INVOLVING PATIENTS IN RESEARCH: THE CHALLENGE OF PATIENT-CENTREDNESS

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ABSTRACT

Background: The concept of patient-centredness is increasingly being incorporated into modern healthcare practice, yet little attention has been given to the development of patient-centred principles in research.

Aims: This study aimed to establish convergent validity for a definition of patient-centredness using abstracts from schizophrenia research and to explore the experiences of psychiatrists and service users taking part in research that was designed to be patient-centred.

Methods: Mixed methods were used in this community study.

Results: Thirteen service users and three psychiatrists took part. Service users rated eight of 60 research abstracts as patient-centred, even though 30 of these had been previously rated as such by psychiatrists. There was some accord between psychiatrist and service user ratings as seven out of eight abstracts were identified by both groups as patient-centred. Process aspects of research were valued by service users, for example, being respected as collaborators. Both groups reported benefits to participation in patient-centred research, such as feeling valued and breaking down barriers between doctor and patient.

Conclusions: While there is some agreement between professionals and service users as to what constitutes patient-centred research, other process-related factors are important. Patient-centred research is valued by both service users and doctors and should be incorporated into future studies.

Key words: patient-centred research, patient-centredness, operational definition, collaborative research, schizophrenia

BACKGROUND

The concept of patient-centredness places explicit value on the subjective, value-laden experience of illness and health (Fulford, 1996). From this foundational position the concept has developed to encompass a sharing of power in the doctor/patient relationship (Stewart, 2003), the development of a therapeutic alliance (Mead & Bower, 2000), treating the patient as unique (Redman, 2004) and putting patients at the hub of delivery and planning of health services (Darzi, 2008; Nicholls et al., 2003).
Many benefits to patient-centred practice in medicine have been reported, for example, increased satisfaction with, and concordance with, treatment (Kinmonth et al., 1998; Stewart, 1995) and continuity of care (Holman & Lorig, 2000). Some medical specialities, for example psychiatry and general practice, have sought to incorporate patient-centred elements into consultation styles: for example, understanding the whole person and finding common ground (Bhugra & Holsgrove, 2005) and reflexivity (Baarts et al., 2000).

Over the past decade health providers in the UK have been increasingly encouraged to involve service users, not only in the commissioning and development of services (Department of Health, 1996a, 1996b, 2005; Darzi, 2008), but also when considering research strategies and proposals (Department of Health, 2006). The NHS promotes a patient-centred approach to research and development which is ‘focused on the needs of patients and the public’ (Davies, 2005). Despite this, little attention has been given to patient-centred practice in medical research (Phillips & Grams, 2003). For example, it has been reported that only 3%–4% of studies in otolaryngology used patient-centred research methodologies (Bem et al., 2004) and only 2% of research findings related to schizophrenia have been patient-centred (Calton et al., 2006).

Service user involvement in research provides benefits for both service users and researchers. For service users, it ensures that research outcomes are relevant to those utilizing health services. Related to this, it facilitates research that service users will be willing to participate in, thus benefiting researchers (Goodare & Lockwood, 1999). A systematic review of studies involving service users in the delivery and evaluation of mental health services concluded that such involvement was not detrimental to research participants (Simpson & House, 2002; Morgan, 2006). Service user involvement in research and development agenda setting in the NHS may be constrained by the need for appropriate skills, resources and time required to support effective service user engagement (Oliver et al., 2004; Trivedi & Wykes, 2002). This is crucial as mental health service users are one of the most disempowered groups in society (Rose, 2008a). A model, ‘FIRST’, has been recommended to facilitate effective patient participation in research (Hewlett et al., 2006). This incorporates facilitation, identity, respect, support and training.

Effective service user involvement requires that flexibility is incorporated into research design. It has been suggested that quantitative research methodologies do not capture patient-centred elements of healthcare such as the subjective views of service users (Jenkins et al., 2005; Redman, 2004; Vlieland, 2002). A qualitative study of healthcare-related decision-making in men with prostate cancer suggested that service user participation in research has benefits in terms of process and outcomes such as improved commitment to prospective studies and increased validation of quantitative findings (White, 2005). Studies involving service users can also be used to help set appropriate and relevant research agendas (Rose et al., 2008) and to challenge research findings (Rose et al., 2003).

It has been proposed that the best way of measuring patient-centredness is ‘an assessment by the patients themselves’ (Stewart, 2001). It might also be considered important, within the research context, to place equal emphasis on both process and outcome. This is because one of the possible consequences of focusing solely on achieving a particular outcome is the subsumption of means into ends, threatening to reduce service users to mere objects in the process of acquiring new facts (Jarvis, 1998).

