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It's important that they learn from us for mental health to progress

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## **It's important that they learn from us for mental health to progress**

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### **Abstract**

**Background:** There is a growing body of research on user involvement in mental health care and it is a key aim of current mental health policy.

**Aim:** The objective of this study was to obtain the views of a sample of users of mental health services regarding user involvement using a qualitative approach.

**Method:** Five exploratory focus groups were carried out with 31 current and ex users of mental health services. A grounded theory approach was taken to data collection and analysis.

**Results:** Four main themes emerged from the focus groups: language, mental health professionals, models of care and information and communication. Each of these also had a number of categories and sub-categories. The focus group findings highlight that this sample of users of mental health services value acceptable language, social inclusion, person-centred care, appropriate training of mental health professionals, information and communication, autonomy/control and peer support.

**Conclusions:** It would appear that while user involvement is frequently mentioned in policy documents, in practice the aims are not yet being fully achieved.

**Keywords:** *Mental health, user involvement, views, grounded theory*

### **Introduction**

Contemporary interest in involving service users in their own care and treatment derives from the philosophical and political critiques of traditional psychiatry that emerged at the end of the 1960s in Europe, the USA and Canada (Chamberlain, 1990; Geller et al., 1998). These movements were a response to anger against psychiatry and institutions. Opportunities for user involvement have been created by the three main factors of de-institutionalization, questioning of the legitimacy of bio-medical theory and practice and consumerism (Pilgrim & Waldron, 1998). The user movement developed out of hostility to ECT, major tranquilizers and the use of therapeutic law to detain citizens without trial. Activity has become most common and globally widespread in the last two decades.

In the United Kingdom, action was mainly stimulated by the growth of consumer satisfaction research with the National Health Service. User involvement has been moving up the political agenda with documents such as *Building Bridges* (Department of Health,

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1995), *Modernising Mental Health Services* (Department of Health, 1998) and *the National Service Framework for Mental Health* (Department of Health, 1999) advocating that service users are involved in their own care and in planning services.

Despite the growing presence of user involvement in the everyday discourse of mental health, some authors have suggested that this is rhetorical and tokenistic. The voices of service users and those who campaign or speak for them still have a limited impact on policy formations (Hannigan & Cutcliffe, 2002). Qualitative studies tend to show a more negative experience than quantitative studies (Lovell, 1995). The one-off, management driven self-completion patient satisfaction questionnaire is extremely common, yet the typically high levels of satisfaction that these surveys record and the limited variability in results question the validity of this method. A global satisfaction score gives little indication of a user's experience of care. Qualitative methods can produce more open, reflective and informative responses (Edwards & Staniszewska, 2000).

Rogers, Pilgrim and Lacey (1993) state that in the history of health service satisfaction research, more often than not the views of service users are excluded. In their review of the literature they find a number of problems. They found that researchers occasionally disregard users' views if they do not coincide with those of mental health professionals. They also found evidence of the notion that service users are irrational and so incapable of giving a valid view, researchers assuming patients and relatives share the same interests, and only giving partial credence to the user's perspective if it fits with the expert view. These authors assert that there must be a questioning of the assumptions of the researcher, and the profession from which they come, coupled with more of an attempt to involve users themselves in research. They criticize research using fixed-choice questions, and recommend a more qualitative approach.

### **Aim and methodology**

The overall aim of the research was to obtain the views of a sample of users of mental health services regarding user involvement using an exploratory, qualitative approach. To genuinely increase user involvement in healthcare, it is important to use methodologies that give users a voice and allow them some scope to lead agendas for change rather than providing data for provider-led agendas (Edwards & Staniszewska, 2000). Focus groups are a useful method to share and compare views. They were chosen as the most appropriate method as the research aimed to obtain a range of ideas, understand differences in perspectives, uncover factors that influence opinions, behaviour or motivation and capture the comments and language used by the target audience (Kreuger & Casey, 2000).

A grounded theory approach was taken to data collection and analysis (Strauss, 1987). A grounded theory approach is particularly useful when a well-established body of theory does not exist (Glaser & Strauss, 1967). The purpose is to discover better ways of thinking about a phenomenon aimed at understanding how groups of people define their reality through lived experience. Inductive reasoning is used to generate data which can be compared in a deductive way to produce theoretical frameworks. "One does not begin with a theory, then prove it. Rather one begins with an area of study and what is relevant to that area is allowed to emerge" (Strauss & Corbin, 1990, p. 23).

