



University of HUDDERSFIELD

University of Huddersfield Repository

Rhodes, Christine, Hardy, Joan, Padgett, Kath, Symons, Jools, Tate, Joannie and Thornton, Susan

The Health and Well-being of Service User and Carer Educators: a Narrative Enquiry into the Impact of Involvement in Healthcare Education

Original Citation

Rhodes, Christine, Hardy, Joan, Padgett, Kath, Symons, Jools, Tate, Joannie and Thornton, Susan (2014) The Health and Well-being of Service User and Carer Educators: a Narrative Enquiry into the Impact of Involvement in Healthcare Education. *International Journal of Practice-based Learning in Health and Social Care*, 2 (1). pp. 51-68. ISSN 2051-6223

This version is available at <http://eprints.hud.ac.uk/id/eprint/21069/>

The University Repository is a digital collection of the research output of the University, available on Open Access. Copyright and Moral Rights for the items on this site are retained by the individual author and/or other copyright owners. Users may access full items free of charge; copies of full text items generally can be reproduced, displayed or performed and given to third parties in any format or medium for personal research or study, educational or not-for-profit purposes without prior permission or charge, provided:

- The authors, title and full bibliographic details is credited in any copy;
- A hyperlink and/or URL is included for the original metadata page; and
- The content is not changed in any way.

For more information, including our policy and submission procedure, please contact the Repository Team at: E.mailbox@hud.ac.uk.

<http://eprints.hud.ac.uk/>

RESEARCH ARTICLE

The Health and Well-being of Service User and Carer Educators: a Narrative Enquiry into the Impact of Involvement in Healthcare Education

Christine Rhodes,¹ Joan Hardy,² Kath Padgett,¹ Jools Symons,³
Joannie Tate² & Susan Thornton²

¹Department of Health Sciences, University of Huddersfield

²Patient Voice Group, University of Leeds

³Leeds Institute of Medical Education, University of Leeds

Corresponding author:

Christine Rhodes, Department of Health Sciences, School of Human and Health Sciences, University of Huddersfield, Queensgate, Huddersfield HD13DH, UK
Email: c.a.rhodes@hud.ac.uk, Phone: +44 (0) 1484473407

Abstract

Service user and carer involvement is increasing in health and social care education as a result of UK policy directives and Professional Statutory and Regulatory Body requirements. The study aimed to elicit the accounts of service user and carer educators' experiences in practice-based healthcare education in the UK. The overall aim was to illustrate the impact this has had on their health and well-being. A narrative inquiry approach was adopted in order to give a clearer and stronger voice to service users and carers by making their experience the primary focus of enquiry.

Narratives were collected from five service users and carers who had extensive experience of involvement in healthcare education. The individual narrative material obtained was distilled into key points following a naturalistic perspective, ensuring that the findings and final story were a re-presentation of the narrator's experience.

Participating in the research enabled the service users and carers to articulate specifically how involvement had positively affected their health and well-being. An additional outcome included the personal artefacts that can be utilised in teaching and learning in order to bring the service user and carer voice to life.

This study contributes to the emerging knowledge and understanding that service user and carer involvement in health education can be a truly collaborative, enriching experience, producing profound personal change, with improvements in health and well-being. Effective involvement is dependent upon appropriate support networks whereby service users and carers develop connections with staff and other service users and carers that result in a sense of belonging.

Keywords: narrative inquiry, health and well-being, service users and carers, involvement, healthcare education

Introduction

The drive for service user and carer involvement in health and social care education in the UK brings with it a plethora of questions as to the risks and benefits for service users, carers and students (Jones 2006, Morgan & Jones 2009, Gutteridge & Dobbins 2010). The aim of the research reported here was to elicit the accounts of service user and carer educators' experiences to illustrate the impact involvement in practice-based health care education has had on their health and well-being. A narrative inquiry approach was used to give a clearer and stronger voice to service users and carers by making their experience the primary focus of enquiry.

For clarity the following terms are used whilst recognising that there are not always standard definitions. The terminology service user and carer is chosen throughout, service user describing people who receive or have received health and social care services in the UK (Beresford 2005). However, this terminology is contentious because of possible negative connotations such as being interpreted as an exploiter, manipulator or illicit user (Beresford 2005, McKeown *et al.* 2010). Despite this, it is the most frequently used terminology in the current health literature. A carer is someone who provides unpaid support to family or friends who could not manage without this help (Carers Trust 2012). Health is defined as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (WHO 1946). Well-being is defined as a positive physical, social and mental state (DH 2010a). Practice-based education is used here to describe education that prepares students to work in practice-based settings.

This paper reports on research undertaken with an established network of service users and carers, the Patient Voice Group, situated in a large higher education provider in the north of England. The group is made up of service users and carers and university staff with extensive experience of involvement in healthcare education in the UK, who have undertaken a series of research projects exploring different aspects of engagement (Padgett *et al.* 2012). The Patient Voice Group is involved in a wide range of involvement activities that prepare healthcare students for practice-based learning. Activities include telling their story to students in order to highlight the importance of a person-centred approach to care; communications skills training with healthcare students and the development of scenarios for interprofessional workshops held in practice settings and which they co-facilitate.

To demonstrate the collaborative nature of the work undertaken the six authors of this paper are service user and carers and academics who participated in the study who have taken on the role of dissemination. For the purpose of this article the lead author, an academic, was assigned the role of narrating the journey on behalf of the group. Member-checking through review and comments on drafts of the article from the group was undertaken to ensure it represented their views accurately (Polit & Beck 2008).