The present study aimed to undertake a collaborative study with service users focusing on the concept of patient-centredness, which attempted to be as patient-centred as possible in terms of the process and outcome of the research. This was a synthesis of two subsidiary aims, reflecting
the interests of the researchers and the patients involved. One aim was to attempt to establish convergent validity for a definition of patient-centredness developed by three psychiatrists (TC, AC, KDS) used in an earlier study. Research was defined as patient-centred if its main aim was to address the patients’ subjective experiences and their relevance and meaning to the patient, with the latter being evidenced by the research:

- Addressing the patients’ individual feelings as ‘lived emotional experiences’

OR

- Considering patients’ ideas and expectations regarding their illness and treatment

OR

- Considering patients’ opinions in determining the aims and outcomes of the research

The second aim of the study was to explore the experience of both professionals and patients taking part in a research project that strove to be collaborative and patient-centred.

**METHOD**

The study was conducted in two stages. Stage 1 involved patients developing their own definition of patient-centredness and applying it to schizophrenia research abstracts, which the study team had already rated using their definition of same. In stage 2 both patients and professionals shared their experiences of taking part in the project.

**Participants**

Fourteen mental health service users and three senior psychiatrists (TC, AC, KDS) took part in the project. One of the psychiatrists was also a mental health service user. One patient dropped out of the study due to ill health prior to the commencement of the first workshop.

**Design**

A mixed-methods approach was employed, with predominantly quantitative methods being used in stage 1 and qualitative methods in stage 2. Participatory research methods were employed throughout both stages. Within this research paradigm the goal is to design studies that avoid objectifying participants and foster collaboration (Cornwall & Jewkes, 1995). Focus groups and semi-structured interviews were used to collect qualitative data.

Ethics approval for the project was granted by the North Nottinghamshire Local Research Ethics Committee.

**Procedure**

Two of the psychiatrists (TC, AC) initially spent several months developing informal links and opening a dialogue about collaborative research with mental health service user groups in the Nottingham area.
Thirteen service users expressed an interest in participating in a collaborative study. The next stage involved attempting to design the study collaboratively; here, the service users’ relative lack of research experience meant that it became more difficult to work in a truly collaborative manner. With support from the study team, the service users contributed to the design, changing several elements, for example removing jargon from the research abstracts constituting the stage 1 data source. Once a study design was agreed, an application was made to the Local Research Ethics Committee, the meeting of which was attended by both a professional and a service user. All the service users provided written informed consent for their participation in the formal data collection component of the study.

The stage 1 research was conducted over the course of three half-day workshops. In order to facilitate an assessment of convergent validity, the service user group developed its own definition of patient-centredness as applied to research practice. Using an iterative process, the service users delineated a number of key factors they considered to reflect a ‘patient-centred’ approach to research. Over 30 factors were generated, which the service users felt was too unwieldy a number. In order to reduce this number the service users devised a novel approach whereby each of the 13 participants selected a factor that they considered best reflected a patient-centred approach. Each factor could only be chosen once and the order of selection was random. Hence the service users eventually generated 13 key factors, which together constituted their definition of patient-centredness.

Next the service users, blind to the researchers’ definition of patient-centredness, evaluated 60 schizophrenia research abstracts selected from the pool of abstracts used in a previous study (Calton et al., 2006). Thirty of these were randomly selected from the pool of abstracts in the earlier study categorized as exemplifying ‘patient-centred’ research and 30 were randomly selected from the pool of abstracts categorized as portraying ‘non-patient-centred’ research. These 60 abstracts were ‘translated’ into jargon-free language using current best practice (Mason & Miller, 2003) by the three psychiatrists before they were presented to service users.

Each service user then reviewed all 60 abstracts and rated them as either ‘patient-centred’ or ‘non-patient-centred’. The majority opinion was taken to be the final rating. Thus if 10 of the 13 service users rated an abstract as patient-centred, then that abstract was given a final rating of being ‘patient-centred’. Notes of group discussions were kept by one of the project team (KD) and general themes were recorded after each group. The service users were made aware that the psychiatrists were available to discuss the impact of participating in the research. After each session the entire study group was debriefed.

Stage 2 was conducted approximately two months after stage 1 by a researcher independent of stage 1 of study (VT). A focus group was conducted with all 13 service users. The psychiatrists were interviewed individually in order to explore their experiences regarding participation in the research. To facilitate attendance at the focus group, a psychiatrist not involved in the initial project (CF) provided medical cover, this being a condition of ethical approval. The psychiatrists involved in the research were interviewed individually using a semi-structured schedule (Figure 1). The focus group and the interviews were audio-taped and transcribed.