### *Participants*

Purposeful sampling was used in the study to identify participants who were most likely to be able to provide information related to the aim of the research. Rogers, Pilgrim and

Lacey (1993) raise the question of the definition of what constitutes a service user for research purposes. Participants were included in the research that had had fairly substantial contact with mental health services. It was intended to include participants who were currently having treatment, were between episodes of care, and those who were managing their condition themselves and making use of services when necessary. There were thirty-one participants in total, 19 were members of user groups and 12 were from community residential settings. The focus groups were carried out over a six-month period during 2003, and the participants were geographically spread throughout Northern Ireland.

It has been asked if those who attend user groups are representative of users as a whole, with some researchers questioning whether these groups provide a forum for the higher social classes in which to articulate their needs, and therefore excluding the views of those from lower socio-economic groups (Lindow, 1991; Rudman, 1996). In an attempt to address this inequality, the researcher approached both established user groups, as well as individuals in community residential settings who were not part of a user group. However, it was agreed that "an articulate user is better than no user at all" (Bramwell & Williams, 1993, p. 19).

The richness of the sample in qualitative research can be considered less important than the richness of the data (Seale & Silverman, 1997), so individual demographic characteristics of participants were not specifically requested. However, some characteristics emerged in the course of the discussions. The most common diagnoses were schizophrenia, depression and bi-polar disorder. The majority of the participants had had multiple contacts with mental health services. Most had been institutionalised on at least one occasion, some on numerous occasions. Some had been sectioned a number of times, others were voluntary admissions. One had been in and out of hospital for 40 years. There was a range of ages, sex and geographical location.

#### *The experience of recruiting participants*

A letter was sent to each user group/voluntary organization detailing the study and asking for help to recruit participants. The researcher then followed this up with a telephone call and a date was organized. The contact person in the organization asked potential participants to take part. Participants self-selected, and attended informally, i.e., arrived at the focus group and left whenever they wanted. Participants were curious about what the research involved and very keen to relate their stories, expressing that this was an unusual and welcome experience. The researcher was questioned fully about the purpose of the research and confidentiality. Some participants were also initially nervous in speaking with a tape recorder present, but after reassurance they became accustomed to this as the discussion progressed.

#### *Procedure*

Five focus group discussions were conducted. Each focus group discussion was planned to last approximately 60 minutes, but this was kept flexible in order to respond to whether the groups had more or less to say. The focus groups took place in locations chosen by the participants, on two occasions this was the university, on the other three occasions in a room within the user group premises. Both a facilitator and an observer who recorded field notes were present. The discussions were semi-structured and the opening statement explained that the research was about user involvement and the researcher wished to hear about their experiences as a mental health service user. After this the discussion was kept as open as possible in keeping with the grounded theory approach. The questions were not intended

to be overly directive, as the research was exploratory, forming the first part of a wider grounded theory study. A prompt sheet of open questions was prepared from the literature should the participants need assistance to relate their experiences. Silverman (1993) suggests a prompt sheet improves the authenticity of the understanding of the participant's experience and improves the reliability of the study. Five focus groups were held as similar themes emerged from all groups and data were considered to have reached saturation. When no new issues seem to be forthcoming, a point of "saturation" will have occurred (Basch, 1987; Kreuger, 1994), and further groups need not be conducted.

#### *Ethical issues and approval*

Participants were suitably informed about all aspects of the research. The scope of participation and goals of the research were all discussed in detail. The right to withdraw from the research for whatever reason at any time was stressed. To ensure anonymity in the focus group discussions, codes known only to the researchers were assigned to participants for use in transcript material. Furthermore, an assurance was given only those involved in analysis would have access to the raw data.

