Keywords

Concept analysis

User involvement

Health & Social Care Education

SUMMARY

This paper presents an evaluative discussion of the literature, and findings from a concept analysis which explores user involvement in the context of health and social care higher education in the United Kingdom. User involvement is increasingly a requirement in higher education and the purpose of the concept analysis was to clarify and elucidate the meaning and nature of the concept. Walker and Avant's (2005) eight step framework for concept analysis was used to provide understanding of the underlying attributes and a model for critique and meaningful evaluation and research. A structured search and discussion of contemporary literature was undertaken. A model case is identified along with antecedents, critical attributes and consequences. The complexities of involvement are delineated with a recommendation for robust research that explores the benefits of involvement.

INTRODUCTION

User involvement in health and social care education has arisen out of the consumer focused orientation of health and social care service delivery in the United Kingdom (UK). This has driven key policy directives for a number of years resulting in a range of policy and legislation from successive governments (DoH, 1999; 2000; 2001; 2003; 2005; 2008a, b) each with their own political agenda. 'High Quality Care for all' (DoH 2008c) describes today's NHS as, 'An NHS that gives patients and the public more information and choice, works in partnership with and has high quality care at its heart'. The ethos of involvement has also been driven by an 'information revolution', whereby access to information is readily available via the internet, for example 'NHS Choices' and 'The Patients Association', and other sources. The perception is, that service users are not passive recipients of health and social care services. Indeed the latest white paper, Equity and Excellence: Liberating the NHS, details putting patients and the public first with the testimony 'nothing about us without us' (DoH, 2010a). A subsequent consultation document, Liberating the NHS: An Information Revolution (DoH 2010b) indicates a national drive to give people information, control and choice.

User involvement in health and social care education is evolving largely due to this policy dictate, resulting in professional body regulations and requirements (Lathlean et al 2006). Medical education, mental health nursing and social work are dominating the field at least in terms of contribution to the literature, perhaps because involvement in these disciplines has been a requirement for longer. Mental health and social work professionals also focus upon therapeutic relationships with service users (Morgan & Jones, 2009; Minogue, 2009). A

literature review conducted by Minogue et al, (2009) identified more than 70 articles written between 2005 and 2007 in the field of mental health nursing and social work. A further structured review of the literature on service user involvement in healthcare education (Morgan & Jones, 2009) reviewed 41 papers, 13 relating to medical education and 12 to mental health nursing. The ever increasing literature base tentatively contributes to the evidence demonstrating the value of involvement (Agnew & Duffy, 2010; Furness et al, 2010; Gutteridge & Dobbins, 2010; Rush, 2008; Simons et al, 2007; Simpson et al, 2008 and Stickley et al, 2009).

Involvement is stipulated in increased areas of health care education (DoH, 2009; NMC, 2010) together with the National Coordinating Centre for Public Engagement's (NCCPE) invitation for every University and Research Institute in the United Kingdom to sign up to a manifesto for Public Engagement (NCCPE, 2010). There is some urgency to establish what involvement actually means and the benefits that arise from it. Furthermore, the scrutiny on teaching and learning due to the significant reduction in public expenditure on higher education, as outlined in the Browne report (2010) provides further impetus. This paper presents a concept analysis exploring user involvement in UK health and social care education. The method of concept analysis is recognised as a rigorous process to inform theory development and enhance communication (Morse et al 1995). It is argued, that theories which attempt to explain user involvement are under-developed, and have not been conceptualised in application to contextual settings. Therefore it is justified to analyse how current theory may well be operationalised to further delineate understanding and knowledge.

METHOD

Concept analysis is a process used to unfold, explore and give meaning and clarification to concepts that are vague or ambiguous. User involvement in health and social care education is a socially constructed concept shaped by social factors with individual interpretation, multiple truths and subjectivity that lends itself to this type of analysis.

