Information in mental health: qualitative study of mental health service users

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Abstract

Background Despite the widespread proliferation of consumer health information provision, little is known about information needs or information-seeking behaviour in mental health. A qualitative study was therefore undertaken to explore these issues for mental health service users.

Design In-depth interview study with purposive sample of 36 men and women with experience of mental health problems.

Results Four main themes were identified. A general lack of information was equated with a lack of respect. People undertook their own research into their condition, and recognized the challenge to professionals. Stigma was widespread and inhibited information seeking. There was a desire for an explanation of mental health problems in physical terms. People particularly valued hearing other people's experience of mental health problems, for reasons of universality, instillation of hope, and understanding and empathy.

Conclusions The findings provide support for a more equal partnership between patients and professionals. Information providers and health practitioners should take account of the value of other people's experience as an information source.

Introduction

Information is an important and integral part of health care. Information for patients can be used to prevent disease, to promote self-care, to support treatment choices and to improve the effectiveness of clinical care.[1] Consumer health information provision is particularly important in the area of mental health problems as they are frequently associated with stigma and isolation,[2] and those affected often do not seek formal help to manage their condition.[3]

In recent years, there has been a proliferation in the health information available for consumers and recognition of the potential importance of health literacy in supporting self-care and the empowered expert patient.[4] However, little is known about health information needs in

general and mental health information needs in particular. The limited previous research in this area shows that significant numbers of psychiatric patients report dissatisfaction with current levels of information provision;[5,6] but most statements on mental health information needs are based on the views of professionals rather than on empirical work. One previous interview study examined the information needs of inpatients with bipolar disorder,[7] but in a review of the literature we did not identify any previous work on the mental health information needs of the vast majority of service users who have mild to moderate mental health problems in the community. We therefore undertook a qualitative study to explore information needs and information-seeking behaviour by mental health users, to identify common themes, and to highlight areas that health services should target.

Methods

Participants

Adult mental health service users were identified purposively and recruited as participants for interviews. Participants were recruited in Oxfordshire in primary (family practice) and secondary care (hospital) settings. Local General Practitioners and psychiatrists were informed about the study and were asked to give information sheets to suitable current patients. Posters were displayed in practices, outpatient and inpatient wards. Participants were also recruited from invitation letters sent to national user organizations (charities and voluntary organizations for people with mental health problems) and via a national consumer health information website. The inclusion criteria were for participants to be aged over 18 years, to have had mental health problems and to have had current or recent experience (within last 2 years) of contact with mental health services. Participants had to be well enough to take part in an hour-long interview.

Maximum variation sampling was undertaken over a period of 6 months in order to ensure recruitment of male and female mental health users from a wide age range and from varying social backgrounds, with experience of various mental health problems including both acute and chronic conditions. Sampling continued until theoretical saturation occurred, when further sampling failed to yield new information.[8]

Procedure

National Health Service ethics committee approval was obtained. In-depth interviews were conducted by one interviewer (JP) either face-to-face, or by telephone where this was impractical. Consent was sought and obtained from each interviewee. All interviews were audio-recorded, and anonymized transcripts were used for analysis. A topic guide based on a review of previous research and the theoretical literature was used. Open-ended questioning was employed,[9] and the order of questioning determined by the flow of each interview. Each interview usually began with a description of the participant's history of mental health problems and their experience of seeking help and information. All aspects of information needs and information-seeking behaviour were then explored. Demographic data were also collected. Self-reported diagnoses were recorded.

Analysis

A grounded approach was used.[8] Two investigators (JP, AC) familiarized themselves with the transcript data through repeated reading and reflection and independently subjected the transcripts to a process of open coding by going through transcripts line-by-line. Interim analysis allowed subsequent interviews to be informed by earlier findings. Constant comparison helped refine emerging conceptual categories through comparison and searching for deviant cases.[10] Once transcripts were read and coded, the investigators met to discuss the open coding and through extensive discussion determined a series of thematic codes to describe agreed groups of categories and subcategories – a process of axial coding.[8] QSR N6 software was used to apply this

agreed thematic coding.[11] This process of selective coding was used to generate related themes to explain the information needs and behaviour of participants.

