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A qualitative study analysing the journey towards an embedded approach to service user involvement for Public Health Nursing Programmes

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Abstract

Service user involvement in the design and delivery of education programmes for professionals is a key tenet of current policy. This study used a qualitative approach to explore the experiences of young mothers, students and academics who participated in an initiative aimed to co-produce and deliver a teaching resource which focused on the young mothers' experiences of becoming a mother and receiving services. The findings from the focus group interviews suggest that involving service users in student learning can provide an opportunity for open and honest dialogue, where assumptions and stereotypes can be both challenged and more understood. It can also encourage users who are often seen as 'hard to reach' to be more actively involved in shaping the development of professionals.

Introduction

Embedding the views of the service users into the Specialist Community Public Health Nursing (SCPHN) programme has been an ongoing challenge for the academic team at the University of the West of England, Bristol (UWE). However, this paper reports on one initiative which aimed to explore the experiences of a group of young mother's involvement with a SCHPN programme. This was in addition to identifying the factors that motivate students to engage in learning that involves service users, as well as, highlighting academic perspectives on the development of appropriate educational methods for involving users.

Key words: public health nursing; user involvement; education; qualitative research; disadvantaged groups

Background

Involving users of services in decisions about their health care is not a new concept. In 1978 at Alma Ata the Global Strategy for Health declared by the World Health Organisation (WHO) and The United Nations Children's Fund (UNICEF) 'Health for All by the Year 2000' had community involvement in healthcare decisions as one of its key themes (Corbin, 2005). More recently a WHO policy briefing echoes the positive role that patient can have in terms of protecting and managing their health (Coulter et al 2008). Internationally, service user involvement is becoming more established, underpinned by an extensive literature, though due to a lack of standardised outcome measures comparison of results can be difficult (Kovacs Burns et al, 2014). Leading the way internationally as can be seen in the growing number of patient organisations are USA, Canada, Australia, New Zealand, Denmark and Norway (McEvoy et al, 2008). The key arguments supporting these developments centre on the fact that the involvement of users and carers in service development and delivery plays an increasingly important role in creating health services that are fit for purpose and effective in terms of improving health and wellbeing.

This picture is also mirrored in the UK with more recent policies relating specifically to the development of specialist community public health nursing services and improving care to

children, young people and families (DH, 2009, Marmot, 2010, Munro, 2011, Francis, 2013). Linked to this is an increasing expectation that Higher Educational Institution (HEI) programmes can demonstrate that service users have been involved in both their design and delivery. To help facilitate this The National Coordinating Centre for Public Engagement (NCCPE) was established in 2008, creating 'six beacon sites, university-based collaborative centres working to support, recognise, reward and build capacity for public engagement' (Spencer et al, 2011 p8). Such expectations are becoming enshrined in guidance from both external and internal drivers including inspection standards, best value and quality assurance systems (The Quality Assurance Agency (QAA), 2015). It is also a requirement of education commissioners who set key performance indicators in relation to user involvement as part of annual monitoring programme. Internal drivers include programme approval, curriculum design and evaluation and improving student experience.

In response to these drivers the Specialist Community Public Health Nursing (SCPHN) team at UWE, Bristol have been working closely with disadvantaged communities to help shape the development of SCPHN students through its post registration educational programme. 'Young Mums becoming Mums' was the first initiative and this paper reports on the qualitative research findings associated with understanding the views and experiences of those who took part The initiative was informed by the work of Tew et al (2004) which describes a framework for developing strategies for involvement that move beyond tokenism toward shared decision making within curriculum development. This 'Ladder of Involvement' in curricular development and delivery is described as a continuum ranging from 'no involvement' at level 1 to a 'full partnership' at level 5. In full partnership, service users and academics work together to make decisions about content and jointly deliver educational sessions (Tew et al, 2004).