#### *Data analysis*

Each focus group was audiotaped and transcribed verbatim shortly after it took place. The grounded theory approach to analysis differs from other styles of qualitative analysis in that the focus groups are analysed as the study progresses, not when the data collection has been completed. Each transcript was subject to open coding (Strauss & Corbin, 1990), the identification within the data of simple concepts. This is tentative, unrestricted coding of the data with the researcher is free to invent and change terms. The rules of thumb of Strauss (1987) were followed. The researcher also looked for "in-vivo-codes" – specific terms used by the people being studied. The frequency of the occurrence of concepts was noted to facilitate their verification (Miles & Huberman, 1984). Concepts sharing similarities were combined to form categories that were then given a suitable name. Axial and selective coding also took place as the research progressed. Data was re-examined throughout the life of the research, and codes, categories and sub-categories were constantly revised. The coding process involved making comparisons and asking questions of the data. The transcripts were then scrutinised for statements of text that supported the categories identified. Illustrative quotes were then extracted using a computer-assisted "cut and paste" approach to arrange under appropriate categories and sub-categories. The categories were then grouped to provide core themes that were verified by re-visiting the transcripts.

## **Findings**

### *Theme 1: Language*

Terminology was considered to be an important aspect of the experience of mental health care. There was discussion around what would be the most appropriate term to describe participants. A number of terms were debated such as service user, survivor, sufferer, patient and client. One participant felt none of the terms were appropriate "There is also the danger if we use safe language people don't realise how serious the condition is. If we wrap it up in nice language we can take away the real hell of the condition." There was no consensus among the participants regarding one term but the most positive comments

Table I. Themes, categories and sub-categories.

Theme	Category	Sub-category
1. Language	Terminology	Patient
		Service user
	Mental illness as a journey	Client
		Sufferer
2. Mental health professionals	Care approach	Survivor
		Stages of illness
	Labelling	What to call mental illness
		Diagnosis
3. Models of care	Required qualities	Media
		Public perception/stigma
		Humanistic
		Relationships
		Individuality
		Humanity
		Honesty
		Common sense
		Empathy
		Listening
		Time to talk
3. Models of care	Medical model & treatment methods	Reassurance
		Caring and understanding
		Respect
		Patience
3. Models of care	Power	Trust
		Compassion
		Service user perspective
		Could happen to anyone
3. Models of care	Lack of stimulation	Student training
		Professionals
		Medication
		Alternative therapies
3. Models of care	Peer support	Life experiences
		Control
		Them and us
		Paternalistic attitude
3. Models of care	Information	Activities
		Intellectual stimulation
		Hospital
		Community
4. Information & communication	Communication	Medication & side-effects
		Benefits & form-filling
		Listening & encouragement
4. Information & communication	Communication	Care planning
		Patient advocacy

(e.g., “not offended by”, “comfortable with”, “it is not brilliant but it is ok”) were made regarding the term service user. One participant felt that not everyone was open about having a mental health difficulty so service user covered everything: “it could have been a service user of the cardiac services, or whatever other services so I remain anonymous”.

Some participants felt that “patient” was more appropriate in a hospital context and “client” in a community context. One patient liked the term sufferer while another felt it was part of a victim ideology and disempowering. There was a feeling that mental health professionals did not like the term survivor. Participants thought the term might be seen as a criticism of professionals, but stressed that their use of the word was in the sense of surviving the illness. Other participants felt that survivor was a very strong term and was perhaps most appropriate to the user group literature: “Survivor, I don’t think I feel like a survivor. I’m coping with manic depression but it doesn’t feel like I have survived it because it’s always going to be there.”

There was much discussion in all of the groups about labelling and terminology, and how participants felt that labelling contributed to stigma. Participants disliked being labelled “schizophrenic” or “manic depressive” as they felt that people then saw the illness first and the person second. “I am a schizophrenic, but if I suffered from cancer I wouldn’t be a canceric”. However, it was interesting that some of the participants introduced themselves by their name and I am a “manic depressive” or a “schizophrenic”. There was consensus that the term “mental health difficulties” was the most acceptable and accurate term. “It is a clear term that is quite neutral I think”. “Mental health is better than psychiatric”. Two participants expressed dislike for the term mental illness: “I don’t agree with the word illness, mental illness. Illness to me is something that can be cured, depression can’t be cured, you just cope with it”.