Figure 1. Topic guide
1 assessment of the research process
2 impact of participation
3 relationships between patients and doctors
4 comparison with other research
ANALYSIS

Stage 1
The categorical ratings of patient-centredness made by the service users were entered into SPSS Version 11.5 and were compared to the psychiatrists’ ratings. The service user ratings were considered the ‘gold standard’ against which the psychiatrist evaluations were compared. Cohen’s kappa was employed to provide an estimate of agreement, with sensitivity and specificity indices being calculated.

Stage 2
Thematic analysis was used (Joffe & Yardley, 2004) to systematically identify and count themes or patterns in the data from the focus group and semi-structured interviews that explored the experience of taking part in the research. Thematic analysis uses theoretically derived themes to replicate and extend prior discoveries (Boyatzis, 1998). Participant verification was sought by sending the themes identified to a representative of the patient group (MG) for comment. The themes were endorsed, thus supporting inductively generated theory (Farsides, 2004). Inter-rater reliability was also demonstrated. An independent researcher (JS) applied coding to 25 data extracts and 92% agreement was recorded.

RESULTS/DISCUSSION

Stage 1
Thirteen factors were defined by service users as reflecting a patient-centred approach to research (Figure 2).

It was clear from the factors delineated, and discussion during the generation of them, that service users were particularly concerned with the process rather than the content of research. Service users felt that for research to be truly ‘patient-centred’, they should be involved throughout the research process as respected, valued and recognized research collaborators.

Figure 2. Factors reflecting a ‘patient-centred’ approach to research
1 ‘respect’
2 ‘holistic view’
3 ‘process fits research’
4 ‘being valued’
5 ‘complete—all—entire’
6 ‘quotes from patients’
7 ‘patients at centre’
8 ‘time for patient’
9 ‘involvement and recognizing’
10 ‘fulfilling patients’ needs’
11 ‘people friendly’
12 ‘individual ownership’
13 ‘of what use to patients?’
Convergent validity
The service user group rated only eight of the 60 abstracts as patient-centred \((\kappa = 0.23, p < 0.05)\). However, of these, seven accorded with the study team’s definition of patient-centredness (which focused primarily on the content of the research being related to exploring the subjective experience of patients). This afforded the study team’s definition a sensitivity of 0.88, a specificity of 0.56 and a likelihood ratio of 2, with regard to identifying patient-centred schizophrenia research abstracts. These results suggest that there was an 88% probability of the study team’s definition stating that an abstract was patient-centred if it was also rated as patient-centred using the service users’ definition, but only a 56% probability of the study team’s definition finding that an abstract was not patient-centred if it had been rated as non patient-centred by the service users. The likelihood ratio value of 2 suggests that an abstract rated as patient-centred using the study team’s definition would be twice as likely to be ‘truly’ patient-centred than one not so rated.

Stage 2

Service users’ reflections on participation in the research
The experiences of service users participating in the research were positive overall. The following themes were identified: value and respect; poor experiences of other research; and language.

Value and respect  Service users were overwhelmingly positive about their participation in the research. They felt valued by the researchers and suggested that their opinions were respected and that efforts had been made to involve them in all stages of the project. For example:

‘Here was someone [psychiatrist] who wanted to work with us, rather than us to work for them.’
(male service user 02)

‘I felt like I was actually being listened to, which was always a big issue for me.’
(female service user 03)

Poor experiences of other research  The service users’ positive experience related to the current research was in contrast to poor experiences related to other research projects in which they had felt objectified. One participant stated:

‘I was involved in a piece of research into serotonin, 5HT and M-waves and that was almost like you could have come at it with a number stamped on your wrist you know, it was so patronizing and… nobody followed [you] up.’
(male service user 02)

Language  Some found the subject matter distressing and the language used in the abstracts complex. This was despite the fact that the researchers had attempted to ‘de-jargonize’ the abstracts before presenting them to research participants. The following extracts illustrate participants’ feelings about research language:

‘There was nothing that was in a normal person’s language.’
(male service user 05)

‘It’s a very personal thing, and some are worried that they’re [abstracts] too abstract really, and they didn’t actually deal with the brain, just parts of it in isolation.’
(male service user 06)
Psychiatrists' reflections on participation in the research
The professionals reported that they found participation in the project valuable. They viewed it as a reaction to the plethora of biological research into schizophrenia and expressed commitment to using patient-centred methods in future research. The following themes were identified: breaking down barriers; challenge and criticism; dynamic nature of research; and poor experiences of other research.