Service user and carer involvement in health and social care has featured on the political agenda in the UK for some time and is a recurring theme in health and social care policy (DH 1999, DH 2000, DH 2001, DH 2003, DH 2005, DH 2008a, DH 2008b, DH 2008c, DH 2010b). This has led to a growing requirement for service user and carer involvement in health care education (Lathlean *et al.* 2006, DH 2009, Nursing and Midwifery Council 2010, Health and Care Professions Council 2013).

The ideology of involvement as a broad concept is based on opposing positions of consumerist or democratic approaches (Beresford 2002). A consumerist approach concerns itself with efficiency, economy and effectiveness; here the power and control remain with the provider. A democratic approach promotes inclusion, autonomy and independence with equal status and shared power and control (Beresford 2002). Regardless of the political

imperative, the notion of involvement from people who receive services is a progressive feature in healthcare education in the UK.

The body of literature on involvement in healthcare education is expanding; recent publications include evaluation studies that investigate the value of service user and carer involvement in order to establish the benefits and pitfalls and inform future developments (Minogue *et al.* 2009, Morgan & Jones 2009, Rhodes 2012). There is acknowledgement that the research relates to mental health and social work, with a limited evidence base for the benefit to the service user or carer involved (Morgan & Jones 2009). The primary focus is often the effect of service user and carer involvement on student learning and influence on practice. Examples from mental health nursing demonstrate improved communication, changes in assumptions and attitudes with the development of empathy and cultural awareness (Simons *et al.* 2007, Rush 2008, Simpson *et al.* 2008, Stickley *et al.* 2009). In social work education examples include the integration of theory and practice and an understanding of social work values (Agnew & Duffy 2010, Duffy & Hayes 2012). Furness *et al.* (2011) evaluated an interprofessional practice-based initiative undertaken with 13 professions in health and social care which yielded thematic results in the categories of reaction, learning, behaviour change and impact. Moreover, Tew *et al.* (2012) detail how dialogue between students from different professional disciplines, service users and carers, had a major impact on professional development.

The positive effect of involvement on service users and carers has been reported, though mainly as an incidental finding (Morgan & Jones 2009). Positive effects include increased confidence (Bailey 2005, Furness *et al.* 2011), self-esteem, and the opportunity to develop new friendships (Bailey 2005, Jones 2006, Minogue *et al.* 2009). An increase in understanding of their own condition, enabling service users and carers to question health professionals, has also been reported in the literature (Shah *et al.* 2005, Jones 2006). Simpson *et al.* (2008) report that involvement in the education of mental health nurses empowered service users to challenge stereotypes and the stigmatising of people with mental health problems. There is, however, a paucity of research specifically focusing on the effect on service users and carers. One exception is emergent findings from a participatory action research study with a focus on developing service user and carer involvement in a university setting (McKeown *et al.* 2012). This identified three broad themes from participants' narratives on the value of involvement: a more positive sense of self, social and relational benefits, and altruism and activism (McKeown *et al.* 2012). Conversely, negative experiences are reported: for example, an imbalance in power and cultural disparity between service users and carers and academics (Felton & Stickley 2004, Minogue *et al.* 2009, Morgan & Jones 2009). Bureaucracy, in terms of university systems and payments, is a major barrier and in the literature is reported as a perennial problem (Morgan & Jones 2009, McKeown *et al.* 2012). The need for training and support has been widely reported as a barrier to involvement in nurse education (Repper & Breeze 2007, Speed *et al.* 2012). Moreover, a study by Dogra *et al.* (2008) explored service user perspectives on their roles in medical education, and found that although service users may have several roles in teaching medical students about mental health, potential challenges include lack of support, training, issues of power and lack of partnership.

Successful involvement is ascribed to effective engagement between academic staff and service users and carers (Downe *et al.* 2007, Minogue *et al.* 2009). The Ladder of Involvement (Tew *et al.* 2004), a five-stage model that is an adaptation of Arnstein's Ladder of Citizen Participation (1969), a framework for assessing social capital, or social cohesion, is often used to locate the level of involvement. The five stages in Tew *et al.*'s (2004) ladder range from Level 1: No Involvement to Level 5: Partnership with the assertion that the higher the level the greater the involvement. The use of hierarchical frameworks is not

without its critics; Tritter & McCallum (2006) suggest they are too rigid, are based on citizen power and do not recognise the complexities of involvement that is dynamic and evolving. The preferred term of social citizenship is proposed, reflecting the relationship between individuals and local institutions and the use of a mosaic as an analogy to illustrate the complex and dynamic relationships. Similarly INVOLVE promoted three main levels of involvement: consultation, collaboration and control. However, in order to move away from a hierarchy of involvement, with recognition that valuable involvement can occur on a number of levels, the suggested term is shifting from levels to approaches (INVOLVE 2012).

In terms of well-being, there is a political emphasis on health and well-being as a quality of life indicator (DH 2010a). The Office of National Statistics has undertaken consultations to ascertain people's views on what matters most in their lives to inform the development of well-being measures (ONS 2013). The body of literature on well-being includes the identification of two dimensions: hedonic, i.e. positive feelings, and eudemonic, i.e. positive functioning, with acknowledgement that a number of factors influence well-being including physical, social, environmental and psychological issues (Friedli 2009). Well-being is measured by individual subjective views and objective social indicators: for example, social integration, acceptance, contribution and coherence (Keyes 1998). Cognisance needs to be taken of the differing viewpoints on what constitutes well-being across different cultures and age groups (Newbigging & Bola 2010).

Method

This qualitative study followed a narrative inquiry approach. Narrative inquiry was chosen because the service users and carers had previous experience of this research approach and valued being fully engaged in the research process as partners rather than subjects. This approach is sympathetic to the topic of enquiry as it creates meaning and increased personal insight with the use of 'self' for both the participant and researcher (Holloway & Freshwater 2007).