Results

Sample characteristics

Thirty-six (25 female and 11 male) participants with ages varying between 25 and 64 years were purposively recruited with varying experience of the mental health system, and were interviewed either face-to-face ($n = 19$) or by telephone ($n = 17$). Thirteen participants were recruited through secondary care, five in primary care, two through user groups and 16 through websites run by a mental health charity (the Mental Health Foundation) or a consumer health information provider (http://www.netdoctor.co.uk). Purposive sampling ensured that participants had experienced a variety of mental health problems and were from a variety of occupational backgrounds. The characteristics of participants are shown in Table 1.

Self-reported diagnoses were recorded. The 'other' category included one person describing a history of childhood abuse, one person describing a history of self-harm and one person who had experienced postnatal mental health problems.

Themes

Four main linked themes were identified from the analysis.

Lack of information equals lack of respect

There was a strong theme of a general lack of information for people with mental health problems (specifically identified by 18 participants). People associated this with a lack of respect (explicit in nine interviews). Exchange of sufficient information was seen as a key element of respect. This included information about diagnosis, investigations and treatment options, and is illustrated by a quote from Interviewee 22, a 38-year-old woman.

Table 1 Characteristics of participants

	Male ($n = 11$)	Female ($n = 25$)
Age group (years)		
21–30	2	5
31–40	3	7
41–50	2	9
51–60	3	4
Over 60	1	0
Diagnosis (self-report)		
Depression	6	10
Schizophrenia	2	4
Bipolar affective disorder	2	2
Anxiety disorder	1	4
Eating disorder	0	1
Personality disorder	0	1
Other	0	3
Employment		
Employed	6	17
Unemployed	3	3
Student	0	1
Homemaker	0	3
Retired	2	1
Recruitment setting		
Primary care	1	4
Secondary care	3	10
User group	1	1
Website	6	10

'I wanted to know more, why I was being treated the way I was and I would have liked a better or any explanation of the diagnosis. I was treated heavily with antidepressants without actually being offered much counselling or talk. So basically I was put on, on quite a lot of medication without any much, much explanation. So going through the why, why have we reached this diagnosis and what that means and are there other types of treatment available I was given none of that, those choices. …It's just been, "this is what is wrong with you", and "this is the cure for it" and I find that extremely patronizing and not very helpful, I mean, as I said to you, you become a uncooperative patient in a sense, you, you don't get well (Interviewee 22, a 38-year-old woman with eating disorder)'.

She explained that she wanted an explanation for her diagnosis and treatment. She interpreted the lack of information on possible choices as patronizing and explained how this was not helpful and the effect it had. The need identified here is for a level of information sharing to enable mental health service users to feel respected, either because they have an understanding

of the reasons for a particular treatment choice, or because they are enabled to take part in decisions about treatment. This was described by Interviewee 1, a 58-year-old man as 'basic courtesy'.

> 'I wasn't told what the medication did positively or negatively – you were just told to take it. I was just told, well "take the medication", and you get talk about change of brain chemistry, well, you wonder what it means? It's a term that's just thrown out generally and the kind of rationale, it's more complicated than that. …Its like going into a psychiatric hospital where [there are] people called psychiatric nurses, there are people called charge nurses, there is someone called the blood lady, what do these people do? She kept on taking my blood, but then didn't tell me the results of it, and someone gave me a physical check and didn't tell me the results of the check … I mean, its just basic, basic courtesy. I was told my diagnosis at a ward round, in terms of, "it's a manic depressive disorder, keep taking the tablets and you will be alright". What do those tablets do? I mean, you are not told what the tablets are for. You were just told to take it (Interviewee 1, a 58-year-old man with bipolar affective disorder)'.

Undertaking research and the challenge to professions

Partly as a result of lack of information, people described carrying out their own research into their problems, often using technical sources, such as textbooks or searching the Internet. Information was seen as empowering, but people also recognized the challenge to professions that this self-learning represented. These areas of personal research and the challenge to professions were identified by 16 participants. One example was Interviewee 2, a 30-year-old woman who complained about lack of information and described wanting to be treated like an 'intelligent adult' rather than a 'dependent child'. She described health professionals' reactions when she took information she had researched at libraries and by contacting mental health charities to consultations.

> 'They hate it, they absolutely hate it I have to say, they really do hate it. I mean, my psychiatrist now is great, he is, you know, he kind of like treats me like an equal now. But people I have had in the past, you know, they didn't really cope with the fact that I could turn round to them and say "yes, but the side-effects of Haloperidol are this, this and this and therefore I am not taking it", you know, they look at you as if to say, "good grief, this woman knows what she is talking about you know". Most of them don't like it very much (Interviewee 2, a 30-year-old woman with personality disorder)'.