One participant commented that “having a term you are happy with, even when you have got it, there is still that stigma”. He felt it was still very difficult to talk to people about his difficulties and gave the example of telling someone he had not seen for some time that he was on a training scheme, rather than the truth that he was not working due to mental health difficulties. “You know there is going to be a reaction. People with mental health problems we understand it, professionals understand it, but the wider public don’t understand it.” Another participant concurred with this: “There needs to be more explanation. The average punter on the street thinks he knows all about it. So there needs to be more education. Even your boss in a firm, they need to have knowledge because they don’t have an understanding”.

Participants mentioned the way mental illness was depicted in the press and believed this was a contributor to stigma: “Because of the media, and any coverage is usually very negative and people who have manic depression or schizophrenia are even perceived to be killers”. Several derogatory terms were mentioned such as “headbin”, “loony”, “bendy” and “monsters”. One male participant described how others had treated him when he first showed signs of depression: “Get a kick in the backside” and “buck yourself up” and “pull yourself together”. One female participant said that stigma had affected her own beliefs and perceptions of mental health care: “I perceived psychiatric hospitals to have padded cells and strait jackets and I was terrified of going in. I was pleasantly surprised when I did go in to find that they were not the way I thought they were going to be”.

Some of the participants had had a number of different labels from different psychiatrists and questioned the value of this. Some had received changing and contradictory diagnoses over the years of their illness. Participants were aware of the current standards used to diagnose mental health difficulties, and felt that these were inherently flawed:

The standard used for measuring mental illness is the DSM. I think that at the moment it has become the bible for psychiatry and like the actual bible it is open to interpretation.

We do present with symptoms which do not fit neatly into those DSM boxes. And there is so much misdiagnosis. I know people who have been through six or seven label changes in as many years. And sometimes a change of psychiatrist brings a different label.

*Theme 2: Mental health professionals*

The approach of mental health professionals formed a large part of the discussion across the groups. Participants felt that it was very important to see the person behind the mental health difficulty: “The word person is terribly important”. Participants felt that mental health professionals who had displayed human qualities and reached out to them as a person had been most helpful – “the human touch”. They felt it was very important for nurses and service users to build up a relationship:

I had already built up a relationship with her over the six weeks that I had been there. So I had got on well with her so we really had broken down the barrier of patient/nurse.

Unless there is a relationship there, there cannot be any healing.

See the whole person like mother or father or brother or sister. Try and see the way, that person, patient, as they would view a member of their own family.

It’s common sense, just treat them the way you would want to be treated if you were in the same situation. It’s not rocket science, it’s just basic human values.

One participant felt very strongly that one type of care did not fit all:

We are not all the same, we have to be treated individually. Not to have this sort of rota that you go to the day hospital and you go to training and then you go somewhere else next. It takes longer, but it has to be done that way because no two people are the same.

I think the care plan can be good as long as it doesn’t expect a patient to go through certain hoops. I think you have to go at the pace of the patient.

People’s needs aren’t getting met. I am sure most people have felt let down, I know I have.

The resources have to be there. You could have the best heart in the world but the resources have to be there.

There needs to be a change of ethos overall.

Participants mentioned a number of qualities which they thought were important for a mental health professional to possess. Listening skills were the most often mentioned. Important skills considered to become a “good” mental health professional were humanity, common sense, empathy, listening, time to talk to you, reassurance, caring and understanding, respect, patience, trust, compassion and practical organisational skills. Those who had been inpatients felt that nurses spent a lot of time in the nurse’s station, and they would have preferred them to spend more on time on the wards.

That time that they spent sitting in the nurses station could be put to better use by interacting with the patient, because you don't know how much of a help it is to find that you have a nurse that understands and will listen to you, and assure you that you are going to be ok.

I have never ever to this very day sat down with a nurse on the ward who allowed me to cry, who took notes from my admission to my discharge.

... somebody to reassure you that this experience is going to end, that you are going to be alright, you are going to get out and you are going to be a part of society again.

You can tell who is genuine and who is not, even when you are unwell.

It is all about compassion, nurses have to show compassion. There was one who would put his arms round me and say we will sort it out together. And that lifted me up out of the hell.