A narrative inquiry approach is used here as a way of knowing, with individual stories collected and developed into artefacts to explore, interpret and assign meaning to the involvement experiences of the participants. The accounts were elicited and interpreted by the service users and carers in partnership with the researchers (Freshwater & Holloway 2010). The research was service user and carer led from the choice of topic explored to the method of data collection and interpretation of the results. The research represents true collaboration, a recognised term used to describe a model for involvement based on the Ladder of Involvement (Tew *et al.* 2004). Narrative inquiry is an example of an emancipatory research approach with reciprocity, gain and empowerment (Oliver 1992) characterised by a close and equal partnership between researchers and participants. This approach fits well with the evolving 'co-production' approach to public service delivery in the UK, with input by people who use services and is a model of partnership and collaboration (Needham 2009).

The verbal recounting of life events as a story, which reflects the speaker's viewpoint, was seen as another benefit as the goal was to give voice to the experience, (Parker & Shotter 1990). The aim was to elicit the personal accounts of users' experiences of involvement, their interpretation of, and the meanings assigned to, the experience. The verbal recounting of events enabled the service users and carers to give a personal account of their motives, experiences and the opportunity to interpret and assign meaning to the experience (Holloway & Freshwater 2007). Finally, this approach allowed us to recognise the close working relationship that had developed over time between the service users and carers and the university staff. The university staff included those employed with a specific role in

the development of involvement and healthcare academics with a special interest in involvement. The acknowledgment that the researchers connect with the participants, engaging emotions and empathy with a high degree of reflexivity fitted the ethos of the study (Connelly & Clandinin 2000).

A non-probability, purposive sample (Parahoo 2006) of five service users and carers from the Patient Voice Group was involved in the study, all of whom had undergone a process of preparation for involvement, the Patient Learning Journey. This entails the service user or carer 'telling her/his story' of experiences and identifying the learning points so far (O'Neill 2008, Morris *et al.* 2009). The service users and carers were aware that becoming involved had affected their lives and wanted to explore this further. The sample comprised four women and one man. Three service users lived with a long-term physical health condition and one with a long-term mental health condition. One of the service users was also a carer for her daughter. The fifth person was the carer of a young man with a learning disability. The service users and carers had extensive experience of involvement and previous experience of narrative approaches and as such provided an appropriate sample that could produce meaningful data.

Ethics committee approval was obtained from the university. Written consent was obtained from participants at the outset followed by further 'process consent' (Kavanaugh & Ayres 1998) obtaining consent at key stages, for example, consent to share the stories and make them available on the web. This was particularly important as the collaborative relationship between the researchers and the participants had the potential to encourage the service users and carers to open up and disclose information that they might wish to keep private (Freshwater & Holloway 2010).

The five service users and carers and university staff met as a group in a comfortable, safe environment familiar to them. In order to allow the voice of each service user and carer to be heard, two groups were formed with two service users and carers in one and three in the other. There were two university staff members in each group who acted as facilitators, interacting with and initiating conversation with the service users and carers to tease out their accounts of their experiences. Each service user/carer was given time to tell their story guided by three overarching questions to encourage them to give their own account of their involvement experiences:

- What made you get involved?
- What has helped or hindered?
- What effect has involvement had on your health and well-being?

Holloway & Freshwater (2007) advocate interaction with participants in a congenial setting, with a small number of questions, where the focus is on the flow of talk from the participants, as interruption can cause the participant to lose the thread of their story. Detailed information from the stories is necessary in order to present a 'Gestalt' or whole that is greater than its parts, allowing the listener to understand the entire story.

The discussions were digitally recorded and facilitators took notes of key points of the individual stories. The service users and carers gave one another time to speak that allowed individual expression; this led to discussion and debate about what each had said. This encouraged richer expressions of opinion and stimulated the service users and carers to think more deeply about their experience, an advantage of group sessions (Polit & Beck 2008). In allowing each individual to tell their story the discussion did not default to a group response, a reported disadvantage of group sessions collecting unstructured data (Polit & Beck 2008).

Content analysis was undertaken, whereby the material from the tape recordings and notes was dissected into sections, and single words belonging to defining categories were identified and documented for each narrative (Sparkes 2005). Once the defining categories had been identified and agreed, the two groups worked together to distil the individual stories down to key elements. This followed a naturalistic perspective (Denzin 1971) with the focus on the content to ensure the final story was a re-presentation of the narrator's experience. In order to ensure the individual voice was heard further work was then undertaken in translating the individual distilled stories into artefacts, for example, a poem or digital story. Assistance and support were provided to service users and carers from a music therapist, who gave them examples of stories she had previously collected and developed into a song, poem or story. Once the service users and carers had decided how they wanted to present their story university staff assisted them in developing this into a digital story. These artefacts are owned by the service user and carers; however, they gave permission for, and actively encouraged, use in the teaching and learning of health and social care students. They see this as an opportunity to reach a wider audience, offering insight into a patient's experiences in order to influence health and social care practitioners to see people as unique individuals with a view to improving patient experiences. In addition, a cross-sectional approach was adopted to identify common defining categories arising from the individual narratives.

The study followed a collaborative method with an approach to analysis that was transparent and theoretically based, increasing the credibility and therefore transferability of the narrative-based findings (Hardy *et al.* 2009). Rigour is therefore based on trustworthiness and authenticity, remaining faithful to the meaning of the experiences of the participants as expressed in their own, unedited stories.

Results

The sample, which included service users and carers with a range of experiences, produced rich data from a variety of perspectives. Although there were similarities, each had their unique interpretation and expression. Here included are three examples of the individual stories. The final individual and personal stories that were distilled from the data are freely available to view at <http://www.alps-cetl.ac.uk/patientvoice.html>.