The need identified here is for an environment that supports patients' understandings of treatments and options and offers the chance for personal research. Patients were conscious that difficulties might arise in the practitioner–patient relationship as a result.

Stigma inhibiting information seeking

Stigma inhibiting information seeking was a prominent theme, identified in 23 of the 36 interviews. Eleven participants used the word 'stigma'. Interviewee 15, a 30-year-old woman illustrated the role of stigma in this description of the embarrassment of public information seeking.

> 'Partly I don't want to ask for mental health [information] because of the embarrassment. But at the same time, you know, in theory, I don't agree with the stigma of it all but when it comes to putting it into practice, yeah, I do get embarrassed and that is an issue, I mean, that's why, its quite hard. I have had information before, sometimes I get this from posters in libraries and things. But you know, even looking at those is, its alright if there is a crowd of people looking at a crowded notice board and you can't tell where you are looking but that sort of public face of it is quite difficult. Before now that stopped me picking up leaflets in a doctors surgery, so I might see a leaflet, and I think "oh that would be very useful" but if there is loads of people waiting there, I don't go and pick it up (Interviewee 15, a 30-year-old woman with alcohol problems and history of self-harm)'.

She goes on to explain how the anonymity of the Internet has helped her to seek information. Interviewees' descriptions of stigma indicated a widespread mind–body dualism in their perception of mental and physical illness. For example, Interviewee 4, a 64-year-old man, highlighted this.

'You know that you can see a broken arm, a broken leg a damaged part of the body, you cannot see a damaged part of the mind and it's desperately easy for people to say "pull yourself together", or "you've got nothing to be depressed about". That sort of throw away remark doesn't help. Like I said, you see a broken arm, you see a broken leg, you appreciate if somebody has got cancer or leukaemia but for mental [illness], there is nothing to show on the outside (Interviewee 4, a 64-year-old man with depression)'.

There was a common feeling among interviewees that mental health problems were seen as less worthy of help and respect than physical problems. This is not a direct information need, but there is evidently a need for an understanding of the impact of stigma and for reducing the stigma associated with mental health problems.

Other people's experience

Other people's experience was one of the main sources of information sought, identified by 30 of 36 interviewees. The benefits of hearing the experience of others could be categorized as: an understanding of universality (a theme in 18 interviews); the instillation of hope (13 interviews); and finding understanding and empathy (14 interviews). Universality refers to the benefit of finding out that one is not alone – that there are other people with similar problems. There was a remarkable similarity in the way many interviewees described this. Two examples are shown here.

'It's reassuring to know that you are not alone and that … you know there are hundreds of people, thousands, I don't know the numbers, out there that are going through these experiences (Interviewee 35, a 27-year-old man with anxiety)'.

'It's nice to know that you are not alone. That other people have got the same problems as you. And they have been through the same sort of things, that's really nice (Interviewee 18, a 41-year-old man with depression)'.

Instillation of hope refers to the benefit of not only knowing that one is not alone, but also that other people have had the same problem and recovered. For example, Interviewee 13, a 27-year-old woman, described the benefits of finding stories of recovery on the Internet.

'As I got a bit braver and kind of went back to work and so on, I did the odd search on the Internet and I would read other people's experiences of schizophrenia and it was often by their families, or sometimes it was by the person themselves, and just hearing that somebody had recovered would mean so much to me because when I was still kind of in the recovering process, I was heavily depressed thinking that I was never going to be the same person that I had been before, I became ill, and reading experiences where people had recovered, it was such a boost, because you thought well, if they can do it, you know, I will be damned if I can't (Interviewee 13, a 27-year-old woman with schizophrenia)'.

Understanding and empathy was the third subtheme relating to the experience of others. Individuals not only wanted to know that they were not alone and that others had got better, but they also wanted to interact with others or read material from others. They reported that only other people who had been through the same experiences could truly understand and empathize with them. As Interviewee 3, a 35-year-old woman stated, other people 'know what it's like'.