The intervention- 'Young Mums becoming Mums'
A group of young mothers volunteered to be involved in focus group discussions about their experiences of using public health nursing services within the city of Bristol. Building on this the initiative aimed to co-produce and deliver a teaching resource focused on their experiences. Drawing on this understanding of becoming a mother and receiving support services, the young mothers recorded their experiences through film, focusing on discussions of inequality, discrimination and practice. A small live audience of students attended the initial live event and the film was subsequently shown during follow up seminars, to larger student groups. Alongside this, academics used additional learning approaches, including discussion and group activities, students were asked to reflect on the young women's experiences, their own personal beliefs and attitudes to young motherhood, and the implications for their practice in health visiting, school nursing and occupational nursing.

Aims of the Study

The aim of this qualitative study was to understand the views and experiences of those who took part in the initiative. This included those who developed the resources (the young mothers), those who delivered them (the academics) and the audiences who took part (the students).

Objectives focused on:

1. Analysing the contribution service users make to the development and delivery within a post graduate public health nursing programme
2. Exploring students understanding of the impact of this approach on their learning
3. Highlighting academic perspectives on the development of appropriate educational methods for involving users

Methodology

The overall research questions focused on understanding the experiences of those involved in this user led educational intervention, using an in-depth qualitative approach. Developing trust as the basis for meaningful service user involvement in research as well as service delivery that is more than tokenistic is in itself important and lay at the heart of this approach (Cleminson and Moesby 2013, Morrow et al 2012, Cribb and Donetto 2013, Wells et al 2008, Tew et al 2004). Challenging traditional power relationships, between professionals and service users can play an important role in shaping student learning in this area as can role modelling user rather than professional led approaches to both research and service development (Cleminson and Moesby 2013, Morrow et al 2012, Cribb and Donetto 2013, Wells et al 2008).

 It is recognised that broader social problems and structural disadvantage continue to be assessed from a professional perspective rather than client led (Hogg et al 2012). Consequently, Morrow et al (2012) argue that this is significant for marginalised groups often referred to as "hard to reach", who report finding access to services challenging and sometimes discriminatory(Cribb and Donetto 2013).   This influences not only their use of services in the future, but also their ability to become involved and influence service development. Traditional research methods have often failed to take into account how issues such as child care costs, transport, disability and language barriers can affect access to service user involvement (Spencer et al, 2011). In order to overcome such barriers, building a strong and trusting relationship between the young mothers' and the researchers was crucial. The work began in 2013 and overcoming any practical barriers was significant to this process. This included holding meetings in the children's centre where the young women attended supported by their existing community support worker.   Familiarity meant that the young mothers were at ease with their surroundings and this allowed them to grow in confidence both in terms of developing the teaching resources and moving

closer to communicating directly with larger numbers of professionals. Within this context the group facilitator played a significant role in supporting the young women and building trust between the researcher and the young mothers. Key tasks included being available to facilitate arrangements, support child care, liaise with the researcher between meetings and offer de-briefing throughout the process.

Sampling and data collection

This research study took place in the city of Bristol, South West of England in the UK. Young mothers were recruited through contact with the third sector, while academics and students were recruited through their involvement in the University based professional programme for public health nursing. All involvement was voluntary, and all those who took part gave informed consent. The sample included two groups of students; a group who attended the initial live event and a comparison group who had declined the invite. In addition, six academics, (including the programme leader and lecturers who taught on the programme) and the three young mothers who had developed the film were also recruited to take part.