In respect of what made service users and carers get involved, each had a different experience. They were, however, all recruited from the community, either via advertisements or by personal invitation from the university patient involvement manager. The service users and carers had attended a 'Patient Learning Journey' workshop where they had been encouraged to tell their story and identify how their experience could contribute to health professional education (O'Neill 2008). None of the service users and carers had really understood what 'getting involved' meant and said that, looking back, had they understood, they would not have thought they had anything to offer (see Table 1).

All of the service users and carers referred to this as the point when they 'joined the club' of which they now consider themselves to be full members. They spoke of the relationships that were established at this point with the facilitators from the university and other members of the workshop. In terms of what helped, they referred again to the Patient Learning Journey workshops that prepared them for involvement. The most important aspects for their continued involvement were support and networks (see Table 2).

In response to the question about hindrances the service users and carers identified a number of issues that over time had been negative and that would, without the support systems available, have affected them more. The agreed defining categories that

Table 1 Getting involved.

Question	Defining category	Quotes
What made you get involved?	The Patient Learning Journey	Invited me to join Was the start of the relationship Gave me the opportunity to get things off my chest Put my own situation into perspective Made me learn to listen Accepted me for what I am Helped me see how I could help other people Gave me the opportunity to give something back

Table 2 What helped.

Question	Defining category	Quotes
What has helped?	Support	Never put in a position I cannot handle Belonging...feel comfortable Friendships...peer support...network of people Having someone to talk to...to talk things through People who care Personal touch

collectively captured these issues were: bureaucracy, lack of support, knocking of confidence and negative or no feedback (see Table 3).

All participants were overwhelmingly positive about the effect on health and well-being, although they had different perceptions and experiences of the benefits. The agreed collective defining categories were: confidence, better health, and a sense of purpose, self-worth and a sense of being valued and respected. Most of the service users and carers identified increased confidence as a result of involvement and perceived that they are more able to speak up and speak out as they feel on a more equal footing with health professionals because of an improved understanding of the health service. The service users described better health gained through increased knowledge and understanding of their condition. This enabled them to take control of their condition, where previously the condition had controlled them. Positive outcomes such as a reduction in medication and the use of alternative strategies to manage the condition were discussed, described as 'the tools to manage my condition'. This was linked to a sense of purpose, having something positive to focus on, giving meaning to life, a reason to get up, occupying time previously spent dwelling on their illness. All the service users and carers talked about improvements in self-worth, learning to accept who they now were with the ability to identify positive attributes where they had previously felt useless. The participants described the sense of value and respect which involvement had given them: others valued what they had to say, with their contributions being asked for and their opinions listened to and respected. Participating in the narrative process enabled them to self reflect and gain a deeper understanding, which helped them articulate specifically how involvement had positively

Table 3 What hindered.

Question	Defining category	Quotes
What has hindered?	Bureaucracy	All the forms that have to be filled in for the university systems I have to pay for a taxi and claim it back...this takes weeks...because of this I take the bus and this takes a lot longer Payments are a problem as it could affect my benefit
	Lack of support	On occasion... involved with someone who doesn't know me, and doesn't take the time to get to know me... Not treated properly...just a tick box Sometimes it's too short notice...no consideration... I need to plan ahead Not supported to 'come out of role' after simulated patient work then I take it home with me
	Knocking of Confidence	There was one occasion where...well it didn't go well... this knocked my confidence and I was going to give up... I went home and had a day of thinking...it was only because... (the patient involvement manager).. got me to talk it through that I got my confidence back
	Negative feedback or no feedback	Sometimes students put on evaluations negative comments that are hard to accept Comments or things said that imply service users are not welcome There have been times when there is no feedback so you don't know how it went

affected their health and well-being. This proved to be a cathartic process and enabled them to identify positive improvements in themselves (see Table 4)

Discussion

The discussion will comment on the research process together with the findings and stories elicited. Additionally, the effect of being involved in the research on the participants and researchers will be explored.

The process of undertaking the study with a narrative approach enabled the service users and carers to identify the subject of enquiry, and to collaborate throughout the study, affirming their perception of an equal partnership. The co-production of the narratives together with the joint analysis of meaning enabled this to occur. Co-construction achieved the aim of giving voice to the experience ensuring the interpretation, understanding and the final story developed, remained the participant's story and not the interpretation of others (Mishler 1986). This included the involvement of the service users and carers in the whole process, including dissemination, giving the same consideration to the end of the research project as to the beginning (Hardy *et al.* 2009). The web-based stories that are open access allow for wide distribution that is particularly valued by the service users and carers. The research is an example of an emancipatory, empowering approach in which service users and carers were the subject of their own learning, a process encouraging critical reflection and self-analysis (Wallerstein & Bernstein 1988).

The collective findings and individual stories demonstrate that service users and carers engaged in this study felt that they had a role and purpose in health education in a university setting. They were 'invited to join', were prepared for their role and felt

Table 4 The effect on health and well-being.

Question	Defining category	Quotes
What effect has involvement had on your health and well-being?	Confidence	The confidence to challenge constructively
		It has completely turned me around. . . more than I ever could have imagined
		To be able to speak to students . . . to speak to lots of people . . . it's amazing . . . just look at me now
	Better health	It keeps my body going
		Reduction in medication
		Has given me the tools to manage my condition
		Reduced time I see the doctor
		Self-healing
		Enhances my life
		Put things in perspective
	A sense of purpose	Not a burden on the NHS
		I call it going to work
		Want to give something back
		To change things for the better
		Purpose to my life
	Self-worth	Grow myself. . . Love myself again
		Better relationship with myself
		That I am capable
		Purpose to my life. . . I felt like I wasn't any good to anybody. . . now I have got some worth
Self-awareness		
Value and respect	Believed in . . . that I have something to give . . . trusted	
	Have something valuable to offer	
	I am a much better patient	
	Accepted for what I am	
	Feeling included. . . being a member	
	Positive feedback	
	The money is useful. . . but there are other kinds of value. . . the Christmas party, going to conferences, training	
How to deal with other people		

supported. They had a sense of belonging and value and felt that through the giving of self they gained something back for themselves. Both groups said that financial reward was not the main driver for their involvement; they were willing and, indeed, did undertake involvement without payment. In their experience they were paid for direct teaching, which is why this may not have been an issue. What was important was reward in a broader sense. This included access to training and funding to attend conferences. The significant factor was feeling valued, 'being a member of the institution' with access to opportunities related to this. However, it was acknowledged that payment should be offered, particularly when participants were involved in teaching, as for any other lecturer.