Some suggestions were made as to how to foster the necessary qualities in students in the mental health field. One such suggestion was to give students an induction as if they were themselves a patient and show the contrasts between the different types of care that are possible, what it is like to be treated in different ways. Other suggestions were made that students should learn about the experience of mental illness from the individual's perspective: "Students have to know that mental illness could happen to them."

Participants thought it would be a good idea for students to read literature written by people with mental health difficulties to see the personal perspective and complement textbooks:

Theory is good, it is good to understand theory but there has got to be a practical side too. You have got to get someone to say well I haven't read such and such a book on depression but I have suffered from depression and this is what I have gone through on a day to day basis.

It was also suggested that it would be helpful for service users to talk to students about their experiences and some of the groups expressed a willingness to do this:

I get a lot of therapeutic value out of sharing my experiences.

It would be good to be able to talk to people about your mental illness. If you have someone who has been there and bought the t-shirt. That is something you can't teach, you have to have experienced it.

### *Theme 3: Models of care*

Participants felt that there was still a heavy emphasis placed on the medical model in hospitals.

I think that a lot of mental health care comes out of that model where we are seen as machines which have somehow developed some obscure fault. You know and if you tweak something or substitute something you will make it all right again and it is almost as

though the psychiatrist is looking at us, you know, as a kind of complex electronic toy which has developed a fault he is not too sure of.

Participants felt that there was pressure on new staff to conform to the established way of working and for this reason change was slow to occur. Criticism of the medical model was mainly based on experiences as an in-patient:

The psychiatrist's job is extraordinarily pressurised and there is almost a necessity there to deal in a mechanical way with the situation.

You mention god to a psychiatrist and they just give you more tablets.

... didn't say hello, how are you, how are you feeling today, he just walked to the next person ... and he did not speak to one patient he didn't say, they were like cattle ...

I think doctors become desensitised. All feelings sort of disappear.

Some participants felt that their experience as an in-patient had been negative "It has taken me sometimes nearly a year to recover, and part of what I am recovering from is not just the awfulness of having got sick, but the awfulness of the hospital experience". Another participant felt that mixing patients was not always appropriate "Mixing very psychotic patients who need a lot of care and are very vulnerable, with depressed patients, often doesn't work". He detailed an experience when a violent in-patient physically assaulted him. However, comments were not all negative: "My sister unfortunately got sick last year and is in a different place, and her experience has been like a model compared to the ones I know. They looked after her. She had a good experience. There was respect there".

In the opinion of the participants, the treatment they had experienced had been based on medication. "I do have strong reservations about medication, I think it is overused but at the same time I know that at certain periods in my mental illness I needed medication. It has to be a package really". While they acknowledged that medication was a necessary part of treatment, they requested more alternative methods of treatment in addition. "I agree with medication but I think there should be more new alternative therapies and there should be more available talking therapies like cognitive therapy". The respondents felt that their life experiences were never taken into consideration:

I believe that it was social factors in my life that caused me to be the way I am.

And they just dealt with symptoms of what was wrong with me, they never asked me about my father's death, they never asked me about the break up with my long-term girlfriend. There was never any reference made to that, not once, I was just pumped full of drugs.

A number of the participants felt that there was a lack of things to do in hospital. One of the participants commented on the fact that he was one of the few in-patients who did not smoke and he found this to be rather exclusive as the recreation rooms were all smoking. It was felt that a wider range of activities would help patients to keep their mind occupied:

When I get afraid and start thinking I don't stop, when I am not well I can't switch off the negative thoughts, so distraction is major, I think there should be a greater range of occupational therapy in hospital.

There was nothing that stimulated me intellectually. And they automatically assume that if you have got a mental illness that you are not intellectually capable.

Participants were conscious of a power imbalance between themselves and professional staff, which they called “them and us”, and this phrase was repeated across all five of the focus groups. Participants felt that the power of the psychiatrist was at the core of the medical model and that change would be difficult. They felt this was a major contributor to the lack of involvement in their treatment. Participants had often experienced a paternalistic attitude from professionals:

The need to be a good boy, Don't be a naughty boy.

Get us to behave like children, manage us.

You are very frightened of the nurses and doctors trying to care for you.

I said they must not treat us like children, we must be treated with respect as adults.