The analysis will build on the literature with the added value of theory development, an imperative to allow accurate understanding of what is discussed. In order to operationalise an analysis of the underpinning concepts, Walker and Avant's (1995, 2005), method was selected as the most appropriate to meet the study's aims. The method is in a series of steps; the selection of a concept, aims of the analysis, all the uses of the concept, defining attributes, model case, borderline, related, contrary, invented and illegitimate cases, antecedents and consequences of the concept and finally the empirical referents. Although there are criticisms that this framework is too rigid (Rogers & Knafl 2000), the framework provides a clear and systematic method, with results presented in a format meaningful to the subject of enquiry. The identification of defining attributes will allow critique of the ladder of involvement, a framework frequently used to assess the level of involvement. This is based on Arnsteins's (1969) ladder of participation, whereby a move up the ladder represents a shift from non-participation, to tokenism, to citizen control. Tew et al (2004) developed this

approach to create a five level model that assesses the level of collaboration; a term that is said to effectively describe the relationship required for true involvement (Table 1). The ladder suggests that the highest order involvement is partnership, where users are full partners in all stages of engagement.

RESULTS

1. Concept

The key focus for this concept analysis is the term *user involvement in the context of health and social care education*. It is important to clarify that this is different to user involvement in research on direct care, and in direct care itself, rather the involvement of users in the education of students who will become health and social care professionals. Initial definitions were obtained followed by a systematic search of the literature. Involvement is the term most commonly used in the literature, followed by participation and occasionally engagement. The Oxford English Dictionary (2010) supplies the following theoretical definitions; Involvement is the action or process of involving; the fact of being involved. Participation is the action or fact of having or forming part of something; the sharing of something. Engagement is the action of engaging; the state, condition, or fact of being engaged. Minogue et al (2009) identify the difficulties in defining involvement that can range from taking part to collaboration and control. For the purposes of this study a user is defined as someone with direct experience of health and social care services (Joseph Rowntree, 2003).

2. Aims of the analysis

The analysis seeks to clarify and elucidate the meaning and nature of user involvement within the context of health and social care education. There is an increasing body of literature pertaining to the subject, but little in the way of definitions of what involvement means. This analysis aims to provide understanding of the underlying attributes and a model for critique, meaningful evaluation and research (Walker & Avant, 2005).

3. Uses of the concept

A structured search of the literature was undertaken from databases including CINAHL, Pubmed and Science Direct; the search was limited to articles published within the last 15 years as it was identified that this would capture key policy drivers (DH 1999, 2000, 2001). A number of relevant articles were selected for inclusion in the analysis. A large proportion of the literature focuses on process, with papers that describe and justify processes of involvement as illustrated by the following examples. Comparative studies in social work and nurse education explored user involvement as a process (Ager et al, 2005), and as an integrated approach (Molyneux & Irvine, 2004, Le Var 2002). Repper & Breeze (2007) conducted a literature review on involvement in health professional education that included 38 papers; they identified that the majority focused on process rather than outcome. Good practice guidelines have also been developed (Levin et al, 2004; Tew et al, 2004) with recommendations on processes for planning and preparing for active and purposeful

involvement. The ladder of involvement is often used to assess the level of involvement achieved and used as an indicator of success. It is evident from the literature that users are involved in the education of healthcare professionals, in a variety of ways. Involvement in the recruitment of students is discussed by Vandrevala (2007), with the involvement of users in the selection of clinical psychology students. Matka (2009) describes the approach to involvement in admissions to social work and clinical psychology, and Rhodes & Nyawata (2010) evaluated involvement in the selection of student nurses. These three papers identified that user involvement had a positive impression on candidates, who felt that users had a right to be involved in recruitment, due to their experience as recipients of healthcare. Service users reported benefits in terms of increased confidence. Academics were also positive, but highlighted concerns as to who should have the final say on who is selected, and the need for appropriate preparation and training for all involved. The involvement of users in curriculum development, direct teaching and the development of learning materials is described by Bennett & Baikie (2003), who discuss a model of client/nurse educator collaboration in mental health nurse education.