A number of the defining categories that emerged reiterate the findings published in previous research articles: as mentioned above, the hindrances of bureaucracy, lack of support, knocking of confidence and negative or no feedback are documented in the literature (Repper & Breeze 2007, Morgan & Jones 2009, McKeown *et al.* 2012, Speed *et al.* 2012). It is worthy of note that the service users and carers in this study reported the sense of belonging, which they felt limited the negative effect of these hindrances.

In terms of positive impact, the service users and carers were able to demonstrate improvements in health and well-being which bear out the findings of the current literature. These include increased confidence (Bailey 2005, Furness *et al.* 2011). Susan's 'confidence to challenge constructively' (see Susan's story) connects to the findings of Shah *et al.* (2005) and Jones (2006) whereby service users were enabled to question health professionals.

Susan's story -

Twenty years have been and gone,

Nobody listened and it all went wrong.

Time after time, they said I was a drunk

By no means, I knew I wasn't a monk.

Over and over,

They called me mad Sue,

Bloody hell!

What was I gunna do.

Lost my job,

Lost my home, lost my integrity too.

So I knocked on door after door,

Until my knuckles were raw.

Stitches, plaster and scalp shaved too

How far was I gunna go?

Guess what

Broken bones and stab wounds too

You clinicians in there what are you going to do.

Please, please listen

If you know what's best for you

That's why you get paid so much for what you do

Now I get paid for you to listen,

And listen you will do!

Hip Hip Hurray,

You have listened at last

I now know what you have subjected me to.

Bi Polar Bi Polar,

You clinicians say,

Bi heck you listened at last to my dismay

Hip Hip Hurray I shall be on my way

Learning to live again

Hip Hip Hurray

This signifies the development of critical health literacy, with the ability to exert greater control over one's life and the ability to make informed decisions (Lin 2000). In addition, the important concept of self-worth, which was articulated by Joannie (see Joannie's story) as 'feeling useful again', was described as improved self-esteem by Bailey (2005), Jones (2006) and Minogue *et al.* (2009).

Joannie's story

My involvement working for the university as a patient/carer began in 2006.

I was a disabled, out of work 55 year old woman suffering from fibromyalgia and chronic fatigue syndrome; plus I was caring for my disabled daughter. I was at my lowest; I thought I my life was over. Due to my illness it meant I couldn't work full time, and I never knew from day to day how my health would be. I thought I was no use.

I started with the patient learning journey (PLJ). It wasn't clear what path it was going to take or how doing this would help me.

The Patient Learning Journey was the first time I was able to tell my story and people actually listened without being judgemental. I was 'The Angry Patient'!

My involvement started with a classroom visit. I was later trained as a Simulated Patient.

I found skills and knowledge I didn't know I possessed. I now have a job to suit my illness with people who understand. My health has improved, so has my understanding and knowledge of myself and how I can help others. I've learnt there isn't a magic answer. I actually feel useful again. Now my involvement is extensive.

It was never a 'eureka moment'. I can only describe it as being given a bag full of jigsaw pieces. I had no picture with an unlimited amount of pieces. Slowly but surely the more I get involved I was able to start putting the jigsaw pieces together. As my jigsaw grows, so do I, I hope I never finish my jigsaw.

Every journey has an end but it starts a new beginning.

A sense of purpose was achieved through the opportunity to contribute to student learning with a view to influencing professional practice and changing things for the better, integrating theory and practice (Agnew & Duffy 2010). Moreover, student feedback was reported by the service users and carers as important to their sense of value and respect. Receiving comments from students which showed that they valued what service users and carers had to say aligns with studies that demonstrate positive outcomes for students (Simons *et al.* 2007, Rush 2008, Simpson *et al.* 2008, Stickley *et al.* 2009). The findings from this study relate very closely to the emergent findings of McKeown *et al.*'s (2012) participatory action research study, which identified three broad themes: A More Positive Sense of Self, Social and Relational Benefits, and Altruism in Activism, comparable to the six positive categories: Support, Confidence, Better Health, Sense of Purpose, Self-worth and a Sense of Value and Respect, identified in this study. Both these studies focus on the value of involvement and are undertaken in universities that have invested significantly in involvement with established teams.

The service users and carers referred to involvement as 'going to work' and having a job that suits their needs. This relates to the evidence base showing that work is generally good for physical and mental health and well-being. A report by Waddell & Burton (2006) found that work can be therapeutic, regardless of whether a person is healthy, disabled or living with a long-term condition. However, the job needs to be of the right nature and social context and should be safe and accommodating. Better health was a theme in this work illustrated by Joan's Equation of Involvement.

Joan's Equation of Involvement

Personal Involvement + Personal Fulfilment = Personal Enjoyment

÷ That By Your Heart

And Realise Your Pain Factor

Can Be Reduced By Any % You Aim For

Joan - successful mathematician

This generally positive assessment of work in the service user and carers' lives has to be balanced against the hindrances identified, with acknowledgement that these could have had negative consequences on health and well-being. The protective factor appears to be the support systems that are in place. In turn, the defining category Better Health relates to the literature on well-being with improvements in the two dimensions identified by Friedli (2009): hedonic, positive feelings and eudemonic, positive functioning. The sense of purpose and belonging, the relationships and connectedness to others and mutual support recognised as a crucial aspect of involvement by the service users and carers correlate with Friedli's (2009) identification of the need for social cohesion and engagements for positive well-being.