In contrast, with the rise of the user movement and service users beginning to have a voice, participants felt that sometimes mental health professionals felt threatened by user groups:

When we do presentations to mental health care professionals often they feel threatened by us and they are concerned about why we are there. They are taught that they are the ones that provide the health care and so they see us agitators from their perspective.

Patients perceived control to be a contributory factor in creating a power imbalance. The perceived control of the mental health professional was mentioned in all of the focus groups, and sometimes participants felt this control was abused in the in-patient setting by bossiness, humiliation, bullying, verbal abuse, forced injections, and ECT.

I had an experience where the psychiatrist assigned to me would not let me see my notes. That caused me a lot of distress.

To try and wrestle control away from the psychiatrist is going to be a major problem.

The medicines that have been produced have been aimed at controlling the condition, rather than curing it.

Instead of being about treatment it is about control.

This perception of professional control was especially daunting to the patient who already felt they had lost control of their life due to mental illness: “When you have a mental illness, the big fear that you have is the loss of control. You feel like you are literally losing your mind, that you will never get back the ability to think clearly.”

The support of peers was considered vitally important to survival and recovery in both the hospitals and community settings. Many examples of this were given in the hospital setting. When an inpatient, the groups felt that helping others gave them a purpose and made them feel a part of things: “Somebody new comes in, you go over and show them the ropes”.

They also found it very helpful to talk with other patients about their experiences and to share information: “you get your supper and comfort from other patients”; “the patients were half of the cure”; “a cigarette would get you plenty of information”; “a word of encouragement went a long way”.

This was also true of community groups where participants felt accepted and could share in a sense of community and talk to others:

You will be talking to people who know all about it and that can help you even more than if they were paid professionals.

It is very important that it is here because it does relieve stress and tension. It takes you away from your home environment where you are sitting on your own all day. Most people who come here are single and live on their own.

I can challenge anybody I like within the structure.

#### *Theme 4: Information and communication*

Information and communication (or lack of it) was reiterated many times by participants in the focus groups. The groups felt it very important for rehabilitation to provide information: “I wish someone would have come along to me and sat on the edge of the bed and tried to encourage me or explain the jargon”. Participants particularly needed information on medication and possible side-effects “There is not enough education or information given to patients while they are in hospital about drugs they are using”. Participants also wished they could have more information and help with administrative forms such as benefits and passport forms.

Effective communication was considered necessary for service users to understand their care and what was happening to them. Someone to listen was mentioned many times. One participant told a story of an experience he had of poor communication in hospital:

I was supposed to be getting out for a weekend, I had been in hospital for six weeks, and I had geared myself up for this weekend, and then suddenly...why it was I don't know...but the psychiatrist said no you are not getting out for the weekend. It was very clear to the nurses that I was very disappointed.

You can't always just store up all that you are thinking and all that you are feeling just for the ten minutes before the person has to write up their report.

I had a named nurse on the bed but I never saw her.

There was some discussion around the value of user involvement and patient advocacy. One participant was rather negative “It is a bit farfetched.” Some had had the option of patient advocacy while in hospital but were not able to make full use of it: “The patient's advocate let me down completely by not turning up”. Another participant felt there were times in hospital when they would not have been in a suitable mental state to have benefited from advocacy: “In hospital for me it was kind of pointless for patient advocacy to be there, I was too ill to use it. That is the flaw in it. I just remember a man sitting on my bed talking to me”.

Most were positive towards the idea and expressed an interest in being involved:

It is important that they learn from us for mental health to progress.

I have been in and out of hospital as last 17 years and I have never been asked once how do you feel you were cared for or looked after, what is your opinion, do you think we should do this, could you give us any ideas on how to improve this service? Never has anyone asked me that question. And how are the people who are spending the money within mental health, how do they know if it is being spent in the right area? If they would do more research and ask because the people that use the services are the real experts.

## Discussion

Language and terminology emerged as an important theme in the research. There was much discussion about terminology used in mental health across the discussion groups. Language is important when considering people's experience and the language we use is important as it defines the meaning and value of that which is labelled (Repper & Perkins, 2003). Rudman (1996) also found differences in the use of terminology amongst user groups with many groups rejecting the term "mental illness" and the word consumer tends to be rejected because of market connotations. "User" and "survivor" were more widely used, as also found in this research. In focus group research by Hostick (1998), service users unanimously disliked the term patient. Client, resident, beneficiary and person were all alternative suggestions.