Focus groups undertaken with students and academics took place at the University, while users were interviewed at a local Children's Centre between March 2014 and January 2015. Data were gathered through four focus group interviews (and three one to one interviews), were up to an hour long and audio recorded with consent from participants. A total of three young mothers, 17 students (6 who attended and 11 who declined) and six academics took part in the focus groups and one to one interviews. Questions included within the topic guides are outlined in the table below:

Students	Importance of user involvement in practice? Motivations for attending event; differences between learning from users compared to other types of learning; preferred educational methods and integrating learning into practice
Academics	Significance of user involvement in teaching and learning; the development of appropriate educational methods and reflections on student learning
Teenage mothers	Experiences of becoming a parent; help and support; views on student learning from the lived experience and views on user involvement and appropriate methods

Ethics

Formal ethics approval for the study was sought and granted by the UWE Ethics Committee at the University of the West of England, Bristol. Participants were given Information prior to involvement and consent and confidentiality, all adhered to the British Educational Research Association's Ethical Guidelines for Educational Research (BERA

2011). All the data collected was anonymised and pseudonyms used to protect the identity of those who took part, participants were informed about data storage and management processes. Participants were reassured that involvement would not impact on them either as service users or students within the programme.

Data analysis

All interviews were audio recorded and transcribed verbatim by independent transcribers. Data were coded using a traditional cut and paste method as part of a framework approach, where data are coded and grouped in relation to key themes and concepts (Gale et al, 2013). Three members of the research team read re-read and coded the transcripts coming to a consensus over emergent themes. Subsequently the dominant themes were developed and agreed by BP and JM. Using thematic analysis in its own right allowed the researchers to derive useful and credible phenomena that would influence the development of education using both social and psychological interpretations (Braun and Clarke 2006). The dominant themes presented within the following findings included views from the three groups. For young mothers this centred on communicating their lived experience and stereotyping, while students focused on openness and honesty and the implications of user involvement in reducing the theory practice gap. Views of academic staff, addressed the practical implications of developing student attributes and actively role modelling user involvement.

Findings

Views of teenage mothers

Overall, the young mothers felt they had achieved their aim and felt positive about their contribution. It was the initial relationship building with the researcher which was reported to have led to the development of trust overtime, and a collaborative and empowering approach throughout the life of the initiative. Young mothers reported wanting to help students to understand their lived experiences which they believed was crucial to building successful relationships with professionals. They felt that this was important because the ability of professionals to develop trusting relationships influenced not only access to services but also the degree to which their needs could be met. Young mothers wanted to provide an insight into how their experience was shaped by the negative impact of stereotyping.

Living with Experiences of Negative Stereotypes

Young mothers felt their experience of making the film with a student audience helped to give them a voice about the impact of becoming a mother in terms of society's negative attitudes towards single young women and the pressures experienced challenging negative stereotypes:

'You want to constantly prove yourself to people or you need to prove yourself to people. I walk in somewhere and one of the first things I want to say is I have got a job

like don't judge me. I have got a job, I work' ......Just a simple statement "I am not going to judge you" ...just a really basic conversation like that at the beginning of the relationship forming I think could go a long way just to address common fears that people have' (R2, young mother)

'...in the media when people ask me what I do and well I am a young benefit Mum and that is sort of the lowest of the low in the eyes of the Daily Mail...' (R 1, young mother)

Young mothers also felt such attitudes shaped their experience of receiving services including health visiting and this was important to communicate to students during their learning on the programme.

'...if you're already a young mum and you feel like people are going to judge you, how are you going to go to a clinic with 20 (other)people...I don't want to say I don't know how to wean my child or something...' (R 1, young mother quote from the film)

These experiences illustrated that user led education can provide opportunities for students to learn about the experience of being stigmatised associated with clients' needs as service users (O'Reilly et al 2010). McKeown et al (2014) argue that service users are interested in more than just being a "guest speaker" and want opportunities that lead to more progressive changes to attitudes and wider narratives about stigmatised groups. Whilst this group of young mothers reported wanting to be candid in their approach and respond honestly to students questions, preparation included acknowledging the challenges associated with speaking in public and encountering negative attitudes of students (Wells et al 2008).

