in terms of developing user and carer involvement in nurse education. The ultimate aim is to help inform the development of practice in this area through a user and carer strategy group that is currently exploring these issues at a local level.

REFERENCES


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