Stigma was still viewed to be a problem in daily life for the focus group participants. The mass media associates people with mental illness with violence, and tends to promote negative public attitudes towards those with mental health problems (Cutcliffe & Hannigan, 2001). Lay conceptions of madness continue to portray people with mental health difficulties as less trustworthy, less intelligent and less competent than others (Link et al., 2001). Such prejudices are a major contributor to social exclusion. Holloway (1996) stated that the appearance of a more controlling mental health policy framework in the 1990s emerged in part as a result of a media fuelled "moral panic".

Participants valued a humanistic approach by professionals, where they felt they had a relationship and were valued and respected. Information and communication were considered essential, particularly regarding medication, side-effects and care planning. Research by Repper and Perkins (2003) revealed the importance of mental health workers focussing on the strengths of people with mental health difficulties as opposed to their deficits and weaknesses. They also assert that "an effective relationship involves mutual respect" (p. 84). Many studies report that users value interpersonal relationships with mental health professionals very highly and this is often what leads to high user satisfaction. Research findings from the Mental Health Foundation's (2000) Strategies for Living Project also reiterate the value service users put on accepting relationships.

Participants felt that user involvement is still in the very early stages and the medical model was still prevalent. The participants in this research had little personal experience of user involvement initiatives to discuss. Much of the funded research in the mental health field is to test new medications. This emphasis on pharmacology is despite the fact that most service users place a much greater emphasis on "talking treatments" than on drugs (Rogers & Pilgrim, 2001), also a finding from this study. These findings are frequently echoed in studies from around the world which investigate what service users want from

their care. Many of the experiences detailed about in-patient care were negative. An understanding of negative experiences is also a useful learning exercise to identify what can make the experience more positive. Although none of the participants were currently in hospital, many of the experiences focussed on care received in acute psychiatric units. Pilgrim and Hoser (1999) also found evidence to suggest that the lives of users of mental health services were often dominated by hospital-based mental health practice.

The findings of this research show that user involvement is not simply a matter of being included in care planning but a holistic method of involvement that incorporates every aspect of the service user's life, at the personal, service and societal levels. This concurs with the view of Double (2002) who states that much of the expansion of psychiatry in the last few decades has been based on a biomedical model that encourages drug treatment to be seen as a panacea for multiple problems (Double, 2002). This author is sceptical of this approach and suggests that psychiatry should take a biological view with psychological and social understanding. Double emphasizes that while biological explanations are important, an understanding of the reasons for a patient's presentation and the meaning of people's distress and the psychological and social aspects of their difficulties is also required.

## Conclusions

The focus group findings highlight that users of mental health services value acceptable language, social inclusion, person-centred care, appropriate training of mental health professionals, information and communication, autonomy/control and peer support. It would appear that while user involvement is frequently mentioned in policy documents, in practice the aims are not yet being achieved.

Given the smaller size of focus group samples, and the non-probability sampling methods employed, empirical generalization is not possible from focus group research. However, Sim (1998) argues that theoretical generalization is possible: "data gained from a particular study provide theoretical insights which possess a sufficient degree of generality or universality to allow their projection to other contexts or situations which are comparable to that of the original study" (Sim, 1998, p. 350). Thus conceptual and logical comparability are possible, rather than statistical representativeness.

While there is currently much research on user involvement in mental health care, there is little using the grounded theory approach. By using grounded theory, this study provides some theoretical insights into the views and meaning of user involvement to service users. Each of the themes, categories and sub-categories generated provide direction and a potential comparative framework for further study. There is currently little research that explores the issue of terminology for service users, and this study highlights that service users consider this topic to be important. Similarly, other key themes such as mental health professionals, models of care, and information and communication could be explored in more depth using the framework of categories and sub-categories. Further research is required to identify and describe the key mechanisms that could make user involvement in mental health a reality for service users like those in this study.