This locates the work at a high level on the Ladder of Involvement (Tew *et al.* 2004) and within the democratic model of involvement, with inclusion, autonomy and independence and with the service users and carers having an equal level of power and control.

As noted earlier, the process of collecting the narratives was a valuable, therapeutic experience for the participants (Atkinson 2002, Overcash 2004). Telling the story is the first stage of Egan's (1994) 'Helping Model' and the service user and carers felt participating provided a way of reflecting on, and making sense of, the effect involvement had on them as individuals in their stories. The development of the stories gave each service user and carer the opportunity for individual expression; each decided how they wanted to illustrate and illuminate their story, allowing them to give voice to their experience (Gubrium 1995). They enjoyed this aspect of the process and expressed a sense of satisfaction in the end products, which they are proud to share. Moreover, the collaborative process was also a positive experience for the researchers; the high level of reflexivity allowed them to engage with the narrators and acknowledge their experiences and emotions about involvement, rather than attempting to set aside existing knowledge, known as 'bracketing' beliefs and opinions (Polit & Beck 2008), so mirroring the established reciprocal relationship of the Patient's Voice Group.

It seems fair, therefore, to draw the conclusion that the reason this study found involvement to be such a positive experience is the level of collaborative or partnership working, equating to a high level of engagement. Substantial investment from all parties – service user and carers, academics and students – is required. The key to successful involvement is genuine collaboration with open and honest relationships, and recognition of contribution and support (Rhodes 2012).

Limitations of the study

The limitations of this research are that the results only illuminate the views of those involved. The service users and carers who participated are people who chose to become and stay involved because it was a positive experience. The focus of the study, chosen by the service users and carers themselves, was to explore and demonstrate the impact involvement had on health and well-being because they felt that involvement had positively affected their day-to-day lives. Hence, the mainly optimistic findings might be considered predictable. The cross-sectional analysis to develop common themes had the potential to lose the coherence of the individual narrative. However, this was balanced by the development of the individual stories that focused on each participant's unique perspective.

Conclusion

This study contributes to the emerging knowledge and understanding that service user and carer involvement in the education of health professionals preparing students for practice-based learning can be a truly collaborative enriching experience, producing profound personal change. The service users and carers in this study articulated that contributing to professional education positively affected their health and well-being in a variety of ways, from increased confidence and self-esteem to better self-management of their long-term conditions. It is apparent that an enabling factor is the high level of involvement on the Ladder of Involvement, with collaboration as full team members and partnerships with joint decision-making. The findings of this study resonate with the findings of previous studies (Bailey 2005, Shah *et al.* 2005, Jones 2006, Minogue *et al.* 2009, Furness *et al.* 2011, McKeown *et al.* 2012). The strength of this work is the specific research focus, the impact of involvement on the service users and carers from their perspective, rather than this being an additional coincidental finding. The narrative approach to the enquiry represents work

that has a truly collaborative approach with co-production, considered to be an emerging model of involvement. Additionally, the development of the service user and carer's stories as a reusable web-based resource allows them to share their experiences for the benefit of others. Although the purpose of this study was not to elicit the outcome for students, the service users and carers do believe they are positively contributing to student learning and practice by encouraging the students to listen to and understand the lived experience. There is a need to explore the impact of involvement on service users and carers in a wider context to provide a more balanced analysis and add substance to claims about what facilitates or impedes the process.

Acknowledgements

The authors would like to thank members of the Patient Voice Group for their contribution to this work.

The research was supported by funding from the Assessment and Learning in Practice Settings (ALPS) Centre for Excellence in Teaching and Learning (CETL)
<http://www.alpscetl.ac.uk>.

References

- Agnew, A. and Duffy, J. (2010) Innovative approaches to involving service users in palliative care social work education. *Social Work Education* **20** (7), 744–759.
- Arnstein, S.R. (1969) A ladder of citizen participation. *Journal of the American Institute of Planners* **35** (4), 216–224. Available at: <http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html> (accessed 21 March 2013).
- Assessment and Learning in Practice Settings (ALPS). Available at: <http://www.alps-cetl.ac.uk/patientvoice.html> (accessed 25 March 2013).
- Atkinson, R. (2002) The life story interview. In: *Handbook of Interview Research: Context and Method* (ed. J.F. Gubrium and J.A. Holstein). Thousand Oaks, CA: Sage, pp121–140.
- Bailey, D. (2005) Using an action research approach to involving service users in the assessment of professional competence. *European Journal of Social Work* **8** (2), 165–179.
- Beresford, P. (2002) User involvement on research and evaluation: liberation or regulation? *Social Policy and Society* **1** (2), 95–105.
- Beresford, P. (2005) 'Service User': regressive or liberatory terminology? *Disability and Society* **20**, 469–477.
- Carers Trust (2012) Definition of a carer. Available at: <http://www.carers.org/what-carer> (accessed 20 October 2013).
- Connelly, M.F. and Clandinin, J.D. (2000) *Narrative Inquiry*. San Francisco, CA: Jossey-Bass.
- Denzin, N.K. (1971) The logic of naturalistic inquiry. *Social Forces* **50** (2), 166–182.
- Department of Health (DH) (1999) *Patient and Public Involvement in the New NHS*. London: HMSO.
- Department of Health (DH) (2000) *The NHS Plan: a Plan for Investment, a Plan for Reform*. London: HMSO.
- Department of Health (DH) (2001) *Shifting the Balance of Power within the NHS: Securing delivery*. London: HMSO.