There are a limited but growing number of papers that attempt to evaluate and validate the concept with a focus on the effect on students, users and staff. Khoo et al (2004) report on a retrospective study, evaluating the influence of involvement on a module in postgraduate mental health education, that has substantive input from users. Findings suggested that this level of involvement was beneficial, and had motivated practitioners to implement positive changes to their practice. A process evaluation, of a strategy for involvement in the design and delivery of mental health nursing, identified involvement to be crucial to the development of mental health nurse education (Masters 2002). Agnew & Duffy (2010) report the findings of an evaluation of two methods of user involvement in palliative care teaching in social work education. The research found that hearing stories direct from service users facilitated integration of theory to practice, in social work students. Furness et al (2010) evaluated practice-based inter-professional educational initiatives, involving service users. They found service user involvement to be crucial to learning, by providing novel insight into 'their' perspectives. It was tentatively concluded that there was a positive impact on student learning, through the development of insight, understanding and empathy, and students believed they would improve their skills and abilities to deliver care holistically in practice. Gutteridge & Dobbins (2010) conducted an evaluation study with members of academic staff in a faculty of health, following a grounded theory approach, and report a positive perception of impact on student learning. Simons et al (2007) evaluated the development of a service user academic post in mental health, and found this proved to be a powerful role-model for the students that integrated service user perspectives into the educational process. Simpson et al (2008) conducted an evaluation of an online discussion forum involving mental health service users in the education of mental health nurses, and established that students reported insight into user's experiences, improved communication skills and motivation to work on mental health wards. The added benefit highlighted, was that users valued the contribution and opportunity to challenge stereotypes and stigmas of people with mental health problems. A participatory action research study by Stickley et al (2009) describes improvement in student's knowledge, cultural awareness and empathy that would give them ideas to consider when working with clients. Additionally Rush (2008) found 46% of nursing students had undergone transformative learning, and that all students would take specific

actions in practice due to mental health service user involvement. The five mechanisms that contributed to student learning were identified as: lived experience, emotional impact, reversal of roles, reflection by students and training and preparation of service users. Furthermore, the literature reports benefits for users with improvement in their health and wellbeing (Minogue, 2009; Morgan & Jones, 2009).

Conversely the literature also highlights the complexity and difficulties encountered (Stickley, 2010). Access to funding and issues related to payment, are reported as a perennial problem (Downe, 2007; Minogue, 2009). Gaining access to users from seldom heard vulnerable groups, who often have the greatest need, is highlighted as a challenge (Agnew & Duffy, 2010; Furness et al, 2010). Alongside this, power differentials and cultural differences between service users and academics, are reported as a barrier to success (Felton & Stickley, 2004; Minogue, 2009; Morgan & Jones 2009). Moreover Simons et al (2007) found unintended discriminatory behaviours and shortcomings in support arrangements for a service user in an academic post. Gutteridge & Dobbins (2010) determined a dominant theme, from most of the respondents, was concern about barriers and solutions. These relate to how resource intensive involvement is, access to local networks and service users from a range of groups and organisational and cultural barriers. An on-going evaluation of a participatory action research project, demonstrates that though the principle of service user involvement in assessment is desirable in theory, when carried out was difficult, because of increased workload for staff and a negative impact on some students (Stickley 2010). The recommendation from this experience, was that service user involvement in the review of student nurse performance whilst on placement, should be implemented and evaluated as an alternative.

To summarise, the current literature on user involvement in health and social care education is making some contribution to the developing evidence base for practice in this area. It is however clear that the majority of authors start with the premise that involvement is essentially a good thing and in general have a desire to find a positive impact. Attempts have been made to offer a more balanced critique (Stickley et al 2010). The lack of substantive evidence on the actual impact of involvement in terms of value added to health and social care education, is repeatedly acknowledged in the literature. This leads to recommendations for longitudinal research in order to justify the development of involvement (Agnew & Duffy, 2010; Furness et al, 2010; Morgan & Jones, 2009; Rush, 2008; Stickley, 2009).

4. Attributes

Reviewing the literature identified themes that are consistently used to describe the concept and enabled the identification of the following five defining attributes:

- A flexible strategy, to meet the needs of different professions, undertaken with users, signifying genuine collaboration with an open and honest relationship. Users and academics work together to make decisions (Downe et al, 2007; Minogue et al, 2009; Morgan & Jones 2009).

- Access to users with a range of experiences, that includes those from seldom heard groups who often have the most need to be heard (Agnew & Duffy, 2010; Furness et al, 2010).

- Recognition for contribution; this can be payment for involvement, as well as affiliate lecturer status, giving users access to training and development opportunities. This also acknowledges that users are part of the team (Downe et al, 2007; Minogue et al, 2009.

- Support, training and development for users, students and academics. This includes adequate preparation and support before, during and after involvement (Rush, 2009).

- Research and evaluation to critically examine the impact and benefit of involvement for users and on student learning and subsequent professional practice (Furness et al, 2010; Morgan & Jones, 2009; Simons et al, 2007; Stickley et al, 2010).