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## References

- Basch, C. E. (1987). Focus group interview: an underutilized research technique for improving theory and practice in health education. *Health Education Quarterly*, 14, 411–448.
- Bramwell, L., & Williams, K. (1993). Changing your role. *Openmind*, 62, 18–19.
- Chamberlain, J. (1990). The ex-patients movement: Where have we been and where are we going? *The Journal of Mind and Behaviour*, 111, 323–336.
- Cutcliffe, J., & Hannigan, B. (2001). Mass media, monsters and mental health clients: The need for increased lobbying. *Journal of Psychiatric and Mental Health Nursing*, 8, 315–321.
- Department of Health. (1995). *Building Bridges: a guide to arrangements for inter-agency working for the care and protection of severely mentally ill people*. London: Department of Health.
- Department of Health. (1998). *Modernising Mental Health Services: Safe, sound and supportive*. London: Department of Health.
- Department of Health. (1999). *A National Service Framework for Mental Health: Modern standards and service models*. London: Department of Health.
- Double, D. (2002). The limits of psychiatry. *British Medical Journal*, 324, 900–904.
- Edwards, C., & Staniszevska, S. (2000). Accessing the user's perspective. *Health and Social Care in the Community*, 8, 417–424.
- Geller, J., Brown, J., Fisher, W., Grudzinskas A., & Manning T. (1998). A national survey of “consumer empowerment” at the state level. *Psychiatric Services*, 49, 498–503.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago: Aldine Publishing Co.
- Hannigan, B., & Cutcliffe, J. (2002). Challenging contemporary mental health policy: Time to assuage the coercion? *Journal of Advanced Nursing*, 37, 477–484.
- Holloway, F. (1996). Community psychiatric care: from libertarianism to coercion. Moral panic and community mental health policy in Britain. *Health Care Analysis*, 4, 235–243.
- Hostick, T. (1998). Developing user involvement in mental health services. *Journal of Psychiatric and Mental Health Nursing*, 5, 439–444.
- Kreuger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research*, 3rd edn. Thousand Oaks, CA: Sage Publications Inc.
- Kreuger, R. A. (1994). *Focus groups: A practical guide for applied research*, 2nd edn. Thousand Oaks, CA: Sage Publications Inc.
- Lindow, V. (1991). Experts, lies and stereotypes. *Health Service Journal*, 101, 18.
- Link, B. G., Struening, E. L., Neese-Todd, S., Asmussen, S., & Phelan, J. C. (2001). The consequences of stigma for the self-esteem of people with a mental illness. *Psychiatric Services*, 52, 1621–1626.
- Lovell, K. (1995). User satisfaction with in-patient services. *Journal of Psychiatric and Mental Health Nursing*, 2, 143–150.
- Mental Health Foundation. (2000). *Strategies for living: The research report*. London: Mental Health Foundation.
- Miles, M. B., & Huberman, A. M. (1984). *Qualitative data analysis: A sourcebook of new methods*. Beverly Hills, CA: Sage.
- Pilgrim, D., & Hoser, B. (1999). *Users' and carers' views of mental health services in the NW of England*. Warrington: NHSE.
- Pilgrim, D., & Waldron, L. (1998). User involvement in mental health service development: How far can it go? *Journal of Mental Health*, 7, 95–104.
- Repper, J., & Perkins, R. (2003). *Social inclusion and recovery: A model of mental health practice*. London: Elsevier Science.
- Rogers, A., & Pilgrim, D. (2001). *Mental Health Policy in Britain*, 2nd edn. Hampshire: Palgrave.
- Rogers, A., Pilgrim, D., & Lacey, R. (1993). *Experiencing psychiatry: User's views of services*. London: MacMillan/MIND.
- Rudman, M. J. (1996). User involvement in mental health nursing practice: Rhetoric or reality? *Journal of Psychiatric and Mental Health Nursing*, 3, 385–390.
- Seale, C., & Silverman, D. (1997). Ensuring rigour in qualitative research. *European Journal of Public Health*, 7, 379–384.
- Silverman, D. (1993). *Interpreting qualitative data: Method for analysing talk, text and interactions*. London: Sage.
- Sim, J. (1998). Collecting and analysing qualitative data: Issues raised by the focus group. *Journal of Advanced Nursing*, 28, 345–352.
- Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. London: Sage.
- Strauss, A. L. (1987). *Qualitative analysis for social scientists*. Cambridge: Cambridge University Press.