Breaking down barriers  Professionals indicated that the research had helped to break down barriers between doctor and patient. They suggested that it had allowed them to communicate with service users in a more democratic fashion. They also found the interaction between doctor and service user felt more equal than in a formal medical consultation where imbalances in power were experienced more acutely. For example:

‘I enjoyed feeling valued rather than seen as someone who wasn’t interested in patients’ experiences, [who] would only prescribe medication.’

Challenge and criticism  Professionals found that they were challenged by the service users as they were seen to represent ‘the system’, and were subject to criticism as a result. They found this difficult to rationalize as they had made a commitment to working in a patient-centred way which may not have been appreciated by research participants. As one stated:

‘They [patient] said “this isn’t very patient-centred is it?”, you’ve already decided how we’re going to split up into groups and we’re going to come up with this definition… we feel as though we’re being rushed.’

Dynamic nature of research  Some anxiety was expressed regarding the dynamic nature of research. Concerns were raised that a great deal of patience and flexibility was required to work in this way. For example:

‘We were allowed to be flexible within the protocol… which doesn’t fit neatly with having a very structured methodology.’

Poor experiences of other research  The professionals were often harshly critical of what they perceived as the predominantly biological focus of contemporary psychiatric research, and which they felt neglected service users’ subjective experiences. As one stated:

‘What does it tell us if someone’s EEG is a bit off, or their reaction time is a bit slow compared to a group of people without the disorder, it doesn’t really tell us anything about the patients’ experiences of having the condition and recovering from it or not recovering from it.’

CONCLUSIONS
This study, with an approach that attempted to be patient-centred, sought to understand the experience of professionals and service users participating in a collaborative piece of research, while also addressing a specific question regarding convergent validity for an operational definition of patient-centredness.
Seven of the eight abstracts rated by the service users as patient-centred accorded with the professionals’ definition of patient-centredness used in the earlier study, which focused primarily on the content of the research being related to exploring the subjective experience of service users. Thus we found some overlap between the service users’ views of patient-centred research and the definition derived by professionals used in the earlier study, that is research addressing subjective experience did appear to be an important factor for service users in reflecting a patient-centred approach to research. However, the factors delineated by the service users and the discussion during the generation of them indicated that other issues were also important, particularly those relating to the process of research. They raised the need for service users to have adequate support when attending research meetings with other health professionals, so that they are able to express their views without feeling intimidated or patronized, and for there to be a recognition that service users might require more support when undertaking research than ‘professional’ researchers (Hewlett et al., 2006). Other studies have identified differences in research priorities between service users and professionals (e.g. Rose et al., 2008). There was also a strong view that research publications should be written in a way that is understandable and accessible, and that research should address issues that service users view as directly relevant to them.

The findings of stage 2 of the study indicate that both service users and professionals found the experience of participating in a collaborative study to be positive. For example, both service users and professionals said that they felt valued and professionals said that the study had helped to break down barriers between themselves and their patients.

The study emphasizes the importance of the process of research in achieving genuine service user involvement. It highlights the potential benefits of collaborative projects for both health professionals and service users despite the need for substantial resources and commitment to undertake such research. That said, some participants found this research experience challenging, which may have related to the power differential that exists between researchers and service users. Despite these challenges, it appears that participants were highly motivated as evidenced by the fact that only one (a service user) dropped out of the study. We hypothesize that this was achieved through respecting and involving participants, who were highly committed as a result. The study was limited by its purposive sampling and small sample size. The participants might have constituted a self-selected group through being affiliated with a mental health service user organization. It might also be that the health professionals involved were partial to this style of research, thus introducing bias. However, it has been noted that all researchers, service users, clinicians or academics bring their own bias or standpoint to their research (Rose, 2008b). Although one service user was involved in the preparation of this paper, training and support could have been provided for this individual to foster equality of input and active participation in research.

It has been noted elsewhere (Hanley, 2005) that the aims and methods employed in conventional, ‘researcher-centred’ projects do not capture or reflect the lived experience of their participants and can even reduce participants to their diagnosis (Rose, 2008b). Our results strengthen this claim, as exemplified by the respondent who, in describing the experience of participating in research involving the reduction of mental distress to disordered brain function, came to feel that he were just a number. This stands in contrast to our findings, which indicate that respondents, both doctors and service users, experienced participating in the present study as valuable, enjoyable and meaningful.

The terms ‘patient involvement’ and ‘patient-centred’ research are increasingly incorporated into research and clinical governance strategies. For this to be genuine and meaningful, there may
have to be considerable changes to conventional research development and implementation so that service users are involved throughout the research process as collaborators rather than simply research subjects; for example, by providing training in research methods as previously mentioned. Despite differences in views regarding rating of abstracts, and the inevitable failure of researchers to be perfectly patient-centred, respondents reported many benefits to participation in this style of project.

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