'I would say that from the books and from the self help group the most obvious thing that comes out is the first hand experience, I would say, because there are books that are written not as manuals, or textbooks whatever. They are written by people who have got depression and actually know exactly what it's like. And I think that's very very valuable, actually I think those are the most useful books I have come across. And then you have the first hand experience of people in the groups so I think that is the, fundamental thing, is the experience of it and people sort of saying what their situation is and then you relating to that. That's the best. And nobody sort of judges you which is very nice, 'cause people don't, I mean, people will just be supportive and they will listen and they won't sort of try and put words in your mouth, and they wont say, "oh you can snap out of it and you will feel better by doing X, Y and Z". They don't do those things because they know what its like (Interviewee 3, a 35-year-old woman with depression)'.

Discussion

Failures in information giving are among the commonest sources of patient dissatisfaction.[12] Our identification of the association between lack of information and lack of respect indicates that individuals feel patronized or disrespected by a health service that does not supply them with sufficient information. In particular this applied to information from mental health professionals regarding diagnosis and explanation of medication and side-effects.

We identified a second strong theme around personal research and the challenge to health professionals. Previous work in other areas of health care has also shown that patients, particularly when dissatisfied with the information they have received from professionals, will undertake their own research.[13] It is interesting that many of the interviewees in our study recognized that their research represented a challenge to health professionals. In these first two themes, lack of information is disempowering. At one level, the need here is for a degree of information giving that makes mental health consumers feel respected, and an environment which supports personal research into illness and which values the contribution patients can make to the consultation. Underlying these needs there appears to be a clear desire on the part of mental health consumers for a strong and more equal partnership with professionals. Our findings support the arguments of Coulter and others that clinicians should facilitate the process of moving away from a paternalistic model of medical care to one where patients are equal partners in the management of their illness.[14]

The third theme, concerning stigma and information seeking, is grounded in the descriptions interviewees gave of how stigma inhibited the seeking of information and other help. In Goffman's terms, mental illness is a 'discreditable' stigma, that is it is (usually) not immediately apparent, but the act of seeking information or other forms of assistance reveals the stigma, thereby rendering the individual 'discredited'.[15] One could postulate that individuals avoid information seeking to avoid becoming discredited. However, participants frequently commented that they would find it easier if they were to have a visible problem, such as a broken leg. Interviewees also valued having explanations of their problems in physical terms, for example, 'a chemical change in the brain'. It appears that having a mental health problem was seen as a personal failing in a way that having a physical health problem was not. This finding is supported by surveys which show that depression is widely viewed as a sign of weakness.[16] The predominance of negative cultural stereotypes of mental illness produces and maintains this stigma. The need here is not a direct information need, but a need to reduce the stigma associated with mental illness.

The desire for experiential information from others has been demonstrated in a few previous studies in other areas of health care.[17,18] We have identified the reasons behind this need. People with mental health problems want to know that they are not alone. One benefit of this was summed up by one interviewee who stated that 'thank goodness I'm not as mad as I thought I was'. People also benefit from knowing that others have been through the same situation and recovered. Our study shows that this information can be gained not only from factual information on prognosis, but also from experiential evidence that there is hope. These needs for universality and hope mirror two of the therapeutic factors in group psychotherapy identified by Yalom, suggesting that meeting these needs may have therapeutic benefits.[19] The implication for health services is that supporting or enabling people with mental health problems to learn about others with similar experiences may be of benefit. This could be not only achieved through formal support groups, but also through informal social networks, the Internet and traditional sources, such as books detailing personal accounts of illness. Learning from such experiential information may also benefit practitioners.[20] In the UK, the Department of Health is already supporting the DIPEx project to provide experiential information online, for example, providing information on the experience of having depression.[21] Online

'patient helpers' (expert patients running their own websites) have also been suggested as a way that the Internet could be used to harness patient experience and support practitioner–patient partnership.[22]

This interview method of study has some possible limitations. The technique of purposive sampling was used to recruit individuals with a wide range of experiences, but some groups may still have been underrepresented, including individuals satisfied with current information provision, and those not in contact with services. In addition, individuals who chose to contact the researchers may have been a particularly motivated and resourceful group. As with any cross-sectional study, data collected at one point in time but based on past experience may be subject to recall bias. The data were self-reported, and there was no corroboration of reported experiences.

In conclusion, mental health problems cause a significant burden to patients, their families and the health service. This study provides the first in-depth exploration of information needs and behaviour in this area. Meeting these needs could improve patient experience, with implications for improving contact with services, treatment concordance and mental wellbeing.

Acknowledgement

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