5. Case examples

Case examples are presented, as suggested by Walker and Avant (2005), to promote understanding of the concept. The case examples are also related to the levels in the ladder of involvement (Tew 2004), detailed in Table 1.

Model case

A model case includes all the defining attributes and demonstrates Level 4 or 5 collaboration or partnership, within the ladder of involvement.

Jane, a service user, participates in the teaching of students within a module focused on long-term conditions. She was involved in the writing of the module and planning the content and timetable. Jane leads two sessions and is a member of the assessment panel for the summative presentations. She has received training at the University on giving feedback to students. Jane is also a member of the course committee, whereby the module is monitored and evaluated. Jane is paid for her involvement, and she has affiliate lecturer status giving her access to an email account, library resources and staff development training.

As well as working in partnership with the module leader, Jane is a member of the service user forum that has a number of members with a range of experiences who meet regularly. Members of the forum are involved in a variety of ways, across the school that includes evaluation and research of involvement. The forum is supported by an administrator, and links with academics that have a role in facilitating involvement.

Borderline case

A borderline case contains some of the defining attributes and equates to Level 3 – growing involvement.

Peter, a service user, is a member of the service user forum at the University. He has been invited to comment on the development of the course. Peter contributes to one session

within the long-term conditions module, and receives feedback on the session. He is not involved in the assessment of students.

Related case

A related case appears to be similar to the model case but does not contain the defining attributes; in this case it demonstrates tokenism and Level 2 – limited involvement.

Mary is asked to come into the University to 'tell her story' about her experience of having a stroke. She does not receive payment, but can claim travel expenses. Mary knows that the students are studying a nursing course, but does not know what the module is about or what the students are expected to learn. Mary is not given any student feedback about the session.

Contrary case

A contrary case contains no defining attributes; Level 1 – no involvement.

Students only come into contact with users in their practice placements: there may be engagement, but there is no collaboration.

6. Antecedents and consequences

Antecedents are described as events that must occur prior to the occurrence of the concept (Walker & Avant 2005). Therefore antecedents to enable involvement to occur are identified as commitment from users and the Higher Education Institution, together with a planned method for rigorous evaluation. There are models of good practice such as the Community Engagement and Service User Support (Comensus) Project, reported in a participatory action research project by Downe et al (2007). This identified that systematic integrated systems of involvement can work if founded on authenticity and trust, with a requirement for a shift from comfortable, and established patterns of engagement from all parties. National drivers have led to the Developers of Carer Involvement in Education; a service user network, publishing guidelines and recommendations on staffing frameworks to support involvement in Higher Education Institutes (DUCIE 2009).

Consequences are events that occur as a result of the concept (Walker & Avant 2005). Positive examples include some evidence of the impact on student learning leading to improved skills and abilities in practice, and upon service user wellbeing (Morgan & Jones, 2009; Rush, 2008; Stickley et al, 2009). A negative consequence identified, is that involvement is costly in terms of time and resources (Gutteridge & Dobbins, 2010). The lack of substantive evidence on the actual impact of involvement in terms of value added to health and social care education is constantly highlighted in the literature. This leads to recommendations for longitudinal research in order to justify the development of involvement (Agnew & Duffy, 2010; Furness et al, 2010; Morgan & Jones, 2009; Rush, 2008; Stickley et al , 2009).

7. Empirical referents

Empirical referents demonstrate existence of the concept. Walker and Avant (2005) describe this as a way of measuring or determining its existence in the real world. The most frequently used empirical referent tool is the ladder of involvement (Tew 2004), this clearly relates to the defining attributes, in that, the higher levels of involvement, 4 and 5, contain statements that marry together, indicating a level of consistency and illuminates the concept.

Definition

The concept analysis undertaken delineates a definition of user involvement in health and social care education as:

A process whereby the users lived experience is utilised in teaching and learning for students undertaking health and social care courses. Involvement can occur at a number of levels, as identified in the ladder of involvement (Tew 2004) from design and development of the course, recruitment, direct teaching, assessment and research.