Views of students

There were no reportable differences between the two student groups (those who attended the initial live event and those who had watched the subsequent film) in terms of the value they placed on service user involvement to their learning and practice. However, the group who attended the initial live event reported hearing the narratives as 'empowering in terms of their learning and practice'. The decision to attend was motivated by the opportunity to learn more about service users' views of themselves as 'future practitioners' and the extent to which they felt practitioners were doing 'a good job'. Overall the students' views highlighted the sense of honesty and openness of the session which also contributed to an acknowledgement of the tensions between policy and practice.

Honesty and Openness

While students reported having previous experience of feedback from users through user satisfaction surveys, listening to mothers 'live' was perceived as more valuable to their learning:

> '... I think they felt that they could actually say what they wanted to say because they knew there would be no repercussions...I think they were very honest' (R2, student from the live event group).

Value was placed on honest communication, and students felt that learning from service users was different to other types of learning available on the programme. It made it possible to have more 'open conversations' with service users in the future and this was 'a better way to learn'. Chalmers et al (2012) endorse this view arguing that such an approach challenges student's assumptions and stereotypes adding to clarity and application of theory and research This can help the students' experience to be more meaningful particularly in terms of reducing the theory practice gap (Wells et al 2008). The following extracts eloquently illustrate these points:

> 'It helps you sort of critique the documents...all the guidelines....and I actually think well they are saying this but this (documents) is saying this and they are not tying up...analyse things differently and not just take everything at face value' (R3, student the live event group).

> 'How do they perceive what we are saying and what we are asking...? Because I couldn't put myself in their shoes to know what it would be like' (R2, student, film group).

Theory Practice gap

Chalmers et al (2012) argue that the classroom also provides students with a space which is relaxing and safe and shifts the balance of power from the student to the service user compared to practice settings (Rush 2008 cited Chalmers 2012). Students recognised that this provided a space and context to learn more critically about service users' experiences and the implications for their own learning and practice. Nevertheless, challenges were also raised about the need for programme developers to be cognisant of placing users account within a wider policy context that was target driven, and working realistically with students to resolve these real life dilemmas.

> 'it gives you a real life window...if the programme is designed in such a way that there is acknowledgement of those tensions...in terms of having targets to meet...and developing trusting working relationships with individuals' (R6 student, film group).

Views of Academics

Academics views were characterised around two main themes, the first connected to the development of student's personal and professional attributes such as empathy and self-awareness. The second focused on the degree to which academics could model their own behaviours specifically in relation to the use of more participatory approaches to service user involvement.

Developing Student's Attributes

Within the SCPHN programme there are six workshops that focus on exploring and challenging the students' personal and professional attributes in line with the Department of Health Guidance (2009) and the DH document "Educating health visitors for a transformed service" (DH, 2011). The aim being to facilitate the development of those personal and professional qualities required to build positive relationships with children, young people, families and communities. The academics recognised that a much more explicit connection to service users could be made in these attributes workshops and considered a particular session on empathy where actual examples could be explored by the students.

> 'Given that understanding the perspective of the service user must be to some degree about empathy … so it's perhaps just bringing it in as a concrete concept rather than expecting them to make the connection' (R2, academic).

One such activity introduces the concept around empathy where photos of people who could be service users with different appearances and expressions are displayed. Students discuss the image being portrayed, highlighting any stereotypes and assumptions. In adopting this approach to attributes there appears to be added value in that emerging evidence suggests that practitioners who demonstrate empathy appear to benefit personally from significant neuro-physiological effects (Nummenmaa et al 2008). This evidence also suggests that the emotional responses of students should be challenged (Nummenmaa et al 2008).

This notion of challenging student thinking was interestingly alluded to throughout the data. The philosophical issues and challenges of service user involvement were considered important to be included in order to challenge student thinking:

> 'I think you could make it more challenging for the students actually' (R2, academic).

> 'And instead of telling students things something that engages them and makes them think and challenges them I think that's more important really' (R1, academic).