- Department of Health (DH) (2003) *Strengthening Accountability Involving Patients and the Public, Practice Guidance, Section 11 of the Health and Social Care Act 2001*. London: HMSO.
- Department of Health (DH) (2005) *From Values to Action: The Chief Nursing Officer's Review of Mental Health Nursing*. London: HMSO.
- Department of Health (DH) (2008a) *Our NHS, our future. NHS Next Stage Review: leading local change*. London: HMSO.
- Department of Health (DH) (2008b) *Real involvement: working with people to improve health services*. London: HMSO.
- Department of Health (DH) (2008c). *Next Stage Review: High Quality Care for all*. Norwich: The Stationery Office.
- Department of Health (DH) (2009) *Education Commissioning for Quality*. London: DH Publications.
- Department of Health (DH) (2010a) *Healthy Lives, Healthy people: Our strategy for public health in England*. London: The Stationery Office. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216096/dh_127424.pdf (accessed 30 July 2013).
- Department of Health (DH) (2010b) *Equity and excellence: Liberating the NHS*. London: The Stationery Office.
- Department of Health (DH) (2010c) *Our Health and Wellbeing Today*. London: The Stationery Office. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215911/dh_122238.pdf (accessed 30 July 2013).
- Dogra, N., Anderson, J., Edwards, R. and Cavendish, S. (2008) Service user perspectives about their roles in undergraduate medical training about mental health. *Medical Teacher* **30**, 152–156.
- Downe, S., McKeown, M., Johnson, E., Koloczek, L., Grunwald, A. and Malihi-Shoja, L. (2007) The UCLan community engagement and service users support (Comensus) Project: Valuing authenticity, making space for emergence. *Health Expectations* **10**, 392–406.
- Duffy, J. and Hayes, D. (2012) Social Work Students Learn about Social Work Values from Service Users and Carers. *Ethics and Social Welfare*. doi:10.080/17496535.2012.654497.
- Egan, G. (1994) *The Skilled Helper: A problem-management and opportunity – development approach to helping*. 7th ed. Pacific Grove, CA: Brooks/Cole Publishing.
- Felton, A. and Stickley, T. (2004) Pedagogy, power and service user involvement. *Journal of Psychiatric and Mental Health Nursing* **11**, 89–98.
- Freshwater, D. and Holloway, I. (2010) Narrative research. In *The Research Process in Nursing, 6th ed.* (ed. L. Gerrish and A. Lacey). Chichester: Wiley-Blackwell, pp188–198.
- Friedli, L. (2009) Mental health, resilience and inequalities. Available at: http://www.euro.who.int/__data/assets/pdf_file/0012/100821/E92227.pdf (accessed 30 July 2013).
- Furness, P.J., Armitage, H. and Pitt, R. (2011) An evaluation of practice based interprofessional education initiatives involving service users. *Journal of Interprofessional Care* **25** (1), 46–52.
- Gubrium, J.F. (1995) Voice, context and narrative in aging research. *Canadian Journal on Aging* **14**, Supp. 1, 68–81.

- Gutteridge, R. and Dobbins, K. (2010) Service user and carer involvement in learning and teaching: a faculty of health staff perspective. *Nurse Education Today* **30**, 509–514.
- Hardy, S., Gregory, S. and Ramjeet, J. (2009) An exploration of intent for narrative methods of inquiry. *Nurse Researcher* **16** (4), 7–19.
- Health and Care Professions Council (2013) Standards for education and training programmes. Service user and carer involvement in education and training programmes. <http://hpc-uk.org/Assets/documents/10004167SUCstandardwebsiteinformation.pdf> (accessed 25 October 2013).
- Holloway, I. and Freshwater, D. (2007) *Narrative research in nursing*. Oxford: Blackwell.
- INVOLVE (2012) Briefing notes for researchers. Available at: <http://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEBriefingNotesApr2012.pdf> (accessed 25 March 2013).
- Jones, C. (2006) Involving NHS service users in teaching advanced clinical skills. *British Journal of Nursing* **15** (8), 462–465.
- Kavanaugh, K. and Ayres, L. (1998) 'Not as bad as it could have been': assessing and mitigating harm during research interviews on sensitive topics. *Research in Nursing and Health* **2** (1), 91–97.
- Keyes, C. (1998) Social wellbeing. *Social Psychology Quarterly* **61** (2), 121–140.
- Lathlean, J., Burgess, A., Colham, T., Gibson, C., Herbert, L., Levett-Jones, T., Simons, L. and Tees, S. (2006) Experiences of service user and carer participation in health care education. *Nurse Education Today* **26** (8), 732–737.
- Lin, N. (2000) Inequality in social capital. *Contemporary Sociology* **29**, 785–795.
- McKeown, M., Downe, S. and Malihi-Shoja, L. (2010) *Service User and Carer Involvement in Education for Health and Social Care. Supporting the Comensus Writing Collective*. Oxford: Wiley-Blackwell.
- McKeown, M., Malihi-Shoja, L., Hogarth, R., Jones, F., Holt, K., Sullivan, P., Lunt, J., Vella, J., Hough, G., Rawcliffe, L., Mather, M. and CIT (2012) The value of involvement from the perspective of service users and carers engaged in practitioner education: Not just a cash nexus. *Nurse Education Today* **32** (2), 178–184.
- Minogue, V., Holt, B., Karban, K., Gelsthorpe, S., Firth, S. and Ramsey, T. (2009) Service user and carer involvement in mental health education, training and research – A literature review. *Mental Health and Learning Disabilities Research and Practice* **6** (2), 211–227.
- Mishler, S.G. (1986) The analysis of interview narratives. In: *Narrative Psychology: The Storied Nature of Human Conduct* (ed. T.R. Sarbin). New York: Praeger, 223–255.
- Morgan, A. and Jones, D. (2009) Perceptions of service user and carer involvement in healthcare education and impact on student's knowledge and practice: A literature review. *Medical Teacher* **31** (2), 82–95.
- Morris, P., Dalton, E., McGoverin, A. and Symons, J. (2009) Preparing for patient-centred practice: developing the patient voice in health professional learning. In: *Beyond Reflective Practice* (ed. H. Bradbury, N. Frost, S. Kilminster and M. Zukas). Oxford: Routledge.
- Needham, C. (2009) *Co-Production: An Emerging Evidence Base for Adult Social Care Transformation*. Research briefing 31. London: Social Care Institute for Excellence.
- Newbigging, K. and Bola, M. (2010) Mental wellbeing and black and minority ethnic communities: conceptual and practical issues. In: *Public Mental Health Today* (ed. I. Goldie). Brighton: Pavilion.