DISCUSSION

The tenuous nature of current theory in user involvement and its application in context is demonstrated by this concept analysis. Therefore, there are no clear definitions and practice standards. Without further empirical work, and development of theory, it would be assumptive, at this point, to state that user involvement in health and social care education is desirable, needed or indeed effective. The concept analysis identified the defining attributes and a model case, however it is argued that to hope to achieve this is idealistic. In the first instance the literature suggests an incremental approach with clear processes and outcomes. This requires a flexible strategy to meet the needs of different professions, undertaken with users signifying an open and honest relationship (Minogue, 2009; Morgan & Jones 2009). The pressing need for more substantial research to critically examine the impact and benefit of involvement on student learning and subsequent professional practice is also repeatedly identified (Furness et al, 2010; Morgan & Jones, 2009; Simons et al, 2007; Stickley et al, 2010).

A number of articles do suggest students and users benefit from involvement (Agnew & Duffy, 2010; Furness et al, 2010; Gutteridge & Dobbins, 2010; Rush, 2008; Simpson et al, 2008; Stickley et al, 2009). The findings are however limited due to small sample size and limited comparison. The barriers and challenges can also not be ignored and contribute to the difficulty in theory development. Namely the ability of the Higher Education Institute to invest the time and resources required, not least to facilitate the cultural change required for involvement to become embedded (Gutteridge & Dobbins, 2010; Morgan & Jones, 2009; Stickley et al, 2009). The transition from passive recipient of services to a ‘customer’ focus within UK health and social care, makes for an ambivalent and changing relationship, which is reflected in this analysis.

The examples included in this paper reveal involvement occurring at a variety of levels, when compared to the ladder of involvement (Tew 2004). For example, level 2, limited

involvement; tokenism (Felton & Stickley, 2004), level 3, growing involvement; consultation (Agnew & Duffy, 2010; Simons et al, 2006) and level 4; collaboration (Furness et al, 2010; Lathlean, 2006; Rush, 2008; Stickley et al, 2009; 2010). None of the involvement projects reviewed appear to have reached level 5; partnership, although the Comensus project (Downe, et al 2007) is striving to achieve this. The ladder relates to the defining attributes delineated from the literature thus both validating the attributes defined, and the framework as a useful tool for defining involvemen

CONCLUSION

This paper contributes towards clarification of the meaning of user involvement in health and social care education. The analysis sought to provide understanding of the underlying attributes for successful involvement, and a structure for future evaluation and research. In order to achieve a high level of involvement, with collaboration and partnership, there is a need for developed and evaluated theories of user involvement that include training, development, support, supervision and process understanding. At present, there is a limited evidence-base relating to the benefits of involvement to health and social care education. It is concluded that in order to support current radical changes in education delivery nationally and internationally, further rigorous evaluation, particularly related to the influence involvement has on transformative learning, and the influence on care delivery, is required.

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Level 1: No involvement The curriculum is planned and delivered with no consultation or involvement of service users or carers.
Level 2: limited involvement Outreach and liaison with local service user and carer groups. Service users/carers invited in to 'tell their story' in a designated slot, and /or be consulted ('when invited') in relation to course planning or management, student selection, student assessment or programme evaluation. Payment offered for their time. No opportunity to participate in shaping the course as a whole.
Level 3: Growing involvement Service users/carers contributing regularly to at least two of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. Payment for teaching activities at normal visiting lecture rates. However, key decisions on matters such as curriculum content, learning outcomes or student selection may be made in forums in which service users/carers are not represented. Some support available to contributors before and after sessions but no consistent programmes of training and supervision offered. No discrimination against service users and carers accessing programmes as students.
Level 4: Collaboration Service users/carers are involved as full team members in at least three of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. A statement of values and aspirations underpins this. Payment for teaching activities at normal visiting lecturer rate. Service users/ carers contributing to key decisions on matters such as curriculum content, style of delivery, learning outcomes, assessment criteria and methods, student selection and evaluation criteria. Facility for service users/carers who are contributing to the programme to meet up together, and regular provision of training, supervision and support. Positive steps to encourage service users and carers to access programmes as students.
Level 5: Partnership Service users, carers and teaching staff work together systematically and strategically across all areas- and an explicit statement of partnership values underpins this. All key decisions made jointly. Service users and carters involved in the assessment of practice learning. Infrastructure funded and in place to provide induction, support and training to service users and carers. Service users and carers employed as lecturers on secure contracts, or long term contracts established between programmes and independent service user or carer training groups. Positive steps made to encourage service users to join in as participants in learning sessions even if they are not(yet) in a position to achieve qualifications.