> '…from time to time depending on the issue I do ask the students to walk in the shoes of your clients and think about how that might feel…'(R4, academic)

Modelling behaviours

In relation to participatory behaviours, there was agreement that academics could be modelling the sorts of behaviours they would like to observe in the students, with one suggestion being to involve students as users of the programme:

> '...maybe we need to be modelling service user involvement in a wider scale so we actually involve students in the same way we would want them to involve clients' (R3, academic).

Similarly, linking back to attributes, there was consensus about academics also modelling those behaviours:

> '...and also there is a significant amount of role modelling that goes on you know I would like to think that we would talk respectfully about users and each other and about students so you know... (R2, academic).

Evidence suggests that role modelling, often underused, as a teaching method has the flexibility to be applied to both simple and complex skills or behaviours expected of students (Murray & Main, 2005). Indeed when thinking about setting an example of the behaviours expected with certain values, Kouzes and Posner, (2007) in their framework of 'Five practices of exemplary leadership', puts 'modelling the way' as the first practice of choice (Kouzes and Posner, 2007).

A common criticism found in the literature (Martin, 2008; Hamilton, 2009) focuses on users' representation and a perceived lack of representativeness, this issue was explored by academics. What emerged from the data however, was a willingness to accept the views of the users as a 'snapshot' of their experiences of the services they received. Concerns about representativeness should therefore not be seen as an obstacle (Robert et al 2003). Academics felt that it was important to reflect back this view to the students who often find criticism of their role or service hard to hear, questioning the representativeness of young mothers' views.

Limitations

There are limitations to this research in that it focused on a single project with young mothers, within the South West of England; it is not possible therefore to establish the extent to which these findings would resonate with other HEI's serving communities with different demographics and student populations. In addition, the project relied on film as the medium for communicating with larger student audiences; while this had some advantages other more creative/interactive methods (such as drama, one to one dialogue, conferences etc.) may generate different results, so comparisons would be interesting.

Discussion

Involving service users in students learning was perceived as 'different' to other types of learning within the programme. From the perspective of both young mothers and students

it offered the opportunity to provide honest accounts from an emic perspective that allowed users to confront professional stereotypes, in a safe setting. Young mothers were empowered to challenge professional dominance, arguing that professional assessments sometimes fail to acknowledge how broader social problems and structural disadvantage are experienced by those living with the everyday reality , making health visiting services less accessible(Hogg et al 2012; Cribb and Donetto 2013; Morrow et al 2012). Nevertheless, this study demonstrates the importance of allowing time and resources to support involvement if it is to be meaningful to users. This allows for the development of ongoing relationships, where users contributions are fully embedded alongside other approaches (Tew et al 2004). Academics, can appreciate the significance of this approach particularly in relation to developing professional attributes, such as empathy and self-awareness. However, teams need to be committed to the approach and the under-pinning philosophies, as modelling a relationship that is more valuing of user led service development is not only crucial to successful student learning but has been identified as an approach that is often under explored and utilised by those teaching on professional programmes. (Spencer et al, 2011)

Conclusion

Given that the aim at the outset was to embed user involvement in the SCPHN programme, this initiative has helped to begin that process. To further progress this aim we need to develop a clear vision and systems to support the process. It is evident that there are many possible approaches to embedding user involvement in the curriculum, providing appropriate steps are taken to mitigate against some of the challenges that can arise. We need to learn from and build on this experience, work in partnership with other programmes and explore sustainability in the longer term.

Key points

Involving service users in student learning can provide an opportunity for open and honest dialogue, in which professional's views and dominant attitudes can be challenged, in a safe environment for students and users.

Students learn directly from members of disadvantaged communities about the impact of negative stereotypes both in terms of relationships and meeting needs.

Embedding user perspectives within SCHPN programmes can encourage users who are often seen as 'hard to reach' to be more actively involved in shaping the development of professionals.

Academics role modelling the value of user involvement, in relation to both development of professional attributes and user led services is crucial to successful student learning.

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