- Nursing and Midwifery Council (NMC) (2010) *Standards for Pre-registration Nursing education*. London: Nursing and Midwifery Council.
- O'Neill, F. (2008) Preparing for Involvement: Evaluation of the West Yorkshire Universities Service Users and Carers Involvement Induction Training (WYUSUIT). Final Project Report to NHS Yorkshire and Humber Strategic Health Authority.
- Office of National Statistics (ONS) (2013) measuring national wellbeing. Available at: <http://www.ons.gov.uk/ons/rel/wellbeing/measuring-national-well-being/health-2013/art-health-2013.html#tab-About-the-ONS-Measuring-National-Well-being-Programme> (accessed 30 July 2013).
- Oliver, M. (1992) Changing the Social relations of RESEARCH PRODUCTION. *Disability, handicap and Society* **7**, 101–115.
- Overcash, J.A. (2004) Using narrative research to understand the quality of life of older women with breast cancer. *Oncology Nursing Forum* **31** (6), 1153–1159.
- Padgett, K., Rhodes, C., Lumb, M., Morris, P., Sherwin, S., Symons, J., Tate, J. and Townend, K. (2012) What matters to users of services? An explorative study to promote shared decision making in health care. *Health Expectations* doi:10.1111/j.1369-7625.2012.00767.x.
- Parahoo, K. (2006) *Nursing Research Principles, Process and Issues*. 2nd ed. Basingstoke: Palgrave Macmillan.
- Parker, I. and Shotter, J. (eds.) (1990) *Deconstructing Social Psychology*. London, Rutledge.
- Polit, D.F. and Beck, C.T. (2008) *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. 8th ed. Philadelphia: Lippincott Williams and Wilkins.
- Repper, J. and Breeze, J. (2007) User and carer involvement in the training and education of health professionals: A review of the literature. *International Journal of Nursing Studies* **44** (3), 511–519.
- Rhodes, C.A. (2012) User involvement in health and social care education: A concept analysis. *Nurse Education Today* **32** (2), 185–189.
- Rush, B. (2008) Mental health service user involvement in nurse education: a catalyst for transformative learning. *Journal of Mental Health* **17** (5), 531–542.
- Shah, R., Savage, I. and Kapadia, S. (2005) Patient's experience of educating pharmacy undergraduate students. *Pharmacy Education* **5** (1), 61–67.
- Simons, L., Tee, S., Lathlean, J., Burgess, A., Herbert, L. and Gibson, C. (2007) A socially inclusive approach to user participation in higher education. *Journal of Advanced Nursing* **58** (3), 246–255.
- Simpson, A., Reynolds, L., Light, I. and Attenborough, J. (2008) Talking with the experts: Evaluation of an online discussion forum involving mental health service users in the education of mental health nursing students. *Nurse Education Today* **28**, 633–640.
- Sparkes, A.C. (2005) Narrative Analysis; exploring the what's and how's of personal stories. In: *Qualitative research in health care* (ed. I. Holloway). Maidenhead: Open University Press, pp191–209.
- Speed, S., Griffiths, J., Horne, M. and Keeley, P. (2012) Pitfalls, perils and payments: Service user, carers and teaching staff perceptions of the barriers to involvement in nursing education. *Nurse Education Today* **32**, 829–834.

Stickley, T., Rush, B., Shaw, R., Smith, A., Collier, R., Cook, J., Shaw, T., Gow, D., Felton, A. and Roberts, S. (2009) Participation in nurse education: The PINE project. *The Journal of Mental Health Training, Education and Practice* **4** (1), 11–18.

Tew, J., Gell, G. and Foster, S. (2004) Learning from Experience. *Involving Service Users and Carers in Mental Health Education and Training. A good practice guide*. Mhhe (Mental health in higher education) NHS (National Institute for Mental Health in England) Trent NHS Workforce Development Confederation. Available at: <http://www.mhhe.heacademy.ac.uk/silo/files/learning-from-experience-whole-guide.pdf> (accessed 5 June 2013).

Tew, J., Holley, T. and Caplen, P. (2012) Dialogue and challenge: involving service users and carers in small group learning with social work and nursing students. *Social Work Education* **31** (3), 316–330.

Tritter, J. and McCallum, A. (2006) The Snakes and Ladders of User Involvement: moving beyond Arnstein. *Health Expectations* **76** (2), 156–168.

Waddell, G. and Burton, A.K. (2006) *Is Work Good for Your Health and Well-being?* London: The Stationery Office.

Wallerstein, N. and Bernstein, E. (1988) Empowerment education: Freire's ideas adapted to health education. *Health Education Quarterly* **15** (4), 379–394.

World Health Organisation (WHO) (1946) Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York, 19–22 June, 1946.